

Children's Health Scotland, formerly Action for Sick Children Scotland, is the only charity in Scotland dedicated to informing, promoting and campaigning on behalf of the needs of all sick children within our healthcare system.

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

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

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

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



Winter 2018



Children and young people with health issues and their education

Alison Closs, CHS Executive Committee writes:

When a child or young person is ill or has a long-term health condition, physical or mental, their families/carers and medical professionals naturally put the greatest effort into ensuring a return to optimal health. Education may be the last thing on anyone's mind yet there are many good reasons why it should be considered as soon as possible.

Future studying, training and working lives may depend on learning achievements while of school age. Later 'catch up' opportunities are limited and they offer a hard path to follow, especially if a young person has a lifelong chronic health problem. For Scotland's children and young people between three and 16/18 years, education is their 'normal' main occupation and schools their main out-of-home

location. Some gain intellectual satisfaction from their education, or from some aspects of it. For many, the biggest attraction in education is the opportunity to enjoy peer friendships.

Participation in education is a basic right for all children, as indicated in Articles 28 and 29 of the UN Convention on the Rights of the Child. The Scottish Parliament fully endorses this right.

Participation in education in school, in hospital or at home, may offer youngsters with health issues additional benefits. It may act as a distraction from distressing aspects of their condition. For those receiving education in hospital or at home, it should offer a better chance of achieving a smooth return to school. It also offers them a similar 'track' to follow in education to that followed by healthy peers. In other words,

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participation in education by children and young people with health issues should act as a normalising developmental experience, yet this is **not** always so, despite supportive Legislation and Guidance from the Scottish Government.

The very first Act passed in 2000 by the new Scottish Parliament was the Standards in Scotland's Schools etc. Act. Section 40(1)(b) required (not merely 'allowed') Education Authorities (EAs) to make educational provision out of school for pupils who could not attend because of prolonged ill-health, constant or intermittent. Section 2(1) of the Act required EAs to ensure that the education of **all** children be 'directed to the development of the personality, talents and mental and physical abilities of the child or young person to their fullest potential'. Official Guidance followed about the education of absent children and medication in schools.

Later the Education (Additional Support for Learning) (Scotland) Act 2004 (as amended) and the Equality Act 2010 were enacted. While both are highly relevant to the education of children and young people with health issues, they are long and complex and links to these youngsters' educational needs are not always explicit. Revised official Guidance followed in recent years: *Guidance on the education of children unable to attend school due to ill health (2015)* <https://www.gov.scot/publications/guidance-education-children-unable-attend-school-due-ill-health/> and, *Supporting children and young people with healthcare needs in schools (2017)* <https://www.gov.scot/publications/supporting-children-young-people-healthcare-needs-schools/> Again both are very extensive and detailed.

Continuing enquiries and complaints from families, both to Children's Health Scotland and to Enquire, the Scottish Advice Service for additional support for learning, indicated that some children and young people with significant health problems are still not receiving the education, additional support for their learning, and healthcare in school to which they are entitled.

Among the numerous barriers to more successful inclusion in education are:

- The rights to education and to healthcare in education, and the practical and legal links between health issues and additional support needs, and between health issues and disability, are not fully grasped by some families and professionals.
- Most EAs and Health Boards are cash-strapped currently, leading to a reduction in support staff, teachers and classroom/ASN assistants, in mainstream and additional support for learning schools. Staff development, especially for training leading to specialist



qualifications for teachers, and to improved knowledge, understanding and skills for teachers and assistants, is very limited. There is a lack of Community Children's Nurses to undertake more complex healthcare in schools for children who for example, have stomas, feeding pegs, tracheostomies, require oxygen etc. Where the local health service cannot help, parents have sometimes been asked to help in school or to keep their child at home.

- There is great disparity between EAs across Scotland in relation to aspects of education vital for those with health issues. Some EAs have a team of support teachers who work in hospitals and in family homes while others have few or none – even the best resourced may only be able to offer a child three hours of education per week.
- Few children and young people with serious health issues have a Co-ordinated Support Plan (CSP) although some may be well 'qualified' to have one, and they therefore miss out on some additional rights. If their health issues are significant, then they should also have a Healthcare Plan affording security to individual youngsters and support for willing but anxious school staff involved in their care, yet this has not been invariably implemented.



