



Partners in Paediatrics

***Paediatric Neurology Stakeholder Conference***

*"We were never given any support..... Nobody came to the house to talk to us, nobody phoned up.... I was grieving for the child that I didn't have and I'd got this other child that I didn't know what to do with. We were living from day-to-day. All of your anchors go ... your whole life changes but there's nobody there to talk you through.."*

*Parent of a child with neurological  
and learning difficulties of undefined diagnosis*

**Proceedings of the Conference held**

**7<sup>th</sup> November 2002**

**Keele Hall, Keele University**

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Copies of the presentations and the report 'Development of paediatric neurology services in the PiP area' are available from:

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# Paediatric Neurology Stakeholder Conference – Proceedings

## 1 Introduction

Partners in Paediatrics (PiP) aims to improve the quality of services for children across the area served by participating Trusts (Appendix 1). Paediatric neurology services have been a priority for development since the inception of PiP. A study was therefore undertaken, in collaboration with the Department of Management Science at Lancaster University, to review this service across all member Trusts. A Stakeholder Conference was held on 7<sup>th</sup> November 2002 at Keele Hall, Keele University, in order to discuss the outcome of this review and agree a way forward. Delegates to the conference are listed in Appendix 2 and PiP is very grateful to everyone who gave their time and expertise to this event. These proceedings summarise the main points of the presentations and discussions.

Dr Andy Spencer, Lead Clinician for PiP opened the conference by outlining the work of PiP and the vision for the development of a managed clinical network for paediatric services.

## 2 Paediatric Neurology – W. Midlands and National Issues

**Dr Stuart Green, Consultant Paediatric Neurologist,  
Birmingham Children's Hospital NHS Trust**

Dr Green provides services to much of the PiP area and is also the immediate past president of the British Paediatric Neurology Association.

### 2.1 Overview

- Paediatric neurology deals with a wide range of acute and chronic problems in childhood.
- About 20% of paediatric consultations are about a neurological condition.
- In the UK, most of these consultations are with general or community paediatricians.
- Paediatric neurologists deal with a small proportion of these cases – mostly through tertiary referrals (referrals from other consultants). This pattern may be changing with families increasingly requesting a specialist opinion.

### 2.2 Range of patients

Paediatric neurology covers a wide range of conditions:

Epilepsy	Cerebral palsy and movement disorders
Headaches	Strokes
Encephalitis and other CNS infection	Neurometabolic disease
Tumours (with surgeons and oncologists)	Idiopathic disorders of gait and vision
Autism and other developmental delays and learning difficulties	Malformations of the CNS
Neuromuscular disease	Neurorehabilitation

### 2.3 Range of services provided

The service based at Birmingham Children's Hospital NHS Trust (BCH) provides the following range of services:

- 24 hour consultation service
- Emergency services
- Out-patient services (including subspecialties such as neuromuscular, neuromotor, neurometabolic). These are provided at BCH and through out-reach clinics in hospitals, child development centres and special schools.
- Liaison within Birmingham Children's Hospital and advice to other specialties.
- Specialised neurodisability service
- Specialised support services including, neuroradiology, neurophysiology and biochemistry
- Teaching, training and research
- Support from specialised physiotherapists, occupational therapists and others
- Nurse liaison, including school and home visits

The service aims to work in a patient and family- friendly way. It adheres to established clinical guidelines and tries to link closely with local community and education services. The service has the following staffing:

- 0.7wte senior lecturer
- 1 NHS consultant
- 0.2 wte and 0.5 wte neuromuscular specialists
- 1 epilepsy liaison nurse
- 1 neurometabolic liaison nurse

### 2.4 Consultant staffing

Currently, most paediatric neurologists practise from major university teaching centres of which there are about 20 in the UK. There are about 60 consultant UK paediatric neurologists. Most services are significantly under-resourced and at least double the current number of paediatric neurologists are required for immediate service needs without taking account of teaching, administration, audit and research requirements.

Dr Green views of the consultant staffing required for the West Midlands (assuming a population of approximately 5.6 million) were as follows:

- 5.5 wte Based on the Tizard report (1990) recommendation of 1 wte per million (total) population. Twice this level would be needed if neurodisability services are addressed fully.
- 4 wte In order to meet the European Working Time Directive
- 5 wte RCPCH staffing directive
- 11 wte For reasonable comparability with other European countries
- 15 – 20 wte To reach comparability with the highest levels of service provision

## 2.5 BCH Plans

The development plans for the Birmingham Children's Hospital service are as follows:

- Appoint a 3<sup>rd</sup> consultant paediatric neurologist (about to be advertised)
- Extend consultation service within and outside BCH
- Develop closer links with DGH colleagues and improve networking
  - Meet with paediatricians throughout the West Midlands
  - Identify those with an interest and expertise in neurology – or in some aspect, for example, epilepsy
  - Develop shared protocols and pathways for referral to and from BCH
  - Support those who need updating or further training
- Increase the number of liaison nurses, particularly for epilepsy
- Improve access to scanning and neurophysiology
- Improve staffing and training of physiotherapists, occupational therapists and other therapists
- Increase the number of paediatric neurology consultants by any of:
  - More consultant paediatric neurologists based at BCH
  - Shared posts with sub-regional centres
  - District paediatricians 'with and expertise or an interest' in paediatric neurology
  - Possibly at a later stage, district paediatric neurologists.

