

Children with Exceptional Healthcare Needs
(CEN)

Annual Event 2020

Area 062
Gyle Square
1 South Gyle Crescent
Edinburgh EH12 9EB
Telephone 0131 275 6575
Fax 0131 275 7614
www.nsd.scot.nhs.uk



Key messages V1 Final

Subject: Key Points from CEN Annual Education Event 2020

File Ref: K:\09PCF\NSD\NMCNs&NMDNs\Networks\CEN\Events\2020CEN
AnnualConference\Fedback&Evaluation\2020-02-
27CENKeyNotesFinalV1

Author: Christopher Williamson

Date of Event: 27 February 2020

Event Title: 'Co-ordination, Compassion, Communication'

Venue: Tollcross International Swimming Centre, Glasgow, G32 7QR

The Children with Exceptional Healthcare Needs (CEN) Annual Event took place on 27 February 2020 in Glasgow and was chaired by **Sally Amor, Lead of the Child Health Commissioners Group, NHS Highland** and also **Ronnie Hill, Associate Director of the Health and Social Care Alliance Scotland**. The event was attended by a wide range of professionals from across Scotland.

- Welcome:** Ms Sally Amor, Child Health Commissioner, NHS Grampian, welcomed delegates to the event, thanked them for attending and introduced everyone to the full agenda consisting of presentations from a range of contributors. Ms Amor highlighted the purpose of the event by reflecting on the words which made up the title of the event and how these were intrinsically linked to ways in which we all find purpose and meaning in life and in relationships. She suggested that co-ordination, compassion and communication, when synergised between people and organisation, enable us to make sense of the world around us, to co-ordinate quality care and our roles within its provision.
- Introductions:** Dr Susan Buck, Lead Clinician, NHS National Services Scotland. Dr Buck highlighted that the main aim of the conference was to share best practice through stories; stories of a personal and a professional nature and made reference to the mission of the network which is to share people's experience to inform us of what excellence should look like and to promote both equity and equality throughout Scotland. It was also noted that co-ordination, compassion and (effective)

communication were not only aspirational but also frequently achieved as we deliver the best service and levels of care for children in Scotland and their families.

3. **Long-term Ventilation: Dr Umair Khan, Consultant in Acute Paediatrics and PICU, NHS Lothian.** Dr Khan introduced his work at the Royal Hospital of Sick Children (RHSC) in Edinburgh and highlighted how the demand for long-term ventilation (LTV) is increasing due to the advances in medical care and children living with LTV needs for longer. He suggested that data has shown a 140% increase in the number of children needing LTV from 2010 to 2020 within the RHSC. Dr Khan referenced how having a child with exceptional healthcare needs at home with their families is beneficial for them and the family emotionally, psychologically, logistically and financially but also identified that children with LTV needs can utilise up to 50% of day care beds in ITU's and referenced the costs of this to the NHS. He noted that references in the media to the amount of time it can take to transfer a child with LTV needs to their home. Identifying that there is a multi-disciplinary team working in the background through a process of communication and collaboration which not only plans everything that is required for the move, it takes into account anticipatory care planning which supports this move, which is a hugely complex process. Dr Khan suggested that what is challenging is balancing the delivery of healthcare with making the right decisions for the child and the family. He reviewed evidence which suggests that after a child is moved home with LTV that there are significant numbers of parents who express regret at their decision. Highlighting that parental comments have been collated which have and will become the focus of further work in order to impact on the level of dissatisfaction experienced and noted. Dr Khan highlighted the level of LTV services elsewhere in the world and informed delegates of areas where there is only one LTV hospital bed to 500,000 children and also where LTV is only available to the financially affluent. He went on to explain that whilst we appreciate the service our NHS provides we need to add questions to this appreciation; questions around what would make things better for the families we work with, thought around ways we can better prepare the families and children we work with, and what can we do to facilitate better levels of story-sharing and family/family contact. Dr Khan highlighted the importance of using networks to enhance the care and service we provide.

