



Helping sick children and young people meet their healthcare needs

Their Health Matters: Children and young people in and leaving care health Who is looking after me when I am ill?

PROJECT REPORT 2007-2010



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Registered in Scotland, Company No. 100114, Scottish Charity No SC006016.
Registered Office, 22 Laurie Street, Edinburgh EH6 7AB.

Email: enquiries@ascscotland.org.uk

Telephone: 0131 553 6553

www.ascscotland.org.uk

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1. BACKGROUND

The Project designed to focus on the health care needs and rights of children and young people in and leaving care has its roots in a number of key elements:

- Action for Sick Children (Scotland) core activity
- What we know from the literature
- Scottish Government Policy
- Health professionals' and health advisors' experience
- The young people's own experience

Action for Sick Children (Scotland) (ASC(S)) promotes the needs of *all* sick children and young people in our health care system working for improved standards and quality of care for children and young people when they are ill in hospital, at home or in the community. How much more so therefore for children and young people in care who may not enjoy the love and care of a supportive family? Healthcare for this group was therefore felt to be a priority area, where the organisation could become involved and make a difference.

There has for a number of years been considerable concern about the vulnerability and great needs of this group and this has been well documented in the literature.

The primary cause of poor health outcomes for this group is not the state of the child's health on the day they enter the system. It is rather the history of unmet need prior to being accommodated...these are compounded by the lack of our current healthcare systems to adapt to the needs of a mobile population,.....

Residential Care Health Project (2004)

While everyone would wish that all children should be in a state of physical, mental and social wellbeing, this should apply even more to children and young people who are looked after away from home. Unfortunately, research shows that they are among our most disadvantaged young people in terms of their health and wellbeing (Residential Care Health Project, 2004; Scott and Hill, 2006). There are problems with longer-term preventive care in the form of health surveillance and routine immunisations. It should also be recognised that they may face difficulties in the shorter term, when they are ill.

Recent Scottish Government Policy has also been focused on the needs of this group, as there has been considerable concern both at political and practice level at the less than favourable outcomes for children and young people who are looked after, whether at home or accommodated either in residential care or foster care. This has given rise to a number of Scottish Government documents and reports all striving to set out strategies and standards to help local authorities, health boards, schools and social work departments to rectify this situation and to improve the outcomes for this very vulnerable group of children and young people.

Looked After and Accommodated Children (LAAC)

The statistics available on LAAC make stark reading:

- At the beginning of the Project there were 14,886 **looked after** children in Scotland (1.) rising to 15,892 by July 2010, representing a 4% increase since March 2009
- One in every 100 children in Scotland is in care
- 30% of those leaving care aged 19 in 2006 did so without being in education employment or training (NEET)
- More likely to abuse solvents than their not-in-care peers

In January 2007, the Scottish Executive produced a report: **Looked After children & young people: we can and must do better** which set out the strategic way forward and signalled their intention to redouble their efforts to improve outcomes for looked after children and young people under five key areas, one of which is **Being emotionally, mentally and physically healthy**.

The report found that the health of our looked after children and young people remains poor when compared to other children and young people. This has the potential to have a serious and negative impact upon educational outcomes and future lives.

The call to greater working together was further outlined in the guidance to community planning partnerships on being a good corporate parent, the aptly named **These Are Our Bairns** (2008). These documents acted as both a spur to the project and as guides to prioritise our work.

ASC(S) works closely with a wide range of healthcare professionals all of whom had been reporting to us for some time their mounting concerns around the difficulties experienced by LAAC&YP when they had to access primary, secondary and tertiary healthcare services. In many cases this was without the support of a parent/carer which would have been available to their peers not in care.

The project also had evidence from the young people themselves, both directly and indirectly, to suggest that at best there was a lack of awareness of the difficulties and issues they face and at worst that lack of understanding manifested itself as stigma and lack of respect.

Development Officer Post

ASC(S) was funded by the Scottish Executive, Unified Voluntary Fund from April 2007 to March 2010 to identify and promote the healthcare needs of the more vulnerable groups, specifically *Looked After and Accommodated Children and Young People*, their families and carers. The funding enabled ASC(S) to implement a Development Officer post to work on this Project.

The work concentrated in the first instance on reviewing the areas of concern in the healthcare of LAAC when they are unwell and subsequently, in partnership with the young people themselves, on the development of information materials, resources and tools that encourage vulnerable users to identify signs of illness and assist them and their carers to access appropriate healthcare in all areas of Scotland.

(1.) Statistics Publication Notice: Children Looked After Statistics 2007-08, Scottish Government, November 2008

2. OVERALL AIM

Overall aim: To ensure best possible health care services are provided for Looked after and accommodated children and young people when they are sick at times of illness by:

- promoting universal recognition of the needs and rights of children and young people in and leaving care and
- developing appropriate resources for them and their carers to combat this vulnerability.

3. AREA

Scotland wide

The Project involved working across Scotland from national to local level, to raise awareness of the healthcare needs and rights of this group of young people via a range of different agencies in the field, through individuals, departments and organisations.

Local Areas

In addition to this awareness-raising on a Scotland-wide basis, 2 exemplar areas were also identified in order to progress the work at local level through hospitals, Community Child Health Teams, Looked After Children's (LAC) Nurses and residential schools and units. These were Fife (selected as being co-terminous and incidentally the only Health Board (HB) without any Specialist LAC Nurses) and Forth Valley (having 3 local authorities and representing a range of different socio-economic settings).

4. TARGET AUDIENCE

In order to ***promote universal recognition*** of the needs and rights of children and young people in and leaving care and to ensure the provision of best possible healthcare services for this group, it was necessary to liaise with and target a wide range of agencies and care providers. This included a range of healthcare professionals who would normally see any child from dentists to GPs, community child health practitioners to acute paediatricians in hospitals. It also included professionals within Education Departments, Social Work Departments and other voluntary agencies across the sector.

The Project found that even within sections of healthcare provision, there was a lack of awareness of the ways in which LAACYP are more vulnerable than their peers who are not in care and an unwillingness to acknowledge the impact that this vulnerability would have on their health outcomes.

The development of appropriate resources to combat this vulnerability and to equip them to better access healthcare services also brought us into contact with numerous different people, professionals, carers, and the children and young people themselves as we first tried to identify their needs before then developing suitable resources for all three of these groups.

5. DESCRIPTION OF THE PROJECT YEAR BY YEAR AGAINST THE AIMS AND OBJECTIVES

(For a full and detailed description of all project activity year by year under the objectives, please see Appendix 5 at the end of the report)

Year 1 – Objective: to identify the concerns and gaps around the healthcare needs of children and young people in and leaving care

This main objective was further broken down into three target areas as follows:

1. Raise awareness of ASC(S) work in relation to the proposed project
2. Identify and review areas of concern in collaboration with the various relevant agencies and networks
3. Relate these key issues to ASC(S) work to date to establish priorities for action

Year 1 Summary

The first year of the project was spent mapping the area of health care needs for this group of children and young people, networking and forging links with key agencies, mapping practice across Scotland, which included identifying good practice as well as concerns and gaps round their healthcare needs and planning how to take the work forward in the coming months.

Raising awareness of the core work of ASC(S) was fundamental to the success of the project and this was achieved through presentations, articles, mailings and exhibition stands at conferences, meetings with key organisations and individuals in the field. Partnership working and networking with the key organisations, agencies and individuals concerned with the healthcare of children and young people in care, as outlined in Appendix 5, enabled the project to identify areas of concern, issues and gaps for this group of children and young people.

