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Services for Children with Neurodevelopmental Disorders

The Hong Kong Experience

VIRGINIA WONG and C.Y. YEUNG

Hong Kong is one of the most densely populated cities in the world

The population of 6 million consists mainly of Cantonese-speaking Chinese (> 98%). Hong Kong is also a Westernised city and a cosmopolitan society. Existing health, medical and educational services for children with various neurodevelopmental disorders (fig. 1) are provided at a relatively low cost.

University Model for a Neurodevelopmental Programme

Over the past 15 years the Department of Paediatrics of the University of Hong Kong (HKU) has developed a number of subspecialties. In 1978, with our orthopaedic colleagues, we started a combined clinic for children with neurodevelopmental problems, in particular those with cerebral palsy. Since then, there have been tremendous changes. With recruitment of new staff and the support of the Society for the Relief of Disabled Children, a custom-built child assessment centre was completed at the Duchess of Kent Children's Hospital (DKCH) in 1987.

Based on a combination of US and UK models, our concept was modified to suit local purposes. It is both a ser-

vice and an educational programme for undergraduates and postgraduates. Our design is to integrate child neurology, developmental paediatrics and rehabilitation into a continuum more cost-effective in the diagnostic work-up and delivery of care for disabled children. This seems to be a feasible option due to lack of resources and frequent changes of staff. In order to adapt to local needs, we also provide a spectrum of mixed primary, secondary and tertiary care within the same setting.

The concept of a combined *Neurodevelopmental Paediatrics Programme* is not new but highly feasible for a small place like Hong Kong. It is unique in that this is the only Child Assessment Centre (CAC) and Child Development Centre (CDC) in Hong Kong functioning under 3 administrative bodies: the Hospital Authority (formerly the Medical and Health Department), the University of Hong Kong and the Society for the Relief of Disabled Children. This may not serve the best purpose for some countries, but it may be a useful model for places where efficient running and organisation is needed with only limited resources.

Child Assessment Centre

The programme started as a pilot project for cerebral palsy children. Initially run bi-weekly with a neurologist, an orthopaedic surgeon and

allied health professionals (clinical psychologist, physiotherapist, occupational therapist, and medical social worker), since 1978 this clinic has operated in the DKCH. The programme subsequently evolved to include a full-time neurologist/developmental paediatrician from the Department of Paediatrics of HKU. The CAC, started in 1982, became fully functional by 1987. The team consists of neurologist/developmental paediatricians, clinical psychologists (CP), speech therapists (ST), audiologist, optometrist, physiotherapists (PT), occupational therapists (OT), medical social workers (MSW) and nurses.

The team conducts multidisciplinary and interdisciplinary assessments for children referred with various developmental and neurological problems. The neurological programme provides investigative and diagnostic services. This includes neurophysiological techniques like brainstem auditory evoked potential, visual evoked potential, somatosensory evoked potential, nerve conduction study, electromyography, paperless electroencephalography, ambulatory electroencephalography and video-electroencephalography. We also provide an ambulatory muscle biopsy programme under local anaesthesia for children with suspected neuromuscular diseases. Multidisciplinary clinics are held to coordinate the delivery of care for

