This report focuses on a project in Afghanistan that coordinates the efforts of several agencies to develop community-directed disability, rehabilitation, and education services. The program stresses community mobilization aided by skills transfer from expatriate specialists, and includes physical therapy, prosthetics, living skills and mobility training for blind participants, vocational rehabilitation, and social integration. This report focuses specifically on the informational content of the project, designed to generate disability awareness and dissemination of information, and on project activities geared toward training community organizers who can involve participating communities in identifying their own resources and setting up necessary services. The idea of regional Disability Resource Centers, with participation by associations of disabled Afghans and caregivers, is developed. An annotated bibliography of approximately 100 items lists materials on disability service development available in various languages. Notes on potential future studies are provided, and possibilities for educational integration of Afghans with disabilities are discussed. An appendix contains a paper titled "Disability Information in Afghan History." (PB)
DISABILITY INFORMATION & AWARENESS: AFGHANISTAN

Report by M. MILES

1993 [Version 2.2]

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A. DISABILITY-RELATED INFORMATION MATERIALS
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RESUME

This report arises in connection with a project coordinating several agencies working to develop community-directed disability/rehabilitation/education services, currently in two provincial locations of Afghanistan and aiming to develop further regional centres, in collaboration with Government and NGO resources. The approach is one of community mobilisation aided by skills transfer from expatriate specialists; commencing with physical therapy, prosthetics and orthotics, living skills and education for blind people, vocational rehabilitation and social integration.

The present version of the report focuses on the information content of the project and activities, in terms of traditional and imported concepts, knowledge, skills and design; and develops the idea of regional Disability Resource Centres, with participation by associations of disabled Afghans and of carers. An extensive annotated bibliography is provided, of information materials available at Peshawar in Dari, Pushto, Urdu and English, relevant to Afghan disability service development. Notes are provided on some topics for future information-generating studies. The possibilities for educational integration are discussed.

1.0 BASIS OF OBSERVATIONS

1.1 The report is based on:

a) A visit to Peshawar from 8th May to 19th June 1992, during which discussions were held with many individuals and agencies engaged in Afghan aid and development work, and the information materials listed in Appendix A were found and examined.

b) 14 years of disability information/resource development work with colleagues in Peshawar, from 1978 to 1992, and international correspondence with a network of disability information developers. This work was centred on Pakistan, but concerned itself also with neighbouring India and Afghanistan.

1.2 The situations, needs and resources of disabled Afghans, whether inside Afghanistan or in refugee villages, have similarities to those of disabled Pakistanis in the North West Frontier Province and Baluchistan; but are not identical. 'Information approaches' to disability planning are an experimental and developing method and set of tools. So the observations and recommendations offered here should be appraised critically. The future for most Afghans with disabilities is quite uncertain. There is no place for dogmatism or rigidity of thought.

1.3 The present situation of the collaborative project is also evolving rapidly. The implementing agencies have been, and largely still are, based in Pakistan and mainly geared to service delivery in refugee villages, whereas the aim is to mobilise community resources for rehabilitation of disabled people in several major towns and their catchment areas, within Afghanistan. None of the agencies involved can predict with much confidence what its situation and activities will be by the end of 1994.

1.4 Much of the information task is highly flexible. Well-prepared information and awareness materials are tools that are hardly time-
dependent. They can be used or re-used much later, in situations not yet envisaged, and at times when those who prepared the materials may be elsewhere. Thus the information task is well suited to situations of change and uncertainty. Any number of staff can usefully be deployed in information tasks when other sorts of work may be blocked or delayed. The volume of information work can be varied to suit the circumstances. By its very nature, its impact is cumulative over time.

2.0 AIMS OF THE DISABILITY PROJECT

2.1 The project aims to establish "integrated and comprehensive services which can serve as a model for larger parts of the population. This will facilitate longer term planning and contribute towards the creation of a service structure for the disabled in Afghanistan. The following components will be developed... production of orthopaedic devices, provision of physiotherapy, training of blind people, integration of disabled children into schools and integration of disabled men into vocational training schemes and income generating activities. Special services for women, and training of female physiotherapy technicians/aides, are envisaged to start." Activities have commenced two rural towns, and are targeted for three further towns in other provinces, which are intended to act as regional resource bases.

2.2 The project strategy "is one of promoting a social process, rather than identifying at this time a specific number of measurable inputs and outputs... This social process includes training and deploying social animators (sometimes called community organisers) who can involve the participating communities in decision-making, including identifying their own resources, in addition to setting up the necessary basic services, such as physiotherapy and orthopaedic device production."

2.3 As already remarked, the project's present situation and prospects are somewhat unclear, on account of the rapid evolution of the political and socio-economic situation in Afghanistan, and the fact that it comprises a loose conglomerate of agencies each of which is adapting at a different pace and in different ways to the evolving situation. However, a creditable start has been made in pursuing the more tangible objectives.

3.0 DISABILITY 'IN THE COMMUNITY'

3.1 Awareness & information

3.1.1 Afghan communities start with some awareness of people with disabilities (see Appendix B). Most visible at present, are war-damaged men. Amidst all the pressing demands for reconstruction in Afghanistan, it is hard to know where disability really comes among community priorities. For the next decade, health and education resources in Afghanistan will be overloaded. For most Afghans with disabilities, whatever is done by way of disability-related service will be done by themselves and their families and people in their neighbourhood. This has consequences for planning:

a) Little of what may be done can be planned and controlled from outside, but much of it could be facilitated by better information
about what people can do to help themselves/their disabled relatives/neighbours. 'Information' is here understood broadly, to include concepts, knowledge, skills and design. Thus, a mother can respond better to her mentally handicapped child if she has been helped to differentiate the concepts of mental handicap and learning difficulties from that of mental illness and its behavioural consequences. The bazaar shoemaker, who already has relevant knowledge and skills, will make a better orthopaedic boot if he has a design to work from and has been informed about the nature of the orthopaedic problem. Physiotherapy treatment by massage and exercise is more likely to be accepted and practised at home if it builds on indigenous knowledge and skills of massage. Provision of such information is of course not easy where there are poor communications facilities, low levels of female literacy, and a lack of familiarity with graphic/visual representations.

b) Elsewhere, organisations of disabled people, and of care-givers or parents of handicapped children, have been among the most active in acquiring and sharing information. It remains to be seen whether self-identification as a 'disabled person' or 'care-giver' or 'parent of disabled child' proves sufficiently strong for mutual collaboration, to override the fragmenting pull of tribe, language, party, and allegiance of Afghans to their extended families.

3.1.2 Some aspects of disability are well-known in local communities, e.g. that there exist people who are blind, and that a blind man can be led about by a boy. The introduction of orientation and mobility training, as a result of which blind men are seen moving about in the community with a white cane rather than being led by a boy, is likely to result in some reassessment of attitude towards blind men. Other aspects, e.g. the lives of blind women and girls, unseen behind four walls, and the existence of children with mental handicap and elderly people with impaired hearing, are less known. There may not be any 'public attitude' toward these disabilities, because they are known only to immediate family members. Others, including community leaders, may even deny that they exist, or may believe they are very rare.

3.1.3 'Community participation' is harder in service provision for aspects of disability that are largely unknown to the community (i.e. that have not become 'public knowledge'). First, information must be provided and concepts developed, some examples shown of effective services and positive attitudes. Then an awareness develops that 'such a type of disability exists, it can be managed by the following methods, and it becomes much less of a problem if the community takes the following attitudes/actions towards people/families who have it.

3.1.4 Formal services for women and children with less-visible disabilities are unlikely to have priority in rural communities that are engaged in rebuilding, but the current, informal, in-home efforts of female relatives are a major contribution to the welfare of such people. Women's efforts within the Afghan home, however, are not the business of outsiders, i.e. the community at large - especially if within the four walls there is someone of which the family feels some reticence, such as a son who is not growing up normally, a daughter who is not speaking and who looks a little odd, or a man who is no longer able to walk, stand or take himself to the toilet. Concealment is the norm.
3.1.5 Competent social animators may draw attention to the invisible disabilities, and to the nearly invisible women and children, and this awareness-raising is a valuable activity. Yet, by itself, it changes little. When people have begun to recognise that a problem exists, they want to know what to do. The animators should therefore be given every encouragement to increase their familiarity with relevant specialised information to help people discover what to do, beyond the important first step of realising that something can be done.

3.2 Building on motivation

3.2.1 When animators or community volunteers refer to a centre where there are professionals with the know-how to solve the problem, the focus shifts to the professionals - who may be less oriented to empowering people by giving away their know-how. A more useful 'referral model' may be one in which social animators accompany interested persons to a disability resource centre and facilitate their choice of information materials relevant to their situation. The animator still acts only as a catalyst. Effort is still demanded from the person with a disability or her carers/family/friends, but such effort is rewarded by the acquisition of tools with which to change their own situation.

3.2.2 By no means all such people will want to make the effort of self-help, using informative material. However, there are several reasons for beginning with those who are sufficiently motivated that, given access to information materials, they would act upon them:

   a) At low cost, very many well-motivated people can be reached, and the fact that this approach first reaches well-motivated people is a psychological boost to the whole program.

   b) Those who are well-motivated to obtain and use information for their own problem are also likely to be (or to contain) a strategic group of evangelists/advertisers/mobilisers within their neighbourhood/community. They are self-selected as being more information-minded and active than the average.

   c) Well-designed information materials engage and re-motivate people to act, to think, to experiment, in a way that would be much harder for a professional therapist to achieve. There is a more equal balance of power between the information seeker and the booklet or video cassette, as compared with the balance between the treatment seeker and the professional therapist.

   d) The experience and skills of the professional are much more important at the next stage, after clients have had time to absorb some information and experiment with it. The next stage, the nuances, the complications, which are hard to explain by print or visual media, can be tackled by the professional, who now has a partly-informed and partly-experienced information seeker. The professional's task is not always made easier by such part-knowledge! The transfer of information is more challenging, but ultimately more effective, where there is a more equal balance between seeker and informant.

3.2.4 In the past decade, Afghans inside and outside their country have
encountered much new information. In some, it has developed an appetite for much more. Those people, who are to be found in both cities and in villages, are the growing points for the future. Some of them are disabled, some are caring for people with disabilities. Their appetite for information must be both catered for and further stimulated.

3.3 Valuing local resources

3.3.1 A balance must be maintained, between drawing the attention of community partners to neglected areas of low perceived priority (e.g. women, children, hearing loss, mental retardation, disabling psychological trauma), and pushing forward with external inputs that are valuable in themselves, but do not necessarily enhance communities' self-help capabilities.

3.3.2 Where collaborating agencies intervene with skilled therapists and technicians, their success appears in the number and quality of patients rehabilitated. Even where the professional is primarily a trainer, there has to be some demonstration of skill with actual clients. The practice of modern rehabilitation skills, at a training base, in an urban setting, does not very clearly 'arise from within the community', nor does it engage the community resources that should be involved in 'community based rehabilitation'. On the other hand, if no modern skills are demonstrated, the program is likely to make very little, or very slow, impact.

