

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.



Newsletter Winter 2017/18

Child Healthcare in Scotland Overcoming the Challenges to Equality



Conference 2017 issue

The CHS conference on 10 November provided insight into the breadth and diversity of developments undertaken and challenges faced in delivering healthcare that caters for the needs of all of Scotland's children and young people.

CHS Chair, Professor Richard Olver welcomed delegates and, after reminding them that inequality of healthcare had a very long history and had persisted in spite of the introduction of the NHS which was meant to bring an end to such inequality, introduced Dr Steve Turner, RCPCH Officer for Scotland, the conference Chair. During the course of the day, Steve skilfully guided delegates through the conference, introducing speakers, highlighting points for further thought and drawing together key messages of the day; all done with a light touch and a clear eye for detail.

Dr Catherine Calderwood, Scotland's Chief Medical Officer, presented her keynote speech on Realistic Medicine and the way it supports child healthcare in Scotland. She gave focus to some of the health issues in society today, advising that Realistic Medicine offered an opportunity to talk about the way we tackle certain situations. Although the prevalence of childhood obesity is falling overall, in the most deprived areas it is

increasing. Similarly, adult smoking is more prevalent in deprived areas and a lower percentage of children in such areas are registered with a dentist. In considering instances of abuse, neglect and family dysfunction, Catherine also noted that their impact on health, mental health and wellbeing rises as the number of instances increase.

The Scottish Government realises there is work to be done. Its introduction of baby boxes will be evaluated to assess impact. The mental health strategy has committed more money to mental health services and established Scotland as the only country committed to setting targets for child and adult mental health. In drawing her presentation to a close, Catherine stressed that rather than talking about people being sick, we needed to see the lives of our children and their families, as much as can be done to change and improve their lives.

The discussion that followed was wide-ranging. For example, Dr Elaine Lockhart, a Consultant Child and Adolescent Psychiatrist referenced

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**Best wishes for 2018
The Year of the Young Person
from all at
Children's Health Scotland**



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Chief Medical Officer, Dr Catherine Calderwood

the misuse of the term 'mental health problems' to describe mental illness and noted it was hard to argue for funding when this condition is not clearly specified. A parent wondered why school lunches included dessert. In response, the Chief Medical Officer reminded delegates of the focus of 'Inch by Inch for Scotland', launched two months ago and encouraged us to question practice in our local communities where we have concerns.

The following session focused on the challenges in establishing a level playing field for all children and young people's healthcare. Dr Anne Mullin, a 'Deep End' GP, spoke about GP services and deprivation, noting that general practice is now less involved in preventative child healthcare and that this reduces a GP's potential for success in working with families in deprived areas. The Deep End report provides information about their journey towards a more integrated approach to healthcare.

Diana Children's Nurse, Evelyn Rodger, focused on end of life care for neonates and explained that because CHAS (Children's Hospices Across Scotland) was only reaching one in three of these children, staff developed strategies to improve this situation. These included memory making with families, offering a choice in where the death takes place and post-death care to support families. Yet, further staff training, dedicated time and resources and a national care plan are still needed to move forward in this area.

Frank McKillop from Enable highlighted the fact that diagnosis can be key to accessing support provision for disabled children. Diagnostic overshadowing can lead to the child's condition wrongly being attributed to the learning disability and the isolation and exclusion from society that many disabled young people experience can

impact on their future lives. Thus, Frank argued, there is clear need for more training to raise awareness of the needs of children with learning disabilities.

Ann Forsyth, Service Manager of the Asylum Health Bridging Team, NHS Greater Glasgow and Clyde, revealed in her presentation that, currently, there are approximately 3,500 unaccompanied asylum-seeking children in the UK. Ann highlighted that establishing healthcare links to GPs and accessing interpreters are examples of a number of challenges they face in undertaking initial healthcare assessments.

This session was brought to a close by Jim Carle, Executive Director, Social Work and Health at Kibble Education Care Centre, who stated unequivocally that children in care are not getting equal access to healthcare. These traumatised children are well known to services but healthcare assessments submitted are often incomplete. He reasoned that we need to work better together to complete assessments when children are younger and that a standardised health needs assessment will ensure that all needs are detected and addressed.

In a lively session before lunch, delegates and panellists considered some of the challenges in sharing information and managing limited resources. Anne Mullin pointed to the benefits of face-to-face conversations, and Allyson McCollam, Child Health Commissioner in NHS Borders, wondered how we could work better together in smaller boards to give equally good care to all our children in different geographical areas. Delegates and presenters followed up such conversations over lunch.

In the afternoon, Steve Turner reminded delegates that the focus was mental health and mental wellbeing and that Helen Minnis, Professor of Child and Adolescent Psychiatry at Glasgow University was leading the address on Levelling the Playing Field.