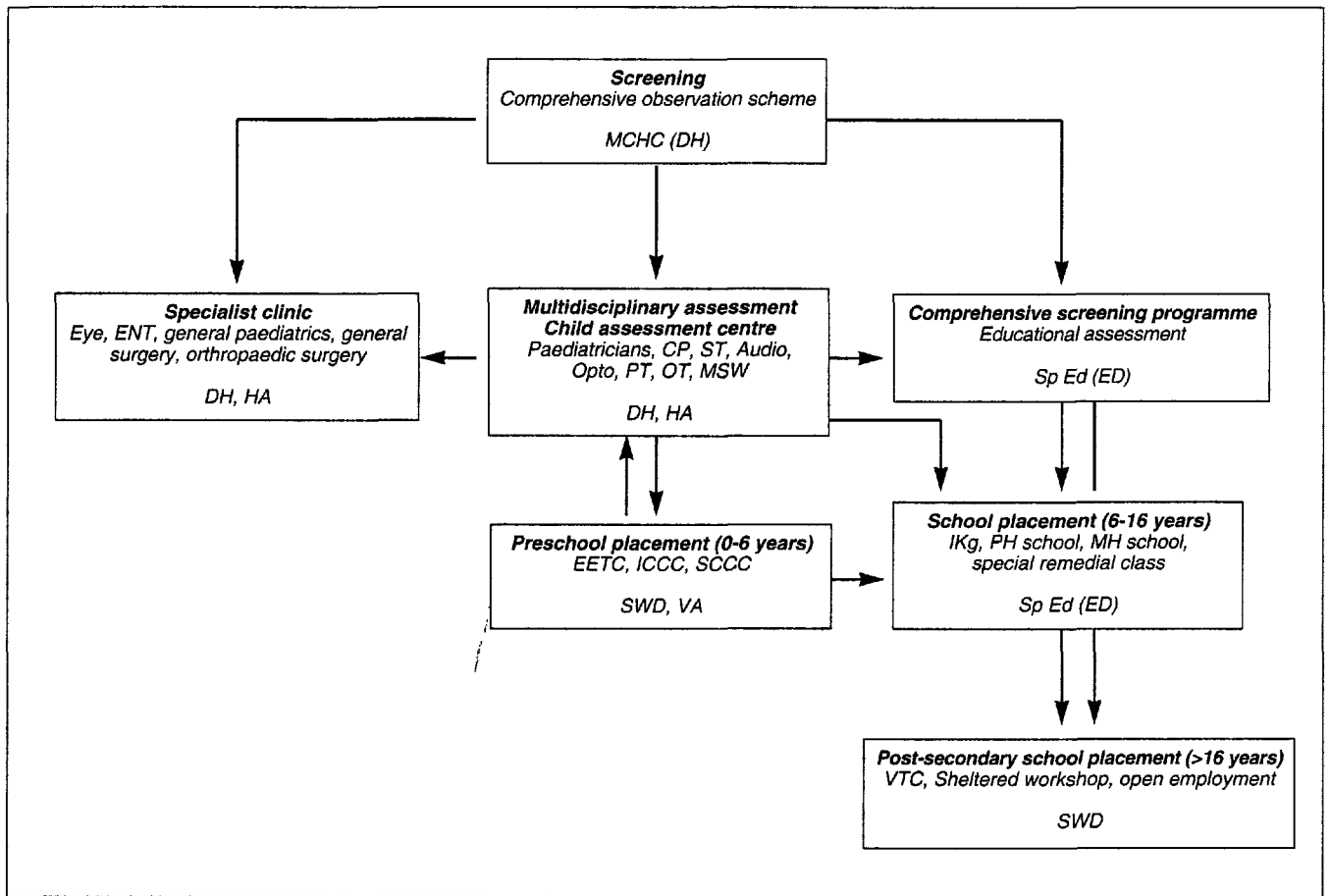


FIG. 1. Existing services in Hong Kong for children with neurodevelopmental disorders. Abbreviations: MCHC = Maternal and Child Health Clinic; DH = Department of Health; HA = Hospital Authority; SWD = Social Welfare Department; VA = Voluntary Agency; ED = Education Department; Sp Ed = special education; EETC = Early Education and Training Centre; ICCC = Integrated Child Care Centre; SCCC = Special Child Care Centre; IKg = integrated programme in kindergarten; VTC = Vocational Training Centre; PH = physically handicapped; MH = mentally handicapped; CP = clinical psychologist; ST = speech therapist; PT = physiotherapist; OT = occupational therapist; MSW = medical social worker; Audio = audiologist; Opto = optometrist.

children with cerebral palsy, spina bifida, neurocutaneous diseases, neuromuscular disease, dysmorphism etc.

The CAC functions within the network of Queen Mary Hospital (QMH), a major University teaching hospital, where back-up services are available; these include biochemistry, haematology, pathology, radiology and consultative services from all the major disciplines of the Faculty of Medicine, e.g. orthopaedic surgery and psychiatry. Regular combined neurology/neurosurgical clinics are conducted for children with various disorders, e.g. hydrocephalus, spina

bifida, brain tumours.

