

## Report from Workshop C: Finding help: Caregiver

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- The information available regards available support has improved but parents still feel that there isn't enough. Parents feel lost when their children are transitioning in the teenage years : from paediatric outpatients to adult .Also in transition from junior school to high school. They feel that they need more support.
- Resource centres are helpful for the parents and also help the patient integrate. Though the number of persons attending has increased the number of carers has remained the same. This causes more pressure on the staff. The carers working in resource centres commented that they like to take the persons out, but sometimes the parents do not cooperate so much as they are afraid.
- The carers also commented that first aid for persons with epilepsy given to them by professionals isn't always the same, which worries them: eg when you should call an ambulance, recovery position. One time even the paramedics panicked while their child was choking during a seizure.
- Both care workers and parents agree that resource centres should have a nurse present. As there are no nurses at resource centres Parents are often told to keep their children at home for minor problems.
- Parents also spoke that although respite homes are good, they are not free of charge. Although they are subsidised they still struggle to pay, as usually one parent is unable to work to care for the child.
- Agensija support was mentioned, for psychological help and they also offer to send caregivers to homes, but the waiting list is very long and the service is not good for psychological help as well.
- Car givers also feel stressed when their child is being assessed as assessments take a long time to be concluded and private assessments are very costly especially if one parent has to leave their job.
- Doctors and care workers also find deficiencies in the system. There is discrimination between physical disability and invisible disabilities, especially to get financial assistance. Some persons never get a diagnoses concluded even though it is evident that they need help.
- Finally the stigma that causes many social problems was mentioned and the burden and problems the fact that the person with epilepsy cannot drive.