

# Autism Working Group Meeting

## Minutes

### Wednesday 30 June 2010

<b>Attendees:</b>	Steve Allen of	Essex County Council
	Chris Martin of	Essex County Council
	Maria Warren of	Essex County Council
	Pauline Stratford	Mental Health Joint Commissioning
	PM	South Essex Trust NHS
	JB	North East Essex PCT NHS
	AL	Service User/Care Representative
	SL	Service User/Care Representative
	CJ	SAFE
	AH	Shenfield Aspergers Support Group
	CB	Service User/Care Representative
	SB	Service User/Care Representative
	WB	Carers Network
	CL	Service User/Care Representative
	DL	South Essex Partnership Trust
	SP	Essex County Council (notes)

**Apologies:** NC of Mid Essex PCT  
MC of National Autistic Society  
PS - Shenfield Aspergers Support Group

**Welcome, introductions, apologies and housekeeping were given.**

Steve Allen welcomed members and defined that the meeting was to discuss and consult on the Fulfilling and Rewarding Lives 'delivery plan' from the Department of Health.

Extracts from the document were read allowed by Maria Warren to assist in focusing the group's discussions on each of the 5 priorities:

#### **Page 5                      Towards Fulfilling and rewarding lives**

Maria Warren attended a conference the previous day and advised that CP of the National Autistic Society said that the guidance document was due out December this year.

Some areas to be looked at today were:

Increasing awareness and understanding of autism within health and social care

At the conference yesterday, CP confirmed that £500,000 had already been sent out directly to agencies for training of front line staff.

**ACTION:** To find out if the funding is ring fenced to deliver frontline training and that it won't be diverted somewhere else. Who delivers the training, is it the General Practitioners? Will the training be nationally recognised?

Maria Warren advised that this point was raised at the conference and taken back to the Department of Health for consideration and comment.

Chris Martin asked has the General Practitioners been included? They should be on the group that is devising the training.

Also comment made that the time frame for delivery of front line training is very short and how will training organisations be monitored or accredited?

Need to reinforce the notion that people with Aspergers syndrome and their families need to be involved with the training syllabus.

WB has paperwork from her visit to Essex University. Behind mental illness Aspergers Syndrome can be hidden.

**ACTION:** WB to email paperwork to Maria Warren.

**Point 2** No comment

**Point 3** No comment

**Point 4** What will be the minimum training standards?

**ACTION:** CJ to send a chart to WB outlining the benchmarking of different peoples' training.

Front line staff will require more training than other people.

A lady spoke at the conference stating that she was given an information paper by her GP once her son had been diagnosed. However this was actually needed 2 years prior to her son's diagnosis to assist in understanding both the disorder and signposting to appropriate services.

### **Increasing awareness and understanding of autism among frontline professionals**

Steve Allen said that his friend manages Harlow job centre plus and that he will ask him to confirm what is happening in terms of training the Disability Employment Advisers.

### **QUESTION: What does Local Service cover in respect of training?**

The Department of Work and Pensions deliver this through the Job Centre Plus.

**ACTION:** Can it be confirmed who the Local Service provider is?

### **Employment and Support Allowance (paragraph 3)**

CJ said that medical assessment is used and doesn't include Autism which is not taken into account if someone is fit for work. Steve Allen commented that training doesn't seem very comprehensive.

CJ said this paragraph doesn't make sense or help the people in Essex.

CB said there was concern that people lack social skills in getting into employment, especially with the lack of work at present.

**QUESTION:** CB asked are they targeting Autism as individual budget holders are using their budgets to employ job coaches? Aspergers people need a system such as Remploy

**ACTION:** Life with Autism – to chase this up.

### **Increasing awareness and understanding of autism within government departments**

**QUESTION:** CJ asked if anyone had seen the DCSD published DVD-based and online in-service autism training materials

**ANSWER:** No one had.

Chris Martin said we need to make a connection here with children at an early stage. It was focused on adults at present and lots of parents are unable to get their children diagnosed. There is no diagnosis in Childrens' Services for this anywhere in Essex.

**QUESTION:** Why can't people in Essex cross boundaries in Essex to get a diagnosis?

**ANSWER:** Chris Martin said it is the cost and who will be liable to pay

**QUESTION:** How can we find out what's happening in South Essex Partnership Trust (SEPT)?

**ACTION:** Once guidance is issued in July the group will invite SA of SEPT to advise what they can offer.

### **Increasing awareness and understanding of autism within businesses and the public**

**QUESTION:** When will the Programme Board be in place?

**ANSWER:** The Programme Board will be in place by December 2010 and will mirror the Learning Disability Programme Board.

Maria Warren advised that a paper defining the need for an Autistic Partnership Board and the governance structure which mirrors the Learning Disability Partnership Board (and is held as a good example) is currently waiting to go to the councils internal executive board for consideration and approval.