The main sources of referrals are from the MCHC, general paediatric clinics, paediatric specialty clinics, and orthopaedic clinics. Urgent consultations are held after initially screening the relative urgency of the problem over the phone. A Developmental Screening Clinic identifies problems which need urgent attention, e.g. autistic features, hearing or visual problems, and social problems. Children suspected of having various neurodevelopmental disorders, e.g. autistic, hearing or visual impairment, or psychosocial disorders, are seen in the centre. We

also assess those with delay in speech, gross motor or fine motor activities.

Children at risk of neurodevelopmental problems are also referred to us for comprehensive assessment, including very low birthweight babies and perinatal asphyxia. Not infrequently, children with emotional problems, conduct disorders or school failure are referred by their teachers as well.

We perform 'sequential multidisciplinary assessment' for the more severely disabled, e.g. those with cerebral palsy, autistic disorder, attention-deficit-hyperactivity disorder.

der, multiple handicap, etc. These conditions often take several sessions, over a few days, to complete. For children with mild problems, such as those with speech delay or mild developmental delay, we perform 'selective assessment' to avoid wastage of resources. For the children who were screened in the MCHC setting, we are providing secondary and/or tertiary assessment depending on the type of disability.

Child Development Centre

Started in 1988, the Child Development Centre became fully functioning by 1994. This centre provides 43 beds for a comprehensive neurorehabilitation programme for children with physical and/or other developmental handicaps. Also, there are convalescent beds, day care beds and respite care beds for children suffering from various chronic medical disorders. Both ambulatory and residential facilities are available. 'Sleeping-in' quarters are provided for mothers.

The CDC also provides an early intervention programme consisting of individual and group training for children with developmental disorders. The group training includes conductive education for cerebral palsy, social communication for language disorder or autistic disorder, play therapy for global delay, a home-based articulation programme for articulatory disorders, and parent sharing groups. Case managers from allied health professionals are assigned to individual children and groups to coordinate various therapeutic manoeuvres.

Children with neurological problems who may receive training and rehabilitation at the centre include those with post-traumatic brain injury, brain or spinal cord tumours, post-meningitis/encephalitis, transverse myelitis, post-cardiac arrest, post-cardiac surgery especially open heart surgery with neurological complications, and sequelae of extreme low-birthweight babies.

Although the CAC/CDC is located on Hong Kong island, referrals are received from other regions of Hong Kong and Macau. Besides Chinese, children of other ethnic origins are also treated in the centre. The main age group is preschoolers, especially 2- to 3-year-olds. The majority of children seen are boys from middle-class families.

Parent/Caretaker Participation and Education

We encourage active participation of parents and caretakers in our programme. Parental involvement and support are essential for the comprehensive care of these children, not only at home but also in the centre. Sibling participation is strongly encouraged wherever possible. We want to ensure that the therapeutic techniques learned in the centre can be used at home. Brochures and information about the centres and services available in the 'Resource Corner'. Parents who need privacy for airing their problems, shedding tears or emotional support are accommodated in a small cosy room within CAC or CDC.

Parent groups such as Epilepsy Parent Group, Autistic Disorder Parent Group, Language Disorder Parent Group and Duchenne Muscular Dystrophy Parent Group have been organised.

The Physical Facility

We have been fortunate that our hospital (DKCH) is a low rise building, 2 to 3 storeys high, situated at the edge of Sandy Bay, where there is plenty of open space. The hospital started as a small convalescent hospital in 1953 and is now a 150-beds children's hospital. It is unique in that it has its own garden, fountains and playground for recreational purposes. Our CAC was built on the ground floor for easy access for children with physical disabilities. The offices are within walking distance, enhancing communications among professionals of different disciplines. The CDC training area, situated on the first floor, is

colourfully decorated for multi-training purposes. Sign-posted areas are specially designed to promote a more positive functional attitude for the children. Designations such as 'dreamland' for sleeping, 'fantasy land' for play activities, feeding area, bathing area, 'good morning corner' for face washing, tooth-brushing or toileting are used to enhance a children-friendly environment.

Our Staff

The Paediatrician's Role:

The paediatrician assumes the leadership role providing the directions for the team and engendering comradeship and a sense of belonging within the unit. The paediatrician is also a constant member of the team, ensuring efficient running and coordination of the various allied disciplines. Each team member is identified and assigned responsibilities.