3.3.3 Staff of all the collaborating agencies may need to understand more about what sorts of existing information are valuable. Two examples:

a) When a child is 'not speaking', the parents may believe that there exists some religio-magic formula, or a surgical operation, that will cause the child to speak. In fact, if the child is severely retarded, she may simply not have learnt the complex process of imitating sounds, forming sounds into words, attaching correct meaning to words, and adding words together to communicate with speech. The child's family has often taken part previously in the process by which other children have learnt to speak - but the family does not realise that it has this experience and knowledge. Mothers and siblings normally reflect sounds back to their babies, help the infant's shaping of sounds into words, and demonstrate correct meanings. But they are not aware that this constitutes a valuable set of skills, which can be used methodically for teaching a mentally retarded child to speak. If the social animator knows this, she may be able to reveal to the family the skills they already possess.

b) For older children with disabilities, or for adults who have lost previous abilities, the community knows the range of normal occupations in their village or town, in a way that no outsider could readily learn. Among this knowledge, there may be some roles and occupations that would better suit the abilities of the disabled youth or adult. The choice of appropriate occupation is something that family members must make, and have the relevant knowledge to make once they perceive that their local knowledge is of value. Part of the task of the social animator is to generate in families sufficient confidence to use their existing knowledge and common sense, rather than waiting for an answer from outside (which is
unlikely to be appropriate to their situation). Of course, another part of the task is to recognise where the family's knowledge needs to be supplemented with fresh information, or guided away from an over-ambitious or foolish choice.

### 3.4 Complexity of Social Attitudes

#### 3.4.1 Experience with information and awareness campaigns elsewhere suggests that the most effective are targeted at specific population groups and aim to motivate the targets to take a specific course of action. Modifying an existing behaviour is of course much easier than introducing new behaviour. To modify the status of a marginal group in a community (i.e., people with disabilities), affording them access to rights and opportunities which they did not previously enjoy, requires careful planning and input. The complexity of the task should be faced at the outset. One can spend a lot of effort proclaiming, for example, that 'Disabled People Have The Same Rights As All of Us'. This worthy sentiment does not, however, demand action of individuals – or the actions required are not at all obvious.

#### 3.4.2 People with disabilities should play a prominent (but not necessarily dominant) part in planning the sort of messages that should go into public awareness campaigns, and in deciding what are the desired outcomes and the strategies to achieve them. Some disabled adults, who have benefitted from whatever rehabilitative services are available, may become keen clients for information across the whole disability field, and should be given every encouragement to make themselves aware of the needs and possibilities by studying whatever materials are available in Resource Centres and by meeting with others who have a similar interest. The disabled adult who has undertaken such study may be of the greatest help in a volunteer capacity or as a member of staff.

#### 3.4.3 Normally, there is an on-going interaction between formal service provisions and social attitudes, the development of each facilitating the development of the other. As rehabilitative services improve, rehabilitated disabled people appear in public doing things of which they were previously thought incapable, which erodes some of the negative attitudes towards disability, and also increases public willingness for resources to be put into further service provisions.

#### 3.4.4 Activities are likely to be much more productive if all parties involved, or who should be involved, are supplied with much more relevant and attractive information, in the form of information materials and access to mutually consultative networks. The secondary thrust is well pointed by Hunte (1991, p.77) in her valuable discussion of health messages and communication among Afghans, emphasizing the importance of

"...meeting the target population as an equal - as a group of people from whom we have something to learn rather than only to teach them new ways. This sharing of information rather than simply imparting it is central to developing people's trust and obtaining their active and sincere participation in the development process."
4.0 INFORMATION FACTORS ELABORATED

Mike Miles: You know, Professor Hasan, I've come to see that in developing disability services, 50 per cent of the battle is personalities and politics.

Zaki Hasan: No.

Mike Miles: Oh, don't you think so?

Zaki Hasan: No. 90 per cent.

4.1 Diversity

4.1.1 Every aspect of planning and implementation involves some sort of information (concepts, knowledge, skills, design). There are many people and organisations involved in the project, and there may be even more in the future, of several nationalities, using several languages, and with a wide range of background and experience in disability and development. There will, inevitably, be quite a number of different ideas floating around, as to what the collaborative project is, what it is doing, what it should become.

4.1.2 This diversity may be productive, if it is given some guidance and management. Part of the guidance may consist simply of writing down the known information factors, and identifying the more obvious gaps in information materials and information flow; and taking steps to fill or reduce them. At the end, participants may still wish to emphasize different parts of the range of information; yet the better informed everyone is, the more likely they are to understand what other people are doing and why; and the less likely to be obstructive.

4.1.3 At present, at least the following information factors are in play:

a) Initial awareness of 'a problem': there are Afghans with disabilities. There are many with a visible disability. There may be many more whose disability is not immediately noticeable.

b) A developing information/awareness:
   - Elaboration of 'the problem'
   - Perspectives of children, human rights, the responsibility of society to make provisions for all its members
   - Indigenous traditional concepts of disability and rehabilitation.

c) Some professional skills, imported and local, concentrated in physical disabilities, prosthetics/orthotics, and community organisation.

4.1.4 The front line / sharp end, i.e. the active means to collect, store, apply or transfer information, comprises:

- Social Animators
- Resource Centres (under development)
- Rehabilitation professionals
- Disabled persons and their families
- Administration/information staff
already existing information resource materials
- the participating organisations
- local communities participating
- Government departments collaborating
- .... (other components as yet unperceived)

4.2 What is information?

4.2.1 'Information' is commonly understood in the sense of 'a small quantity of data' e.g. a page in a railway timetable, or a set of statistics on the number of blind women of different ages living within a ten mile radius of the centre of Herat. However, the word 'information' can have broader meanings.

4.2.2 In the 'Information Approach' to disability planning (described in more detail in Miles, 1990a, 1990b), information is understood in a very much broader sense. It includes

   a) Concepts
   b) Knowledge
   c) Skills
   d) Design

   a) Concepts: ideas, attitudes and beliefs, e.g. about what disabilities are, what does it mean to be disabled, how do disabilities affect social relationships between people, does a disabled person have the same legal rights as anyone else, etc. These ideas, attitudes and beliefs can be expressed in words and pictures. They can be communicated, like other sorts of information, though to do so is not always easy.

   b) Knowledge: whatever people know, in the normal senses of these words.

   c) Skills: the activities that people learn and become capable of doing by the practical application of knowledge and by repetition with modifications in the light of experience.

   d) Design: the application of concepts and skills, in making a piece of equipment, planning a building, lay-out of a page in a manual, etc.

4.2.3 If one studies the problems and obstacles that have occurred in the development of formal rehabilitation services for people with disabilities, the following phrases recur:

   "People don't know that anything can be done...."

   "They believe that a blind person cannot...."

   "The specialist did not explain what it meant..."

   "The attitude we meet is that the person with mobility problems is also unable to think or to do anything else...."

   "This mother wants to help her mentally retarded daughter, but she does not understand what exactly is wrong with the girl, so does not
know where to start...."

"The teacher was unwilling to let this hearing-impaired boy join his class because he had no idea how to adapt his teaching approach so that the boy could benefit...."

4.2.4 Of course, the lack of knowledge and the negative concepts of disability displayed in the above remarks are not the only problems. But they are powerful obstacles. Part of their power arises because they are often invisible. If a man is unaware that anything can be done to remedy a problem, then he will not even look for knowledge or examine his concept to see if there is any flaw in it.

4.3 Concept development and attitudes

4.3.1 A study in the North West Frontier Province (Miles, 1983), among people with many cultural and socio-economic similarities with the Afghan population, suggests that the 'general public' may have a wide range of concepts and attitudes concerning disability and disabled people. The range was organised step-wise as follows. People changed their views one step at a time, if at all.

- **a) Rejection**: Disabled people are a burden, a nuisance, beggars, under a curse, they can be mocked.
- **b) Fatalism**: Disability is their fate. Nothing can be done.
- **c) Condescension**: It’s not their own fault; it’s God’s will. They should not be mocked.
- **d) Pity**: We should feel sorry for them; pray for them.
- **e) Charitable duty**: It is our duty to give alms.
- **f) Willing to help**: We should do more than pity them and give alms. We should give them actual help.
- **g) Empathy**: What would I find really helpful if I were in the situation of that disabled person?
- **h) Acceptance with**: There must be acceptance of disabled people by society, dignity and a life of human dignity.
- **j) Right to normal life & esteem**: Acceptance must be on terms of equal value and esteem. People with disabilities must be enabled to live with a normal range of choices, and to make their contribution to the life of the community.

4.3.2 The distribution of self-reported attitudes was heavily skewed towards the first four items on the list. Quite possibly, in Afghanistan, the perception that a disability has arisen while someone was fighting for his country and in defence of Islam, or was caused to an innocent person by enemy action, might reduce the number of people holding view (a), the most negative on the list. However, it is likely that the majority of the
population, who themselves are economically poor, have suffered immense hardships during the 1980s and face the prospect of continuing poverty, may hardly rise above the attitudes expressed in (b), (c), (d) and (e), which fall short of an active involvement in disability issues and re-shaping society to be accessible to all.

4.3.3 Observation of Government activities on behalf of disabled people, in Pakistan and elsewhere, has led to the formulation of a further developmental table, through which the official mind tends to progress, sometimes spanning several items at once:

<table>
<thead>
<tr>
<th>a) Ignorance</th>
<th>: The 'problem' of disability is not yet perceived.</th>
</tr>
</thead>
<tbody>
<tr>
<td>b) Attention</td>
<td>: Ah! So there is a problem!</td>
</tr>
<tr>
<td>Identification</td>
<td>: What is it? Who are they?</td>
</tr>
<tr>
<td>Differentiation</td>
<td>: They're different! There's something wrong with them!</td>
</tr>
<tr>
<td>Quantification</td>
<td>: How many are there? How serious is it?</td>
</tr>
<tr>
<td>c) Accommodation</td>
<td>: Something should be done about it!</td>
</tr>
<tr>
<td>Segregation</td>
<td>: There should be a place for them!</td>
</tr>
<tr>
<td>Prevention</td>
<td>: Can it be stopped?</td>
</tr>
<tr>
<td>Economisation</td>
<td>: How much is all this going to cost?</td>
</tr>
<tr>
<td>d) Adaptation</td>
<td>: This thing must, and can, be managed!</td>
</tr>
<tr>
<td>Conceptualisation</td>
<td>: We are examining the nature of the problem.</td>
</tr>
<tr>
<td>Specialisation</td>
<td>: We have found its place and are getting familiar with it.</td>
</tr>
<tr>
<td>e) Normalisation</td>
<td>: It's not so different or unusual after all.</td>
</tr>
<tr>
<td>Integration</td>
<td>: Maybe it can be managed in the normal health, welfare and educational provisions and facilities.</td>
</tr>
<tr>
<td>f) Optionalisation</td>
<td>: This can be handled in many different ways, each with benefits and problems. To provide several options gives the best chance of suiting individual needs.</td>
</tr>
<tr>
<td>Individualisation</td>
<td>:</td>
</tr>
<tr>
<td>g) Reconceptualisation</td>
<td>: The whole thing can be seen in ways quite other than we at first thought.</td>
</tr>
</tbody>
</table>

4.3.4 Government officials, local politicians, and many other people involved with planning and implementation, may find their current personal and official viewpoints reflected somewhere in the above two tables. For example, some people become fixated on 'quantification', so that "nothing can be done until 'precise data' is known about the number and type of disability". Yet such data is not in fact known even in the Nordic and North American countries where they have vastly greater resources to discover such facts. Plans must be made with rough estimates, and may embody several apparently conflicting concepts. The tables above do not solve any problem, but they indicate something of the complexity of information in the disability field, and may be useful in understanding differences of approach between collaborators.
4.4 How information spreads

4.4.1 Many sorts of information are spread among Afghans through at least four overlapping mechanisms:

a) Person to person  
  e.g. Shopkeepers / shoppers  
  Barbers / clients  
  Health clinic staff / patients  
  Dais / clients  
  Mothers / daughters  
  Fathers / sons  
  Older relatives / younger relatives

b) By formal and informal groups  
  e.g. Men at tea shops  
  Teacher / students  
  Students in playground  
  Women at ceremonies (e.g. weddings, feasts, religious occasions)  
  Jirgas/Shuras  
  Informal meeting at the mosque, the bath-house  
  Story-tellers / audience

c) Public address  
  e.g. Maulvi at mosque / anyone in reach of loudspeaker  
  Posters on walls  
  Cloth posters, hung or worn on person

d) Mass Media  
  e.g. Radio / listeners  
  Television / viewers  
  Newspapers & magazines / readers

e) Specifically chosen media  
  e.g. Videocassettes / viewers  
  Books, pamphlets / readers  
  Audiocassettes / listeners

4.4.2 There are virtually no reported evaluative studies of how disability information spreads among Afghans, whether in Afghanistan or in refugee situations. It may be assumed that all the above methods can play their part, though not every method would be appropriate for every sort of disability-related information. It is unlikely that men with disabilities would discuss their problems of sexual functioning at the tea shop, or that the question of early stimulation of blind infants would be on the agenda for a regional shura. A proposal that the design of all new public buildings should incorporate access ramps might however come before a shura or other public deliberative meeting.

