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Report of a Workshop on Registers for Disabled Persons

WORKSHOP QUESTIONS

It is necessary to have access to adequate and accurate information re disabled persons so that effective priority and resource decisions can be taken.

It is important however, to identify the best methods for this information to be collected if this objective is to be attained.

- 1. Which are the most suitable and humane methods for the compilation of this information?**
- 2. How can we study the medical, social and educational needs of disabled persons?**
- 3. How can we ensure that this evaluation will be scientifically valid and technically efficient?**
- 4. How can we ensure that these proceedings are legally correct?**
- 5. Last but not least, how best should this information be used?**

1. It is important for each register to have an accurate definition of handicap. The international classifications must be kept in mind, i.e. impairment, disability and handicap. These classifications must be clearly defined in each register or part of register, and we must be guided by the international classification pertaining to this field.
2. There must be a central place and a central register to be used by all who make use of services. This central register must be supported by a number of other registers developed from this person oriented main register.
3. There is a need for professional education and the public, regarding the collection of the required data, so that their relative co-operation will be assured. This co-operation has not always been forthcoming not because the members do not wish to co-operate, but because of their fear, or because they would not have clearly understood, the objectives for the collection of the data. This is why there is a need for the education of the public.
4. Naturally privacy and confidentiality must be preserved. In certain cases there may be a need for informed consent. But on the otherhand, it was noted that there must be a simple system whereby confidentiality may be preserved. Otherwise this would restrict necessary research.
5. It was also noted that in Malta there are no laws regulating these matters and these matters are left to the integrity of the person responsible for the register.
6. It was commented that 'patients' have a right to know exactly what their condition is. Sometimes this is not the case.
7. A question was put regarding whether registration, according to outlined objectives, should be obligatory and on the other hand, whether it was ethical for this registration to be obligatory. We do not have answers for this!!
8. Lastly it was stressed that these registers should be continually updated. Previous registers have not been updated because of lack of staff.

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