



THE DISABLED CHILD IN GHANA

Whose Fault and Who Cares?

J.O. OLIVER-COMMEY

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J. O. OLIVER-COMMEY

Professor, University of Ghana Medical School, Accra, Ghana

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PREFACE

My sincere thanks go to the Vice-Chancellor, the Pro-Vice-Chancellor, Deans of the Medical and Dental Schools, Deans and Directors of Faculties and Schools, Serving and Retired Officers of the University of Ghana, Members of the Council of State and Honourable Ministers of State, Leading Personalities of Civil Society, Invited Ladies and Gentlemen for honouring our invitation to Legon to hear me comment on an issue that I believe should be of great concern to all Ghanaians. I refer to the title of my lecture. *The Disabled Child in Ghana — Whose Fault and Who Cares.*

I wish to express my gratitude to a few persons who have played major parts in my life up to the present day. I will start by remembering people of blessed memory without whose influence I could possibly not have become a doctor but who unfortunately departed this earth before I could reach this high level. These people include — Mr Joseph A Commey, my senior uncle and guardian who tried for years to convince me that it was more important to get a mark equal or close to the perfect score of 100 per cent than being the first among any group of examination candidates; Ataa Doku and Komenye Okailey, my humble parents who did everything within their power to help me overcome my fear of dead persons to study medicine because they were convinced that I would be a valuable asset to our entire family; Professor C. O. Easmon, the UGMS's very kind and fatherly foundation Dean, Professor D. R. Haddock, Professor Kofi Sey, one of the very wonderful and supportive tutors for the so-called 'medical guinea-pigs' of Legon Hall in those early days of considerable uncertainty; and Dr. E. K. Newman and Dr. T. S. Ghosh. May their Souls Rest in Perfect Peace.

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of my research activities. To the various governments and people of Ghana, I say "Thanks a million times" for supporting my tuition from the middle school level through to the university. Without this assistance, I doubt whether I could have acquired the training that has brought me so far. After giving thanks to God, the Almighty for my being, my circumstances and opportunities, and the companionship of my family and friends, I wish to acknowledge my absolute dependence on my wife Naa Sakua and our four children Adjeley, Adjetey, Naa Okailey and Adjorkor by saying: *Nye Fee Nye Yi Wala Donn, Nyɛnmɔ Aadzoo Nye.*

Legon
September 23, 1999

J. O. O.-C.

INTRODUCTION

On a fairly recent visit to a special school for disabled children in Accra, I came across an attempt by a concerned writer of earlier times aimed at addressing society's reaction to its members with sub-normal performance through a relatively simple poem:

WHO IS DISABLED ?

If you fail to See the Person but only his disability,
Then Who is Blind ?

If you cannot Hear your brother's Cry for justice,
Who is Deaf ?

If you do not Communicate with your sister But separate her
from you,
Who is Disabled ?

If your heart or mind Does not reach out to your neighbour,
Who has the Mental handicap ?

If you do not Stand up for the Rights of all Persons,
Then Who is the Cripple ?

Bearing the wisdom of this poem in mind, I doubt whether many of us in the present gathering can confidently describe ourselves as persons without disability.

The World Health Organization (WHO)¹ defines disability as a disadvantage for a given individual resulting from an impairment that limits or prevents the fulfillment of a role that is normal for that individual. The resulting limitations on the quality and quantity of the experience such an afflicted person is able to obtain produce inevitable consequences on his intellect, his emotional development as well as his learning process, which in turn tend to increase his total disability. Because the degree of each person's disability varies with changing circumstances and at different times, the needs of disabled people also undergo adjustment within the limits of their individual capabilities. It is thus healthier, closer to the truth, and more rewarding to think of all disabled persons, especially children as having abilities, limitations, and needs which vary from time to

time depending on the circumstance of their being and that of their socio-cultural environment.

Traditional consideration of disabled children often limits itself to the:

1. physically disabled;
2. visually impaired;
3. hearing impaired;
4. communication disordered;
5. intellectually challenged;
6. learning and behaviour disordered;
7. children with recurrent uncontrolled convulsions, and
8. children with multiple disabilities.

Accepting the broad WHO definition of disability, I wish to suggest for inclusion children with other important disabling states that have existed in Ghana for generations but which have become much more important in recent times, possibly related to the socio-cultural and economic difficulties of our sub-region. These include:

1. socially deprived or economically crippled children,
2. short statured or stunted children, and
3. teenaged mothers.

