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The revised article concerns social responses to children with hydrocephalus and spina bifida in African countries, and the historical development of ways in which various resources have been used to improve their life chances, and overcome the disabling effects of these conditions.

## **CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS IN AFRICA: CAN MEDICAL, FAMILY AND COMMUNITY RESOURCES IMPROVE THE LIFE CHANCES?**

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## **ABSTRACT**

Hydrocephalus and spina bifida are potentially life-threatening conditions affecting between one and three per thousand infants, often resulting in severe disabilities. Risks are much reduced by immediate surgery and careful management, but neither has been available for most of the African population. This paper traces the growth of medical, family and community solutions and some African socio-cultural resources that historically have supported family and community care for children with severe disabilities, drawing on evidence from 24 countries, mainly Benin, Egypt, Ethiopia, Ghana, Kenya, Malawi, Morocco, Nigeria, Somalia, South Africa, Sudan, Tanzania, Uganda, Zambia and Zimbabwe. Some community-based rehabilitation (CBR) efforts with children having spina bifida and hydrocephalus are described, with challenges to the CBR approach from the increased survival of children and adults with severe disabilities requiring a complex continuum of care and opportunity. More appropriate information, recognition of indigenous knowledge, enlistment of community resources and financial assistance are needed to enhance the lives of Africans with hydrocephalus, spina bifida, and other severely disabling conditions.

**KEY WORDS:** hydrocephalus, spina bifida, neural tube defects (NTD), myelomeningocele, neurosurgery, ventriculostomy, history, social responses, attitudes, community based rehabilitation, African traditional healers, indigenous knowledge, parents, family resources, infant mortality, Benin, Egypt, Ethiopia, Ghana, Kenya, Malawi, Morocco, Nigeria, Somalia, South Africa, Sudan, Tanzania, Uganda, Zambia and Zimbabwe.

## **1.0 INTRODUCTION**

The present review and study is concerned mainly with hydrocephalus and spina bifida in African histories, traditional cultures, and current medical, surgical, and family care practices, while also visiting some broader issues of poverty, development, severe disability, and access to cost-effective services. Little formal literature has been found that deals specifically with the main focus. The review will build from a background of disparate sources. It must begin with medico-surgical management, without which few children with hydrocephalus or spina bifida survive to encounter the disabling or enabling effects of socio-cultural practices. The efforts of families and community based rehabilitation (CBR) workers will then be considered.

Hydrocephalus and spina bifida, [1] separately or in combination, [2] are serious impairments affecting between one and three infants per thousand in most parts of the world, often leading to death or severe life-long disabilities. [3] During the later 20th century the profiles of these conditions diverged sharply between Western Europe and sub-Saharan Africa. In Western Europe the incidence of live births with spina bifida has diminished in recent years through a combination of primary prevention (folic acid dietary supplements through the first trimester of pregnancy) and so-called “secondary prevention” (detection of neural tube defects [NTD] in the foetus at 10 weeks, and abortion). Babies born in Western Europe with spina bifida are likely to have operations within 24 hours to repair and protect the spinal cord defect and prevent infection from reaching the brain.

Similarly hydrocephalus, a dangerous enlargement of the head from blockage of fluid

circulation and consequent intracranial pressure, can be prevented by early detection and surgical insertion of a shunt, or surgically creating a different escape route. Meanwhile, in many African countries the achievement of reducing under-5 child mortality from a rate of around 40% in the mid-20th century to between 10% and 15% in the late 1990s has enabled far more children with severe impairments to survive and to make demands on health and education services that are hardly ready for them. Attention to women's pre-natal care continues to be weak, so primary prevention of neural tube defects is rare. Thus the differences in health provisions generate a substantially different context for West European as compared with sub-Saharan African lives having severe impairments, much before children reach the age when socially-produced aspects of disability become more apparent, e.g. difficulties of access to formal education, employment or leisure facilities.

Before turning to the life chances of Africans with spina bifida and hydrocephalus, some hazards facing all African infants and children must be stated. Among 1,000 newly born African babies in 2006, between one and three may have spina bifida and/or develop hydrocephalus. Although the survival rate has improved as noted above, it is highly likely that among the 1,000 live babies 140 will die within five years, though less than 20 have serious impairments at birth. Of the 140 who die, at least 110 could be saved by well-known, basic, low-cost practices. For various reasons these are not being used effectively by families, communities and governments (Brockerhoff & Derose 1996). Arguably, further major social, educational and economic changes are needed. These are the kind of adverse odds that every African baby needs to beat. [4]

The situation in more affluent European nations is strikingly different. The 142 /1000 Under-5 Mortality Rate [U5MR] for Tanzania in 2003, with a per capita annual GNP of US \$290, contrasts with 4 /1000 in Norway, having per capita GNP of \$43,350 dollars (UNICEF 2005). Improvement in the African U5MR from the 1960s to the mid 1980s had levelled out, or significantly reversed by the mid 1990s (Ibid., pp. 141-145). The AIDS pandemic is expected further to cancel out efforts to reduce the U5MR or to worsen the rate, according to recent UN/UNICEF/UNAIDS data. Urban, middle-class African families have a much higher female education rate, better infant nutrition and hygiene, and a much lower U5MR than the regional average; but they are a small, modern, 'minority culture', diverging from the dominant regional pattern.

## **2.0 HISTORICAL SKETCH**

Hydrocephalus and spina bifida have existed in Africa since antiquity. Egyptian and Nubian evidence for hydrocephalus between the 1st century BC and 6th century CE has acquired greater prominence (e.g. Derry 1912-1913, and discussion by Nunn 1996, 79-80; El Batrawi 1935; Armelagos 1969) perhaps because enlarged skulls are an archaeological signal of immediate and obvious human interest; yet pitfalls of interpretation have been detailed by Richards & Anton (1991), who doubt some claims to have identified hydrocephalus. [5] Spina bifida in African antiquity has attracted less attention, yet evidence of it has been found in more than half of 133 skeletons in Tatoralt Cave, North Eastern Morocco, during the period 10,000 - 8,500 BC (Ferembach, 1959 & 1963; Ferembach et al 1962; see also Kuttner 1978). [6] Spina bifida was also recently found at Bahariya, Egypt, dating to c. 1600 BC (reported by Charon 2005).

Surgical treatment of skulls took place more than 10,000 years ago in Africa by trephination, also called trepanation, i.e. boring and scraping holes in the skull, apparently to relieve headaches or pressure caused by head wounds, as documented by Dastugue (1959; 1962, pp. 138-139, 158, + plate V), with later evidence in Margetts (1967) and others. Khamlichi (1996) reviews mainly North African literature, and provides historical extracts on hydrocephalus from Abul Qasim (936-1013 CE), whose work spread to North Africa from Spain. Trephination continued into the 1990s in East Africa, following traditional safety rules, i.e. protection of the brain and its membranes, and avoidance of suture lines (Grounds 1958; Furnas 1985; Nunn 1996, 168-169; Rawlings & Rossitch 1994). Attention to the infant fontanelle has also figured prominently in traditional health care in the region (Gelfand et al. 1985; Nunn 1996, p. 50). It is important to recognise this 10,000-year background of African knowledge, culture and surgical practice. Ojiambo in 1966 noted the “widespread belief in certain areas of Kenya that the indigenous medicine man (‘witch-doctor’) has superior healing powers in respect of neurological disorders.” Neurosurgery using modern European skills and knowledge within Africa is a comparatively recent experiment of which the long-term directions remain uncertain. A leading neurosurgeon from Zimbabwe finds “a general strong desire for neurosurgery in Africa to be developed using first what is available locally, then what is available in Africa and only then to turn to the world at large” (Kalangu 2000). [7]

## **2.1 Slowly Developing Observations and Services**

Moving toward more recent history, European physicians noticed occasional hydrocephalus in South Africa (Livingstone 1858, 202) and spina bifida in Ethiopia (Mérab 1912, 52-53). It is possible that some neurosurgery took place for these conditions before 1920 by general surgeons as occasion arose, with whatever skills and materials they could muster. Early ‘casual neurosurgery’ has not been closely studied in the present article, but some documentation may exist. Organisations for the benefit of “crippled children” were beginning in South Africa in the first two decades of the 20th century. An historian of orthopaedic surgery notes that, in this period, “Among the lower-income groups, tuberculosis of the spine and extremities was endemic, poliomyelitis and chronic pyogenic infection to bone and joint were a scourge, and there were other intractable conditions such as congenital anomalies, spastic paralysis and rickets” (Dommissie 1982, p. 2).

In the 1920s, some general surgeons in Africa were operating on these conditions where they could, using methods current in Europe at the time. Beyers (1927, reprinted 1976) reported on the “principal surgical conditions occurring among 18,000 Bantu in-patients of the Johannesburg Hospital between March 1921, and March, 1926”, tabulating 7 cases of hydrocephalus, and “Meningoceles, common”, then confirming that “Hydrocephalus and meningoceles, both cranial and spinal, are fairly common.” Interest in the 1920s in Nigeria is indicated by a description of a neonate with spina bifida, in the national yearly medical report (Wilson 1924). As soon as the West African Medical Journal began publication, an article appeared on “affections of the spinal cord and meninges” in Nigeria (Wynne Davies 1927), though this concerned young male adults. Khamlichi (1996) notes the start of neurosurgery within colonial general surgical services in North Africa from the 1920s on, and separate, dedicated neurosurgery services beginning mostly in the 1950s and 1960s. [8] Khamlichi locates to Egypt the commencement in Africa of dedicated modern neurosurgery, but the Egyptian surgeon El Gindi (2005) offers the palm to South Africa, on the return of Hermann

de Villiers Hammann from Germany in 1946. Hammann's obituary recalled his "single-mindedness, his Teutonic medical approach, and his constant adoption of the latest methods of neurosurgical treatment" (Keet & van Niekerk 1975). Published reports on neurosurgery and neurology in North Africa began to rise between 1930 and 1950, e.g. with notes on a case of spina bifida and hydrocephalus in Morocco by Maurice Bonjean (1936). In East Africa, Kampala saw an early survey of neurological conditions in 1940-1942, including two cases of hydrocephalus (Muwazi & Trowell 1944), but neural tube defects were comparatively rarely seen. Among 2,068 consecutive newborn babies at Mulago Hospital, Kampala, 1956-1957, two had hydrocephalus; in none was spina bifida noticed, and earlier hospital records of 5,498 babies showed only two with spina bifida (Simpkiss & Lowe 1961; similarly Hutton 1956).

## **2.2 Early 'Third Ventriculostomy'**

Jarvis (1949 & 1951) at Nairobi, Kenya, described current surgical options and their problems in developing countries, reporting briefly on his four operations on hydrocephalus c. 1949, and two more by 1951, using closed third ventriculostomy. This aimed at a minimally invasive, strategic puncture to achieve the disposal of cerebro-spinal fluid without need of a shunt. However, to locate correctly the point of puncture, without effective endoscopy, was a delicate affair. Some guidance was had from injected dyes and radiography, but success still depended "entirely on a keen sense of touch, backed up in the first few cases by a certain degree of courage on the part of the operator" (Jarvis 1951). Jarvis, was surgeon in charge of an Ear, Nose and Throat clinic, and was undertaking a survey of "deaf and dumb children" at the time, to see if a special school was needed for them (Notice, 1950). He also had the courage to invite East African practitioners to send children with hydrocephalus to Nairobi so that third ventriculostomy "may be given an extended trial"; but no further published report on this has been found. Third ventriculostomy was tried with four Kenyan infants having hydrocephalus by a later ENT surgeon, reverting to the frontal approach first described by Dandy in 1922, but results compared unsatisfactorily with those obtained using five other methods (Clifford 1963). Some decades would pass after Jarvis's report, before developments in imaging and ventriculostomy enabled East African surgeons to understand more clearly what was going on inside the head, reflected in more substantial surgical success. [9]

## **2.3 Ethics & Survival**

Interest in ethical issues concerning spina bifida was rising among South African professionals in the 1960s. David Chapman (1963) at Durban reviewed 164 cases of spina bifida from 1955 to 1962, noting that almost all were in the neonatal period and most were expected to die in their first year. In the blunt terms of the time Chapman asked, "If then only a few mentally retarded cripples are expected to survive, why not give token treatment and secretly hope that the mite will die?" (*Ibid.*, 86). In fact, Chapman rejected this position and took a positive view, seeing these infants as "a challenge ... to our moral standards, to our ingenuity. They cannot be discarded." He also recognised that

"The baby is a source of exceptional anxiety for the parents. How are they to manage the sac, ulcerated, weeping cerebrospinal fluid, and likely to rupture? They are constantly reminded of their guilt. The burden is heavy. One parent may reject the child while the other shows special love. The outcome of treatment involves the clinician in complex moral and ethical tangles."

