

# PAEDIATRIC NEUROLOGY AND CHILD DEVELOPMENT SERVICES IN SOUTH AFRICA

April 2003

## Introduction

There are an estimated 18 million children in South Africa, 10% will have significant neurodisability (WHO guidelines) i.e. 1.8 million children in South Africa who should be seen by a specialist in paediatric neurology and / or child development. There are current 11 full-time and five part-time specialists based in government practice attempting to provide this service. This means that each specialist is responsible for some 133 000 affected children. The above figure is likely to be an underestimation of the increasing burden of disease from HIV and TBM. All children with HIV have neurodisability, (data collection, Red Cross Children's Hospital). Tuberculous meningitis is the most prevalent form of meningitis in the Western Cape and most probably South Africa.

More trained doctors are needed to reduce the patient to specialist ratio and attempt to tackle effectively the huge burden of disease. Clearly both paediatric neurology and child development are in dire need of *expansion and transition*, not just *basic strengthening*. For the purposes of National needs there is much overlap in the running of Paediatric Neurology and Child Development services. Although many of the specialists cover both areas this is a massive task and the services should be recognised as separate specialities. The specialties are complementary and function best with specialists able to concentrate on one area and support colleagues in the other, both fields cover a diverse and complex range of disorders.

Five out of the nine provinces have no established paediatric neurology or child development service (Limpopo Province, Eastern Cape, Northern Cape, Mpumalanga, North Western Province). Targets must be set to train sufficient numbers of staff to consolidate established services and to create services in the remaining five provinces. More training posts and subsequent specialist posts must be created.

## STAFF COMPLEMENT

### Western Cape: Two centres (Red Cross Children's Hospital & Tygerberg Hospital)

Full-time specialists: n=4

Part-time specialists: n=2

### Bloemfontein: (Universitas Hospital Bloemfontein)

Full-time specialists: n=2

### Gauteng: (CH Baragwanath Hospital, Johannesburg academic complex & Pretoria)

Full-time specialists: n=4

Part-time specialists: n=1

### KZN Durban: (King Edwards Hospital & Inkosi Albert Luthuli Central Hospital)

Full-time specialists: n=1

Part-time specialists n=2

### Total n=13<sup>1</sup>/<sub>2</sub>

Limpopo Province, Eastern Cape, Northern Cape, Mpumalanga, North Western Province No specialists

### Trainees: n=2

*Ideal requirements would be **minimum 36** specialists, aiming for one specialist for every 50 000 **affected** children- a reasonable generous request considering the European figures (1 specialist for every 300 000 of the **general paediatric population** i.e. not necessarily affected).*

### Other needs:

**Medical officers** – this is a huge untapped resource. Doctors based in the secondary and primary sector should be given the opportunity to form an interest in an area. Neurology is ideally suited for this. These doctors could then become the contact link in each regional centre, assisting with satellite clinics and being “trained” by the outreach specialist (who currently exists at a sub-optimal level due to lack of numbers).

Ideally each secondary level service should have a doctor affiliated to the speciality to act as a link with the outreach specialist (who supports a number of regional hospitals).

