



*Promoting the Healthcare Rights and Needs of
Children and Young People*

Strategic Plan 2016 – 2019

CONTENTS

Executive Summary	3
Introduction	13
1. Development of CHS	13
1.1 Origins.....	13
1.2 Milestones in Development.....	13
1.3 History of Funding Secured	15
2. Operating Principles	15
2.1 Our Vision	15
2.2 Mission Statement.....	15
2.3 Our Values	15
2.4 Core Business	16
2.5 Strapline	17
3. Our Services and Activities	17
3.1 Current Projects	17
4. Governance and Management Structure	18
5. Current Position	19
5.1 Our Client Group	19
5.2 The Need for the Services	19
5.3 The Demand for the Services	21
5.3.1 Hospital Admissions.....	22
5.3.2 Support Needs Services.....	23
5.3.3: Children with Exceptional Health Needs	23
5.3.4 Dental Services in Scotland	24
5.4 Benefits of our Work.....	25
6. Monitoring and Evaluation	26
7. Development Context	26
7.1 Key Influences on Development	26
7.2 SWOT Analysis	28
8. Strategic Development	28
8.1 Long-term Aims.....	28
8.2 Strategic Aims and Priority Areas for Development	28
9. Sources of Required Income	33
Appendix One: Organisation Chart	34

Executive Summary

This Strategic Plan describes the proposed future development of Children's Health Scotland for the period April 2016 to March 2019.

1. Development of Children's Health Scotland (CHS)

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 the Office of the Scottish Charity Regulator (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. In July 2017 the company changed its name to Children's Health Scotland (CHS).

Over the years CHS 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. CHS 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, reflects the UNCRC and supports the aspirations of the Scottish Government's Children and Young People (Scotland) Act 2014. The Charter is recommended for use as a benchmark against which NHS Boards should review their child health services in the Scottish Government's 'Delivering a Healthy Future: An Action Framework for Children and Young People's Health in Scotland' (2007).

Over the years CHS has secured funding from various sources including the Scottish Government, Trusts, Area Health Boards and regional authorities. At the end of March 2015 CHS had an annual gross income of circa £225,000 and eight staff.

2. Operating Principles

CHS is the *only* Scottish charity which works for all sick children and young people irrespective of their illness and condition, and their families.

Our Vision is for every child and young person in Scotland to realise their right to best quality healthcare.

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.

Our Organisational Values are to:

- believe in the healthcare rights of children and young people
- listen to children and young people to meet their healthcare needs

- 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:

Promoting the Healthcare Rights and Needs of Children and Young People

3. Services and Activities

CHS's work includes:

1. Working with the Scottish Government, NHS and voluntary sector to ensure that health services are planned for children and young people in child-focused 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 their 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 equity of services and access across Scotland.

CHS currently delivers or has recently completed the following projects.

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.

NHS Tayside and NHS Greater Glasgow & Clyde: CHS staff in these Board areas provide practical support, information and advice to 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 focuses on looked after children and young people, delivering workshops to support foster and kinship carers to look after the health care needs of the children and young people in their care.

Self Management Project (Lothian): this assists children and young people with long term conditions by supporting them to self manage their condition.

National Office Support Services: co-ordinates all projects and encourages partnership working and collaboration with key partners in the health services, social work, education and the voluntary sector.

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

CHS 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, as enshrined in Article 24 of the UNCRC.

CHS welcomes the implementation of the Children and Young People (Scotland) Act 2014 and will work to support its aspirations. Children and young people's healthcare rights are described in the EACH Charter and underpinned by the UNCRC. They have yet to be fully implemented and failure to meet some of these rights were highlighted in CHS's latest Parental Access and Family Facilities Survey¹ of all NHS hospitals admitting paediatric patients which reported in 2014.

The UK has one of the worst child mortality rates in Western Europe; 350 to 450 children 0-18 years die each year in Scotland; the majority are under one year and the second largest number are in the 15-18 year age group.² Poverty and inequality impact on the risk of premature death.

Most children admitted to hospital are in the 0-9 age group with those up to four years having the highest admission rate. 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 specialist health services may involve travelling outwith local areas to tertiary centres for specialist surgery so children may be unable to benefit from a pre-admission visit and access to specialist play preparation support.

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. They need support to manage their conditions as early as possible as they move from childhood, through adolescence and into adulthood. Scottish Government estimate that by 2037 the number of people with long term conditions will rise by 83%.

¹ <http://www.ascscotland.org.uk/default.asp?page=19>

² Why children die: death in infants, children and young people in the UK Part D: October 2014

During 2013-14, 49,525 child patients in Scotland had at least one tooth extracted and an additional 7,245 had extractions in a hospital dental setting. While the oral health of children is improving, tooth extraction remains 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.

At July 2014 15,580 children were looked after by Local Authorities. 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/carers especially those facing poverty, families made vulnerable, or those caring for looked after children and young people, sick children or those with long term conditions can find their situation challenging. Supporting parents and carers will help their children achieve healthier outcomes.

5.3 The Demand for the Services

There are over 1.03 million children and young people aged up to 18 years in Scotland representing just under one fifth (19.3%) of the population of 5.34 million (mid 2014 statistics).

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

5.3.1 Hospital Admissions in Scotland³

Of the 1.43 million hospital admissions annually in Scotland (in-patients and day cases) around 8.6% (123,000) are for children under 18 years.

During 2013-14, there were approximately 72,000 emergency admissions for children under 18 years (68,000 in 2012-13) and approximately 51,000 elective (planned) admissions (52,000 in 2012-13).

