

Concluding Remarks Mr. Alfred Bezzina KNPD

I will only stress 4 points regarding this Conference in order that when we meet again for another Conference of this kind, some progress will have been made regarding these 4 points.

The first one is: Should people with epilepsy say that they have the condition at school, at work or at social clubs ? We look forward to the day when our society is capable of accepting people with epilepsy without embarrassment for the people with epilepsy. We cannot give support unless we know that support is needed, but if society is not ready to accept them, there is no point in us saying that there is that need of support. We therefore need to be courageous and with some sacrifice say of our condition. Easy to say, but from my own experience (of my deaf daughter) I can say that it can be done. We have to help society be more adjourned and accepting of people with a disability or difference.

The second point is that epilepsy seems to have been the orphan in the sphere of disabilities in that up till recently people with epilepsy were still shunned and ostracised. From the medical aspect there have been great strides in medication resulting in people with epilepsy having a better quality of life. There is still a big BUT. For a better quality of life, we also need to focus on educational and social needs. This is the case in other disabilities where focus has been turned not only to the medical aspect but also to the social aspect and indeed to human rights. We no longer talk only of physical care where medicine has been very instrumental; we now also talk of the duties of society to accommodate the person with a disability. Our emphasis must be more focused on the world of education, the world of employment, of leisure and of family.

Here we come to the new Act Equal Opportunities. In itself, it is not a magic wand. Firstly because it is not retroactive to past injustices and secondly this law is as strong as we enforce it. It has to be us, to come forward with cases of injustices for the Act to be effective. Here we must mention the better social services. Our social services fall short of compensating for the extra expense incurred by the disability. To go from the medical to the social model it is important for alliances to be made with persons having different disabilities. It is not appreciated enough that different disabilities have similar issues, common to all disabilities. It is true there is a small number of issues that are sectoral but the great majority of issues are common. This highlights the importance of getting together to be louder in our requests to policy makers and the list of priorities.

My last point is on the educational sector. Today's Conference was on children. Although education is very high in Malta's priority list, I feel that today we have not talked enough in favour of the best possible education for children with epilepsy. On the web page of the Ministry for Education there is a document in "Inclusive Education" that stresses an individual educational programme for each of the children with different disabilities. I invite you all, especially the members of this Association to study this document and apply it to children / students with epilepsy.

I wish to thank all those involved in the organisation of this Conference for giving me the opportunity of sharing my thoughts with you and for the excellent organisation. I auger that it will help people with epilepsy obtain a better quality of life. Thank you.