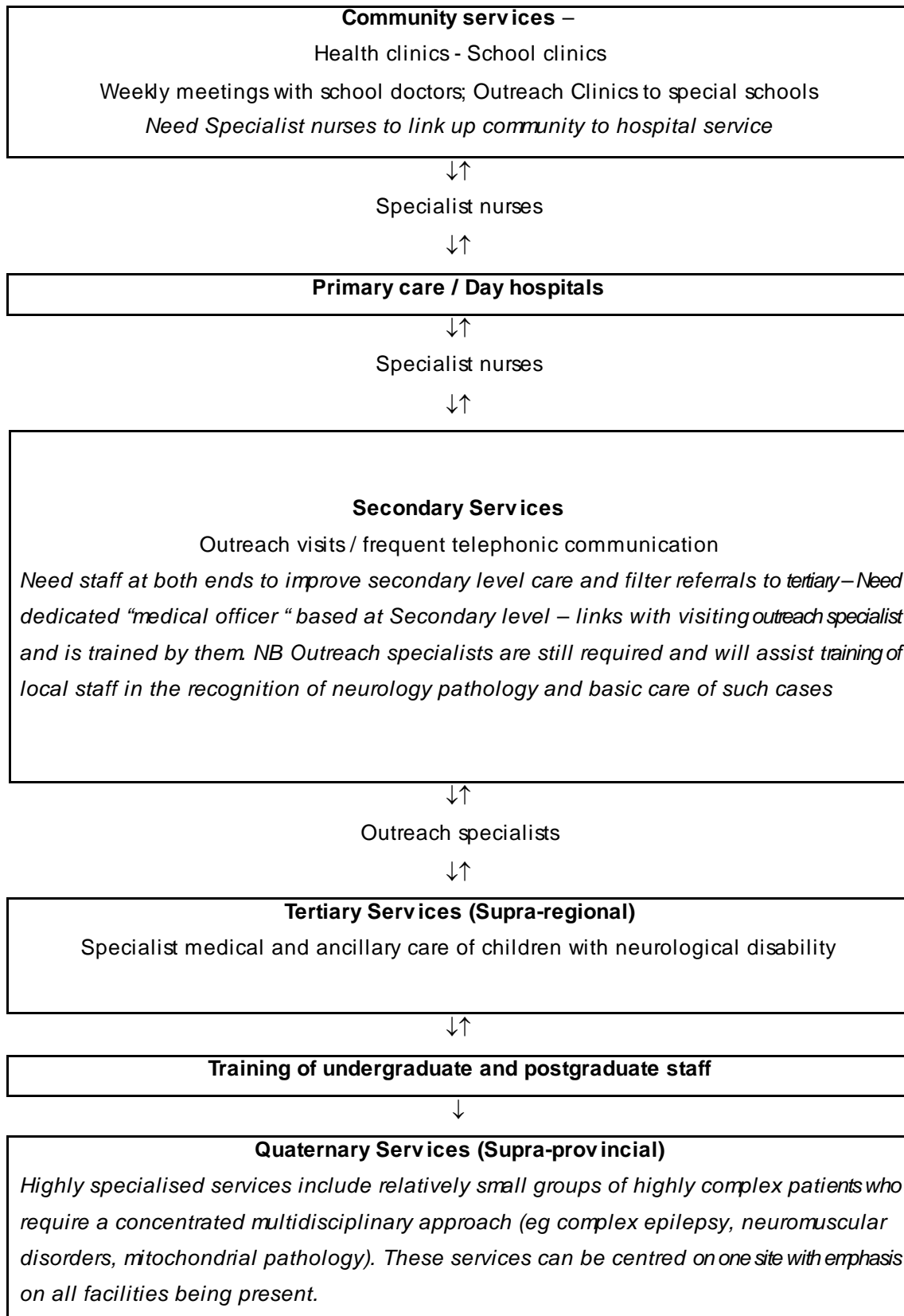
**Neuropsychology:** There basically is no neuropsychology support service available to specialists in paediatric neurology and child development. The few which exist are affiliated to child psychiatry and have their time dominated by these patients. Every tertiary centre requires at least two neuropsychologists, one for the cognitive mapping tests and the other more for the neuropsychological support required by many children with neurological disability e.g. adjusting to having a hemiplegia, especially if the dominant hemisphere is involved and the language centre is involved – children with neurodisability are very susceptible to behavioural problems. With the advent of epilepsy surgery - a potential cure for some children with seizure disorders – this service cannot reach its full potential without neuropsychology support.

**Nursing** – Specialist nurses could provide significant support throughout the service – linking the primary and community services through to the tertiary and quaternary level services. These practitioners could visit the homes and schools, enhance communication, be involved with counselling and improve access to hospital care. They could assist in training other nurses and generally raising awareness. Examples of ideal areas badly in need of such resources are epilepsy, tuberculous meningitis, and neuromuscular disease. Ideally each tertiary centre (supra-regional) needs two such nurse specialists to support the service.

**Speech therapy, physiotherapy, occupational therapy and dieticians.** Putting this group together is a **disservice** to them – however their needs are very similar. Within the field of child development and paediatric neurology these practitioners in the tertiary centres have a high level of expertise. Their level of knowledge and excellence of patient care is not appreciated in the government sector and we are losing these skilled specialists in droves to the private sector or abroad. Recognition of their experience must be provided by promotion and staffing numbers must be maintained to allow them to provide the appropriate level of care. An excellent example of this use is through a neuromuscular service – a specific physiotherapist is affiliated to the clinic and has skills in posture and motor disorders – assists with seating, contracture and scoliosis avoidance, links with the special schools to ensure continuity of intervention is maintained. Within the dieticians service there is an increasing need in tertiary centres to provide the ketogenic diet regimen for severe epileptic patients – a dedicated and well trained dietician is integral to this, he/she spends up to 40 hours per patient calculating diet schedules and continues to support the family over the subsequent 2 years they remain on the diet if it is successful.