Children under four years of age have the highest admission rate, largely emergency admissions. The under four age group represented over half of all emergency admissions of children under 18 years..

In 2013-14 around 44,000 planned procedures/operations were carried out for children under 18 years or age, 58% for the 0-9 years age group.

³ <http://www.isdscotland.org/Health-Topics/Child-Health/Other-Information-on-Child-Health/>

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, twelve NHS Boards use SNS and as at August 2011, when the statistics were last published annually, 15,541 children were registered.

5.3.3 Children with Exceptional Healthcare Needs (CEN)

The number of children with exceptional healthcare needs on the Support Needs System increased to 300 in 2015 rising from under 100 in 2009. The number of CEN children is however likely to be an underestimate due to under-ascertaining the youngest children with exceptional healthcare needs.

CEN children recorded on SNS are more likely to live in more deprived areas (24.8% of all CEN children live in the most deprived quintile).

Hospital admission rates for CEN children are similar across all NHS Boards. Emergency and planned admissions are similar across CEN and non CEN children although within planned admissions, CEN have more elective and fewer day case admissions.

Length of stay for CEN children in hospitals is around 4 overnight stays for planned admissions and five for emergency admissions. This is higher than for the general child population (2.3 for planned admissions and 1.7 for emergency admissions)

Emergency admission rates are highest in the youngest age groups of CEN but there is no trend in admission rates by deprivation. This differs from the general child populations where there is a clear gradient of increasing emergency admission rates with increasing deprivation.

5.3.4 Dental Services in Scotland

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

The Public Dental Service provides a general dental service for people who cannot access care from an independent dentist. These may include children, who are in disadvantaged groups and those with special needs or learning difficulties. The Public Dental Service also provides a 'safety net' for those who are unable to access GDS and plays 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. The programme does not routinely extend to children with additional support needs unless resident in the most deprived quintile of the population, despite these children being at higher risk of dental disease.

92 % of Scottish children were registered with an NHS GDS dentist at 30 September 2014, an increase from 67% at 31 March 2007. The 13-17 age group had the highest percentage of population registered (100%) compared to 44% of 0-2 year olds.

Socio-economic inequalities in the oral health of children remain. 47% of children from the most deprived areas have some dental decay at the age of 5 years compared to 17% of children from the least deprived areas. (Source: 2014 NDIP)

5.4 The Benefits of our Work

Children and young people we support 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/young person during illness or hospitalisation; better awareness about the health needs of children and young people including those with complex additional support needs or those who are looked after; improved knowledge about child healthcare rights and parental responsibilities; improved parenting skills and ability to communicate with healthcare professionals to access appropriate health care services;

Healthcare professionals will benefit from a greater awareness of: the rights and needs of children and young people at times of illness including those with long term conditions; the needs of young parents; 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

CHS uses a self evaluation resource and logic modelling as an evaluation tool and monitors and evaluates its work through internal reporting systems and via qualitative and quantitative methods. Funders are provided with regular progress reports.

7. Development Context

7.1 Key Influences on Development

The principal political and legislative influences on CHS's future development are:

- Scottish Government's Children and Young People (Scotland) Act (2014) which puts children at the centre of service planning and aspires for their needs and rights to be respected across health, social care and education.
- 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 - Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible, Included (SHANARRI).
- 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 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); Mental Health Strategy for Scotland (2012-15); Play Strategy for Scotland (2013.)
- 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); National Foster Care Review (2013).
- Early Years and Early Intervention Framework (2008).
- 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.
- Why Children Die: death in infants, children and young people in the UK: RCPCH and RCPCH (Scotland) 2014.

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

- Reduced funding to Scottish Government from Westminster and an economy which will continue to face a serious financial squeeze
- Scotland Bill – including Smith Commission recommendations and increased fiscal autonomy in Scotland
- Welfare Reform – Benefits cuts which will impact on vulnerable sectors
- Pressure on resources resulting in moves towards more 'partnership' working.
- Increased reporting requirements arising from a changed contractual arrangement in government funding from statutory bodies.

Social considerations include:

- Increasing number of children and families in poverty as a result of welfare cuts
- An ageing population and resultant pressure on NHS
- Scotland is more multi-cultural and therefore needs to be more inclusive
- Children are becoming less physically active, child obesity is increasing
- The way people communicate (web sites, facebook, blogs / twitter) may encourage social involvement but less personal interaction
- An expectation in constrained 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 Our overarching aims are to:

1. Promote universal recognition of the needs of and rights of sick children and their families.
2. Enable children, young people and families to have appropriate information and equitable access to best quality health services.
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. Work with partners to ensure the best possible health services are provided for children and young people.
5. Influence the service specification of health care provision for children, young people and their families.

8.2 Strategic Aims and Priority Areas for Development

Priority areas for development are:

1. Awareness Raising and Campaigning
2. Information and Training Provision
3. Service Support and Service Delivery

In each of the three areas for development, our work will be aligned to the key principles of the Children and Young People (Scotland) Act 2014.

Priority: Awareness Raising and Campaigning:

CHS will review its marketing strategy and communications in order to further raise awareness of the needs and rights of children and young people. Areas of focus are: CHS knowledge and expertise in children's and young people's rights; 2017-18 Parental Access and Family Facilities Survey and findings; 40th Anniversary Conference in Autumn 2017 on aspects of the healthcare rights and needs of children and young people; Direct contact with opinion leaders and key groups.

Campaigning activity will focus mainly on the EACH Campaign which highlights gaps in children and young people's healthcare provision including age appropriate service provision; education; children in and leaving care; disability and additional support needs, mental health and health promoting play.