On thanking Dr Khan for his contribution, Dr Susan Buck informed all present that there was a Facebook Group for parents of children with exceptional healthcare needs being set-up by Kindred which would be launched during the course of 2020.

4. **Ethics, Decision-making and the Paediatric End of Life Care Managed Clinical Network (PELiCaN): Dr Chris Kidson, Consultant in Paediatric Intensive Care Medicine and PELiCaN Lead Clinician, NHS Greater Glasgow and Clyde.** Dr Kidson began his talk by describing himself as an intensivist; a physician who provides special care for critically ill patients and moved on to review the ethical principles that influence the role of all medical professionals:
 - i. Do good – what do we mean by this and can we quantify it?

- ii. Don't do any harm – what does this mean for the people who are organ donors?
- iii. Enable autonomy – what does this mean for the children who cannot decide for themselves?
- iv. Justice – who do we justify our actions to and to what extent?

Dr Kidson reviewed contemporary principles, the role of proxy decision-makers, the art of making decisions and perceiving the act of 'not doing something' as positively as the act of 'doing something'. Within this Dr Kidson asked delegates to consider as an ultimate goal, and focus their work around, what the child would choose for themselves. To facilitate this, he suggested that it is always necessary to consider the rich experience of the people within the community, the people around the child, as it is this level of expertise which ultimately informs us of what is 'the best' that can be done. Here Dr Kidson introduced the Paediatric End of Life Care Network (PELiCaN) and suggested that this network would focus attention on ensuring we get things right for the people that are left behind in an attempt to lessen the burden bestowed upon them, as well as highlighting what we can do to get things right for the child that is receiving end of life care. He confirmed the mission of PELiCaN was to standardise the processes and delivery of paediatric end-of-life care for all ages, all diagnoses, all illness trajectories, Pan-Scotland, as well as increase deliverable family choices (hospital, hospice, home) and improve the patient and family experience (and outcome) of care.

Questions were asked of Dr Kidson which attempted to bring forth his opinion on what his actions might be if he was the parent of a child in certain instances and this was answered openly and honestly. The group went on to highlight the need to connect with and refer to other parents who have made these decisions. It was also suggested that medics would need to consider what boundaries were required in order to keep themselves safe in an end of life situation and the UN Convention on the Rights of the Child (UNCRC) were referenced as a framework which might help.

5. **Clinical Audit System; using data to tell our story: Mrs Claire Lawrie, Programme Manager, Information Management Service (IMS), NHS National Services Scotland.** Mrs Lawrie highlighted that data is the evidence of why we do what we do and is used to ascertain baselines, forecast demand on services, review variation and ultimately improve the services that we offer to patients. It was explained that CAS is the clinical audit system that is exclusive to the national clinical networks and is available in all Scottish Health Boards free of charge. Mrs Lawrie and the IMS team can offer support to train staff how to use CAS in all Health Board areas and provide ongoing training support. It was noted that there is currently a Child Health Commissioner quality improvement project ongoing with CEN which is to have all Board inputting CEN figures on to CAS by the end of 2020. IMS are supporting Boards currently with training and re-training of staff in order to complete this project. Mrs Lawrie invited delegates to get in touch if they have any queries or questions on CAS or data in general.

