

The National Council for Child Health and Well-being

5th September 2018, 10:30 – 13:00

The Annie Altshul room (101), Royal College of Nursing, 20 Cavendish Square, W1G 0RN.

Honorary Chair: Dame Marion Roe, DBE

Honorary Secretary: Fiona Smith

NOTES

1. Welcome

Dame Marion Roe opened the meeting and welcomed council members. She mentioned the importance of having NHS Improvement representatives around the table.

Attendees:

Dame Marion Roe, Honorary Chairman, NCCHW

Fiona Smith, Professional Lead for Children and Young People, Royal College of Nursing

Xavier Baby, Nursing Coordinator, Royal College of Nursing

Norma Jun-Tai, Lecturer – Health Play Specialists, National Association of Health Play Specialist

Angela Horsley, Head of Children, Young People and Transition, NHS Improvement

Nicola Dean, Clinical support Manager, NHS Improvement

Margaret Jeal, Chair, Action for Sick Children

Lizzie Chambers, Director of Research and Programmes, Together for Short Lives

David Bloomfield, Chief Executive, National Migraine Centre

Davina Richardson, Children's Continence Advisor, Disabled Living

Sophie Dodgeon, Policy and Campaigns Manager, Rainbow Trust Children's Charity

Karen Dobson, Consultant Nurse, Newlife the Charity for Disabled Children

Sue Flohr, Policy Officer, British Dyslexia Association

Rachel Perrin, Partnership Development Manager, Family fund

Catherine Godack, Development Officer (Health), Council of Disabled Children

Sally Vincent, Young People and Families Service Manager, Arthritis Research UK

Dan Catchsides, Trustee, Freddie Farmer Foundation

Danny Catchsides, Speaker, Freddie Framer Foundation

Samantha Darrell, Deputy Director, Rainbow Trust

Gillian Mulloy, Grants Fundraiser, Ronald McDonald House Charities

Anne Ward, Head of UK Development, Ronald McDonald House Charities

Jane Gates, Director, Sebastian's Action Trust

Candida Hazard, Trustee (Oncology), Sebastian's Action Trust

Lynn Regent, CEO, Anaphylaxis Campaign

Joanna Heath, Children's Heart Federation

Comfort Momoh (MBE), FGM/ Public Health

2. Apologies

Holly Shaw, Nurse Advisor, Allergy UK

Julie Watson, National Specialist Advisor, Children & Young People, Care Quality Commission

Brian Donnelly, Chief Executive, Community Equipment Code of Practice Scheme

Lynn Hoppenbrouwers, Strategic Health Lead, Contact

Lorraine Mulroney, Children and Young People and SEND Lead, NHS England

Dr Dick Churchill, GP Principal, Chilwell Valley & Meadows Medical Practice

Janice Allister, Adviser in Child Health, Royal College of General Practitioners

Sophie Dziwinski, Programme Manager, Roald Dahl's Marvellous Children's Charity

Dr Vimal Tiwari, Adviser in Child Health, Royal College of General Practitioners

Anne Ward, Head of UK Development, Ronald McDonald House Charities

3. Notes of meeting held on 9th May 2018

Confirmed as an accurate record of the previous meeting.

4. Matters arising

There were no matters arising.

5. Correspondence

There was no correspondence to be shared with the group.

6. Presentations & discussion

6.1 NHS Improvement Review – update

Angela Horsley, Head of Children, Young People and Transition, NHS Improvement.
(Please find presentation attached)

Angela Horsley presented her review of the CQC's reasons for rating children's services requiring improvement or inadequate, which was followed by the development of an Improvement and assessment framework for children and young people's health services

The review of CQC's reports identified CQC's reasons for rating children and young people's services in the four NHS Improvement regions as 'requiring improvement' or 'inadequate'. The common themes behind the poor ratings were used as the basis for developing the framework that providers can use to focus their improvement efforts in future to achieve 'good' or 'outstanding' ratings.

Some of the main reasons given by CQC for poor ratings of children and young people's services were:

- Low nurse staffing
- Poor culture of incident reporting or inadequate processes for reporting back to staff involved in the incident and learning from the incidents
- Staff did not have the right training or skills to undertake their role
- Poor risk management processes
- Lack of CYP strategy and leadership

As a part of quality improvement programme the Children's Improvement Framework was developed in February 2018 and endorsed by the CQC. Since then, people have been using it, which is very positive and CYP departments in NHS trusts have improved.