They currently constitute a sizeable suffering minority in our society whose future depends entirely on their early recognition and possible rescue through social interventions quite different from what have been proposed and adopted for the traditionally-recognized children with disabilities, e.g. re-introduction of scholarship and bursary awards for poor but brilliant students of secondary and tertiary institutions.

MAGNITUDE OF CHILDHOOD DISABILITY

The 1993, Ghana Demographic and Health Survey (GDHS)² reported that among children aged 3–35 months, as many as 27 per

cent were underweight, 26 per cent stunted and 12 per cent wasted. These limitations in physical size, in addition to contributing significantly to Ghana's under-five mortality, also contribute negatively to the outcome of common infectious diseases in children, particularly in the causation of disability.

Depending on the criteria used, the proportion of children considered to be disabled or having special needs varies greatly, but is certainly not less than 10 per cent of the whole childhood population. Rates as high as 15–20 per cent have actually been reported for many developing countries.^{3,4} A pilot community survey on "exceptional" children carried out by the Department of Educational Foundations of the University of Cape Coast in the Agona District of the Central Region in 1987, however, identified only 286 exceptional children within the local population of 131,605 (this constituting 0.2 per cent of the total population).⁵ This finding lends considerable support to the conclusions of a United Nations Expert Group Meeting in Geneva in December 1977, which had observed⁶ that planners of developing countries tended to overlook the needs of disabled persons. They observed further⁷ that this practice of neglect was underpinned by two invalid assumptions, namely,

1. the existence of a prevalent notion that disability affects only a small and specific segment of the total population, and
2. a generally-held view that it requires very expensive and in many cases cost-ineffective procedures to institute prevention and rehabilitation programmes for disabled persons.

These misconceptions are, unfortunately, further buttressed by the claim⁸ that because the social potential of the disabled person was limited, it did not really matter if it remained unfulfilled. As a result of this, many disabled persons are routinely deprived of their human and legal rights with obvious serious ethical and social consequences.⁹

SOCIAL DIMENSIONS OF DISABILITY

Traditional beliefs in Ghana often attribute disability to evil influences or curses within the family. These beliefs unfortunately discourage relations from becoming closely associated with family units in which there are disabled children, thus denying such children many of the social benefits usually associated with the extended family system.

A very worrying aspect of disability concerns the ethical conflicts it often generates, thus leading many people to claim that the disabled existence of an afflicted individual may be injurious to the family responsible for his/her care, should his care create demands and stresses that impede the healthy development of other members.

Researchers^{10, 11, 12} have actually reported that the stresses involved in the care of a severely-disabled child could be damaging to the family in many ways, including the risk of developing difficulties in psychological adjustment as well as marital and economic dysfunction. Society itself has often argued that if an entire family is penalized by the deficit of one member, then the balance of pleasure over pain has been negated as well as the greatest good for the greatest number obviously by-passed.

The problem of disability is unfortunately never a diminishing one; for example, as the management of complications in pregnancy and delivery have become better in our circumstances, the improved curative measures for previously-mortal conditions have increased the prevalence of disability. Disability is, therefore, one of the major problems faced by children in developing countries still struggling with the development of their health delivery systems. Since many developmental defects tend to be minor, they do not prevent most children from leading ordinary independent lives in the very early months. As more children qualify to attend school, the less obvious impairments that involve seeing, hearing, learning and social adaptation become more important.

The unacceptable spectacle of children and adults with disabilities engaged in active begging at the traffic intersections of our cities and towns highlights the inadequate and often unfulfilling

response of the Ghanaian society to issues involving disabled persons. If disabled children are treated with affection and respect, and are given the same rights and support as other children, they will surely grow up to be respected and useful adults in society.

The documented history of the world has records of achievements in various fields by people with disabilities, including Viscount Horatio Nelson, the military genius with multiple disabilities, who commanded the successful English naval fleet in the battles of the Nile and Trafalgar; Sir John Cornforth, the completely deaf Australian-born Nobel laureate in organic chemistry; and Franklin Delano Roosevelt, the greatest American president, who overcame poliomyelitis and dependent on the use of a wheel-chair went on to rule the world's greatest democracy for more than twelve years. The music of the world has rich contributions from people with disabilities including Beethoven, Stevie Wonder, Ray Charles and our own Onipa Nua of blessed memory.