**Neurophysiology technologists.** The art of interpreting and indeed performing neurophysiological investigations in children is fraught with difficulties. As children's brains and peripheral nerves mature so do the findings from the tests. At the current time there has not been a single trainee passing through a dedicated paediatric centre for 5 years. Accordingly most of these investigations (EEG, Nerve conduction studies, Brain stem evoked potentials, Visual evoked potentials, Electroretinograms) are performed by practitioners in an adult environment not confident in performing such tests on children and unlikely to be formally trained in the interpretation of such studies. Any centre with the facilities to perform any of these electrical studies must have at least one technologist with formal training in paediatric electrophysiology.

## Paediatric Neurology / Child Development Flow Diagram



### Summary of Current Centres

Centre	Service	Staff complement	NOPD (children seen per yr)	Inpatient (per yr)	Outreach (per yr)
Tygerberg	Paed neurology and Neurodevelopment	Specialists (n=2) <sup>5</sup> / <sub>8</sub> specialist (n=1) Rotating reg (n=1) Sessions (n=3)	1992	279	330
Red Cross	Paed neurology	Specialist (n=1) <sup>5</sup> / <sub>8</sub> specialist (n=1) Sen registrar (n=1) Sessions (n=6) Neurophysiology technologists (n=2) Nursing (n=2)	4200	280	150
Red Cross	Child Development	Specialist (n=1) Sen registrar (n=1) Sessions (n=13.5) CP physio sessions (n=16)* Social worker (n=1+1*)	2310 (docs)  5388 (ancillary team)	-	198
Johannesb urg	Paed Neuro / Child Dev	Specialist (n=3) <sup>5</sup> / <sub>8</sub> specialist (n=1)			
<u>Johannesb urg (TMI)</u>	<u>Child Development</u>	<u>Specialist : 1 full time</u> <u>Sessional specialist</u> <u>8 hours per week</u> <u>Sessional medical</u> <u>officer 20 hours per</u> <u>week</u>	<u>2841</u>		<u>Professio</u> <u>nals</u> <u>trained</u>  <u>About 300</u>
Pretoria	Paed Neuro /Child Dev	Specialist (n=1)			
Bloemfonte in	Paed Neuro /Child Dev	Specialist (n=2)	1297	125	None - no staff
Durban	Paed Neuro /Child Dev	Specialist (n=1) <sup>5</sup> / <sub>8</sub> specialist (n=2)	2700	240	100

*Additional 10% increase in work-load every year for last 3 years. Services now becoming saturated – see waiting lists in tables below. \*Funding from outside source for post*

## **TERTIARY SERVICES:**

### **Role of Paediatric neurology service**

*Vision:* The diagnosis and management of children with *progressive* neurological disorders To provide comprehensive support to affected families.

*Mission:* To aim for a cure but also to maximise the affected child's potential and quality of life, preventing secondary complications via a comprehensive a multidisciplinary approach to the whole family. To assess for potential genetic implications and aim towards prevention of disease.

Availability of the following services are essential at a tertiary level at all Supra-Regional Centres. The service load and waiting lists that follow after, demonstrate the need for this

Main conditions managed:

- Epilepsy and associated paroxysmal and non-paroxysmal disorders
- Neurodegenerative disorders
- Neurometabolic conditions
- Neuromuscular disorders
- Neuroinflammatory disorders (eg ADEM, MS)
- Acute and life threatening neurological disorders including all acute encephalopathies, raised intra-cranial pressure and neuroinfective and post infectious disorders such as Guillain Barré syndrome
- Headache
- Behavioural disorders
- Assessment of Learning and associated difficulties (school age children)
- Assessment and management of a variety of other disorders including neuro-cutaneous syndromes, chronic CNS infections etc.

### **The role of the Child Development and Neurodevelopmental service**

*Vision:* The diagnosis and management of children with *static* neurological disorders.

*Mission:* To maximise the child's potential and quality of life with a comprehensive approach to the whole family and to potential genetic implications using a multidisciplinary approach.