Other Team Members:

Other team members include: 2 clinical psychologists, 2 speech therapists, 2 occupational therapists, 2 physiotherapists, 1 audiologist, 1 optometrist, 2 medical social workers, 4 nurses and 4 clerical staff. Equipment and aids for feeding, dressing, bathing, incontinence, and mobility are tailor-made for children in the hospital. Adaptations within the home setting are emphasised. The Prosthetic Department provides the supporting facilities for measurement and manufacture of special seats and locomotive aids.

Aids for postural control and mobility, and regular hydrotherapy sessions, are provided for children with cerebral palsy, neuromuscular diseases, or clumsiness in locomotor activities.

Intellectual and psychological assessments, family counselling and therapy, and bereavement therapy for children and their families are conducted by the CP. An audiovisual room for observation and training purposes has been constructed for children with behavioral problems. Our CP visits schools where there are children with special needs.

Our ST conduct assessment of speech and language function and provide articulation therapy for those with disarticulation. Methods of behavioural reinforcement improve the outcome of children with expressive language problems.

The audiologist routinely screens at-risk children for hearing problems. The distraction test or conditioning test is used. Behavioural audiometry, tympanogram, otoacoustic emission audiometer, and brainstem auditory evoked potential are also used to document the type and degree of hearing impairment.

The optometrist performs visual screening using the STYCAR mounted ball test, optokinetic drum, preferential looking test, 1mm beads, STYCAR 5-, 7-, 9- letter matching test, toy matching test, or picture matching test depending on the chronological age or developmental age of the child. He also performs detailed optical assessment including slit lamp examination, fundoscopic examination, test of stereoscopic and colour vision, and checks visual acuity. Electrophysiological techniques such as visual evoked potential and electroretinogram are also available.

The MSWs conduct parent groups, family counselling, and support and information services. Day and short-term care are provided, including holiday outings for families, birthday parties, short-term residential care and emergency care. Home visits with other team members are also arranged for those in need. Disability allowances, compassionate rehousing, and reunion of families with mothers in China who have difficulty coming to Hong Kong are arranged.

Nurses provide most of the daily coordination work of our CAC, with another team of in-patient nurses running in-patients' care. The growth parameters of the children, including head circumference, bodyweight, and body height are regularly monitored by the nurses. Health care assistants are trained to perform some of the less intense daily routine care of the children. 4 clerical staff provide the

secretarial support for the unit, including the Central Booking Services, and typing of reports.

A number of assessment tools are available at the centre. They include the Griffiths Mental Developmental Scale, Symbolic Play Test, Bayley Scale of Infant Development, Weschler Preschool and Primary Scale of Intelligence, Hong Kong Weschler Intelligence Scale, Stanford Binet Test, Reynell Language Developmental Scale, Reynell Zinken Scale for the Visually Impaired, Luria-Nebraska Neuropsychological Test Battery, Watkin Bender Gestalt Scoring System, Derbyshire Language Scheme Picture Test, Bankson Language Test, Test for Auditory Comprehension of Language and Leiter International Performance Scale. A computerised Gait Analysis Machine is also available to provide objective analysis of the stance and swing phases of gait in children with cerebral palsy or neuromuscular disorder to plan the procedure and monitor the success of surgery to the joints or limbs.

We also have a photographic service and a toy library which provides loaning of toys for educational, therapeutic and recreational usages. Currently this service is under separate disciplines.

The Hong Kong Red Cross provides the education for hospitalised children, especially those who require prolonged stay after orthopaedic surgery; they also have a school library service for these children.

Allied Services

Children are referred to the available special services in the community depending on their age, disabilities, and special needs. Preschool training services including the Early Education and Training Centre (EETC), Special Child Care Centre (SCCC) and Integrated Child Care Centre (ICCC) are organised by the Social Welfare Department (SWD). Children aged 6 years and above, including those with behavioural problems, have to be referred to the Special Education Section of the Education Department

(ED) for admission to schools for mental handicap (MH) or physical handicap (PH), blind or visual impairment and hearing impairment. Special provision for autistic children is provided in both special child care centres and mentally handicapped school settings.

Undergraduate and Postgraduate Training

Our centre is the training centre for the medical undergraduates of HKU and postgraduates for the 2 subspecialties of child neurology and developmental paediatrics. Trainee paediatricians of the Department of Paediatrics of HKU are rotated through the training programme for a period of 3 months before sitting the conjoint Hong Kong and MRCP (UK) examination. Fellowship training programmes are also offered to local doctors and those coming from other Asian countries including China, Philippines and Macau.

