14th European Conference on Epilepsy & Society, Prague, 15 – 16 September 2016

Session IV: "Overcoming Stigma in Epilepsy: Education & Employment" - Workshops

In this session, delegates worked in small groups to discuss 6 questions relating to epilepsy in education and employment and to prioritise their recommendations to reduce stigma in these settings. The questions were:

- What should educators know about epilepsy?
- What do the other children in the class need to know about epilepsy?
- How should children with learning disabilities and epilepsy be integrated in the class?
- What strategies can help transition from education to workplace?
- How can PWE prepare for employment?
- How can employers be educated about epilepsy?

Key points are summarised below.

Two themes recurred in all workshops in response to each question. These were **the importance of raising awareness and developing understanding of epilepsy** and **the role of legislation in promoting equality of opportunity and tackling discrimination.**

One group noted that **some children with epilepsy are often absent from school** and that it is critical to ensure that schools are "epilepsy friendly" to reduce barriers to attendance. Good first steps are to **ensure access to medication in schools** if required and to provide **epilepsy awareness education** for teachers, students and parents. As well as educating everyone how to manage seizures, this would reduce fear and stigma, and create an atmosphere of **solidarity and friendship.** Teachers would also understand **the wider impact of epilepsy on learning and memory.**

For individual children, groups noted the importance of having a **correct diagnosis, identifying the impact of the epilepsy / additional disability** and **assessing learning needs.** Access to **adequate and appropriate resources** was seen as vital, including use of a wide range of teaching aids and supports (e.g. audio and visual aids, classroom assistants). Support to manage behavioural problems was also identified as important.

Groups agreed that **children with epilepsy should have the same opportunities as everyone else, and should be included in all activities**, including sports and trips, and **work experience** to ensure that children with epilepsy develop **good employability and life skills.**

Thinking about the **transition from education to work,** groups agreed that young people with epilepsy should have **appropriate careers advice that balances high aspirations and realistic expectations.**

Groups agreed that lay organisations have a role to play in **supporting young people to develop an understanding of their epilepsy and how to manage it, the impact of lifestyle choices, and how to present themselves and their epilepsy in a positive way** to prospective employers. This could be done through the provision of **"job clubs",** designed to develop job-finding skills and **support young people with epilepsy to recognise their talents**, and become **strong, confident and proud of themselves.**

There was discussion of **the difficulties that many young people with epilepsy have when trying to find suitable employment** and **safety issues people with poorly-controlled seizures face in the workplace.**

Epilepsy awareness education was seen as one answer to this, with one group suggesting that **employers should have a legal duty to provide epilepsy awareness education to their staff,** and that **pharmaceutical companies that manufacture AEDs should be obliged to employ people with epilepsy.**

Educating employers about epilepsy in the context of equality legislation was seen as another important area for lay organisations, as was **reviewing current regulations and campaigning against unnecessary restrictions from particular occupations.**

One group had a lively discussion about whether young people with epilepsy should disclose their condition to their employer and colleagues, and agreed this should be a personal choice.

One group suggested **that self-employment might be an option for some young people with epilepsy,** and recommended that discussion of this should be included in careers guidance.