*The developmental service has a critical role in the training and support of other disciplines. As part of (or to lead) the multidisciplinary team in the development of intervention programmes to maximise the life of the child with a disability including the emotional or physical trauma due to child abuse .*

Main conditions managed:Cerebral palsyDevelopmental delay secondary to static encephalopathiesAssessment of learning difficulties (pre school age). Assessment of school going children to exclude, diagnose or manage medical problems which contribute to or cause the learning disability e.g. ADHD, epilepsy, brain damage.Spinal defects and associated congenital CNS defectsBehavioural disordersAssessment and management of the child who had a visual or hearing impairment.Assessment and management of cases of child abuse of a more complex nature especially where the child has a disability.~~Main conditions managed:~~~~Cerebral palsy~~~~Developmental delay secondary to static encephalopathies~~~~Assessment of learning difficulties (pre school age)~~~~Spinal defects and associated congenital CNS defects~~~~Behavioural disorders~~**QUARTEARNARY SERVICES:****i. Western Cape****Tygerberg:**

- **Infections of the CNS**, including tuberculous meningitis (TBM), HIV, Cryptococcosis, “shunt” infections.
- **Acute encephalopathies**, Acute raised ICP, acute demyelinating disease. Coordinating of special investigations and investigations.
- **Acute neurology of the newborn**, including HIE, intraventricular haemorrhage, early genetic counselling.

**Red Cross Paed Neurology**

- **Epilepsy and Epilepsy Surgery**– > 60% of our case load is epileptic (approx 2800 per year) of these some 300 have intractable epilepsy (ie failure to respond to anticonvulsant therapy). For these patients we are evolving a “comprehensive epilepsy approach”. Patients are reassessed in detail with appropriate avenues followed – potential alternative anticonvulsants, delineation of seizure type – via videotelemetry, MRI, spectroscopy, and potential surgical candidates are identified. We are referred patients from throughout the country.
- **Neurophysiology department.** Within the paediatric neurology service there is a dedicated paediatric neurophysiology team. The technologists are training in performing and interpreting studies on children. They perform EEGs, NCS, EMG (with medical

support), VEP, ERG and BSAER. I am not aware of any such service elsewhere in South Africa. The recently acquired video telemetry service is similarly the only dedicated paediatric neurology equipment in South Africa. Patients are referred for seizure event delineation from throughout the country.

- **Neuromuscular** – Red Cross Children’s Hospital has run a specialised neuromuscular clinic for 20 years. The service has expanded significantly over the last 3 years and the clinic load has tripled. The service has a dedicated physiotherapist. Patients are managed in a multidisciplinary manner – aiming not only to confirm diagnoses but also to potentiate quality of life and genetic advice. The service can perform molecular genetics for a number of conditions (SMA and Duchenne MD). Muscle biopsies usually confirm diagnoses in the remainder. The close association with the histopathology department has resulted in a team approach to many complex patients both from the locality and out of area. The service is just setting up to complete staining for the Limb girdle muscular dystrophies, which should lead to potential linkage analysis being available for affected families. The service works closely with the Muscular Dystrophy Society and frequently liaises with schools specialised in the care of children with muscle disease (eg Astra School)
- **Mitochondrial** – Referred patients are assessed initially to establish whether they comply with any of the recognised sub-groups. Investigations include a combination of neuroimaging (MRI), blood and CSF studies (lactate, pyruvate, mitochondrial DNA), muscle and skin samples are taken for mitochondrial analysis and fibroblast culture. Families are advised of appropriate treatment interventions and given genetic advice.
- **Neurocutaneous** – This complex group of disorders is frequently managed by a large number of different specialists who may be in different centres. We centralised care of these patients over a year ago and now run a monthly clinic. The team involves – neurology, neurosurgery, child development, plastic surgery, genetics, ophthalmology and access to dermatology and orthopaedics. This multidisciplinary approach has been most effective in co-ordinating management and ensuring the same advice is given, following international guidelines.

## ii. Johannesburg

### iii. Pretoria Mitochondrial disease

### iv. Durban IALCH and KEH

- CNS infections related to the HIV epidemic. These constitute a considerable load on our services. TBM and cryptococcal meningitis are an emergent challenge for the service.
- Epilepsy: IALCH and KEH manage most of the intractable cases in the Durban functional area and the province. Poor drug procurement and lack of trained medical officers in the periphery means most other patients are managed at the quaternary level. Again epilepsy constitutes the bulk of the academic practice. Video telemetry: currently being procured for IALCH as a provincial resource to share with adult neurology service

- Neuromuscular service -at IALCH/KEH is well established and the predominant case seen are SMA, DMD and congenital myopathies. The unit works in collaboration with the genetic team led by Prof Winship; and Prof P Bill an adult neurologist who is an expert in neuromuscular diseases and histopathological interpretation of muscle biopsy specimens. Weekly muscle biopsies are done. A research laboratory under Prof Bill offers molecular genetics tests for DMD.
- A neurodevelopmental team runs a weekly clinic for children with behavioural disorders, disabilities and performs neuropsychological assessments. This is a multidisciplinary team of OT, PT, speech therapist, social worker, psychologist and neurologist. Currently based at KEH