Currently there is a serious risk that, while Scotland may have comprehensive legislation and guidance relating to children and young people with health conditions and their education, it may also offer increasingly poor access to support and healthcare in education.

What can be done?

Parents, carers, children and young people must continue to be informed about relevant rights and to push EAs and their MSPs to ensure these are recognised and met. Children's Health Scotland will continue to support children, young people and families, will campaign at a national level and provide relevant information. We have already collaborated with Enquire to produce 2 Factsheets to support families and inform others, about the educational rights of children and young people with health issues. These can be downloaded or obtained from Enquire. They are:

1) *When a Child Can't Go to School*,
<http://enquire.org.uk/3175/wpcontent/uploads/2017/11/when-a-child-cant-go-to-school-1.pdf> and

2) *Supporting children and young people with healthcare needs in school* <http://enquire.org.uk/3175/wp-content/uploads/2018/06/supporting-children-and-young-people-with-healthcare-needs-in-school.pdf>

New Enquire factsheet

'Supporting children and young people with healthcare needs in school'

Written in partnership with Children's Health Scotland

"Enquire made a super difference to my family. When I hit a brick wall Enquire was there to help and give advice."

helpline 0345 123 2303

For more info visit the "My child has healthcare needs" page of our website



Catriona Thomson, Enquire Manager writes: When pupils feel listened to, respected and included in school life, they're more likely to do well at school. That's why we are fortunate that in Scotland all pupils have the right to have their say about what they need to get the most out of their education. And since January 2018, pupils aged 12-15 can now be even more involved, having a direct say in decisions about their support.

Reach, an online resource which helps pupils understand their rights to be supported, included, listened to and involved in decisions at school, has created 3 new animations to help pupils feel more confident about speaking up. They are called:

- **It's not easy to talk**
- **Help to make your voice heard at school**
- **Your rights, your say**

The films also signpost pupils to 'My Rights, My Say', a service which can help children aged 12-15 share their views about the support they need and have a say when decisions about their learning and support are made.

Zain a pupil involved in making the films, believes that "the messages [in the films] for young people are really important if they are struggling, so they know that help is available."

To view the films visit Reach at www.reach.scot





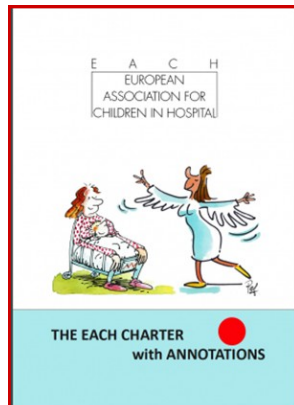
EACH celebrates special anniversaries

It was a time for celebration when delegates from Austria, the Czech Republic, Finland, Germany, Iceland, Ireland, Italy, the Netherlands, Sweden, Switzerland and the UK gathered in Frankfurt in September, to celebrate the 25th anniversary of the founding of the European Association for Children in Hospital (EACH) and also the 30th anniversary of the 'birth' of the EACH Charter, which was written in Leiden in the Netherlands in 1988. Coincidentally AKIK (Aktionskomitee Kind Im Krankenhaus) the German host sister organisation, was also celebrating its 50th anniversary.

Children's Health Scotland and Action for Sick Children in England, have been members of EACH since its foundation in 1993, representing the UK. EACH is an international umbrella organisation which is open to European non-governmental, non-profit associations involved in the welfare of children in hospital and other healthcare services. Associations or individuals from other countries are also welcome to join.