The vital gathering and processing of information was also conducted via education events with NHS Education Scotland and others, and through policy documents and responding to consultations with the Scottish Government.

The combined activity of the first year made it possible to put together a picture of what the needs and issues were for this group of children and young people and begin to match these to the resources available within ASC(S) - how these might be utilized and how new materials might be developed. The following outlines their health issues and follows with some of the ways ASC(S) could meet these:

- Neglected health
- Health checks and missed appointments
- Self-care and hygiene
- Missed immunisations
- Navigating the system
- Registration with GP and Dentist
- LAAC&YP in hospital
- Oral health care and checks
- A parent/carer figure who knows them
- Transfer of health information

How ASC(S) could help:

- ✓ Awareness raising and policy
- ✓ EACH Charter and standards for health care
- ✓ General information
- ✓ Guides on coping with pain and needles
- ✓ Dental Play Box and Special Smiles Project for Additional Support Needs (ASN)
- ✓ Children and Young People's Healthcare Rights Resource Pack

Year 2 – Objective: adapt ASC(S) work and resources to the needs of this group

1. Adapt ASC(S) Standards of Care for CYP in Hospital/EACH charter specifically to enhance the care for vulnerable families
2. Review materials and publications and consider accessibility for a group who move frequently and may have difficulty with written formats.

Year 2 Summary

In its second year the Project gained considerable momentum and consequently credibility with key partners and other agencies, not only through attending conferences and workshops but also by being invited to present on the healthcare needs and priorities of LAAC&YP when they are sick. Highlights from the year included giving a workshop at the **Who Cares? Scotland 30th Birthday Conference**, presenting at the **SACCH Conference on Children and Poverty**, the **Care and Justice Team at the Scottish Government** and the **Scottish Child Health Commissioners Group**.

It was in September 2008 that the first LAAC Advisory Group meeting was held to advise on the direction and running of the project and since then these have been held quarterly. The membership is drawn from health professionals across the sector some of whom are co-opted as and when necessary some of whom remain in touch via the group's distribution list for example, Caroline Selkirk, Child Health Commissioner, NHS Tayside (See Appendix 9) and their support is much appreciated.

The Project Officer (PO) was delighted to be able to work in partnership with other agencies in particular NHS Scotland on the 2nd edition of their LAC A-Z Health Resource Pack for Carers (see Appendix 2) and is delighted to be part of the Scottish Healthy Care Network management committee.

We were also very pleased to be invited to contribute to the SIRCC's Journal – Scottish Journal of Residential Child Care - Special Health edition.

The main thrust of the work in Year 2 centred round the findings from the healthcare professionals' surveys and interviews, the work with staff and young people in residential care settings and the development of resources and materials to meet the identified needs of this group. This work is ongoing and includes the new ASC(S) booklets for carers ***What to expect when a child goes to hospital*** and ***The GP Service for Children and Young People***.

(For a full description of the resources and materials produced as a result of the project, please see Appendix 7 for an outline of the toolkit.)

Year 3 – Objective: Disseminate findings and resources across relevant sectors particularly social work and education.

1. Raise awareness amongst those who look after vulnerable children and young people about their care during times of illness (to include coping without parents, consent to treatment, advocacy and young carers when they fall ill)
2. Pilot relevant materials in to school health promoting sessions as a tool to enhance school curriculum (e.g. how to access healthcare services at times of illness)
3. Provide information and support for carers and staff

In the final year of the project, the survey and interview findings, along with the development of the toolkit materials, formed the major part of presentations on the project. These were delivered to groups from Government level to local level, NHS Boards and Local Authorities' Social Work and Education Departments, as we sought to raise awareness and report on the work of the project amongst those who look after vulnerable children and young people, about their care at times of illness.

One of the main outcomes of the year was the development, design and publication of the toolkit resources and in particular the podcast interviews with healthcare professionals involved in the care of LAAC&YP. These represent a rich seam of knowledge and information designed to promote cross-fertilisation of ideas amongst healthcare staff and celebrate good practice. They can be found on the Action for Sick Children Scotland website at:

<http://www.ascscotland.org.uk/default.asp?page=86>

6. BARRIERS, CHALLENGES AND RESOLUTIONS

Knowledge of ASC(S) and its work.

Amongst the “Looked after and accommodated Children’s sector, there was little instant recognition or awareness of ASC(S) as an organisation. It was therefore necessary to spend some time at every event or presentation describing our core activity and outlining what ASC(S) could offer before there could be any understanding of how we would meet the demands of C&YP in and leaving care and the healthcare staff looking after them. Over the life time of the Project, awareness of our work was developed and respect and credibility won with key partners but at the beginning of the Project, the challenge of working with a blank sheet was immense/considerable.

Alignment in an already busy field

In the early days of the project, it was often the case that there was confusion about the precise nature of our involvement in the healthcare of LAAC, particularly with regard to already existing services and whether we might be duplicating their work. This made the first year challenging at times. Once it was made clear that the Project was working for the needs of LAAC at times of illness i.e. *Who looks after me when I am ill?* then there was greater willingness to work with ASC(S). There are a considerable number of agencies and projects in the field providing promotional or preventative initiatives, from sexual health to substance and alcohol use, mental health, healthy eating and exercise and smoking cessation, but it became apparent that none of them was focussing on young people’s access to primary, secondary or tertiary health services at times of illness.

It took time to break into a new field, win people’s trust and make an impact so it was gratifying to hear at the launch of the toolkit at the Scottish Healthy Care Network conference in March 2010, the ex-chair of the Network saying,

That's great it's turned out really well. I bet you could never have imagined that back in December 2007 when you were just starting out.

Time delays even after identifying the right person.

Despite the initial mapping exercise, it was at times very difficult to contact the relevant leads in the Local Authorities. One example of this was when trying to locate the officers responsible for LAC in schools. We were able after some detective work to get to the right department and even identify the correct lead, but getting a response from them was often difficult and meetings got pushed further and further into the distance. On reflection, this may be due to being an outside organisation and outwith the usual LAAC networks or even because we were not based in the same geographical area (we are often working in an outlying area). We could easily have been ignored if we had not pushed very hard indeed. Key contacts and much persistence were needed and in the end we found that although time-consuming, we were able to make some surprising breakthroughs.

Accessing the Young People

Perhaps the hardest part was gaining access to the young people themselves. Although the exceptions were the residential schools in Stirling and Fife, who showed great willingness to work with us and to let us talk to the young people. Often we would be approached by a healthcare professional for information, and preliminary meetings suggested that we would be able to engage with the YP, but after consultation with line managers, nothing else would happen and the trail would go cold. Following the group and focus group work carried out in the schools earlier in 2009 and 2010, it was decided to conduct individual interviews with the YP and this met with some success. It was almost as if they felt freed up from the peer pressure of the larger group to express what was actually in their minds and some of them were very forth-coming and articulate about their experiences in accessing healthcare services.

Policy Groups

Two of the key LAAC policy initiatives were already well underway by the time the PO came into post and by the time the Project was properly up and running, were well advanced in, if not concluding their work. They were the Scottish Government's **We can and must do better** health working group and the NHS Health Scotland's A - Z resource Pack for Carers and staff. In the case of the former, however, it was possible to meet and discuss the work of the group with the Chair and obtain the final report and in the case of the latter, while it was not possible for ASC(S) to be referenced in the first edition, the organisation was included in the reprinted edition.