CHS will influence policy development via consultation with children, young people and their families; supporting families to input into policy and practice; via representation on local and national policy forums; by responding to key policy consultations and via the findings of our Parental Access and Family Facilities Survey.

Priority: Information and Training Provision

Promoting universal recognition of the needs and rights of sick children and their families is central to our work. A key focus will be to promote awareness of the rights of children and young people amongst parents, carers and professionals, so that they can assist children and young people to have their rights upheld and their healthcare needs met. Work will cover:

Development of Rights Information Packs for parents/carers and professionals; Workshops and presentations to parents/carers including those from harder to reach groups; Development of online training for professionals; Exploring accreditation for training; Parent/Carer Leaflets, Guides, toolkits; Redevelopment of CHS web site; communication materials; social media.

We will also aim to develop delivery of seminars/presentations/training on child health care issues and rights to external organisations and professionals.

Priority: Service Support and Service Delivery

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

A programme of work will include: maintaining highest standards of governance; building our capacity to improve and plan through self evaluation, reviewing existing policies, procedures; developing our capacity to build on core and project funding from various sources.

Service Delivery Development

CHS 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.

Development of Existing Projects/Workstreams

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

Special Smiles Dental Project

- Secure funding during 2015 for roll out across Scotland by 2019
- Work in partnership with the Childsmile Programme as appropriate
- Develop work with parents/carers of children with additional support needs.

Self Management Project

- Evaluate impact of work in 2016 to inform the future resourcing, development and delivery of this work with children and young people.

Children and Young People In and Leaving Care

- Develop further and deliver workshop programme to kinship and foster carers on issues relating to the health needs of children in their care
- Explore possibility of accreditation and having programme included in mainstream training provided by foster carer agencies.
- Adapt workshop modules for LearnPro and promote amongst agencies.

Parental Access and Family Facilities Survey

- Develop plan to fund and carry out a survey of NHS hospital wards admitting paediatric patients during 2017-18, to launch the findings and to promote and disseminate these during 2019.

Tayside Workstream

- Funding will be sought to continue work in this area beyond March 2017.

Greater Glasgow & Clyde Workstream

- Continue to promote child health rights within NHS Board work area.

Local Service Planning and Support

- Consider how funding can be secured to increase CHS work activity in health board areas particularly in the North of Scotland.

Development of New Service

- Identify possible new service development areas taking into account findings of the 2017-18 Parental Access & Family Facilities Survey.
- Submit funding applications for new Service Initiatives as required.

Potential new areas of service development include:

- Workstream around Training provision on children and young people's rights
- Work with under-represented/harder to reach families supporting them to access child health services

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 Children's Health Scotland (CHS) over the period 1st April 2016 to 31st March 2019. 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 CHS

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 Children's Health Scotland.

1.2 Milestones in Development

Since becoming a Scottish entity in 1977, CHS 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. Milestones and achievements have included:

- Translation of information from users into standards of care in the national health service which has resulted in CHS becoming regarded as an 'expert' in standard setting in all areas of children and young people's healthcare
- Campaigning since our inception for the rights of children and young people in health care services and the development of the European Association for Children in Hospital (EACH) Charter in 1988. The EACH Charter which sets out ten healthcare rights of children and young people, reflects the UNCRC and supports the aspirations of the Scottish Government's Children and Young People (Scotland) Act 2014. The EACH Charter was included in the Scottish Government's 'Delivering a Healthy Future: An Action Framework for Children and Young People's Health in Scotland' in 2007 as a benchmark against which NHS Boards should review their provision of children's hospital services.
- Since 1985 conducting periodic surveys of parental access and family facilities at Scottish NHS hospitals admitting paediatric patients.
- Launch of EACH Child and Young Person's Health Matters Campaign at Scottish Parliament in October 2009.
- Campaigning for the right of children and young people to receive appropriate and equitable education provision when absent from school due to ill health. This resulted in the publication in 2015 of new Guidance on Education of Children and Young People unable to attend school due to Ill Health.

- Influence on and input into Scottish Government and NHS policies, guidance, procedures and services eg: Working with Scottish Government to develop specific guidance governing the provision to children of food in hospital (2015) Provision of evidence to the Scottish Parliament, Health and Sport Committee on transition between paediatric and adult services in the NHS (2014); Input to the National Foster Care Review Learning and Development Framework (2014- 2015).
- Representing the voice of sick children, young people and families on groups such as the:
 - Scottish Government Children & Young People's Health Support Group (2012–)
 - Scottish Government Administration of Medicines and Healthcare Procedures Group reviewing the 2001 Guidance (2014-)
 - National Steering Group for Specialist Children's Services Implementation Group (2010-14)
 - National Managed Clinical Network for Children with Exceptional Healthcare Needs (2009 –)
 - Scottish Government Children and Young People Acute Deterioration Management (CYPADM) (2009-10)
 - NHS National Services Division (NSD) National Managed Clinical Network Review Group (2009)
 - NHS National Services Division (NSD) Transition to Adult Care for Chronic Disease Working Group (2011-12)
 - RCPE Transition Steering Group, Think Transition (2008)
 - National Steering Group for Specialist Children's Services in Scotland Age Appropriate Care Working Group (2007).
- The only voluntary organisation represented⁴ on the Healthcare Improvement Scotland: Scottish Paediatric Patient Safety Programme, Clinical Reference Group and on the Scottish Government Specialist Services for Children and Young People Monitoring Group which concluded in 2014.
- Developed projects as exemplars of good practice which demonstrated the importance of play as a means to prepare children for medical and hospital treatment (Hospital Playbox lending project 2002-05 and Community Specialist Play Pilot 2008-10).
- Developed and delivered 'Special Smiles' – a dental play project delivered in ASL schools in response to the Scottish Executive's commitment to Improving Children's Oral Health in Scotland Action Plan (2005), This project was chosen in 2011 as one of Inspiring Scotland's Early Years Early Action ventures.
- Stay Well Lanarkshire - CHS's generic self management programme - the first to be developed and delivered in Scotland for children and young people with chronic conditions 2009-12.
- Since 2007 awareness raising of the healthcare needs of looked after children and young people and development of educational resource via our Children in and Leaving Care Workstream.
- Establishment of area staff who work locally, identifying and responding to grass roots issues that impact on the health of children and young people.