NOTABLE CAUSES OF DISABILITY IN GHANAIAN CHILDREN

Recent research findings^{13,14} from NGOs working with disabled persons in the northern regions of the country have concluded that many causes of childhood disability could have been prevented if parents had followed routine medical advice including ante-natal clinic attendance, prescribed childhood immunizations, and prompt seeking of medical care for the health problems of their infants and young children. Undue reliance on herbalists and direct or indirect self-medication were also noted to be highly contributory to the causation of disability.

Central nervous system involvement complicates almost all childhood illnesses, while neurological disorders account for many of the chronic disabilities in childhood. Chronic childhood neurological disorder was the presenting complaint in 1316 (5.9%) out of the 22,298 new attendants referred to the paediatric service of the Korle-Bu Teaching Hospital (KBTH) in Accra over the ten year period, 1981-1990. The following are the main disease entities managed in children who subsequently became disabled.

Cerebral Palsy

Cerebral Palsy (CP), a disorder of posture and movement often associated with recurrent convulsions, as well as abnormalities of speech, vision and intellect, is a common childhood developmental problem among African children^{15, 16, 17} Three hundred and thirty-three such children were referred to the KBTH children's neuro-developmental clinic over the decade noted earlier. The main clinical events associated with cerebral palsy in these children (Table 1) were

1. delayed or absent cry at birth;
2. feeding difficulties in the early post-delivery period;
3. severe jaundice of the newborn;
4. convulsions in the newborn period; and
5. infections of the developing brain of young children.

TABLE 1

Major Clinical Events Associated with Cerebral Palsy in Children Referred to KBTH: 1981-1992

<i>Clinical Event</i>	<i>Cases (%)</i>
Delayed/Absent Cry at Birth	75 (22.5)
Severe Neonatal Jaundice	61 (18.3)
Intracranial Infections	49 (14.7)
Neonatal Seizures	39 (11.7)
Feeding Difficulties in the Newborn Period	37 (11.1)
Unknown (None)	155 (46.5)

In nearly half (46.5%) of our cases, however, we¹⁸ found no significant abnormality in the pre-natal, birth and early developmental histories or the physical examination to account for the development of cerebral palsy

Paralytic Poliomyelitis

Paralytic poliomyelitis (Polio) has been reported to be the commonest cause of difficulty in moving in West African children with an incidence range of 0.7–0.97 per cent quoted by Ofori-Amaah and his associates.¹⁹ In Ghana, it is the commonest cause of crippling among older children and adults attending a rehabilitation centre in the Accra Metropolis. Though records at the orthopaedic and physiotherapy departments of KBTH over the 1985–1993 period included only 40 childhood cases, reports from the regional capitals, on the other hand, have indicated persistent higher prevalence, especially among pre-school children, in spite of public health reports of high immunization coverage rates using the highly-effective oral polio vaccine. A very worrying aspect of acute polio is the common association of the onset of flaccid paralysis with a history of a provocative local injection immediately preceding the paralysis. On most occasions, the injection was an intramuscular (IM) injection of either penicillin or chloroquine commonly given for a fever of undetermined origin. Since most drugs currently have tablet or solution forms of established efficacy, one fails to understand the need for the widespread use of IM injections in childhood disease management in our health facilities, especially the privately-owned ones.

Congenital Talipes

Congenital talipes (Clubfoot), the commonest congenital deformity of the lower limb, has a rather high incidence in Ghana. The orthopaedic clinic at KBTH registered an average of 44 new cases every year during the 1991–1994 period. Most cases referred early for conservative or operative correction achieved good results whereas those referred much later seldom had satisfactory outcome. In the absence of some corrective manipulation, the ambulatory future of most affected children is invariably bleak.

Accidents

Accidents in children, especially those on our roads, contribute

considerably to childhood disability. Road traffic accidents across the country are closely related to the:

1. deplorable state of many of our road network (often including roads in the inner cities);
2. poor condition and maintenance of most commercial vehicles patronized by the average and lower income groups of workers (especially the *tro-tros*);
3. total disregard for traffic regulations by drivers and pedestrians alike; and
4. unfortunate national habit of condoning vehicular control by drunk and apprentice drivers in the full view of personnel from the embattled Motor and Traffic Unit (MTU) of the Ghana Police Service as well as the Ghana Private Road Transport Union (GPRTU).

