Afghan children and mental retardation: information, advocacy and prospects

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Summary

The family and community situation of children with mental retardation (learning difficulties/disabilities) is discussed within the Afghan cultural heritage and the current realities of civil war and refugee villages. Some formal services are being developed for children with physical and visual impairments. Mental retardation and hearing impairments are comparatively neglected, as skills are lacking and progress tends to be much slower. Some casual integration occurs in ordinary schools and kindergartens, which should be supported. Experiences in family counselling can be developed and also extended by enlisting indigenous counsellors and healers. The major strategy for the foreseeable future will be support and enhancement of family resources.

Introduction

The future for all disabled Afghan children is highly uncertain, as the national political situation in 1997 continues to evolve. Their needs and family resources, whether inside Afghanistan or in refugee villages, have many similarities to those of disabled children in Pakistan's North West Frontier Province and Baluchistan, but are not identical. For much of the past 15 years disability agencies and formal resources have been based in Pakistan serving refugee villages, with experimental efforts at cross-border services. The broad, medium-term aim is the mobilization of community resources for integration, education and rehabilitation of disabled children and adults, starting in major towns and their catchment areas within Afghanistan. A multi-agency effort has been underway during the past 4 years to establish community-based rehabilitation programmes in four regions. None of the agencies involved can predict with confidence what its situation and activities will be by the end of 1997.

This paper will consider particularly the prospects for children with developmental delay or ‘mental weakness’, as it is understood by Dari- and Pashto-speakers. Terms based on ‘mental retardation’ will here be used as an inter-cultural compromise. This is the condition or disability category for which the least efforts have been made to provide formal services. The UN Comprehensive Disabled Afghans' Programme (CDAP) merely hopes for ‘mainstreaming of disabled children’, notes the contribution of a ‘high rate of birth complications’ to cerebral palsy, and admits that people with sensory and multiple impairments are a ‘much less visible group’. Mental retardation has been practically invisible in service planning. The head of CDAP recently noted that in most of Afghanistan less than 5% of all children have access to primary education, so the prospect of access for those with disabilities is extremely poor.

Amid these doubtful prospects the background of Afghan cultural heritage should not be forgotten. Islam once carried the torch of knowledge and development through the Middle East and Central Asia. Enlightened measures were used at Baghdad to treat mental illness, some ripples of which reached across the Islamic world. Muslim Jurists of the tenth century debated mentally retarded people's civil rights in detail, embodying an attitude of much more serious attention than the traditional dismissal of the ‘village fool’. This debate must also have been known to the savants of Afghanistan. Much disability information has been known by some people at different points of Afghan history. However, the knowledge and therapeutic skills have seldom been institutionalized in the best sense, i.e. recorded in permanent form, at least since the time of Ibn Sina (Avicenna, 980–1037 CE). There has been little handing-on of knowledge by formal training of practitioners. Local healers have passed skills to their sons and daughters, but the transfer has seldom been
monitored for quality, and there have been no mechanisms for expanding and testing knowledge and skills.

There is no implication in Islam that disability must result from wrong-doing, yet such an opinion is not uncommon among Afghans. Most families care for their disabled members as far as possible, but ‘the disabled person is usually confined to the house’. These impressions are confirmed in the experience of many rehabilitation workers. However, if skillfully handled, the cultural and religious heritage may serve as a foundation for modern knowledge. For greater effectiveness in the community it is useful to show that ‘modern’ approaches do not inevitably mean adoption of a ‘western’ package with elements repugnant to Islam. Traditionally, mentally retarded children have been, and still are, taken to saints’ shrines for religious healing. Such practices do not necessarily conflict with modern approaches. Shrine counsellors, as well as some traditional village healers, may actually be quite experienced ‘barefoot psychologists’, ready to dispense practical advice to clients if they think it beneficial. Where ‘modern’ resource centres take the trouble to acknowledge the practice and potential of such counsellors and healers, and to supply them with relevant information, they may be quite effective channels. They may, for example, continue to advise parents to attach an amulet (tanzf) to the child, but also to engage in a simple developmental programme, and to trust in Allah. The good Muslim seeks knowledge from all quarters. If Allah mercifully provides knowledge by which families can teach their mentally retarded child, this mercy should not be rejected.

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 very probably exceeds 30%, and was higher in earlier times, as it was in Europe. In the often-harsh rural environment, children born with severe or multiple disabilities must be over-represented in the death toll, especially if female, both through neglect and their lesser ability to demand a share of food. However, regional folklore does not lack stories of the sort that begin ‘There were two brothers, one clever, the other very stupid...’. Further, the entire population is at risk of iodine deficiency. Only in the 1990s has iodine prophylaxis begun. Undoubtedly, several hundred thousand children’s mental functioning is significantly below their potential, through iodine deficiency disorders.