Chapman's successors at Durban reviewed 193 cases from 1963 to 1969, weighing the

prospects for the majority who reached the hospital more than a week after birth, mostly with severe paralysis. Prospects were very poor. Aftercare was extremely weak as home conditions seemed to the surgeons to afford neither the time, the knowledge nor the means (Henry & Mickel 1974). In the same period, 1965-1967, results with 166 African children with hydrocephalus treated at Johannesburg were characterised as “disappointing” by Beck & Lipschitz (1969).

The surgeon’s job was to operate; but even the delicate probing and cutting inside the brain was dependent on an immediate series of other people’s work in preparing instruments, anaesthetics, and maintaining sterile conditions, which in turn assumed a background of specialised knowledge and training, dexterity, personal hygiene, attention focus, and similar qualities in dozens of people, not all of them directly under the surgeon’s supervision. Yet beyond that, unless perinatal care was modernised, with home-delivering midwives sending neonates promptly for specialist attention, and families being followed up with appropriate aftercare, the surgical teamwork seemed to be pointless. Similarly disappointing observations were made on 153 children with hydrocephalus seen between 1961 and 1970 at Salisbury (now Harare, Zimbabwe): 123 had shunts inserted, 20% survived, 63% died (17% were not traced). The surgeons concluded frankly, “There was no evidence that surgery was of statistically significant benefit” (Seligson & Levy 1974).

These surgeons understood the problem for families to “bring their infants from outlying districts on infrequent, time-consuming and expensive transportation for clinic visits, during which frustratingly little seemed to be done.” They also noted that, “The poorer the parents, the less likely are they to be able to provide reasonable, safe conditions for the child or to have the money to return the child to hospital if the [shunt] valve blocks.” (*Ibid.*, 358, 359). Certainly, families were not indifferent to the impairments. A review of childhood neurological problems in Kenya, 1969-1970, noted that nearly a quarter of all children admitted had hydrocephalus and spina bifida, and “These malformations are very distressing to the parents ... Limited resources here in Kenya preclude any heroic treatments” (Oduori & Shah 1973). Results seeming more positive were reported between 1971 and 1974 at Khartoum, and from 1979-1982 at Cape Town, perhaps due to technical progress in surgery (Aziz 1976; Peacock & Curren 1984). Yet the resource limitations noted by Oduori and Shah were a dominant factor in most African countries. Okeahialam (1974), reporting on congenital malformations at Dar es Salaam, also realised that patterns of morbidity were likely to change over 20 years, with childhood deformities achieving greater prominence, creating further ethical dilemmas in budget priorities.

During the 1970s, surgeons at Ibadan, Nigeria, saw a rising demand for spina bifida surgery, though Adeloje remarked that “malformed children” born outside hospital were “never voluntarily reported by the parents; such infants are likely to be concealed or neglected” (Adeloje 1971; Olumide & Adeloje 1980). Adeloje (1989, 155) sometimes took the pragmatic view that where the child with spina bifida was brought late to hospital, already with limb paralysis, it was reasonable in Africa conditions to delay surgery a little further: “After some months, the fittest survive and operative closure can be considered” on several grounds, parental wishes being among them. Later, Mezue & Eze (1992) at Enugu, Nigeria, offered reasons for accommodating parental wishes: “a visible deformity is culturally and religiously unacceptable ... The belief that people may reincarnate with the same abnormality necessitates removal of any abnormal swelling, even when the chance of survival is poor. In

this context a well-formed limb that is not functional is not regarded as an abnormality, whereas hydrocephalus is definitely abnormal and the family insists on having it corrected.” Socio-cultural research once again underlined the importance of family factors in managing spina bifida in Nigeria, as will appear below. Changing socio-medical viewpoints also enter the equation. Using modern equipment and techniques among a uniformly poor clientele, surgeons in Cairo, Egypt, somehow accommodated scientific, humanistic and fatalistic points of view:

“The outcome is far from being satisfactory in the sense of producing an ambulatory, intelligent healthy individual, especially in a meningomyelocele patient having a high-level lesion. The authors believe that there is still much to be done for these children marked by fate...” (Assaad et al. 1989).

## 2.4 Recent Neurosurgery

**It must here be emphasized** that the present account of surgical developments and modern options is merely a broad sketch based on the published work of paediatric neurosurgeons who describe a highly complex and fast-moving field. There are conflicting expert interpretations of the significance of the detailed data. The sketch aims to present some background and trends in a comprehensible way, without plunging into confusing detail. No surgical, administrative or parental decision should be based on so broad a sketch. Specialist advice must be obtained, taking in the particular, local details.

Moving forward to neurosurgery in Zimbabwe in the mid 1990s, the list of procedures and electronic equipment is now more impressive, as is the local design of a cheap and effective valve for hydrocephalus. Yet some factors have not changed: results are good “particularly in children of more educated mothers”, but for rural children with hydrocephalus, “the long-term results are disappointing, with a 20% mortality rate” (Kalangu 1996). Expectations have obviously risen since the 1960s, when 20% was the rate of post-surgery *survival*, rather than of mortality. Results with spina bifida at Zaria, Nigeria, also improved through the 1990s, but “selective management” was still found necessary because the lack of facilities made care and rehabilitation difficult; the burden of care was heavy for most families, and “in consequence that child receives little attention” (Shehu et al. 2000). The first paper reviewed in the new millennium, from April 2001, surveys infant hydrocephalus in Central Africa and notes that “Patient selection for shunting as practised in Malawi and Zimbabwe is not favoured in Zambia”, apparently as a result of parental protests against discrimination (Adeloye 2001). Professor Adeloye noticeably makes more reference to the thoughts, feelings and practices of parents than in earlier papers noted above. His frank comment also appears on the variety of “neurosurgeons, paediatric surgeons, general surgeons and clinical officers” having a go at ventriculo-peritoneal shunting in Zambia. “The technical skills vary in these disparate groups” (*Ibid.*), with the result of a higher rate of repair or adjustment operations.

In his major survey of African neurosurgery, Adeloye (1989) made no direct mention of third ventriculostomy; but in 2001 he discusses recent improvements in neuroendoscopic technology which might suggest that third ventriculostomy for hydrocephalus could have a revival in East Africa, fifty years after Jarvis’s reports of it in Nairobi, but now with vastly more effective instruments, technique and an evidence-based theory of ventricular functioning. Such a revival has indeed been started in the past five years by Warf (2004, 2005a, 2005b, 2005c, 2005d) and colleagues. Warf describes a carefully monitored beginning

of paediatric neurosurgery at Mbale, Uganda, in 2001, building a clientele and database of over 1000 mostly very young children, among whom 550 received endoscopic third ventriculostomy (ETV) by late 2003, while most of the others were given appropriate shunts. Attention is given to lower operating costs, and further procedures are described that have improved outcomes. Training and updating of African surgeons is also under way. An international prospective study has now begun to assess in a rigorous way the value and efficacy of ETV as compared with shunting (Sgouros et al. 2006), though it is unclear how far this can take account of some African factors, or more broadly the evaluation of methods appropriate to regions with high levels of serious poverty. [10]

## **2.5 Parents' Voices and Issues of Access**

Until recently, the voices of parents and local communities have been practically absent from the development of medical and surgical treatment for hydrocephalus and spina bifida, though they have slowly begun to make some impact on public and professional awareness of their difficulties in raising children who survive (see below), with or without surgery. [11] Not surprisingly, it is the more educated, urban parents who tend to be the first to have the confidence to speak out, and to command the medical professionals (Oyewole et al. 1985; Adeloje 2001; Gallagher & Stratton 2001). As such parents are also better placed to understand and afford home after-care for their child and the return visits to the urban hospital for check-up or shunt revision, they may be the natural allies of Africa's neurosurgeons, at least for one kind of development policy. Understandably, neurosurgeons prefer to expand dedicated neurosurgery departments, in the endless hospital battles for budget priority, beds, operating theatre time and expensive equipment, and in fierce competition with all the other surgical demands. Yet they may be pressurised to cooperate in devising strategies to increase rural community access to all kinds of specialisms, in the national struggles over priorities in health policy, e.g. between expenditure on one highly specialised regional referral centre, or on larger numbers of local referral hospitals with broader competencies, or on still greater numbers of rural health centres, or on a complete reversal of the pyramid with a bottom-up approach of basic health education and primary care to empower (or at least, to try to force) the mass of the population to take responsibility for their own health, nutrition and living environment. [12]

While these various policy trends and waves have been rising, flattening or falling at different times across Africa, specialisms such as neurosurgery were trying to get themselves established, and perhaps to formulate extension policies that would be plausible within the changing local and national balance of skilled and semi-skilled resources, along the spectrum from Primary Health Care to the magnificent urban 'disease palace'. To reconstruct how this worked out for neurosurgery in different countries is beyond the scope of this article, if it is possible at all; yet some broad points can be made. Despite the longstanding efforts of 'barefoot neurosurgeons', i.e. Africa's trephiners, it is clear that actual brain surgery is not something that community health workers can do a little bit of, at a basic level, under any modern, government-approved health scheme. On the other hand, where there is no neurosurgical unit, some general and paediatric surgeons in referral hospitals across Africa have continued to undertake some basic neurosurgery, with or without further specialist training and updating, with or without the most appropriate equipment and techniques, saving some lives, avoiding some life-long impairments, and getting into difficulties with some more complex cases. Adeloje (1989, 13) rather pointedly recalled a "daring neurosurgical attempt" by a thoracic surgeon in Ghana in 1968, before neurosurgery was adequately

established there. That attempt was “more celebrated for its bravado than brilliance.” Some of the less-specialised neurosurgery has probably been appropriated by neurosurgeons as they became available; but their availability remains very thin outside urban South Africa and the North African countries. Some neurosurgeons will have spread the load and increased the available skills by inservice training and supervision, so that non-specialists had more competence to continue with routine neurosurgery, to better interpret scanned images and know when cases were liable to complications, and to weigh up the comparative risks in doing urgent but difficult work themselves or in sending a patient on a long journey to a specialist (Kalangu 2000). Others may have preferred to give a full neurosurgical training to a few, whom they could supervise and equip properly, rather than multiplying a modest level of skills and appearing to bless risky procedures in hospitals ill-equipped for them.

### **3.0 CULTURAL AND FAMILY RESOURCES**

The brief sketch above suggests some progress and some large gaps, e.g. between traditional and modern treatments, between operating theatres and home care by families, between family hopes and the difficult decisions of surgeons managing with limited resources, between the services available to the urban middle class and to the mass of rural and urban poor, between ‘care’ alone and care that gives opportunities for growing responsibility and self-care. Behind the visible gaps there are also significant differences in cultural perceptions of health, wholeness, value of life, ethics of resource distribution. Rather than discussing the vast topic of these gaps and differences, some efforts to bridge the gaps will be considered.

#### **3.1 Recognising Indigenous Knowledge**

Europeans with a strong faith in ‘modern medicine’ have often dismissed African traditional treatments; but some earlier medical professionals saw enough to generate a measure of respect. On trephining, a visitor in 1962 noted that “The West Kenya Medical Department have cautiously recognised this specialty”, practised among the Kisii (Coxon 1962). Practitioners were liable to the full rigor of the law if their patients died, which seldom occurred according to a British monitor in the 1950s (Grounds 1958). Such reports were part of a tradition of European ‘cautious recognition’ of African surgery and medicine during four centuries, in contrast to the sad tradition of European contempt for all aspects of African cultures [13]. The African past need not be idealised as though all indigenous practitioners had access to wonderful knowledge. Yet the great leprologist Stanley Browne was hardly being romantic when he recalled that in the Congo around 1940, “I learned my clinical leprosy sitting between a cannibal chief and a cannibal witchdoctor - and good teachers they were, pointing out scarcely visible differences of skin surface that I should not have noticed unaided” (Browne 1980, 76). Browne realised that these men had a lot to teach him.