## 2.6 The way forward

Dr Green stressed the following points:

- There needs to be a cohesive plan for discussion with PCTs, possibly through specialised services mechanisms.
- This plan needs to be realistic and costed. It will have major training and staffing implications.
- The plan needs to be sensitive to patient needs and not limited by organisational boundaries.
- The development and implementation of the plan needs to be managed and supported.
- *The overall aim is to produce an integrated W.Midlands-wide managed network of modern, up to date diagnostic, management and therapeutic services that are sensitive to patient needs. The services should be available for all children with neurological problems, including both acute and chronic problems, with easy, timely access to services in appropriate settings.*

### 3 Development of paediatric neurology services in the PiP area

**Dr Dave Worthington, Department of Management Science,  
University of Lancaster**

Dave Worthington presented the findings of the study undertaken as a collaboration between PiP and the Department of Management Science at the University of Lancaster. He acknowledged the contribution of Joe Headley and Stylianos Dermentzoglou who had carried out the work under his supervision.

In this study, both qualitative and quantitative data were used to describe current services and look at options for service development. Semi-structured interviews were carried out with representatives of each of the acute Trusts in the PiP area. Some parents' views on the services were based on information from support groups. Expected incidence and prevalence levels were calculated by applying national estimates to the local population.

#### 3.1 Current services – Outreach from tertiary centres

<b>PiP Acute Trust</b>	<b>Outreach from:</b>	<b>Referrals to:</b>
Walsall Hospitals Burton Hospitals Mid Staffordshire Gen. Hospitals	Birmingham Children's	
East Cheshire Hospitals Mid Cheshire Hospitals* North Staffordshire Hospital	Manchester Children's	
Princess Royal Hospital, Telford Mid Cheshire Hospital*	Alder Hey, Liverpool	
Royal Shrewsbury Hospital Royal Wolverhampton Hospitals	None	Alder Hey, Liverpool Birmingham Children's

\* Outreach services and patient referrals are from / to both Manchester and Liverpool

#### 3.2 Clinics run by local paediatricians

<b>Type of clinic</b>	<b>PiP Acute Trust</b>
Epilepsy	East Cheshire Hospitals Mid Cheshire Hospitals Royal Shrewsbury Hospitals (Shrewsbury and Ludlow) Princess Royal Hospital, Telford RJAH Hospital, Oswestry Walsall Hospitals Royal Wolverhampton Hospitals

Neurology	Royal Shrewsbury Hospitals Princess Royal Hospital, Telford RJAH Hospital, Oswestry
None	North Staffordshire Hospitals Mid Staffordshire Gen. Hospitals Burton Hospitals

### 3.3 Access to EEG facilities and neurophysiologist

Type of service	PiP Acute Trust	Referral to
EEG facility and neurophysiologist	Mid Cheshire Hospitals North Staffordshire Hospitals Royal Wolverhampton Hosp.	
EEG facility	Walsall Hospitals Mid Staffordshire Gen Hosp.	
Referral elsewhere	East Cheshire Hospitals Royal Shrewsbury Hospitals Princess Royal Hosp., Telford RJAH Hospital, Oswestry Burton Hospitals	Liverpool Stoke Stoke Stoke Derby

### 3.4 Facilities at Tertiary Centres

Tertiary Centre:	Alder Hey, Liverpool	Royal Manchester Children's Hosp.	Birmingham Children's Hosp.
Catchment population	2.8 million	4.5 million	5 – 5.6 million
Paediatric neurologists	3 wte	4wte + 1(Preston)	2 wte
Beds for paediatric neurology	12	12	4

The study also showed that access to specialist paediatric neurology services depended on the level of provision of staff and beds and decreased with increasing distance from a tertiary centre (ie. those living closest to the tertiary centre were most likely to access the service).

### 3.5 Overview of local services

Trust	Outreach clinics per year	Neurology interest locally	Outreach clinics per 10,000 children per year	Satisfaction *
Mid Cheshire	10	1	1.8	√
East Cheshire	6	1	1.6	√
North Staffordshire	12	1	1.3	XX
Mid Staffordshire Gen.	12	0	2.2	XX
Burton Hospitals	12	0	2.7	X
Royal Shrewsbury	0	1 + SCP	0.0	√
Princess Royal, Telford	2	1 + SCP	0.5	√
Walsall Hospitals	6	1	1.1	X
Royal Wolverhampton	0	3	0.0	XX

\* An indication of Trusts' overall satisfaction with services: √ satisfied. X moderately dissatisfied. XX very dissatisfied.