6. **Wellbeing and how the NHS can create it:** Professor Sir Harry Burns, Professor of Global Public Health, University of Strathclyde. Professor Burns' presentation highlighted the effects of wellbeing on Healthcare, he began by reviewing what wellbeing is. He suggested that for any person to have a sense of wellbeing there needs to be optimism, a sense of control, purpose and meaning along with the confidence to act within a support network, a nurturing family background and environment. If at any time the world becomes difficult to understand, unmanageable or lacks meaning we will all feel stress. He explained that if this is consistently experienced in childhood certain areas of our brains develop differently as an adaptation to threat and lack of control. He explained that research has proven that we can recover from this developmental consequence through mentoring, physical activity and mindfulness but highlighted the importance of understanding the significance of wellbeing on the lives of developing children. He referred the group to research the effects of Adverse Childhood Experiences (ACE) and Maslow's hierarchy of needs. Professor Burns argued that Maslow's hierarchy was wrong and it is self-actualisation that takes precedence over community-actualisation and therefore we should begin relationships by making people feel good about themselves. In order to do this, in order to make a difference in someone's life, we need to build trust, listen to the answer to the question "What do you need?" and work with that information. It is this that will provide us with all the information required to ensure the people we are working with have everything they need to enable and facilitate wellbeing. Professor Burns highlighted this as 'co-production'; sharing power and resources in order to instil a sense of well-being.
7. **What has been good for me?** The voice of a young person with exceptional healthcare needs: Mr Azeem Ahmed. Mr Ahmed highlighted that for him, 'good support' is delivered when staff know a person, know the treatment involved and listen to the point of view of the person they are caring for. He also recognised that 'good support' helps a family to be a family and that for him, having good quality of life means being well, being able to socialize, be independent, make an income and move towards non-reliance on an adapting and developing service where he is able to choose what level of assistance he requires with challenges he identifies himself; self-determination. To conclude his presentation Azeem suggested that from his point of view the network's goal should be to help agencies work together as resource co-ordination, including the sharing of information which would make better, more continuous care for everyone involved. Questions from the audience were invited, the answers further highlighted the significance of young people being included in decision making processes, even if the agreed outcome did not deliver their original requests. Mr Ahmed concluded with the hope that he would have further opportunities to tell the story of his journey and experience again in the near future.
8. **What makes a good day?** The voice of a parent of a young person with exceptional healthcare needs: Ms Jane Holmes. Ms Holmes kindly introduced the delegates to her family of three sons and in particular Ben her youngest, who is 18, exquisitely

sharing their story. Jane highlighted that **co-ordination, compassion and communication** are pivotal in terms of the difference they make to any given day. Each day begins with an assessment of how Ben is and whilst all plans need to be moveable for the family as well as for Ben, the default setting is about going out and when this happens, family life, with all its plans, can continue. Jane explained that whilst good **communication** is key to successful delivery of services, so is a can-do attitude. Ms Holmes highlighted various experiences, the culmination of which has led her to assume the role of **co-ordinator** for Ben's services. If, when communicating, Jane could hear the words "Leave that with me, I will sort that" it would feel like there was another responsible professional person co-ordinating services and in that sense the role or parent could be regained and reinforced. As a parent or family member Jane stressed how important it is to be recognised as being the voice of the person receiving support. In terms of services it is vital that this voice is heard and recognised as valuable in terms of the input it gives. Ms Holmes experience unfortunately is that this voice is not always heard. By showing **compassion** and asking "Is there anything you wish me to know as I make this decision about your child?" we would be able, as a team, to include the voice of the parent and in that sense, the voice of the child / young person receiving the support or care. Questions were asked around the transition from children to adult services, the answer to which uncovered that for Ben there had been none. Ms Holmes told of the challenging journey the family had had to undertake in terms of organising Ben's education and this highlighted to the need for different organisations and services communicating with one another. If services are connected, this results in the parent being at the centre of a lot of good people, co-ordinating care, when in essence they need to be with their child, being a parent, with another professional taking ultimate responsibility for co-ordinating and communicating care packages compassionately.

9. **Children's and Young People's Mental Health and Wellbeing Programme Board: Ms Jessica Galway & Ms Jacqui Wray, Scottish Government.** Jessica and Jacqui explained how the Programme Board had been set up to oversee the development of a whole system approach to children and young people's mental health in Scotland. The task was to create a set of reforms designed to ensure that children, young people and their families receive the support they need, when they need it. Reform that is underpinned by the values, principles and components of Getting It Right for Every Child (GIFREC), the Scottish Government's approach to supporting children and young people. The make-up of the Programme Board was explained to delegates; there were nine key deliverables and particular attention was paid to the CAMHS and Neurodevelopmental Services within the presentation. Jessica and Jacqui reviewed the Community Mental Health and Wellbeing Framework which sets out the expectation of support that should be in place in every local area to ensure that no child or young person is left with nowhere to turn. They introduced a 24/7 Crisis Support Service for 5 to 25 year olds which they explained is undergoing user testing. It was identified that there would be a revised guideline that first appointments with CAMHS would be offered within four weeks of referral. During questions from

delegates Jessica and Jacqui confirmed that the Scottish Government would be providing additional funding to Health Boards to help this become achievable.

