

The National Council for Child Health and Well-being

9th May 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 apologised to the group for the cancellation of the February meeting due to adverse weather conditions.

DMR informed the group that NCCHW member Stewart Long is now the Director of Involvement and Services of Arthritis Research UK. Sally Vincent, Young People & Services Manager will represent Arthritis Care at NCCHW meetings in the future. Dame Marion Roe thanked Stewart for his past contributions.

Attendees;

Dame Marion Roe, Honorary Chairman, NCCHW

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

Kate O'Molloy, Nursing Coordinator, Royal College of Nursing

Emma Rigby, Development Manager, Association for Young People's Health

Kath Evans, Experience of Care Lead – Maternity, Infants, Children and Young People, NHS England

Chezelle Craig, Whats in a kiss?

Carrick Brown, Senior Care Service Manager, Newlife the Charity for Disabled Children

Margaret Jeal, Chair, Action for Sick Children

Emily Wragg, Deputy Director of Care Services, Rainbow Trust Children's Charity

Lizzie Chambers, Development Director, Together for Short Lives

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

Jane Miles, Chief Executive, Roald Dahl's Marvellous Children's Charity

Tracey Hancock, Head of Fundraising & Marketing, Roald Dahl's Marvellous Children's Charity

Dr Sarah Earle, Director of Research, The Open University

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

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

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

Maggie Morrissey, PR & Media Campaigns Manager, 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

Julia Walport, Chair, The Amber Trust Music for Blind Children

Nicole Walker, Head of Early Years, BookTrust

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

Stephen Fenning, Young People's Coordinator, Fixers UK

Beth McCleverty, Parliamentary and Campaigns Officer, BLISS

Joanna Heath, Project Manager, Children's Heart Federation

2. Apologies

Holly Shaw, Nurse Advisor, Allergy UK

Elaine Ward, Deputy CEO, Anaphylaxis Campaign
 Lynn Davinson, Children's Services Manager, Care Quality Commission
 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
 Davina Richardson, Children's Continence Advisor, Disabled Living
 Norma Jun-Tai, Lecturer – Health Play Specialists, National Association of Health Play Specialist
 Lorraine Mulroney, Children and Young People and SEND Lead, NHS England
 Angela Horsley, Head of Children, Young People and Transition, NHS Improvement
 Anne Harris, Director of Care Services, Roald Dahl's Marvellous Children's Charity
 Dr Dick Churchill, GP Principal, Chilwell Valley & Meadows Medical Practice
 Janice Allister, Adviser in Child Health, Royal College of General Practitioners
 Dr Vimal Tiwari, Adviser in Child Health, Royal College of General Practitioners
 David Bloomfield, Chief Executive, National Migraine Centre
 Sally Payne, Professional Adviser – Children, Young People and Families, Royal College of Occupational Therapists

3. Notes of meeting held on 29th November 2017

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 Key data on young people's health and wellbeing

Emma Rigby, Chief Executive, Association for Young People's Health
Please find slides attached

Emma Rigby informed the group of the Key data on young people's health and wellbeing resource which was published last year. Resource is also available online.

The Association for Young People's Health (AYPH) bridges the world of policy, practice and evidence to promote a better understanding of young people's health needs. They support young people's involvement in health and wellbeing and helps in the development of youth friendly health services and improved practice.

AYPH is currently working on a model of group clinics for young people with diabetes located in East London.

Young people are defined as 10-24. Also important are adolescences, clarified as 10-19, and youth, clarified as 15-24. There are currently 11.7 million young people in the UK. This offers a big opportunity to deal with challenges that arise within the age group.

By age 25 years old, 25% of young people are living at home longer and are also in education longer. 1,032,520 young people aged 11-19 live in families where there is financial struggle.

6.5% of 16-18 year olds were not in education, training or employment in England 2015. This is a vulnerable age group with young people's shifting and changing at this point.

There are positive trends in young people with under 18 conception, illegal drug use amongst pupils, smoking and alcohol consumption decreasing. However, on average teenagers consume eight times the recommended daily sugar allowance.

Mental health is a big issue for young people with approximately 100 of every 1000 people under 18 having mental health problems. Girls aged 18-24 are a particularly high risk group for mental health issues and suicide is a concern with older young men.

Data shows that inequality greatly impacts young people's lives. Young people living in socially deprived areas were more likely to be admitted to hospital with asthma. Smoking and under 18 conception are both two times more likely in young people living in deprived areas.

Key data on young people 2017 can be found online at www.ayph.org.uk/key-data-on-young-peoples-health. Includes a highlights summary, a PowerPoint presentation, infographics and the numbers behind the data.

Q: Is gang life replacing the family?

A: There seems to be a link between gangs and inequality. ER highlighted [Red Thread](#) as an organisation working with young people.

Q: Have there been comparisons with the other three countries in the UK?

A: There are challenges with each country collecting different data but yes, where possible we do compare. There is also some comparable international data.

Q: There has been a decrease in commissioning of school nurses in England. Is there any evidence of trend going in the opposite direction?

A: Withdrawing school nurses won't show up in data for a few years.

6.2 Improving Children and Young People's Experiences of Care, what more can we do?

Kath Evans, Experience of Care Lead - Maternity, Infants, Children and Young People, NHS England

Chezelle Craig, What's in a kiss? Campaign

Please find slides attached

Kath Evans introduced herself and updated the group on her work with Fixers UK – helping to get better at hearing young people's voices and asking children about their experiences.

Commitment from NICE to develop a standard on CYP care. Programmes such as CYP Me First and We Can Talk have been launched with the intention to initiate a 'moment of connection' with young people. Helping to improve understanding in cancer experience, mental health experience and primary care experience.