**v. Bloemfontein - none**

## A. CLINICAL SERVICES:

### 1. NOPD:

The role of the outpatient service is to provide tertiary / quaternary level support to complex patients and to coordinate where appropriate multidisciplinary care. Patients after first consultation are “filtered” into those who can only be managed at tertiary and quaternary levels (neuromuscular disorders, neurocutaneous disorders, complex epilepsies); those whose care can be shared with the secondary level facility or day hospital (non-complex epilepsy) (this system frequently fails when the secondary service or day hospital does not have the staff to act as the referral person) and finally those patients who should be seen elsewhere (eg the school clinic). Current major problems with this system include getting the patient to the hospital – transport is a major issue. Patients who live substantial distances from the tertiary centre should not be compromised, the referring centre must take responsibility for these patients and establish swift and efficient transport systems to enable smooth continuity of patient care. Extending this – it is totally unacceptable to make such a patient attend the tertiary centre on a monthly basis to collect medication – the transport system must also be utilised to collect the medication so the patient receives it locally.

Below are examples of the clinics established at tertiary and quaternary level in the Western Cape and the waiting lists at the current time.

Centre	Clinics	Number of clinics per week	Waiting list time for new patients
Tygerberg Neuro / Neurodev	General Neurology	7	4-6months
	Epilepsy	1 (1 clinic / quarter - complex cases)	4-6 months
	Cerebral palsy	1	Indefinite
Red Cross Neurology	General neurology	12	5 months
	Neuromuscular	1	5 months
	Epilepsy	1 (4-5 doctors)	Old pts only
	Behaviour	1 (2 doctors)	5 months
	Neurocutaneous	1 per mth	4 months
Red Cross Child Development	Developmental (docs)	7	6 months
	Developmental (psychologist)	1	
	Developmental (social	1	

	worker)		
	Cerebral palsy (docs)	5	
	Cerebral palsy (health therapists)	4	
	Cerebral palsy (social worker)	4	
	High risk neonates	1 per month	
	Spinal Defects	1	
	Deaf Child (diagnostic)	1	
	Deaf Child (assessment & fitting)	1	
	Deaf Child (Paernet training)	1	
Bloemfontein	General neurology	1	6 months
	Epilepsy/gen neuro	2	6 months
	Learning difficulty	1	>6 months
	Developmental	1	6 months
	CP(with orthopaed)	1/month	new clinic
	Paeds psychiatry	1	> 6 months
	Clinical genetics	1	4 months

## 2. Inpatients:

Centre	Number of dedicated beds	Median duration stay (est. days)
Tygerberg	10	11
Red Cross Neurology	6	4 (1-30)
Johannesburg		
Pretoria		
Bloemfontein	35 beds shared by all tertiary care	
Durban: IALCH	10	8

Access to beds often limited by overflow from other departments (especially during gastro and RSV season). The teams number of in-patients will be underestimated as patients are frequently “managed” on a referral basis when in other wards.

In addition patients are often referred as an emergency when the referring centre cannot perform a CT scan of the child’s brain. This situation in the current day is inappropriate. Transferring children who maybe at risk of acute neurological decompensation (coning) without having excluded this potential is unforgivable. All children in whom raised intracranial pressure is suspected must have a CT scan performed as a baseline and medical support instituted to ensure transfer to tertiary centres is safely carried out.

**Typical admissions:**

*Acute:* Complex epilepsy patients, atypical CNS infections, AIDP (acute flaccid paralysis), ADEM, movement disorders

*Chronic:* Neurometabolic “work-up”, Neuromuscular “work-up”, Complex epilepsy “work-up”, Neuroregression “work-up”

**3. Outreach:**

Outreach clinics work extremely well when appropriately staffed – at the current time the South African paediatric neurology service does not have the staffing levels to provide an appropriate level of support to regional centres. Systems which have worked well in the past and should be facilitated now include a medical office based at each regional centre who gains skills in recognition of neurological disorders and is able to continue the tertiary established management plan. This person is supported by an “outreach consultant” – who does not exist in South Africa at the current time. This person assists the regional centres, performs regular clinics and is the specialised contact link. The outreach consultant will cover a number of regional centres and the post itself may rotate between members of the tertiary centre as the post is likely to be tiring with large amounts of travelling.

Establishing an efficient telemedicine service will improve communication between centres, however as repeatedly stated this cannot work without sufficient staff.

Basically one “outreach consultant” should be established in every tertiary “supra-regional centre”.