### 3.6 Problems with current services – Professional views

During interviews with Trusts in the PiP area, the following problems with current services were identified:

#### 3.6.1 Problems with tertiary paediatric neurology services

- Numbers of neurologists particularly low, and a shortage of dedicated neurology beds at Birmingham.
- General national shortage of paediatric neurologists, and not enough trainees are specialising in paediatric neurology.
- Numbers of outreach clinics to Stoke, Stafford, Walsall and Burton are not adequate. Waiting lists are long. No outreach clinics to Wolverhampton - all paediatric neurology services provided at Birmingham through block contract.
- Difficulties for many Trusts in getting access to specialist advice, such as for patients on wards who do not require PICU. The lack of backup causes problems for complex disorders.
- Although Shropshire service is adequate at present, it is dependent on the presence of a community paediatrician with specialised neurology training and expertise. There will be future problems when this paediatrician retires.
- No 24-hour on-call paediatric neurologist based in the PiP area.
- No joint outreach clinics in many community Trusts, so no direct access for community paediatricians and therapists. Also, contact with tertiary centres is not maintained once the child has been referred back to the community.

Deleted:

#### 3.6.2 Problems relating to other specialist services or expertise

- Lack of suitable staff (neurophysiology, neuroradiology and radiology), or staff overstretched for reading scans - both funding and recruitment problems.
- Lack of transitional handover clinics for adolescents between paediatricians and adult neurologists.
- Lack of formal Gait Analysis cited as a problem at some Trusts (but available in Oswestry).

- Can be long waits for follow up at epilepsy clinics.
- Paediatrician's travelling time and having to carry/take notes are issues if clinics are held in several centres.

### **3.6.3 Problems relating to specialist equipment**

- Lack of EEG service in Shropshire and can be long waits for EEG at Stoke
- Access to MRI can be difficult. There can be a long waiting list for MRI, particularly at Birmingham and Stoke. This can mean children who should receive MRI are not referred in order to give better access to higher priority cases.
- Muscle service needs non-invasive respiratory support.

### **3.6.4 Problems relating to multidisciplinary team staffing numbers**

- Absence of an epilepsy nurse at some Trusts (Crewe, Walsall, Macclesfield), which can hinder the effective running of epilepsy clinics.
- Psychology services/CAMHS are totally absent in some areas. Large shortfalls in psychology services in other areas. National shortage of qualified psychologists; numbers of places on courses is a bottleneck.
- Lack of psychiatry services or long waiting times for these services; major recruitment problem for single posts.
- National recruitment problems for all other therapies, as well as funding problems in some areas (the main cause of the shortage varies between areas, and for different therapies).
- Shortage of therapists can mean that multidisciplinary assessment involving all necessary therapists is sometimes not possible.
- Lack of therapists working in acute hospital Trusts to deal with ward cases
- Problems in accessing neuropsychology at tertiary centres
- Lack of specialist nurses at Liverpool for paediatric neurodisability and neuromuscular disorders

### **3.6.5 Other issues relating to multidisciplinary teams**

- Wheelchair services cited as a problem in many areas, due to funding problems or shortages, and long waiting times for specialist wheelchairs.
- May be no dedicated funding for paediatric equipment

### **3.6.6 Problems relating to emergency cases**

- Birmingham PICU frequently full
- No paediatric neurologist on site to advise on cases referred to Stoke PICU

### **3.6.7 Coping strategies**

- Depending on their local circumstances, Trusts use different means of coping with inadequacies in service provision that affect them. In the Staffordshire area, this can mean prioritising referrals to outreach clinics so that the more urgent cases are seen more quickly, but this can mean that some cases are not referred and ideally should be. Clinics might also be overbooked to ensure a complex case receives tertiary advice quickly. The lack of an MRI scanner at Wolverhampton means that similar prioritising of referrals also takes place.

- Epilepsy clinics held in local areas are a means of reducing the need to refer for tertiary advice. The lack of access to tertiary services over a prolonged period has brought about the development of greater local expertise to handle cases that should otherwise be referred. In Shropshire, many cases are referred to specialist community paediatrician with outreach clinic numbers being very low as a result.
- At a tertiary level, the lack of beds for neurology at Birmingham Children's Hospital means that beds designated to other specialties may be used. In some situations, patients are referred away to Nottingham and Leicester.