Research and Ethics

The final hurdle, which arose from a misunderstanding, centred around whether or not ethics approval was needed in relation to the Project's survey which was seeking the views of healthcare professionals and young people. The Project had gathered feedback and information from these groups within a Patient Focus Public Involvement (PFPI) agenda where patients' views are used to shape and inform the delivery of healthcare services. Unfortunately, at a presentation to a Scottish Government health care group, the Project was incorrectly described as a research project and this precipitated concerns within NHS Fife, who insisted that ethics approval was necessary before proceeding. A considerable amount of time had to be devoted to investigating the situation. In the end, ethics approval was not needed for any aspect of the Project on the basis that it was not a research Project.

7. DEVELOPING THE PROJECT IN THE FUTURE

Two distinct areas of work have emerged which will form the strands of future project work, after a successful application to the Scottish Government for a further year's funding.

The production of the LAAC toolkit, coupled with ASC(S) Children and Young People's Healthcare Rights: A Resource Pack and other ASC(S) materials, will allow us to develop training resources for carers and professionals caring for LAACYP both through the Fostering and Kinship carer agencies and networks and the Inclusion Teams in Education Departments within the Local Authorities.

The second strand of future project work centres round the Scottish Government sponsored Seasons for Growth Programme and ways in which it could be adapted for children and young people in care to enable them to identify ways of coping with change and loss. A programme will be developed and delivered amongst YP to help them develop greater resilience and enhanced self-esteem in order to better cope with times of ill health.

8. CONCLUDING REMARKS AND RECOMMENDATIONS

In recent years, there has been increasing awareness and focus on the need to improve outcomes for children and young people in and leaving care within both Social Work and Education. However, the focus in Health tended to be on the promotion of physical, mental and emotional well-being and much less on the healthcare needs and rights of looked after and accommodated children and young people at times of illness.

From 2007 – 2010 this Project has worked to raise awareness of the healthcare needs of and rights of this group of children and young people and has developed materials to combat their vulnerability. We believe it has made a valuable contribution not only within the wider health agenda, but also across Social Work and Education.

Action for Sick Children (Scotland) will continue to work for all children and young people, including those looked after at home, accommodated away from home with foster or kinship carers, in residential care homes, residential schools or secure units, in order that they have access to the highest standard of healthcare at times of illness. ASC(S)'s current manifesto outlines healthcare gaps in child health provision. Manifesto points 4 and 5 make specific mention of looked after children and young people and ASC(S) asks the Scottish Government, MSPs and those responsible for child health policy to address these along with the other manifesto points.

In conclusion, the Project would like to make the following recommendations:

In conclusion, the Project would like to make the following recommendations:

1. Respect and understanding

Children and young people in care have the same rights and expectations of healthcare as those who live in supportive families. Healthcare staff should be assisted to develop awareness and understanding of the difficulties and issues for this group so that their care is as inclusive as possible.

2. Access to healthcare services

Health and social services can be expected to make provision to prevent delayed or inadequate assessment or treatment resulting from lack of health record availability or frequent relocation of CYP.

Health professionals and NHS administrators encountering children and young people in care must recognise the vulnerabilities associated with this experience and must have the knowledge and skills to facilitate timely and effective delivery of health care. This may involve prioritising access to services, pre-assessment clarification of parental rights and responsibilities and enhanced tracking of non attendances or flexible opportunities to attend necessary appointments.

3. Systems, practice and protocols

Systems, practices and protocols should be flexible enough to take account of the extra vulnerability and additional support needs of these YP so as to allow staff to act in accordance with the child's best interests. For example, the Scottish Care Information (SCI) gateway (National IT referral system) should include a box for 'looked after child' that can be ticked by the referring GP so that secondary care is alerted to their status.

4. Education and inclusion

Absence from school due to ill health may compound problems of frequent changes of school and loss of social relationships with peers. It is incumbent on all children's services to ensure inclusion and Additional Support Need provision encompasses any child or young person who is looked after or accommodated whether in statutory care or other forms of care involving absence from the parental home.

5. Self Care and self management

Children and young people in care need extra support to empower them to obtain the help they need during times of illness, including coping with chronic disease that affects their daily lives. This may involve specifically written information, the availability of a key worker, mental health and well-being support, access to self-management programmes for CYP with long term conditions, peer education and the support of condition-specific support groups or other individual actions.

Children and especially young people in care should be offered support in identifying their health needs and accessing health care appropriately. This support may include the Specialist LAC Nurse Service, information on young people's healthcare rights and responsibilities via the YP EACH Charter. Guidelines should also be developed to help YP articulate their needs e.g. that they want their **carer** to accompany them.

6. Carers and others (e.g. foster, kinship and residential staff)

All healthcare training should increase awareness of carers' roles and responsibilities so that this important role is acknowledged and understood. It would be helpful to have a system for identifying carers such as the one exemplified in the BMA toolkit for Children and Young People. (1.)

Foster carer training should include information on CYP healthcare rights, including consent, to ensure carers are aware of potential barriers and how to overcome these to ensure YPs' access to appropriate healthcare.

The last word of all should be left to one of the young people who worked with the Project and who when asked what helped gain their confidence during an appointment with a healthcare professional said:

I like it, ken, when they tak time tae explain an they've got that look on their face that says we do care what's going on wi people

**Anne Wilson
Project Officer
Children and young people in and leaving care healthcare project
Action for Sick Children (Scotland)
2010**

(1.) http://www.bma.org.uk/ethics/consent_and_capacity/childrentoolkit.jsp

APPENDIX 1 – ADVISORY GROUP REMIT

ACTION FOR SICK CHILDREN (SCOTLAND) CHILDREN AND YOUNG PEOPLE IN AND LEAVING CARE HEALTH PROJECT ADVISORY GROUP REMIT

Overall Purpose

The Project Advisory Group is responsible to the ASC(S) Executive Committee for oversight of the Project. The project will, over a three year period, promote the healthcare needs of *Looked After and Accommodated Children and Young People*, their families and carers. The work will concentrate, in the first instance, on reviewing the areas of concern in the healthcare of LAAC when they are unwell and subsequently in partnership with the young people themselves, on the development of information materials, resources and tools in ways that encourage vulnerable users to identify signs of illness and assist them and their carers to access appropriate healthcare in all areas of Scotland. The work will initially be carried out in two or three exemplar areas and subsequent findings and resources rolled out across Scotland.

Key Responsibilities

- To steer the overall direction and development of the Project through provision of advice and guidance to the Development Officer and ASC(S) Executive Committee
- To ensure that the Project operates within the parameters of its aims and objectives
- To ensure it meets all necessary reporting requirements and to report to ASC(S) Executive Committee on the progress of the Project.
- To uphold the duty of trust invested in the position of a member of the Advisory Group, ensuring these duties are carried out in a way which increases public trust and confidence in Action for Sick Children (Scotland)

Accountability

The Children and Young People In and Leaving Care Health Project Advisory Group is accountable to ASC(S) Executive Committee.

Frequency of Meetings

Quarterly and where possible by telephone conference (with the exception of the introductory face-to-face meeting).

Membership of Group - maximum number 9

Chair: Dr. Una MacFadyen, Consultant Paediatrician, NHS Forth Valley and ASC(S) Executive Committee Member

Elizabeth May, ASC(S) National Co-ordinator

Anne Wilson, Development Officer and LAAC Project Officer

Caroline Selkirk, Child Health Commissioner, NHS Tayside (minutes only)

Dr Aileen Stewart, Community Paediatrician, Fife

Susan Milne, Community Children Nurse, NHS Forth Valley

Dr Sharon MacHale, GP. Edinburgh

Gillian Lauder, Specialist LAC Nurse, Dundee

Kirsty Anderson, Scottish Community Children's Nurses Forum (minutes only)

Carol Watson, Specialist LAC Nurse in NHS Lothian (minutes only)

APPENDIX 2 – BIBLIOGRAPHY

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8. NHS Health Scotland (2009). *Caring About Health: Improving the health of looked after and accommodated children in Scotland. An A-Z health resource pack for staff and carers*. Edinburgh: NHS Health Scotland.