Even where this is recognised, modern neurosurgeons are hardly likely to invite trephiners into the theatre to try their hand with hydrocephalus! Yet some traditional healers could certainly advise on how to talk to rural mothers about post-operative home care in such a way that the mothers understand what is needed and are motivated to do it using their existing resources. From Tanzania, Feierman (1986) described the type of village healer who  
“stood at the juncture between two worlds: the world of concerned lay people - the patient’s relatives and neighbours - and the world of specialised practitioners.  
Relatives and neighbours lacked specialised knowledge; practitioners lacked intimate

understanding of the patient's household. Hamisi combined the two. He therefore served as a gatekeeper. He often sent patients and their relatives to the hospital or to specialised healers."

The need for such bridges became apparent in the same researcher's detailed field study of medical beliefs and theories in rural Tanzania, underlining the complexities, with narratives "filled with uncertainty at every level: uncertainty about the status of expert knowledge, about how the body works, and about the likelihood of isolating one possible disease-cause from amongst many." (Feierman 2000). This sounds similar to the status, at the research level, of western medical beliefs and theories. One might compare another neurological battlefield, i.e. the complex constructions of epilepsy in East Africa, the apparently sharp contrast in Swaziland over issues of contagion and contamination (Whyte 1995; Reis 2000), or indeed the searing, graphic tale of a family in search of understanding, relief and cure for its epileptic member, via official and unofficial channels, in 'modern' France, 1964-1994 ("David B." 2005).

The support of people with bridge-building skills and local authority would clearly be an asset to any 'modern' health and disability services. The strengths of traditional healing resources have been reported extensively by Gordon Chavunduka, Professor of Sociology at the University of Zimbabwe, who has also been president of the national association of traditional healers. He notes that much of their practice "is concerned with prescribing preventive remedies", and instances the herbal baths used to protect neonates (Chavunduka 1994, 77). Peltzer & Kasonde-Ng'andu (1989) have also described ways in which traditional practitioners can assist Zambian families with disabled children.

Some unattractive or damaging sides of traditional practice cannot, however, be overlooked. For example, Greco & Antoniotto (1988) describe from Somalia eleven cases of hydrocephalus in children aged 3 months to 7 years, treated in hospital at Mogadishu by modern European surgical methods. Interviews were also conducted with relatives, and with some traditional doctors. It was learnt that children showing signs of hydrocephalus (*madaxwein* = big head) were first taken to a religious practitioner for traditional therapy using Qur'anic verses worn as amulets, or where the ink has been dissolved in water; secondly, a traditional Somali doctor used red-hot wooden sticks to produce small burns on the scalp. The aim of both procedures was to drive away the evil spirit believed to be causing the head swelling. For the modern medical personnel, the amulets were not a problem; but the cauterisations, with some subsequent local infections or complications, presented a serious and continuing hazard to children's health. Similarly, for another congenital abnormality with cranial problems and multiple symptoms, Adeloye (1989, 105-107) showed a patient whose "feet had been burnt to stimulate the child to walk (though he did also, pp. 360-361, mention African use of cautery as a legitimate pain-control procedure, citing one of Egypt's pioneer neurosurgeons, Sorour et al. 1972).

Rasmussen (1989) described the beliefs of some Tuareg village people in Niger, on the occurrence of spina bifida cystica in a baby girl, seen there in 1978. It was explained "in terms of the mother's lack of modesty". Allegedly the mother, while pregnant, had shamelessly allowed a non-related man to see and admire her hair at the back. Her bun of hair now 'reappeared' on the back of the baby, and the feature was referred to not by words signifying a swelling or an ugly lump, but as 'lack of shame'. That she belonged to a noble family made the infringement graver. However, the ready identification of fault in the mother

apparently did not prevent some villagers from asking their visiting anthropologist if she knew anything about the baby's abnormal appearance, "what it was, and whether it could be cured". Control over women's lives also appears in one traditional West African explanation for hydrocephalus. In a survey on female circumcision in Nigeria, a 'reason' given for the practice was that "contact between the clitoris and the baby's head might give rise to congenital hydrocephalus, and consequent infant death". The associative link with swelling appears in another supposed reason, i.e. that the clitoris may swell during childbirth and obstruct the delivery of the baby's head (Badri 1984).

### **3.2 Spectrum of Religious Resources**

African religious or traditional 'beliefs' or 'superstitions' have routinely been linked with many of the social and medical problems of hydrocephalus and spina bifida, by people of modern, scientific outlook (who are not always aware that their own 'rational convictions' may appear implausible or ridiculous to people of different cultural background). There has been increasing documentation of formal religious beliefs, as well as customary, traditional beliefs, connected with disability in Africa [14], among which a few points will be sketched. Some of these beliefs may be seen as 'modern' and 'positive' by rehabilitation therapists, others appear unattractive or neutral. It can hardly be doubted that serious and unexpected bodily events, such as spina bifida and hydrocephalus, will continue to be interpreted in some kind of religious terms by many family members in Africa (as in every other continent) for the foreseeable future. Some awareness of the range of religious terms and resources is advisable if health and therapy workers wish to enlist families' best efforts for ongoing care and increasing participation in everyday life.

Some ancient Egyptian experiences of disability have religious affiliation, as in the case of the dwarf god Bes (Dasen 1993); and also in an anencephalic neonate with spina bifida found in the Touna el-Gebel graveyard, near Hermopolis, dated perhaps between 300 and 600 BC. Dasen & Leroi (2005) describe in some detail the curious 'animal' interpretations placed on this neonate, and how a 19th century theory of foetal development arose from its spina bifida. They suggest, however, that the ancient Egyptians probably found in the abnormal remains a more elevated significance in the religious cosmology. Manniche (1991) considers that Egyptian musicians who were blind (or who were represented as such) were for this reason allowed to perform 'in the presence' of deities who must not be gazed at by humans. A notable theologian of the early Christian church was Didymus the Blind, who became a famous teacher at Alexandria, having learnt his letters by a tactile system engraved in wood (Lascaratos & Marketos 1994). The early tradition of blind musicianship was continued in the Coptic Church to the present (Ragheb & Roy 1991), and was paralleled in the Muslim era by blind reciters of the Qur'an and of religious songs across North and West Africa (Dodge 1974, 44, 86-87, 101, 165, 206; Haafkens 1983, 5-9, 29, 32, 42-43, 47-49). The major Christian theologian Augustine lived and worked in North Africa, and c. 389 CE gave probably the earliest surviving statement from antiquity that clearly recognises the reality and depth of signed communication between deaf people and between hearing and deaf people (Augustine, transl. Russell 1968, 13). In the Orthodox and Coptic churches in Ethiopia and Egypt, deaf or disabled people are believed to have had their impairments removed through the ministry of famous saints expelling harmful spirits, in medieval times (Life of Takla Haymanot, transl 1906, I: 95-101), and up to the present (Meinardus 1999, 97-110, 151-154). There are similar beliefs about the healing powers of Muslim holy men, past and present, at shrines across North Africa.

Traditional African religious belief includes some cosmologies where disability is linked with divine action. Among the Yoruba of West Africa, the deity Orisanla (Obatala) is believed to be responsible for making people's physical bodies, as "Blacksmith of heaven. / Husband of hunchback. / Husband of lame. / Husband of dwarf with a big fat head" (Abimbola 1994). The Wagogo of Tanzania also have a cosmology in which efforts to collect fire from heaven (for peaceful purposes) are thwarted because those seeking it did not respond properly to disabled people they met on the journey. Eventually a woman made the trip, displayed kind and inclusive behaviour to disabled people, and also got along well with God. She brought back fire (Cole 1902). Credo Mutwa (1998, 5-41) recounts the origins of physical imperfections among the Bantu peoples of southern Africa, as part of a creation story. Some of these systematic beliefs are not so different from what can be discovered e.g. in European folklore, with perhaps an apparent thread of logic that makes it easier for the modern European mind to grasp.

Other beliefs involve a way of thinking that is harder to follow. Helander (1995, 83) for example notes ailments among the Hubeer in southern Somalia where "although the locally recognized symptoms may correspond to those recognised by medical science, the meaning of the illness is totally different. A good example of that would be *walkoraad*, which phenomenologically corresponds more or less to hydrocephalus but is locally believed to be caused by the shadow of a bird." Among the Songye of Eastern Zaire, beliefs about children having some abnormality take the form of categorisation into 'ceremonial', 'bad', or 'faulty' children, not according to what European science might consider the severity or visibility of the impairment, but on some other lines. In the strongly stigmatised 'bad' category, are "albino, dwarf, and hydrocephalic children", who are expected to die soon (Devlieger, 1995, 96). Gbodossou (1999) sketches some analytical categories that might act as a bridge between West African and francophone European thoughts and beliefs concerned with impairment.

### **3.3 Families Coping at Home and in the Community**

Historically, home management of children with severe impairments and disabilities has had little sustained observation and careful reporting in African countries. However an interesting early example is recorded from archaeology at Wadi Halfa, in Sudanese Nubia, concerned with 'X-group' population, dating between 350 and 550 of the Christian Era. In a study showing links between nutritional deficiencies and morbidity risks facing mothers and children in earlier ages:

"A final way that this linkage has been demonstrated is by the skeletal evidence for care of a hydrocephalic child. This child X-group lived until the age of around 10 although a quadrapelegic [*sic*]. It is clear s/he was cared for in a meticulous way and that this care had an effect on the distribution of resources and labor in the group. What this example so clearly reminds us of is that disease is not an isolated event, but is one that affects families and larger social groupings." (Goodman & Armelagos 1989, 238-239). See also [15]

From rural Ethiopia in the 1840s, a striking picture is preserved of local rural community behaviour toward a mentally retarded man. He was observed by Mansfield Parkyns (1854), who travelled rough around the country, wearing local dress, sleeping on the ground, eating local food. Parkyns befriended a man named Merratch, who was "usually accompanied by an

idiot, named Maghovai, - a poor fellow whom he took about with him as an occasional source of amusement.” Maghovai suffered much harassment from the boys of the neighbourhood, who would goad him until he flew into a rage and engaged in some crazy actions. Parkyns offered to try to cure Maghovai if he could have him for a while, to which Merratch agreed. Parkyns engaged in a textbook program of behaviour modification, rewarding desirable behaviour step by step, while at the same time working a change in public behaviour: “I forbade any one to laugh at him, or speak to him otherwise than to a sensible person. Even when he made any absurd mistakes in the little jobs I set him to do, I punished severely any of the people who might happen to titter.” Under this regime, Maghovai “became quite steady and tolerably reasonable”. Merratch was then shown how to continue Maghovai’s treatment, which he did successfully, according to Parkyns (1854, I: 276-278).

The earliest 20th century series of recorded observations was probably that by Hugh Stannus reporting on people with various impairments seen during his travels as Medical Officer in rural Nyasaland (Malawi), 1907-1914. He saw “no typical case” of meningocoele, but one possible spina bifida occulta (Stannus 1914). Stannus saw no home management of severe childhood disabilities, presumably because “It is the custom among all the tribes of this country to destroy deformed children at birth”, and the under-5 mortality rate in that era would also probably have been around 50%, carrying off most of those with early acquired impairments. This harsh rural environment could be contrasted with the story of a deaf, blind and physically impaired Zulu infant called Radcliffe Dhladhla, who was cared for by his mother Rhoda in the 1920s while she worked as a maid in Durban. Rhoda learnt from a hospital doctor that Radcliffe’s mind was working, so she should encourage him to do whatever he could. (In Britain at this time, a similar mother would probably have been advised to put the boy into a care institution and forget him). Rhoda followed the doctor’s advice for eight years before handing over an active, inquisitive lad to Florence Blaxall for more formal education (Blaxall 1948).

Some positive early reports appeared from other foreigners with long African experience. In the 1930s, anthropologist Margaret Field found that what she called “the idiot” was revered among the Ga people in West Africa, “particularly if he is so feeble-minded as to be incapable of speech, or if he is of grotesque appearance.” Such people were believed to be incarnations of divine beings:

“They are always treated with the greatest kindness, gentleness and patience, are kept very clean and well-dressed, and are given daily good food at a low table with a white calico cloth while the rest of the family squat on the ground round a common dish. ... Not only do his family care for him but all the neighbours help to keep an eye on him. If he shambles into any compound he will probably be given food, and if he eats it messily his face will be cleaned for him before he is sent home.” (Field 1937, 183)

This clearly made a strong impression on Field; but Elam (1967) in Nigeria stated a contrary and negative view of the position of “mentally retarded children” in ‘primitive culture’. (Europeans with a strong belief in normalisation and independent living might also have mixed feelings about the ‘separateness’ of the existence described by Field). Between these two stands the positive but qualified impression of paediatricians Edgell & Stanfield (1972):

“On the whole the uncomplicated severely subnormal child is cared for by the extended Ugandan family and the threat of rejection and abandonment arises only where there is either totally unacceptable antisocial behaviour or no family support -

for example, the unmarried or deserted mother.”