Very few surveys have noted any Afghan disabilities, especially such a locally constructed, unquantifiable feature as mental retardation. However, Ovrid and Tvedt, in a brief pilot study in 12 Afghan refugee villages with 170000 registered refugees, asked community health personnel to identify children from birth to 10 years who were mentally retarded, understood as ‘incapable of age-appropriate tasks’ such as walking, or dressing self. In nine villages, 147 were identified (54 girls, 93 boys), after discounting 22 cases as over age or having only physical disabilities. From three villages none were reported. If the target age-group population was roughly 25% of those registered (estimating low, since infants 0–24 months old would seldom be identified), and compensating for traditional under-reporting of females (counting 80 instead of 54) the results suggest that around 4/1000 were locally perceived as mentally retarded. The figure is within the expected range (i.e. between 2/1000 and 7/1000) for this type of rough survey in the North West Frontier. Among the identified children, hearing problems were also reported for 33, and eight were identified as cerebral palsied.

Mobility first; communication later

Like much service development elsewhere, programmes for disabled Afghans began, and have largely continued, with an emphasis on blindness and physical disability, conditions that are comparatively easy to conceptualize, and in which the immediate problems are mobility and motor control. Programmes start in this way because:

1. Physical disabilities tend to account for 50% of all disabilities; they attract the introduction of aids and gadgets, which give a satisfying impression to communities and donor agencies that ‘something is being done’.

2. Orientation, mobility and literacy for blind people all involve techniques which, while seldom easy, are comprehensible in their essence and purpose, and have been tested over decades.

3. Deafness and mental retardation are less visible and less easily conceptualized. When mild their effects are insidious, and may not be perceived or traced back to the cause. Primarily involving problems of communication, understanding and mental process, there are no quick fixes. The main gadget potentially involved, i.e. a hearing aid, is expensive, liable to break down, and seldom gives anywhere near as immediate a help as a crutch to a lower limb amputee.

Because of these factors, and because of their own problems with communication, Afghans with hearing impairment or mental retardation need much more
advocacy, while usually getting less. This pattern exists in
the early stages of most disability programmes until
experience, resources and community interest have
increased. Unfortunately, the problems of mental re­
tardation and deafness often continue to be confined to
pious wishes and vague proposals such as ‘main­streaming’. Refugee aid agencies and in-country de­
velopment programmes seldom have specialist skills in
deafness or mental retardation. Agencies that would like
to do something have not found the resources to enter
the field, or have realized that it promises a long, slow
grind with comparatively little to show to donors. Social
animators certainly encounter deafness and mental
retardation in Afghan communities, but have lacked
appropriate information to address the problems. A start
was made with an experimental programme in Kabul for
transferring skills to families with mentally handicapped
members and assisting them to develop and implement
home training objectives. The International Labour
Organization also published some booklets following
studies of sign language among deaf people in Kabul.
These experiments remain unconsolidated, due to the
disturbed situation at Kabul in recent years, though
some renewed efforts for deaf people have begun at
Mazar in northern Afghanistan. The field remains one
of extremely low perceived priority amid the vast tasks of
achieving peace and trying to rebuild the shattered
infrastructure of Afghanistan.

Undocumented experience suggests that deaf children
usually suffer considerable socially produced handicap,
being thought of as disobedient and/or mentally re­
tarded, and progressively losing the socialization of
language that would enable them to take their place in
society. Adult, urban, 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 audible communication. It is
not that they have no problems – but their problems are
less than those of women and children. Deaf men are
also better placed to find their own solutions. Deaf
Afghan women can easily become very isolated at home,
being unable, through social restrictions on women’s
mobility, to seek the company of other deaf women and
being largely excluded from the social world of hearing

Afghans with severe mental retardation suffer from
the dismissive categorization 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 and
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
developmentally delayed, although there are no
standardized norms against which they could be
measured. The notion that, with a little advice to
teachers, many such children can be swept into the sort
of ordinary schooling available to Afghans inside or
outside their country, and that the resulting ‘socializa­
tion’ will somehow be beneficial, lacks practical credi­
bility. On the other hand, a certain proportion of
children with mild disabilities are in fact already casually
integrated in ordinary schools, without any official
attention being paid to their disability.

Casual integration

The picture is somewhat confusing, but can be
elucidated. Studies in ordinary schools in the North West
Frontier and in many other countries suggest that at
least 2% of pupils have disabilities – at a level that the
classroom teacher, without external prompting, notices
and can report when asked. Beyond this level, when
audiological and ophthalmic tests are conducted on
schoolchildren, between 20% and 50% are found to
have impairments – depending on the criteria used.
Many of the visual defects are correctable with lenses,
and would result in children being able to read textbook
or blackboard much more easily. Some hearing defects
could be helped with hearing aids, which have seldom
been available in the North West Frontier, and are even
rarer in Afghanistan. Servicing facilities and battery
supplies are also rare or non-existent.