APPENDIX 3 – BACKGROUND PAPER

Looked After and Accommodated Children and Young People

Action for Sick Children Scotland (ASCS) is the only Scottish charity which promotes the needs of all sick children and young people in our health care system. We work for improved standards and quality of care for children and young people when they are ill in hospital, at home or in the community. We aim to represent their and their families' needs and ensure that their voices influence health policy, planning and practice. We do this in partnership with carers, professionals and children and young people themselves. The leaflet in your packs will tell you more about what we do.

Looked After and Accommodated Children (LAAC)

The current statistics available on LAAC make stark reading:

- There are 14,886 **looked after** children in Scotland (Statistics available for 2007)
- One in every 100 children in Scotland is in care
- 30% of those leaving care aged 19 in 2006 did so without being in education employment or training (NEET)
- More likely to abuse solvents than their not-in-care peers

In January 2007, the Scottish Executive produced a report: **Looked After children & young people: we can and must do better** which set out the strategic way forward and signals their intention to redouble their efforts to improve outcomes for looked after children and young people under five key areas one of which is **Being emotionally, mentally and physically healthy**.

The report found that the health of our looked after children and young people remains poor when compared to other children and young people. This has the potential to have a serious and negative impact upon educational outcomes and future lives. Some emerging issues:

- Regular medical and dental health checks
- Registration with GP and Dentist
- Immunisations
- Therapeutic support
- Navigating the healthcare system and accessing appropriate care

Development Officer Post

As part of this post, ASCS has been funded by the Scottish Executive to focus on promoting the healthcare needs of the more vulnerable groups, specifically *Looked After and Accommodated Children and Young People*, their families and carers. The work will concentrate in the first instance on reviewing the areas of concern in the healthcare of LAAC when they are unwell and subsequently in partnership with the young people themselves develop information materials, resources and tools in ways that encourage vulnerable users to identify signs of illness and assist them and their carers access appropriate healthcare in all areas of Scotland.

To assist us in this work, we would like to hear the views of healthcare professionals caring for LAAC on their health needs and priorities. If you would like to participate in this work, then we want to hear from you. Contact Anne Wilson at: a.wilson@ascscotland.org.uk Tel: 0131 553 6553

APPENDIX 4 – AIMS AND OBJECTIVES

Their Health Matters: Children and young people in and leaving care health project

Aims and objectives

Overall aim: To ensure best possible health care services are provided for Looked after and accommodated children and young people when they are sick at times of illness by:

- promoting universal recognition of the needs and rights of children and young people in and leaving care and
- developing appropriate resources for them and their carers to combat this vulnerability.

Year 1 – Objective: to identify the concerns and gaps around the healthcare needs of children and young people in and leaving care

1. Raise awareness of ASC(S) work in relation to the proposed project
2. Identify and review areas of concern in collaboration with the various relevant agencies and networks
3. Relate these key issues to ASC S work to date to establish priorities for action

Year 2 – Objective: adapt ASCS work and resources to the needs of this group

1. Adapt ASC S Standards of Care for CYP in Hospital/EACH charter specifically to enhance the care for vulnerable families
2. Review materials and publications and consider accessibility for a group who move frequently and may have difficulty with written formats.

Year 3 – Objective: Disseminate findings and resources across relevant sectors particularly social work and education.

1. Provide information and support for carers and staff
2. Pilot relevant materials in school health promoting sessions as a tool to enhance school curriculum (e.g. how to access healthcare services at times of illness)
3. Raise awareness amongst those who look after vulnerable children and young people about their care during times of illness (to include coping without parents, consent to treatment, advocacy and young carers when they fall ill)

APPENDIX 5 – DETAILED DESCRIPTION OF ACTIVITY IN YEARS 1, 2 AND 3

Year 1 – Objective: to identify the concerns and gaps around the healthcare needs of children and young people in and leaving care

This main objective was further broken down into three target areas as follows:

1. Raise awareness of ASC(S) work in relation to the proposed project
2. Identify and review areas of concern in collaboration with the various relevant agencies and networks
3. Relate these key issues to ASC(S) work to date to establish priorities for action

These were achieved via the project activity set out under three main headings:

1. Raising awareness
2. Networking and partnership (forging links with key agencies)
3. Gathering and processing information

all three of which were designed to meet the target areas described above.

1. Raising awareness (i) conferences, ii) meetings, iii) presentations, iv) articles and mailings) was carried out via various activities. This served a triple purpose of informing people of the work of ASC(S), telling them about the focus of the present project and allowed the PO to collect information and map the area in order to set project priorities.

1. i) Raising awareness at conferences

In September 2007, the PO attended the inaugural meeting of the Scottish Healthy Care Network (SHCN) with the new ASC(S) publicity materials of poster, and general leaflet. A background paper (Appendix 3) had been prepared at this point to publicise the project, setting out the scope and aim of the project. At this meeting, the PO had the opportunity to meet with many of the Specialist LAC nurses and the Senior Programme Officer at NHS Health Scotland responsible for the LAAC A-Z Health pack and agreed that ASC(S) contact details could be included in appropriate sections of the pack.

In November, the PO attended Children's Hearing System National Panel School in Dunblane, where the theme of the weekend was LAAC and each delegate received an ASC(S) leaflet and a briefing document on the Project. This was an awareness raising exercise which received very little direct response, but did afford the opportunity to speak to and later to meet the Scottish Government lead for corporate parenting, Anna Fowlie, who, subsequently become a staunch supporter of the Project.

In the spring of 2008, there were three major national events which were relevant to the work and which allowed the PO to widen the field of awareness to include Primary Care, Community Child Health and the Scottish Government, NHS Health Scotland and the Residential Health Project:

- **Walk the Talk Conference**, - a stand at this conference looking at health, primary care provision for young people. The PO also attended a workshop on LAAC in addition to networking and meeting colleagues in the field.

- **Scottish Association for Community Child Health (SACCH) Conference** where several contacts amongst LAAC paediatricians were forged and plans made to take these forward in Fife and Borders.
- **A-Z Resource Pack for LAAC, Health Scotland** launched at Edinburgh Secure Services. This proved an excellent opportunity to network and create future opportunities. Caroline Selkirk, CHC Tayside, chair of the Health Working Group within **We can and must do better** asked to meet to discuss the ASC(S) project. Nuala Healy (Health Scotland YP Programme Manager) expressed an interest and hope that we can be included in any reprint of the LAAC A-Z Health Pack for Carers (See Appendix 2 (8))

1. ii) Raising awareness through meetings

Individual meetings with lead officers for various agencies both statutory and voluntary, health care professionals, Scottish Government (SG) officials etc all enabled the PO to raise awareness of ASC(S), explain the aims and objectives of the project and gain valuable insights and information about the healthcare issues for children and young people in and leaving care. These meetings included the following;

