

Note of Meeting – Cross Party Group on Epilepsy, 30 January 2014

In Attendance:

Declan Ahern, Epilepsy CNS	Nanette Milne MSP
Jean Barclay, Epilepsy Scotland	Hilary Mounfield, Scottish Epilepsy Centre
Celia Brand, Paediatric Epilepsy Nurse	Caterina O'Connor, West of Scotland & Tayside Epilepsy MCN
Gerard Gahagan, Scottish Epilepsy Centre	Allana Parker, ECS Secretariat
Kenneth Gibson MSP	Phil Robinson, Lanarkshire Epilepsy Support Group
John Heaney Chairman West Dunbartonshire Epilepsy Support Group	Brian Rocks, West Dunbartonshire Epilepsy Support Group
Cara Hilton MSP	Michelle Small, Paediatric Epilepsy Nurse
Andrena Hughes, Observer	Jacqui Telfer, Epilepsy Scotland
Alison Johnstone MSP	Anissa Tonberg, Epilepsy Scotland
Claire Leonard, Epilepsy Connections	Jean Urquhart MSP
Helen MacDonald, Lanarkshire Epilepsy Support Group	Nic White, Quarriers
Lorraine MacKenzie, Observer	Sam Whitmore, Epilepsy Connections
Peter Martin, Observer	
Pam Martis, NHS Lothian	
Ann Maxwell, Muir Maxwell Trust	
Laura Meikle, Scottish Government Support & Wellbeing Unit	

Apologies:

Jo Campbell, ESN Aberdeen	Jennifer Simpson, Special Products
Janet Henderson, New Directions West Lothian	Richard Simpson MSP
Jen Irvine, ESN	Jane Stuart, NHS Lothian
Jamie McGrigor MSP	John Toland, ESN
Alison McInnes MSP	Darren Wilkinson, ESN
Anne McTaggart MSP	Lesslie Young, Epilepsy Scotland
Pamela Parker, ESN Glasgow	Susan Yule, ESN

1. Convener Kenneth Gibson MSP welcomed attendees to today's meeting.
2. The draft note of the September 2013 meeting was approved. He gave an update on activities:
 - MSPs were deeply saddened when Helen Eadie MSP died in November. She had been a stalwart supported of this Group over many years. Since September four MSPs have joined the Cross-Party Group including George Adam, Colin Beattie, Cara Hilton and Cameron Buchanan. This brings us to 36 members.
 - Next month on 14 February sees the planned launch of the Stamp Out Stigma campaign for schools. This campaign is led by member of the Scottish Youth Parliament along with Epilepsy Connections and the Scottish Epilepsy Initiative. The campaign asks for first aid and epilepsy awareness to become part of the Curriculum for Excellence. Materials for schools have been developed for teachers' GLOW site. Pupils can also pledge their support for the Stamp Out Stigma campaign with a virtual footprint. It will be good to see local schools get involved in this.
 - Purple day is on Wednesday 26 March this year. Many MSPs will be taking part and putting forward or signing motions supporting this international epilepsy awareness day.
 - Cross-party support has been secured for a Members debate on Wednesday 21 May at 5pm during National Epilepsy Week. The focus of the debate is to highlight issues around stigma and the need for greater epilepsy awareness. It will feature the latest progress with the Stamp Out Stigma schools campaign. If you would like to come and listen to the debate in the chamber please contact the Secretariat who will let you know how to arrange this.