Some children gain admission to school even with a
degree of disability. They are then more likely to be
among the 50% of children failing to complete the
primary cycle, through inability to keep up with their
lessons or from other factors. Some families think that,
since children with disabilities may be disadvantaged in
normal unskilled work, it is all the more important for
them to be educated. Others take the opposite view, i.e.
since the child is disabled it is a waste of time trying to
push her/him forward by whatever means; or that the
disabled child will be badly treated at school by other
children. Some Afghan children with mild to moderate
disabilities are in fact admitted to school in casual,
unplanned integration, and many drop out after a year
or two, with varying family responses. What benefit they
actually gain from their few years in school has not been
studied objectively. Common-sense advice and
awareness-raising, by which teachers develop skills for teaching children with mild or moderate disabilities in their classrooms, is certainly worth providing to school staff and teacher trainers. Such advice is at the level of the Dari translation of parts of the WHO disability manual.18 It does not, however, contribute credibly to education for children with severe mental retardation, severe hearing impairment or severe behavioural problems, in classrooms where a single teacher manages 60 or more pupils with traditional pedagogy. The transfer to Afghanistan of recent western trends, still keenly contested or barely adopted in many European countries, is a hazardous game.

The number of children with severe problems cannot accurately be known; but family counselling experiences at the Mental Health Centre, Peshawar, throughout the 1970s and 1980s, suggest that they constitute a substantial perceived problem in their families. Progress depends largely on the willingness of some family members to acquire the relevant information and to embark on determined home training. Possibilities also exist for community education. Currer and Currer recall, among the unexpected successes of a rural community mental health project in the North West Frontier, a ‘behaviour modification programme involving a whole village which helped a young man who was mentally retarded to gain a valued place in his community’.18 The essential part that a formal disability service development programme can play, through its collaborating agencies and resource centres, is to make available substantial amounts of detailed information in appropriate language. Without that, families and communities are unlikely to make progress. Even with it, progress is slow and uncertain, but nevertheless can be made. Some valuable experience has already accrued of integrating blind and visually impaired Afghan children into ordinary schools, by giving them preliminary tutoring, then using trained resource teachers to support them in the classroom, with brailled textbooks.11 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.

Early childhood education resources

The Afghan child with severe mental retardation, deafness 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 they must have some understanding of how skills progressively develop, how to stimulate such development, how to find alternative routes, some basic behaviour modification techniques, and the importance of exploratory play in the child’s development. These ‘basics’ already make a big package of innovations and unaccustomed concepts for Afghan mothers; and, indeed, for local teachers and health workers. Fortunately, there are some field-tested Dari and Pushto information materials on these topics.18 Much of this useful information material has been prepared for a kindergarten development project known as KEP, with three major components:

1. A 6-month training in early childhood education, to selected Afghan women
2. Assistance to its graduates to set up and run their own kodakistans (‘place of children’ = kindergarten), for children aged 6 months to 7 years.
3. A resource centre to develop suitable materials for the programme.

Dozens of 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. The KEP programme was not designed to make specific provision for children with disabilities. It was aiming to introduce substantially new concepts of learning and child development to Afghan women, and did not initially wish to overload the programme with additional complications, until its groundwork was firmly laid. However, among the hundreds of Afghan children attending daily, there are undoubtedly some with mild impairments and developmental delay. This is recognized by a chapter on special needs, in the kodakistans Resource Manual.19 For children with disabilities the sort of early education programme being conducted in the kodakistans is a vital introduction to the world of learning and to the ordinary school later on.

Another local source of relevant material is the Mental Health Centre (MHC) at Peshawar, which has been developing, testing and publishing material in Urdu and English for the past 15 years, and training personnel for children with all types of disability. Though not specifically an Afghan aid agency, it has in recent years trained some Afghans for development of disability resources and community-based approaches. Most of the MHC’s information materials have already been made available to other organizations directly involved with Afghan disabled children. Some parts, such as radio scripts on childhood disability and a manual on teaching mentally retarded children, have been translated into Dari or Pushto, and field-tested over several years. Some
MHC material has been taken up and further developed by the Radda Barnen Training Centre, Peshawar, collaborating with the CDAP. Mental retardation now occupies 4 days in a 95-day training curriculum for Afghan mid-level CBR workers. It is hardly adequate, for people working in the field with minimal technical support; but it is a start.

Conclusion

Life prospects for all disabled Afghan children, and especially those with mental retardation, remain extremely poor by urban, western standards. Realistically, improvements will take decades. For the great majority, whatever is going to be done will be done by their immediate family and neighbours, with minimal professional intervention or assistance. On the other hand the strength, ingenuity and cultural heritage of Afghan families should not be underestimated. Several million Afghan refugees have been exposed, intentionally or involuntarily, to childhood disability information available through aid organizations. Information access and distribution through strategic local outlets, careful monitoring of effectiveness, and follow-up of the more motivated families, are growing points which will support the essential indigenous efforts.

References


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