ECUADOR

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FINAL REPORT

PHILOSOPHY ON REHABILITATION SERVICES FOR PEOPLE WITH MENTAL RETARDATION AND PROBLEMS TO SOLVE

Nowadays, handicapped persons specially mentally retarded are isolated and ill managed, because of, as soon as they are diagnosed they are putting aside by overprotection or rejection, instead of this, is imperative to promote the equilibrium between family and professionals in order to achieve a stimulant environment to help disabled person to interact with a "normal world" considering their limitations, in such a way that accepting the differences could be integrated to a regular life inside their communities. In this fashion is expectable that disabled persons could get a good quality of life in all the mankind spheres including affective and employment that are quite neglected.

MAKING PHILOSOPHY AN ACTUALITY WITH LOCAL RESOURCES

CBR

As a developing country Ecuador faces difficulties to achieve all goals proposed for any health program, including Mental Retardation or any disability:

1. Lack of resources in terms of financial and specialized people
2. Is compulsory to allocate more resources for basic and urgent needs as primary health care, basic sanitation and nutrition.
3. Not enough organization, and a feudal approach to administrative matters with excesive centralization of resources and political power.
4. Complex system where administrative affairs are mixed up with technical affairs, and ruled by medical professional instead of administrators
5. Socially misunderstanding about disabilities, human environment offers mostly overprotection or neglection
6. Insufficient acomplishing of law matters

On the other hand, as a new stream of strategies to cope with underdevelopment and poverty, emerges the community programs, those programs are easy to implement, because people specially in rural areas and shanty towns is keen on sharing, so the health network use to gather community groups for al health issues, so is possible to attach Community Based Rehabilitation (CBR) programs to the schemes of Primary Health Care (PHC), the health workers can manage the basics of rehabilitation programs as well as gross diagnosis and orientation for specialized diagnostic and therapy .

Unfortunately even if it is not difficult to start a CBR program, difficulties appear at the time of transfer the technology of CBR entirely to the community, and moreover to make of this something selfsusteinable, so it is necessary to prepare efficiently health workers to keep together with community representatives all the matters related to CBR. (In my personal opinion I think that is not possible yet to leave to the community the responsibility for carry on a CBR program, is still necessary to support them from the Health network, moreover it will be important to start at least with minimal items and trend to open and qualify constantly the program.)

Nevertheless, community based programs should be one of the most important strategies. Community based projects are in progress, in the whole country, because of the shortage of resources only in 3 places, but optimistically they will widespread, the sooner the better. From my point of view it will be good to settle down the program in all the health network in a very basic way with the expectancy of improving the quality of services according the possibilities of carrying on research (through surveillance systems and evaluation of services provided). This kind of approach is very good, because at the same time is possible to develop specific areas for working with good quality services and preparing staff with help of the universities. All of them following guidelines established in the Manual for Community-Based Rehabilitation (RBC) from PAHO (OMS- Panamerican Branch) with some modifications according to local needs, specially in term of educational activities.

Currently, it has been initiated a survey in order to identify persons with any disability, this kind of surveys are applicable to all families in the area that will be attended; the community chooses adequate persons to becoming "community- promoters" who will apply the methodology from the Manual above mentioned, at the same time they teach to disabled person and families involved, how to manage basic therapy and solve problems related to institutional offer. A physician makes the diagnosis, determines the treatment and carry on follow up attendance, and eventually decides about delivery.

In summary, with this strategy is possible gather most of resources in health and education in order to improve coverage and quality of attentions. This strategy should be attached to Health Primary Care program in the Ministry of Health because of its wide coverage, and considering that isolated projects do not achieve signifivative impact.

Prevention

Basic education focusing problems about mental impairment is a field has been forgotten. It will be necessary to develop a policy about this issue.

Prevention is the most important strategy to avoid increasing the problem of disabilities, specifically in reference to traffic accidents, pre/perinatal care, better nutrition, hearing/sight screening. All prevention needs campaigns of information and continuous education.