Many children fall from great heights in the home, school buildings, and abandoned houses and/or houses under construction with serious damage to the head or spinal column. Many also fall from big trees in the forest or tall coconut trees on our long national coastline, while others fall into deep trenches and industrial excavations in the mining communities and road construction sites across the country. These falls are, very often, associated with serious damage to the skeleton and nervous system leading to recurrent convulsions, limb amputations or paralysis of the spine.

Recurrent Convulsions

Between 1981 and 1992, 60–70 children with chronic recurrent non-febrile convulsions were registered annually at the Korle-Bu children's neuro-developmental clinic, constituting 3 per cent of all childhood consultations.²⁰ As many as 72 per cent of these cases had no clearly associated cause. This figure is not very different from the 60–69 per cent quoted by many African researchers^{21, 22} commenting on childhood convulsions. About a quarter of these

patients, however, had significant association with a confirmed history of obstetric difficulties and/or postnatal brain damage. Convulsions, were in addition, often part of the clinical presentation in children with severe brain damage caused by head injuries or infections of the brain.

Because the majority of our patients were initially controlled with the help of standard anti-epilepsy drugs, many parents unilaterally discontinued therapy believing erroneously that their wards were cured. Subsequent relapse was often managed by the alternate health services including traditional healers, spiritualists and homeopaths thus depriving these children of the benefit of the highly-effective anti-epileptic drugs now available on the Ghanaian market. In addition, the high drop-out rate, from follow-up among such parents/guardians, did not give us the opportunity of determining the long-term outcome of recurrent convulsions in many Ghanaian children.

Recurrent convulsion is a serious disabling condition in Ghana where a child's school attendance can be terminated by a headmaster who fails to recognize that convulsions are neither contagious nor are they visitations from the gods or one's long-departed evil ancestors. Since convulsions can be treated and in many cases completely cured by anti-epilepsy drugs, it should not remain a cause of disability in modern times.

Intracranial Infections

Acute bacterial meningitis, a medical emergency in all age groups (especially in children aged 0-5 years), is associated with about 10 per cent mortality in the developed world and rates as high as 22-40 per cent in developing countries, including Ghana. Many survivors are often left with varying degrees of residual brain damage including deafness, blindness, recurrent convulsions, cerebral palsy, and mental retardation. Unfortunately in a 1992-93 study in Accra,²³ only 8 per cent of children with this dangerous disease secured appropriate referral from their primary care attendants to KBTH within 24 hours of the disease's onset. As many as 20.4 per cent of such patients were actually referred to KBTH eight to twelve days later. The attendant mortality of 22 per cent would have been much

lower with earlier referral. The possible reason for such delays was that the primary attendants did not consider bacterial meningitis as a possible cause of the fever they were treating. In fairly recent times, patients presenting with fever are invariably treated as cases of malaria for varying periods of time, and often without early consideration and exclusion of other possible causes of high fever, especially when accompanied by history of undue drowsiness or convulsions. Furthermore, the organisms isolated, from many of our patients with meningitis, showed significant resistance to the antibiotics prescribed routinely for major infections in many developing countries.

The Ministry of Health (MOH) has recently drawn up plans for the re-training of medical personnel across the country in the performance of lumbar punctures, an essential requirement in the early diagnosis of brain infections. It is my hope and prayer that these plans will be implemented in the very near future. In addition, there is an urgent need for our health authorities to negotiate for appropriate tax exemptions in order to bring the more efficacious and yet more costly antibiotics for treating brain and other serious infections within the purchasing reach of the average Ghanaian family.

Obstetric/Perinatal Problems

Prenatal and neonatal deaths are largely the result of poorly-managed pregnancies and deliveries. Infants damaged at birth often do survive only to become physically or mentally-disabled for the rest of their lives. Most newborns are damaged because of birth injuries (including deprivation of oxygenated blood to the brain), and infections of the brain. The deliveries of many of such children had invariably been managed in environments which lacked the appropriate equipment or clinical competence for carrying out the necessary resuscitative care. Over 60 per cent of delivery units spread across the country that responded to a survey by questionnaires in 1994 were found to be grossly inadequate in this respect.²⁴ Our national health records indicate that the majority of deliveries in the country, especially those in the rural areas, take place either unassisted or with assistance from traditional birth attendants who are

currently equipped with only limited skills in modern newborn resuscitation and early neonatal care techniques.