Other professionals also utilise our centre for training. They include clinical psychologists and educational psychologists from HKU, speech therapists from The Department of Speech and Hearing Science of HKU, medical social workers from the Chinese University of Hong Kong, the Polytechnic University and the City Polytechnic University.

Research Activities

Research is an integral part of our centre. Current interests have focused on epidemiological study of:

- myasthenia gravis in Hong Kong
- DNA analysis of Duchenne and Becker muscular dystrophy
- language and behavioural problems in preschool children of Hong Kong.

Also studied are children with:

- autistic spectrum disorder
- attention deficit hyperactivity disorder
- intractable epilepsy (the use of new anticonvulsants)
- neurofibromatosis
- thalassemia (neurophysiological study)

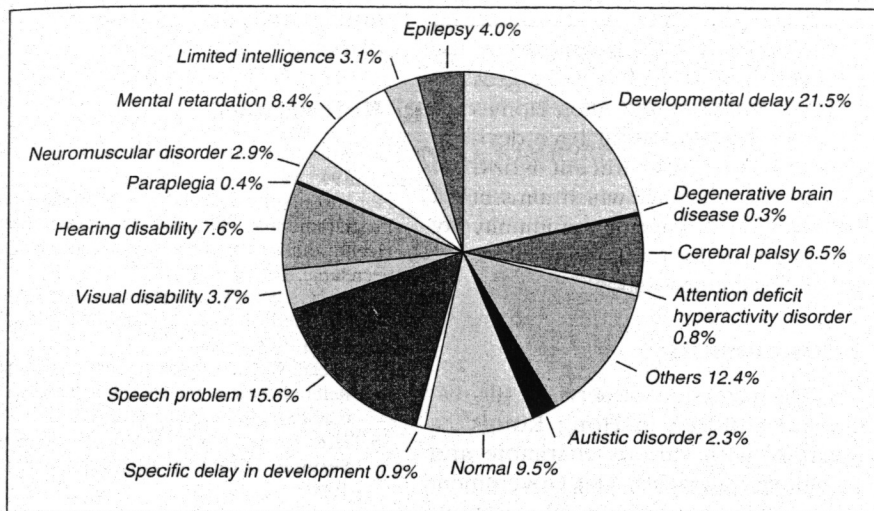


FIG. 2. Types of neurodevelopmental disorders.

- Down's syndrome (ocular abnormalities)
- very low birthweight babies (neurodevelopmental outcome)
- cerebral palsy (intramuscular botulinum injection).

Our Cumulative Experience

Around 6000 children had been assessed in our CAC over the past 15 years (1980-1995). The children had various problems such as: global developmental delay, language delay or disorder, mental retardation, hearing impairment, cerebral palsy, epilepsy, visual impairment, limited intelligence, neuromuscular disorder and autistic disorder.

Other rarer neurodevelopmental disorders were also seen including specific delay in development, attention deficit hyperactivity disorder, conduct disorder, spina bifida, degenerative brain disease and tic.

The types of neurodevelopmental problems are illustrated in figure 2.

Mental Retardation

The majority of children with severe mental retardation (MR) were those with Down's syndrome or other syndromal disorders. Only a

small number of boys had Fragile X syndrome detected by chromosome studies. Most of those with mild grade MR had no specified causes. Family history of MR was also rare. Routine baseline investigations for all the children with unspecified MR have included serum thyroxine, TSH, lead, chromosomal study, urine for amino acid, and metabolic screening. However, the positive yield was low.

Ongoing studies of molecular genetic analysis of DNA for trinucleotide repeat in all children with unspecified MR are undertaken to delineate more accurately the prevalence rate of Fragile X syndrome in our male MR population.

Cerebral Palsy

The commonest type of cerebral palsy (CP) was spastic diplegia (28%). Other types included hemiplegia (24%), spastic tetraplegia (18%), dyskinetic (12%), mixed (9%), ataxic diplegia (5%), and bilateral hemiplegia (4%).

Autistic Disorder

The majority of children with autistic disorder (AD) were referred to us at 3 years when failure of speech development was causing concern. Most parents were unaware

of the unusual autistic behaviour of their children.

