Children with Exceptional Healthcare Needs (CEN)

Strategic Planning Session 2020

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Key messages V01

Subject:	**Key Points from CEN Strategic Planning Day 2020**
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The Children with Exceptional Healthcare Needs (CEN) Strategic Planning Session took place on 29th October 2020 in on MS Teams and was chaired by Dr Una MacFadyen, Lead Clinician CEN and Miss Shelley Heatlie, Programme Manager CEN. The event was attended by a range of stakeholders from across Scotland. The purpose of the event was noted as being part of a larger overall refresh of the network following a number of staffing changes. The refresh will include reviewing the strategic aims and objectives of the network, re-engaging with stakeholders old and new and thinking about the overall look of the network including branding and website.

1. **Welcome and Introductions:** Dr Una MacFadyen, welcomed delegates to the event, thanked them for attending. She went on to explain her career history and previous involvement in CEN through to being appointed as Lead Clinician earlier this year.
   Mrs Catriona Johnson, Programme Associate Director, NHS National Services Scotland (NSS), provided an introduction to some of the background of CEN in terms of commissioning and to NSS as an organisation.

2. **CEN Who are we? Where have we been? Where are we going?** Miss Shelley Heatlie, provided the group with a recap of who the CEN cohort of patients are and how the CEN criteria should be applied as well as looking at the complexity of the overall strategic landscape in which CEN finds itself. Some of the network's key achievements were noted as; education, face to face through education events and peer reviews and written education through the current e-learning modules, Interagency working and Signposting resources and information via the network website which continues to be improved. Dr Una MacFadyen, then provided some clarity on where the network wants to be in the future, specifically noting that the focus will be to not reinvent the wheel focussing on those recommendations from the 2016 review which have not yet been completed. She emphasised the

importance of having a full data set on CAS from all Boards and urged all to ensure their data is on the system. It was noted there was a need for the network to define the 'CEN standard of care' which patients should be receiving and how to measure this in practice. It was highlighted that the current seven LearnPro modules would be reviewed as a matter of urgency.

3. **Group Session A – Network Maturity Model**
Delegates were split into two working groups and were introduced to the network maturity model, an assessment tool which helps to identify priority areas for networks to improve and develop. It was explained that Networks are not assessed against this in any way it is a supplementary tool which can be used to start a conversation and focus improvement. Each group looked at four elements of the model;

Working Group 1	Working Group 2
Purpose and Direction	Integrity and Vitality
Governance and Structure	Learning and Improvement
Leadership and Facilitation	Impact and Value
Knowledge Capture and Reuse	Sustainability and Renewal

Results from the day are summarised below;

Element	Agreed Score	Summary of comments/Justification & Suggestions for Moving Forwards
Purpose and Direction	3	Definite level 3 working towards level 4 on some elements, there was a clear plan in place however some minor improvements could be made to certain elements. Clear objective and obvious plan to drive network.
Governance and Structure	3	Definite level 3 score really well on this overall, well-structured and very clear to others. Felt that Education group would be level 3 but others could be working more to level 4. Terms of reference were rated highly however it was pointed out that some elements of the document should be reiterated to members e.g. sending a deputy to meetings. It was noted that historically meeting dates were often changed at last minute causing difficulties in attendance.
Leadership and Facilitation	4	Level 4 agreed, leadership was described as exemplary with leaders showing they have time for members and always working to help. Sub-group leadership was noted as being very effective and the group felt comfortable with current leaders. Better planning of meetings in advance was noted as a key area of improvement for this.
Knowledge Capture and Reuse	4	Level 4 was agreed for this, it was noted that the website was very helpful and goes beyond a frequently asked questions. E-learning modules available were noted as useful and add to the score of 4.
Integrity and Vitality	3	Majority vote for 3 however some thought 2 working towards a 3. It was suggested there was a need for more vitality and integrity. Could make use of social media tools-

