

Parents Mobilisation Action Group - P M A G

Summary of a short presentation in Acapulco November 2006

Basics of the PMAG concept

PMAG is a program not an NGO or an association. It is a joint venture program between Inclusion International and its member in a developing country. It aims at strengthening and promoting the local member association. A PMAG joint venture program is for a limited period of time. It may last till the local partner can advance without the support of Inclusion International.

Parents and parents' empowerment

At least 95% of intellectually disabled persons are deprived of school education and health care. Only some 5 % will see a school or a teacher in their life or will have access to some health care center. This is a startling observation. But this is the reality despite the existence of human rights legislation and provisions in many developing countries.

These 95% will in practice depend mainly on their parents, their family or occasionally of a good neighbor. That is why PMAG programs focus on parents. To empower parents, to make more parents aware of human rights and provisions for their child, to help them in becoming more efficient as responsible parents. Too often the so called "professionals" in school education or in the health sector consider parents as those that are incompetent and lacking the knowledge on how to raise their child in the right way. They are however, the prime caregivers of their child. They should be supported and encouraged to play that role.

Providing services to parents

The PMAG program is to provide support and services to parents. Bringing parents together in parents associations where parents can share with other parents. Services addressing school education, health issues, vocational training and income generation. Seminars on how to lead a Parents' association, seminars on effective fund raising, seminars on effective working with the media are provided.

The PMAG program helps to make intellectual disability more visible in society. The focus is on parents.

The parents' empowerment process is a slow process. Parents must be encouraged and supported to get together in associations to learn about human rights, equal opportunity, education and citizenship of their disabled child.

Voicing the parents

But the PMAG program may also allow to bring the voices of many parents together. To represent the parents in the dialogue with the authorities on human rights issues. Parents are encouraged to formulate their recommendations and advice to their local or national authorities. The parents' association or several parents' associations together may become the voice of a great number of parents. In a way they can together become a pressure group aiming at better human right provisions and a better implementation of their rights.

We have learned by experience that usually it is better to start regional and then step by step expand to more regions aiming eventually at a national program.

Round Table model

We have good experience with the Round Table model. At regional level parents /parents' associations get together and have a full day to talk and interact about important issues. At the end of the day a paper with conclusions and recommended action is produced. The next day is the Round Table where a delegation of the parents present the conclusions and recommended action to a delegation of regional authorities and other stake holders. Together they try to come to a number of agreed action points that are formulated at the end of the round Table. The third step is the formation of a committee that is committed to undertake the action.

Urban and rural area

Parents' groups and associations are still mainly restricted to the urban areas whereas the vast majority of the population - in many developing countries some 70 % - live in the rural area. The challenge for the PMAG program is to reach out to the public and particularly to the parents in these rural areas. A slow process in which the mass media must be involved next to intensive local programs such as the CBR approach.

Resources mainly human resources

PMAG programs depend on human resources in the first place. They usually do not require intensive financial support. There is a PMAG Program manager. He or she works closely with the employees of the local partner. This is essential. He reports to a Steering Group that is composed of two representatives of Inclusion International and two representatives of the local member association. They meet twice a year to discuss the past 6 months of the PMAG Program, to deal with current issues and to agree on a program for the next 6 months.

Funding

PMAG management costs are funded through Inclusion International. For PMAG Program costs local funders must be found. We have learned by experience that too often parents associations have little knowledge of how to do effective local fund raising. The PMAG program makes parents aware that local fund raising is a must and that the art of fund raising can be learned.

This summary does not refer to any particular country specific issue. It provides, however, a model that could be applicable in many more developing countries. The model is based on my experiences of PMAG in India, the Philippines and the hard lessons that we learned in Indonesia.

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Acapulco, November 2006