4.4.3 During the coming years in Afghanistan, every field of reconstruction and development will be seeking to discover the most appropriate channels and media for spreading information and changing attitudes. The 'disability' field is unlikely to have the funds, clout or expertise to lead the way in these respects. Most probably, the following strategies should be adopted:

  a) Examine and benefit from studies already reported / in progress /
being planned by Government/NGOs in the health, education and communications fields. (The only detailed, recent study seems to be the valuable work of the medical/social anthropologist Pamela Hunte, 1991, not as yet formally published, a draft of which was discovered at a late stage in the preparation of the present report; which, happily, seems to support the points made here). Much of these results will be relevant to disability information and awareness.

b) Discover what studies are being planned, and infiltrate some disability elements into the investigations.

c) Add disability messages to existing or planned health/education/vocational information programs.

d) Target highly strategic groups. For example, mass media workers spend their time producing and broadcasting/publishing material every day to the millions. If these mass media personnel are convinced of the importance of including disability-related information in whatever they do, they can make a massive contribution, in three ways:

(i) by disseminating specific information about disabilities and their management;

(ii) by including people with disabilities casually, as part of the population, as people who have views and news and talents (and who also happen to have a disability);

(iii) by programs/items intended specifically to help viewers/readers to shift their own attitude towards the positive.

4.4.4 Some information/awareness studies are listed in Appendix A. Their findings are suggestive in some respects, but overall they illustrate the fact that every aspect of socio-cultural life and communication in Afghanistan is in a state of rapid evolution, and that aid agencies are mostly working with only a superficial grasp of these realities.

4.4.5 One report, for example, notes that half of the dais under study had learnt their profession from their mothers, and many of them were actively teaching it to their daughters (Hunte & Sultana, 1984, p.9). But another report notes that the influence of older female relatives on younger women is changing and perhaps diminishing, because there are many fields of knowledge opening up about which the older people are seen by the younger to be poorly informed (Murphy et al, 1992, pp.11-12). A few studies note that a modern experiential, student-centred approach was being experimented with in some schools, while the bulk of teaching is done in traditional ways. Some studies recommend the Maulvi as a medium of communication, but doubts have been expressed as to his effectiveness for health messages that need to reach women (Murphy et al, 1992, p.23). Poster campaigns may be useful for some messages. Hunte (1991, p.73) did not find any memory of large, wall-painted EPI posters in Kabul, but large, durable cloth posters on mine awareness seem to have been more effective (p.75). Probably any poster has a reducing impact over time, until it serves only to reinforce a basic 'brand image'. One study cautions that if the posters are to be used in mosques (which is considered a strategic location), the messages should be written rather than pictorial.

4.4.6 There appears to be substantial variation in points of view about different media, and on questions such as the access of women to
information communicated by the mass media. Video cassettes in some places are associated with pornography, since they are the standard medium for this sort of diversion. Elsewhere, both videos and television are considered dangerous media by some people, but are seen by others as useful and powerful means of acquiring needed information (McGrane, 1990, pp.8-23).

4.4.7 Experience is already being won, and mistakes are being made and paid for, by agencies developing health and education services, as well as agricultural extension, mine clearance etc. It is not necessary for the disability field to repeat the clearly reported blunders of others. The time spent recovering from a serious blunder is invariably much longer, and the damage far more costly, than the amount of time and expense involved in studying other people's information efforts and in small, local pilots and pre-testing.

4.4.8 Apart from development and reconstruction workers, there are local businessmen and politicians who are keenly interested and knowledgeable about communications media and influencing public opinions. Disability service developers usually call on businessmen only to ask for donations of money or goods; and on politicians only for grants-in-aid or personal influence. If these members of the community were asked first to give the benefit of their experience in terms of communications and attitude change, they could feel themselves more personally involved, rather than being treated merely as sources of money or power.

4.5 Disability information - Awareness gap

4.5.1 Previous reports and recommendations for Afghanistan, first in the health field since the 1970s and later in the disability field, have stressed the needs for information, information materials and information awareness:

"Lack of information represents a more serious barrier to improved health than does the lack of availability of services." (A Field Survey..., 1975)

"Fundamental to successful VHW training was the development of a simple, appropriate training curriculum designed to train literate villagers. A set of three manuals was developed (in the Dari and Pashto languages) to assist the VHW in learning basic skills and in performing necessary curative and preventive tasks in the village. By using the manuals, the VHW could 'look up' anything he was unable to remember." (Solter & Cross, 1981)

"Needs. 1) lack of data or appropriate information management. This includes collection of baseline information regarding project justification as well as ongoing program evaluation... 2) Lack of cross-referencing, monitoring and survey information...... (J. PLAN: 1) Information management..." (McDonnell, 1989, pp. 2, 4)

"Information, comprising knowledge (theoretical information) and skills (practical information) is at the heart of rehabilitation strategy. This has often not been adequately recognised..." (Miles, J. Visual Impairment and Blindness, 1990, 86:262-265)
"The Study Group identified a number of problems in the areas of policy and planning, education and training, and management of Human Resources for Health. It also noted the underlying causes of these problems, which include:
- inadequate data definition
- lack of relevant information
- poor coordination of available information
- inadequate methods of analysing and presenting information
- insufficient or unsuitable research
- inadequate matching of information and research to decision-making needs
- poor communication...."

(WHO Study Group, 1990, p.45)

4.5.2 Despite this sort of recommendation, the practical information gap in the disability field in Peshawar in June 1992 appears in the following:

- Substantial lack of awareness, among disability-related workers, of existing information resources in English, Dari and Pushto, as evidenced in a spot survey (Appendix C);

- Comments such as "Yes, of course we have developed a skills training curriculum in Dari, but it's not something we could show anyone else, it's not in printed shape, we photocopy bits and pieces...";

- Curricula for training Afghan health workers and teachers have either a small 'additional' section on disability, or nothing at all;

- Mild embarrassment among disability personnel, with the tacit view "Yes, we ought to do more about information, but it's a question of time, there's no budget, besides most of these people can't read, the existing material is not very good so not much use is made of it, it's not a high priority ..."

4.5.3 This apparent lack of information awareness, the absence of 'information-mindedness', among people already engaged in the disability service field, indicates that there is much work to be done 'at home', before success can be expected with awareness campaigns 'in public'. Looking at experiences in the field of Primary Health Care (PHC) development, which tends to be 10 or 15 years ahead of community-directed disability service development, it has taken many years to reach the point (now) where the health field is being reconceptualised in information terms. So it is unlikely that the disability field will suddenly 'log on' to the information world, but there can be little doubt that this is the direction in which planning and development must go. It can be expected to happen much more quickly, because the PHC experience is there to be learnt from; and because the 'information revolution' of the 1980s is becoming institutionalised and is entering the basic mental processes of the rising generation of planners and developers.

4.6 Language/concept factors

4.6.1 An awareness of the pitfalls of translation, the difficulty of cross-cultural translation of concepts and of medical/social anthropology, is not common among collaborating agency staff. Translated material is
seldom independently back-translated, or even very seriously field-tested. Health (or disability) information material that has been got 'just right' in English is most unlikely to sound 'just right' when translated into Dari or Pushto, or even to sound anything like the Dari or Pushto that Afghans use in everyday discourse. To achieve the latter desirable result, the efforts and skills of several people over months or even years may be required, depending on the length and complexity of the information to be transferred.

4.6.2 In the present report, it is regretted that no evaluative comments appear on the Pushto and Dari information materials in Appendix A. This defect must not be allowed to down-grade the status of the available Pushto and Dari material. On the contrary, it is strongly recommended that a searching appraisal of this material should be made by Afghans with experience in the disability field and with the necessary language competence, and that their views should weigh heavily in decisions about the priorities for translating further material - or writing fresh material conceived in local languages.

5.0 RESOURCE CENTRES

5.1 Information in, Information out

5.1.1 It is intended that collaborating agency offices in the various target areas should progressively grow into Disability Resource Centres (DRCs). The essence of a DRC is that it gets many sorts of information in, sorts it and stores it, and gives many sorts of information out. This is a vital role, especially where 'information' develops beyond merely 'bits and pieces of information' and takes on the fuller meaning of 'concepts, knowledge, skills, design'.

5.1.2 A properly functioning DRC will have detailed and regularly updated pieces of information on, for example, what formal services/help/aids are available, in the shape of hand-outs which may have been printed or photocopied (depending how often they need updating). Obviously, it will stock the sort of information materials listed in Appendix A, section A, i.e. skills-related materials in several languages and at several levels of depth and detail, for hand-out or on loan or for photocopying at cost.

5.1.3 Beyond this, the DRC should develop a counselling service, where person-to-person information exchange takes place - according to Hunte (1991, p.48), "the major means of communication among Afghans is through simple word-of-mouth" - supplemented by written and visual materials. There should also, progressively, be a 'self-education' section, where interested persons can watch rehabilitation videos, listen to audio-cassettes with slide sequences and build up a broader knowledge across the disability field. These types of materials should be brought in for use in regular staff training/refreshers/seminars, but should also be available to anyone with reason to access them.

5.2 Disabled People's participation

5.2.1 Ideally, a local Society of Disabled People should be closely associated with the developing DRC, and may perhaps share premises, use
information equipment, and have some consultative part in the management of the developing DRC. The Peshawar-based FWSAD (Free Welfare Society of Afghan Disabled) hopes to develop and coordinate an information service "for disabled people, by disabled people", through a structure of largely voluntary local sub-committees. One of the stated purposes is to "save the community some of the millions of man-hours and transport costs currently wasted by disabled persons and their families in fruitless travels here and there in search of authoritative information".