Centre	Local	Regional
Tygerberg	Paarl School 2X per mo Alta Du Toit 1X per quarter	Paarl Hospital 1X mo Eben Donges 1Xmo Karl Bremer 1Xmo
Red Cross Neurology	3 schools (12 clinics a year) (Bel Porto, Agape and Eros)	-
Red Cross Child Dev	1 per week – cover 15	George x 1 a yr

	different sites in the Metropol	
Durban IALCH	1 school / month	KEH x 1 / week

Bloemfontein - no staff for outreach

#### 4. Referrals / Consultations

The services are inundated by calls from all levels of carers – parents through to private paediatricians. Clinics are routinely interrupted up to 10-15 times ie at least 3 times per consultation. This is a totally underestimated work-load and strain – advice must be clearly given and remembered as the caller often returns for more advice a few weeks later. At Red Cross the neurology department is attempting to centralise these calls during clinic times – however the staff must still return calls at the earliest opportunity. This system is already working well in the Red Cross Child Development service. Examples of the work-load are listed below. These numbers are under-estimations and are increasing every year.

Centre	Inpatient (per year)	Telephonic (per year)	Multidisciplinary case conferences
Tygerberg	250	795	
Red Cross Neurology	170	802	240
Red Cross Child Dev	20	792	

In Durban the single full time specialist has to field calls from the whole province and the regional hospitals throughout the day. The clinics take longer as one attends to urgent telephonic consults and requests for advice..

#### 5. FACILITIES on site / closely affiliated

Without adequate facilities tertiary / quaternary services will not be able to function, all supra-regional centres must have ready access to an MRI scanner, all regional hospitals should have CT scan facilities, all supra-regional centres should have facilities for performing the neurophysiological studies (EEG, NCS, EMG, BSAER, VEP, ERG) (with staff trained to perform the tests and interpret them in children), video-telemetry is a time consuming service and should be available in all supra-provincial services (again with adequate staffing levels – medical and technical). Nuclear medicine studies overlap several specialities however brain and muscle studies are very useful and necessary at supra-regional level.

Centre	Facility	Number per year	Waiting list	Emergency service
<b>Tygerberg</b>	MRI (on-site)	240* est on 5/12	3 months	Yes
	CT (on-site)	1722	3 months+	Yes
	EEG	> 600 (2002)	3 months +	Yes
	NCS / EMG	28	1 month	
	BAER	Data not		

		available		
	Nuclear med (SPECT)	Data not available		
	Video tel. equipment	Not currently functioning		
<b>Red Cross</b>	MRI (at GSH)	200	2 months	Yes
	CT (on-site)	700 approx	1 month	Yes
	EEG	1500	1 month	Yes
	NCS /EMG	85	2 months	Yes
	BSAER	130	1-2 months	-
	VEP /ERG	180	1-2 months	
	Video telemetry	Acquired 2002	1-2 mths	-
	Nuclear med eg spectroscopy	40 (approx)	1 mth	-
<b>Johannesburg</b>				
<b>Pretoria</b>				
<b>Bloemfontein</b>	MRI (on site) CT (on site) EEG EMG BSAER (2 years inoperative) Genetic laboratory	Data not available		Yes Yes No No
<b>Durban IALCH / KEH</b>	MRI (IALCH)	120	2 months	Yes
	CT scan	300	1-2mths	Yes
	EEG	500	3 mths	Yes
	NCS / EMG	150	2 mths	Yes
	BSAER	Data not available		
	Video telemetry & sleep studies	Being set up at IALCH		
	SPECT	10	None	
	VEP / ERG			

#### 6. Community support services:

Close links have been developed with several community services this is both on an advisory level and some societies are able to provide financial support for research. The MD Society are often in contact and had support with direct advice and lectures given

(JW) at local meetings. They have requested the Red Cross Neuromuscular service assists updating of their parent support booklets (JW). Epilepsy South Africa (previously SANEL) work very closely with the neurology service at Red Cross, they attend our epilepsy clinic on a weekly basis to improve social awareness and provide families with another support outlet. Dr Birgit Schlegel is on the EPSA committee as their paediatric medical representative.

Centre	Support service	Regional / National
Red Cross Neurology	Muscular dystrophy society	National
	Epilepsy South Africa	Regional
Red Cross Development		
Bloemfontein - none		

### B. MANAGEMENT / ADMINISTRATION

Centre	Clerical support	Specialist time on admin
Tygerberg	None dedicated	10 hours per week
Red Cross Paed Neuro	Clerks (n=2)	10 hours per week
Red Cross Child Development	Clerks (n=1)	10-15 hours per week
Johannesburg		
Pretoria		
Bloemfontein	None dedicated	5-6 hours
Durban	Clerk (n=1)	10 hrs per week

**Roles:** Much of the administrative duties which are completed by each unit's specialist consultant could well be covered by a central secretary eg collection of monthly statistics, unit job descriptions, co-ordination of bookings and referrals (for the information gathering and co-ordination of logistics of getting the patient in). Communication with local medical aids to ensure fair and correct billings are sent out. Clerical staff in all departments are currently already stretched to their limits – additional posts need to be created. Each supra-regional service requires at least two clerks to filter calls, take bookings, type reports and perform basic admin duties which currently fall to the departmental medical specialists.

