

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.



Is access to good transition a rights issue?



How to help young people to cope with the move from receiving healthcare in a paediatric setting to adult healthcare has been the subject of many discussions, conferences and research for well over forty years.

This was mostly driven by professionals with a paediatric background and growing evidence suggests that a good transition process produces hugely positive outcomes for the physical and mental health of young people and young adults, and does in fact save resources.

The UN Convention on the Rights of the Child (UNCRC) and the Children and Young People (Scotland) Act 2014 outline the importance of a child's right to be involved in decisions that

affect them, while the EACH (European Association for Children in Hospital) Charter, which underpins the work of Children's Health Scotland (CHS), describes 10 rights related to children's and young people's healthcare.

Here are some of the EACH Charter Articles, interpreted by some of our young people, that are particularly relevant when we think about transition:

Article 5: Young People should be listened to and take part in all decisions affecting their health care.
"Listen to me and hear what I've got to say."

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Inside: Caring for children who are born too early - Healthcare in Schools - New Healthcare Rights e-learning resource - CHS at the Refugee Gathering - A Parent Reflects - New Area Officer in Tayside



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Article 8: Young People should be cared for by staff trained to understand and meet their physical, emotional and development needs.

“Staff should understand what makes us tick.”

Article 9: Young People should be provided with continuity of care for as long as required even after their stay in hospital.

“Work together for us.”

Article 10: Young People should be treated with the respect, understanding and privacy they need at all times.

“Get to know and respect me.”

The Year of the Young Person #YOYPI8 is a good opportunity to think about these rights and how we support and empower young people with ongoing or long term health conditions to take control of their health and achieve the best possible wellbeing for their adult lives.

We see it as our role to share examples of excellent practice so that they can be replicated in NHS Boards across Scotland.

CHS is in a unique position to hear about or be part of initiatives that are demonstrating how good transition can improve outcomes. We see it as our role to share examples of excellent practice so that they can be replicated in NHS Boards across Scotland.

Good Practice in NHS Greater Glasgow & Clyde

Dagmar Kerr, our Area Co-ordinator for NHS Greater Glasgow and Clyde (NHS GG&C) reports on some of the work happening in her area. NHS GG&C has recently taken the bold step of employing two diabetes specialist nurses who are jointly funded by paediatric and adult services and who work together across both services. They support young people through their transition process and organise joint transition clinics (EACH Article 10). They listen to young people, hear what they need from the health service (Articles 5 and 8), and can help young people to make healthy choices. The nurses encourage team work with professionals from health, social care and education and work on developing a service that addresses young people's needs, for example by communicating with them through different channels and using technology (Article 9). Early audits already show that young people are engaging in a more positive way with the service.

Another excellent initiative is one led by Dr Heather Read who is based at the Royal Hospital for Children (RHC) Glasgow. This looks at improving transition for young people with Cerebral Palsy (CP) and other similar conditions. Young



people with CP often need care and treatment from a range of different professionals, including paediatricians, orthopaedic surgeons, neurologists, physiotherapists and occupational therapists. They may also need equipment and aids from orthotics and wheelchair services. Most of these services are based and managed at the RHC and/or in the community. Smooth transition is further complicated because there isn't a similar co-ordinated service in the adult health service and young people and their families often find the change confusing, frustrating and overwhelming. This initiative is looking at how IT systems can be adjusted so that important information can be safely passed on to adult IT systems (Article 9). There will be consultation with young people and families about their expectations and experiences of transition (Articles 5 & 8). There are already joint monthly clinics taking place where paediatric and adult staff meet with the young person and prepare them for the change (Article 10). The aim is to develop a pathway to help young people and professionals to negotiate a complicated process and

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get the right service for every young person.

NHS GG&C is currently working on a generic transition guidance document which will form the basis for transition pathways for specific conditions. The aim is that every young person,

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regardless of their condition, will be able to get the right support when they move to adult services.

Isn't it time that we stop looking at separate budgets? This could help progress a multi-agency approach into adult services. Investing in some courageous and imaginative programmes to prepare young people for adult services while, at the same time, preparing adult services to be ready for well educated and prepared individuals would surely be a positive way forward. We suggest that integrated services which currently focus on elderly care should not be age limited but also applied to young adults who need this. And isn't it time that excellent transition programmes and pathways are available to all young people and not just some who have certain conditions with better access to funding?