- Anna Fowlie, lead for *Corporate Parenting at SG* – orientation meeting with useful contacts. Possible input to the Health Subgroup of the SG's **We Can and Must Do Better** policy group/be kept informed as to their activities.
- Steve McCluskey from *Scottish Healthy Care Network* – orientation meeting for the project which planted the seeds of the GP survey and GP Publication (see below) and future involvement in the network management group and conferences.
- Ian Millar from *British Association for Adoption and Fostering (BAAF)* - orientation meeting for the project
- LAAC Nurse Specialist, Jackie Dougall for NHS GGC who shared her knowledge and expertise and expressed a willingness to support the work.
- Dr Juliet Farquhar, Lead paediatrician for LAAC, NHS Forth Valley who invited the PO to meet the LAAC team and also provided many useful contacts in this area.
- NHS Fife, Maxine Moy, Nurse Consultant for Vulnerable Families and the Barnardos's Fife Children's Rights Officer
- Further meetings with healthcare professionals both paediatricians and LAAC nurses in Tayside and Fife have enabled a deeper understanding of the issues for this vulnerable group

1. iii) Raising Awareness Through Presentations

The PO was very fortunate to be in a position within the first year to deliver presentations not only on the work of ASC(S) but also on the emerging work of the project. These took place as follows:

- *LAAC Team in Greater Glasgow and Clyde* to talk about the project. It appears that Glasgow is an area which is very well served and may provide numerous examples of good practice.
- *British Association for Fostering and Adoption* on the aims of our work and made further useful contacts
- *Rachel House workshop on transition for parents and kinship carers of children with exceptional health care needs* – this furnished a valuable insight into the issues for children and young people who are in care by virtue of their very significant and complex health care needs
- The LAAC team in Stirling and through this links with the Through Care and After Care nurse

1. iv) Raising Awareness through articles and mailings

- Wrote a short article to encourage interest in the work available on the ASC(S) website, a shortened version of which appears in the newsletter, Spring 2008
- Designed flier to advertise the project at relevant conferences throughout the autumn.
- The background paper (Appendix 3) was sent out with a covering letter and ASCS publicity material to all residential units across Scotland and members of the Scottish LAC Nurses Forum with in the case of the latter a preliminary questionnaire.

2. Networking and Partnership (forging links with key agencies)

As already mentioned, all networking and partnership opportunities worked at three different levels to further the aims of the project. The officer forged relationships with the following and was able to engage in joint working through various different levels of engagement.

- The Scottish LAC Nurses' Forum – This group assisted the Project through a survey, individual meetings and enabling the Project to co-opt one of the nurses to the Project Advisory Group
- The Scottish Throughcare and Aftercare Forum (STAF) – enabled a greater understanding of the issues for care leavers through attendance at their conference on transition
- British Association for Adoption and Fostering – an initial meeting with the Scottish Officer led to an opportunity to present to the BAAF Medical Advisory Panel and an open invitation to return and to keep them updated on progress
- Residential Units and schools throughout Scotland – Mailings allow these to be kept informed and the possibility of working with specific units as and when appropriate
- NHS Health Scotland – this connection has proved advantageous not only for the LAAC Health care project but for ASC(S) as a whole – contributions to the Youth Health Bulletin under Nuala Healy and Jo MacLennan
- Scottish Healthy Care Network (SHCN) – after the initial meeting, the officer was invited to their conference with a stand which then paved the way for greater involvement in the SHCN management committee and subsequently the opportunity to present the final project toolkit (see year 3 below).
- Scottish Government, 2007 ***Looked after children and young people: we can and must do better*** and the Health group, *being emotionally, mentally and physically healthy* under the direction of Caroline Selkirk, Child Health Commissioner for NHS Tayside

3. Gathering and Processing Information (understanding policy and gathering views)

- December – attended the NES Educational Event for LAC Nurses to draw up a draft of competencies for this post for the *Looked After Children's Nurses Capability Framework, NES*
- *Through Care and After Care Team* attended training meeting with City of Edinburgh SWD
- Designed and disseminated background paper and questionnaire for LAAC health professionals to help gather their views in order to establish more precisely where the gaps are and how ASC(S) could develop resources and tools to help fill these. (Appendix 7)
- 2 consultations for comment:
 - *The Looked After Children (Scotland) Regulations, Scottish Government*
 - *Looked After Children's Nurses Capability Framework, NES*
- LAAC Project Advisory Group. This involved identifying members, preparing the necessary paperwork, group remit, progress report of work so far, aims and objectives and future work plan. (Appendix 2)

Year 2 – Objective: adapt ASCS work and resources to the needs of this group

1. Adapt ASC(S) Standards of Care for CYP in Hospital/EACH charter specifically to enhance the care for vulnerable families
2. Review materials and publications and consider accessibility for a group who move frequently and may have difficulty with written formats.

Although not specifically set out as a target under Year 2, the work of raising awareness, as described in Year 1, was still extremely important to maintain relationships and awareness of the project and to forge new ones with partnership organisations and individuals. It was also only in this way that the project was able to keep abreast of developments in the field and continue to keep its work on the radar of partners. Accordingly, this has been reported here in Section 1 along with networking and partnership with key agencies.

To meet the second of the two targets outlined above under the Year 2 Main Objective, it was also necessary to continue to gather information and as this activity forms an integral part of the development of resources and materials, it has been included to support target 2.

1. Raising awareness through networking and partnership

1.1 Conferences

- **Children 1st conference in Aberdeen, *Relatively Speaking* on kinship care** – exhibitor stand and excellent networking opportunity. John Brown of Health Scotland invited the project officer to review the LAAC A-Z Resource Pack for NHS Health Scotland
- **Scottish Healthy Care Network** – Stand to display work and ASC(S)'s Children and Young People's Healthcare Resource Pack (CYPHRP) which attracted a great deal of interest
- **Scottish Institute for Residential Child Care (SIRCC) Day Seminar on Transition** for CYP leaving care and for young disabled people moving on –

useful contacts leading to invite to deliver workshop at the Who Cares?Scotland Rights of the Child conference on 20 November (See 1.2 Presentations below)

1.2 Presentations

- **Who Cares Scotland 30th birthday celebration conference** - having attended the Transition seminar (above), the PO was invited to conduct a workshop based around children and young people's healthcare rights on this International Children's Rights Day to fit the conference theme, **challenging stigma and celebrating success**. Considerable thought and discussion went into this with both the officers at Who Cares and the conference-organising body SIRCC.
- **Scottish Child Health Commissioners Group** – presentation on the work of ASC(S) and the LAAC project. It was warmly received with an invitation to return to report on the project.
- **Scottish Association for Community Child Health**, at RCPE in Edinburgh on the Effects of Poverty on Children (stand and presentation) the National Coordinator and the PO attended and heard Harry Burns, CMO for Scotland, deliver his inspiring talk on *The Biology of Poverty*. The PO presented on **Helping CYP in care when they are sick**, taking as her theme the corporate parent and the contribution made by the many health care professionals involved in the care of LAAC or YP when they are ill.
- **LAAC Health Forum in NHS Fife** – contact through Maxine Moy who expressed concern around the gathering of information from the young people. The forum felt that ethics approval was needed. (see Section 6 on Barriers etc. in main report, page 6)
- **NHS Dumfries and Galloway** – presentation on the work of ASC(S) and the LAAC healthcare project. This resulted in an opportunity through their LAAC Nurse for other work, a publications order and request for training and audit of CYP healthcare provision.
- **Scottish Government's Care and Justice Team** – Presentation at Divisional Meeting through Anna Fowlie, Lead for corporate parenting. She had participated in the Who Cares?Scotland workshop and wanted to experience the Healthcare Rights Pack activities.

