

Workshop C

This workshop, chaired by Dr. Doriette Soler, tackled the issue of support but not over-protection. This report focuses on issues that were raised by members of the group ranging from individuals with epilepsy, parents, learning support assistants, teachers, counsellors, health professionals and members of non-governmental organizations. The sections which follow were tackled in chronological order.

-At the school level:

The parents in our group expressed their concerns about the well-being of their children in schools. Among the issues that were highlighted, it was stressed that more support and training should be offered to teachers, to enable them to adapt their teaching methods, in order to cater for the individual needs of students in the context of inclusive education. In addition, learning support assistants (formerly called facilitators) should receive more training and be more knowledgeable about the impact of epilepsy on education and the learning of the individual student. Currently, learning support assistants are given a 20-week block training course which includes exposure to a wide range of special needs including epilepsy. However, members in our group suggested that the learning support assistant should be attend an induction course prior to applying for the post in schools, besides being given specialist training with regard to particular special needs.

The importance of the school nurse emerged. This health professional is indeed necessary if the needs of students are to be effectively catered for in schools. The role of the early intervention teachers was mentioned including the good practice of organizing seminars with the objective of empowering parents of children with special needs.

In the case of students that experience recurrent epileptic seizures, more specialized attention would be necessitated besides that offered by the learning support assistants in mainstream education. An epilepsy resource unit should ideally be set up to cater for the need of these children. The role of this unit would be to assess the children, design a tailor-made educational plan that would then be carried out at school and address the behavioural and emotional needs of the children. The members of the team constituting the unit should comprise health professionals and education specialists including care workers, psychologists, a psychiatrist, specialized physicians and an epilepsy nurse specialist. The epilepsy nurse specialist would be able to give advice on medications and actions that should be taken in case of emergency, based on a careful study of the medical records of the students. In addition s/he could provide a liaison between the family and epilepsy consultant and offer advice to the school teacher and facilitator.

The peer-preparation program organized by learning support assistants to prepare the class for the inclusion of peers with special needs was encouraged. However, it was stressed that education of children to develop an inclusive mentality should be an ongoing process.

-At the community level.

Parents stressed the need of support and the importance of home tutoring after school hours. In addition, a team of health professionals should be set up at the district level to make timely intervention possible so that the requirements of individuals with special needs would be effectively catered for.

People in the entertainment industry should become more sensitive to people with special needs. This increased awareness could be attained by exposing organizers, bouncers and media operators to education programs that would equip them with the necessary skills to cater for people with special needs. Issues in this area which could be addressed could include, for instance, the impact of certain light emitting sources on photosensitive epilepsy and how to deal with emergencies in places of entertainment.

At the locality level, information could be disseminated during community gatherings, for instance inviting a speaker with the condition to speak about epilepsy and share his or her personal experience with the public, during Sunday mass. The media can also play an important role by inviting individuals to share their experiences with the public through television programs and interviews. Through these means, the media can empower individuals and their relatives to acknowledge and accept the condition and thus be more receptive to supportive endeavours undertaken by society.

-Employment

Employers need to adopt a mentality of inclusion in their choice of employees. This could be achieved by designing education programs for employers. In addition, university students as future managers and employers should receive training on how to deal with people with special needs at the work place.

- Adolescence

Adolescence is a stage in life when the individual becomes more autonomous. The parents in the group felt the need of counselling support services that would provide them with guidance about how to interact with their children. In addition, since adolescents would be going through a number of physical and psychological changes during this period, the emotional needs of these individuals should be addressed by clinical and educational psychologists.

A very interesting point emerged during the course of the discussion. The subject was the need for the organization of a teenage camp designed to empower adolescents and prepare them for adult life. The subjects addressed during this activity could range from coping strategies, job interviews, driving, self-esteem and work. In addition, adolescents could voice their concerns and be offered support by counsellors who would form part of

the organizing team. This teenage camp could have a multiplier effect through interaction of attendees with other adolescents in youth centres and communities, education institutions, and the work environment.

However, it must be acknowledged that the nature of the condition may render some adolescents totally dependent. Therefore, it is important to address the needs of these adolescents as they approach their adult life.

Conclusion

The members of the group felt that more support for people suffering from the condition should be offered in schools, the local community, in the work setting and places of entertainment. In addition, there were a number of other points that resurfaced frequently during the discussion. A common theme was the importance of education at all levels of Maltese society including children in schools, adolescents, the local community, employers and future employers. Another interesting point which gained immediate approval by the whole group was the importance of the organization of teenage camps designed to empower adolescents to approach adulthood more independently and effectively.