GREAT YARMOUTH AND WAVENEY JOINT HEALTH SCRUTINY COMMITTEE MINUTES OF THE MEETING HELD ON 29 January 2013.

Present:

Peter Byatt Waveney District Council
Michael Carttiss (Chairman) Norfolk County Council
Michael Chenery of Norfolk County Council

Horsbrugh

Tony Goldson Suffolk County Council
David Harrison Norfolk County Council
Alan Murray Suffolk County Council

Colin Walker Suffolk Coastal District Council

Also Present:

Christine Harrison Member of the Public and Member of BRAME (the Blue

Ribbon for the Awareness of Myalgic Encephalomyelitis)

Elaine Mash Children's Commissioner, Great Yarmouth and Waveney

Clinical Commissioning Group (HealthEast)

Anne Ebbage Autism Anglia

Kim Arber Programme Board Manager for Mental Health and

Learning Disabilities, NHS Great Yarmouth and

Waveney Clinical Commissioning Group

Theresa Harden Democratic Services (Suffolk)

Keith Cogdell Scrutiny Support Manager (Norfolk)

Tim Shaw Committee Officer (Norfolk)

1 Apologies

Apologies for absence were received from John Bracey (Broadland District Council), Marlene Fairhead (Great Yarmouth Borough Council), Elizabeth Gibson – Harries (Mid Suffolk Council).

2 Minutes

The minutes of the previous meeting held on 16 October 2012 were confirmed by the joint committee and signed by the Chairman.

3 Declarations of Interest

There were no declarations of interest.

4 Items of Urgent Business

There were no items of urgent business.

5 Public Participation Session

The Chairman explained that he had agreed to accept a request from Barbara Robinson to speak to the Committee about the ME/CFS Service. He said that this

could take place as an urgent business item called "public participation session", for the benefit of others not present, for example the relevant NHS bodies. Mrs Robinson had been informed that this matter was on the agenda as an "information only" item and that it could not be discussed without the appropriate NHS representatives being present.

In the unavoidable absence of Mrs Robinson, the Chairman agreed that Christine Harrison, a Member of the public and a Member of BRAME (the Blue Ribbon for the Awareness of Myalgic Encephalomyelitis), should explain the latest developments with the ME/CFS Service in the Great Yarmouth and Waveney area but that Members should not discuss the matter.

Mrs Harrison said that as a result of collaborative working the Great Yarmouth and Waveney area had the opportunity to have the first biomedical ME/CFS Service in the country led by a specialist in ME/CFS at consultant level. She said that ME patients, including those with severe ME, had been left feeling abandoned in the community with little or no care since Dr Mitchell, a specialist consultant in ME, retired in 2006. Christine Harrison went on to stress the importance of the ME/CFS Service returning to a biomedical service led by a specialist consultant in neurological ME.

Christine Harrison said that it was important that promises repeatedly made to patient representatives were adhered to and that patient representatives continued to be involved at every stage of the development of the ME/CFS Service i.e. in writing documents such as service models, developing and writing care pathways. She said that it was important for the Needs Assessment (2012) and the Service Specification (November 2012) documents to be fully implemented and adhered to, including the latest international criteria and management advise of the ME International Consensus Primer (October 2012)

Catherine Harrison laid on the table an information leaflet by BRAME, the Blue Ribbon for the Awareness of Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome.

The Chairman suggested that the joint committee might like to consider if they wanted to receive a report about the ME/CFS Service when they consider the forward work programme at the end of the meeting.

6 Autism Services for Children

The joint committee received a suggested approach from the Scrutiny Support Manager (Norfolk County Council) to a report by Elaine Mash, Children's Commissioner, Great Yarmouth and Waveney Clinical Commissioning Group (HealthEast) about autism services for children and young people.