Change in Disease Pattern

We have observed a changing pattern of developmental disease over the past decade. It is difficult to attribute such change to the result of actual real increase, or a result of heightened awareness by the public or the medical profession.

One of the important contributing factors is the change in child-rearing practice over the past 3 decades. In the past, extended families with 3 generations often lived under the same roof, sharing facilities and emotional burdens among a large number of family members. Now, dramatic changes have occurred; young couples tend to form small, nuclear family units. They live in their own small apartments, depending heavily on help from inexperienced domestic helpers from Philippines, Thailand and Indonesia, who speak different dialects and 'handle' their children in non-traditional Chinese ways. Also, children are exposed to new electronic gadgets like gameboys, television, videos and CD-ROMs. Instead of 'tender, loving care' with the emphasis of a strong family tie, fidelity and loyalty, which the older generation of Chinese culture passed on, we now witness the 'mercenary care' that the young ones are receiving. There are less interactive and communicative skills amongst people. The multilingual and multicultural exposure may be contributing to the dramatic increase in children with language delay or other communicative disorders. It may also exacerbate the increase in many neurodevelopmental disorders, e.g. autistic behaviour, attention deficit syndrome, hyperactivity and conduct disorders, which have occurred over the past couple of decades in this locality.

One cannot exclude the possibility of environmental factors, e.g. pollution and infections, exerting an effect on the developing brain in the

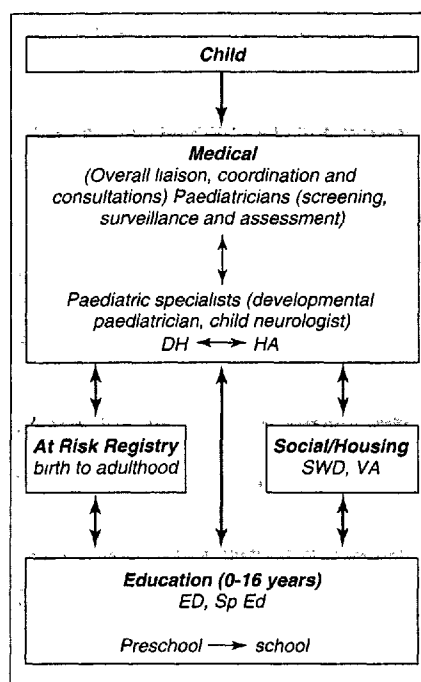


FIG. 3. Ideal services in Hong Kong for children with neurodevelopmental disorders. Abbreviations: DH = Department of Health; HA = Hospital Authority; SWD = Social Welfare Department; ED = Education Department; Sp Ed = Special Education; VA = Voluntary Agency.

prenatal or postnatal period, thus causing an actual increase. With the rapidly escalating advancement of molecular genetics in recent years, it will not be long before we can understand more fully the genetics of neurodevelopmental disorders also.

Recent Establishment

Due to increasing public demand, the Hong Kong Government has decided to expand the services for severely mentally handicapped children and adults. The number of beds for these patients in two community hospitals has been designated to

increase. The SWD has also improved the services for these patients by the establishment of Day Care Centres (DAC) and Care and Attention Homes (CAH). These undertakings have deviated a little from the recent world trend for rehabilitation which aims at integration of care in the community through 'deinstitutionalisation' rather than 'institutionalisation'.

Conclusion

The provision of services for disabled children in Hong Kong lies mainly with various charitable and voluntary agencies. The Government has usually been drawn into supporting certain targeted programmes started by these agencies. There is a lack of coordination of various services to ensure continuity of care. It is about time that a better coordination of services for disabled children, from birth to adulthood should be introduced (fig. 3).

The following suggestions deserve consideration for implementation:

1. Interested parties from the respective departments should 'sit together' and agree on the best approach to provide care for our disabled population, in terms of redistribution of funding and staff to be more cost-effective.

2. A proper legislative statement should be drawn up, to avoid duplication and fragmentation of these services.

3. A Statutory Central Registry needs to be established so that accurate data can be collected to form the basis of better planning and implementation of services. This is particularly urgent, to ensure that when Hong Kong returns to China in 1997, a service is available to cope with the possible influx of handicapped children from China who may have been deprived of rehabili-

tation and social services in their places of origin.

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