5.2.2 It is unclear at present whether FWSAD will be able to implement its idea, and whether it will do so in collaboration with existing organisations within Afghanistan. However, the idea is certainly going in the right direction. It is also quite possible that funding for a counselling / information service / resource centre may more easily be attracted by an organisation of disabled people, or an organisation constitutionally controlled by (if not exclusively consisting of) disabled people.

5.2.3 There are also certain sorts of information that will be known almost exclusively by Afghans with disabilities, as a result of their personal experiences. Resource centres should make every effort to support and value this repository of knowledge, and facilitate its deployment in counselling roles.

5.2.4 The formation of an Organisation of Carers - whether parents of disabled children or people caring for severely disabled adults - should also be encouraged / facilitated, where possible. In other countries, such bodies have been strong campaigners for finance and for practical assistance. (Their views do not always coincide with those of Disabled People's organisations) It is not clear what the possibilities are in Afghanistan for such organisations to take firm root in the cultures and social structures. However, Radda Barnen animators report at least one active interest group of parents, among Afghans in the North West Frontier.

5.2.5 A pro-active DRC, with a body of interested disabled volunteers, will gather and supply information relevant to the reconstruction/redesign of public services in its area. It will, for example, campaign for physical access to banks, post office, main shops, public reading rooms, and will demonstrate to head-teachers how their schools can become more user-friendly to children with disabilities. This sort of activity takes time and personal effort, which might be considered beyond the duties of titled staff - but not beyond the scope of local disabled volunteers. The type of activity suggested is probably new in most parts of Afghanistan, but in principle there is no reason why it should not gain a measure of success, provided the supplied information makes good sense and has a moral appeal.

5.2.6 The DRC should, of course, itself be a case of concrete good information, incorporating good design features and displaying relevant aids, equipment and information materials in an attractive way. This is unlikely to be the case at the start, where donated or loaned buildings may be far from ideal in design. However, even the worst-designed building will have some opportunities for improvement, and as such may carry a greater credibility than would a new, purpose-designed building. (The latter often looks and feels too unlike anything normally encountered).
5.2.7 Good, locally-serviceable, information-handling equipment should be a high priority at the DRCs (depending on the electricity supply position). Each DRC should, as a minimum, have a photocopier, micro-computer with letter-quality printer, filing cabinets, display racks, and probably basic video equipment. Afghan mujahideen living in mountain deserts used sophisticated modern weapons, learning from zero to full operational use, because they were highly motivated to do so. The weapons of peace can also be sophisticated, and can be made to work. (It is also possible that specific countries might be interested to send in equipment for this sort of purpose). Ideally, the operators of modern information technology at the DRC should be disabled people - as a permanent visual advertisement that disabled people can handle the modern world.

5.3 Feedback and exchange

5.3.1 The Disability Resource Centres should engage in systematic collection of feedback from all their participants/clientele. This can be done by short, semi-structured interviews with people visiting the Centre, to elicit and record some of the following:

- How did they hear about the Centre?
- What sort of help are they seeking?
- What help are they willing to offer? (Examples: offer to take part in further information-gathering/action-research exercises; offer to make DRC facilities known to other people with disabilities; offer of material help or influence).
- feedback on information given to the client by the DRC on a previous occasion, e.g. an information sheet: was it understandable? useful? capable of improvement?

5.3.2 These questions need not take very much time, and the responses can be jotted down on a standard pro forma. (If it is felt that it would take too much time to engage in this exercise, data can be taken from every second, third or fourth client). Over a few months, DRC staff will in any case build up their own impressions of how the DRC is perceived by the public, and how the information is being received - and the semi-structured interview records will help to support or balance this picture.

5.3.3 DRC all-staff meetings should review regularly (e.g. quarterly) the quantity and quality of information/feedback being gathered, and may then re-direct the questions accordingly. This is not something over which staff should be too much pressuered. Some will be more enquiry- and information- minded than others. Some professional staff may feel that they have little or nothing to learn from 'the public'; while other staff may feel quite unconfident about their ability to respond to information-seekers' questions. How soon, and how successfully, the staff acquire an 'information' frame of mind will depend to a large extent on the Office/DRC leadership.

5.3.4 If the DRC director is not particularly experienced or competent in the information field, while some other member of staff is experienced, then responsibility for setting the pace on information may be delegated to
this person, who should then act as a trainer/mentor to all the other staff, developing their information skills and awareness.

5.3.5 The interface between professionals' skills and their clients' needs is often quite unsatisfactory, to all parties. The onus is on the professional to improve the interface, to be more user-friendly, to communicate more effectively, to be more accessible. As far as possible, all staff should from time to time engage together in information exercises, such as review of materials and preparation of a revised version of some material. Here, clerks, drivers and other less-educated staff can play a very useful role - they are likely to be better judges of what the 'ordinary person' can understand, whether in language or illustrations.

5.3.6 Even in well-organised centres, there is likely to be some waiting time, during which clients have nothing to do but sit on a bench until someone can attend to them. This time does not have to be wasted time. The waiting area should have a variety of information on the walls, whether posters or racks/wall-pouches, and the furniture lay-out should be such as to encourage exchange of information between clients. These things do not have to be left to chance - some lay-outs and some display arrangements are clearly better than others at promoting information use and exchange.

5.3.7 In due course, a lending library of information materials, aids and educational equipment for children with disabilities, should be built up. The priority stock should be the things that clients most often ask for - which can be known by maintaining a record over a period of several months.

5.4 Some motivated clients

5.4.2 Experience in existing DRCs in other countries suggests that there is a wide variety of people within the community who are already motivated to receive certain sorts of disability information. They include:

- parents/grandparents of a disabled child;
- brothers/sisters of a disabled person;
- adults and children with disabilities;
- wives and husbands caring for a disabled partner;
- staff of disability service centres
- staff of basic health units or mother and child centres;
- health, education and welfare planners;
- school teachers with disabled students integrated in their classes, either casually or deliberately;
- community leaders, advisors, maulvis, politicians;
- journalists and other mass media workers;
- students of medicine, public health, social work, psychology;
- traditional practitioners e.g. hakims, dais, bone-setters.

5.4.3 Among all these clients, there may be differences of language, education and intelligence; and differences in the amount of previous information they have received. Initially, a DRC cannot expect to have information materials that address every situation and level, but this should be a long-term goal. Again, this can be attained only by keeping some brief note of information demands that were not fulfilled, or were inadequately met. Only by doing so can the DRC identify, over a period of time, what materials it should be preparing as a priority.
5.5 Using Independent Channels

5.5.1 Many people who need disability information never reach a DRC. They may never have heard that it exists, or it may be too far away, or there may be social restrictions on their possibilities for travel, or their problem may be too embarrassing for them to risk a face-to-face meeting, or they may simply be unaware that information exists that addresses their need, or they may believe that they will have to pay more than they can afford for the information, or there may be many other reasons. But there also may be many other channels through which some of these people can be reached with useful information.

5.5.2 Apart from the possibilities offered by the mass media, the following are some of the organised public service channels which may be interested to have a stock of disability information materials, and which could also refer clients to the DRC:

- Health Institutions: District Hospitals, BHUs, MCH clinics; EPI program; Public health training schools;

- Social Welfare Agencies: Voluntary welfare organisations, e.g. Red Crescent, Islami Khidmatgar, Family Planning Organisation; Orphanages, women's welfare homes;

- Educational Agencies: Schools and colleges; Teacher training institutions; Kodakistans (kindergartens);

- Local Government: Urban and rural local councils/shuras (or whatever system comes into force);

- Religious organisations: Local maulvis; neighbourhood zakat committees;

- Publishers & Bookstores: (Although not 'public service' agencies in the same sense as those listed above, the commercial publisher and bookstore represent a valuable independent channel for spreading information, at least in cities).

5.5.3 The DRC should draw up a short inventory of such agencies in its catchment area, and pro-actively prepare and offer a selection of suitable material to them, taking note of the response and modifying the approach accordingly. In addition to being potential channels, all the above-listed agencies are likely to need, for their own internal use and planning, more disability information than they have. They may not be aware of their own needs however. The greater the strength and depth of information the DRC accumulates, the better it will be able to work pro-actively, arousing awareness in public bodies by presenting them with material that both reveals a short-coming and shows how it may be remedied.
6.0 STUDY DESIGNS

6.1 Indigenous knowledge

6.1.1 The study topic "Indigenous formal/informal mechanisms for rehabilitation services and traditions" is an interesting and potentially useful general topic, to which some introduction is given in Appendix B, 'Disability Information in Afghan History'. It may best be approached by seeking information at several levels and from various sources, which can be built together subsequently.

6.1.2 Several possible lines of approach may be 'offered' to staff working at different levels and in different agencies, and to interested persons in local communities, so that people may choose one or more aspects which they feel they could usefully follow up.

6.1.3 The purposes of studies should be to facilitate the spread of practical, useful knowledge and skills, by discovering what already exists, what obstacles may be presented by false or questionable information and practices, and what are the channels of communication by which traditional and informal rehabilitation information are transmitted and made accessible.

6.2 The field under investigation

6.2.1 Assuming a 2% minimum level of perceived disability, among an Afghan population of 15 million, there would be 300,000 people with disabilities, among whom 150,000 might be assumed to be over 20 years old, and 150,000 under 20. Numbers in each broad category of disability may be 120,000 physically disabled, 60,000 blind or visually impaired, 60,000 mentally retarded, 60,000 deaf or hearing impaired. Among those perceived as blind or deaf, a higher proportion are likely to be in the older age-groups, while among those perceived as mentally retarded, a higher proportion may be under 20. Male/female ratio may be assumed to be 50/50. An unknown proportion of these people, and a further unknown number of other people, will also be suffering from appreciable psychological disturbances.

6.2.2 Any of these assumptions and figures can be challenged and adjusted at will, without making very much difference to the present field of study, which is more concerned with practical, qualitative aspects of disability, care and daily living.

6.2.3 A further assumption is that, on average, three females and one male take some daily part in the care of each of the 300,000 persons with disabilities, i.e. a total of 1,200,000 carers. (If the assumed level of disability had been, for example, 10%, i.e. including large numbers of people with mild impairments, the average number of carers would be much lower, though the absolute number might be rather higher). For the infant, child or youth with a disability (2% level), the most prominent carers are likely to be some among mother, sisters, grandmother, aunts. For the adult and elderly, the most prominent are likely to be some among wife, mother, sisters daughters, nieces. The males involved may be father, grandfather, sons, cousins. Some proportion of people with disabilities may manage almost entirely with self-help skills, while others may need help with almost all their daily living activities.
6.2.4 'Care' given to children is likely to consist of feeding, dressing, washing, toileting, socialisation, teaching language/communication/speech, with some adaptations to the child's disability. 'Care' for adults/elderly people may consist of help with taking food, dressing, washing, toileting, and psychological needs e.g. company, cheering, and facilitating occupations.