Organisations nominate one delegate to the Co-ordinating Committee which meets every year. In 2019 Children's Health Scotland will be hosting the meeting. The General Assembly and a conference are held biennially. At that time EACH issues a resolution in order to promote and advance the rights of all sick children throughout Europe. This year the EACH Coordinating Committee met and the biennial meeting of the General Assembly took place where delegates shared information about their respective organisations and countries and discussed a new resolution. A thought provoking Conference was held at Frankfurt University, arranged by AKIK and open to the public, which covered the subjects of pain and communication. This was followed by a visit to the Clementine Children's Hospital in Frankfurt the next day, thus rounding off a stimulating and motivating Congress.

In keeping with the theme of the conference, delegates agreed the following resolution. The particular articles of the EACH Charter relating to the subject of the resolution are referenced along with the supporting articles and General Comment from the United Nations Convention on the Rights of the Child.



Gwen Garner, Vice Chair of Children's Health Scotland and Secretary of EACH

Resolution 14th EACH Conference Frankfurt 2018 on avoiding pain, fear and stress

In line with the EACH Charter for the rights of all sick children and its annotations, specifically article 4, 8 and 10, we call upon all governments to ensure that:

Having regard to ethical and legal considerations and as a fundamental part of the quality of healthcare for children, managers, healthcare professionals and insurance companies should strive for optimal patient cooperation without restraint, for patient comfort and the avoidance of suffering, pain and fear.

In order to deal with pain, fear and stress and to promote positive cooperation and engagement with sick children, professionals in child healthcare should:

- have the competence, interpersonal and social skills to make a connection with and to gain the trust and co-operation of children. They should be able to communicate in an empathetic and patient manner with children and their parents;
- have the professional skills, competence and experience to administer safe, effective and comfort-directed pain management procedures, and to ensure that children understand and accept such procedures (either verbally or non-verbally).

Delegates represented Austria, Czech Republic, Finland, Germany, Iceland, Ireland, Italy, Lithuania, the Netherlands, Sweden, Switzerland and the United Kingdom.

The EACH Charter

Article 4.1: Children and parents shall have the right to be informed in a manner appropriate to age and understanding.

Article 4.2: Steps should be taken to mitigate physical and emotional stress.

Article 8: Children shall be cared for by staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families,

Article 10: Children shall be treated with tact and understanding and their privacy shall be respected at all times.

UN Convention on the Rights of the Child

Article 3.1 and Art 3.3: Best interests of the child

Article 12.1: Respect for the views of the child

Article 19: Child's right to protection from all forms of violence

Article 24: Children's right to health and health services

General Comment No 15 (2013) on the right of the child to the highest attainable standard of health (Art. 24)

For further information visit:

<https://www.each-for-sick-children.org/>

<https://www.unicef.org.uk/what-we-do/un-convention-child-rights/>



Adult Hospice Leads Way in Providing Age Appropriate Care for Young People



The Young Adult Lounge at the Hospice

Due to advancements in medicine, many young people are living longer with life-limiting and life-shortening conditions that were once limited to childhood, with the population of young people living with these conditions growing.

One adult hospice 'The Prince and Princess of Wales Hospice' (PPWH) based in the Southside of Glasgow recognised this need many years ago when the commissioning work for a new hospice started. Throughout this time the hospice has continued to consult and work alongside young people, their families and the organisations that support them to understand their needs and wishes.

On 6 November 2018 the hospice finally moved into its new home located on a 7.5 acre green site in the city's Bellahouston Park. The hospice has sixteen en-suite bedrooms with private terraces, open-plan kitchens, young adults lounge, sensory room, complementary therapy rooms and spa bathrooms. The extensive hospice grounds and beautiful park beyond offer an overriding sense of tranquility and calm; the benefits of this on health and well-being are well researched.

