

## **The National Council for Child Health and Well-being**

**08 May 2019, 10:30 – 13:00**

**The Annie Altschul Room - 101**, Royal College of Nursing, 20 Cavendish Square, W1G 0RN.

Honorary Chair: Dame Marion Roe, DBE

Honorary Secretary: Fiona Smith

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### **NOTES**

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#### **Attendees**

Amena Warner, Head of Clinical Services, Allergy UK  
Stephen Kingdom, Campaign Manager, Disabled Children's Partnership  
Rachel Perrin, Partnership Manager, Family Fund  
Sophie Dodgeon, Policy and Campaigns Manager, Rainbow Trust Children's Charity  
Samantha Darrell, Deputy Director of Care, Rainbow Trust Children's Charity  
Karen Smith, Charity Centre Manager, Freddie Farmer Foundation  
Daniel Catchsides, Trustee, Freddie Farmer Foundation  
Julia Walport, Chair, The Amber Trust  
Samantha Barber, CEO, Batten Disease Family Association  
Sue Flohr, Head of Policy, British Dyslexia Association  
Rachida Takal, Children's Mental Health, Department for Education  
Joanna Heath, Project Manager, Children's Heart Foundation

#### **Apologies**

Janice Allister, Adviser in Child Health, Royal College of General Practitioners  
David Bloomfield  
Anne Ward, Head of UK Development, Ronald McDonald House Charities  
Margaret Jeal, Acting Chair, Action for Sick Children  
Norma Jun-Tai, National association of health play specialists  
Sally Vincent, Young People & Families Service Manager – England, Versus Arthritis  
Lynn Hoppenbrouwers, Strategic Health Lead, Contact  
Jane Gates OBE, Chief Executive, Sebastian's Action Trust  
Candida Hazard, Sebastian's Action Trust  
Lizzie Chambers, Director of Programmes, Together for Short Lives  
Tara Parker, Director of Programmes, WellChild  
Dr Sue Jennings, Child and adolescent faculty  
Dr Spencer Pitfield, CEO, Paces Sheffield  
Sarah Baker, Campaign Manager, Anaphylaxis Campaign  
Sarah Champion, MP, Member of Parliament for Rotherham  
Dr Sarah Earle, Associate Dean for Research & Enterprise in The Faculty of Health and Social Care, The Open University  
Jennie Albone, Acting Head of Programmes, Booktrust  
Karen Dobson, Nurse Consultant, Newlife the Charity for Disabled Children  
Carrick Brown, Newlife the Charity for Disabled Children  
Lynne Regent, CEO, Anaphylaxis Campaign  
Anne Harris, Director of Care Services, Rainbow Trust Children's Charity  
Brian Donnelly, Chief Executive, CECOPS CIC

**1. Notes of meeting held on 20<sup>th</sup> February 2019**

No concerns from the notes raised and all happy with content

**2. Matters arising**

Number of letters to go to various parliamentary officials. Delay sending until advised by Dame Marion.

**3. Correspondence**

No correspondence received to be shared with the group

**4. Presentations & discussion**

**4.1 The Disabled Children's Partnership: Campaign Update**

Rachel Perrin, Partnership Manager, Family Fund and Stephen Kingdom, Campaign Manager, The Disabled Children Partnership (see slides)

Rachel from Family Fund which is one of the 11 charities that sit together to create The Disabled Children's partnership. Stephen acknowledged the mixture of attendees in the room from differing backgrounds. Explained that there are 11 charities together with over 60 organisations who have joined the partnership.

They have two key aims, to bring the challenges and reality disabled children and their families face to the public's attention and to those who influence debate. The aim is to ensure that disabled children have access to the services they need and are entitled to, as well as increase the quality of provision.

43% of population do not know a disabled person, with 97% of parents with a disabled child saying the public does not understand the challenges they face.

The focus is mainly on health and social care although they do work with education authorities

The partnership carried out a short survey this time last year and 75% of those surveyed said the quality of health provision had declined and two thirds said social care had declined.

The partnership set up a five-step plan they put forward to the government which was launched just over a year and half ago:

- 1 – Make disabled children a priority. Difficulty around decline of funding and practices needing to prioritise core practices and care. Starting to move provision to voluntary sectors
- 2 – To review the current funding (short breaks)
- 3 – Clarifying existing rights including update of government policy and outdated rights
- 4 – Create a central fund to be a source for organisations and families
- 5 – Change the system

There is a £1.5bn gap in funding for disabled children's health and social care services. 1bn in health and 500m in social care

The presenters spoke about a renewed campaign to have a big impact on the public. Aiming to make the 'Secret Life of Us' campaign to have an impact as big as the campaign against plastic bags. Realise this must be hard hitting and attention grabbing to influence the spending review and shifting government policies in lead up to the general elections.

The partnership ran a survey last month and received 3400 responses. Thanks were given to organisations that helped to share. They are creating a new short film, which will follow a child, who is not obviously disabled, but will explore hidden disabilities. This will be launched with a new hashtag. The partnership have always balanced positive and negative, however with the renewal of secret life of us campaign, they will push more in negative and look to achieve greater impact.

DMR commented that they wished the partnership all the best in the campaign and grateful around the number of organisations getting involved.