		it was noted that CEN can't have a Facebook group however Kindred do have one that may be of help to CEN families. It was suggested to create formal system of asking and answering questions for members, this could be through the website- it was noted that there was more work required on the website and this would be taken forwards by the new comms and engagement group. it was noted that online meetings were working better as agenda is adhered to and more members can attend. To improve this score, the network could; make meetings more interactive asking more members of groups to take a lead in speaking, publicise the network and really advertise its existence, cut back on use of 'NHS speak' and jargon, create distinct paths for disseminating information to other organisations/ professional groups, publicise resources for families. A key area for improvement was noted to be links with acute hospitals and the need for these links to be made, increasing exposure and involvement in these areas.
Learning and Improvement	3	Level 3 agreed, it was suggested that the network begin to organise and host peer-review sessions as these went really well. Mr Gordon Linton asked to chair this group however work seemed to fall away- call to restart this work.
Impact and Value	3	Level 3 agreed however noted as an area for improvement. Suggested there were isolated bits of good work going on but not working as a whole collectively to bring this together- all Boards not coordinated. Suggested to speak to families to gauge what they would view the minimum best practice the network would achieve. It was noted that without a full data set it is difficult to measure the impact of the network- a full data set will help with this. Noted that links with 3rd Sector agencies such as Kindred, PAMIS an CHAS may help with engaging with families across Scotland.
Sustainability and Renewal	3	Level 3 agreed, query around membership growing organically or if a database/record is kept. Suggestion to link with a number of different groups including community development groups and community paediatricians. Suggestion to ask professionals to discuss CEN with families to increase awareness, share newsletters, create information postcard to hand out etc. Work to be done in engaging with families from across all Boards. Gone through a period of static growth, optimistic for the future following this event.

4. **CEN Programmes of Work:** <u>Dr Una MacFadyen</u>, highlighted some of the key work priorities for CEN going forwards from the 2016 review, a summary of each is below.

➢ Transition – the network intends to work with ARC and other relevant partners to review the current LearnPro and transition care pathway in order to ensure it is relevant and up to date. This will also allow the network to update information on the CEN website.

➢ Under 2 Age group- it was identified that CEN should focus on engaging with the 0-2 age group which currently is not really captured at all within the network. The network will engage with the National Perinatal Strategic network to look at capturing data and engaging with this group.

➢ Long Term Ventilation – there is a piece of work in regard to scoping for LTV in Scotland for both children and adults which is being conducted by NSS, CEN will be involved in this but the work will not sit directly under the network.

➢ Primary Care – Discussions are taking place around the creation of a GP training module, there are options being explored for this as other networks with an interest in 'complex' conditions may wish to be part of this work. This is being progressed within NSS.

➢ Continuing Care Framework – the network plan to revisit the work which was completed on this previously within the steering group in order to bring this to a conclusion.

➢ Family engagement increasing – the network will, following today, be distributing an invitation for a new 'experts by experience' group we would appreciate network members sharing this invitation with families they think may be interested in joining. We also continue our partnership with the Kindred Exceptional Families project.

It was also added that the network would like to introduce an additional item focussed on mental health support – for families and professionals which was not included in the review but was agreed to be important piece of work to take forwards.

It was identified that of course COVID-19 will impact the way in which CEN carry out work for the foreseeable future but reassurance was given that the network would still be able to move forward priorities.

5. **Strategic Landscape of CEN:** <u>Ms Carolyn Wilson, Team Leader, Children and Families' Directorate, Scottish Government,</u> provided an update on the work of her team and its impacts on CEN Children and Young people and their families. She noted that the Directorate has been inevitably focussed on Corona Virus issues with updating guidance and ensuring publications are updated. There is a new Director, Michael Chalmers, who has broad experience in working in children's services and the focus for the coming year will be a 3 strand approach

1. Incorporating UNCRC into Scottish Law
2. Refreshed GIRFEC

3. The Promise – the Looked After Children Review Report and Benefits for children

Ms Wilson also noted that their work will encompass social care, child protection, Health Visiting, Family Nursing, maternity and neonatal services with an emphasis on core outcomes. She explained that there is a National Performance Framework that must lead to Scottish Government Outcomes. Some of the Key Professional Leads were noted as Dr Eddie Doyle as Medical Adviser to the Chief Medical Officer Directorate and Ms Wendy Mitchell is Nursing Adviser to Chief Nursing Officer, Fiona McQueen

It was identified that the Directorate will relate to the Child Health Commissioners (CHC) who are in each Health Board and Ms Wilson was keen to ensure she has links with CHCs and happy to support CEN's activity.

Another core activity of the Directorate was noted as Early Years - Pre 5 and Child Health Surveillance.

6. **Group Session B- Service Development and Delivery (Care Pathways):** For this task the working groups were allocated three of the current CEN care pathways and asked to provide feedback on the following; Overall look and feel of pathway, actual content, anything missing, who should review content and how to measure its use/uptake in practice. Each group was allocated three pathways to review as follows;

Working Group 1	Working Group 2
Early support and Identification Child in Hospital Assessment Planning Discharge Planning	Child at Home – Community Support Transition to Adult Services Paediatric Palliative Care

Firstly, delegates were asked to comment on both the overall look and feel of the pathways and the categories/titles of the pathways, combined feedback from both groups is summarised below;