### C. TEACHING / LOCAL MEETINGS

All departments have significant responsibilities for teaching and training – dedicated fixed times are allocated for University responsibilities. Teaching occurs at undergraduate (MB ChB) and postgraduate level (FCP, Mmed, etc). This is formal (lectures and workshops) and informal (tutorials, clinic and bedside teaching). The small country-wide staff complement has

an enormous task to cover training at these levels to a sufficient degree that our doctors can practice soundly in the area of child neurology. Considering the specialist to student ratio it is not surprising that disorders such as paediatric epilepsy are so badly managed outside the tertiary centres. Much of these teaching commitments are undertaken in addition to the clinical service responsibilities, with the current service load it is impossible to allocate protected teaching time.

**Local meetings** are integral to the support network between complementary services (child development, neurosurgery, adult neurology, radiology, pathology etc). General paediatric meetings are also routinely held in all centres – these enhance awareness within the hospital of various sub-speciality's activities and patient management. These are also good forums for discussion of multidisciplinary needs patients. Predictably these meetings are difficult to attend when clinics are over booked or patients have attended unbooked as they have nowhere else to go.

#### D. TRAINING

At the current time Red Cross Children's Hospital, in the Western Cape, is the only centre in South Africa with a dedicated training post in the department of paediatric neurology and another in child development. The centre is formally recognised by the HPCSA as a training centre. Other centres (Johannesburg/ Pretoria, Tygerberg and Durban) should gain recognition as training centres in the near future and should be allocated training posts if there is to be any chance of reducing the current patient to specialist ratio. Each centre should be training 2-3 senior registrars in order to allow maximisation of exposure to the training (SRs rotate and cross cover, thus gaining adult neurology and child psychiatry experience). Access should be possible for trainees from other African countries to spend time attached to tertiary / quaternary centres.

Training includes - Neurology outpatient exposure (general neurology and speciality areas), inpatients acute and chronic, neurological emergencies, training in neuroradiology, electrophysiology (EEG, NCS, EMG, VEP, ERG, BSAER), interpretation of neurometabolic investigations, interpretation of muscle and nerve biopsies, multidisciplinary team approach eg neurosurgeons, child psychiatry, orthopaedic, child development combined care of child. Working with ancillary services eg physiotherapy, speech therapy, occupational therapy, dieticians etc. Exposure to adult neurological conditions and approach to patient care.

#### E. RESEARCH

##### i. Western Cape

##### Tygerberg

Areas of interest:

TBM in childhood

Granulomas

ICP monitoring

Transcranial Doppler: non-invasive monitoring of ICP

### **Red Cross Paed Neurology**

Areas of interest:

Muscle disease

Peripheral Neuropathies

Epilepsy in Childhood

Neurofibromatosis

Tuberous sclerosis

Mitochondrial disease

Movement disorders

Use of Melatonin in neurological patients

### **Red Cross Child Development**

Areas of interest:

Fetal alcohol syndrome

#### **ii. Johannesburg**

#### **iii. Pretoria**

#### **iv. Durban**

Areas of interest:

HIV related CNS disease and associated development disabilities

Neuromuscular disease

Treatment of acute bacterial meningitis

Epilepsy

#### **v. Bloemfontein**

Multidisciplinary research group: Children with special needs

Three focus areas:

Learners with special needs

Street children

Sensory integration

Attention deficit hyperactivity disorder

## **ADDENDUM: Specific responses to the Modernisation of Tertiary Services Draft**

1. **Table on page 16** – there are columns which should have marked “YES”
  - There is a growing impact on the speciality from HIV / AIDS and TB
  - There are a number of new drugs and interventions now available which should be accessible to all South African patients
  - There are certainly going to be major developments in technical capacity in the next decade (eg epilepsy surgery)
  - This document should clearly high-light that the current availability of specialists is totally inadequate
  - There are bottle necks and critical dependencies in other specialities (eg neuroradiology)
  - Clearly the current geographical distribution is inadequate, even in areas where a few specialists exist.
  