We also need to look at and enhance the important role of GPs and explore local specialist services so that young people can access them more easily when they leave paediatric care in a specialised tertiary centre.

In answer to the question heading this article: Yes, CHS sees good transition as a rights issue.

- **We need to listen to and involve young people in the planning and preparation for their future.**
- **We need to work together across paediatric and adult sectors and in partnership with social care, education and the third sector to offer a service that is right for everyone.**
- **We need to train people in adult settings how to engage with young people and how to treat conditions that, until recently, were not commonly seen in adults.**
- **Every Health Board should have a strong transition policy, based on these rights and they need to have robust governance structures to ensure that policies will be implemented.**

Isn't it time that excellent transition programmes and pathways are available to all young people and not just some who have certain conditions with better access to funding?

Our Self Management project in Lothian is starting to produce strong evidence that empowering children and young people to take responsibility for their own health improves their wellbeing and resilience. Some of the children and young people who have completed the programme have felt less of a need for CAMHS (Child and Adolescent Mental Health) intervention; others feel confident about their future and their general wellbeing has improved. They know their rights and feel able to cope independently in adult services.

Dagmar Kerr, Area Co-ordinator, NHS GG&C

CHS has produced a position statement on Transition from Paediatric to Adult Health Services. Read this on our website. Access <https://www.childrenshealthscotland.org/childrens-healthcare-rights/campaigning/under-transition>

Talking about Self Management at RCPC Event



Our Self Management Project Officer Simita Kumar was delighted to present to 50 clinicians at the Royal College of Paediatrics and Child Health Annual Conference in Glasgow in March. Her talk focused on how young people who take part in the project contribute to its development. Four young people pictured above with Simita also attended to share their experiences of living with a long term condition and the support received from our Project. A poster about the Project was also displayed (see photo above).



**Slav; 你好; Bonjour; Salaam; buna; hello; Hola; Marharba ;
Jambo ; cześć ; مرحبا ; سلام**

We said 'hello and welcome' to many new Scots at the Refugee Gathering in April. Armed with our hospital playbox, banner, bubbles, shortbread, sweets (shh tell no-one!), and a suitcase full of information we joined the organisers Amnesty International; Church of Scotland and The Scottish Refugee Council in Glasgow for a day of information, music and connections in Glasgow.

In the crèche, our Area Officer Dagmar had a starring role. Children loved the hospital play, dressing up and learning new words with her. The children had a good understanding of the real medical equipment (stethoscopes, bandages) and were 'treating' each other as well as 'patient' teddies and puppets. All the children had had some hospital experiences.



All the children we met at the Gathering had had some hospital experiences

New Resources

Arabic and Romanian versions of our 'GP Service for Children and Young People' can be downloaded from our website. Go to: <https://www.childrenshealthscotland.org/how-we-help/families/>.

Scroll down the page.

In the main hall the stall attracted interest. I learned the power of 'word of mouth' as the message spread amongst the children. A quote from the film 'Field of Dreams' comes to mind 'if you build it they will come'. Attracted by free bubbles they came. Crowded round the table, the children pointed or asked to find out what things were called, played with the puppets and borrowed stethoscopes to practice on parents. Parents came to see what interested their children; some took bags and information away, others asked what we do. It was busy and great fun.

'We thank you for what you have done for the happiness of our children and thank the Glasgow Assembly for this meeting and I hope to meet you again.'

People were generous with their feedback; One parent said 'We thank you for what you have done for the happiness of our children and thank the Glasgow Assembly for this meeting and I hope to meet you again.' Sweet anyone?

Development Officer, Linda Alexander





My child in hospital a parent reflects one year on

Deborah Brown our Area Officer in Tayside recently met with a parent whom she had previously supported. Now one year on from her daughter's heart surgery at Great Ormond Street Hospital, (GOSH) the parent has shared information and offered some suggestions which she hopes will be of help to others in a similar situation.

