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DEMONSTRATION PROJECT ON EPILEPSY IN BRAZIL

WHO/ILAE/IBE GLOBAL CAMPAIGN AGAINST EPILEPSY

A foreword

PROJETO DEMONSTRATIVO EM EPILEPSIA NO BRASIL – CAMPANHA GLOBAL CONTRA EPILEPSIA DA WHO/ILAE/IBE: PREÂMBULO

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In 2002, ASPE (Assistência à Saúde de Pacientes com Epilepsia)* initiated an Epilepsy Demonstration Project (DP) in Brazil as part of the Global Campaign Against Epilepsy “Epilepsy out of the Shadows”, led by the World Health Organization (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE)¹⁻⁴. Demonstration Projects have been carried out in several countries and their main aim is to develop treatment models for people with epilepsy in primary health care settings, improving the quality of life of people with epilepsy and their families⁵⁻⁹.

The project in Brazil has targeted areas in Campinas and São José do Rio Preto municipalities, both in São Paulo State, in Southeastern region⁸. A task force has been established to assess strategies to expand this nationwide. The DP was carried out in six phases as shown in Figure 1.

The Brazilian DP was officially closed during the IV Workshop of the WHO/ILAE/IBE Global Campaign Against Epilepsy “Epilepsy out of the Shadows”, held on May 4-5th 2006, in Campinas. The workshop re-

viewed the results of the project and discussed the establishment of a National Epilepsy Policy. This supplement presents some results from all phases of the Brazilian DP which were discussed during the Workshop. In brief, we believe that the DP had an impact in our society and brought a new perspective on epilepsy. Awareness campaigns are now carried out on September 9th (Epilepsy Awareness Day) annually in many sites around the country. Regulations and Bills related to epilepsy have been proposed in several regions. Epilepsy has been officially adopted as a theme to be considered in elementary education by the Ministry of Education. Currently, a National Epilepsy Programme, endorsed by the main Brazilian non-governmental organizations in the field of epilepsy, is under review at the Ministry of Health. We hope that this will benefit some of the many people with epilepsy in the country and will eventually bring epilepsy out of the shadows in Brazil.

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*ASPE is a non-governmental organization founded in 2002. The ASPE mission is to promote bio-psycho-social health and to improve the quality of life of people with epilepsy and their families. The ASPE vision is to create centres of excellence and models of epilepsy in education, science and arts, guaranteeing integral and high quality assistance to people with epilepsy and their families.

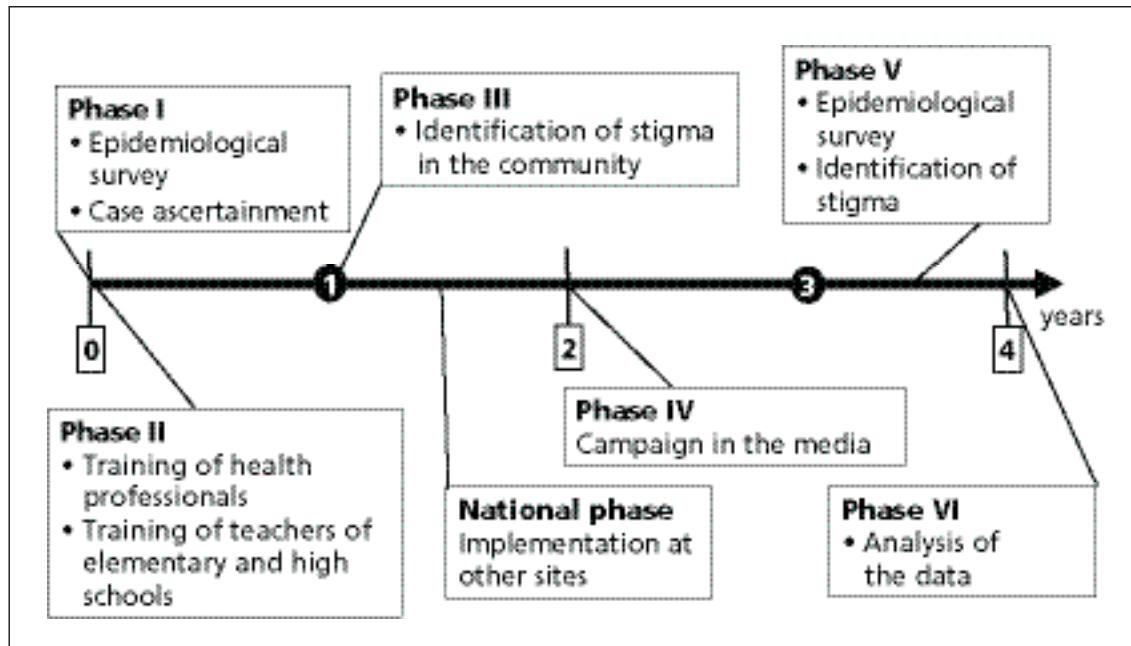


Fig 1. Demonstration Project on Epilepsy in Brazil, a WHO/IILAE/IIBE study from 2002 to 2006.