6.2.5 It would be interesting to gather data informally to test some of the above assumptions, e.g. who actually gives what care to what category of disabled person, involving how much time, what activities and what level of skills, with what male/female and age-group differences. A pilot study could begin at any of the service-giving centres, in Pakistan or in Afghanistan, with two or three simple questions, either to the 'next 50 clients'; or if it is felt that this would take too much time, to perhaps the 5th and 10th client on each day over a month - depending on client inflow and time available. (Even with a very informal pilot study, some care can be taken over sampling, e.g. taking the first two clients each day could be much more biased hour-wise than the 5th and 10th). Results of this sort of small, informal pilot may suggest the lines along which a more formal study could be undertaken, and how much staff time and effort it would be likely to involve. Adult clients could mostly answer for themselves, though their answers might vary according to whether or not some of their care-givers were present. Children are most likely to be 'answered for' by an adult care-giver. Staff conducting pilot studies would need to consider how far they wish to delve into the differences of perspective between those who 'care' and those who are 'cared for'. The studies that might be undertaken by an organisation of disabled people could produce substantially different answers.

6.2.6 Making, for the moment, the assumptions outlined above, there would be at least 1,200,000 Afghans taking some part in informal daily care-giving to at least 300,000 people with disabilities. The quantity of this informal care-giving vastly exceeds the amount of formal care-giving, whether by traditional or modern practitioners. It would be of great interest and benefit to know:

a) Who does What, How, To Whom, When, and with What Effect?

b) What are the major needs for supplementing the care informally given, as perceived by the disabled person, and as perceived by the care-givers?

c) What information do the carers have, and where did they get it? To whom do they turn for help? What information/help do they receive?

d) How do people with disabilities perceive the help/care they receive?

6.2.7 The traditional health/disability practitioners seem to be mullahs, shrine keepers, tawiz makers, dais, hakims, drug dispensers, barbers (circumcisers, blood-letters, burners, toothpullers), bone-setters, masseurs. It would be of great interest to know:

a) Which sorts of disabilities are seen by which practitioners? What concept do the various practitioners have of the different disabilities and their cure, treatment or management?
b) What do they actually do, how, when, with what effect, at what cost, and what information do they give the families?

6.2.8 Particular traditional activities might usefully be studied by their 'modern' counterpart, e.g. traditional massage, by the trained physiotherapist. Surprisingly little seems to have been done in this respect, despite Frederick Leboyer's lyrical account of traditional Indian baby massage (Loving Hands, 1977, London: Collins). Hunte & Sultana (1984, p.29) note that babies are usually given a complete massage by the Baluchi dai, and they mention other instances of massage on women (p.36) with counterparts in Afghanistan (Hunte, 1985, pp.57-8). Massage is also commonly used to ease the labourer's muscles after work in the fields. From the point of view of introducing modern physical therapy, the usefulness of traditional massage, even if sometimes crudely and over-vigorously applied, lies in the familiarisation of people with activities such as applying one's hands and pressure to someone else's body in a systematic way, and discovering how the bones, muscles and skin work together.

6.3 Sources and levels of approach

6.3.1 Information gathering can and should take place at several different levels, by people who feel comfortable in making enquiries at each level. This requires some circumspection. Hunte (1985, p.68) during her enquiries into knowledge, attitudes and practice of fertility regulation, noted that "Afghan respondents often attempted to present Western medical orientation and withheld information of a more traditional nature." This problem could be expected both with foreign researchers and modern big-city Afghan researchers. It might indicate the need for a community-defined 'participatory research' approach instead of the top-down investigation.

6.3.2 Among the 'ordinary' Afghan population. This population is unlikely to be very well informed, but enquiries could be part of a study of attitudes towards disability and towards disabled people (cf. Miles, 1983), which naturally would also survey knowledge of what is done/can be done to manage/reduce disability and prevent disabilities from ever occurring.

6.3.3 Among traditional practitioners, as detailed above (5.2.7).

6.3.4 Among Western-trained health/rehabilitation practitioners. What do they know of traditional practices? (They may have an overly pessimistic view, since they are more likely to see the 'failures' of the traditional sector. Those successfully treated by traditional methods are less likely to seek the modern sector). Do the modern practitioners see any useful practices in the traditional sector?

6.3.5 In Kabul, with University staff/postgraduates, who may have access to anthropological studies, reference material.

6.3.6 With organisations of people with disabilities, who are likely to have a different perspective on the various types of assistance offered. And among 'carers'.

6.3.7 Among the various groups and sources of opinion, there may be some who take the purpose of the study to be a 'campaign' against traditional practitioners. This should be avoided.
6.3.8 An evaluative report by Dupree (1989) provides a good example of a type of information study/production of which far more is needed. Dupree observes and lucidly describes what actually happens during her visit to a Mother and Child Centre, the games, the interactions, the important role of older siblings, the novelty of the learning process (pp.16-28). More straightforward narrative reporting is needed of what actually goes on in the socialisation of ordinary children and their introduction to new tasks and learning games. These will set the tone and pace for positive intervention with disabled children.

7.0 EDUCATIONAL APPROACHES

7.1 Mobility first; Communication later?

7.1.1 Like most disability service development schemes, the present project has begun with a heavy emphasis on physical disability and blindness, i.e. disabilities that are comparatively easy to conceptualise, and where the immediate problem is one of mobility and motor control. Most programs start in this way, because

(a) physical disabilities tend to account for 50% of all the disabilities;
(b) physical disabilities lend themselves to the introduction of aids and gadgets, which give a satisfying impression that 'something is being done';
(c) orientation, mobility and literacy for blind people all involve techniques that, while not so easy to do, are fairly easy to understand in their essence and purpose, and have been widely known for many years.
(d) deafness and mental retardation are less easily conceptualised. They are not 'visible', and when mild their effects are insidious and may not be perceived or traced back to the cause. They primarily involve problems of communication, understanding and mental process, and there are no quick and easy solutions. The main gadget that might be involved, a hearing aid, seldom gives anything like as immediate a help as a crutch to a lower limb amputee, and is a great deal more expensive and liable to break down than a crutch.

7.1.2 As a result of the above factors, people with hearing impairment or mental retardation stand in greater need of advocacy, while normally getting less. This pattern may be present in the early stages or a project, until experience, resources and community interest have built up. However, the problems of deafness and mental retardation should not indefinitely remain under vague proposals for 'integration in schools'. This may have arisen here because no refugee aid agency is currently specialising in problems of deafness or mental retardation. Several agencies have considered it, but have not found the resources to enter the field, or have realised that it would be a long, slow grind, with not a great deal to show to the donor constituency. The Radda Barnen social animators certainly encounter deafness and mental retardation in refugee communities, and should be equipped with more information to address the problems. Some progress has been made with an experimental program in Kabul (Darur, 1991) for transferring skills to families with mentally handicapped members. The ILO has also produced some booklets on sign language current among deaf people in Kabul (Sign Language, 1991).
7.1.3 Adult deaf men often manage to find companionship and communication with other deaf men, and traditionally find certain occupations, such as tailoring, which are in continual demand, are individual and do not require much aural communication. This is not to say that they have no problems - but problems may be of a lower order than those of women and children, and deaf men are in a better position to solve their own problems. Deaf Afghan women can easily become very isolated at home, being unable to seek the company of other deaf women and being largely cut off from the 'social world' of hearing women. Deaf children usually suffer very considerable socially-produced handicap, being thought of as disobedient and/or mentally retarded, and progressively losing the socialisation of language that would enable them to take their place in society.

7.1.4 Afghans with severe mental retardation suffer from the dismissive categorisation as 'simple', 'a fool', or the confusion with psychiatric illness (which may, of course, also be present as a result of the lack of family/neighbourhood comprehension of their disability). Among Afghan refugee children, there is some evidence of deep psychological trauma producing withdrawal and regressive behaviour, mimicking mental retardation or reinforcing an existing mild retardation, sometimes in association with brain damage from physical trauma and untreated epilepsy. Many children appear to be in some respects 'developmentally delayed', although there are no standardised norms against which they could be measured.

7.1.5 The notion that, with a little advice to teachers, such children can simply be swept into normal schools, and that the resulting 'socialisation' will somehow be beneficial, lacks very much practical credibility. On the other hand, a certain proportion of children with mild disabilities are already 'casually' integrated in normal schools, without any official attention being paid to their disability. The picture is somewhat confusing, but it is possible to make sense of it, as follows.

7.2 Educational integration

7.2.1 Studies in normal schools in the North West Frontier (Miles, 1985, and the literature reviewed in that study, from other developing countries) found that about 2% of children enrolled had an appreciable disability - a disability that the classroom teacher, without external prompting or consciousness-raising, had noticed and could report when asked. Further to this level of perceived disability, when audiological and ophthalmic tests were carried out on schoolchildren, between 20% and 50% were found to be suffering from defects - depending where the line was drawn between 'normal' and 'defective'. Many of the visual defects were correctable with lenses, and would result in children being able to read their textbook or the blackboard with much greater facility. Some hearing defects would be correctable with hearing aids, which have not, however, been generally available in the North West Frontier, and are likely to be even less available in Afghanistan.

7.2.2 Thus, many children gained admission to school even with some level of disability. They were then more likely to be among the 50% of children who failed to complete the primary cycle, through inability to keep up with their lessons (or from many other factors). Some families took the view that, since the child with a disability might be at a disadvantage in normal unskilled work, it was all the more important for him or her to get
as much education as possible. Others took the opposite view, i.e. that the
card was disabled and therefore it was a waste of time trying to push
her/him forward by whatever means; or that the disabled child's life would
be made unbearable at school by teasing from other children. It seems
likely that some Afg children with mild/moderate disabilities are
similar, admitted to school in 'casual, unplanned integration', and many
drop out after a year or two, with varying family views on the matter. What
benefit these children actually gain from their few years in school has not
been the subject of any reported study.

7.2.3 There is a level of 'common sense' advice and awareness-raising, by
which ordinary teachers become more capable of integrating children with
mild or moderate disabilities in their classrooms, and it is certainly
worth giving such advice to teachers, head-teachers and teacher trainers.
This advice is at the level of the WHO disability manual [see (Pushto)
Training Packages, RBTU]. It does not, however, contribute credibly
to education for children with severe mental retardation, severe hearing
impairment or severe behavioural problems.

7.2.4 The number of children with severe problems is not known, but they
constitute a substantial perceived problem in their families. The extent to
which progress can be made with them depends very much on the willingness
of some family members to acquire the relevant information and to embark on
a long-term program of home training. The essential part that the project
can play, through its collaborating agencies and embryonic Resource
Centres, is to make available substantial amounts of detailed information,
in appropriate languages. Without that, families are most unlikely to make
progress. Even with it, progress is slow and uncertain, but can
nevertheless be made.

7.2.5 Some valuable experience has already accrued of integrating blind
and visually impaired children into ordinary schools, by giving them some
preliminary tutoring, then using trained resource teachers to support them
in the classroom, with brailled textbooks. The staff involved
should be
encouraged to build on this experience, to make observations of any
existing 'casual' integration of children with other sorts of disability,
and to explore the possibilities for supporting such children.

7.3 Early childhood education resources

7.3.1 There are already more information materials available than may have
been realised. The child with severe deafness, mental retardation or
behavioural problems is, first of all, a child; and can be expected to
follow, up to a point, most of the normal sequences of childhood
development, at a slower pace and sometimes by different routes. For
families to give substantial help to such children at home, they must have
some understanding of how skills progressively develop, how to stimulate
such development, how to find alternative routes, some level of behaviour
modification, and the importance of exploratory play in the child's
development. Fortunately, there are already some information materials on
these topics, as indicated in Appendix A, section A.