⁴ As at June 2015

1.3 History of Funding Secured

From its inception CHS has maintained a history of stable funding over more than 38 years, and has successfully applied for funds from various sources.

Core funding and funding for our Special Smiles project is provided by the Scottish Government Third Sector Early Intervention Fund, while other projects and posts are currently funded from the following: NHS Board funding, Trusts and Foundations.⁵

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

CHS has developed into a well established organisation, with an annual gross income of £227,000⁶ and a staff of eight.

2. Operating Principles

Children's Health Scotland works for ALL sick children and young people irrespective of their illness and condition, and their families. As an overarching principle, a belief in the healthcare rights of children and young people is at the centre of everything we do.

2.1 Our Vision

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

Our Vision is for every child and young person in Scotland to realise their right to best quality healthcare

2.2 Mission Statement

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.

2.3 Our Values

CHS has the wellbeing of children and young people as its central focus which aligns with the aims and aspirations of the Children and Young People (Scotland) Act 2014. The rights and needs of sick children, young people and their families are widely protected and promoted through our work which 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). The values which are important to CHS's Board and staff are to:

Believe in the healthcare 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

⁵ Position at June 2015

⁶ As at 31 March 2015

Listen to children and young people to meet their healthcare needs

We focus on meeting the needs of children and young people in our health care system, ensuring that these are central to the work 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 that 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

When we challenge the policies and procedures of healthcare and other providers, it is to assist them in providing services which are appropriate to the changing needs of children and young people and their families

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 children and young people in child-focussed 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 their treatment and care.

3. Raising awareness and representing children and young people's health 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 family facilities for sick children and young people in hospitals across Scotland.
6. Working to provide a network of CHS 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 responsible for education of healthcare staff 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:

Promoting the Healthcare Rights and Needs of Children and Young People

3. Our Services and Activities

3.1. Projects

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

Special Smiles Dental Project Since its successful external evaluation in Tayside in 2009, Special Smiles has extended into new local authority areas. It 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 practise good oral health and helps reduce child dental anxiety. It assists teachers, parents and carers to support these children's oral health needs. It was one of Inspiring Scotland's Early Years Early Action ventures. It has been recognised for its success in 2015 by the International Association of Paediatric Dentistry.

Children and Young People In and Leaving Care Health Project This focusses on the healthcare needs of looked after children and young people. It has developed resources for professionals working with this group and a toolkit resource including a DVD for foster carers. It delivers workshops to support foster and kinship carers helping them to look after the health care needs of the children and young people in their care.

Self Management Project (Lothian) This delivers generic self management workshops to children and young people with a range of chronic conditions who are supported to develop the skills and strategies to self manage their condition.

NHS Greater Glasgow & Clyde This workstream ensures that the voices of sick children, young people and their families are represented to health care service providers and planners so that their healthcare rights and needs are reflected in policy, practice and service delivery. It works closely with the Royal Hospital for Children Glasgow. Families in the area are provided with information, advice and practical support.

NHS Tayside This workstream supports families in Tayside by raising their awareness of child health rights and enabling them to better support their child at times of illness. It also represents the needs and concerns of these families amongst statutory and voluntary agencies in the area.

National Office Support Services

These projects and workstreams are co-ordinated through the central office. The office 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

Children's Health 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, child care, education, accountancy, law. The Committee can also call on the services of a wide range of voluntary Professional Advisers for guidance. In addition to the voluntary Executive Committee, CHS 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)
- Area Officer (Tayside)
- Project Officer (Lothian)
- Dental Project Co-ordinator
- Dental Project Officers (2)

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

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

CHS 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

Children's Health 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 CHS is involved is in the separate Statistical Appendix.

5.2 The Need for the Services

- As enshrined in Article 24 of the UNCRC, 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 choices⁷.
- CHS welcomes the implementation of the Children and Young People (Scotland) Act 2014 and will work to support its aspirations. Children and young people's healthcare rights are described in the EACH Charter and underpinned by the UNCRC. They have yet to be fully implemented and failure to meet some of these rights were highlighted in CHS's latest Parental Access and Family Facilities Survey⁸ of all NHS hospitals admitting paediatric patients which reported in 2014
- The UK has one of the worst child mortality rates in Western Europe; 350 to 450 children 0-18 years die each year in Scotland; the majority are under one year and the second largest number are in the 15-18 year age group. Poverty and inequality impact on the risk of premature death.
- Children can suffer psychological trauma through illness and /or poor hospital or healthcare experiences, which can lead to a lifelong aversion to/fear of hospitals/medical treatment. CHS 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 0-9 years and many of the children CHS supports are in this age range. Children up to the age of four years have the highest admission rate. Children from deprived backgrounds are hospitalised more and supporting these children can result in a better outcome for those already 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