10. **Afternoon content:** Mr Ronnie Hill, Associate Director of the Health and Social Care Alliance Scotland, welcomed delegates returning to the event following the lunch-break and thanked the contributors thus far for their input. Mr Hill informed all present about the work of his organisation (Health and Social Care Alliance Scotland), which acts as a conduit for those with lived experience, without filtering stories, a theme discussed in all the presentation. Ronnie highlighted Alliance's commitment to providing free training in Scotland and referenced on-line training materials that bring individual voices to the fore and empower service users to be in the driving seat in terms of GIFREC.

11. **"It feels like I just have to handle it": Supporting young carers who look after a sibling:** Ms Tracey Stewart, Operations and Development Manager, Edinburgh Young Carers (EYC). Ms Stewart explained how the work of Edinburgh Young Carers is replicated across Scotland in various young carers organisations where the focus is on the impact of caring, not on the duties that are involved. Ms Stewart highlighted how almost 40% of young carers that are supported by EYC are caring for a sibling and that this number is growing as they receive more referrals for sibling young carers on a weekly basis. She explained that children who care for their siblings experience a unique set of circumstances and issues, different from non-young carers, but also with significant differences from young carers caring for parents or other relatives. EYC do occasionally encounter a lack of understanding of this issue and she identified that there is also a research gap around this topic. Therefore, Ms Stewart organised and facilitated meetings with young carers, and their parents, which highlighted some of the challenges being faced by young carers along with what support they need. Ultimately this need focussed in on 'hearing the voice' and also 'thinking about the person and the situation'; the whole story. It became apparent through the conversations that young carers would feel more supported if they were checked-in on, for example in healthcare appointments, asked about their emotional wellbeing and referred to other services for support. It was highlighted that this requires the professional to be aware of what support is available in their particular area. Ms Stewart advised all present that EYC provides training on what it means to be a young carer and is also encouraging individuals to become young carer champions in their regions/sectors. Questions asked at the end of the presentation focussed on the positive benefit of mentioning, asking about and attempting to understand caring responsibilities and the dynamics of these. Also focussing on the advantages of discussing the availability and work of young carer organisations within appointments.

12. **Navigating housing systems – experiences of home seekers and housing providers:** Professor Isobel Anderson, Stirling University. Professor Anderson presented a synopsis of research completed by Stirling University alongside Housing Options Scotland and Horizon Housing Association, which took place during the course of

2019. The research was qualitative/experienced based and co-productive in nature. The focus of the research was “the continuing, often negative, impact of unsuitable housing on the lives of disabled people”. The report concluded with recommendations for registered social-housing landlords and local authorities, the Scottish Housing Regulator as well as the Scottish Government. Which focussed on co-productive / multi-organisational, flexible working practices with widened needs assessments. Potentially including minimum accessibility standards and technology which could provide property intelligence, and enable remote viewing for example. Professor Anderson reviewed how advocacy and a collaborative approach across organisations was achieved in some cases with the Occupational Health Therapist coming forward as a key person with a very important role, especially when working around adaptations. Questions on this presentation and the research focussed on the importance of collecting data (on CAS) so that a focus can be reviewed on housing requirements and independent living.