Developing the Child Bereavement Experience Measure (CBEM) with 400 families currently sharing their experience of bereavement.

KE introduced Chezelle Craig. CC informed the group of her son's story. He was born in 2012 and would have celebrated his sixth birthday soon. CC's son lost his life to neonatal herpes.

At a few days old he had stopped engaging. CC took him to hospital where they ran some tests. Her son was a silent baby, showing no reaction to the tests but he was sent home as a healthy baby.

Trusting her gut CC brought him back to hospital the next day. The hospital maintained that if it was anything serious or life threatening, her son would let them know through crying. He then died but was brought back to life. He was transferred to

a hospital in Tooting where he was eventually diagnosed. CC's son survived another ten days but died at 19 days old from cranial bleeding.

CC highlighted what had gone wrong. Not enough attention had been paid to his extreme lethargy and lack of response to pain. No PCR test had been given. His raised ALT levels were not followed up or flagged as concerning. A lack of senior experience within the ward. Cannula was wrongly inserted, causing injury

The What's in a Kiss campaign was developed in 2012 with support and guidance from Doreen Lawrence OBE. It endeavours to raise awareness, encourage detection and prevention.

CC has spoken at numerous events. The campaign is also raising awareness with Neonatal HSV awareness posters now in six UK hospitals. Croydon University included a paragraph on neonatal HSV in their new mum's booklet. Bounty Baby feature the poster on their app, have a three page article in their Bounty Baby Journal and an awareness leaflet will also be launched in May 2018.

CC introduced Stephen Fenning from Fixers UK. They worked together to produce a Neonatal HSV awareness film launched at the NCCHW meeting 9th May 2018.
<https://www.youtube.com/watch?v=iz9nAt3KUvU&feature=youtu.be>

For more information follow the campaign on Twitter at #whatsinakiss or email neonatalhsv@gamil.com. The official What's in a Kiss campaign [website](#) launches in June 2018.

Q: The work you have done since your son's death is extremely inspirational. It highlights the broader work that needs to be done on silent babies.

A: Everyone who dealt with my son was a junior member of the team. We would like quarterly refresher training for all neonatal staff and midwives to keep the virus at the forefront of their minds. Prevention is better than any cure.

6.3 How to use the law to improve equipment provisions for disabled children

Carrick Brown, Senior Manager - Care Services Department, Newlife the Charity for Disabled Children

Please find presentation notes and slides attached.

6.4 Magical Power of Play Appeal

Margaret Jeal, Chair, Action for Sick Children

Please find slides attached

Margaret Jeal introduced herself and Action for Sick Children (AfSC). They are committed to ensuring that children and young people receive the very best standard of health care which meets their individual needs by supporting parents, carers and healthcare professional in their pursuit of a high quality, dedicated service.

Dental Play Box – AfSC recently joined with Manchester University to provide parents with programme.

Hospitals can be scary and traumatising environments for children. The Magical Power of Play Appeal provides essential play resources to sick children in hospitals across the UK.

The project was introduced in 2017. It complements the work of other charities such as Fairy Bricks - who donate large amounts of Lego, Lime Arts - who provide arts in Health through innovation and creativity, Get Well Gamers - who donate games / DVD's / consoles etc. and Readathon, - who sponsor reading events.

AfSC believes that children should be nursed in company with other children of the same age group. They should have facilities for inside and outside play and colour schemes should be cheerful.

The aims and objectives are to assist Health Play Specialists in supporting the objectives of play therapy in hospital. To enhance a child's journey through their hospital experience. New sensory room built in Pinderfields hospital.

Lack of outside play areas for children are increasing

A recent study revealed that 94% of Play Specialist's spend their own money on play resources, with more than half of the hospitals surveyed having no budget for play resources. £250 was the average amount of budget when it was available. The majority of hospitals rely heavily on donations of toys from the general public and other external sources.

AfSC raise the £2,500 needed for each play box. A recipient hospitals then select from a 'shopping list' and their chosen resources are sent to them along with the launch a press release.

Within six months of AfSC follow up with a visit to the hospital to engage with staff on how the resources have been used. A second press release is then produced and distributed.

To date play boxes have been given to Stepping Hill Hospital, Stockport (Feb 2017), New Cross Hospital, Wolverhampton (Apr 2017), Pinderfields Hospital, West Yorkshire (Aug 2017) and Royal Berkshire Hospital, Reading (Dec 2017).

The project is ongoing with hopes to deliver 12 boxes in 2018 and 24 boxes in 2019. Working with companies, in particular Tesco, on funding for boxes for the North West of England.

Q: How are recipient hospitals chosen?

A: We look at hospitals through discreet visits to see what they currently have available. We avoid children's hospitals, as they get funding, and look at smaller ones.

Q: Are there child specialists in every children's ward?

A: No, and they are at risk of being removed further.

Q: The importance of distraction for pain management and boredom has been highlighted for the 10-24 age group.

A: iPads from local businesses are a huge help.

7. Any other Business

Reports received and available for members. DMR asks members to suggest other charities that may wish to join the NCCHW, more information about NCCHW can be found on the RCN's [website](#). Please send details of potential new members to Kate.O'Molloy@rcn.org.uk.

8. Focus of future meetings:

Wednesday, 5th September 2018: 10.30 – 13.00

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

Title TBC: Freddie Farmer Foundation

Title TBC: Elaine Ward, Deputy CEO, Anaphylaxis Campaign

Title TBC: David Bloomfield, National Migraine Centre

9. Dates of future meeting:

Wednesday 5 th	September	2018: 10:30 – 13:00
Wednesday 28 th	November	2018: 10:30 – 13:00

Please contact Kate O'Molloy to confirm your attendance or give apologies
Tel: 0207 647 3847 Email: Kate.O'Molloy@rcn.org.uk