⁷ Scottish Government: Wellbeing Wheel: healthy

⁸ <http://www.ascscotland.org.uk/default.asp?page=19>

may therefore be unable to access pre and post admission play opportunities, be 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 prevention is needed to help those children at risk and 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.
- The number of children looked after by Local Authorities in Scotland as of July 2014 was 15,580; of these 27% were placed at home with parents, 36% were in foster care, 27% were formally in kinship care and 10% in residential accommodation. This is the third year in a row where more children are looked after by foster carers/prospective adopters than looked after at home. However experts believe the actual figure in kinship care is nearer 17,000. The number of children looked after by Local Authorities has decreased by 4% from 2012 when it was at its highest level (16,248) in 30 years.
- 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%). The Office of National Statistics reported in 2004 that 50% have a mental health disorder compared to 10-15% in the general child population and that the majority of looked after children have mental health problems.
- 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 they also suffer from illness or chronic conditions.
- Supporting parents and carers, including those who have become vulnerable and those caring for looked after children 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 the tools to manage their illness. CHS's Stay Well Lanarkshire self management project (2009-12) provided evidence of the positive impact of support on young participants.
- Children and young people with severe and complex additional support needs are at higher risk of dental disease because of their conditions and therefore of dental procedures and surgery.
- During 2013-14, 49,525 children had at least one tooth extracted in the general dental service and another 7,245 had extractions in a hospital dental setting.
- Tooth extraction is still the largest single reason for children receiving general anaesthesia in hospital, representing 16.36% (7,245) of elective procedures in 2013-14.
- Children's dental health in Scotland has improved significantly over the last decade. Nevertheless the 2014 National Dental Inspection Programme (NDIP) Report of the oral health of 5 year old children in Scotland shows that 32% of children had some dental decay.
- The 2014 NDIP also reported ongoing socio-economic inequalities. 47% of Primary 1 children in the most deprived communities have some obvious dental decay compared to 17% in the least deprived. This differential has remained constant over the last four inspections since 2008.
- The 2013 NDIP Report on the oral health of Primary 7 children found that 27.2% of children had some dental decay. In 2013, the 2010 Scottish Government target of 60% of children in Primary 7 with no obvious decay was met for the first time across all SIMD deprivation quintiles.

5.3 The Demand for the Services

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

Mid 2014 statistics show that there were over 1.03 million children and young people aged up to 18 years of age in Scotland, representing 19.3% of the total population of 5.34 million. The 1,033,183 children and young people comprised:

- Children aged <1-4 years: 292,230
- Children aged 5-9 years: 288,585
- Children aged 10-14 years: 271,862
- Young people aged 15-18: 180,506

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

Summary Table of Population Age by Area Health Board Area: 2014

	ALL Ages	<1 to 4	5 to 9	10 - 14	15 to 18	<1 to 18
ALL AREA BOARDS	5,347,600	292230	288585	271862	180506	1033184
Ayrshire & Arran	371,110	19,123	19,778	19,323	13055	71279
Borders	114,030	5,821	6,017	6,003	3,816	21,657
Dumfries & Galloway	149,940	7,141	7,790	7,391	5,013	27,335
Fife	367,260	20,521	20,460	18,954	12,614	72,549
Forth Valley	300,410	16,179	16863	16322	10904	60268
Grampian	584,240	32,725	31536	28477	18647	111385
Greater Glasgow & Clyde	1,142,580			56425	37815	
Highland	320,760	64,168 15871	59445	16859	11194	217853
Lanarkshire	653,310		37863		23638	
Lothian	858,090	36,617	46601	41131	26913	134235
Orkney	21,590	49,127	1170	1053	755	163772
Shetland	23,230	1,033	1340	1335	852	4011
Tayside	413,800	1,349	21103	21056	14372	4876
Western Isles	27,250	21,289	1434	1415	919	77820
		1,267				5035

- o Mid-year population estimates:

<http://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2014>

5.3.1 Hospital Admissions

Of the 1.43 million hospital admissions annually in Scotland (in-patients and day cases) around 8.6% (123,000) are for children under 18 years, an increase to the 2009-10 level due to increased rate of emergency admissions in those under four years. Admissions had been decreasing between 2010-13.

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.

Overall for children under 18 years of age, emergency admissions are more common than planned admissions but this varies between age groups. During 2013-14 for the:

0-4 age group	72% of all admissions are emergency admissions.
16-18 age group	51% of all admissions are emergency admissions
5-9 age group	56% of all admissions are planned admissions
10-15 age group	53% of all admissions are planned admissions.

This pattern was similar over the years 2011-12 and 2012-13.

During 2013-14, the emergency admission rate for children under 18 years was 71,694 (68,311 in 2012-13) – 58% of all admissions. The elective admission rate was 51,348 (51,917 2012-13).

Children under four years of age have the highest admission rate, largely emergency admissions. In 2013-14, 72% of admissions in this age group were emergency admissions. The under four age group also represented 54% of all emergency admissions of children under 18 years.

In 2013-14, 44,275 planned procedures/operations were carried out for children under 18 years or age, 25731 (58%) for children up to 9 years.