1.3 Network and partnership working

- **Children's Hearing System** – exhibition stand at a resources fair in the City Chambers in Edinburgh –resulting in an introduction to a residential school in Fife (Falkland House School) to work with staff and boys.
- **Kirstie Anderson, Community Children's Nurse (CCN) in Shetland**, chair of the CCN Forum re membership of the LAAC Advisory Group representing the remote and rural perspective from a CCN perspective. This resulted in identifying Susan Milne (NHS FV) for the LAAC advisory group while Kirsty remained on the email distribution list
- **GP Involvement** – Dr Sharon MacHale, GP in Edinburgh and Royal College of Paediatrics and Child Health (RCPCH) Scottish Committee GP Rep became a member of the LAAC Advisory Group
- **SHCN management committee** meeting –invitation to join the SHCN management group. Proof of the growing acknowledgment and credibility of the project
- **Caroline Selkirk, CHC for Tayside**, liaised on outcomes of the **Being emotionally, physically and mentally healthy** working group

- **Gillian Lauder, Specialist LAC Nurse** collaborated on the development of the Questionnaire for healthcare providers
- **CAMHS in NHS Fife** – met with Rhona Sime, child and adolescent psychiatrist in NHS Fife to talk about the project and her possible involvement to give the mental health perspective to the project
- **Compass for Health Project in Forth Valley** - met Helen Manson, project coordinator to talk about the LAAC project and introduce her to the Healthcare Rights Pack which she ordered
- **National Managed Clinical Network (NMCN) for Children with Exceptional (healthcare) Needs CEN** - launch in Edinburgh on 17th June. Many children and young people in this category are in care by virtue of the fact that their exceptional healthcare needs mean they require respite, at which point they become technically **looked after and accommodated**. We have engaged with the hospice staff at Rachel House and Robin House to gather views on the needs and priorities for this group
- **SHCN Meeting** - discussion with Residential Unit Care Manager round A and E arrangements for YP in care, compliance, waiting times, separate waiting rooms and consent and adherence to treatment. The PO liaised with ASC(S) contacts in Glasgow to take this forward at A and E management level.

2. Review Materials

2.1 Information Gathering (understanding policy and gathering views)

2.1.1 Policy

- **Patient Rights Bill Scottish Government** – collated ASC(S) staff comments on the consultation and compiled ASC(S)'s response.
- **Improving the Lives of Children in Scotland - are we there yet?** – attended a Scottish Government event to discuss the government's response to the UN Committee on the Rights of the Child. It goes without saying that while we might be falling very far short of meeting the needs and rights of all children and young people in the UK today, the group for whom this remains of paramount importance is C&YP in and leaving care
- **Consultation on the Scottish Government's response to the 2008 Concluding Observations from the UN Committee on the Rights of the Child** – the PO collated ASC(S)'s response having collated feedback from the three events which staff attended on the following themes: (the ones in bold are the most relevant to this project)
 - Education and Play
 - **Children and young people with disabilities**
 - **Health and Wellbeing**
 - Family Life

2.1.2 Learning

- **Rock Trust** - attended lecture on promoting the resilience of vulnerable young people
- **Learn the Child** – supporting the education of traumatised children – the PO attended seminar run by Children in Scotland in Glasgow. This was an excellent event and gave rise to more useful contacts.

- **Abuse and Beyond** – participated in the Children’s Hearing System National School on all types and levels of abuse, chaired by Barbara Hudson the CEO for BAAF. This was very pertinent to the LAAC healthcare Project work
- **Looked After Children and Young People: ensuring the achievement of potential** (Holyrood Conferences) Excellent opportunity to learn more about the issues needs and priorities and to network with key agencies and partners in the field. Link forged with fostering network Tact and meeting arranged.
- **Health Information for Children Workshop** organised by the Patient Information Forum on information development for children and young people and included a session on **Staying Positive** the Young Expert Patient Programme on self management. This workshop informed the development of the project toolkit on producing information for children.

2.1.3 Gathering information and views

In the first year of the Project information had been gathered from the Scottish LAC Nurses and others to inform understanding of the issues and to help take the work forward. It was then suggested at a LAAC Advisory Group meeting that the information gathering strategy should be widened to include **all** health care professionals involved in the healthcare of LAAC&YP. Taking as its guidance for this the recommendations in **These are our bairns**, the questionnaires were developed and adapted to fit the individual remit of the specific healthcare professional.

Surveys These were then sent out with a background paper on the Project, covering letter explaining the rationale for the approach and the methodology, and where necessary a SAE for return by a specified deadline to the following healthcare professionals:

- GPs (NHS Fife and NHS Forth Valley, followed by NHS Lothian after a very small response from the first 2 areas)
- Specialist LAC Nurses (Scotland wide and to each HB area)
- Acute Paediatricians (Scotland wide and to every hospital with paediatric provision)
- Community Paediatricians (through the SACCH membership)
- Community Children’s Nurses (through the Scottish Community Children’s Nurses Forum)
- CAMHS Through care and after care specialist nurse (individual)
- Residential Care Staff
- Hospice Care Staff in Rachel and Robin Houses
- Health Coordinator at *Includem* (individual)
- Hospital Play Specialist (individual)
- Young People including those in Secure Accommodation and Residential Care

A total of 93 questionnaires were returned and the responses have been collated in reports on each healthcare specialty where full details can be found.

The overall picture presented some encouraging findings and there were some very positive examples of good practice initiatives which have been documented in the various reports. Certainly, what did emerge very strongly was the sheer variety and disparity in practice across Scotland with a clear need for more standardisation in

working practices particularly when one considers just how mobile this population is particularly in regard to information handling and tracking etc.

Interviews

Just prior to the postal and electronic questionnaires being sent out, a series of telephone interviews with healthcare professionals and young people (face-to-face) were conducted. This material has proved invaluable in informing the development of the project materials, the SACCH conference presentation (*Who looks after me when I am ill?*) provided information for the Journal article (See 2.2.3 Scottish Journal of Residential Child Care) and has formed the basis for the website podcasts which form part of the final project toolkit. The range of people interviewed also included foster carers.

FOI Request

Concerns had been raised at an Advisory meeting around consent and confidentiality for children and young people in care and a wide variety of practice and knowledge was reported amongst professionals. The question arose as to whether Health Boards (HB) provide guidance on this and how this was made available to staff and to parent/carers. Accordingly a Freedom of Information request was sent to the CEOs of all HBs on their arrangements vis-a-vis consent guidelines for CYP. Most HBs did provide guidance but this varied enormously both in content and form and a few boards either did not reply or did not have anything. This is widely considered to be a very complex, unclear area and one which would merit further exploration and guidance.

2.2. Materials Development

After consultation, it emerged that much of the information made available to LAAC C&YP is not in written format and in fact is given to them verbally by their healthcare worker, usually the LAC Nurse or residential care staff. Thus the rationale behind the Project's resources and materials strategy took account of the fact that it was equally important to have resources for **staff** to help and support their care of the young person.

It also became apparent that different media would be important, hence the decision to include in the ASC(S) website, the podcast interviews and the audio versions of some of the guides. The very visual nature of the Young People's EACH Charter was also designed to appeal and to facilitate accessibility for all young people.

At this point in Year 2, the ASC(S) website was being redesigned with the inclusion of the pages dedicated to the project on the healthcare of children and young people in and leaving care.

2.2.1 Publications

- LAAC flier edited for conferences so that it read more sensitively to the work of the LAAC specialist nurses i.e. *clinic appointments*, replaces *health checks*.
- Update and rewrite of ASC(S) booklets, *You and Your GP*, *What to expect when you go into hospital* and *Teenagers in Hospital*. These take account of a wider audience which aims to be more inclusive and will therefore refer to **carers** rather than parents and birth children ensuring that these publications are inclusive of all children including LAAC without labelling them as such in order to avoid possible stigma.

