

Minute of JEC Education Group Meeting.
NCYPE Lingfield Tues 29 June 2010

Present: Leanne Creighton, Sharon Wood, Gina Freeman, Elaine Faulkner, Gill Gallagher, Lynnette Oldman (minute)

Apologise: Shirley Maxwell, Chris Morley, Grant Wright, and Jennifer Preston.

Notes of the Voice Conference of 9th March 2010 agreed as correct.

Matters Arising

Chris Morley was to attend meeting, but travel very difficult to NCYPE.

Sharon to contact re Liverpool study:

Action SW

Due to staff changes, current caseloads of ESN's not yet confirmed follow up.

Action LC

Enquire re Paed ESN's and their case loads. In EA survey the numbers very low.

Action GG

NUT document – request update

Action GG

Seizure Poster for Teachers. Original artwork found. Update to be agreed later in meeting.

Action All

Agenda

Sharon reported on Govt changes and opportunities from this. Changes have meant good deal of supportive MPs have been lost. Endeavouring to get APPG reinstated.

All new MPs were sent a letter about the JEC with a questionnaire about epilepsy to ascertain if they had an interest, 6 replied saying happy to meet.

In view of Govt cuts there is fear that momentum in improvements in services will be lost but efforts to influence both health and education agendas will continue. In discussion it was agreed that the educational aspect of epilepsy had gathered some momentum within the JEC. The approach to getting epilepsy included as a SEN needs to be looked at in order to feed in effectively.

Educational group work plan 2009:

Reviewed as 2 year plan.

Complete evidence based list of key issues. Gill to compile a list of the evidence and circulate. Any further evidence can be added. Strategy to be examined when list agreed – item to be brought forward to next agenda.

Action GG

JEC website:

Recent updating has proved difficult, currently plans underway for complete redesign with website manager. It is intended here will be a password protected member's area for confidential documents.

Action SW

Develop proforma letters for inclusion on website so that parents can download to send to MP's. Leanne has examples and will forward to Sharon.

Action LC/SW

The JEC Executive will invite group Chairs to attend one executive meeting per year. Each working group discusses ideas which are then forwarded to the Executive committee so that all groups do have an influence, the strategy being to get groups working together.

Update on current projects.

NSE: Elaine fed back the publication "About me "has been published, the third in a series about mood, aimed at people with a learning disability. The schools awareness raising programme is continuing, going out whenever possible. Focusing on year 8 and not necessarily targeting schools where there is a child with epilepsy. Very labour intensive. Evaluating currently what is being done and what schools want. Paid staff undertake this with a trained volunteer, so it is costly in terms of time and training.

In Epilepsy week an "app" was launched which shows a first aid presentation. This has been widely downloaded.

Quarriers: Provide training in schools when requested, usually because a child at the school has epilepsy and it may be for training for staff in using rescue medications. This is carried out by a Fieldworker, although a support group in Grampian is keen to go into schools and raise epilepsy awareness by telling their story, but the volunteers will need training and support. The Fieldwork Service provides a range of information to children and families. Special school in the area also have close links with the service and paediatric ESN.

Quarriers are building a new assessment unit in Glasgow for adults.

Epilepsy Action: For National Epilepsy Week a questionnaire was sent out to young people. The 267 responses to a range of questions about health,

social and medical issues, resources and education, made it the largest young people's study yet carried out. The majority of 13 – 17 year olds responded on line and this included a section where the young people could write anything they wished and in the main these comments were positive.

Education Awards to highlight E.A.'s diamond jubilee were launched, the aim being to promote good practice. Following 34 nominations 13 were awarded but normally it will be 5. Geographically a good spread throughout England. The criteria was broad, based on having policies and procedures in place. A pre-school red cube system highlighted the creative ways these were met, not just written. The winners will be showcased and a good practice guide drawn up using examples, and distributed to schools.

Education Advisory Panel, some members coming to the end of their term and others are being invited to join. The elected panel meet 4- 6 times a year and is comprised of Trustees and Council members.

SCR/play decide. European project. Research. Goldsmith University. Migraine Trust, Autistic Society and Epilepsy action. Cue cards – gave video footage. ? Debate and discuss how it should be supported. Game expression of public opinion and thoughts. Useful for teacher's toolkit.

JEC: Sharon fed back on the political aspect of the JEC's work, making contact with new MPs. After lengthy consultation with members re. the action plan it was agreed these should feed into the update of the strategic plan making people feel more involved. Strategic plan will be more concise and update will be for the next 3 years.

It is hoped that new, more detailed, statistics re. epilepsy prevalence will be available soon. Evidence gathered from GP database. However Epilepsy specialist do not all agree on the increase in numbers which are not

explained by population change. This is currently delaying launch of the figures and a Parliamentary reception will be planned to launch.

NCYPE: Gill fed back that the 3rd parents and family conference is due to be held in Manchester. There will be separate workshops for parents and teenagers. They will cover a wide range of topics including Ketogenic diet, VNS, siblings and emotional aspects of epilepsy and the family. The parent's handbook has been reprinted and is now available free for parents. New publications in the autumn will provide information on intractable epilepsy and a second handbook with a reprint of the seizure diary for children.

Epilepsy Champions for Schools - pilot study complete and the report is available, downloadable from NCYPE website. Further ways of disseminating the information being looked at to raise awareness and get it embedded in policies in schools.

NCYPE continuing work within schools and school staff are attending NCYPE study days as well as outreach sessions. A health study day was held aimed at school nurses based at therapist level as well as an educational session aimed at teachers/carers/foster carers. Funding is needed to take it further afield with a Paed focus and to repeat next year.

Epilepsy West Lothian: Gina attended the national network of support groups in Dundee with a parent who has epilepsy. Advised that Epilepsy Scotland has a new publication for schools.

Community Health Development Course – Using GP figures, going out to different areas with a focus on family workshops.

Tea Pot Café. This is an online forum for teenagers with epilepsy.

www.thetearoom.org.uk

Lots of parents contact re unsympathetic consultants including comments such as "all in the mind" or "making it all up".

Alisis Project. At the moment of diagnosis a card can be given with website and linked to a local epilepsy group, being worked on with Scottish Govt and NHS.

LTCA and SD have a survey - for children themselves. Link to be forwarded so child can fill in.

In one secondary school 3 teenagers met up. The school nurse can be present if they want her to be. May be a way to progress in other schools. Some presentations are given to schools. These tend to be connected with fitness week. A youth group may be started in Lothian as more teenagers are being referred.

AOB:

David Lewis Centre. Focus is changing to become broader than just epilepsy. The school has been closed. Antony Waters, Chief Executive of David Lewis as advised intention to withdraw from the JEC.

An application has been made by NCYPE for funding state of the Secondary specialist epilepsy provision, St Elizabeth's, the Meath. Query older school population and unclear about numbers in further education.

Thanks were expressed to Sharon for supporting the group to date. Sharon is no longer provider minuting services to the working groups and it was agreed that this will be undertaken by education group members on a rota basis.

Following the meeting there was lengthy discussion re. updating the poster for Teachers, used in schools. Changing the basic text was more complex than first envisaged and Sharon agreed to take it back to original designer and discuss a possible change in design layout as well.