5.3.2 Support Needs Services

The Support Needs System (SNS)⁹ records information about children and young people under 20 years with additional support needs. Its aim is to monitor their progress and ensure they have access to services or support they require. Implementation and utilisation of the system varies across the NHS Boards; currently 12 Boards use the system. A minimum of around 2% of the child population (circa 20,000) would be expected to be eligible for registration on SNS with 15,541 actually registered in 2011. Statistics have not been published annually since 2011 but information is provided to SNS user boards and to the National Management Clinical Network for Children with Exceptional healthcare Needs (NMCN CEN) for planning purposes. The NMCN CEN estimate that 7,200 children in Scotland have met the definition of complex needs but only 3,321 of these are registered on the SNS.¹⁰

5.3.3 Children with Exceptional Health Needs

The NMCN CEN impairment categories used for assessing the children and young people are: *learning and mental functions; communication; motor skills; self care; hearing; vision*. A child or young person is defined as having exceptional healthcare needs if they have severe impairment recorded in at least 4 categories together with the need for enteral/parenteral feeding **OR** have severe impairment recorded in at least 2 categories and require ventilation/CPAP **AND** the impairments are sustained and ongoing or expected to last for more than 6 months.

In February 2015 there were around 300 children with exceptional care needs. This means thirty children (under 20 years) per 100,000 child population in Scotland. This number is likely to be an underestimate of true prevalence due to under ascertaining the youngest children with exceptional healthcare needs.

⁹ <http://www.isdscotland.org/Health-Topics/Child-Health/Children-with-Support-and-Care-Coordination-Needs/>

¹⁰ <http://www.cen.scot.nhs.uk/>

The number of children with exceptional healthcare needs on the SNS has increased to 300 in 2015 rising from under 100 in 2009.

CEN children recorded on SNS are more likely to live in more deprived areas (24.8% of all CEN children live in the most deprived quintile).

Hospital admission rates for CEN children are similar across all NHS Boards. Emergency and planned admissions are broadly similar across CEN and non CEN children although within planned admissions CEN have more elective and fewer day case admissions.

Length of stay for CEN children in hospitals is around 4 overnight stays for planned admissions and five for emergency admissions. This is higher than for the general child population (2.3 for planned admissions and 1.7 for emergency admissions).

Emergency admission rates are highest in the youngest age groups of CEN but there is no trend in admission rates by deprivation. This differs to the general child populations where there is a clear gradient of increasing emergency admission rates with increasing deprivation.

<http://www.isdscotland.org/Health-Topics/Child-Health/Children-with-Support-and-Care-Coordination-Needs/>

5.3.4 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.

Public Dental Services (PDS) provide a general dental service for people who cannot access care from an independent dentist. These may include people (including children) who are in disadvantaged groups and those with special care needs or learning difficulties and the elderly in residential care, or those living in areas where there were few NHS dentists providing GDS.

Hospital Dental Services (HDS) accept patient referrals from both dental and medical practitioners and from other hospital services. The main specialist areas are oral and maxillofacial surgery, oral medicine, orthodontics, restorative dentistry and paediatric dentistry. 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.

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 and has contributed significantly to the improvement of children's oral health.

92% of Scottish children up to 17 years were registered with an NHS GDS dentist as at 30 September 2014. This is an increase from 67% at 31st March 2007.

100% of the 13-17 age group were registered with a GDS dentist and 48% of the 0-2 age group – an increase on previous years. Participation rates (contact with patient over a two year period) amongst child patients fell from 100% to 86% and this decreases with age.

Children from the most deprived areas are more likely to have already had dental decay at the age of 5 years than children from the least deprived area (47% of children compared to 17%). (Source: 2014 NDIP)

5.4 Benefits of our Work

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

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

- Learning about and exercising their rights to healthcare
- 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:

- Improved understanding of the health rights of children and young people
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
- Increased awareness of the impact of illness on children and young people and the importance of continued contact with education services during times of illness and recovery.

6. Monitoring and Evaluation

In 2015 Education Scotland produced a self evaluation resource for the third sector which will be used as an evaluation framework. CHS also uses logic modelling 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.

7. Development Context

7.1 Key Influences on Development

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

- The Children and Young People (Scotland) Act (2014) which puts children at the centre of service planning and aims for their needs and rights to be respected across health, social care and education.

- 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).
- 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 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 Patient Safety Programme
- 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.
- Royal College of Physicians of Edinburgh (RCPE): 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.
- Why Children Die: death in infants, children and young people in the UK: RCPCH and RCPCH (Scotland) 2014.
- Election in 2016: any change of Government may lead to changes in Ministerial priorities with unpredictable outcomes.

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

- Reduced funding to Scottish Government from Westminster and an economy which will continue to face a serious financial squeeze
- Scotland Bill – including Smith Commission recommendations and increased fiscal autonomy in Scotland
- Welfare Reform – Benefits cuts which will impact on vulnerable sectors
- Pressure on resources resulting in moves towards more 'partnership' working.
- Increased reporting requirements arising from a changed contractual arrangement in government funding from statutory bodies

Social considerations include:

- Increasing number of children and families in poverty as result of welfare cuts
- An ageing population and resultant pressure on the NHS
- Scotland is more multi-cultural and therefore needs to be more inclusive
- Children are becoming less physically active and child obesity is increasing
- The way people communicate (web sites, facebook, blogs / twitter) may encourage social involvement but less personal interaction
- An expectation in constrained 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. Actions required will be transferred to planning documents and individual action plans.

8. Strategic Development

8.1 The long term strategic aims of CHS are to:

1. Promote universal recognition of the needs of and rights of sick children and young people and their families
2. Enable children, young people and families to have appropriate information and equitable access to best quality services at times of illness
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. Work with partners to ensure the best possible health services are provided for children and young people
5. Influence the service specification of health care provision for children and young people and their families.