The hospice's commitment to developing young people services for those aged 16 years and older, living with life-shortening conditions, continues to grow. To date they have transitioned eleven young people from children and young people services and will continue to learn from their experiences of this. The young adults' feedback has been instrumental in creating a monthly pilot social group built on the interests of the young people and has included a virtual reality project working with Strathclyde University. The relationship that young people have with their peers is so important to them. They want to be together with other young people who may have the same condition in an age appropriate environment, with staff who understand their needs and create as much normality as possible. The hospice is committed to supporting this ethos. Feedback on the service includes:

'I now feel that I would really miss the service, I really enjoy every month going to the art as I find it so relaxing. I am excited about the art service in the new building as there is a lot you could do in the grounds with photography; have your art sessions outdoors in the park or go for a walk in the park.'
Young Adult

'We are finally moving away from the perception of hospices being solely a place of peace and tranquility to spend the last days of life to more of a hub where young people can concentrate on life whilst their health and well-being needs are met. The hospice service is becoming an integral element in the patient's healthcare journey for this fast growing population who are living longer lives as well as providing support, education and preparation for the young adult and their family to face what can in many cases be an uncertain future.' **Marina Di Marco, Principal Neuromuscular Physiotherapist, West of Scotland Genetic Services**

'Children's Health Scotland fully supports the PPWH initiative on creating a service that is recognising the different and particular needs of young adults. We are impressed that the hospice is taking the initiative to improve transition services from an adult perspective. We are proud to have been working in partnership with the hospice and look forward to sharing good practice in the future.' **Dagmar Kerr, Children's Health Scotland**

'My experience working with the young adults transitioning from other services has been an extremely rewarding. The range of services offered is exemplary and staffed by highly skilled professionals whose aim is to indeed get it right for every young adult. It is a privilege and pleasure to be involved with the PPWH and promote the high standard of care delivered.'
Wilma Stewart, Specialist Advisor in Neuromuscular Conditions for Glasgow & West of Scotland

Fiona Wylie, Senior Nurse for Strategy Implementation and Leadership Development.

For further information contact Fiona on 0141 429 5599



The Sensory Room



Participate to create change

What is participation or engagement?

Participation has been described in different ways but here is one definition we like:

'Engagement in a piece of work, which must include action, that has a positive impact on children and young people's healthcare access and experience.'

Why is it important and necessary?

A great deal of recent legislation and guidance on health, education, social services and the early years advocates the involvement of users in planning services. Increasingly, government agencies, health boards and other organisations are involving families in shaping services because it benefits everyone and can lead to a more efficient and cost-effective service.

These are some of the key pieces of legislation in Scotland which will inform and guide the involvement of the voice of children, young people and their families in matters which affect them:

- The UNCRC - especially Article 12 (the right to be involved in decision-making) and Article 24 (the right to have the best healthcare possible).
- The Children and Young People (Scotland) Act 2014 which requires ministers and public bodies to consider giving further effect to the requirements of the UNCRC and to obtaining the voice of children and families as paramount to ensuring the wellbeing of children and young people.
- The Equality Act (2010) states that responsible bodies have a duty to make reasonable adjustments for disabled children and young people. For example, the duty may require steps to be taken in schools in relation to the administration of medication or to meet other healthcare needs.
- The Healthcare Quality Strategy for NHS Scotland, with its focus on person-centred care, puts people at the heart of the NHS. The Chief Medical Officer for Scotland says in her 2015 Annual Report, *'person-centred care means to be focusing completely and relentlessly on what matters most to the people who look to us for care, support and treatment'*.

What are the benefits? With or without direction from policy and legislation, there are clear benefits to both users (families) and providers (health services).

Benefits to families

- Ensures the views of children are heard and listened to
- Better care, better health
- Improves families' experience of services
- Builds trust between families and professionals
- Families' needs are met
- Enables families to sustain their children's care

Benefits to professionals

- Identifies families' needs
- Provides evidence for change
- Creates services to meet needs
- Service satisfaction
- Professional-parent relationship
- Families more able to sustain the care of their child
- Time and money saving



A parent talks about caring for her disabled young person at a CHS event at Scottish Parliament

How is it done?

There are opportunities to become involved at different levels:

National Level – The Scottish Government (SG) publishes public consultations on new legislation and guidance and any person or organisation can respond. For example, read our response to the SG draft Guidance Supporting Children and Young People with Healthcare Needs in Schools <https://www.gov.scot/publications/supporting-children-young-people-healthcare-needs-schools/>

Local Services – This could include at board level (check your health board website under *Your NHS* or *Get Involved*, health and social care partnerships or your GP practice.