Under-Nutrition and Social Disadvantage

Under-nutrition continues to be a common clinical phenomenon among the children of most developing countries. Apart from its associated high mortality, under-nutrition tends to worsen the outcome in common childhood infections such as measles, diarrhoea, and respiratory infections (including pneumonia and tuberculosis). Neonatal hypoglycaemia or low blood sugar in the newborn, especially that occurring in the first two days of life, is frequently associated with evidence of brain damage as the child grows older. This particular event is not uncommon in many Ghanaian children born too small for their age of gestation (the proverbial *Akitiboges*) who often have to depend only on weak sugar drinks delivered by cup and spoon for their survival while awaiting the establishment of effective lactation in their undernourished mothers, especially the primiparas.

The socially-deprived, in particular, suffer more significantly from the effects of under-nutrition. The lower parental educational background and income level, accompanied by a social environment devoid of any meaningful stimulation, may be partly responsible for the low primary school enrolment, particularly for girls, and the high-school drop-out rate. Though early schooling is free to all children, inadequate supervision and hunger encourage truancy to such an extent that a sizeable percentage of children aged between 8 and 18 years do not attend school as a direct result of parental poverty, indifference or absence from the home. It is common for families that have migrated to the urban areas to send their children back to the rural areas to stay with their relatives, especially grand-parents, when they fall on hard times. Such displaced-children, generally, lack the necessary discipline to enforce their continued school attendance, hence the high school drop-out rates in peri-urban and rural communities.

Children born to very young mothers are particularly liable to become disabled. These early pregnancies are usually unplanned and often poorly supervised in the ante-natal period. In addition,

most of these teenaged mothers are underfed, anaemic and of poor physique. Their deliveries tend to be difficult and are prone to complications because most of their supervising attendants fail to determine the readiness of such young mothers for the difficult task of the first delivery. These immature mothers subsequently have considerable difficulty with the feeding and care of their children and often fail to recognize the onset of severe disease. In modern times, the cost of management of disease in the infants and children of such young mothers is generally well beyond their economic capabilities, as well as that of their invariably absent spouses or partners. In the absence of an effective comprehensive national health insurance scheme, we can only expect the lot of such children to get worse.

I have often wondered whether these unfortunate children and their teenaged-mothers should not seek legal action against the state and the various women's organizations in the country for exposing them to such trauma and frustration by failing to provide them adequate protection against their unplanned and usually-unwanted pregnancies. With all the recent advances in contraceptive practice and the well-documented increased sexuality of the modern youth,

1. Why have we failed so miserably to offer them the necessary protection?
2. Where are the community family planning clinics?
3. Which Ministry in Ghana has the primary role of protecting the girl-child from premature motherhood?

We need answers to these questions today, not tomorrow. The girl-child has been a loser for far too long.

The Stunted or Short Child

Research in many developing countries have shown that cognitive function, physical capacity and productivity are reduced in stunted children entering adulthood as stunted adults. Stunting, a long-term indicator of nutritional deprivation, is commonly found in children of poor households. Many stunted children, in addition to suffering ridicule from their taller colleagues in school, are much later in life

often denied inclusion in the prestigious sports of modern times — soccer, basketball, boxing and athletics — where millions of dollars or cedis could be earned after only a few hours of exhaustive physical activity. Greater height is similarly preferred for enrolment into the lucrative security services through out the nation. Short statured women also run the risk of obstruction during child birth if their babies happen to be large, a condition we desire and often promote with so much enthusiasm. The safe natural rule is for smaller women to deliver smaller babies, but many such under-sized children succumb early in life or survive with multiple disabilities. Providing extra feeding to the girl-child and adolescent has been advocated for the eventual improvement of the stature of women. We are yet to see the planned food supplementation for adolescent girls and pregnant/lactating mothers become a local reality.

In the absence of the above measures being implemented soon, many more children will become stunted and more deprived of the possible social advantage of greater height.

MANAGEMENT OF DISABILITY

Children with disabilities are still capable of development, even though their development may be slower or may never reach the same standard as other children. With the right orientation and support, many can receive appropriate education and training in our local environment.