Helen stated that the University of Glasgow's study of Adverse Childhood Experiences underlined the impact of childhood adversities on health in adult life. The damage is done when a child experiences many such adversities and her study had found that genetic factors may be part of the issue. Her team's study of the Prevalence of Attachment Disorders in North Glasgow had shown that 1.4% of the case studies had an attachment disorder and at least one



The challenges in establishing a level playing field panel speakers



Tuscany McKenzie



Professor Helen Minnis



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neurodevelopmental disorder. Thus, she has increasingly become aware of the stressful lives of people living with deprivation and argued that CAMHS teams and social workers need to work out a realistic and achievable way of assessing children in this group. Early intervention is key to making a significant difference, because of the impact these problems can have on the future lives of the children. She advocated the usefulness of establishing and maintaining on-going links between school health screening, CAMHS assertive outreach with young people, voluntary sector self-referrals and social work caseloads. Helen concluded by stressing the need to explore ways of finding this group of children, as they need our help.



The afternoon continued with presentations focused on the approaches and challenges in addressing children and young people's health and emotional wellbeing. Juliet McCann, Service Leader, Additional Support for Learning, outlined how the outreach service worked in Edinburgh. Getting it right for every child approaches and the well being indicators are used to address children and young people's needs and teachers aim to provide continuity and progression for children when they are absent from school, or in hospital, but well enough to learn.

Russell Brown, Principal Teacher, Care and Support, Carnoustie High School, talked about Health and Wellbeing's place in the curriculum and the positive impact the school as a caring community can have on pupils' outlook and lives. He outlined the different ways schools identify pupils with emotional vulnerabilities and the types of support available, from one-to-one support, small, targeted group work, in-house support and the use of the counselling service, to working with other agencies to deliver intervention. Russell stressed the importance of a school's partnership with parents and links with outside agencies.

Margaret McEwan, Health Play Specialist looked at the different aspects of her role. She works with others in the Edinburgh Cancer Centre to develop coping strategies for children, and stressed that children who have been through treatment need opportunities through play to talk and express their feelings about what is happening. Margaret offers families advice about charities offering support and uses information from her meetings with the multi-disciplinary team to prepare children for treatment and to identify distraction methods to support them.

Thomas McEachan and Chloe Robertson, Members of the Scottish Youth Parliament ended this session by talking

about last year's campaign on mental health, with its report, Our Generation's Epidemic recommending that information about mental health support services be made available in schools, colleges and universities, that schools implement a mental health plan and that CAMHS services be extended to those up to 25 years of age. They also stressed the importance of young people being aware of their healthcare rights.

A brief discussion relating to the presentations was followed by a successful group activity to identify approaches and challenges delegates knew of through their areas of work. The effective approaches identified ranged from the Daily Mile, the Speak Your Mind campaign, Bookbug, and CHS self-management workshops, to changing terminology from 'Did not attend,' to 'Child not brought.' Meanwhile, challenges flagged up, among others, the lack of support staff in schools, accessing appropriately skilled primary care, funding issues and data-sharing across organisations and boundaries.

The theme of Growing Up and Moving On in the final session enabled presenters to highlight good practice in how we ensure children and young people's rights are not overlooked in adult services. Jean Davies, Clinical Nurse Manager, Paediatrics in NHS Ayrshire and Arran talked about developing a pathway for young people cared for in adult settings and provided an example of her Health Board's assessment of risk for young people aged 14-16 years. Helen Bauld, parent of a young person who had transitioned from child to adult services, noted that this experience had caused her to change the perception she, a paediatric nurse, had of this process. She had been pleasantly surprised by the positive approach of adult services and advised that transition isn't only about the child; it's also about the parent. It isn't something you 'do' to people; it's organic and should be adapted to the needs of the people involved, and she stressed that person-centred approaches are being delivered in adult services. Tuscany Brown, a young person who had participated in CHS's self management programme in Lothian and who had transitioned to adult services was the final speaker to address this theme. Tuscany stressed the importance of the parent's role in developing a young person's independence to assist with the transition process. Following the delegates' discussion with the panel of presenters, Steve Turner thanked the panel. Richard Olver then brought the proceedings to a close by thanking all who had contributed to the success of the day.

Sylvia Smith, CHS Executive Committee member

To listen to an audio recording of the conference and/or to view powerpoint presentations visit <https://www.childrenshealthscotland.org/accepted-the-challenge-wish-me-luck/>



Ensuring the continuity of care of sick children of refugee and asylum-seeking families

The experience of asylum seekers and refugees (ASR) is well documented. You, like me, might find it hard to imagine the trauma of leaving home far away, to hopefully arrive safely, wherever that might be. Think then, how you would get a house, see a GP, get your children into school, buy what you need, and how difficult that would be, if you do not have knowledge of the systems, or speak and read the indigenous language. Scotland welcomes ASR families and unaccompanied children. Led by COSLA (Coalition of Scotland's Local Authorities), and in partnership with local NHS Boards, ASR families are supported to settle and build new lives here.