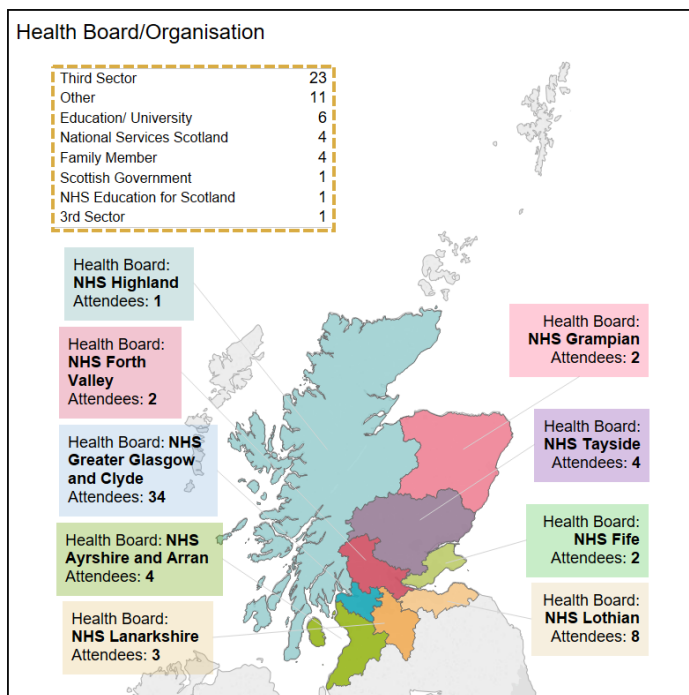
13. **The transition from child to adult health services for young people with complex learning disabilities:** Professor Michael Brown, Senior Fellow and Academic Lead, Queens University, Belfast. Professor Brown presented the results of the three-year research study and its findings. The recommendations entail strategic level planning and leadership in all NHS Boards, clear process and pathway development and implementation within education, health and social care services which has young people with learning disabilities and their families centrally and fully involved. There were recommendations around identifying lead health professionals who are responsible for the co-ordination of the transition process with nurses supporting and facilitating the transition following further education on effective transitions. Qualitative aspects of the research identified themes within the family’s experiences of the transition from child to adult services, which were quantified with a deep sense of loss, finding the process overwhelming and unbearably pressured with the adults themselves making the transition into a ‘shocked’ adult care system happen. The study highlights co-production as pivotal to a successful transition and even suggests the question “What are the outcomes you would like from this process?” It was identified that this report will be disseminated to the Government, NHS Boards and Social Care services. Questions asked following Professor Brown’s presentation included a question around the possibility of the network using CAS to identify the numbers of people needing to undergo transition in Scotland in order to highlight the amount of planning that is required for transition to become more successful for all involved.

14. **Preventing harmful sexual behaviour involving children and young people with intellectual disability:** Dr Jana de Villiers, Consultant Psychiatrist, Intellectual Disabilities Forensic Network Clinical Lead, The State Hospital, Carstairs. Dr de Villiers presentation focussed on the Scottish Government commissioned report entitled ‘Preventing Sexual Offending Involving Children and Young People’ which was published in January 2020. She explained that the background research suggests that