Particularly is important to prevent mental impairment, and it should be possible to achieve this goal using the background of health programs, as the Program for Rehabilitation of Malnourished Children that will include prevention matters:

1. Mass screening for pregnancy and birth (Metabolic- chromosomal- displasic disorders)
2. Awareness campaign, for general public to know about MR and disabilities
3. Preventive programs involving nutrition, traffic accidents and similar matters.
4. Early intervention initiate with health control, monthly under 12 months and every 3 months up to 3 years
5. Treatment in an integral scheme that takes account community participation
6. Education in order to achieve skills for self care of PWMR or at risk.
7. Research including surveillance systems and intelligent systems for inmediate response

Down Syndrome (DS)

For the children with DS is imperative start developing quickly, a program to cope with problems of ageing, nowadays they are adolescents and they are still in elementary school . Japanese idea of giving education in an integrated way with special curriculum and individual evaluation, keeping the DS children at the level according to age instead of goals achieved, is the main idea to implement in my center, and with a bit of effort and a lot of luck in the educational system of Ecuador. Moreover I will emphasize about a sheltered workshop and facilities for community living, in the same area of educational services as a milestone experiment in Ecuador, I understand that this is not the best way, but at the same time without many financial resources and having a minimum of facilities should be interesting to explore all this possibilities, but maybe it will be very difficult to convince parents to let children be as most independent as they could. Because as we saw even here, not all parents are interested on giving independence to children with DS or another disability.

COMMENT ABOUT SERVICES IN JAPAN

Applicability

The overall system of individual management is something that should be applicable in any country, it means, that could follow the next sequence, providing alternatives at any stage according to the specific and individual needs or abilities:

Prenatal and birth diagnosis
Counseling
Early diagnosis
Early intervention and therapy continuously for life
Education Integrated
Education Special
Vocational training
Employment protected
Employment open
Residential facilities
Autonomous life - Halfway house
Autonomous life - Group Home
Autonomous life - Independent living
Retirement institutions

All the parts of this process, are keeping together thanks to a supportive society, in case of Japan, it follows the guidelines administrative and financial coming from the governmental sector through the Ministries of Health/Welfare, Education and Labor; and these are put on practice via specialized staff and well designed facilities; supported by a society that recognizes the importance of living with equity.

Applicability will depend on the resources and ingenious of the applicants, and eventually the political will.

Criticism and recommendations for change

Services are extremely restrictive, avoiding contact with parents, because, even if family is allowed to participate, they have exact limits for participation, and most decisions specially in inpatients are in hands of professionals. Community participation is very small, at this point who takes the responsibility is the system through professionals. Long staying in hospital facilities is a byproduct of this issues.

I think should be easy to encourage persons, here in Japan, to enrole CBR programs, it depends only in decision of professionals, because, conciousness of people is really high. The most important fact is that the resources are more than enough to need CBR. Maybe CBR must keep the community in an advisory instance, because the system is enough to support all the needs of the community, as it start happening with the help providing through respite programs.

Is necessary to take account and moreover to dialogue and even to ask family and patients about their needs and desires. Circumstances are different but I rather prefer the close contact and the most interaction between parents and children as it used to be in countries like mine and Europeans.

COMMENTS ABOUT THE COURSE ON MENTAL RETARDATION

Needless to say that organization was excellent, without space to complain.

The course was very interesting because of the mixture of lectures and visits, it gives a variety of situations that make the time enjoyable. Individual training, in spite of not being according to my total interest, where adequate, interesting, with many alternatives and finally it configurates a perspective of a whole block of life span attention for a PWMR. Visits to hospital and neurologic center were extremely interesting, specially because was possible to be in touch of new technologies and see different cases that are good as references in my professional life.

Personal contacts are going to be fruitful in the future, and will open perspectives for the programs related to MR services, Rehabilitation Medicine, Mass Screening among others.

The course could be a little shorter, avoiding to waste time in compensatory days off, or short visits occupying a whole day, and others. It should be necessary to reduce as much as possible the translation, in order to keep the interest and not to waste time. Maybe should be good to stress on English level and specific knowledge of participants.

It will be important to have a follow up method, it means, to have a continuous exchange of information specially about the achievements, related to this course, in every country of origin.

According to my needs the course had been worthwhile, and I am sure that will help me a lot to improve the quality of services under my responsibility in Ecuador.

Deeply grateful