Hospital – Parents/carers of children who attend hospital regularly could join the hospital's Family Council or speak to the Community Engagement Manager for children and families. Children's Health Scotland helped organise a roadshow at the Royal Hospital for Children, Glasgow in January 2017 to celebrate children's rights, educating staff and patients to mark the 25th Anniversary of UNCRC.

Individual patient focus level – A child may have a child's plan or a healthcare plan (school). Their parent or carer should be involved in setting up the plan and in its review. More importantly, the child should be involved and now under new legislation has a right to have a say from the age of 12 <http://enquire.org.uk/myrightsmysay>

Children's Health Scotland is involved at all levels of planning and policy-making locally and nationally. We do this with input from families – parents, carers, grandparents, children and young people. One of our key roles is to empower families to influence the planning and delivery of services and it is their knowledge, experience and needs which inform and shape our work.



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Through our **Family Participation group**, Children's Health Scotland has engaged with families as follows:

Being part of a committee, forum etc – Rights of the Child Group, Royal Hospital for Children, Glasgow

Responding to consultations – *Supporting Disabled Children, Young People and their Families* draft resource and *Progressing Children's Rights in Scotland: an Action Plan 2018-21* <https://www.childrenshealthscotland.org/childrens-healthcare-rights/consultation-responses/>

Commenting on patient publications and policies – Children and Young People's Acute Deterioration Management Family information leaflet; Children's Health Scotland's Pain and Needles Guides.

Interviews – Website podcasts by a young person with long term condition; and by healthcare professionals on health needs of children in foster and kinship care.

Surveys and research – Children's Health Scotland's Parental and Family Facilities Survey; The Salvesen Mindroom Centre, Research Priorities for Learning Difficulties.

Focus groups to gather users' views – Children with Exceptional Healthcare Needs (CEN) event with Scottish Government Participation team to feedback on the SG draft *Supporting Disabled Children and Young People and their Families* resource.

Contributing to a DVD – Grandparents Parenting Again & Kinship Carers (Midlothian) collaborated on our *Health Matters for Children and Young People in Kinship Care* DVD.



Kinship Carers at the launch of the DVD

Conferences – Speaking at events eg CHS conference *Child Healthcare in Scotland: Overcoming the Challenges to Inequality* and the Royal College of Paediatrics and Child Health's Young People Participation seminar.

Short life working/planning/steering groups – For example contributing views to the Supporting Children and Young People with Healthcare Needs in Schools groups (Scottish Government) and the Royal College of Paediatrics and Child Health (Scottish Office).

Children's Health Scotland News

What makes engagement and participation go well?

Links containing rules for engagement processes are included at the end of the article. However, here are some families have told us are most important for them:

- The motivation of health service users and services' genuine interest in listening to them. It should not be a tick box exercise to comply with legislation.
- Inclusion with attention paid to equality and diversity so all parts of the community are represented.
- Services should make it easy for people to get involved when arranging venues for meetings, times and other matters eg child care. A good example was a recent CEN engagement event held in the Forth Valley Sensory Centre between 11am and 2pm, with lunch and on-site creche facilities.
- Offering alternative methods of involvement. For example, the use of digital and social media is important for those unable to attend face-to-face meetings.
- Feedback following the engagement is vital not only on what will happen next but on the outcome of families' involvement.

Join Our Family Participation Group

If you would like to join our Family participation Group to take part in this work, please sign up using the questionnaire on our website

<https://www.childrenshealthscotland.org/how-you-can-help/join-our-family-participation-group/>

Note: This article is not a toolkit on how to conduct engagement or participation. The following links and references will give you lots of ideas. The asterisk * denotes toolkits.