A mentoring programme and leadership master classes were put in place to support CYP nurses for leadership roles.

CYP is fully integrated into the NHS 10 year plan. Concerns were raised about recruitment and management skills in children's emergency department. CYP needs to be at the top of the political agenda.

Angela has been meeting with nursing directors and her findings will be part of a review for next year.

6.2 **Freddie Farmer Foundation, who we are and what we do**

Danny Catchesides, Freddie Farmer Foundation

The charity was formed in 2011 to raise £250,000 to set up a specialised subsidised physiotherapy centre in south-east England for children and young people with cerebral palsy and mobility problems. The inspiration behind it was Freddie Farmer who was born at 28 weeks with cerebral palsy. Danny Catcheside who is Freddie's uncle shared his story and played a short video. It was amazing to see children finally standing up and enjoying playing as a result of the intervention.

Freddie's family had been taking him three times a year to a centre 100 miles away for unique and intensive physiotherapy involving a piece of equipment called the 'spider'. It helped Freddie make great progress and it soon became clear that a centre nearer home was needed.

In 2011 they launched the 'Ready, Freddie, GO!' campaign to set up a specialised physiotherapy centre for Freddie and children like him. The driving force behind the campaign was simply getting children like Freddie to walk. Having started out with one physiotherapist in May 2015, the Freddie Farmer Physiotherapy Centre has now increased to two physiotherapists and two therapy assistants and continues to help scores of disabled children with varying conditions and mobility problems.

We need to built on Freddie Farmer's model and link it with other foundation and expand it. Having a patron could help raise the FF foundation profile.

ACTION: Fiona to connect FF foundation with Council for Disabled Children

6.3 **Anaphylaxis, its impact and prevalence**

Lynne Regent, CEO, Anaphylaxis Campaign

Please find presentation attached

What is Anaphylaxis?

It is a severe and potentially life-threatening allergic reaction affecting more than one body system such as the airways, heart, circulation, gut and skin. Symptoms can start within seconds or minutes of exposure to the food or substance you are allergic to and usually will progress rapidly. People of all ages are affected and research shows that the number of people with allergies is increasing. Severe allergies such as peanut allergy can be fatal.

Lynne Regent introduced Anaphylaxis Campaign to the group. Anaphylaxis Campaign support everyone affected by Anaphylaxis and severe allergies. The foundation works closely with families who are anxious about their children with allergies.

Anaphylaxis Campaign organisation have 400 volunteers and a large network across the UK. They offer prevention and training to assist when incident happens. They have been campaigning for adrenaline drug (pens) in school and have been collaborating with FSA for better food labelling.

Even though allergies are on the rise due to an overly clean environment, fatalities are not increasing.

Independent schools are more responsive about adrenaline pens than state schools where less nurses are available.

Training for GPs is also available. Scotland provides free training to all GPs.

7. Any other Business

David Bloomfield of National Migraine centre mentioned the Migraine Awareness week (2-8 September); it was an annual campaign, which drew attention to migraine, educating the public and reducing stigma. New drug has been released. An interesting BBC documentary was produced for this occasion and worth watching.

Comfort Momoh gave an update about night crime awareness campaign.

Julia Walport of the Amber Trust, providing music therapy to blind or partially-sighted children, is working on a music/ singing project in schools.

Dame Marion was very pleased to notice that the membership of NCCHW meetings was growing. It is a great networking opportunity for its members.
The 2019 meeting dates have been circulated and presentations requested.

ACTION: Xavier to add/amend NCCHW information on webpage and to provide information about the website to members.

8. Focus of future meetings:

Wednesday 28th November 2018: 10:30 - 13:00

- Jane Miles, Chief Executive, Roald Dahl's Marvellous Children's Charity
- David Bloomfield, CEO, National Migraine Centre
- Joanna Heath, Children's Heart Federation

9. Dates of future meetings:

- Wednesday 20th February 2019
- Wednesday 8th May 2019
- Monday 16th September 2019
- Thursday 12th December 2019

Please contact Xavier Baby to confirm your attendance or give apologies

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