### **Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment**

**ACTION:** Can we confirm when the N.I.C.E. publication guideline will be available?

### **From diagnosis to assessments**

**QUESTION:** What comeback do we get when assessors don't understand Autism?

**ANSWER:** Steve Allen said everyone can have an assessment – however that person will only get a service if they meet the criteria. We need to recognise a vulnerable person.

Does it mean that with a Community Care assessment, a person in the system has the right to this assessment if they have Aspergers Syndrome? Steve confirmed that every vulnerable adult has the right to an assessment. People also have the right to have a 'face to face' assessment and not a telephone assessment. Steve Allen confirmed that services are available if a person meets the criteria and the 'criteria' is a national document.

CB said it would be better if they had specific sheltered housing which is suitable for Aspergers.

**ACTION:** Steve Allen to send a copy of the national criteria to CB and SB.

### **Improving access for adults with autism to the services and support they need to live independently within the community**

Have the people that provide housing made adjustments for Autistic people? Autistic building requirements must be known and considered prior to any new building works taking place. There will be some sub groups within the proposed partnership board (housing, health,

transitions, being safe and employment) and it will be one of the housing sub groups projects to review.

### **Making reasonable adjustments to services**

What is meant by reasonable adjustment?

### **Giving adults with autism more say in their care and support**

There are 8 trail blazing sites to test the Right of Control from late 2010 and Essex is one of them. These can be found at [www.officefordisability.gov.uk/working/right-to-control.php](http://www.officefordisability.gov.uk/working/right-to-control.php)  
Draft regulations for these Trailblazer sites were published at the same time and consultation will continue until 19 May 2010.

### **Helping adults with autism into work**

No comment

### **Reforming existing provision**

More information can be found on the DWP website:

[www.dwp.gov.uk/supplying-dwp/what-we-buy/welfare-to-work-services/specialist-disability-employment](http://www.dwp.gov.uk/supplying-dwp/what-we-buy/welfare-to-work-services/specialist-disability-employment).

### **Building on Valuing Employment Now**

The draft definition can be seen on the VEN resource hub,

[www.valuingpeople.gov.uk/venresources](http://www.valuingpeople.gov.uk/venresources)

50% of people with autism also have learning disabilities

Chris Martin said the idea is to get people back into work with a variety of support

Might be advisable if someone from the Job Centre could attend one of the future meetings.

**ACTION:** To invite Steve's colleague from Job Centre Plus, Harlow to attend a future meeting.

### **Third sector approaches**

No comment

### **Improving information about employment support and benefits for adults with autism**

No comment

### **Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities**

No comment

### **Setting out the role of local Government**

No comment

### **Regional planning and local planning**

AR is the Regional Valuing People Now co-ordinator.

**ACTION:** Can this be clarified and is the post ongoing?

**QUESTION:** What numbers of service users are we talking about in Essex?

**ANSWER:** We already have good data from OPN in Essex. Research undertaken covers the whole spectrum, further work required, so specific numbers are known within each district area.

Data work to be clarified on future documents. Numbers in areas and services required to be mapped.

Sharing of data to ensure SWIFT system is updated. Autism and learning disabilities need to be recorded on records. Investigate if there would be a problem with the Data Protection Act in this respect.

The twelve local General Practitioner Commissioners in Essex need to start work on all this so it will come together.

### **Developing local governance structures**

No additional funding available.

### **North East Consortium (NEAC)**

CJ said the Autism Programme Board was a good outcome from all of these. There is disability discrimination in housing with nothing for high functioning autism people. Guidance will be produced by January 2011 to indicate some kinds of adjustments that might be useful.

Maria Warren advised that LW is the East of England lead for learning disabilities and will also be taking the lead on the Regional Autism Programme Board.

**ACTION:** Does MC know of any other appointed people for this?

**QUESTION:** What does East of England cover?

**ANSWER:** Suffolk, Norfolk, Cambridgeshire, Peterborough, Essex, Bedfordshire, Luton, Southend and Thurrock. The lead for Essex is Steve Allen, Chris Martin and Maria Warren. Steve Allen said the crux is to form a function group and get governance set up and the Programme Board with dedicated people in sub groups to filter into this. We must get the paperwork approved and the Programme Board set up and signed off by Jenny Owen and Liz Chidgey. Voluntary organisations, parents and carers will be on the Programme Board and those that cannot, can sit on the sub groups. We need to get the right mix of people.

**ACTION:** When date of next meeting is agreed, an email will be sent the week before to advise everyone.

**ACTION:** 28 July agreed as a provisional meeting for consultation on DH guidance with a 10.00am start and finish at 2.00pm. Refreshments and lunch are to be provided.