Health workers in particular have the important role not only in preventing disability but also in helping to meet the special needs of disabled children and their families. At the very onset, health workers need to be able to recognize these children so that appropriate health care can be given. They need to recognize that many mothers find it difficult to admit or talk about the problem, often fearing that they may be blamed for the child's condition. Most importantly, health workers need to help families to accept that children with disabilities have the same rights as other children, including the right to the same health care such as: Immunization, Growth monitoring, and the Prescription of necessary drugs.

Lastly, children with disabilities have the same needs as other children: Support and Stimulation, Play and Education, and the Company of other children. Disabled children treated with affection and respect, and given the same rights as other children, can and usually do grow up to be useful and respected adults in society.

The secondary and tertiary complications of chronic disability, which appear distasteful to most of us, can be prevented by the early identification of the primary disability and the establishment of an effective management programme. The high degree of plasticity as well as the rapidity that characterizes childhood growth and development make the early years of life the best time to arrest or correct developmental problems of both biological and environmental origin. Babies gain experience right from the day of birth and their parents, being the first to note the progress that results, are the ones who gradually suspect the possibility of a disability through such factors as:

1. the lack of response to the environment,
2. delayed motor development, especially head control, sitting, and crawling;
3. delayed speech and language development, and
4. much later, learning and/or behaviour difficulties at the nursery or kindergarten.

The single and most critical determinant of any child's development is thus the quality of his/her parents, particularly the mother. The nature and degree of the disability, the child's own personality characteristics, and the socioeconomic circumstances in which he grows up are all important, but the mother's attitude to her child will always have a profound influence on the extent of the ultimate disability.

The rationale for early intervention in the management of disabled children lies in the crucial need to maximize such children's potential in several developmental domains. Most disabilities, especially those of cerebral origin, lead to significant delay in

development. Recognition of such delay makes it possible by further examinations to identify the underlying disability and subsequently its cause. The child with developmental delay can be identified by developmental screening examinations.

If children with disability are to be identified early, then all infants and children must have a series of periodic developmental screening examinations during which the growing child is examined to see if appropriate new skills have emerged with the passage of time. If a health worker or nursery attendant finds reason to suspect that a child has delayed development, he/she is expected to refer the child to an expert, usually a paediatrician or a neurologist for further assessment, treatment, and parental guidance

The main components of the developmental screening examination involve the assessment of the child's function in four main areas:

- 1 locomotion and posture;
- 2 vision and fine manipulation of hand and fingers,
- 3 hearing, language and speech development, and
- 4 the performance of everyday skills as well as the development of social behaviour

Certain early clues have been associated with subsequent sub-optimal development, and need to be looked for in all children reporting to a medical out-patients' department (OPD), including the privately-owned ones. These include:

- 1 abnormalities of tone – hypotonia or hypertonia,
- 2 excessive crying or undue silence in a young infant;
3. absence of a social smile beyond the age of 3 months,
- 4 persistent fisting of the hands beyond the age of 3 months,
- 5 absent or poor head control beyond the age of 3 months, and
6. establishment of definitive handedness before the age of 12 months.

Developmental screening examinations are most conveniently carried out at: 3 months, 6 months, 9 months, 12 months, 24 months, and once or twice between 36 and 60 months.

In many countries, most children are seen several times in their first year of life for advice, routine examination and immunization by health attendants at the general out-patients' clinics or 'well baby' clinics. Though the value and interest of these visits could be considerably enhanced by the addition of developmental screening, I doubt whether such screening examinations take place in more than 10 per cent of childhood clinics across the entire country at the moment. Similarly, though the idea of periodic physical examination of children at school have long received acceptance in many countries, the recommended number of such examinations varies in different countries.

Whereas all children in some countries, including the United Kingdom, are carefully examined immediately before or shortly after admission to school, the recommended pre-admission medical check-ups in Ghana are so casually handled by both parents and the school authorities that only very few defects are hopefully detected. The classical yearly determination of the weights and heights of pupils is carried out in only a few schools now. The mandatory requirement of yearly assessment of visual acuity in all first and second cycle school pupils, and the performance of hearing tests on at least two occasions during the primary education years are events of yesterday.

The true picture of intervention in most communities indicates that most children with disabilities start receiving remedial help at a relatively-advanced age?²⁵ Many children with CP were brought to our attention when aged more than two years. The delay in referral for help was often based on:

1. the societal consideration of disability as a maturational delay capable of self correction with time; and
2. the desire for a definitive diagnosis by many medical attendants prior to initiating treatment or referral for help.