Subsequent brief reports of indigenous practices cover a wide range from infanticide to tolerance and provision of legal protection (Burck 1989, 60-67; Edgerton, 1970; Kanimba-Misago, 1980). A few African novelists have given predominantly negative historical portrayals of disability in families and communities, e.g. Chenjerai Hove (1996) from Zimbabwe, and Ben Okri (1991) from Nigeria. Reports of infanticide are sometimes dismissed as merely ignorant colonial denigration of indigenous customs; yet the reality of infanticide has been asserted by modern Africa scholars, giving economic, cultural, and religious rationales (Mshana 1992, 117-120; Mutwa, 1968/1998, 23-41; Devlieger, 2000). One study of blindness endorsed positive views of traditional family and clan care; but two decades later an extensive report dismissed the “commonly held view that the handicapped child is cared for and accepted in village life” in East Africa (Blindness, 1948; Anderson 1967, 38-39). This 1967 report found substantial neglect, attributed partly to huge problems facing families, especially in urban areas where kinship duties had dissolved. The conflicting views might be attributable to different motivations. Colonial government wished to avoid any long-term ‘burden of care’, so was disposed to believe that disabled people were adequately cared for by village communities; some missionaries providing care to compensate for what they believed to be family neglect, thought otherwise.

### **3.4 Wide Variation in Different Circumstances**

It is quite plausible that there were real and significant differences from area to area, from community to community, from family to family, from one period to another period, and at different life stages, in the level of care afforded to those in need of care, or of opportunity to those whose need was to show how well they could care for themselves. [16] Varying treatment of disabled babies among Tanzanian tribes was documented by Van Pelt (1982). Even where tolerance and care toward disabled people was customary, it could diminish sharply during famines (Iliffe 1987; Turnbull 1972). In Ethiopia, Hallpike (1972, 128, 283, 310) recorded different responses to village imbeciles depending on whether they were jolly and amusing, or merely irritating and ugly. Between these various conflicting positions is the Kenyan who showed his profoundly disabled child to an anthropologist. The man admitted going to the river to do his ‘social duty’ by drowning the infant; but then “she looked up at me and smiled and laughed. I couldn’t do it then” (Edgerton 1970, 530). This Kenyan baby, bereft of any power or life-prospects, apparently laughed away the ultimate patriarchal oppression backed by centuries of tribal custom. (Had she been conceived in Europe, her impairments might have been detected *in utero* and an abortion performed before she had the chance to laugh).

A more formal chance for the ‘condemned’ infant to refuse death was noted by Herskovits (1938, I: 262 + plate 43b) in Dahomey (now Benin). Many children born with abnormalities were classified as belonging to river spirits, so they ought to be given back, “in which case the child is taken to a river bank and after certain ceremonies is left there. Some children whom Fate orders to be returned to the river refuse to accept this verdict, and cry out, or speak their protest - [such children are believed capable of speaking from birth] - until they are taken home.” Herskovits illustrated such a case with a photo of a large-headed child, captioned “This macrocephalic boy”. The account suggests the ambivalence families may have felt, between the voice telling them the child belonged to the crocodiles, and the other voice saying the child was their own. Some African communities apparently evolved this

kind of quasi-legal loophole, by which they could decide that the voice of Fate had been overturned by the protest of the child. Such a child had rightly earned its reprieve, and the crocs would accept this and the ancestors would not give them a lot of grief. [17]

More recent and detailed home studies have been conducted by Kasonde-Ng'andu (1988) and Katwishi (1995) in Zambia, and Ingstad (1997) in Botswana. Both earlier and later studies tend to support the view that in every African country some families are willing to go to great lengths, exercising ingenuity and good sense to enhance the life chances of their unexpectedly different child. Whether such families are one in a hundred or in ten thousand can hardly be known, but they are a reminder that ordinary people in great material poverty sometimes overcome considerable challenges using resources of kindness and imagination. It may however be doubted whether many such people would also have the time and interest to join campaigning organisations, the pattern by which some families in Europe have given a stronger voice to their experiences and needs. The African regional development of disability-related organisations, including those of parents and self-advocates, has been slower and more fragmented (Miles 1998). A different African response might be to join cults or groups of people to engage in 'rituals of affliction', as a way of coping with the disabling vicissitudes of life and community pressures (Janzen 1994).

### **3.5 Muted Voices; Mutual Support**

Voices of parents caring for infants with hydrocephalus and spina bifida have been very thin in the historical record; those of people growing to adulthood with these conditions have hardly been heard before the late 20th century. In fact, no historical African statement by parents was found in this study. [18] The ambivalence of parental feelings may be reflected in a Nigerian study in the 1980s. The researchers learnt that "many parents had tried to hide their children's condition from friends, neighbours and extended family. The birth of the child was taken as a personal failure which must be concealed ... pressure was exerted on mothers by their families to get rid of the hydrocephalic child by abandonment in the bush..." In the face of such pressures it is unsurprising that "All the mothers of the children who died expressed relief rather than sorrow" (Oyewole et al. 1985). (These are plausible responses by unsupported parents in situations of considerable stress and difficulty. Twenty years on, African parents in a more supportive situation, with access to appropriate medical or surgical intervention and aftercare support, might well express more positive views, without denying that they still face appreciable difficulties).

Parents of children with spina bifida and hydrocephalus from Tanzania, Kenya and Uganda reported modest progress at East African conferences in 2001 and 2005, organised by the International Federation for Spina Bifida & Hydrocephalus with local partners. There has been some mutual support within urban parents' groups, and some development of awareness among medical personnel about families' needs for information, appropriate counselling, and financial assistance with the expenses of hospital attendance, home care, equipment and adaptations (Mrawa 2001). However, two parents who were both in employment reported great difficulty finding any domestic assistance for a son with paraplegia arising from spina bifida,

"mainly because of the attitudes of domestic staff we wanted to employ. No matter what we offered, almost 95% of them would not be willing to work because of Martin's disability. The few who took up the challenge worked for a month or a few days and disappeared. Even our own relatives could not assist" (Bakkide 2001).[19]

These conferences held in Africa have also given some opportunity for young adults with spina bifida and/or hydrocephalus to discuss their experiences and present their views, as well as meeting counterparts from other countries where the life chances have improved significantly during recent decades. A Tanzanian, Lawrence Frank Mrawa (2001), presented his experiences of growing up with hydrocephalus, at the Dar es Salaam conference. Presentations at Nairobi were made by two Kenyans with spina bifida. Fransisca Naijipu (2005), a hospital technician, underlined the need for accurate and appropriate information to be available at every stage to dispel prejudices and to avoid increased impairments of function. Billy Ng'ang'a (2005), whose education had been hindered by recurrent illness and operations, had persevered for 16 years to reach college.

International organisations with national and local branches can do a useful job of improving access to information and funds, and of putting well-informed parents and people with hydrocephalus and spina bifida together with families in countries where very few are well informed. That may also serve to balance the equation in relation to surgical experts who are very willing to provide their best service, but sometimes find their patience tested by parents who seem to be busy undoing the hard-won benefits. Adeloje (1989, p. 125), for example, noticed in the 1970s a complication of shunt procedures, in which the parents have received back their child, whose operation wound has not yet healed over. The implanted silicon shunt tube can be identified under the skin, and the parents "enthusiastically finger through the wounds to reach the 'whitish worm' which they extract", mistaking it for the ascaris worm. One can hardly fault those parents for pursuing what they believed was an identifiable worm in their child's head and neck; but clearly there is a case for independent organisations to make it their business to master all the necessary information and communicate it with sufficient clarity, in the relevant languages and dialects, to all families who find themselves caring for children with these conditions, and to those who themselves have the conditions and must participate in understanding and decision-making. Kalangu (2000) emphasizes that "a well-informed mother, irrespective of her level of education, can be the best nurse of her child." He also notes that "children of mothers who were educated women but had not been given appropriate information did not do well. This is an important factor to keep in mind, as a skilled and technically good neurosurgeon may obtain poor results if the little time required is not taken to explain the child's condition and the possible complications linked with poor nursing to his or her mother."

#### **4.0 COMMUNITY BASED REHABILITATION?**

The term 'Community Based Rehabilitation' (CBR) has been adopted for widely differing varieties of work since 1976, some of which were recommended to African countries in the 1980s and 1990s. Most CBR programs give high priority to helping families care for disabled members at home and in the neighbourhood, with some idea also of influencing communities and creating more social, educational and employment opportunities for disabled children and adults. One substantial CBR program in Tanzania has reported working at home with 54 children with hydrocephalus / spina bifida out of 369 children being visited (nearly 15% of the caseload), while its weekly family clinic saw 79 new children with hydrocephalus and 29 with spina bifida, some of whom received surgery and aftercare (Zambaldo 2001; Nicol & Zambaldo 2001). The latter report gives considerable detail of a project that was basically raising awareness and providing information to families, with prospect of a more sustained

surgical capacity developing subsequently. Two extracts from CBR reports in Tanzania suggest some positive and negative sides of the social environment. In Dar es Salaam, for example:

“We visit J, an alert, nervous kid with big hydrocephalic head, sitting under a tree on a slope near some dwellings. From the thin little body supporting the head I see a girl aged 7 or 8; but in fact this is a boy of 15. J begins chattering as soon as he sees Mrs Idda. Some women and children appear, but J’s mother is out. We help J onto a stool; he has very little leg control. J thinks I have come to teach him to read and write. He tries out a few English phrases. I ask his name and he gives a string - his own, his mother’s name, father’s name and other details, to the mirth of the bystanders. He has a repertoire of parrot phrases and tricks to hold people’s attention. J insists he wants to do school work. Mrs Idda finds some paper and balances it on the jigsaw puzzle box. J grips a pen awkwardly and gets the point on the paper, but it is uneven and the ballpoint slippery. His hand wavers and makes a thin scribble. The watching women and children scream with laughter. Idda holds J’s hand to write capital ‘J’s. Small kids mimic J’s wavering hand with further bursts of glee. This is the harsher side of rehabilitation ‘in the community’. Mrs Idda moves on to positioning and physical exercises, which are also difficult on the slope. J is exposed to more laughter. The adverse setting and lack of anything fun to do is becoming oppressive. J has some grip and arm strength, so I show him my cheap telescoping umbrella. He grasps it. Idda and I show him how the handle extends and the fabric shakes out. We open the umbrella a little. J is fascinated by the double array of spokes. He gets the idea of pushing the mechanism up the shaft. The spokes unfold and the umbrella magically takes shape. Now he is inside the umbrella pushing it open. Near the top more force is needed. He is excited, he pushes hard. He nearly completes it then gets stuck. I get my head under too, and together we push until it clicks. J’s eyes brighten. He peers intently around the little world of skilful design that he has caused to unfold.” (Miles 2000)

The Kilimanjaro-CBR rural program at Moshe, Tanzania is also currently active with these children, surgery being provided at Kilimanjaro Christian Medical College. The Community Rehabilitation Workers, with several weeks training plus supervised experience and ongoing training and support, make visits of which the following excerpt may be typical:

“Flora, Merci and I walk uphill for 25 minutes, then take a footpath and reach a small dwelling amidst the trees. Here lives RH with his grandmother. His parents are 400 miles away at Dar es Salaam on the coast. RH was born with spina bifida. Now three years old, he has already survived tuberculosis and epilepsy. His parents toured the hospitals and specialists, with little benefit. They brought RH back to this cooler rural area, where he was found by the rural CBR program. RH is happy to see Flora, and so is his grandmother. The women get busy. Small wooden bricks appear from Flora’s bag. RH picks one up in his left hand and bangs it on the tin tray in front of him, producing a satisfactory noise. Then he begins throwing bricks vigorously in all directions, using his left hand. He sits in a specially shaped wooden chair with sponge padding to protect the bag of nerves on his spine. His eyes gleam as he makes three grown-ups jump around picking up his bricks. RH could not walk six months ago but is now making some progress. After a severe fit last year he stopped using his right

arm. That was shortly before he got onto Flora's list of families. The epilepsy is now controlled by medication. Flora and Grandma are trying to get RH to exercise his right hand. He can still grip things but does not like doing so. Flora starts some exercise with his legs, making him squat and take some weight on his feet. RH is not very happy with this, but Flora sings to him so the exercise is almost a game. Grandma calls to RH, encouraging him, reflecting back his sounds. Merci joins in. The exercises take a few minutes. Grandma tells us it's a pity there are no other kids at home for RH to play with. Now Grandma brings a solid table and places against it a wooden standing frame made locally to a given design. There is a little platform for RH to stand on and sponge padding covered with plastic so he can lean forward to work with his arms and hands at table activities. Grandma secures the frame to the table with a tie-up. Flora places RH on the frame and stabilises him by wrapping a long cloth around him and the frame. The table play activities proceed for a while. Grandma produces the visit record sheets in a plastic folder, and some notes are made. As we leave, RH is banging cheerfully on the tin tray again." (Miles 2001)

This sort of therapy in the community can be very useful, especially when family members participate. It is vastly less prestigious than brain surgery; yet close observation suggests that it is hardly less complex and demanding. Day by day, week by week, these mothers, grandmothers, sisters and aunts, together with CBR workers and sometimes a few men, are shaping the small child's body, mind and communication abilities, exercising, teaching, encouraging, refining, cutting new paths, revisiting earlier gains, with the child's own participation, refusals and demands. The impairments throw up unexpected obstacles to traditional child-rearing practices, challenging the women's patience and ingenuity, stretching to the limit their adaptation of ordinary household objects as learning resources and their little bag of further low-cost equipment. (When national resource inventories are being compiled, these domestic skills are as likely to be listed as the air, or the leaves on the trees).

#### **4.1 Critical Thoughts on CBR**

While appreciating the quiet, ongoing, frontline work, there is a need for more general and critical appraisal of CBR theory and practice. An early study of the effectiveness of CBR was reported by Hindley-Smith (1981, 22) from South America, with a factual balance that was soon lost in CBR reporting:

"It is true that some 30% of disabled persons solve their problems unaided; but almost 40% of the total can be assisted through this approach [*i.e. basic rehabilitation methods taught by existing Community Health Workers*]. About 18% need help from more highly trained personnel and approximately 12% require institutional care." (italicised comment added).

If this sort of modest, unmassaged data had characterised later WHO claims, much irritation could have been avoided, e.g. between specialised centres and advocates of 'CBR' (Serpell 1986). Unfortunately the 1980s saw high-pressure advocacy of CBR, but little research-based evidence. The early report of self-help by 30% of disabled people was among the first data to disappear. Some Pakistani development activists have reported in astonishment tinged with fury the methods used by European consultants to inflate the apparent 'success rate' of a CBR project in the Punjab, against the much lower estimate of local and neutral observers (Jaffer & Jaffer 1990/1994). The ILO Vocational Rehabilitation section also summarised its

experience of a decade of 'CBR' thus: "The existing models of community-based rehabilitation have proven to have serious shortcomings as they are professionally unsatisfactory, difficult to organise as a self-sustainable programme and not feasible without major back-up from outside the community." (Momm & König 1989) There was clearly a need for more serious study of 'CBR' in the 1990s. Yet after some 25 years, the formal knowledge base providing evidence for the merits and flaws of various sorts of 'CBR' in developing countries remains poor and has weak research methodology.

CBR results in sub-Saharan Africa have seldom been measured carefully and reported independently, but a few serious studies exist, reviewed in Miles (2004) and Finkenflügel (2004). The broad impression has been of isolated, small-scale project successes but very few larger-scale successful programs (Vanneste 1997). The poverty of solid CBR research data, whether in Africa or elsewhere, has been noted by Jadin (2001) and Jadin et al. (2005) who recently contributed a substantial set of data from Benin and Ghana, mainly on CBR with physically disabled children and young people. The paucity of successful large-scale programs is perhaps not the fault of CBR workers, nor of program managers. The widespread geopolitical conflicts and economic decline have hardly favoured a program that calls for people living in poverty to exert themselves, usually on a voluntary basis, on behalf of their still more disadvantaged neighbours. The imported 'package' of CBR has often failed to build on or even recognise the existence of indigenous traditions and resources of care and healing skills, or more recent resources of disabled people's organisations (Burck 1989; S. Miles 1996; Mpofu, 2001) The rise of AIDS has already removed and will continue to remove large numbers of the 'parent' generation aged 20-45. AIDS orphans are absorbing more of the energies of the grandparent generation, so that entire countries have a seriously reduced margin for offering care to children with disabilities. Before AIDS took a serious grip, Feierman (1986, 210) in Tanzania pointed out that "Healing and nurturing have been mostly the job of the old", and that "People beyond their productive years heal the sick, provide nursing, and oversee childbirth" while the middle generation produce food and earn cash. Obviously this does not work well when the middle generation is decimated and the elders overburdened.

The WHO CBR ideology involved a myth of idyllic rural communities where people had mutual duties of caring for one another, and needed only the addition of a little low-cost technology and know-how to be able to manage disability in the community. The real picture was less rosy; it varied greatly from place to place and could be heavily damaged by armed conflicts, famine, severe epidemic disease, and rapid socio-economic change, which have occurred in most African countries in the past century. Overviews of disability in Africa in the 1960s and 1970s seem to have been influenced by large numbers of polio cases, where much could be done to restore mobility by exercises and low-cost callipers (Huckstep 1964) which accorded with the WHO program. WHO CBR was also primarily aimed at accommodating people having mild to moderate impairments not involving life-threatening illness. Thirty years on, the laudable reduction of Under-5 mortality, and the hugely increased population across Africa, means that the Community Rehabilitation Worker's caseload includes far more children surviving with severe and multiple disabilities, who would challenge an experienced multidisciplinary team let alone a briefly-trained CRW. The specialists and referral centres have seldom been developed to support those CRWs, partly because European 'anti-institutional' rhetoric of the 1980s and 1990s has progressively diverted aid and development budgets into other channels.

To solve these difficulties, foreign aid and disability organisations advocate the “Rights of the Disabled Person”, in some contrast to the basic CBR premise of ‘mutual caring’ in the old-style rural community; plus sociological theories derived from economically powerful countries in which needs for ‘medical’ care are assumed to be catered for, and the trend has been to blame society for ‘creating disability’ by negative attitudes and environmental barriers. The latter trend may be a logical and appropriate step in Western Europe; its relevance to Africa is more speculative, given the inadequacy of even basic health care for much of the population. Nor are ‘rights-based’ programs necessarily practicable in African countries where the capacity for implementation is weak, enforcement mechanisms are negligible, and the social sector has been driven steadily towards ‘market economy’ values by external financial advisors. A senior medical officer of Uganda remarked wryly on the need to “monetise all the benefits of CBR in dollars. This will include weighing ‘humanness’ or ‘Obuntu’ as we say in parts of my country.” (Nganwa 2000)

## **5.0 SHARP-EDGED COMPARISONS**

A more accurate prediction of the effort needed to improve the life chances for children and young people with spina bifida and hydrocephalus may be discerned from a much ‘simpler’ surgical and social target that has gone further along the road, i.e. work on raising the cataract surgical rate. ‘Modern’ knowledge of cataract surgery extends over 150 years. Eye camps have been held in rural areas of Southern Africa for at least 60 years (Hill 1984). Intra Ocular Lenses have been developing for 50 years. In the past decade massive efforts have been made to provide the latest highly effective surgery at low-cost, across the world. Yet remarkable numbers of elderly people remain blind or with very low vision, because of a series of social, economic, religious, attitudinal and managerial barriers (Vanneste 2001). Those barriers are being tackled in various ways; but they will not yield to a ‘technical fix’ alone. They seem to require a continuous, accurate, culturally appropriate, personalised and well-targeted flow of information through a system that includes hospitals, health clinics, community health workers, town and village councillors, schools, families, and people with cataracts. The involvement of traditional healers is now being added to this list as a result of experiences in Malawi and elsewhere (Courtright et al. 2000).

Yet while appropriate information flow through a complex social system can be facilitated in some ways by applying money and technology at strategic points, it is not something that can be pumped up merely by pouring in aid. [20] Nor can impairments and disabilities be ‘solved’ by a ‘technical fix’ at a single point, as has been indicated in a comparative study of attempts to eliminate leprosy, cataract, iodine deficiency disorders, poliomyelitis and lathyrism in the southern hemisphere (Miles 2003). The same can be expected with hydrocephalus and spina bifida, except that here the most appropriate ‘surgical fixes’ have not yet been perfected, stabilised, tested over a sufficient period and steered into low-cost distribution; while family and community thoughts and beliefs about the physical conditions are far more complicated than for cataracts or polio lameness. The requirement for aftercare in the family and community is vastly greater than that required for the post-surgical cataract patient, and the perceived priority in the health development world is regrettably low. This does not mean that efforts to solve these problem should be abandoned. On the contrary, they should proceed with greater awareness of variety and complexity in what is required,

borrowing freely from experience in many other fields.

## 6.0 CONCLUSIONS

Based on evidence from more than 20 African countries, the chances for children with hydrocephalus and spina bifida to survive and grow up to a life with some dignity and some opportunities for education, work and leisure activities, can be improved; yet in most of Africa this would be achieved with considerable difficulties. Beyond the further development and spread of medical and surgical interventions, there needs to be a much greater enlistment and facilitation of community and family resources and information. At present, such resources are often weak and scattered, especially in the rural areas and urban slums, as shown by the continuing high and sometimes rising mortality rate of infants and children without impairments. There are some commendable examples of families making extraordinary efforts, and some community traditions providing a positive environment. The useful advances in surgical approaches and rehabilitative care must be matched by greatly enhanced efforts to build in culturally-sensitive ways on the best of existing concepts, knowledge and skills within families and communities, with greater attention also to the various ways in which children and adults with spina bifida and hydrocephalus perceive their own lives.

While the life chances may slowly be improved for some, it is also open to African countries to promote dietary supplements as part of Primary Health Care for all women of child-bearing age. Folic acid supplements should significantly reduce the chances of babies being born with neural tube defects, while further supplements in a more effective PHC programme should limit other well-known deficiency disorders and reduce the continuing high child mortality. The cost of primary prevention compares favourably with that of brain surgery and the many hidden costs and human suffering involved in living with neural tube conditions. Preventive measures as part of national Primary Health Care programmes do also require some political will and responsibility in society at large, as part of a political agenda that may measure 'human value' in ways appealing to African cultures. [21]

In all such activities, a word of caution reaches us from the 1930s, speaking of the African child, but having wider application: "We good-intentioned folk would be well advised to find out something more about the system and ideas which African parents themselves practise or hold regarding this subject before we rush in to criticize, interfere with, or offer advice to those who in the long run are mainly responsible - namely, the children's own parents." (Rattray 1933, p. 456).

## 7.0 NOTES

[1] Spina bifida is a term for a range of defects in the development of the infant's spine and immediate vicinity. It may be concealed (*occulta*), usually having little effect in early years;\* or it may be visible as a lump on the back (or neck), containing spinal fluid (*meningocele*), or both spinal fluid and spinal cord (*myelomeningocele*). The latter in particular, myelomeningocele, is a high risk condition with a range of associated disabilities. Hydrocephalus is a condition where the fluid that normally flows within the head and the spinal cord gets blocked at some point or is not adequately absorbed in the body. Pressure then builds up and causes swelling of the head and often considerable

internal damage. Children with the more serious forms of spina bifida are likely (about 80%) also to have hydrocephalus; but hydrocephalus may also occur for other reasons in babies and children not having spina bifida. More specific and detailed information can be found by a search on reputable medical websites, and from the International Federation for Spina Bifida & Hydrocephalus, <http://www.ifglobal.org>. This Federation has African partners in Kenya, Malawi, Sudan, Tanzania, Uganda, Zambia, and contacts in other African countries, and has produced, with the World Health Organisation, an explanatory guide in non-technical English (Binns & Bardos 1996, obtainable from the website). Spina bifida and hydrocephalus are often found under the broader heading of ‘neural tube defects’, which includes some other major problems of a similar nature.