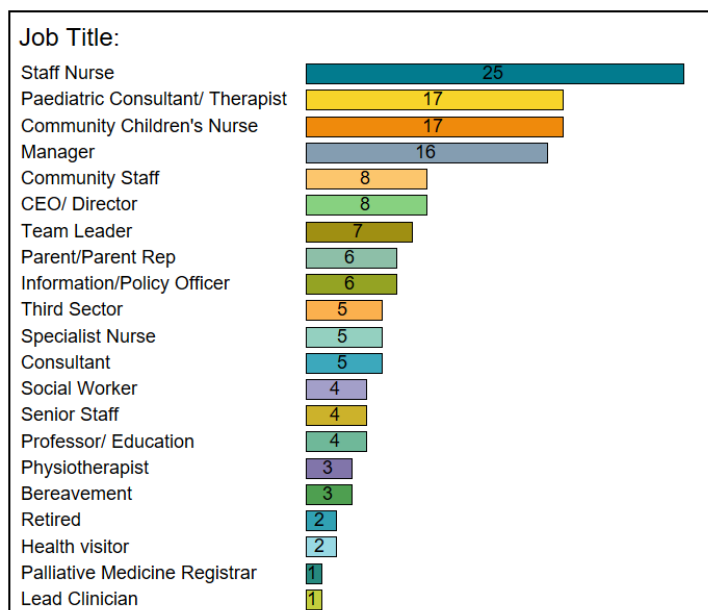
about one third of all harmful sexual behaviour towards children and young people is committed *by* children and young people. Dr De Villiers detailed an NSPCC sponsored UK study that suggests that by the age of 15 children are more likely than not to have seen online pornography with 44% of males and 29% of females reporting that this pornography has given them ideas of the types of sex they wanted to try. Dr de Villiers went on to highlight that many frontline professionals assume that the person causing the harm will be an adult and therefore there is a lack of appropriate response services when the perpetrator is a child. However, where there is detection and effective intervention, children exhibiting harmful sexual behaviours are at relatively low risk for future behaviours. Whilst primary, secondary and tertiary prevention strategies were put forward within the report, and highlighted as part of the presentation, Dr de Villiers talked the delegates through the overarching proposal of establishing a multi-agency group to oversee and ensure continuous service improvements, reporting on progress to the Minister for Children and Young People. It was stipulated that all relevant guidance published for use by parents and carers should make reference to the Hackett Continuum and the Brook Traffic Light Tool and that a matrix should be developed to guide all frontline practitioners regarding the evaluated services available for children and young people. Along with information pertaining to how to access qualified professionals who can facilitate contact for early assessment and referral. In this respect CARM (Care and Risk Management) processes were introduced as a means to providing a framework for professionals in relation to the management of risk for young people who present a risk of harm. Questions from the room highlighted the work of the organisation 'Stop It Now!' who are available for support and resources.

15. **Key Messages and Close:** Dr Susan Buck, Lead Clinician, NHS National Services Scotland. Dr Buck closed the event with thanks for everyone's attendance and contribution, in particular thanks was offered to Ms Sally Amor and Mr Ronnie Hill for their contributions chairing the event and the organisations present within the Marketplace. **Co-ordination, compassion and communication**, the title of today's event was reviewed within the parameters of the work CEN is undertaking, the details of which, with links and resources, are available at www.cen.scot.nhs.uk. Dr Buck invited all present to contact the network in order to take part in the working and education groups but also to spend a few minutes talking to colleagues about what their take-home message was and what could be done differently as a result of the conference, along with taking a moment to complete the feedback forms included in the information packs provided at the outset of the day.

Evaluation Data



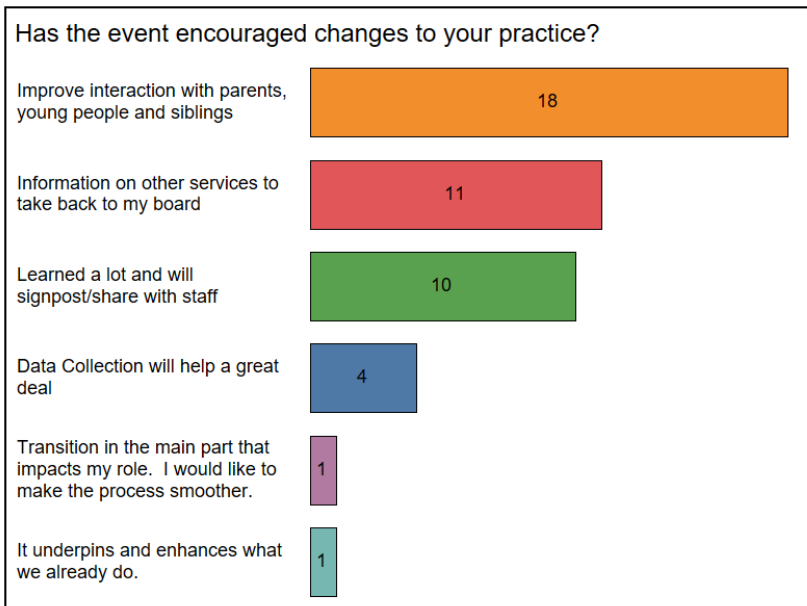
Registrations grouped by Board



Registrations Grouped by Job Title



35 of 51 Evaluation responses thought the event could not be improved.



Impacts of the Event of practice

- All presentations on the day received a rating of 3 (good) – 5 (excellent)