In the course of discussion the following main points were made:

 After children and young people were identified as possibly being on the autistic spectrum they were assessed and diagnosed by appropriate community health professionals (including speech and language therapists and mental health professionals) at meetings of a multi-disciplinary

- assessment panel.
- Following diagnosis, in the Great Yarmouth locality the implications of the condition were discussed with parents, usually in the parents home, and a care plan was agreed
- In the Waveney locality, parents were invited to return to the multidisciplinary assessment panel to discuss and agree on the approach that would be taken.
- HealthEast was looking to apply the approach taken in the Waveney locality across the whole CCG area for Great Yarmouth and Waveney.
- It was noted that a referral might typically involve speech and language therapy and a Early Bird Programme for pre-school children or Early Bird Plus for primary school age children with a follow up appointment from a nurse, psychologist or paediatrician where appropriate.
- In reply to questions it was pointed out that it was usually the Chairman of the multi-disciplinary assessment panel that signed off on the statement of special educational needs that set out the pathway to be followed by the newly diagnosed child or young person.
- It was also pointed out in response to questions that health professionals could provide reports to support a child's Special Educational Needs (SEN) assessment. A diagnosis of Autistic Spectrum Disorder (ASD) did not, however, automatically mean that a child would receive a Statement of SEN. SEN statements were being replaced by an Education and Health Care Plan aimed at helping to smooth the transition for children from nursery into school and onwards.
- The multi-disciplinary team should be able to strengthen inter-agency working between Community Health Services and Children's Services provided by a County Council, particularly where the child had more than one specific disorder, thus addressing concerns from parents about meeting the educational needs of children and the SEN process.
- It was pointed out that it was not possible to obtain a true diagnosis of autism before a child was two years of age.
- The greater proportion of a school age child's autistic needs were in social care and education, rather than in health.
- Cases were reviewed by a multi disciplinary team when the child reached fourteen years of age.
- Mr Goldson asked for statistical information to be sent to him after the meeting about the number of children waiting for a referral and the length of time that this could take.
- The Great Yarmouth and Waveney area was recognised to be in a better position in terms of early diagnoses for children, than elsewhere in Norfolk and Suffolk.
- School age children were able to access support through a variety of sources from teachers through to Autism Anglia.
- The joint committee noted the evidence that they had received.

7 Autism Services for Adults

The joint committee received a suggested approach from the Scrutiny Support Manager (Norfolk County Council) to a report from Kim Arber, Programme Board Manager for Mental Health and Learning Disabilities, NHS Great Yarmouth and Waveney Clinical Commissioning Group about Autism Services for adults.

In the course of discussion the following main points were noted:

- It was recognised that adults with an ASD which had not been previously been recognised, who exhibited signs of mental disturbance, could be referred direct to Norfolk and Suffolk Healthcare Trust for assessment..
- Some adults with ASD grew up without the condition being recognised, sometimes through their own choice.
- If during the critical "transition stages" between school, higher education
 and employment young people were not offered support with living
 independently or getting a job they could find themselves more embedded
 than ever in the family home, increasing the stress on the family and
 leading more isolated lives.
- Where someone with autistic needs was at university and wanted to be diagnosed with ASD, the assessment would be funded by the CCG where the person was registered as a permanent resident with their GP.
- Autism was regarded by the NHS as a serious, life long and disabling condition. Adults were not expected to have to pay for an assessment or a diagnosis.
- Members expressed an interest in the availability of awareness training for ASD for the emergency services including the police, the fire service and the coast guard, and Anne Ebbage of Autism Anglia agreed to provide a copy of the proposed awareness training document to Members of the joint committee.

8 Information Only Items

The joint committee noted information on the following subjects:

- An update on ME/CFS Services.
- An update on Maternity Services (this was sent to Members after the despatch of the agenda papers)
- Details regarding the Specialist Commissioning Group's review of changes to neonatal services at James Paget University Hospitals NHS Foundation Trust.
- System Leadership Partnership update.
- The future of NHS Care in Lowestoft.

9 Forward Work Programme

The Committee agreed its Forward Work Programme should include the following:

- That towards the end of 2013, the joint committee should receive an update on progress by HealthEast in commissioning health services as from 1st April 2013.
- That, after the proposed ME/CFS Service has been in existence for a suitable period of time, a report should be brought before the joint committee on the operation and development of the Service, that includes the views of NHS partners and ME/CFS patient and carer support groups

- That a report on the provision of out of hours services should be brought to the next meeting of the joint committee.
- That the governance and accountability structure at the James Paget University Hospitals NHS Foundation Trust should be examined at a future meeting.
- That the response and turnaround times for ambulances at A & E at the JPH should be examined at the next meeting.
- That the future of NHS Care in Lowestoft should be examined at the next meeting.

10 Date and Time of Next Meeting

It was agreed that the next meeting of the joint committee should be held at the Great Yarmouth Borough Council Town Hall on Tuesday 2 July 2013 at 10.30am

The meeting concluded at 1.15pm.

CHAIRMAN



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