\* As spina bifida occulta was the condition prominently found in skeletons at Taforalt, Morocco in the early 1960s (see **note 6**, below), a contemporaneous expert view of that condition may be noted: “Probably about 25 per cent of all children will show some minor defect of a vertebral spine or lamina on roentgen examination. Most of these occur in the lumbo-sacral area and persist into adult life in normal individuals who show no evidence of either neurological or musculo-skeletal deficiency. By far the majority of occult spinal disorders, therefore, are of no clinical significance.” (Ingraham & Matson, 1954, p. 7) A ‘minority report’ also appears in the experience of a teacher and headmistress working in Uganda and Kenya from 1954 to 1970, who learnt only in 1988 that she had spina bifida, though it had been on her medical record since 1968. “When I found out that the problems I’d experienced all my life were caused by spina bifida, it was a huge relief” (Woolman 2005). Mary Woolman had “a bump just above my coccyx and slight curvature of the spine, but no name had ever been given to my condition. My feet are also deformed which means I have always had poor balance ... I was teased throughout my school years ... I was the clumsy, clever child, who couldn’t dance or do gym, although I had no problem running or climbing trees”.

[2] In many African hospital-based reports, “neural tube defects” (NTD) are said to be “common”. When actual figures are given, there is often no clear definition. When lower and upper boundaries of incidence might be (something of the order of) 0.35 /1000 and 7.0 /1000, a carefully monitored and sufficiently large study population is required to find statistical significance in differences within these boundaries. It would also be useful to know whether the figures are purely hospital based, and whether ‘deliveries’, or ‘live births’; whether hydrocephalus alone, spina bifida alone, hydrocephalus with spina bifida, other varieties and combinations of NTD, to avoid double counting or omission. Enhanced detail has appeared in some hospital reports through 40 years, e.g. from Chapman (1963) who considered that much closer attention to understanding each child’s lesions would lead to improved long-term outcomes, through to Oneko et al (2003), who paid greater attention to studying the whole process of families with children having NTD, from first contact through diagnoses, treatments and follow-ups. Not all medical authors find it feasible to collect or present such detail; but much of it may then need to be researched again later, without the benefit of historical depth.

Medical journals mostly impose strict word limits on authors, who are also expected to use the ‘shorthand’ of technical jargon. Yet conditions once described by a single term (e.g. ‘spina bifida’) are now recognised to be quite diverse, including many rarely-seen additional features. Precise scientific communication then needs more single terms, which, after energetic debate, may be classified together into new categories. This process moves at different speeds between the dozen major international languages in which scientific findings are published, to the surprise of people who imagine there is only one international language, and the confusion of 98% of the public, who have no access to medical journals in any language but increasingly demand to know what ailment they or their close relatives have, and what can be done about it.

[3] The mostly-invisible reality during a study period almost anywhere in Africa might be (as a fictive example, compiled from a range of actual hospital data) something like 20 babies with probable NTD among an estimated 8000 (plus or minus 500) live births in both hospital and local community; nine are actually seen at hospital within three days (six born in hospital, three brought quickly from the community) two being anencephalic, three spina bifida with hydrocephalus, one

hydrocephalus alone, one encephalocele with several complications, and one seen only by a junior nurse (who reported a 'very big head') before the family suddenly left the premises; seven are operated on within a week of birth, four are seen alive at three months while contact is lost with the others; but two more with gross hydrocephalus and multiple impairments, not previously seen, come in from the community four and six months after birth. (One baby's details from the above fictive hospital count, taken by a temporary clerk in a heavy rush period, have somehow disappeared). Incidence reports from this kind of confusing, and perhaps typical, background can be widely variable. Prevalence can be determined only where there is reliable recent census data for the catchment area, which is seldom available at present in Africa. Borman & Cryer (1990) indicate that problems of inaccuracy and non-uniformity in epidemiological data of NTD are widespread, much beyond Africa.

The present paper, working from published Africa data over a century during which terminology steadily evolved, and practitioners' sensitivity to statistical precision also slowly increased, cannot achieve the desired clarity. Initially, a familiar international figure of "one or two per thousand" was quoted, for incidence of spina bifida and hydrocephalus per 1000 live births. This paper now offers "one to three per thousand", to accommodate several African reports where a significantly higher local incidence has been reported. Aerede (1992) reports a NTD incidence of 7 /1000 deliveries in a three year prospective study in a Nigerian city. Ncayiyana (1986) extrapolated figures of 3.79 /1000 NTD among rural black babies in the Transkei, nearly three times the average reported elsewhere for black populations in southern Africa. Venter et al. (1995) report NTD incidence of 3.55 /1000 live births in hospital in Northern Transvaal, South Africa. However, Kinasha & Manji (2002) find NTD incidence of 1.82 /1000 live births at the national hospital in Dar es Salaam. Buccimazza et al. (1994) studied the frequency of NTD over a 20 year period at Cape Town from multiple sources, and find NTD prevalence rates ranging from 2.56 /1000 births for white babies to 0.95 /1000 for black, with a still lower 0.45 /1000 for babies who were the sixth child in a family. In Tunisia, Khrouf et al. (1986) found 2.2 /1000 NTD in 10,000 consecutive live or dead births; while Gaigi et al. (2000, abstract only) report spina bifida alone as 1.05 /1000 live births. Possible reasons for differences or fluctuations cannot be discussed here. Certainly, much remains to be learnt about the ecology and epidemiology of NTD across Africa. Adeloye (1989) assiduously collected relevant publications across Africa, and differentiated, as far as possible, the precise conditions and reported incidence for neurosurgical business from the late 1940s to late 1980s.

[4] The UNICEF (2005) figure for sub-Saharan Africa Under 5 Mortality Rate [U5MR] in 2003 was estimated as 165 /1000, over a population of 665 million. However, five North Africa countries (Algeria, Egypt, Libya, Morocco and Tunis) had a U5MR of 35 /1000, over a population of 150 million. With adjustment for population weighting, this brings the Africa-wide U5MR figure down to c. 140 /1000 in 2003. This is a broad, secondary calculation, with considerable local variation across the continent. (Improvement of the reported U5MR had ceased by 2003 in Angola, Burkina Faso, Burundi, Central African Republic, Chad, Congo, DR Congo, Gabon, Liberia, Mauritania, Somalia, Tanzania, Zambia; and had reversed into significant worsening in Botswana, Cameroon, Ivory Coast, Kenya, Rwanda, South Africa, Swaziland, Zimbabwe).

In 1860, when England reportedly had an infant mortality rate of c. 170 /1000, and Scotland 149 /1000, the rates of infant death from hydrocephalus were reportedly: England 4.4 /1000; Scotland 7.1 /1000 (Stark, in Farr 1866). (However, the diagnosis of 'hydrocephalus' may have included various other conditions). Shija (1975) reporting paediatric surgery in Dar es Salaam, compared data for Edinburgh in 1863, predicting that Dar es Salaam would take 50-100 years to reach the situation of Edinburgh in 1975. Among 440 consecutive paediatric admissions, Sept. 1972 to Sept. 1973, Shija noted 11 hydrocephalus and 7 myelomeningocele).

[5] Armelagos (1969) remarked that interpretation of skeletal lesions was sometimes difficult, sometimes obvious; and that the "skull of a hydrocephalic child from the X-group site" at Wadi Halfa, Nubia, Sudan, of which he showed a photograph, was an example that "presented no problem of

interpretation". Richards & Anton (1991), while conceding that this might be so, remark that "the published data are too limited to allow conclusions", then show a more scientific approach to presenting cranial measurements, putting the reader in possession of verifiable data on which their interpretation is based. This difference of approach arises partly from the normal progressive development of a field of investigation during 23 years (from 1969 to 1991), toward more rigorous measurements that are independent of individual know-how and expertise. Richards & Anton omit mention of El Batrawi (1935, 183-187 and plate XXII), working some decades earlier, who did give detailed descriptions, measurements and photographs of two hydrocephalic skulls from the X-group in Nubia, the first obviously hydrocephalic, with large size, light weight, and the face "very peculiar, being of very small size in proportion to the cranium; the second "not as self-evident as it is in the previous one", so Batrawi gave reasons for his diagnosis. (Nunn 1996, 84, notes a negative review of another earlier hydrocephalus diagnosis).

[6] The Taforalt cave had been partially excavated from 1950 onward (Roche 1953, 1963), adding useful early evidence of humans in the Maghreb (Lubell 2001). Sacral anomalies were reported briefly by Ferembach (1959), without the term "spina bifida"; but later they became "spina bifida occulta in prehistoric human skeletons" (Ferembach 1963), with Figure 2 titled "Sacrum of specimen XI, with an almost complete spina bifida occulta". Ferembach stated that the adult sacra "are characterized by the presence of a more-or-less developed dehiscence of the crista sacralis mediana known as spina bifida." In a detailed description of the human remains (Ferembach et al. 1962), the same "Sacrum of specimen XI" is Figure 32, "montrant une spina bifida presque complète" (p. 93). Several Taforalt sacra exhibited "la présence, avec un développement variable, d'une déhiscence des apophyses épineuses, ou rachischisis [\*] sacré (la spina bifida occulta de certains auteurs). On peut difficilement penser à une spina bifida aperta étant donné l'âge des individus où elle se remarque, cette anomalie n'étant pas compatible avec la vie" (pp. 93-94; cf p. 17).

Considering the high early mortality (out of 186 skeletons, 80 were adult, 44 or 45 died in their first year, 23 or 24 in their second year, and 30 or 31 between 2 and 6 years, pp. 16-18), Ferembach found it easier to consider spina bifida aperta (now usually 'spina bifida cystica'): "Selon certains auteurs (et en admettant que le même gène est responsable de cette malformation et de la suivante), à l'état homozygote la spina-bifida occulta se transforme en spina bifida aperta et l'individu porteur n'est pas viable. La très forte mortalité observée à Taforalt pourrait donc, en partie, être due à ce gène léthal (et aussi à d'autres, peut-être, affectant les parties molles ou la biochimie, donc en général non visibles sur le squelette) se maintenant dans le groupe et apparaissant plus fréquemment à double dose chez une personne par suite des nombreux mariages entre parents. // Mais cela n'est certainement pas la seule cause. Il est très probable qu'un manque d'hygiène doit aussi être incriminé." (Ferembach et al, 1962, p. 17). For the shift from 'occulta' to 'aperta', Ferembach (1963) mentioned "Shamburov" in her text, citing RR Gates (1952) *Human Genetics*, New York. The 1946 edition of Gates refers (vol I: 487) to work by [Dimitrii] Shamburov, and on p. 488 to "Schamburov". (Work by this author can be found under: Shamburov; Schamburov; Schamburov). Gates's citation was: Schamburov D.A. 1932. Die Vererbung [= inheritance or transmission] der Spina Bifida, *Arch. f. Rass. Biol.* 26: 304-317. The paper is cited on the internet as: DA Schamburov & JJ Stilbans (1932) Die Vererbung der Spina Bifida, *Archiv für Rassenbiologie* 26: 304-317. This "Archive for Racial Biology" is not easily found. It now seems to be cited mostly in historical research on Eugenics under Germany's National Socialism era; however, Schamburov's studies of spina bifida were not necessarily influenced by racial bias and non-scientific notions.

Ferembach also noted that "the mode of inheritance of spina bifida is considered by many geneticists as least reliable". This "least reliable" rating appears in another Ferembach (1963) reference: Neel JV & Schull WJ, 1954, *Human Heredity*, New York, which on pp. 80-82 tabulates "Diseases in which it may be possible to recognize a carrier state". Listing "Spina bifida", the table shows "spina bifida occulta" as the possible "Characteristics of Carrier State"; and under "Genetic relationship of carrier to manifest disease" it shows "Both heterozygous for same gene", with "Reliability" rating of 4 ("least reliable"), citing Schamburov & Stilbans (1932). The latter reference

is not given in full, but presumably is the paper mentioned above. Ferembach seems to have placed some reliance on Shamburov's work from 30 years earlier. Shamburov had continued publishing in Russian, e.g. in 1959 on "status dysraphicus and lumbosacral radiculitis" [\*] (see Old Medline), while Ferembach was studying the Taforalt skeletons; and Shamburov's earlier work was listed by Gates (1946 / 1952). [\*] Gates (p. 489) notes that "By *rachischisis* is understood congenital fission of the spinal column (i.e. the failure of the axial skeleton to close) spina bifida being a terminal form of rachischisis. The various types of failure to close the spinal column are regarded as aspects of the *status dysraphicus*..."

