# Handicapped children in Pakistan: targeting information needs

*M Miles, Mental Health Centre, Peshawar*

## Problems

Many children in Pakistan suffer a disabling impairment, associated with the familiar impoverished health and nutrition status. Parents with a disabled child seldom receive help from outside the family.[1] Families usually have no idea what to do with a child who does not develop or function normally. Very few have any reliable source of information or advice. Our study on attitudes towards disabled persons[2] suggests that the general public is aware of disabilities, and has some ideas about prevention, but is largely ignorant of rehabilitative measures. Whatever knowledge exists is muddled with inaccuracies, superstitions and fear.

Professionals to whom handicapped children are brought seldom know more than the parents about positive management of disability. Medical personnel may correctly diagnose the impairment, but few have any training in assessment of disability or in rehabilitation techniques. We often see children who have been further impaired by the mistaken (or misunderstood) advice of health professionals.

Lack of information compounds all the problems. Parents better informed about basic hygiene, nutrition, maternity care, immunization etc. could more easily prevent impairments in their children. If professionals knew more about how to detect, assess and manage impairments, some at least would be willing to make better efforts.

## Solutions

Historically, solutions have been seen in terms of increasing institutional structures, with more money and influence for people with college qualifications. They then dole out their knowledge (at a price) to those who gain access to them. Certainly, some institutional and professional structures are necessary, but they can easily become islands of privilege and may even act to prevent anyone else from acquiring and disseminating useful information.

The World Health Organization's (WHO's) Community Based Rehabilitation scheme,[3] once hailed as an antidote or alternative to institutions, has generally been implemented as *home*-based rehabilitation rather than *community*-based, and results have been unconvincing.[4] Ten years after its inception, India's senior rehabilitation planners report that the WHO scheme 'has been utilised in several developing countries, including India, but the program is still under experimentation and there is no report of any success'.[5]

The Government of Pakistan is substantially increasing its institutional rehabilitation structures and various professional groups are circling around trying to get a share of the action. In 10 years time, at the present rate of expenditure and allowing for the population to increase to 140 millions, some formal help could be available for perhaps 10% of all disabled children.

**Solutions are urgently needed for the other 90%**

### Information packages

Instead of debating structures, whether institutional, home- or community-based, it may be more fruitful to consider the rehabilitation enterprise as an *information system*. Solutions are then seen in terms of accurate and appropriate information, disseminated to relevant targets, with suitable reinforcement, feedback and evaluation. 'Information package' here indicates a defined quantity of rehabilitation/prevention information conveyed by any medium, e.g. a pamphlet, manual, a radio broadcast, a TV public services ad., etc.

During the past five years some information packages have been produced and tested in North West Frontier and the Punjab. Most are written in simple Urdu and present relevant information about aetiology, prognosis and rehabilitation for particular childhood disabilities, aimed at parents, family members and basic health workers. The major task at present is to adapt and translate Werner's magnificent compendium *Disabled Village Children*.[6]

Production, however, has been small. Dissemination has been uncoordinated with PHC propaganda or other potentially supportive channels. Distribution media have not been evaluated. **The information that could start solutions for rural disability is lying in the cupboards of a few urban institutions.**

A similar situation exists across the PHC field: health solutions are known, in urban institutions. Information packages have been prepared. A significant proportion of the rural population would be willing to act if they had the information. But dissemination media have not been activated or, if active, have not been evaluated and systematized. There are no on-going, self-activating and self-propagating information systems.

with any sort of information. Literate intermediaries are required in the short term to overcome the barrier of non-literacy and to reinforce radio and visual messages.

- Attitudes tend to shift slowly, one stage at a time, with periodic relapses. It is difficult to monitor attitude change, or to make causal attributions. Nor is rehabilitation progress a simple matter to assess. Prevention of disability is difficult to quantify, where there are no accurately assessed health benchmarks.
- Rehabilitation information and methods that have been successful in the West during the past decade are based on concepts of children that are fairly different from those common in Pakistan and many other countries.

## Conclusion

Current activities are remote from the potential solutions. Planning that focuses on structures, whether of institutions and professionals or of home and community, is unlikely to make a significant impact. The number of disabled children is increasing both by biological growth and by survival as infant mortality rates fall. The information systems approach offers one means, perhaps the only means, to enable large numbers of children to avoid disabling impairments or to enjoy a fuller life even if they suffer an impairment.

## References

[1] Miles M. 1981. *A survey of handicapped children and their needs in NWFP.* Peshawar, Pakistan: Mental Health Centre.

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[3] Helander E et al. 1983. *Training disabled people in the community* (3rd edn). Geneva: World Health Organization.

[4] Miles M. 1985. *Where there is no rehab plan* Peshawar, Pakistan: Mental Health Centre.

[5] Narasimhan MC and Mukherjee AK. 1986. *Disability: a continuing challenge* Delhi: Wiley Eastern.

[6] Werner D. 1987. *Disabled village children.* Palo Alto, USA: Hesperian Foundation.

## Note

M Miles is Administrator of the Mental Health Centre and Consultant to the FAMH/UNICEF Community Rehabilitation Development Project.

M. Miles
Mental Health Centre, Peshawar,
Pakistan - at Mission Hospital

Reprinted from :-

HEALTH POLICY AND PLANNING Vol.2 No.4 (1987) pp 347-351

Oxford University Press

This list by no means exhausts the organized, accessible and accountable health, education and welfare bodies that could be expected to welcome a supply of information packages for their clientele. Some at least could be persuaded to collaborate in monitoring the effectiveness of the packages and measuring the on-going demand.