"If a parent or carer is not happy with what they have been told about their child's treatment then they can always get another opinion from another centre and could use a charity like Children's Health Scotland to help. If a parent is going through a particularly stressful time they could try to get a coping mechanism/time away from home doing something they enjoy or to help them relax like yoga. Another relaxation technique to learn may be meditation. Some parents may find it useful to join support groups. I joined the Heart Mummies for Scotland Facebook Group and managed to get in touch with two other mums with children who had undergone heart surgery at GOSH. They gave me lots of useful information about accommodation, facilities nearby, even just things like there being a laundry onsite and letting us know about the Sick Children's Trust. We even met one of the parents when we went down to GOSH the first time, as her little girl had just had surgery before my daughter. Her first date for surgery had been cancelled at the last minute, the same as my daughter.

Find out about transport costs and if the home Health Board will pay for transport costs. I wouldn't have been aware of this if it hadn't been for Children's Health Scotland. Make contact with the liaison nurses in the hospital where the procedure will be taking place, to help you with advice and support when you're there.

Think about how you will share information and update family and friends about your child's progress, as this can be overwhelming. Have a main contact that will disseminate information to others on your behalf. I created a closed Facebook group and gave updates through that.

Following surgery when a child is in ITU (Intensive Therapy Unit) they are sensitively cared for and are sedated. Whilst it's important for the parent/carer to be there, if possible, they can also take this opportunity to try to rest for short periods in their accommodation, because when their child is moved to the ward it's difficult for them to get a break. It's ideal if another parent/carer



can be there to share the care. Find out as much as you can about the canteens in the hospital, opening hours etc. and ask staff if you are entitled to food vouchers. This was something we didn't find out about, but other parents told us they had received them.

Ask about Family Support services in the hospital and activities for siblings. At GOSH siblings may be able to attend a school or nursery.

If this advice can help just one other family I will be really happy. We have been so lucky with how everything has turned out for our daughter, she's our wee miracle and it's certainly been life changing being her parents. She never complains about being unwell and is always happy, she's such a blessing. It all went so well at GOSH and was a positive experience.

Really my main piece of advice is to get in touch with the excellent staff at Children's Health Scotland! Thanks so much again for all you have done for us."

'If this advice can help just one other family I will be really happy.'



Caring for children who are born too early



Dr Una MacFadyen, Consultant Paediatrician and Trustee of Children's Health Scotland highlights an important guideline which aims to support children and young people born preterm and their parents and carers, and healthcare, education and social care professionals.

In most nursery classes of twenty or more there are likely to be two or three children who were born premature. This means that they were born two weeks or more before their due date. A few of these children will have been born up to 15 weeks before term and may have health problems or significant developmental delay that is identified in their records and likely to lead to an assessment of needs and a plan for any additional support for their education. However, more are 'Moderate and Late Preterm Infants' with no obvious health problems and no identified developmental problems, but may benefit from recognition of the potential benefit for education professionals being alert to the challenges that any preterm birth can pose.

The National Institute of Care Excellence (NICE) guideline on 'Developmental follow-up of children and young people born premature' published in 2017, confirms that

premature birth can impact on brain development in ways that may become apparent only in the long term, particularly in relation to specific sensory processing difficulties that can present as learning difficulties including dyscalculia, as well as dyslexia, or affect the pattern of emotional intelligence, maturity and relationships.

Every child is different and many children born preterm do not differ from their peers in health, growth or development, but for some it may help to keep their early birth in mind when they seem to struggle with what is expected of them.

Every child is different and many children born preterm do not differ from their peers in health, growth or development, but for some it may help to keep their early birth in mind when they seem to struggle with what is expected of them. Being born early may put their birthday into the 'year ahead' for nursery and school entry resulting in their classmates being almost a year older, physically



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bigger and developmentally more mature. In addition the child may find multiple sensory inputs overwhelming. This can show itself as apparent extreme shyness, 'over-reaction' to busy, noisy or fast-moving situations (like the average nursery class).

It is not always routine for information about children's birth to be recorded but it can be very helpful to both parents and child care professionals to have an understanding of its relevance. Often parents will be aware that this child is different from their other children in how they cope with new and exciting experiences, but they may find it hard to describe what they observe and so their enquiring about deferred school entry may not be explored or accepted as appropriate.