- All 32 local authorities have given details about first aid and epilepsy awareness training in local schools. The quality of information varies between councils. It will be collated shortly by the Epilepsy Consortium Scotland and will be a useful data source for the Members debate.
 - We have just been sent information by the British Medical Association about recent changes to the GP contract involving epilepsy. A copy of their letter is available for you to read. This is an area of concern both for epilepsy-related organisations and clinicians. Epilepsy Scotland is meeting with the BMA in February to discuss the removal of these Quality Outcome Framework indicators for epilepsy. We will update you on any progress.
 - Please remember to complete the evaluation sheet for today's meeting before you leave.
3. The Convener introduced guest speaker Laura Meikle. She is Head of the Supporting Learners team with the Scottish Government's Support and Wellbeing Unit. She outlined educational policies and programmes supporting learners with epilepsy:
- A wide range of education legislation exists to develop the personality, talents and mental and physical abilities of a child or young person to their fullest potential. This is primarily covered in Standards in Schools etc Act 2000. The Equality Act of 2010 introduced a series of duties around the proactive prevention of direct and indirect discrimination, including epilepsy. The Disability Strategies etc Act 2002 also gives key duties for educational authorities/responsible bodies around planning to improve accessibility for pupils who have a disability. This Act covers access to classes/ buildings, the curriculum and school information. These three pieces of legislation are fundamental for inclusion, the prevention of discrimination and making sure that everyone has the same opportunity to be engaged in learning
 - The Additional Support for Learning Act 2004 provides the framework for helping children and young people access support to overcome barriers with their learning. This could be a health, disability, social or emotional factor that is challenging to them. There are also specific legal requirements for education authorities to plan and provide education for those who are unable to attend school due to prolonged ill health. Finally, the current Children and Young People Bill (now an Act) introduces duties on services to work together to plan and identify what learners need
 - Curriculum for Excellence is very important and far broader In terms of policy and guidance. It encompasses health and wellbeing which affords opportunities for others to understand how epilepsy affects children and young people and to consider factors like safety. The Secretariat provided preparation information for this meeting including materials for the Stamp Out Stigma campaign. It is the first time that Laura has ever been given information by a body which has followed the Curriculum for Excellence experiences and outcomes criteria, understands and then clearly presents the materials in this context, so she was absolutely delighted. It makes the job of getting people engaged much easier and she really commended this
 - Learners also have an entitlement to support in the broadest sense under the Curriculum for Excellence. Learning support covers anyone in school up to the age of 18. Education Scotland's website explains what that framework means in terms of universal support that pupils can expect and targeted additional support for learning. New guidance, reviewed by stakeholders including the voluntary sector will be published this April regarding children and young people who are unable to attend school due to ill health. In addition, the current Administration of Medicines guidance covers how children and young people get medication when they are in school. The impact of medication on learning seems to be an issue that is causing some concern
 - In terms of current developments, two consultations were published on 20 December. One is on guidance for revised accessibility strategies for disabled pupils and the other proposes changes to extend the additional support for learning framework to give children with capacity rights regarding resolution and tribunal appeals (partial) or to mirror in full the rights currently provided to parents and young people and goes further to include rights to request assessment and to make placing requests (full). It also covers possible changes in how section 70 complaints to Ministers are considered where an authority has failed to deliver a statutory duty
 - The Code of Practice for additional support for learning is also being revised while the Bill is currently going through Parliament. It is very important this is done quickly and clearly. Moreover, work starts in March to revise the guidance on Administration of Medicines in schools
 - The approach taken to design the Stamp Out Stigma campaign using Curriculum for Excellence is commendable. This work with Education Scotland to support schools to challenge those issues and deal with those issues is astounding. It is a lesson, and approach others could learn from.

4. The Convener thanked Laura for her presentation and invited questions:

Anissa Tonberg asked if there was an opportunity for wider comment on the Code of Practice and the review about access to medicines. Laura Meikle agreed; both the Code of Practice and the review of Administration of Medicines will go through a full public consultation in time.

Ann Maxwell commented that she was surprised by the number of primary learning disabled children who are included in main stream school during her talks about epilepsy across Scotland. As the mother of a profoundly learning disabled child and representative of a charity which supports children with complex needs, she attended a recent Scottish Government conference to discuss GIRFEC. There she raised the question if it right to include some of the more profoundly learning disabled children in main stream school because of its impact on the education of more abled children. Her question attracted delegate support mainly from teachers.

Laura Meikle mentioned that legislation states that children with additional support needs should be educated in main stream schools unless certain exceptions apply. There is a perception that since that duty has been in place, there has been a significant change in the population of children and young people who would have previously been learning in a special school and who are now learning in main stream schools. In fact this is not the case, numbers are fairly stable.

Ann Maxwell was alarmed by the level of disruption that prevails. She felt profoundly learning disabled children are steered more towards main stream schooling because local authority budgets are a factor. The message seems to be there is no money when families apply to get their children out of main stream school into residential care or special schools. Assessment outcomes for affected children also differed between local authorities. Kenneth Gibson offered a similar instance where a special needs school was being closed with pupils being mainstreamed against the wishes of their parents - their perception was it was due to a council budget measure. Laura Meikle understood the views being expressed. Unfortunately, they did not reflect the evidence overall from the statistics she monitors every year.

Allana Parker asked if the complaints process to Ministers included social work assessments. The answer was no as section 70 only covered statutory education duties.