For her brief note that "The occurrence of spina bifida can be influenced both by environmental and genetic factors", Ferembach (1963) cited a non-existent paper in the *Lancet*, 1961, i, 296, by Doran & Guthkelch. That might have been: PA Doran & AN Guthkelch (1961) Studies in Spina Bifida Cystica. I. General survey and reassessment of the problem. *J. Neurology, Neurosurgery & Psychiatry* 23: 331-345; or Ibid. (1962) The epidemiology of spina bifida, *Developmental Medicine and Child Neurology* 4: 307-309. (Both papers have brief discussion of the contribution of environmental and genetic factors). This degree of muddle in source citation is odd, given Ferembach's meticulously detailed catalogue, and well documented discussion, of each skeletal fragment. How Ferembach used her sources and how much she understood about spina bifida is pertinent because she also showed some uncertainty in interpreting the evidence, in terms of ideas about spina bifida that were available in the 1950s and early 1960s, using the Latin, English or French medical terminology then current. Detailed radiographical studies on the "deformities of the lumbosacral region of the spine" had appeared at least 30 years earlier, e.g. Brailsford (1929). Detailed presentation of spina bifida by the contemporaneous surgeon and researcher Chapman (1963) in South Africa suggests that specialists (at least, the anglophone ones, but probably also the francophones) had a more complex understanding of the range of conditions and possible outcomes, between 'occulta' and 'aperta' (cystica). Later researchers on prehistoric NTDs describe the "prevailing view that the genetic basis of neural-tube defects is a polygenic one" (Devor & Cordell 1981), with a confusing variety of local environmental factors also playing a part. (See also Saluja 1986). These fields of knowledge may have been less familiar to Ferembach, whose D. ès Sc. thesis (1956) concerned cranial measurements.

[7] Manipulation or deformation of the skull, for cosmetic or other purposes, has been a worldwide practice (Dingwall 1931). Efforts to arrest the hydrocephalic expansion and perhaps shrink the cranium back to an acceptable size, by different kinds of plaster or ointment, were among the treatment suggestions c. 900 CE, by the Persian physician Al-Razi (Rhazes) in chapter 3 ("On Enlargement of the Heads of Children") of his widely disseminated paediatric treatise, introduced and translated by Radbill (1971). One of Abul Qasim's recommendations was surgery for external drainage, "then close the wound and tighten the skull with a bandage" (quoted in Khamlichy 1996). Treatment by wrapping or bandaging has been practised in many times and ways (Gjerris & Snorrason 1992; Lifshutz & Johnson 2001; Ramoutsaki et al. 2002). Adeloye (1989, p. 128, quoting MJ Joubert) mentioned a traditional, 'common-sense' approach to congenital hydrocephalus among Black South Africans: "A tight 'Alice band' made of cut flax is tied around the head, progressively tightening it until a cure is obtained". Such efforts to contain or compress the skull, by shrinking ointment or by bandaging, may or may not have any scientifically measurable efficacy or risk. *Belief* in their efficacy probably had reinforcement from up to 40% of cases of hydrocephalus that could have been self-limiting (see **note 11** below). Such procedures might have had some secondary merit as 'therapy for the family', giving close relatives a simple and affordable task that would make sense in traditional medical thinking where swellings were normally anointed and closely bound.

[8] In an extensive survey of tropical paediatrics based at Ibadan, Nigeria, Jelliffe (1952) mentioned six hydrocephalus and six meningoceles, but cautioned that "In most severe congenital deformities, treatment is beyond the scope of the small, inadequately equipped hospitals of tropical Africa." Odeku (1971), recounting his experiences when starting Nigeria's first neurosurgery service in 1962,

mentioned “a steady stream of spinal meningoceles and encephaloceles”. He confirmed and extended Khamlichi’s list of pioneer qualified neurosurgeons across the major regions of Africa (Nigeria, Ghana; Senegal, Morocco, Algeria, Tunis, Egypt; Uganda, Rhodesia [Zimbabwe, Zambia], Malawi; South Africa) by 1971. By 1996, Khamlichi added the Ivory Coast, Kenya, Sudan and Zaire. See also Gindi (2002 & 2005).

[9] Jarvis acknowledged the inspiration of McNickle (1947), a surgeon at Wellington, New Zealand, who published in a general surgical journal his “simple method of performing third ventriculostomy”. This was founded on an admittedly modest experience base, i.e. four ‘non-communicating’ and three ‘communicating’ cases of hydrocephalus; and was expressly intended to encourage surgeons who had been “hesitant to use more formidable procedures”. The history behind McNickle’s simplification is sketched by Jallo et al. (2005), and Li et al. (2005), illustrating how the early endoscopes were rather primitive devices borrowed from other surgical fields and giving a very limited view, while the operations were based on insufficient knowledge of the inner workings of the ventricles and cerebrospinal fluid. Neuroendoscopy thus remained under some cloud, while use of ventricular shunts gathered strength from the early 1950s onward and revolutionized hydrocephalus treatment. Li et al. trace some ongoing problems with shunting, then the “rediscovery of neuroendoscopy” through technological advances. Sixty years after McNickle’s experiences, and with advanced imaging technology, the range of mechanisms within the ventricular system for adjusting to pathologies or to surgical processes is still not fully understood (Preul et al. 2006), though incomparably better than the knowledge base of the 1940s. The present status of neuroendoscopy is indicated by an online ‘expert review’ of 175 items (mostly journal articles, a few book chapters) for the World Federation of Neuro-Surgeons, on the “impact of neuroendoscopy on the treatment of pediatric hydrocephalus” (Cinalli 2003).

[10] Warf (2005a) reviews some literature on cost-effectiveness of ETV (endoscopic third ventriculostomy) compared with shunt insertion, noting that even in the US there is a continuing significant level of shunt failure requiring urgent revision. He argues for prioritising ETV in developing countries where hydrocephalus is more often infection based, where monitoring of shunts is harder, and families face more obstacles in returning to hospital.

Attention was recently drawn to the “billion-dollar-a-year cost of hydrocephalus treatment in the U.S.” (Sussman & McAllister 2005), where the “average shunt procedure cost \$35,816, with a range between \$137 and \$814,748”. There is worldwide interest in assessing costs and benefits of alternative procedures, yet comparisons across sharply different economic environments are seldom straightforward. For example, Garton et al. (2002) give details of ‘direct costs’ of ETV in hospital studies in Canada and the US, including “costs of head computed tomography scans and magnetic resonance imaging studies”, which were calculated as “a capital cost plus labour and nonlabour costs”. These advanced scanners have been standard equipment for 15-20 years in big western hospitals, and their capital and operating costs per patient or procedure are calculated across large numbers and a significant time period. In much of Africa, such equipment was not standard in 2000, a situation unlikely to have changed in six years (Kalangu 2000); nor are its peripheral and indirect costs part of normal working budgets. The full costs of imaging equipment, and of trained staff and peripherals, cannot reasonably be loaded onto local ETV cost analysis; yet it is necessary to consider what is the minimum equipment, plant and staff capacity reasonably needed for any particular operation, and to know whether in actual fact hospitals are able to make such capital investment and recurrent expenditure.

For shunt surgery, the costs are more clearly known across Africa. Even the modest cost (c. \$35) of the cheaper shunt (shown by Warf 2005b, to be as safe and effective as a standard European shunt costing 20 times more) may be a barrier to access for some families. Onoko et al. (2003) at a referral hospital in rural Tanzania without specialist neurosurgical services, note that it was the free supply of shunts by the International Federation for Spina Bifida & Hydrocephalus, plus financial support for treatment and seminars for district hospital staff, that enabled the referral hospital to offer

surgical treatment for hydrocephalus and spina bifida to much larger numbers of children than previously. In Madagascar, a recent news item mentions shunt treatment costs of around 500 Euros, “unaffordable by a number of families” in the context of a Japanese donation of Doppler echograph (value c. 50,000 Euros) to a program for children with hydrocephalus, which was seeking donations for a neuro-endoscope (Henintsoa Andriamiarisoa, 2006).

[11] Some proportion of infants, children and adults with hydrocephalus survive despite considerable swelling of the head. In infancy the head has more capacity to expand than it does later when the cranial parts knit together firmly. Hydrocephalic swelling may also spontaneously arrest, without medical or surgical attention. A classic study (Laurence 1958; Laurence & Coates 1962a; 1962b) was made of 239 cases of hydrocephalus in children (below 13) under a conservative, low-intervention policy in England. Through 20 years, 57 children did undergo surgical operations, 26 (45.6%) being still alive when the study ended in 1958. Among the unoperated 182 children, 81 (44.5%) were found alive in 1958, with hydrocephalus arrested; 3 more (1.64%) were assumed to be alive, as spontaneous arrest occurred before contact was lost; in 9 more (4.94%), hydrocephalus was progressive; the other 89 (48.9%) children had died. (The original papers must be read closely for details of age distribution). About a third of the survivors were of normal intelligence, some being talented, and were being educated. Torack (1982) noted that these “astounding” findings were challenged at the time (see e.g. Lorber, discussion, in Laurence & Coates 1962b); but there was no further such study “because of the general reluctance to deny anyone the benefits of shunt therapy.”

Spontaneous arrest may account for some of the earlier sporadic reports of people with (probable) hydrocephalus seen unoperated in African communities, such as at Wadi Halfa (El Batrawi 1935, 183-187), in South Africa (Livingstone 1858, 202) and in Benin by Herskovits (1938, I: 262 + plate 43b). The latter might have been ‘macrocephalic’ only, i.e. large-headed without hydrocephalus -- the cautious distinction was made by Holmes (1973) at Moshi, Tanzania, reporting one case of neonatal hydrocephaly, and one of macrocephaly with “no definite evidence of hydrocephaly”, (see also Lorber & Priestley 1981). There are other probables and possibles, such as the person of unspecified age seen in Lekenti, Ethiopia, by Hall (1961); the son of a woman known to the anthropologist Ingstad (1997, 208) in rural Botswana, who steeled herself to ignore other women’s intermittent laughter and hints about shameful behaviour because of the boy’s hydrocephalus; an infant seen in Mali (Dettwyler 1994, 136) whose hydrocephalus was probably progressing, with much lower survival prospects; a 14-year old boy in Benin, “the worst case of hydrocephalus anyone on our team had seen”, the team being American visitors with a shipment of wheelchairs (Benin Africa Wheelchair Distribution 2003); a more thoughtful note of a 3-year old girl with hydrocephalus in Swaziland, who was “able to eat well, but had stiff joints and made no sounds” (Connell 2005); a young Ugandan boy in a home for disabled people, blind and unable to lift his huge head, yet well liked for his “cheeky, friendly way of talking” (Austin 2004). Recently, aid agency publicity departments seem to have ‘discovered’ African children with hydrocephalus as appealing objects to display in fundraising efforts, with colour pictures and sometimes names, on websites.

An observer familiar with the socio-medical opportunities and hazards for disabled East African infants and children has pointed out an additional problem, even where hydrocephalus surgery has been successful. Physicians seem reluctant to prescribe treatment for the ordinary, incidental ailments of such children, once they know the child has undergone brain surgery. The child is now seen as requiring specialist examination and care indefinitely for everything -- whether or not these are available and affordable (A. Zambaldo, personal communication).

[12] Since the 1920s in sub-Saharan Africa, some efforts have been made to develop and extend schemes for providing basic health care and sanitary services in rural areas, recognising that health and nutritional education and preventative work could greatly reduce the disease burden, and should also mean that hospitals would be able to function more effectively instead of being permanently flooded with people having both acute and chronic severe conditions. French and Belgian efforts in this direction were contrasted favourably with British approaches by discussants with Paterson

(1928). It was noticed that in coastal West Africa, the British “had gone to enormous expense to provide magnificent hospitals”; but these were not much appreciated by the Africans, who preferred something on a more modest scale where they were actually living, which might be far away. Debate and experiment on these issues continued through the 20th century, with an (apparently) increasing swing from ‘magnificent hospitals’ toward Primary Health Care (PHC) from the 1960s through 1980s, and a more confusing or pluralistic picture of trends in the past 15 years. (With massive urbanisation and the reappraisal of socialist ideologies, some large populations, such as those in China, allowed their PHC systems to be overtaken by strategies with a quite different economic basis).