In order to improve the lot of the disabled child in Ghana, we must

demand the inclusion of developmental screening examinations at all well-baby clinics across the country.

THE GHANA NATIONAL RESPONSE TO THE DISABLED CHILD

Though many agencies (both governmental and non-governmental) often lay claim to being capable of helping disabled persons, their efforts tend to be too scattered and generally not very effective. Children with disability and their families require a set of services substantially different from those provided for the majority of each nation's children, and our health care and educational authorities cannot escape their responsibility to provide these services just as there is no escaping the presence of disabled children and their families. There needs to be sustained national attention to the broad and specific needs of children out of step with their peers in all spheres of life. There needs to be someone or a group of persons who are responsible for co-ordinating the help given to an individual child and interpreting this to the parents who often remain ignorant of what can be done. Many such parents feel that there is nobody to whom they can turn for advice or to discuss their problems with. Paediatricians²⁶ and child-care givers are among those likely to offer such help since they are the practitioners who get to know a broad spectrum of chronically-ill children and their families. They are thus responsible for

1. informing the family of the child of the diagnosis as soon as possible;
2. offering hope, encouragement and guidance; and if possible
3. ensuring the continuity of care

School teachers,²⁷ particularly those in the kindergarten and lower

grades, also have considerable contact with children and can be another important resource group in the identification and programming of help to disabled children. Paediatricians and teachers can also be a truly-informed and effective voice, articulating to their local communities the need for special services for this population of children. The School Health Programme (SHEP) of the Ministries of Education and Health can play a truly vital role in this regard if it is appropriately programmed and adequately provided with the necessary resources.

Ghana, a nation with its children constituting between 50 and 60 per cent of the total population, currently has less than 20 certified paediatricians providing specialized child care (a paediatrician to child ratio of 1,500,000). There are no paediatricians directly involved with the day-to-day deliberations on child-care from birth through to adolescence in our Ministry of Health, while only a few children, living beyond Kumasi in the Ashanti Region, have access to the services of trained native paediatricians. We are reliably informed, however, that there are well over 50 certified Ghanaian paediatricians (most of whom were trained in our local medical schools) now practising the specialty in parts of the world where the childhood population is much more insignificant. Many of these specialists would have preferred to be working in Ghana but have been kept away by the current low remuneration as well as the rather austere service conditions under which most doctors in the country strive to offer some child care service.

COMMUNITY-BASED REHABILITATION

Since 1960, the various governments of Ghana have been providing diverse services for the disabled but these have had very little impact because:

1. the services being mostly urban-based within specialist institutions do not reach the greater majority of disabled persons who are mostly restricted to the rural areas.
2. the vocational training provided in most government

- rehabilitation centres is unfortunately sub-optimal; and
3. the excellent special education in special schools benefits only a very small number of disabled children, the majority of whom rarely secure satisfactory and fulfilling employment in adult life.

At the request of the Ghana Government, a UNDP delegation visited the country in 1991 to advise on the development of a Community Based Rehabilitation (CBR) programme for people with disabilities. A national CBR programme was subsequently set up in 1992 with special assistance from the Norwegian Association of the Disabled (NAD) and the Swedish Organization of the Handicapped Aid Foundation. It currently receives considerable additional support from WHO, UNESCO, UNDP, and ILO.

The Ghana CBR was integrated into the existing systems within various government ministries with the main expectation that it would mobilize resources directly from within the community for their rehabilitative work instead of being wholly dependent on central government funds and/or donor funding. The CBR was thrown the challenge of improving the quality of lives of children and adults with disabilities within their own communities, be they rural or urban. The main strategic actions were aimed at:

1. raising the awareness of the general population about the disabled;
2. mobilizing resources within the local village community;
3. establishing linkages between service providers in health, education, community development and social welfare down to the village level;
4. strengthening the associations of people with disabilities to enable them to play a role in the mobilization of the community and the implementation of village-level activities; and

5. promoting the human rights of the disabled.