Brian Rocks wondered what help was available so that teachers would know what to do if a child had a seizure including cases where a child did not tell anyone about having epilepsy. Laura Meikle said that trainee teachers will have an understanding of additional support needs while Continuing Professional Development enabled teachers to understand more specific issues. General training and awareness of epilepsy is helpful and materials suitable for the Curriculum for Excellence are very important for teachers. The best way to deliver support is when a need is known and given the appropriate response but it is very challenging. A series of measures can be put in place like child health plans and emergency response procedures, but those things won't be developed until teachers know about a child's epilepsy.

Lorraine Mackenzie was interested in who provided epilepsy training for schools across the 32 local authorities on epilepsy and any Scottish Government plans to provide that epilepsy training. Laura Meikle explained that the responsibility of training of staff lies within education authorities rather than the government as local authorities are the employers of school staff. To her knowledge a number of voluntary organisations like Epilepsy Scotland deliver training. The three organisations that have developed the Stamp Out Stigma Campaign also have training experience. Education authorities would decide the organisations best placed to provide training. As employers, they are required to train their staff but not specifically on epilepsy.

Kenneth Gibson mentioned that he wrote on behalf of the Epilepsy Consortium Scotland to all local authorities to try and find out what the level of training for first aid was. Allana Parker added that while first aid training in schools was mandatory, epilepsy awareness training depended on whether a child develops epilepsy. Aberdeenshire council had opted to include epilepsy awareness training in its first aid courses. This seemed a useful approach.

Claire Leonard who is involved in the Stamp Out Sigma Campaign visits schools to meet teachers and pupils and raise their awareness of epilepsy and local services. Celia Brand mentioned that specialist nurses work with schools too. The Scottish Paediatric Epilepsy Network

did a recent scoping exercise to see who was training around Scotland and every region does something different. The Stamp Out Stigma Campaign would be excellent to reach more people.

Ann Maxwell remarked that a number of schools were not responsive to free invitations to learn more about epilepsy. There is still a barrier there. Claire Leonard agreed. Epilepsy Connections' field work team would refer cases to her where a family want their child's school to know about epilepsy. She would contact the school to come and raise awareness. Either the school was not interested or didn't respond, but would have if it was compulsory. That was why the Scottish Youth Parliament put forward the motion that first aid and awareness of epilepsy and other long term conditions should be a compulsory part of the curriculum in Scotland.

Celia Brand believed some of these issues in schools could be addressed if the Administrations of Medicines policy review was harder hitting because currently much of it is voluntary. The Getting it right for every child (GIRFEC) policy should enable schools to invite agencies in who are helping children with epilepsy. Laura Meikle explained that guidance is only guidance but as she meets with key networks of senior education staff she would draw their attention to this issue. She would mention the forthcoming Stamp Out Stigma Campaign and highlight that training would be available to accompany it. Today's points can be brought to the attention of colleagues on the Additional Support for Learning advisory group who advise Ministers on implementation. At a strategic level she can inform all the people know who are responsible for supporting learners in local authorities. They make the decisions about what training comes into schools.

Declan Ahern questioned how schools could vet the quality of the training being proposed. Ann Maxwell commented she did not train teachers on how to deal with seizures. Her organisation was heightening awareness of epilepsy among pupils. Allana Parker noted from the local authority responses so far that several councils used in-house trainers for schools training.

Anissa Tonberg wondered what could be done to help ensure that local authorities do take up the Access to Medicines guidance? Laura Meikle accepted that ultimately it is a task for her team to raise with the relevant local authorities through strategic groups and networks.

5. The Convener invited any updates from representatives around the table.

Gerard Gahagan remarked that the SIGN guideline for adults with epilepsy is now in a draft form. It is available to the public and there will be an open meeting to discuss this key clinical document next week in Edinburgh. Secondly, the National Neurological Advisory Group has made it a priority to review the neurological standards on epilepsy. Thirdly, the Scottish Epilepsy Centre welcomed a visit from the Cabinet Minister for Health Alex Neil last week. It was a very positive meeting and showed his support for partnership work in the voluntary sector and the NHS.

6. Kenneth Gibson thanked everyone for their contribution. The **next Cross Party Group for Epilepsy** meeting will take place on **Thursday 24 April** at 1pm which is also the AGM. The topic is developing epilepsy services in a rural area with a speaker from NHS Dumfries and Galloway.