- The new booklets are entitled *The GP Service for Children and Young People, What to expect when a child goes to hospital* and *Young People in Hospital*. These required extensive revision, consultation, planning, research, review, editing and design.
- EACH charter adaptation to the needs of LAAC&YP in consultation with staff and young people.

2.2.2 Review

- Reviewing the **Caring about Health A-Z Pack** for staff and carers – a raft of recommendations were made and ASC(S) has been included in the new edition both in the introduction and in the section on Dental Health. This was a very welcome and major step forward and acknowledges the organisation as a key player in the healthcare provision for all children and young people.

2.2.3 Article

- The Scottish Institute of Residential Child Care invited the PO to contribute an article to their special healthcare edition of the Scottish Journal of Residential Child Care, which drew extensively on the interviews carried out earlier in the year with YP and healthcare professionals

2.3 Working with staff and young people

One of the most significant barriers to this work has been the difficulty in accessing young people in care and this is reported in the appropriate section. It was clear from the outset that in very many cases there was a protective cordon placed around them as is right and proper. However, it did not make the project work any easier, so it was fortunate that through a series of contacts, it was possible to engage in joint working with residential schools in the two exemplar areas and in a secure service unit.

In both schools, work was undertaken with staff members, young people (both in classes and on an individual basis) and followed a similar model.

Snowdon School in Stirling

- Initial exploratory meetings with head of care and the head of school to establish dates for sessions at Snowdon school with the YP 1:1, the staff and the classes.
- 1:1 interviews with 2 of the girls were conducted and 6 classes participated in sessions (S1-S5/6) over 2 afternoons (36 girls in total), trialling sessions adapted from the Children and Young People's Healthcare Rights Resource Pack.
- This was then followed by a staff training session on the work of ASC(S), the Project and the CYPHRRP and the administration of the completed questionnaires to residential care staff.

Falkland House School

- Visit to Falkland House School for boys in care to meet with the Social Work Manager and set up dates for staff and student sessions.
- Dates were arranged to present 2 sessions to the teaching staff and care staff. Work with the boys started after the Easter 2009 break.
- Work with the boys started on 13th May and concluded by the end of June.

- Sessions with YP on adaptations of activities from the CYPHRRP. The boys also explored their understanding of the 10 health care standards in the EACH Charter and gave their views on what the Charter would look like for them.

In the case of the Secure Unit, the face to face interview was carried out individually.

All the information gathered, whether from the staff sessions, the questionnaires or the sessions with the young people, informed the development and production of the final toolkit materials.

Amongst many impressions gained from the work in the schools, was how striking the difference was between the behaviour and attitude of the YP when in a 1:1 or pair situation. They seemed far freer to express their feelings without losing credibility or succumbing to peer pressure. This will have implications for the proposed work of the new project. (See page 8)

Year 3 – Objective: Disseminate findings and resources across relevant sectors particularly social work and education.

1. Raise awareness amongst those who look after vulnerable children and young people about their care during times of illness (to include coping without parents, consent to treatment, advocacy and young carers when they fall ill)
2. Pilot relevant materials in to school health promoting sessions as a tool to enhance school curriculum (e.g. how to access healthcare services at times of illness)
3. Provide Information and support for carers and staff

The Year 3 activity is in some respect still ongoing as there has been a considerable time lag due to the PO coming into post in July 2007 with a subsequent quieter period while many people were still on annual summer leave. Thus substantive activity did not start until into the autumn of 2007, with a period of mapping needed before work could begin in earnest.

Nevertheless, in reporting Year 3, the three targets under the main objective have been adhered to and the Project activity reported under each.

1. Raise awareness amongst those who look after vulnerable children and young people about their care during times of illness (to include coping without parents, consent to treatment, advocacy and young carers when they fall ill)

- The Rights of the Child Group at Yorkhill – an update on the project and presented the findings of the healthcare professionals survey.
- Action for Sick Children (Scotland) EACH Campaign Launch – gave an opportunity to showcase the work of the project as a practical example of the EACH Charter points at an event in the Garden Lobby of the Scottish Parliament.
- Scottish Child Health Commissioners (SCHC) Group Meeting –updated the group on the project which had first been presented the year previously. This afforded an excellent opportunity to showcase the development of the Project work and to enter into a dialogue with the SCHCs about how ASC(S) can work with them and others to further the objectives of improving the health outcomes for LAC&YP in Scotland

- Scottish Throughcare and Aftercare Forum Annual Conference in Dundee – opportunity to meet and network with delegates working with children and young people in and leaving care from all across Scotland. Follow up work to benefit the project and further its aims and outcomes e.g. Edinburgh Connect and meeting with Gita Ingram, CAMHS Specialist
- Seasons for Growth Programme – the PO attended a 2-day training course in this programme (which helps young people confront and cope with loss and change) and learned that in some areas this is being used with C&YP in and leaving care in an adapted form. The PO will develop and deliver this course to young people running 2010-2011
- Report on the healthcare questionnaires –these were in the final report stages although work is ongoing as questionnaires are still being collected
- ASC(S) Autumn newsletter – Article on LAAC
- NHS Dumfries and Galloway – delivered staff training on the EACH Charter and Health Care Rights Resource Pack

2. Pilot relevant materials into school health promoting sessions as a tool to enhance school curriculum (e.g. how to access healthcare services at times of illness)

- Further interviews with YP in residential schools and a secure unit have been completed. They also gave their views in relation to the toolkit and in particular the YP EACH Charter identifying Charter points which were the most meaningful to them.
- Inspector 8, Youth Issues Group and NHS Dumfries and Galloway and Dumfries Council –worked alongside the YP to help them develop their own local version of the EACH Poster and Charter while at the same time consulting them on the *Young People in Hospital* booklet and the *YP EACH Charter for LAAC*
- Education leads in the exemplar areas and local authorities have been contacted and the PO has met with the officers responsible for inclusion, pupil support or ASL. (This would also include LAAC in Schools) to make the toolkit available and deliver training around it to education and social work staff.

3. Provide Information and support for carers and staff

- A new flier for the Project has been developed for the various conferences and in particular for ASC(S) EACH Campaign Launch at the Scottish Parliament when the project will be showcased with a stand and presentation as part of the EACH Child and Young Person's Health Matters Campaign in the presence of 105 delegates
- The toolkit is made up of the following elements all of which will be available on the web and some will also be available as hard copy:
 - *The GP Service for children and young people* booklet
 - *What to expect when a child goes to hospital* booklet
 - *Young People in Hospital* booklet
 - *YP EACH Charter*
 - An A4 size poster raising awareness of the ASC(S) website and the healthcare of LAAC and associated useful links
 - An A6 post card to raise awareness or enable people to take

- Podcasts of interviews and FAQs for professionals working in the field of LAAC healthcare
 - Web links to other useful sites
- It is hoped to be able to include as many of these resources as appropriate in audio format on the website
- The development and launch of the toolkit will provide invaluable information and support for carers and staff (see detailed description of the toolkit above).
- The complete roll-out of the materials to professionals, carers and staff was not able to be completed by the end of March 2010 and will be taken forward as part of the new project referred to under Section 7, Developing the project in the future (See main report page 8).

APPENDIX 6 – MODEL QUESTIONNAIRE



Healthcare Project for children and young people in and leaving care when they are sick Community Paediatrician Questionnaire

This questionnaire forms an important part of Action for Sick Children (Scotland)'s LAAC Healthcare Project. The information you provide will be used to assist us to gather key information, identify the issues and gaps in the care of children and young people (CYP) in and leaving care when they are sick and enable us to identify key action points for the project to take forward.