8.2 Strategic Aims and Priority Areas for Development 2016-19

CHS's strategic aims (8.1) were reviewed between March and August 2015 and Priority areas for development identified:

- 1. Awareness Raising and Campaigning**
- 2. Information and Training Provision**
- 3. Service Support and Service Delivery**

In each area of the three areas for development, our work will be aligned to the key principles of the Children and Young People (Scotland) Act 2014.

Some activities described below contribute under more than one priority area. All of the priority activities will contribute to our Strategic Aims.

Priority: Awareness Raising and Campaigning

Marketing Strategy: CHS will review its marketing strategy and communications plan to further raise awareness across Scotland of the health care needs and rights of children and young people. The following areas will be included:

- Use of CHS's knowledge and expertise in children's and young people's rights to raise profile and awareness
- 2017-18 Parental Access and Family Facilities Survey and report findings
- Plan and resourcing of 40th Anniversary Conference in Autumn 2017
- Direct contact with opinion leaders and key groups.
- Campaigning activity

EACH Child and Young Person's Health Matters Campaign: A key focus over the next three years will be around the need for children and young people to have age appropriate health care and transitions services regardless of condition or location. Work will be undertaken to highlight a range of issues around age appropriate service provision; education; children in and leaving care, disability and additional support needs, children and young people's mental health; health promoting play. Specific activities will include:

- Developing a detailed campaign programme: agreeing how this work should be taken forward; the priorities to be pursued; and an action plan to take this forward
- Organising and hosting a conference focussing on aspects of the healthcare rights and needs of children and young people in Autumn 2017 for a range of professionals, policy advisors, and local practitioners
- Preparing and circulating promotional material covering key themes

Influencing Policy: CHS will also undertake a range of other work to influence the development of policy at a local and national level. This will include:

- Consulting with children, young people, families to ascertain their views and needs
- Supporting families to input into development of policy and practice
- Participating in 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
- Using the findings from the Parental Access and Family Facilities Survey to inform future policy development
- Supporting the implementation of Rights of the Child Groups in all Health Board areas.

These activities will contribute to realising all five strategic aims as detailed in 8.1.

Priority: Information and Training Provision

Promoting universal recognition of the needs and rights of sick children and their families is central to our work. A key focus will be to promote awareness of the

rights of children and young people amongst parents, carers and professionals, so that they can assist children and young people to have their rights upheld and their healthcare needs met. Work will cover:

- Development of Rights Information Packs for parents/carers including those from under-represented/harder to reach groups and professionals
- Workshop and presentation delivery to parents/carers
- Development of online training for professionals
- Exploring accreditation for specific training provided
- Review and further development of parent/carer leaflets, guides, toolkits
- Redevelopment of CHS web site
- Regular communications via Newsletter, e-bulletin, reports and social media

We will also aim to develop the extent to which we deliver seminar, presentations, training on issues around health care rights and specific issues relating to children and young people's health to external organisations and professionals. We will decide how to take this forward.

These activities will contribute to realising all five strategic aims as detailed in 8.1.

Priority: Service Support and Service Delivery

Service Support: CHS will seek to strengthen the infrastructure of the organisation to support staff and volunteers taking into account quality, efficiency and value for money.

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

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

maintaining the highest standards of governance; building our capacity to improve and plan through self evaluation, reviewing existing policies, procedures; developing our capacity to build on core and project funding from various sources.

Service Delivery Development: CHS has a track record in developing new and innovative health related services for children and young people across Scotland. CHS will seek to develop and pilot new projects in response to local needs, as exemplars of best practice with potential for inclusion in main stream healthcare services. The service development approach of CHS is based on the following:

- Ongoing programme of information gathering and analysis to identify new and emerging needs, and also to identify examples 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 and the Scottish Government as appropriate with a view to mainstreaming new service developments
- Consideration of providing ongoing training to support professionals in delivering the project.

Development of Existing Projects/workstreams: *Special Smiles Dental Project*

- A two year pilot project to develop dental play resources for children with additional and complex needs in Tayside was evaluated as successful in 2010 by the Dental Health Services Research Unit at Dundee University
- The project continued in Renfrewshire and Glasgow from Jan 2010 to September 2011
- Scottish Government Early Years Early Action funding via Inspiring Scotland enabled further work in Glasgow and in South Lanarkshire between 2011 – June 2013
- Scottish Government Third Sector Early Intervention funding enabled extension into North Lanarkshire, Falkirk, East and West Dunbartonshire, Stirling and Lothian from July 2013 to March 2016

The project will have the following objectives:

- We will seek to secure funding for this activity during 2015 for roll out across Scotland by 2019
- CHS will work in partnership with the Childsmile Programme as appropriate and will seek opportunities to provide additional support through training to professionals
- Develop work with parents/carers of children with additional support needs

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 were developed.
- The project evaluation provided evidence of the positive impact of teaching self management skills to young people with long term conditions
- Managing Me in West Lothian piloted self management workshops for children aged 8-12 years between 2013 and 2014.
- Funding has been secured to deliver these programmes to children and young people in partnership with the Royal Hospital for Sick Children (Edinburgh) until Autumn 2016

The project will have the following objectives:

- The impact of the 2015-16 project will be externally evaluated
- We will seek to secure funding to further develop and deliver this work to help children and young people to self manage their long term conditions

Children and Young People In and Leaving Care

- Between 2007 and 2015 the work focussed on the health care needs of looked after and accommodated children and young people and developed a toolkit for professionals.
- It piloted a support programme for LAC children and young people to help them manage challenging healthcare situations
- It developed and delivered a workshop programme, which was externally evaluated in 2014, for foster and kinship carers to help them to look after the health care needs of the children in their care.
- A toolkit including a DVD for foster carers has been produced.