7.3.2 Much of this useful information material has been prepared for the
IRC Kodakistan Education Project (KEP). The KEP has three major components:
(a) it gives a six month training in Early Childhood Education to selected Afghan women. More than 50 have graduated from this course;

(b) it assists its graduates to set up and run their own kodakistsans ('place of children' = kindergarten), for children aged 6 months to 7 years.

(c) its Resource Centre is responsible to develop suitable materials for the program, in Dari and Pushto.

Twenty or more books/booklets have been prepared and field tested in both languages, the contents of which are highly relevant also to the development and early education of children with disabilities.

7.3.3 The KEP program does not appear to have made any specific provision for children with disabilities. It has been a developing experiment since 1989, introducing substantially new concepts of learning and child development to Afghan women, and has not wished to 'overload' the program with additional complications, until its groundwork was firmly laid. (However, among the hundreds of Afghan children attending kodakistsans daily, there will undoubtedly be some with mild impairments and developmental delay).

7.3.4 For children with disabilities, the sort of early education program being conducted in the kodakistsans would be a vital introduction to the world of learning and to the normal school later on. (Much of what is now basic to early childhood education was in fact pioneered by Maria Montessori as a result of her experiences teaching mentally retarded children). The IRC KEP intends that its materials and experience should be made more widely known. The project can undoubtedly benefit from this, and should also explore future possibilities for collaboration with IRC, both in production of information materials and in adopting KEP-type training for mothers with disabled children.

7.3.5 The other local source of relevant material is the Mental Health Centre, Peshawar, which has been developing, testing and publishing material in Urdu for the past ten years, and training personnel, for children with all types of disability. The MHC is not specifically an Afghan refugee aid agency, but its resources are available without regard to nationality. Most of the MHC's information materials have already been made available to the project, and some parts have been translated into Dari or Pushto.
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APPENDIX A

DISABILITY-RELATED INFORMATION MATERIALS (Annotated)

Information materials relevant to disabled Afghans exist in at least four languages - Dari, Pushto, Urdu and English - and there is no one place where all these relevant materials are collected and available.

The following bibliography records what was found (or at least reported) in June 1992 at various Peshawar locations, so that future enquirers may not start from zero. The spot study reported in Appendix C indicates that much of the existing material is unfamiliar to people working in the disability field in Peshawar. Studies from the health, communication and child development fields are even less known, though some are highly pertinent to the design of future disability services. By no means does the present bibliography claim to be exhaustive. It merely provides a base to be built upon, so that planning and service delivery may be founded on more information, and more relevant information. The annotations are the author's alone, and do not commit any organisation.

Urdu materials are included because a) if a document is available in English and in Urdu, some Afghans prefer the Urdu to read rather than the English; b) if it comes to translating material from English to Dari or Pushto, it may help if an Urdu translation can be consulted; c) as long as Pakistanis are involved in training and skills development for Afghanistan, they may prefer to work from Urdu into Pushto and Dari, rather than from English or from zero.

In many cases where a document is available in more than one language, some adaptation has taken place as well as translation, so that the new document is described e.g. as a 'version' in Pushto, Dari etc. The transliterations given here, of Pushto and Dari to English, have not been systematised but should be decipherable by anyone familiar with the relevant vocabulary.

Indexing of material in this list is by author's name, where available, and by English-language title where author's name is not available. Titles have mostly been underlined for convenience of reference, but this does not necessarily indicate that the material has been formally published.

[HERC], [RBTU], [ARIC] or [MHC] after each citation indicates that a copy of the document is held at the following locations:

HERC: Health Education Resource Centre/IRC, 84-E Rehman Baba Rd, Abdara Rd University Town Peshawar, tel. 44122.
RBTU: Radda Barnen Training Unit, 3 Canal Lane, Canal Rd, University Town, Peshawar, tel. 43905.
ARIC: ACBAR Resource & Information Centre, 2 Rehman Baba Rd, U.P.O.1084, University Town Peshawar, tel. 40389.
MHC: Mental Health Centre, Mission Compound, Dabgari, Peshawar, tel. 211289.

NE (a) Some documents may be held at all four locations, but this is not necessarily indicated here.
(b) All 5-figure telephone numbers are liable to change.
A) DISABILITY-RELEVANT SERVICE / SKILLS MATERIALS

AMAN, QAMAR (1991) (DARI) Pattern Book for Toys for Children 6 months to 7 years, (Kitiak bozichahah barai atfal 6 maha - 7 sola). Peshawar: IRC Kodakistan Education Program. 35pp. [ARIC]

Produced for IRC's Kodakistan ("place of children" = kindergarten) early education and learning through play program. Toys from simple and primary materials, with illustrations. (See note under LEMON, C.)


BRITISH BROADCASTING COMPANY (1989 onwards) Weekly PUSHTO broadcasts on health topics including Coping with disability. Some audiocassettes available from IRC/HERC.

(PUSHTO) Child Care Course (Da Mashoom de Paliney Course) (1989) (PUSHTO version with illustrations; English version, text only), Peshawar: GTZ Pak-German Bas-Ed. 260pp. [HERC, ARIC] DARI & URDU versions also available.

Early childhood development material is relevant for families with children having developmental delay/disabilities.


For families where a child is developmentally delayed (from whatever sort of impairment) a detailed chart of normal child skill development is necessary for setting appropriate goals and monitoring progress.

(DARI) Children's Games for Pre-School, (Boziha barai atfal kodakistan) (1989) Compiled by Mother & Child Centre ECETP students. Peshawar: IRC Mother & Child Centre. 12 sets (c.60pp.) [ARIC]

These and other similar IRC booklets are relevant for work with families with children who are developmentally delayed, from whatever type of impairment. See note under LEMON. C.


When looking for a suitable short book to translate into Urdu on hearing impairment and special education, this seemed the best (also chosen independently by a specialist in Sri Lanka seeking suitable material). Balanced approach between various schools of thought on education for deaf children.
Older children/peers giving health education to younger/other children, checking them for hearing and visual impairment and developmental delay, and introducing games and toys that include children with disabilities.


In a booklet on six common diseases, pp.1-4 is on polio. This reappears as pp.6-9 in (PUSHTO) The Immunisation Programme of NWFP Health Department (q.v.)

Disability and Community-Based Rehabilitation. Curriculum for 11-Day Course for CHSs and CHWs. (1989) Revision 1, Working Draft. Peshawar: Save the Children Fund-UK. 100pp. [ARIC, RBTU] PUSHTO version is available from SCF-UK, with much additional illustrative material, in photocopied pamphlet format. [RBTU]

Detailed training course material developed and tested over several years with community workers in refugee villages.


The 4th edition introduces useful modifications to the WHO CBR scheme, but unfortunately it is not widely known. Many people are still working with the rather doctrinaire 3rd edition (1983). There is useful material among the 4th edition's Training Packages, but often it is concealed amidst the repetition of primary health care slogans of the early 1980s.


A very practical manual, well illustrated, produced originally in Indonesia and suitable for other Islamic countries.


Concerning children's play, with details of games. This, together with other IRC booklets on play and early childhood education, is also in progress towards a Pushto version. Later, these booklets may be more formally published.


Plan and description of a children's developmentel play centre, with rationale and designs. (See note under LEMON, C.)


Incorporated later into the revised version of MILES, C. Special Education for Mentally Handicapped Children.


DARI: some parts transl. at RBTU, e.g. Chapter 1, What is Mental Handicap. PUSHTO: some parts transl. at RBTU e.g. Chapter 2, Causes of Mental Handicap.

Practical manual based on a decade's experience of teaching children and training teachers in Pakistan, with activities, examples and illustrations suitable to the Asian Islamic context.

MILES, M. (1986) Rehabilitation Broadcasts for Rural Areas. Peshawar: Mental Health Centre; Brussels, ILSNH. 46pp. [HERC, MHC, RBTU, ARIC]. ERIC ED 280 244. PUSHTO audio cassettes of broadcasts are at MHC. Some of this material also appears in the PUSHTO Disability and Community Based Rehabilitation Curriculum from SCF-UK, see listing). [HERC]

Broadcast to Afghanistan in 1984 as part of a Health series. No evaluative feedback. BBC Persian and Pushto service have subsequently broadcast a lengthier series on disability (See 'British Broadcasting Company...').


(PUSHTO) Prevention of Disabilities (Da mayoubiatoono mokhneway) Peshawar: RBTU. 10pp. (Handwritten, unpublished) [RBTU]

(DARI) Pressure Sores (Zakhmhai Bester) (No date given, probably 1991). Transl. by Dr Zarghoona Ubaidi. Kabul: ILO. 20pp. [ARIC, RBTU]

RADDA BARNEN TRAINING UNIT (1991/2): apart from items already listed, RBTU has some 100+ pages further handwritten material on disability in DARI and PUSHTO, produced or translated during training and orientation courses for social animators and community volunteers. These materials are at present being collated and organised. Photocopies may be available for use by other organisations.


Written on the basis of several years' experience of training physiotherapy assistants and counselling families with physically disabled children in Peshawar. Uses illustrations from Huckstep's Poliomyelitis and Werner's Disabled Village Children, with some local modifications.


Practical guide to integrate blind children in ordinary schools, based on experiences in many countries.

SATARZAI, ABDUL SHAKOOR (1991) (DARI) Rehabilitation of Disabled Persons Using Local Resources. (Bas tawanye maloolin wa mayoubin wa manabey mahali). Kabul: ILO. 18pp. [ARIC, RBTU]


Designs for baby/infant danglers, rattlers, patterns, stimulaters. Useful for early stimulation where there is developmental delay. (See note under LEMON, C.)


Efforts to formulate and codify the sign language used among deaf people in Kabul, with a basis in American Sign Language.

How to make aids for sitting, walking and physiotherapy using simple carpentry tools. Not entirely clear who would actually make and use these gadgets, involving activities and postures unfamiliar in Afghanistan. Might stimulate some people to design their own culturally relevant aids.


(PUSHTO) The Immunisation Programme of NWFP Health Department (Da Maafiat Stano Programme Da Soba Sarhad Roghteya Idara) (1988) Peshawar: HERC & Deputy Project Director Health-EPI. 29pp [HERC]

See (PUSHTO) Child's Leg is Paralysed: Polio.


Some other Training Packages have been translated at RBTU.

(PUSHTO) Training Packages for a Family Member of: 1/2. Child/person who has difficulty seeing; 3. Child who has difficulty with hearing and/or speech; 4. Person who has difficulty moving; 5. Person who has fits; 6. Guide for School Teacher; 7. Play activities to help a child develop; (18 packages altogether have been translated, by Mr Asad, for RBTU. Handwritten.)

UBAIDI, ZARGHOONA (1991) (DARI) Problems of Disability (Problem hai malooliat). (Based on part of WERNER, D. Disabled Village Children, q.v.) Kabul: ILO. (37pp.) [RBTU, ARIC]


URDU (12 booklets) Islamabad: Directorate General of Special Education. [HERC, RBTU]

DARI extracts transl. by M. Hashim Ataiee, How Can We Help Disabled Children (Chigoonah metawan atfal-e-natawan ra kumak kard) (1989). Peshawar: Sandy Gall Afghanistan Appeal. 174pp. [HERC, RBTU] Some other parts have also been translated into DARI at RBTU. PUSHTO: some parts have been translated at RBTU, e.g chapter 46, Playgrounds for All Children.