2. **Points from page 41**
  - The “Enabling Framework” has placed paediatric neurology in the “Basic strengthening” category. This document clearly demonstrates that the service need should be in the “Expansion and Transition” category
  - The specialists currently operating within the service have already implemented openings for training more staff – three centres have applied for training status (one confirmed, two outstanding). These centres are equipped to train up personnel. The responsibility must now lie with the National and Provincial government to create these training posts and to then ensure that specialist posts will be created in areas of the country currently devoid of any support and in centres clearly badly understaffed.
  - The categorisation of the speciality is inappropriate, as the needs for child development must be considered separately. The current format is likely to underestimate service and staffing needs.
  - Please see updated table which follows. Basically we are already functioning below the lowest possible scenario and the suggested numbers are probably still an underestimation of the service needs. As access to disability services becomes more available and practitioners become more aware of pathology the work-load will increase further. This has been demonstrated by two excellent general paediatricians in George Hospital who are detecting large numbers of disorders requiring tertiary level intervention.
  - Hence in answer to the next point we are already below the worst scenario
  - We cannot maintain the service at our current capacity; waiting lists are extending 6 months in most centres (a devastating and unacceptable delay when considered in terms of a child’s neurodevelopmental lifetime). Further children are either not being detected or only referred on when disability is already far established. All services are being stretched

and fitting in extra cases around their already overstrained work load. For our needs models A and B may even be underestimations.

- A dedicated Children's Hospital is an excellent idea. Red Cross Children's Hospital functions as such, all facilities and staff approaches are directed at pure paediatric care. All staff are competent with handling children – this can be of great importance for the support services – nursing, radiology, neurophysiology, physiotherapy etc. These practitioners have insight into paediatric needs and experience into paediatric conditions. The quality of care is significantly improved and the working environment more “Child friendly”. Predictably children are an emotive subject and fundraising (as demonstrated at Red Cross Children's Hospital) more successful with such a specific focus. South Africa should aim for 2-3 dedicated children's hospitals – affiliated but separate to adult services – when considering that the childhood population is some 18 million (over a quarter of the total population) this is a small move. All tertiary units should be enabled to “ring” off their paediatric units even if they are based within a large adult / paediatric institution. Within this structure attempts should be made for the support services to appropriately provide for children eg in radiology a separate waiting section for children with a dedicated paediatric trained staff, similarly for physiotherapy, OT and Speech therapy. All departments should review the needs of what is likely to be over a quarter of their work load and not expect them to function like “little adults”.
- Left with Model D the system would probably collapse and the service disintegrate, Models C and A would be similarly not move the service forward. Even Model B is an underestimation of the service needs.

### Organisation of services

	<b>Regional hospital</b>	<b>Provincial tertiary – Supra Regional Tertiary</b>	<b>National referral – Supra Provincial Tertiary (Quaternary)</b>
<b>1. Which service to be provided</b>	General paediatrics	Full paediatric neurology service with appropriate radiology, laboratory services	Complex epileptic surgery. Complex neuromuscular patients Neurodegenerative and metabolic patients.
<b>2. Which personnel required Min / Ideal</b>	Paediatrician – Medical officer (1/3), OT, ST, PT. Pharmacist	Paediatric neurologists (2/3), developmental paediatricians, Specialist nurses (2/3), OT, ST, PT. Radiologists, neurosurgeons, Neurophysiology technologists(3/4) social workers, clerical assistants, psychologists, psychiatrists, telemedicine technicians	Same Additional paediatric neurologists (1/1) Senior registrars – training posts (2/3)
<b>3. Which resources</b>	Wards, X-ray, basic laboratory,	Wards, CT scan/MRI,	<b>Same</b> and video telemetry,

	pharmacy, CT scan	spectroscopy, X-ray, full laboratory, ICU, theatres, EEG & EMG, out patient clinics, lodger facilities for parents, IT facilities, data collection, telemedicine, pharmacy	intracranial mapping, neuro-metabolic lab,
<b>4. Other linked services</b>		Neuroradiologists, laboratory, OT, ST, PT, neurosurgeons, child psychiatry, molecular genetics, dieticians, pharmacy, library	<b>Same</b> and histopathology, molecular genetics, metabolic specialist
<b>5. Case mix</b>	Epileptics, CPs, chronic rehabilitation patients,	Full diagnostic facilities where patients can be referred for diagnosis	<b>Same</b> and complex epileptic, neuromuscular & neurodegenerative patients
<b>6. Which teaching functions</b>	Basic paediatric, OT, ST, PT	Full teaching – Undergraduate / Postgraduate	<b>Same – Subspeciality training</b>