Many well-trained people with disabilities now head the various associations for disabled persons which are actively championing the cause for their members. These include: Dr. B. I. Koray, the blind law scholar and current President of the Ghana Association of the Blind, Mr. Charles Appeageyi, a graduate in English who teaches his classes from a wheel chair in the Queen of Peace JSS at Madina, an Accra suburb, also heads the Ghana Association for the Physically Disabled, Nana Boakye Ofori-Atta, aka Pozo Hayes, a victim of polio is a celebrated musician as well as the current supervisor of a unit in the Personnel Section of the Ghana Lotteries Head Office in Accra, while Mr. Francis Boison, the President of the Ghana Association of the Deaf and his associates are busy developing sign language material suitable for use and training locally. Mr. Halm and his fellow blind colleagues are developing educational text in Braille based on materials currently in use in our regular school system, as well as manufacturing walking aids for local use and possible export within the sub-region.

The Ministry of Health (MOH) has a central role in all aspects of the prevention, management and care of the disabled. It is thus very worrying to note that it is the only major participating ministry without a fully-developed division or directorate. CBR is still an unofficial appendage of its Institutional Care Division without a clearly-designated senior official in charge. An earlier call to the MOH to help develop and incorporate CBR teaching into the curricula of the schools of medicine and nursing across the country is yet to be taken up. Recent visits to both private and public first and second cycle schools in the densely-populated areas of the Accra metropolis confirmed very low enrolment of disabled children, including the highly-educable ones whose major difficulty involves moving. This clearly shows that CBR activities are yet to make any real impact even in the peri-urban areas with better financial and social capabilities.

I am disappointed by society's cool reaction to issues affecting disabled persons. Many professional colleagues and family members behave as if they do not believe that disabled persons have the right to exist, even in their unfortunate state of deprivation.

Two dramatic events have sustained my interest in children out of step with their peers over the past two decades. At an international conference on mental deficiency in Toronto, Canada in 1982, an educable sub-normal child surprised the audience by this simple message: "They call us retarded but we are not retarded. We are slow learners and if given enough time we shall surely achieve our aim". In more recent times in London, England, a teenaged boy of West Indian extraction who had dropped out of school on account of poor academic performance has been discovered to be only the second person in history with two rare talents — one for classical music and another for graphic/technical drawing.

CONCLUSION

I wish to conclude by clearly stating that the prospects for children with disabilities here and elsewhere have never been brighter. Educators and medical experts know much more than ever before about the prevention of many disabilities, especially those caused by environmental and health hazards. Research in human engineering have created the necessary suitable appliances and environmental adjustments in the home and public places for an almost independent existence for most people with disabilities. Currently in Ghana, private initiative is providing excellent but unfortunately expensive training for only a small proportion of disabled children in the very enabling environment of schools such as the New Horizon Special School for Educationally Challenged persons. Appropriate governmental funding of similar special facilities integrated into formal state institutions will improve the chances of many more children.

Anything that can be done to promote a positive and caring approach by parents to the task of bringing up disabled children will contribute materially and psychologically to the reduction of their disability. Once a born child has survived under his own steam and is developmentally on his way to maturity, it is a gross devaluation of him as a human being to deny him help or worse still to confine him to services that are neither rewarding nor stimulating,

but rather oppressive and de-humanizing as existed in the mental homes, religious shrines and psychiatric homes of yesterday, if today as well.

It is important to consider each child on the basis of individual merit rather than on stereotyped assumptions about disabilities.

The stress experienced by the parents of a disabled child, an amalgam of: (1) guilt and disappointed hopes, (2) physical burden, feelings of inadequacy, and (3) anxiety about the future, can be ameliorated by a whole range of supportive measures including: material help, practical advice, wise counselling, and most important of all, continuing interest and understanding from official and community leaders.

It is profoundly important for our nation that:

1. we pay attention to the issue of disabled children;
2. that these children are neither forgotten nor pushed aside,
3. that we retain our belief in the strength of the Ghanaian family, and to an extent appropriate for each child, that we aim at integrating disabled children with people who are not disabled in all activities taking place in the home, at school and in the larger community.

I believe the time has come for every Ghanaian citizen to commit part of his or her dwindling resources towards the 10–20 per cent of our population who are exceptional. We need to approach them with renewed hope and enthusiasm while we anxiously await the completion, acceptance, adoption and implementation of the national policy on disabled persons. We need to encourage the many associations of disabled persons to submerge their differences and rather work together under one national umbrella association committed to the promotion of the collective interests of all, especially those with multiple disabilities. Let us all pay heed to the clarion call of the talented Ghanaian singer Pozo Hayes to the hearing community through his popular song: "DON'T LEAVE ME THIS WAY".

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