Links and references

Children's Health Scotland acts as a bridge for families to have their voice heard to shape services. To join our Family Participation Group, complete the questionnaire at <https://www.childrenshealthscotland.org/how-you-can-help/join-our-family-participation-group/>

* **The Royal College of Paediatrics and Child Health** has publications and resources relating to participation and engagement - <https://www.rcpch.ac.uk/resources/working-children-young-people-families>

* **Contact** has resources on participation - <https://contact.org.uk/get-involved/parent-carer-participation/>

For Scotland's Disabled Children -

<https://www.fsdc.org.uk/information/parent-participation/>

The Children and Young People's Commissioner Scotland has developed a resource 7 Golden Rules for participation - www.cypcs.org.uk/education/workshops

* **Scottish Health Council** -

<http://www.scottishhealthcouncil.org/home.aspx>

Anne Wilson, Development Officer

A.Wilson@childrenshealthscotland.org

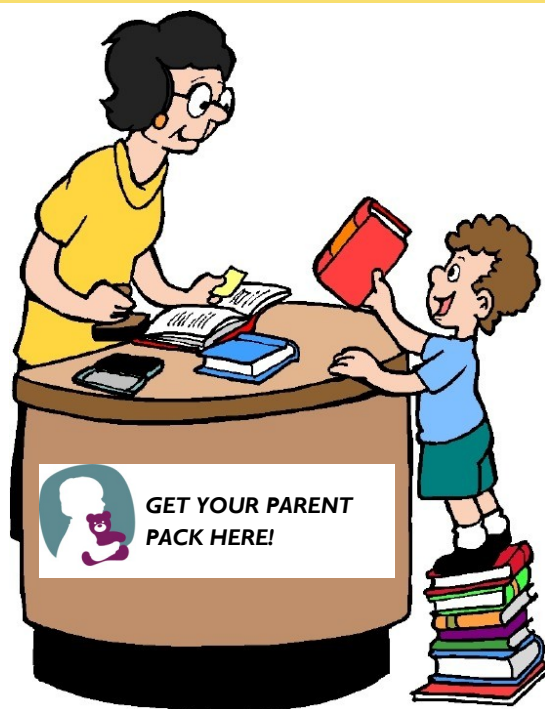


New face at self management project



A warm welcome to Conor Smart who takes over from Dani as project assistant in our Lothian Self Management Project. Conor will work with our Officer Simita Kumar delivering workshops to children and young people with long term conditions.

Conor also works as Youth Support Coordinator for NHS Lothian. In this role, funded by the Teenage Cancer Trust, he supports young people aged 13-18 socially and emotionally as inpatients and in the community during treatment for cancer.



Next time you are passing your local library, pop in and see if you can get hold of our parent pack. Our marvellous volunteer Jenny, is tracking down folders, stuffing in leaflets, and wrapping in recycled paper. She then becomes a wizard with the scales to literally balance the cost. All in our endeavour to get information into local areas. You can pick up our GP leaflets in Romanian and Arabic there too. Still lots more to do. Can't wait? All information is on our website. Thanks Jenny, you're a star. ★

Children's Health Scotland is grateful to the Scottish Government which provides Children, Young People and Families Early Intervention Funding.



How well do I know the NHS?



How well do I know the NHS? Scotland has welcomed refugees and asylum seekers, European and other people migrating to make this place home. I've met many settling in after fleeing conflict or other humanitarian reasons; to study or work. Each time I've been welcomed with food and a smile, as I chat about what we do and their children's health rights. As I do so, I wonder how hard it must be to keep healthy and use health services. The complexity of the new and unknown. I've pondered this more as I moved and had to find a GP, navigating websites, filling in forms, looking at maps. I imagine...verpleegster, imenovanje, navnišan, 鉴定, saludwhere would I start?

Linda Alexander, Development Officer

Email: L.Alexander@childrenshealthscotland.org

Become a Member of Children's Health Scotland in 2019

If you support our vision for the best quality healthcare for children and young people in Scotland, why not become a member? It only costs £10 for individuals. You can download an application from <https://www.childrenshealthscotland.org/how-you-can-help/become-a-member/>

Easyfundraising for Children's Health Scotland

Another way to support us is when you buy goods online to do so via <https://www.easyfundraising.org.uk/causes/childrenshealthscotland/> There is a huge range of suppliers who will donate to the charity of your choice when you make a purchase. Best of all it's at no cost to yourself!



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