Methods of approach

*Monitored dissemination*

The public-contact channels must be assessed for compliance and handling capacity. On these estimates, stocks of information packages may be produced. Distribution of packages should coincide with mass media coverage of a general attitude-change nature and specific stimulation of the public demand for information packages, together with directions for accessing them locally. (Experience indicates that the public demand for rehabilitation information is considerable, but is normally disappointed.)

*Evaluation/feedback*

This requires:

- reports from the institutional channels handling dissemination, backed up by spot inspections of physical stock.
- survey sampling of the clients' opinions.
- general opinion polls.
- in-depth home and centre studies of a sample of disabled persons undergoing rehabilitative treatment.

The package *contents* and the format and channels for package *dissemination* need evaluation.

*Systems*

The ultimate goal would be that in every appropriate Government and NGO public-contact sphere there should be a steady, targeted and monitored flow and feedback of appropriate prevention and rehabilitation information to clients whether they are aware or unaware of their need for information. Such a goal is not yet in fact achieved by economically advanced Western societies, but there has been some progress towards it. Technically it is feasible. The prevention/early-intervention achieved by such an information flow is much less expensive than rehabilitation of long-neglected disability.

*Priorities*

Realistic goal priorities need to be carefully defined. An example:

| | |
|---|---|
| Area: | Rural District X |
| Terminus: | 31 March 1988 |
| Agency: | Public Health School |
| Personnel: | LHVs and registered dais |
| Coverage: | 70% of personnel |
| Disability: | Mental and/or physical disability |
| Client: | Mother of disabled child under 10 years old |
| Sub-clients: | Grandmother, aunt, cousin or sister of disabled child |
| Preparation: | a) Video of in-home rehabilitation; group discussion<br>b) Hands-on practical sessions at District HQ special school or physiotherapy clinic<br>c) Role play of contact with mother/relative |
| Info-pack: | 8-page cartoon-strip story pamphlet, covering main points portrayed on video |
| Replenish: | Information store at basic health unit |
| Motivation: | Intrinsic interest of video and pamphlet; confidence arising from knowledge |
| Feedback: | a) Stock records of BHU<br>b) Report-back session by 10% of personnel, selected from high, median and low utilizers<br>c) Periodic general refresher courses |

*Constraints*

- There is a worldwide dearth of experience of this type of project.
- In Pakistan there is little experience of planned information systems, of giving away non-political information, or of empowering people by informing them.
- There may be opposition from professionals, perceiving some threat to their livelihood or community standing if preventive and rehabilitative information and techniques are made accessible to the general public.
- There are social and cultural barriers to involving women in public information tasks, or indeed to reaching the majority of women

Target audience

Experience in previous rehabilitation programs suggests that among the *already-motivated* clients for information packages are:

- parents with a handicapped child.
- siblings of a handicapped child.
- other relatives of handicapped persons.
- handicapped adults and handicapped older children.
- staff of rehabilitation centres and special schools.
- staff of basic health units/mother and child health centres/district hospitals.
- health, education and welfare planners.
- personnel in general social welfare agencies.
- school teachers with casually mainstreamed disabled pupils.
- community leaders, advisors, maulvis, politicians.
- mass media personnel.
- Students of medicine, public health, social work, psychology.
- Traditional birth attendants, hakims, non-formal practitioners.

Targeting audiences more specifically tends to increase the effectiveness of propaganda. In the list above, for example, Nos. (1), (2) and (3), which could easily be lumped together as 'Family of handicapped child', are listed separately with good reason: the level and content of information for these groups may differ significantly, as may also the channel of communication. Parents, for instance, may be preoccupied with rehabilitative treatment, prognosis and aetiology (relevant to future offspring). Siblings may be more immediately concerned with their own fears of contagion, gaining a fair share of their parents' attention and the negative attitude of peers. Parents may more easily be given information through existing health institutions, while for siblings an approach through school text books, cartoon strip novels and children's TV may be appropriate. More distant relatives may need advice on how to respond positively in an unusual family situation.

**Potential dissemination channels**

Apart from the usual mass media, many organized public-contact channels could successfully disseminate specifically targeted information packages if available, and could monitor their application, e.g.

- *Provincial Health Directorate:*
  - public health school (health visitor and dai training)
  - district hospitals/health centres
  - schools health service
  - family welfare services
  - EPI programme
- *Provincial Social Welfare Directorate*
  - local social welfare officers
  - voluntary welfare agencies
  - orphanages, women welfare homes and hostels
- *Provincial Directorates of Information, Employment, Technical Training*
- *Provincial Education Directorate*
  - schools and colleges
  - textbook board
  - teacher training institutions
- *Universities and Degree Colleges: students and staff in*
  - medicine
  - social work and sociology
  - psychology and anthropology
  - journalism and information science
- *Special Schools and Rehabilitation Centres*
  - federal
  - provincial
  - local NGO
  - disabled persons associations
- *Service organizations, e.g.*
  - APWA, Behbud,
  - Girl Guides, Scouts, children's academies
  - Rotary, Lions, Jaycees,
  - Red Crescent societies
  - Family Planning Association
- *Private and Semi-Government Facilities*
  - private schools and hospitals
  - police, railway, WAPDA, schools and hospitals
  - Church schools, mission hospitals and clinics
  - bank employees welfare services
- *Armed Forces Health and Welfare Services*
  - Fauji Foundation centres
  - combined military hospitals
  - camp and base schools
- *Local Government, Rural and Urban Councils*
- *Local Zakat Committees*
- *Commercial Publishers and Book Stores*