Earlier this year we asked our NHS Board Child Health Commissioners (CHC) how, as part of an International and European approach to children and young people's health rights (United Nation's Convention on the Rights of the Child) they are meeting the European Association for Children in Hospital (EACH) Charter and its updated resolution, which asks Health Services how they ensure that:

- the enforced relocation of refugee/asylum seeking families with a sick child is avoided to provide continuity of care and avoid separation from parents. It also applies to children under the age of 18 who have arrived unaccompanied, and to those who have a trusted carer(s);
- all health care professionals are informed by their own national health system of the specific practice in place for children who are refugees/asylum seekers. In turn, this practice should be explained to these children and their parents / carers;
- sick children and their health records are systematically traceable within and across countries;
- extra efforts are made to communicate with refugees/asylum seekers in a clear, understandable way (by oral and written translation) in a manner appropriate to age and understanding.

NHS Boards practise under a plethora of policy and guidelines which informs what they do. The EACH charter forms part of this wider Rights based approach to healthcare policy and practice. <http://www.healthscotland.scot/health-inequalities/the-right-to-health>

What they said

All 14 NHS Boards responded. The Syrian Resettlement programme, as well as people arriving from other countries, meant that all had some direct contact with asylum seekers and refugee families, with different numbers and experience accounting for their response. Each evidenced knowledge of their obligations and practice to meet ASR children's health needs, including taking into account the views of the child and family if relocation for health services was necessary.



The information provided by the NHS Boards showed that all are meeting the charter resolution by working in partnership, undertaking specific strategic and operational planning and introducing or modifying health service delivery to address barriers to health care. This ensures ASR and unaccompanied children receive the health care they need. Approaches include:

- Participating in local multi-agency, integrated service groups, community planning partnerships and health and social care partnerships. Local authority housing departments cited as a key department.
- Establishing specific teams or posts to plan, assess and target health services such as resettlement groups, an Asylum Health Bridging Team, Looked After and Accommodated Children (LAAC) nursing team as a focus, or establishing lead doctors with responsibility for the protection of unaccompanied children, for example.
- Ensuring that staff support GP registration, liaise with clinical colleagues, complete immunisation checks, register and accompany children and families into the child smile programme, and make contact with ASR's through midwifery and optician services. Third sector organisations and religious groups are also involved to provide support through partnership working.
- Boards have established specific pathways for ASR families. These include Unaccompanied asylum-seeking children (UASC) Pathways for under 16's. Development of Pathways for Unaccompanied Asylum-seeking Children (UASC) 16-18 years – subject to age assessment, as well



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as developing resources to assist staff working with UASC.

- While accepted as desirable, patient health records were usually not available from their departing country and staff relied on the medical assessments undertaken by the UK Home Office. These assessments allowed a Board to plan to meet the child's health needs before relocation, especially where an ongoing medical need existed.
- All Boards were aware of their duty to ensure translation, interpretation and communication (TIC) needs were met. Translation services (some in-house), materials in different languages, signposting to English lessons, and staff guidance were some of the approaches provided.

In summary, the arrival of asylum seekers and refugees, specifically the Syrian resettlement programme, has necessitated considerable joined up work between local agencies, including NHS Boards.

It is encouraging to see that each Board is aware of their role and developing strategy and changing operational practice as required to ensure ASR children's health needs are met and/or anticipating meeting those needs.

Based on the information provided and the honesty of Boards, there is an indication that meeting the health needs of ASR families, children and young people has flagged up some gaps between the strategic intention and operational delivery, despite good practice and knowledge of responsibilities. These include capacity, funding, interpretation and translation, staff skills, knowledge, responsibilities, age assessment for child services, consultation and feedback.

The information provided will inform the 'harder to reach' work as it develops.

Linda Alexander, CHS Development Officer

CHS Self Management Project nominated for 2017

All of us at Children's Health Scotland were delighted when our Lothian Self Management Project was one of 6 projects nominated for the Alliance Self Management Project of the Year Award. We attended the Awards Ceremony at Scottish Parliament on 4 October and heard about the fantastic work that is being carried out in Scotland.

Funding from The Robertson Trust and BBC Children in Need will enable us to continue this valuable work. The next workshop programme starts on 3 February. Visit the project page on our website for dates for the year ahead and information on how to refer.

Getting it right for looked after disabled children with complex healthcare needs

Our Children and Young People in and Leaving Care Project continues to deliver projects to more than 100 foster and kinship carers each year.

As part of this work, we can deliver a series of two to three-hour sessions designed to address some of the issues encountered when caring for children with more complex healthcare needs.

To find out more contact Anne Wilson on

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



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