

Workshop A :

Lobbying for children with epilepsy

Facilitator Mr. John Bowis, report by Dr. Janet Mifsud

Workshop A started with a brainstorming session to the question:

Who would you refer to if you had a problem regarding epilepsy?

The participants in the workshop were coming from various fields (doctors, pharmacists, school staff, care workers, pharmacology students, parents of children with epilepsy, persons who have epilepsy themselves) so the outcome of this brainstorming session was quite interesting.

A lot of participants mentioned doctors, neurologists and other specialised medical staff. Plenty mentioned teachers, educators, head teachers, facilitators and school staff. Others mentioned organisations and support groups. Ministers of education, health and social services were also mentioned, as were directors of health, social services and education departments. Some people mentioned discussing problems with colleagues, family members and people who have the condition or their families. Others mentioned looking for information on the Internet or from books and other literature available.

Mr Bowis helped us to divide these into five basic groups; mainly the **health professionals**, the **education professionals**, the **politicians**, associations and the **social care professionals**.

Therefore we now started to tackle each group separately to see what is expected from each group. For each group with did another brainstorming session and came to some conclusions.

Everyone seemed to agree that health professionals are expected to be well informed about the condition, should all (including nurses and other hospital staff) be able to recognise seizures and have know-how to deal with them and all collaborate with each other. Most participants demanded more research about the condition and about medication; especially about side effects of some anti-epileptic drugs. We also said that we'd all like to see more collaboration between health professionals and persons who have epilepsy and their families. We'd like more information about the condition from them and we'd like them to be more sympathetic and sensitive towards the patient's needs. Health staff should undergo continuous training and maybe it would be a good idea if we had more specialised staff.

We expect educational staff to be aware of possible learning problems that children who have epilepsy might have and in such cases we'd like to see individual educational programmes for these children. We would like to see epilepsy included in the curriculum so that children who actually have epilepsy are accepted more easily at school and the bullying that they may face decreases. Other children will benefit from this too since epilepsy can affect anyone at any age and they, their friends or family members may get it in the future. It is also very important that teachers and school staff are aware of what epilepsy is, know how to recognise a seizure and can give the correct first aid when necessary. Where necessary precaution and safety measures at school should be taken (for example changing neon tubes, or putting glare guard screens on computers etc). Educational staff should work in liaison with parents and other professionals in other sectors so that children will get the best education possible. We also mentioned the fact that the school has to be the role model for the community as regards epilepsy education; there should be no stigma at school and the school should do its best to reach out and educate the community about it too eg by means of talks to parents etc.

From politicians everyone seemed to demand more funds for medication, research, individual and family benefits and funds towards support organisations. We also would like laws to outlaw discrimination in employment and in obtaining promotions for persons who have epilepsy. Politicians should also be more informed about the condition in the participants' opinion. Reviews of existing policies should be done and new policies should be set up where necessary. The fact that anti-epileptic drugs are free of charge is very much appreciated but participants felt that a lot still has to be done in order to avoid the unfortunately common shortages in stock.

Support to persons with epilepsy, their families and their friends is what seems to be expected by all from associations and support groups. They are expected to hold campaigns to raise awareness of the condition and minimise the stigma it carries. It was also mentioned that they should provide resources and information to the public, whether having epilepsy or not and to organise activities. Such associations and support groups are expected to do research among persons who have epilepsy to identify their needs and act upon them. They should also work with other similar organisations or groups who may be working in the same field so that they reach common goals.

All participants in the workshop agreed that social care professionals should be well-trained staff as adequate social care is expected. Adequate financial support should be given to those who cannot find work. Others who manage to find work might need monitoring and

support at work and this too should be provided. Social care professionals should help so that as many people with epilepsy as possible ultimately find a job that they are able to do and enjoy; and not one that society thinks is suitable for them.

We also mentioned the media as a possible powerful tool to help in lobbying for persons with epilepsy. However due to lack of time we didn't manage to go in depth about the topic.

Finally Mr Bowis also mentioned a few ways which could help to raise awareness such as an educational video for children, increased epilepsy education in teachers' training and including epilepsy in first aid training courses held at youth centres and similar places.