Werner's original is a gold-mine of information, based on village experiences. Further efforts should be made to translate parts of this book and to adapt the illustrations - which have not come out well in the existing Urdu and Dari versions.
DISABILITY MATERIAL REPORTED BUT NOT YET AVAILABLE IN PESHAWAR:

Some videos of training seminars concerning home-based work with mentally handicapped children are reported by ILO Kabul. Some further parts of the WHO manual have been translated by ICRC/Afghan Red Crescent, presumably into DARI and concerning physical disabilities. Other DARI booklets have been published by a Disability Resource Centre at Kabul, and some documentary films exist on disability awareness.

It is thought likely that the Physiotherapy Training Course run by the International Assistance Mission (IAM), Kabul, has generated some printed or photocopied material in local languages. The IAM Blind School will also have some brailled materials and possibly some public education/awareness material on visual impairment.

A substantial manual (? in DARI) is reportedly under preparation by Handicap International, Quetta, on physical disability and prosthetics/orthotics.

Some useful disability-related materials in Persian will undoubtedly be available in Iran, e.g. through rehabilitation service centres and colleges for training teachers (special education departments)

B) DISABILITY-RELEVANT INFORMATION / AWARENESS STUDIES


Salutory evidence was found of misinterpretation of drawings by FHWs, and the need to field test material for use by non-literate people.


Revised version produced in January 1991, following data update in late 1990. Circulated to listed organisations and through ACBAR.

Glossary of Terms Relating to Disability in English, Dari and Pushtu (March 1990 revision). Peshawar: ACBAR Task Force on Assistance to Disabled Afghans. 6pp. [ARIC]

Lists 58 common English disability terms with Dari and Pushto equivalents in both Roman and Persian script.


Detailed review of communication and the transfer of information among various Afghan groups, with a view to health education. Findings are highly
relevant to the disability information field.


Short, practical guidelines based on worldwide experience. Photographs are mostly Western but recommendations are worth serious consideration at all socio-economic levels. Includes guidelines for communications by organisations of disabled people.


Reports a startling range of surgery undertaken with rudimentary levels of knowledge - a situation typical across the rehabilitation field, though the case of surgery more dramatically claims attention. James and Winter waste no time agitating for the barefoot surgeons to be stopped; but recommend measures to give them better information.

KOLUCKI, B., MARCHAEL, K. & DUNCAN, B. (no date given) How To Improve Our Communications about People with Disabilities. Based on the recommendations of the Workshop on 'Media and People with Disabilities', February 1988, Islamabad. Islamabad: UNICEF. 26pp. [MHC]

EMPHASIZES THE LACK OF INFORMATION MANAGEMENT AND THE LACK OF COORDINATION IN TRAINING AND HEALTH SKILLS DEVELOPMENT. INFORMATION PROBLEMS OF THE GENERAL HEALTH FIELD ARE LIKELY TO BE EXPERIENCED BY THE DISABILITY FIELD IN COMING YEARS.


Detailed and useful study of male views, positive and negative, about video and TV materials. Includes discussion of communication styles. Relevant baseline for any future use of visual media in Afghan disability field.


After 7/8 years of staff training with 'cultural adaptations' of Western methods, the author began to realise the deeper conceptual differences in the meaning of e.g. 'learning', 'child'. Salutary lessons for trainers of staff for Afghan children with special needs and family counsellors.

Survey of 286 urban and rural Pakistani respondents in North West Frontier. Suggests 10 steps of incremental attitude change towards disability, and discusses public awareness media campaigns. Should be largely relevant to Afghan situation, with a decade's time lag.


Suggests common stages of attitude development in five groups: disabled people, rehabilitation professionals, mass media workers, Government officials, general public.

MILES, M. (1990a) A resource centre developing information based rehabilitation. In M. THORBURN & K. MARFO (ed.s) Practical Approaches to Childhood Disability in Developing Countries: Insights from Experience and Research, pp.261-276. St John's, Canada: Project SEREDC, Memorial University of Newfoundland. [MHC]

Development of a small local service centre into a national information resource centre, with lessons learnt on the way.


Small, low-cost, participatory studies on various aspects of disability provided an appropriate context for discussing issues and spreading information to Government and NGO health/education/disability professionals.


Useful discussion and guidelines, contrasting positive and negative messages about people with mental handicap.


Discussion and recommendations are highly relevant to the disability field now, though several years may pass before this is recognised.


Detailed, illustrated, practical guidelines based on a decade's experience accumulated in 40 countries.

Useful section on Helping Disabled People pp.279-288. Urdu and Dari versions in progress. Includes activities recommended for FHWs to do, and hints for trainers of FHWs to teach them these activities. Bibliography is recommended in the Foreword for its cultural/anthropological material, but unfortunately is missing from the publication.


Details (pp.33-49, 68-74) the extremely weak health, education, training and communications infrastructure in Wardak Province at January 1991


Describes briefly the work of social animators for self-help, mobilised by one of the DAP collaborating partners, Radda Barnen.

Child Care in Islam (1985). Cairo: Al Azhar University, supported by UNICEF. 101pp. [HERC, RBTU, ARIC]

By a working group from Al-Azhar. Sections more relevant to childhood disability are pp.5-18 on child care and pp.47-55 on child rearing.


Contains some useful insights into the ordinary living situation and problems facing Afghan children.


Broad program guidelines drawn up in May 1989 by representatives of the major UN bodies having an interest in disability, focusing primarily on the situation of Afghans living in Pakistan.


Reviews psychological problems among Afghan refugee children.

Reviews several years' psychiatric work among Afghan refugees.


Briefly describes the beginnings of a scheme for home-based training of people with mental disabilities in Kabul.


Discusses among other things the common media of communication, and survey data on their use. "Currently radio is the most underused aid to development in Afghanistan" (p.44).


Data on 3,500 Afghan disabled clients (89% male) of the Employment Support Services, from Sept.91 to Jan.92, in various areas (Kabul 80%, Parwan 10%).


DUPREE, N. (1988) Afghan refugee women in Pakistan, the psychocultural dimension. WUFA, 3 (1) 34-45. [ARIC]


Useful cross-cultural insights on interactions between Afghan women and children, and on innovations and the views of rural women.

Field Survey of Health Needs, Practices and Resources in Rural Afghanistan. Conclusions and Recommendations (1975) Kabul: Ministry of Health. Cambridge, Mass.: Management Sciences for Health. 5pp. (The first 100pp are not available, but only the conclusions are given). [HERC]

Conclusions of Survey in five areas of Parwan-Kapisa Province. Widespread use of both modern services and traditional e.g. mullahs, shrines, bone-setters, hakims, dais, barbers, dokhans.


Scholarly description of medical facilities and conditions up to 1968. Section on Poliomyelitis, p.121, said to be "imported in the 1950s and has
spread fast since then". Also p.91 on the 'Mother and Child' organisation.


Analysis of several years' data accumulated at the SGAA Clinic in Peshawar.


Tabulation of health facilities and health manpower, by locations etc.


Draws on Hunte's PhD on Afghan perinatal care. Prevention of some cerebral palsy, and early diagnosis of many impairments, rests with the dai.


Useful insights into a very personal field of female knowledge. Underlines the depth and complexity of traditional knowledge and customs. Some indications of how knowledge is communicated.


Discusses traditional health system, customs and beliefs in some detail and suggests the importance of the dai in communicating with the less educated female population. Relevant to cross-border Baluchistan.


Includes discussion of Afghan views on disease and death, also the author's perspectives on how development work may be viewed from the receiving end.


Discusses some war trauma, both physical and psychological, and the varieties of reconstructive surgery performed by Dr Iqbal.

Total of 15,533 people were seen, among whom were 763 with war-related injuries/disabilities and 1791 with non-war related injuries/disabilities. Categories are tabulated.


Study among Afghans now living in USA. Topic relevant to 'disability' in that it causes uneasiness and avoidance, and involves beliefs and attitudes about unwanted events and their possible causes and prevention. Relevant to future studies of disability knowledge, attitudes and practice.


Pertinent comments on problems with information transfer/use/management in developing primary health care in Afghanistan, and methods of overcoming them, especially pp.29-36.


This statistical survey unfortunately has only a single table on disablement, in which it appears that 15 people are disabled, out of a total survey population of c.8,854.


Proposing a minimum necessary program based on the points upon which all parties could agree, regardless of what might be the eventual political outcome. "Assistance to Disabled Afghans" (pp.63-69) appears as the first of the "Priority Health Care Programmes", with major emphasis on physical disabilities.


Survey of 262 households, in 20 villages, to determine the effectiveness of EPI program. Unable to evaluate the efficacy of polio immunisation. Report most useful in indicating the difficulties for EPI and surveillance. Brief comments on media for health education (pp.60/61).


Two recommendations remain relevant, after 3 years: (a) a workshop for Afghans in education, on possibilities for educational provision for children with disabilities; (b) Efforts to reach general planners with disability awareness, so that reconstruction plans include access and participation by people with disabilities.

Study of 104 Pakistani schools in North West Frontier Province showed that nearly 2% of pupils had a disability (noticed by their teacher, with no prior training in disability awareness). This level of 'casual integration' is likely to be present in schools in Afghanistan, and would repay study.


Emphasizes information factors, networks and needs.


Islamic and cultural background are largely relevant to Afghanistan also.


Includes data on the sources of information/advice reported by mothers (p.11-12), and some possible changes in the traditional advice-giving roles of older females. Also discusses targets for information/training, and preferred media (pp.13,23).


p.2: "[Disabled] men also ask the teacher to have patience with them, because before they were looking after goats and sheep and so [to] sew with machines is completely new to them."


Report on the Apprenticeship Scheme for Young Afghan Refugees. Out of 621 placed apprentices, 178 were disabled. For some of these "a new trade of Memorising the Holy Quran has been introduced..."


Detailed evaluation of the VHW program developed in the 1970s. Many apparent similarities with the problems and opportunities facing potential 'Community Rehabilitation Workers' in the 1990s. The whole O'Connor (ed) book has many other insights.


Discusses the realities and problems of home life for more than 1,000
Afghans and Pakistanis with spinal cord injury, after discharge from the ICRC/PRC Paraplegic Centre.


Includes a small amount of data and discussion on disability (p.3, 27-28), mostly physical disability. Notes (p.12) the particular difficulty of determining individuals' age. (This has some relevance to the perception of mental retardation).

(DARI) UN Convention on Children's Rights. Peshawar: RBTU. 2pp. [RBTU]
(PUSHTO) UN Convention on Children's Rights. Peshawar: RBTU. 2pp. [RBTU]


Sections on Health Services/KAP (p.40-47) and on Education are informative, e.g. comments on access by Afghan women to new ideas (p.52-4), Curriculum and pedagogy (p.59-62). Short section on disability (p.47-50) lacks data and is less informative.


Disability services and prospects under the UN umbrella at October 1990 are reviewed on pp.81-2, and also under Health (pp.69-80), Vocational Rehabilitation (pp.88-9) and Disadvantaged Groups (pp.90-1).


Some indications (pp.10-13) that experiences in Pakistan have raised expectations for women's social life and children's education, so that changes may come when people resettle in Afghanistan.
APPENDIX B

DISABILITY INFORMATION IN AFGHAN HISTOR Y

"Ehsan is the next higher stage after Adl in the Quranic social order. Ehsan means a condition where an individual lagging behind in spite of his best efforts gets his deficiency made good by others to restore the disturbed balance of society. This is not by way of charity but as a matter of right."

