

Take the initiative!

Danish research on living conditions for persons with epilepsy



Report by Lone Nørager Kristensen, President of the Danish Epilepsy Association (pictured far left) and Claus Langkjær, Project Manager, Danish Epilepsy Association (pictured left)

In Autumn 2006 the Danish Epilepsy Association (DEA) conducted a questionnaire survey focusing on living conditions of adults with epilepsy (PWE) in Denmark. In May 2007 the report was presented at our biennial epilepsy conference. The report can be downloaded free of charge from our website and there is a Danish, as well as an English, summary in the report. The questionnaire was sent to 1,000 adult members of the DEA and the response rate was 65 percent, which was very satisfactory.

The purpose of the survey was to obtain solid and scientific knowledge of the living conditions for PWE. Most of the epilepsy related research in Denmark, as in many countries around the world, is very specific, i.e. it is medical research on a specific topic or is very vague in its epilepsy focus, i.e. it is a general disability research project. Before we launched this research project, there was no comprehensive, scientific knowledge of how epilepsy influences people's lives in terms of cognitive problems, psychological disorders, side effects of medicine, barriers to education, labour and leisure, health, quality of life etc.

Take matters into your own hands

Therefore, we initiated the research ourselves. It was very important for us to ensure the quality of the research in order to obtain valid and reliable knowledge and in order to get the results recognized professionally and

politically. This is why we chose to enter into a partnership with a recognized Danish senior researcher who has carried out disability research for a long period of time.

At the present time, we are carrying out questionnaire surveys among children with epilepsy (0 to 17 years) and their parents, young people with epilepsy (18 to 30 years) and their parents, and spouses of people with epilepsy. In additions, we are planning to do research (qualitative or quantitative) on siblings of children with epilepsy.

Comparability is vital

In all surveys we use questionnaires and questions which have been used in recognized, scientific surveys on the issue at hand. Using recognized methods for the survey increases the probability of the results being used practically and politically. For the survey on children, for instance, we have used many questions from the *Health Behaviour in School-aged Children (HBSC)* - a WHO international study involving 40 countries. Using standardized questionnaires such as the HBSC allows us to compare data for children of the same age in the Danish 'normal population'. This is a powerful tool, politically, because we can point out specific focal points where children with epilepsy differ negatively from those without epilepsy. Furthermore, it is possible for us to compare results over time (continuing surveys) and place (40 participating countries).

Use the results

It is immensely important for epilepsy associations world wide to be active in the production of knowledge of PWE. With this knowledge we can qualify and focus our work on improving the living conditions for PWE and we will be able to help epilepsy professionals to have better understanding of the living conditions of PWE and, ultimately, we will acquire a powerful political tool to influence legislation and public administration in the field of epilepsy. All reports will be available for download at the Danish Epilepsy Association website: www.epilepsiforeningen.dk.

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