Area	Comments/Improvements
Overall look and feel of the pathways	• Clear and straight forwards to read • 'Breaking bad news' – re-articulate this to be seen as sharing information not necessarily 'bad' news. Could potentially use the phrase 'sharing a concern' or 'difficult conversations' • Number of linked organisations/places have changed their name- in need of a refresh • Celebrate the positives more • Good information – makes you think 'visual' rather than 'words' • Would prefer a flow chart style- take into account stages may not be linear though and may differ for different people • Make visuals to support text to be more accessible • Links need reviewed to make sure they all work

Categories / Titles of Pathways	• Reduce number of abbreviations on pathway and website • Section on 'self-management' potentially 'My life my condition' and offer the ability to ask questions • Provide guidance message around the use of googling symptoms/diagnoses – could signpost to other resources • Consider incorporating mental health element to pathways • Recognise the expectation on families which can be huge – not project managers of child's condition. How can the network prepare parents for the future? • Ensure rights of parents and children are incorporated • Add in 3rd sector support available to pathways • Incorporate information on support available throughout Covid and after – reintroducing families back into normal life.

The second part of the task was to look at each pathway in turn and comment on its content and decide what professional groups should be responsible for updating the document, results are summarised below;

Pathway	Comments/Improvements
Early support and Identification	• Enteral/parenteral feeding is unclear on the criteria • Criteria wise, there is confusion around current definition • Can the remit of the network be expanded? • Identifying patient numbers would help stratify support in areas • Collecting data would highlight CEN children and young people and would mean they get correct support quicker and not being missed • Generally clear and easy to read, good font- possibility of an overly clinical tone but relevant to audience • Support for parents/carers – happy to see use of education resources which are relevant • Very text based, could use more visuals
Child in Hospital Assessment Planning	• Measure should state "this is regularly updated and referred to" so that it is 'live' • Good resources included in parent section • Continuing care packages- reference to the need for discussions with social work. Would be good to get social work input here to amend the text as often discussions are challenging and would be good to have social work opinions in regard to expectation and understanding the role of social work to support a holistic approach to package development/funding. • Financial support section- link broken no page available

	• Need to confirm named person status with Scottish Government • Communication – mention PAMIS and Talking Mats resources • Education -no longer admin of medicine in schools, need amended- Could add fact sheet 'children in school and home with health care needs' from Children Health Scotland and Enquire
Discharge Planning	• Information clear • Exchange use of word 'service user' to something more human • Importance of training for parents and carers along with healthcare support staff so everyone is up to speed needs to be emphasised • GIRFEC – Team around the Child needs to be added to ensure unified approach is known before leaving hospital • Could link to WellChild campaign "not a nurse but"
Child at Home – Community Support	• Should include input from clinical psychology, social work in terms of review • Domestic violence increased during Covid- high risk area, could provide signposting to services • Parents and carers could provide info on perceived gaps in the pathway from their perspective • Parents could identify self-help groups • Link to 'my condition my life' website
Transition to Adult Services	• Be more considerate of transitions other than moving to adults; e.g. school transitions – more information on these areas
Paediatric Palliative Care	• Family carers- create bereavement and loss pack and section on the reality of caring for a CEN child.

Finally, delegates were asked to share their thoughts on how CEN could measure the impact and use of Care Pathways, the following results were gathered;

How CEN could measure Care Pathways use/application in Boards (KPI)?	• We can see how many people VIEW the pathways on the website – can we ask for feedback on the website? Encourage feedback from parents as well as professionals. • Can use be a tick-box on CAS to confirm use of pathways? • Look at different ways to encourage parent / carer involvement for feedback purposes. • Respiratory patients and highlighting to the relevant teams that these patients exist

7. **Group Session C – Stakeholder Communication and Engagement:** For this session both groups worked on slightly different tasks, Group 1 looked at a current Stakeholder Map and highlighted any gaps that should be filled, Group 2 worked on developing a three-year communication and engagement plan for the network.

A summary of findings from Group 1 session are below:

Suggested Stakeholder	What group they should sit on	Purpose / what they would bring to group
Secondary Care	Physio and Occupational Health – Allied Health Professionals dieticians A&E Health Psychology	A&E – Zero day admissions input, first port of call, there are care plans on Trak system, Documentation with them too, alerts for patients within the Scottish Ambulance system, alerts on trak system – are these used across other boards? Can we help implement this? Psychology should be involved throughout
Primary Care	Psychology GPs Social Work School nursing (Although could be in other areas)	Should be involved throughout care GP involvement at an early stage looked after children Social work should be involved – lead on welfare of CEN kids, should be involved early on.
NSS	Linking in with other networks	Crossover of remits – VINCYP, Neonatal, HINCYP, PELiCaN
Other Organisations	General Paediatrician Education support	Not just head teacher – Name these people, class teachers, assistant support, nursing
Third Sector	Local Charities Counselling services (Crossreach) Home start Barnardos Father's network Scotland	Counselling services can help during perinatal period but could link with other orgs to support mental health. Family support and befriending services Support/Input for fathers
Patients, Families and General Public	Third sector links also Parents/Carers/Named Person Children and Young	Third sector has links to help with families Push what the patient themselves wants, bring in