This work will have the following objectives:

- It will continue to deliver workshops to carers
- It will explore formal accreditation with the target of having this programme included in the mainstream training provided by foster care providers.
- It will aim to adapt workshop modules on LearnPro for professionals and to promote amongst relevant agencies.

Parental Access and Family Facilities Survey

- Since 1985 CHS 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 reported in 2014. It made recommendations on areas which required further attention and informed our campaigning activities

This work will have the following objectives:

- A plan will be made to fund and carry out a survey during 2017-18 and to launch the findings.
- A plan to promote and disseminate the findings will be developed and implemented in 2019.

Tayside

- Between 2006 - 2012 work focussed on supporting vulnerable families and young mothers. A DVD and child health workshops were developed and delivered to parents to help them support their child at times of illness
- Information on the needs of young parents was disseminated in Tayside
- Work resumed in 2015 with a new Area Officer post and work focused on supporting families caring for sick children and representing their needs amongst statutory and voluntary agencies.

This work will have the following objective:

- CHS will seek funding to continue this work beyond March 2017.

Greater Glasgow & Clyde

- CHS has worked in this area via an Area post since the 1987, supporting statutory and voluntary sector agencies to reflect the needs of children, young people and their families in their policies, practice and service delivery.
- Families in the area caring for a sick child have been provided with support, advice and information or are signposted as appropriate
- CHS Dental Playboxes were first developed through this workstream.

This work will have the following objectives:

- Continue to promote child health rights and support the NHS Board to enshrine the rights agenda in all areas of its work
- Expand work in the area subject to funding.

Local Service Planning and Support

- Funding will be sought to implement CHS area staff across Scotland. Grampian has been identified as a priority area.

Development of New Services

- Potential new projects will be assessed against criteria including: justification in terms of need/demand taking into account current Scottish policy landscape; 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 as appropriate

- Review by CHS to be undertaken during 2018 to identify possible new service development areas taking into account findings of 2017-18 Parental Access & Family Facilities Survey and needs arising from the implementation of the Children and Young People (Scotland) Act 2014.

Potential new areas of service development include:

- Workstream focussing on training provision on children and young people's rights
- Work with under-represented/harder to reach families supporting them to access child health services

These activities will contribute to realising all five strategic aims as detailed in 8.1

9. Sources of Required Income -

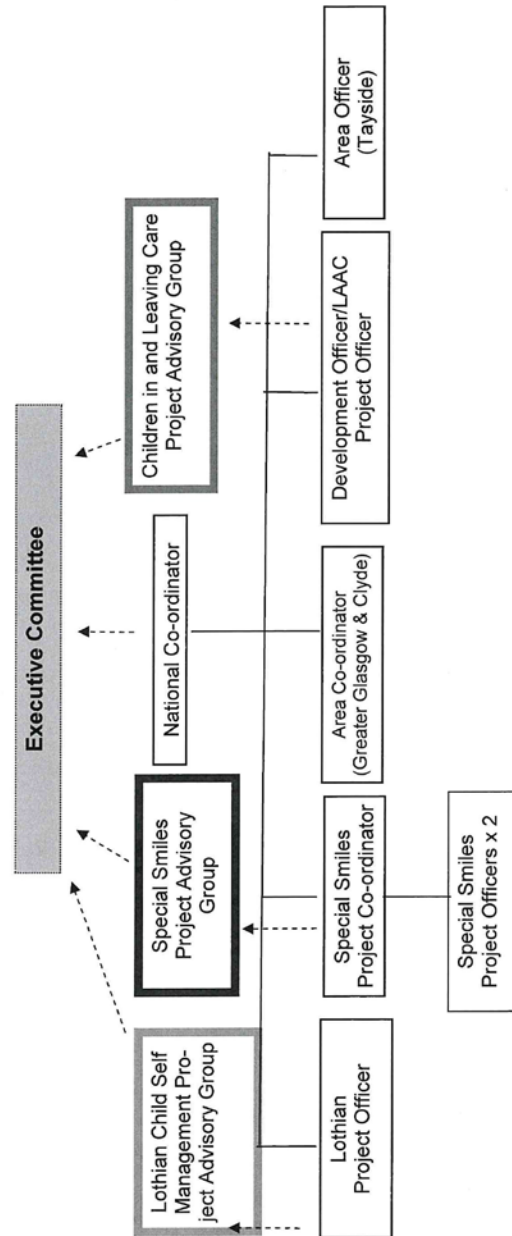
Potential funding sources to support the future development of CHS are outlined below. They all have criteria which are consistent with the aims of CHS's development priorities.

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	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 CHS activity.
Scottish Government	Ongoing work to secure funding from the Scottish Government which will focus on the impact of the work of CHS.
Local Authorities/Local Community Planning Partnerships	Opportunity to link the work of CHS to Local Authorities and Local CPP's.
Private Sector Sponsorship/Philanthropic Funding	CHS Funding Subgroup is looking at all opportunities to generate funds.
The Big Lottery	The opportunity exists for CHS to develop a major initiative through this source and look to secure 5 year funding programme.
Income Generation	Opportunity to develop income generation for CHS including sale of play box; training materials; training courses, conferences; etc.

Appendix One: Organisation Chart

Organisational Structure

Promoting the healthcare rights and needs of children and young people



Solid line denotes line management structure
 Dotted line link to and from project advisory groups

2015

Children's Health Scotland
22 Laurie Street
Edinburgh
EH6 7AB

Tel: 0131 553 6553
www.childrenshealthscotland.org
enquiries@childrenshealthscotland.org

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