FS asked if they would be reaching out to organisations to get on a signature on a letter, with organisations such as the RCN which would help in strengthening the open letter to government. The partnership at the current time wish for the people's voice to be heard especially from those with disabled children/families and living in the situations with their stories which would have a greater impact. FS indicated should the partnership wish to, to contact the RCN around promoting the voice of the child and promoting the campaign to a much wider membership.

- 4.2** Rachida Takal (RT) from DFE, children's mental health and wellbeing dept. leads on wellbeing gave an update on DfE work. Currently working on a wellbeing toolkit for schools for students to help monitor wellbeing. Not compulsory but more of a helpful tool. Also looking into a mental health guide for teachers to help them identify mental health issues and vulnerable children. Non statutory piece of work so not an additional burden to schools

Toolkit will be published by July prior to schools summer holidays. Working with schools and other government departments to make sure all aspects are covered and working school nurses and reference groups, SEN workers, teachers, head teachers and those on the ground so that develop a comprehensive toolkit. Looking currently at how the schools can use it and producing a guide for the school, how to and how not to use. The toolkit will cover all areas and aspects such as bullying and bereavement, and specific elements that cover a whole school approach.

The Dyslexia association are concerned that there are a lot of campaigns and work streams currently on tackling mental health and concerned that there is nothing out there looking at the underlying issues on mental health

#### **4.3 Spotlight on food Allergy, Amena Warner, Head of Clinical services, Allergy UK (see slides)**

Thanked all for attending. AW confirmed that we now know that allergy is the most common chronic disease across Europe referring to allergy epidemic. Media coverage has been quite high profile recently. Currently the majority of deaths in under-fives derive from milk allergy, common misconception of peanut allergy.

AW explained what Allergy UK is and does. Patient organisation representing people with allergy. The voice of people with allergy, amplifying their voice to higher places in organisations. Started with clinicians that came together and thought they needed to give greater voice in light of the growing number of allergy sufferers. The organisation was set up over 25 years ago.

Allergy UK mission is to raise the profile of allergy at all levels and of all types from simple hay fever (spoke about hay fever season and children's exam season coming together at same time) to anaphylaxis and asthma.

They have a strategy group made up of patient groups and clinical groups, as well as parliamentary groups which try to influence government. Have a patient organisation, which links into real world problems such as air quality which is a major world issue now and how pollution is further affecting allergies.

The group will gain a better understanding of food allergies by end of session, which can be taken back and shared.

Looking at empowering both allergen sufferers and providing healthcare professionals with knowledge. Most children in most schools now have allergy and carry adrenaline pens with many teachers aware but not knowledgeable on its uses.

Explained the risk factors such as family history and existing allergic conditions. Existing skin allergies and certain food type allergies create or could lead to more allergies being developed. Explained that introduction of allergic foods at the early stages of life can help build tolerance. Concern raised that Australia and US have changed guidelines however, although the study was undertaken in the UK, the UK is yet to change policy.

Common allergy foods are on the rise and now people are becoming allergic to newer foods such as banana and lentil. AW explained about cow's milk protein allergy and how this could be affected even during an infant's breastfeeding stage with parent being required to change her own diet. There is a rise in the number of patients in hospitals admitted for severe allergy

There is also a rise in non-validated and expensive allergy testing. Alternative therapies are also being sought with NICE guidelines strongly recommending parents do not use such methods. The organisation is addressing eczema too.

AW highlighted allergy action plans with a guide to Emerade, e – pens and Jext. Concerns around asking allergy sufferers to keep on top of their allergy

medication but public not trained as well as a nurse. Allergy UK set up a website with lots of factsheets and online information to help allergen sufferers with travel, language translation and guides on how to care for themselves.

DMR asked if food labelling is getting across to manufacturers. Legislation changed in 2014 and highlights 14 allergies on labels. This however was not comprehensive enough, as food prepared on site did not require this to be on their packaging. Following high profile cases and deaths now need to label all ingredients with highlighted of all potentially allergenic ingredients used.

Questions were raised around working with catering colleges. It was noted that this is on the horizon. Healthcare staff are taught from the start and trained around allergy and so catering industry should be targeted. FS highlighted that the organisation should lobby to get it into the curriculum. Suggested raising with local authority as well.

Questions were asked about medication usage. It was noted that addressing this is an issue as there is a lack of resources. It was suggested that they get in contact with NYA (national youth association) as this is tapped into by local authorities for youth centres and would therefore be a good way to get more info out to teenagers.

## **5. Any other business**

DMR thanked all that presented and good luck for their work streams

Any organisations that are not part of the disabled children's partnership that would like to join, to get in contact.

Written reports from members to be circulated with notes

## **6. Focus of future meetings:**

### **16<sup>th</sup> September 2019**

Joanna Heath, Children's Heart Foundation – topic to be confirmed

Representative from Barnardo's – topic to be confirmed

Representative from Department of Education – topic to be confirmed

### **12<sup>th</sup> December 2019**

Valerie Jackson, CEO, Action for Sick Children – topic to be confirmed

Representative from Department of Education – topic to be confirmed

## **9. Dates of future meeting**

- Monday 16th September 2019
- Thursday 12th December 2019

**Please contact Ahmed to confirm your attendance or give apologies**

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