For the purposes of this questionnaire *children and young people in care* refer to those looked after away from home e.g. in foster care, kinship care, residential care and in respite care.

Health Warning

This questionnaire should take no longer than 15 minutes to complete

All information will be treated in the strictest confidence in accordance with our Data Protection Policy.

Questions for Community Paediatricians caring for Children and Young People in and leaving care

1. Do children and young people (CYP) in care face particular issues (not experienced by other CYP) when they access secondary or tertiary healthcare services?

YES

NO

If yes, please describe these:

2. The GP Service

What is your understanding of the CYP's experience when they go to the GP? Is there a general awareness of their issues or have the CYP experienced difficulties? (You may have had feedback from CYP you work with.) Describe below

3. Are there issues around **consent** where a lack of clarity led to difficulties obtaining treatment? YES NO

If yes, could you describe these?

4. Are you aware of issues relating to **confidentiality**?

YES

NO

If yes, could you describe these?

5. In the same way as we have the UNCRC, **Who Cares? Scotland** has developed a charter of rights for young people in care. Would a healthcare charter for CYP looked after away from home be useful in relation to hospital and GP services, outlining what they can expect from health services?

YES

NO

6. In relation to Community Paediatricians receiving/accessing information:

- Do community paediatricians have access to GP letters?

YES

NO

- Do community paediatricians have access to hospital records?

YES

NO

- Who receives copies of reports on the CYP in care?

GP

Hospital

Social Work Dept

Carer

CYP

Birth Parent

Selective Cases

YES NO

YES NO

(If YES to Selective Cases can you expand on this?)

7. Do you provide health information for CYP e.g. leaflets on the medical assessment or general information etc.? YES NO

If yes, please describe

8. Do you think there are any other issues we should consider?

Thank you for taking the time to complete this questionnaire

Name of Respondent:

Address

: _____

email : _____

Date: _____

Please return to
Anne Wilson
Development Officer
ASC(S)
22 Laurie Street
Edinburgh EH6 7AB

or email to: a.wilson@ascscotland.org.uk

by Friday 28 August 2009

APPENDIX 7 – TOOLKIT

Toolkits (Carer/professionals and young people) for the LAACYC Healthcare Project. Some of the items below are generic and will also form part of the carers' packs and other resources.

- ***Young People in Hospital*** (a guide) – a much-needed and long-awaited guide for young people to help them prepare for a visit or stay in hospital. This signposts YP to many other very useful resources and will be available as an audio version on the website to aid accessibility for those with ASN.
- ***The GP Service for Children and Young People*** – a guide for carers to help them better understand and access the GP Service when caring for a child.
- ***What to expect when a child goes to hospital*** – guide for carers as to what to expect when a child in their care has to access hospital services.
- ***A series of podcasts*** with a range of different healthcare professionals all of whom may have involvement with the healthcare of LAAC to raise awareness of the different roles, the challenges and ways in which these have been met.
- ***An A4 poster (single-sided for display) for the healthcare of children and young people who are looked after*** signposting professionals and others to the ASC(S) website. This website aims to raise awareness of the health needs and rights of children and young people in and leaving care and contains information which is relevant for all staff and carers looking after these children and young people.
- ***Accompanying postcard*** (double-sided) linked to the poster for professionals to take away with them with specific information about the resources available on the website.
- ***Web links to other useful resources***, other agencies and organisations e.g. Health Scotland Walk the Talk and Learning and Teaching Scotland so that professionals who are looking for specific information on health will be directed to ASC(S) website.
- ***Young People's EACH Charter*** – small credit card sized 24-page booklet containing the 10 EACH charter points and on each facing page the YPs' interpretation of the charter point in photographic form with their caption interpretation superimposed in a speech bubble.

APPENDIX 8 - KEY CONTACTS

SCOTTISH GOVERNMENT

Children's Hearing System National Panel School

Anna Fowlie, lead for **Corporate Parenting** in the Care and Justice Division

Now - Murray Paterson as successor

Kate Macleod, National Coordinator for the Seasons for Growth Programme

Caroline Selkirk, Chair of the Health group for **We can and must do better** working group

Mary Sloan and Gillian Garvie, Vulnerable Families Group, Child and Maternal Health

HEALTH

All members of the LAAC Advisory group for the Project (Appendix 2)

Ailsa Clunie and all at the Scottish LAC Nurse Forum

John Brown, Senior Programme Officer at NHS Health Scotland

Nuala Healy, NHS Health Scotland

Jo MacLennan, Youth health programme NHS Health Scotland

Jackie Dougall, LAAC Nurse Specialist, for NHS GGC

Dr Juliet Farquhar, Lead paediatrician for LAAC, NHS Forth Valley

Maxine Moy, Nurse Consultant for Vulnerable Families, NHS Fife

The LAC Team in Stirling, NHS Forth Valley

Scottish Association of Community Child Health

Scottish Child Health Commissioners Group

Linda Williamson, NHS Dumfries and Galloway

Kirstine Burns, NHS Dumfries and Galloway

Kirsty Anderson, CCN in Shetland

Marjorie Gillies, Lead Nurse for patients in Yorkhill

Jackie Flynn, Specialist LAC Nurse for Throughcare and aftercare

Christine Cairns, Assistant Director of Nursing, NHS Fife

Dr Lesley Morrison, GP in NHS Borders

Dr. Andrew Eccleston, Consultant Paediatrician Dumfries and Galloway Royal Infirmary

Ann Wilson, Specialist LAC Nurse NHS Dumfries and Galloway

Sue Hogg, Head of Care and colleagues at Rachel House, Children's Hospice

EDUCATION

Sheena Murray, Falkland House School, Fife

Diane Kilgannon, Snowdon School, Stirling

SOCIAL WORK

Judy Furnivall, Scottish institute of residential child care

LOCAL AUTHORITY

Irene Rodgers, Youth Issues Worker, Inspector 8

VOLUNTARY SECTOR

Ian Millar, lead officer at the **British Association for Adoption and Fostering**

Sue Hogg, Head of care Rachel House, CHAS

Who Cares? Scotland.

OTHER

Scottish Healthy Care Network, Steven McCluskey and Ailsa Clunie and others on the management committee

APPENDIX 9 – GLOSSARY

- LAAC/LAC – Looked after and accommodated child/Looked after child
- LAAC&YP – Looked after and accommodated children and young people
- ASC(S) - Action for Sick Children Scotland
- BAAF – British Association of Adoption and Fostering
- SWD – Social Work Department
- STAF – Scottish Throughcare and Aftercare Forum
- SHCN – Scottish Healthy Care Network
- SIRCC – Scottish Institute of Residential Child Care
- CCN – Community Children’s Nurse
- NHS FV – NHS Forth Valley
- NHS Fife
- RCPCH – Royal College of Paediatrics and Child Health
- SG – Scottish Government
- CAMHS – Child and Adolescent Mental Health services
- YP – Young People
- ASL – Additional Support for Learning
- CCH – Community child health
- PO – Project Officer
- EACH – European Association for Children in Hospital
- NMCN – National Managed Clinical Network
- HB – Health Boards
- ASN – Additional Support Needs
- SACCH – Scottish Association of Community Child Health
- PFPI – Patient Focus Public Involvement
- CYPHRRP - Children and Young People’s Healthcare Rights Resource Pack
- LTS – Learning and Teaching Scotland
- BMA – British Medical Association

Anne Wilson
Project Officer
Children and young people in and leaving care healthcare project
Action for Sick Children (Scotland)
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