A small country that has succeeded in developing an all-season network of roads, with telecommunications keeping pace, might reasonably plan for safe and speedy transfers from any point to a national centre; while a larger country with many islands or mountainous provinces might combine two apparently conflicting national strategies, with partial reliance on private, charitable or religious resources, or a ‘flying doctor’ service. Advanced telecommunications can now link community health workers and local hospitals, or local with specialist centres, potentially giving rapid access to expert guidance at distance, in countries that are materially poor but have prioritised telecomms over (for example) jet fighters. The point is that there is no single, global ‘Best Way’ for all, and most of the planning options are highly contested by political dogma, vested interests, and sometimes research data (Miles 2006).

[13] See Norwich (1971) on William ten Rhyne’s observation of indigenous medicine at the Cape in 1673; Darley-Hartley (1903); Davies (1959); Roles (1967) ranging from simple treatments to “the Masai and the Ganda dealing boldly and skilfully with complicated conditions and curing people despite a complete lack of knowledge of asepsis”; Harley (1941, 217-228; and Appendix “The native doctor succeeds where the white doctor fails”, pp. 250-253). Flint (2001) gives a recent review of materials.

[14] This section draws on the author’s forthcoming work, provisionally entitled “Disability, Beliefs and Religion in Africa, Past and Present: a short bibliography with some annotation”, currently listing about 200 items. This is an extension, with considerable difficulty, of similar work, partly published, on disability among belief systems of the Middle East, South Asia and East Asia, now reviewing about 350 items (see *J. Religion, Disability & Health*, 2002, vol. 6 {2/3} pp. 149-204, and supplement forthcoming, 2007). Neither item is a comprehensive review of literature, leaving aside the question whether the compiler has understood what the authors were writing, or whether the authors understood the beliefs they were writing about or mentioned in passing. The annotated bibliographies are an attempt to engage seriously with some of the range of beliefs connected with disability, in Asia, the Middle East and Africa.

[15] As seen in **note 5** above, some archaeologists are sceptical about the identification of hydrocephalus in early skulls, and also toward detailed ‘social reconstructions’ of scenes from archaeological excavation, e.g. Richards & Anton (1991); and Dettwyler (1991) one of whose examples was the skeleton of a teenager with spina bifida aperta from c. 5500 BC. In the present case, Goodman & Armelagos outline in some detail the techniques of analysing multiple indicators of lesions and growth, underpinning their claims. They do not show the evidence demonstrating ‘meticulous care’ of the hydrocephalic and quadriplegic child. That seems to be inferred from the child’s survival through 10 years, added to other points gleaned from a detailed analysis of the bone record of nutritional and other stress. (However, Dettwyler 1991 pointed out that survival is evidence only of survival. In modern African field-work, she noticed two disabled adults who were “routinely stoned, beaten, and jeered at in the marketplace”, while their families had ensured their survival by providing lifelong food and shelter).

Dastugue more cautiously interpreted further evidence from the pathology of the Taforal Cave skeletons in Morocco (Ferembach, with Dastugue & Poitrat-Targowla 1962, 133-158). One

woman survived severe injuries and her bones healed, which implied some basic level of care and feeding by others over a significant period, more than 10,000 years ago. [“Ayant subi un accident grave, atteint d’une fracture de clavicule et des deux avant-bras (au minimum), cette femme a pu survivre assez longtemps à ses blessures pour consolider ses fractures et ensuite développer une arthrose cervicale. De plus, si on en juge l’aspect des cals et par celui de la tête humérale gauche, elle a dû être affectée d’une impotence fonctionnelle définitive à peu près complète de son membre supérieur gauche et partielle du droit. La survie prolongée de cette blessée grave suppose donc non seulement qu’on ne l’a pas supprimée comme bouche inutile mais encore qu’on l’a soignée et assistée pendant longtemps. Cela implique des notions de solidarité tribale ou familiale déjà bien développée et s’inscrit contre l’évocation d’une vie dans l’abrutissement et la sauvagerie.” (p. 158)]

These sedentary cave-dwellers, considered by Dastugue (*Ibid.*, 155, 175) to subsist mainly on a diet of snails (though this is doubted by Lubell, 2001), might seem a curious and unlikely group of survivors spread thinly through 1500 years. Yet reports still exist in modern times of small, dwindling populations of Africans in particular ecological niches, slightly reminiscent of the Taforalt folk, suffering in common the disabling consequence of probable dietary deficiency. Fuchs et al. (1934, 122-123) described the Elmolo, lake fishers in Turkana Province, Kenya, who “suffer from an almost universal deformity” in their lower legs making it hard for them to walk, probably through lack of calcium.

[16] The physician, missionary and explorer David Livingstone (1858, p. 202) who noted “but one case of hydrocephalus, and a few of epilepsy” during his long residence among native rural South Africans, was struck by their variety of moral character: “They sometimes perform actions remarkably good, and sometimes as strangely the opposite...” This led him to reflect (in October 1855) that “they are just such a strange mixture of good and evil as men are everywhere else”, showing “frequent instances of genuine kindness and liberality, as well as actions of an opposite character” (pp. 204-205). Livingstone might have found a similar balance reflected among white South African physicians 80 years later, debating ‘Eugenic’ views about ‘mentally defective’ people. Dunston (1932) cited data that there were more than 14,000 such people in South Africa. He advocated sterilization, and suggested that “before the white man interfered” eugenic practices had been indigenous to South Africa especially among the Zulus, so that “feeble-mindedness, epilepsy and mental disorders were practically unknown amongst them.” The *SAMJ* published Dunston’s paper, but also a rebuttal by Brown (1932), who argued that “the establishment of special classes both for feeble-minded and retarded children will go much further towards solving the problem of the expense to the State of the feeble-minded than any amount of sterilization.” An Editorial (1932) shared Brown’s doubts, on both scientific and humanitarian grounds.

[17] Molleson (1999) cites work by Etter & Schneider (1982) discussing a Swiss-German practice in the early Middle Ages, whereby weak infants were subjected to a ‘trial by water’ to see if it would be worth rearing them: “only if they cried long and loudly enough - whether exposed or immersed in cold water - were they taken back into society.” While citing examples from here and there, it may be noted that the *locus classicus*, i.e. alleged infanticide among the Spartans, has suffered some debunking among classical scholars, e.g. Huys (1996).

[18] The earliest parental voice found was that of a Turkish father of a boy with hydrocephalus in 1647. Father and son were seen by the famous travel writer Evliya, at Shin Kara Hissar, begging outside a barber’s shop: “the boy was about eight or nine years of age with a stupendous head ... like pumpkins of Adana and cabbages of Ván, on a neck no thicker than an arm, which not being capable of bearing such an enormous weight the head was supported by a wooden fork, which was fixed in the ground, and on it the weight of the head rested.” (The full description is much more detailed). En route from Erzerum to Istanbul, Evliya stopped to hear the father’s story, a mixture of the banal and the superstitious. When the father said that the boy’s mother was again pregnant, Evliya suggested that her body should be bandaged tightly to make her miscarry, because if the new baby’s head was

like its brother's, "its entrance to the world might cause an inconvenient enlargement." To this somewhat rude remark, the father replied, "You are joking, but I assure you most earnestly, that when the mother of this boy laid in with him, the birth was so easy that she was aware of nothing at all and thanked God for such an easy deliverance." (Eвлиya Efendi, transl. von Hammer, 1834, II: 207-208).

[19] Economic hardship in African countries clearly affects a large majority of accounts of family and community care for people with hydrocephalus and spina bifida across the continent. Yet is salutary to recognise that a different poverty may still afflict the person with these conditions in situations of affluence. Gallagher & Stratton (2001) give a detailed history, from hospital records and staff interviews in the United Arab Emirates, of 'Zahira' (a pseudonym), born with spina bifida, resulting in paraplegia, chronic renal problems, and frequent hospital admissions. Amidst great familial affluence, technology and modern services, the young girl can clearly be seen to experience *significant poverty of personhood, relationship and dignity*, apparently being treated by her wealthy parents mainly as a sackful of trouble and nuisance. Her physical care was repeatedly passed between the family, hospital medical staff (expatriates of many countries), and the Sri Lankan maid who did most of the home care, i.e. dealing with incontinence and recurrent urinary infections. The different cultural perspectives, paradigms and practices of these parties turned Zahira's body into a battleground between them all. Her own views and wishes slowly began to be heard as she moved toward teenage years.

[20] The difficulties are recognised in the People's Republic of China, where massive efforts have been made to tackle the national problem of cataract; yet very similar barriers exist as in Africa, including that of cost: "Most of the farmers in rural China have to pay for their own medical expenses ... the average cost is around 2,5000 - 8,000 Yuan per eye ... the surgical cost alone equals 2-4 years of their annual income." (Lin Yan 2006). The 'information approach' to disability service planning has been described by Miles (1993). This involves far more than an increased use of information media. It means analysing all aspects of social responses and service provisions in terms of participants' concepts, knowledge, skills, design and feedback, in order to optimise strategies at every stage.

[21] Mention of these broader preventive measures is evoked by an otherwise slightly ironic aspect to the plea for preventive treatment with folic acid from hospital doctors in Niger (Sanoussi et al, 2001). Whatever may be its national strengths, Niger has one of the world's highest Under-5 Mortality Rates (262 /1000 in 2003; with high rates of wasting and stunted growth), suggesting a very weak Primary Health Care programme. Female literacy in 2000 was reportedly below 10%, the lowest level in the world. The hospital doctors are not wrong to make their plea; yet the basic data suggest that a very great deal of basic survival resources and measures for women's uplift will need to be put in place, before folic acid supplements can be distributed effectively enough to make any noticeable difference.

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**NB For a fuller picture, a few further items are listed that are not cited in the text. Further African references appear in Adeloye (1989), particularly in his chapter on Congenital Malformations, pp. 93-160.**

### Main Abbreviations

<b>Am.</b>	<b>American</b>
<b>DevMedCN</b>	<b>Developmental Medicine &amp; Child Neurology</b>
<b>EAMJ</b>	<b>East African Medical Journal</b>
<b>J.</b>	<b>Journal (of) (of the)</b>
<b>MJ</b>	<b>Medical Journal</b>
<b>SAMJ</b>	<b>South African Medical Journal</b>
<b>Univ.</b>	<b>University (of)</b>
<b>UP</b>	<b>University Press</b>
<b>WAMJ</b>	<b>West African Medical Journal</b>

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Having a child with spina bifida increases the chance that another child will also have spina bifida by 8 times. In about 95% of cases of spina bifida, however, there is no family history of neural tube defects. Research has suggested that many cases of spina bifida can be prevented by adequate intake of folic acid (folate) before and during early pregnancy. However, people with spina bifida appear to have abnormal metabolism of folic acid. The most common complications are tethered spinal cord and hydrocephalus, which can have very severe consequences. Each person with severe spina bifida requires intensive and complex care by a trained and coordinated team. Before turning to the life chances of Africans with spina bifida and hydrocephalus, some hazards facing all African infants and children must be stated. Among 1,000 newly born African babies in 2006, between one and three may have spina bifida and/or develop hydrocephalus. Hydrocephalus and spina bifida have existed in Africa since antiquity. Egyptian and Nubian evidence for hydrocephalus between the 1st century BC and 6th century CE has acquired greater prominence (e.g. Derry 1912-1913, and discussion by Nunn 1996, 79-80; El Batrawi 1935; Armelagos 1969) perhaps because enlarged skulls are an archaeological signal of immediate and obvious human interest; yet pitfalls of interpretation have been detailed by Richards & Anton (1991). Children born into lower socioeconomic families are at higher risk for spina bifida. Researchers think that poor diet may be a factor. What are the symptoms of spina bifida in a child? Symptoms can occur a bit differently in each child. They can include

- Your child may need surgery to: Fix and close the defect. Treat hydrocephalus. Treat bone (orthopedic) problems. Bone problems may include curvature in the back, hip dislocation, ankle and foot deformities, and contracted muscles. Babies and children with spina bifida are also at risk of breaking bones because their bones may be weaker than normal. Fix bowel and bladder problems. Surgery can help with going to the bathroom, incontinence, and constipation, or when the bladder does not empty fully.