Legend: The Demonstration Project on Epilepsy in Brazil, part of the WHO/IILAE/IIBE Global Campaign initiative was carried out by ASPE (Assistência à Saúde de Pacientes com Epilepsia) from 2002 to 2006. The timeline shows the six phases in the study.

PHASE 1 – EPIDEMIOLOGICAL SURVEY

The prevalence of epilepsy in Brazil is similar to that in other resource-poor countries, and the treatment gap is high^{10,11}. Epilepsy is more prevalent amongst less wealthy people, and elderly people (over 59 years old) are more likely to be affected by active epilepsy¹¹. Nevertheless the treatment gap is similar amongst the different social classes. Commitment of the Brazilian health system towards improvement of the quality of health management for people with epilepsy and consistent and regular AED supply is urgently needed¹² (**article 1: Demonstration project on epilepsy in Brazil: situation assessment**¹³).

PHASE 2 – TRAINING COURSES

The training courses were divided into three modules, for health professionals; trainers (**article 2: Training the trainers and disseminating information: a strategy to educate health professionals on epilepsy**¹⁴ - and **article 3: Training medical students to improve the management of people with epilepsy**¹⁵) and teachers (**article 4: Teachers perception about epilepsy**¹⁶). The health professional training courses promote confidence in dealing with patients with

epilepsy, better knowledge about the condition, fewer wrong beliefs and myths about epilepsy, more knowledge about dealing with AEDs and less referral to neurologists. The training the trainers course promotes low cost and highly effective actions in the management of epilepsy and can quickly expand the training program nationwide. Children may have negative perceptions about epilepsy¹⁷. For this reason, it is important to develop continuous efforts in elementary schools to change the negative perceptions about epilepsy in our society. In this context, the teacher's educational courses were performed and the results showed that they were effective and had a long term effect on the knowledge, attitude and perception of teachers in elementary schools.

PHASE 3 – STIGMA IDENTIFICATION

To perform this phase, we completed the conceptualization of stigma¹⁸ and the elaboration of the instrument^{19,20}. The article presented here (**article 5: Stigma scale of epilepsy: validation process**²¹) refers to the validation process of the Stigma Scale of Epilepsy, the first instrument to measure this perception in a poor-resource country. The final results of

this research performed with 1,850 people in the community showed that the negative social attitudes and feelings observed in certain segments of the community can create inappropriate behavior, difficulties in social relationships, work and school and consequently perpetuate stigma in society²². The magnitude of stigma is different within different segments of local society (gender, social class, school level and religion) and for this reason, mass media campaigns should target these social segments in order to fight prejudice and improve the social acceptance of people with epilepsy²³. Also, we identify the epilepsy perception of university students (**article 6: *Epilepsy perception amongst university students: a survey***²⁴), which is often negative.

PHASE 4 – MASS MEDIA

We observed that the attitude (**article 7: *Stigma and attitudes on epilepsy: a study with secondary school students***²⁵) and language expression²⁶ seems to have consequence in the stigma perception about epilepsy. In this context, we should consider the proper usage of language as it matters for bringing epilepsy out of the shadows. Furthermore, effective mass media campaigns²⁷ should consider specific language of the different segments of the society to take out labels and improve social acceptance and reduce epilepsy stigma²⁸.

NATIONAL PHASE

The modules created and developed in this DP (training, de-stigmatization, social network) can be implanted easily and tailored to the requirements of each region of the country²⁹⁻³¹. This has been tested in several cities in the country (**article 2: *Training the trainers and disseminating information: a strategy to educate health professionals on epilepsy***¹⁴). Furthermore, the DP has been instrumental in sensitizing society^{32,33} and bringing together related organizations for an awareness campaign carried out all over Brazil during the National Week of Epilepsy^{34,35} (**article 8: *National epilepsy movement in Brazil***³⁶).

PHASE 5-6 - DATA ANALYSIS

The developed model of epilepsy treatment for primary health level based on the existing health system with strategic actions centered on the health care providers and the community has been shown

to be effective and efficient. We demonstrated that, using our model, people with epilepsy can be effectively treated at the primary health level, with important reductions in seizure frequency, as well as improvements in general well being. This model can be applied nationwide, as the key elements exist provided that the strategic measures are put forward in accordance with local health providers and managers (**article 9: *Demonstration Project on Epilepsy in Brazil: outcome assessment***³⁷).

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