S.A. Wadud, writing in The Pakistan Times, 28/3/86.

Afghanistan was an East-West crossroads of the classical world. Even before the arrival of Islam and the 'right of the disabled individual to have his needs met, to restore social harmony', some knowledge of the scientific and therapeutic discoveries of the great civilisations of China, India and Greece would have been carried across Afghan territory by merchants, itinerant healers and pirs, diplomats and armies.

More than 2,000 years ago, the University at Taxila was a centre for medical and surgical training. Detailed orthopaedic knowledge was taught, as in the Susruta samhita [1]. Rhinoplasty was well known. The Mauryan emperor Ashoka (3rd century BC) is recorded as having set up hospitals for the treatment and accommodation of disabled people [2]. Ashoka's edicts engraved on columns are still found in parts of Afghanistan [3], the northern limit of his empire. The Indian Laws of Manu also made some provisions for the maintenance of people with disabilities, though these were accompanied by some less enlightened provisions [4].

The Royal Code in ancient China provided maintenance for disabled people of various categories [5]. Blind musicians were well established as an occupational category in China, providing music at court as well as elsewhere. Massage by blind persons was also well known in ancient times. Detailed knowledge of massage and the body's sensitive points was well established in China some 2,500 years ago [6]. Parts of this knowledge have been filtering westward along trade routes ever since. The Chinese used iodine in seaweed, and thyroid extracts, in the 6th century CE to treat goitres [7]. This knowledge had travelled through to Europe by the 12th century and must have been available at many places in between, but without lasting effect until much later [8].

Medical knowledge spread northwards and eastwards from Greece, to which Afghan hakims still trace their ancestry. This knowledge would at some time have included the view of Hippocrates that epilepsy was not 'sacred', nor a matter of possession by a djinn, but a disease to be treated by careful observation, the adjustment of diet and environment, and certain drugs [9]. Historically, this view did not overcome the 'djinn' theory, either in Afghanistan up to now or in much of the rest of the world until the 20th century.

Civil pensions were also granted to disabled citizens in some of the Greek city-states [10]. There is no clear evidence that provisions such as this, or those of China, India and Sri Lanka, in fact influenced people in Afghanistan, but there can be little doubt that the knowledge of these customs and practices was transmitted and recounted in Afghanistan between 1,000 and 2,500 years ago. Therapeutic knowledge would always have been of value to people who were often
at war, and whose survival depended on keen sight, hearing and physique.

Later, when Islam carried the torch of knowledge and development throughout the Middle East and Central Asia, enlightened measures were used at Baghdad to treat mental illness [11]. The Islamic Jurists of the 10th century CE debated the civil rights of mentally retarded people in detail, embodying an attitude of much more serious attention than the traditional dismissal of the 'fool' [12]. This debate must also have been known to the savants of Afghanistan.

Much disability information has been known by a few people at different points of Afghan history. However, the knowledge and therapeutic skills have not been institutionalised - very little has been written down or recorded in permanent form. There appears to have been little or no handing-on of knowledge by formal training of practitioners. Local healers have passed on their skills to their sons and daughters, but the transfer has not been monitored for quality, and there have been no mechanisms for expanding and testing knowledge and skills.

Some blind people have achieved standing in their communities. Dupree shows a photograph of a blind singer of epic poetic history, accompanied by a blind musician, and also records the lengthy rule of Khurasan by Shah Rukh, who had been blinded at an early age by a rival [13]. Another traditional occupation for the blind man has been to memorise and recite the Holy Quran, taught by the local mullah. The perception seems well established, that a blind person can be a 'community bank' of knowledge and skill. He may even become a distinguished teacher, as was Zain-Din al Amidi, professor in the university of Moustansiryeh (Iraq), whose system for identifying his books and notes antedated Louis Braille by some five centuries [14]. On the other hand, the Pakhtun view of the helplessness of the blind man, on matters of vital concern, appears in the cynical proverb, "The blind man entrusted his wife to (J'od".

People with physical disabilities may traditionally have been perceived in a different way. Serious physical trauma, loss of a limb or paraplegia, would often have led to death from shock, bleeding or infection. Milder physical disability would have been understood simply in its own terms - a man might use only one arm, or might walk with the aid of a crutch, and so be unable to fight, but could take part in the power games of social life with little or no communication problem. Childhood physical disability is now largely contributed to by poliomyelitis, but apparently this has arisen only in the past 40 years [15].

The British surgeon Pennell, nearly a century ago, noted the skill of village women in sewing up their wounded warriors, using hairs of their own head and ordinary needles. He was less enthusiastic about the quality of bone-setting. However, Pennell may have seen a disproportionate number of 'failed' cases that had to be turned over to Western skills, while the bone-setters' successes were happily running about, uncounted [16]. Concerning the prevention of disabilities, Pennell also noted that "the custom of inoculation was at one time almost universal in Afghanistan", whereby the crust of a smallpox sore was rubbed into an incision on the wrist of the person being inoculated, producing usually a mild infection and consequent immunity. This was, however, a risky business, and Pennell added that "the people have not been slow to recognise the great advantage which [Jenner's] vaccination has over inoculation".

As compared with blindness and physical disability, people with deafness or mental retardation have in most societies posed problems of communication and therefore of understanding 'what is wrong', and of apprehending what might be
done to manage the problem [17]. The Pushto proverb "Amongst the blind, one deaf man plays the leader", which Thorburn includes among 38 proverbs on "ignorance and foolishness" is hardly flattering to any of the parties [18]. Pennell in fact used to see lines of blind men arriving for treatment, gripping one another, led by one who still had a little sight [19].

It is not clear how far mental retardation occurs, or is noticed, in traditional rural communities such as those in which most Afghans have always lived. Child mortality in rural Afghanistan still probably exceeds 30%, and will have been higher in earlier times, as it was in Europe. Children born with severe or multiple disabilities are likely to be heavily represented in this death toll. Those with much delayed development are less likely to survive in the often harsh conditions of daily life, especially if they were female. On the other hand, the folklore of the region does not lack in stories of the sort that begin "There were two brothers, one of whom was clever and the other very stupid..." [20].

Mental retardation and slowness of wit used to be a public problem only when the son of a ruler was thus disabled, and could not be relied upon to learn statecraft and inherit his father's kingdom. Such a problem befell an Indian ruler, some time in the early centuries CE, whose sons were 'blockheads'. One of his courtiers undertook to teach the princes, and compiled a book of animal fables, now known as the Panchatantra. This book, the earliest known collection of material for special education, was translated into many languages of the region, and stories from this collection appear among the folk tales all across Asia and Europe [21].

These brief glimpses of ancient and traditional disability information are intended to counter the idea that "nothing is done for disabled Afghans" or that modern knowledge is being brought to a people living in total ignorance. On the contrary, the recognition of current and traditional knowledge is the only sound basis for establishing new practices.

References


19. Pennell, op cit, p.91

20. Thorburn, op cit, e.g. pp.193-201, 207-211.

APPENDIX C

ACBAR DISABILITY TASK FORCE SPOT SURVEY

The following questionnaire matrix has been used as a frame to show the total of crosses (X) made in each box by 20 respondents at the ACBAR TASK FORCE ON DISABILITY on 27 May 92.

[Please mark X in the right box, if you have a copy of each item listed, or if you have seen it but do not have it, or if you have never seen/heard it.]

<table>
<thead>
<tr>
<th>There is a copy of this at my home or my workplace</th>
<th>I have seen it, but do not have a copy at my home or workplace</th>
<th>I have not seen/heard a copy of this book or material</th>
</tr>
</thead>
</table>

1. DISABLED VILLAGE CHILDREN (English, Hesperian Foundation) 12 0 8
2. [ ] DARI EXTRACTS from Disabled Village Children, SGAA. 10 1 9
3. REHABILITATION BROADCASTS FOR RURAL AREAS. (English text, Mental Health Centre) 3 1 16
4. PUSHTO AUDIO-CASSETTE of Rehabilitation Broadcasts for Rural Areas (M.H.C.) 2 6 12
5. COMMUNITY BASED REHABILITATION OF THE RURAL BLIND. A TRAINING GUIDE FOR FIELD WORKERS (English text, Helen Keller Interntl.) 5 3 11
6. [ ] URDU VERSION of Community Based Rehabilitation of the Rural Blind. 6 2 12
7. SURVEY OF HEARING & SPEECH PROBLEMS IN AFGHAN REFUGEE CHILDREN: Rene Dupont (NCDS) (French) [0] [1] [17]

Totals (ignoring bogus item No.7) 38 13 68

- 48 -
Discussion

The above 'spot-check' survey has no formally constructed sample - it was taken among the 20 people who happened to attend the Task Force on Disability at ACBAR office on 27. May. 1992. Among these people, one or two have been in Peshawar for only a few weeks, while others have been involved in Afghan and Pakistan disability work for several years. Several of those present were specialists in disability therapies, several were trainers of social animators covering a range of welfare problems, several were program administrators. At least two respondents were themselves disabled. Six were Westerners, one African, at least six Afghans, at least four Pakistanis. The common factor was that all have an interest and involvement with Afghans and disability. The survey results therefore cannot in any sense be conclusive. They may, however, be suggestive of the current level of distribution and awareness of relevant disability information material among a group known to be interested.

The questionnaire was administered in English, without prior notice, so the results depend on the comprehension and memory of the respondents. Several participants were seen helping one another with translation of the English questions - though all present could be assumed to have some understanding of spoken English, since that is the customary language medium of the Task Force.

Some respondents may in fact have seen parts of the material referred to, but did not recall it by the title given. On the other hand, item no.7, which does not exist, was 'recalled' by only one person, who later explained that there had been some sort of survey of Afghan deafness conducted earlier by SERVE, and he had thought item no.7 must refer to that survey. This bogus item was included as a quality check, because some respondents might be inclined to claim more knowledge than they in fact possess. (The questionnaire was filled anonymously, to avoid any possible embarrassment).

There should have been a total of 140 crosses, but respondents left three blanks (one against no.5, two against no.7) so the total was 137 crosses. Ignoring bogus item no.7, there were 119 crosses. Of these, 38 (32%) claimed to have a copy at home or at work; 13 (11%) claimed to have seen, but not to have, a copy; 68 (57%) believed they had not seen/heard the material. There was a broad range of claimed knowledge/access. Three respondents stated that they knew of none of the material, three others had access to all but one item, while the remainder fell somewhere in between.

Item No.6 in Urdu was perhaps not strictly relevant to Afghans and disability, but it has been the author's experience that some Dari-fluent Afghans prefer to read Urdu than to read English. One of the minor purposes of the survey was to draw attention to the availability of disability information material in local languages. Thus, only three original works were named, with versions in Dari, Pushto and Urdu. Ideally, the survey should have reached beyond print and audio-cassette, to cover a range of visual materials. However, it was felt that a single-page questionnaire would be best suited for a quick on-the-spot response.

Items No.s 1-6 have all been available in Peshawar for at least one year, some of them for as long as six years. One might hope that in each organisation concerned with Afghan disability, new colleagues would be given (or at least shown) a copy of each item as part of their orientation to the field. Quite clearly this has not happened, although the ACBAR Task Force has been used in the past as a forum for exchange and advertisement of information materials. (Items 1-3, 5,6 are available at HERC. Item 4 is with Mental Health Centre, Dabgari).