We may now be seeing the need for 'less is more' for stimulation and paced learning for some children with quiet time-out options

In paediatrics we have learnt that premature infants' brain development is influenced by their early sensory input and we practise 'developmental care' to try to optimise the creation of normal neural pathways and to minimise adverse or traumatic early experiences. We encourage effective positioning, limiting bright light exposure and noise levels and encouraging skin to skin 'kangaroo care' by parents to give positive touch, smell, sight, sound and limb and joint position input. We may now be seeing the need for 'less is more' for stimulation and paced learning for some children with quiet time-out options and more individualised learning plans to help this growing group of learners have the best childhood and future possible.

• **To read the NICE guideline - Developmental follow-up of children and young people born preterm visit www.nice.org.uk/guidance/ng72**

This article first appeared in Early Years Scotland's Parent Chat magazine, Summer 2018.



Healthcare in Schools

We reported in a previous newsletter <https://www.childrenshealthscotland.org/wp-content/uploads/2017/06/Spring-2017-Newsletter-email.pdf> about our activity in relation to healthcare support in schools.

Following the publication of the Scottish Government Guidance – Supporting Children and Young People with Healthcare Needs in Schools <http://www.gov.scot/Publications/2017/12/3694> we developed a position statement on this issue, outlining the legal and policy background, the main issues as we see them and advice for families. Read this at <https://www.childrenshealthscotland.org/childrens-healthcare-rights/campaigning/> in the Education section.

In recent months we have also worked with Enquire: the Scottish advice service for additional support for learning, to develop a fact sheet to inform and support families when their child needs healthcare support in schools. This will soon be available on our website and on Enquire's website.

We are also contributing to The Royal College of Paediatrics and Child Health's short life working group. This has been set up to look at issues around who delivers healthcare support in schools and whether anything can be done by health colleagues to resolve some of the issues relating to the support of children and young people with health care needs in schools. We will keep you updated on progress in this area.



Children and Young People's Healthcare Rights digital e-learning resource

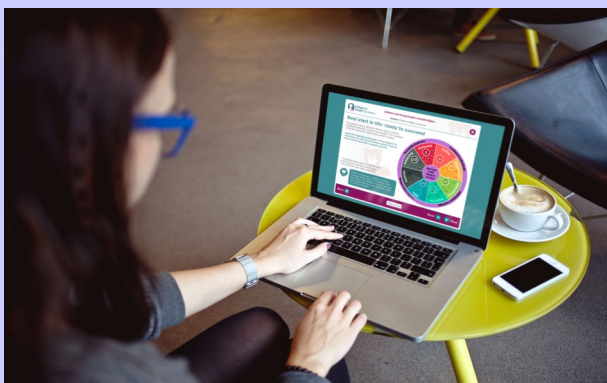
Development Officer, Anne Wilson writes:

Children's Health Scotland has just completed a Children and Young People's (CYP) Healthcare Rights e-learning resource for practitioners in health and social care who work with children and young people.

As a rights-based organisation, with children and young people's healthcare rights at the heart of our work, we have used our knowledge and expertise to develop this resource. Its aim is to help practitioners give further effect to UNCRC articles in their daily practice.

The resource sets out the policy framework, duties and responsibilities under the Children and Young People (Scotland) Act 2014. Practitioners will gain a greater understanding of the UNCRC by exploring the European Association of Children in Hospital (EACH) Charter points allied to the Wellbeing Indicators and then link them back to the corresponding UNCRC articles. This understanding will be applied to examples of scenarios and case studies which will allow learners to reflect on practice in their own work place.

Thanks to the Scottish Government GIRFEC team and Rights team and to Ecom in Dunfermline for their help in the development of this resource.



To access the course self register on www.enetlearn.com/childhealthscot

For further information contact a.wilson@childrenshealthscotland.org.

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



CHS Development Officer, Anne Wilson and Colin McEwan, ECOM demonstrate the resource at the NHS Health Scotland conference in June.

New Area Officer in Tayside

We welcome Michelle Wilson to our staff team, as our new Area Officer in Tayside while saying goodbye and thanks to our outgoing Officer, Deborah Brown.



Michelle has a nursing background and extensive experience in early

intervention and in providing help to families in Dundee.

To find out more about our work in Tayside email m.wilson@childrenshealthscotland.org.



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