	People Siblings	their own opinions as they get older and are more able to share their views on their own care. Siblings see a lot more than parents, Go by the terms they want

A summary of findings from Group 2 are noted below, all suggestions were gathered as tasks for year 1 (2020-21) with the exception of one in year 3 (2022-23). Objectives timescales will be amended to ensure realistic for achieving success, see details below;

Objective	2020-21	2022-23
Who do we (CEN) need to engage with and how should we do it? (objective 1)	• Network to consider what expectations they have for each representative within the network and formalise with them - refer to Terms of Reference and publicise. • Communicate with current membership on expectations • Make links with Social Workers, Clinical Psychologists, Family Carers, AHP's - in hospital and community, Hospital Paediatricians, Scottish Government, NHS Education for Scotland, Other organisations; Autistic Society/ CHAS • Make links with Children and Families - via the Exceptional Families Project • Make links with Schools – education / head teachers • Link with Respite Care • Highlight stakeholders relevant for each child / care pathway	
What should we (CEN) do to promote the work of the network more widely? (objective 2)	• Make better use of newsletters, website, twitter • Highlight expectations on role and responsibilities as a member of the network. • Core Team to devise a presentation to be sent / published on Website on the work of CEN - consistent message. • Consider recruiting retired health care professionals to provide their expertise. • Reinvigorate the Peer Review Sessions.	• Roadshows; tour of health boards and organisations re the work of the network "CEN on Tour"

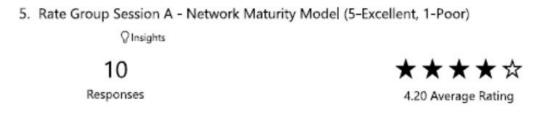|		
	• Newsletters – ask members to contribute more regularly- Spotlight sessions	
How should we (CEN) measure our 'communication and engagement' impact on stakeholders? (objective 3)	• How do we measure impact on communication and engagement strategy on stakeholders? • Stories about the impact CEN has made on a particular individual or group.	

Both groups were also asked to consider the role of 'CEN Champion' and what that might look like, overall it was felt that this would be an advantageous role for CEN to have however expectations would need to be clear from the outset. Key responsibilities suggested for this role from discussion were, information sharing with Boards, raise profile of CEN and to attend multi-professional groups.

8. **Audit and Continuous Improvement (Clinical Audit System (CAS) & Data):** Miss Shelley Heatlie, explained to the group the need for networks to capture data, noting that data is required to evidence the beneficial impacts and reasons for existence of the network. Also highlighting that network data can also be used to illustrate a populous of patients if it is unclear or unknown. It was identified that CEN have a number of out of data Care Quality indicators for CAS, as the network don't have a full patient data set, these could never be used historically. It was explained that by the end of the year the network should have a full data set which will allow for a refreshed set of Care Quality Indicators (Key Performance Indicators) to be created around this data.

9. **Summary and Next Steps**: Dr Una MacFadyen, thanked everyone for coming along to the event and for their contribution to group sessions and discussions. She noted that the next steps for the Network were to analyse results from today in order to update network documents such as the strategic workplan and three network strategies. It was noted that once these were reviewed they would go to the steering group for approval. Dr MacFadyen also reiterated that what we need from delegates is to get involved and stay in touch with CEN and its network groups.

10. Feedback

A feedback survey was available on the Teams link, the Network received 11 responses to this. A summary of key points to note from feedback are below.

- All group sessions were rated good-excellent as can be seen from the image below.

5. Rate Group Session A - Network Maturity Model (5-Excellent, 1-Poor)

Insights

10
Responses

★★★★☆
4.20 Average Rating

6. Rate Group Session B - Care Pathways (5-Excellent, 1-Poor)

Insights

9
Responses

★★★★☆
4.11 Average Rating

7. Rate Group Session C – Stakeholder Communication and Engagement (5-Excellent, 1-Poor)

Insights

8
Responses

★★★★☆
4.25 Average Rating

- Overall delegates felt they clearly understood CEN's priorities going forwards with an average of 4.11 (5=totally agree, 1=totally disagree)
- Delegates felt extremely positive about engaging with CEN in the future with an average score of 4.56 (5=extremely positive, 1=extremely negative)
- The length of the session was highlighted as an area for improvement with a number of delegates suggesting the session was too long or felt rushed.
- Another issue raised was around the assumption delegates knew more about CEN than potentially they did.
- Overall all responses noted the session was extremely well organised and run smoothly on the day.