### **3.7 Problems with current services – Parents views**

Contact was made with UK support groups; the following sent publications or feedback about parents' perceptions of paediatric neurology services: British Brain & Spine Foundation, The Neurological Alliance, Children's Acquired Brain Injury interest group, Mencap and Dyspraxia Foundation. The main problems were:

- Long waiting lists for appointments with neurologists
- After diagnosis, delays in seeing multidisciplinary team members.
- Difficulties in accessing appropriate equipment for diagnostic tests.
- Shortage of information about the diagnosed condition.
- Variations in neurology care between different parts of the country, including widely varying prescription rates for some drugs.
- Lack of coordination and communication between and within specialties
- Lack of psychological support

These concerns echoed those that professionals within the PiP area considered were of greatest concern to parents. Difficulties getting wheelchairs was also mentioned as a problem within the PiP area and facilities are not always appropriate for children in wheelchairs.

### **3.8 Managed Clinical Networks**

The characteristics of managed clinical networks were explored by the study and local Trusts were asked for their views. Many positive aspects were supported by organisations within the PiP area, including:

- Services more geared to patient pathways
- More efficient use of resources
- Vulnerable services become more sustainable
- Greater equity of access to care and consistency of advice and patients' experience
- Improved coordination between services
- More efficient delivery of education, training, audit and research
- Improved service for patients and their families

Some of the theoretical challenges of managed clinical networks were also mentioned locally:

- Cultural differences between organisations within a network
- Conflicting priorities within and between organisations

- Confusion over accountabilities
- More travelling time for professionals
- Despecialisation of general paediatricians
- Increased cooperation may add to time pressures

### **3.9 Options for the future**

The study discussed options for the future in some detail. These were then summarised as:

- A Expand the current services using the existing 'hub and spoke' model.
- B Expand the current services and develop a network model of care.
- C Develop a centre for paediatric neurology within the PiP area.
- D Develop two linked centres for paediatric neurology within the PiP area.

More detail of these options is included in the full report, including an assessment of the impact on travel times. The effect on the main problems identified by the study is also included.

### **3.10 Conclusions**

The overall conclusions of the study were as follows:

- The existing services have been described and show clear shortfalls and disparity in service provision.
- Various methods of managing this shortfall are being used.
- Specific models for the development of services have been outlined.
- Managed clinical networks have been investigated and shown to hold potential benefits for the PiP area.
- Further debate will be needed to agree the best way forward.
- Close working between health professionals will be needed in order to develop an appropriate model.

## **4 Parents' and carers' views of paediatric neurology services**

**Dr Sarah Derrett**

**Centre for Health Planning and Management, Keele University**

Sarah Derrett presented the results of her discussions with parents and carers, obtained through three focus groups in Stoke, Crewe and Wolverhampton. The aim of the meetings was:

*To obtain and explore parents views of the paediatric neurology service and ensure that these contribute to the improvement of the service in the PIP area for children, young people and their families.*

The topics discussed included parents experience of being told their child's diagnosis, first contact with the neurology service, ongoing care and impact on their family. Copies of the full presentation are available and include several quotes from the meetings with parents. The main issues identified were:

### **4.1 First contact**

- Communication between health professionals and parents / carers, especially at the time of diagnosis
- Need for more information and information tailored to the needs and wishes of parents
- Need for more support, especially following the initial contact with the service.

### **4.2 Ongoing contact**

- The need for health professionals to believe what parents said and experienced – although some parents were very appreciative that they were listened to.
- Need for ongoing support, time and information.
- Some concerns about waiting times – but not a major issue for most parents.
- Variations in experience of follow-up, including some problems of communication between secondary and primary care.
- Problems with discharge planning – especially getting services in place quickly.
- Lack of suitable facilities for children with disabilities in several hospital departments.
- Transition to adult care: “it seems everything finishes at once”; lack of planning and suitable provision
- Poor inter-agency links, including between health, education and social services.
- Difficulties getting respite care or home relief.

### **4.3 Suggestions for improvement**

- Sensitive communication at first contact
- Ascertain parents' desires for information
- Counselling provision for families and/or individual family members

- Written information
- Local support groups
- Parents as supporters or a telephone list of parents willing to be contacted
- Improved follow-up
- Improved admission and discharge planning
- Strong need to develop services for young adults.

#### 4.4 Finally .....

*“It sounds as if I’ve moaned all the way through and I don’t want to sound like that because it has been fine .... I’ve always known there’s been someone there on the other end of the phone.”*

*“Specialists have been wonderful – in the way they’ve spoken to us and in their honesty – they’ve been superb.”*

### 5 Improving Care – Striving for Excellence

The conference participants then developed the following principles that should underpin the development of future services:

- 1 Care and services should respond holistically to the needs of children, young people and their families and to changes in these needs – irrespective of where they live.
- 2 Support for children, young people and all family members, including their siblings, should be available when they need it and kept under review. This support should include:
  - A key worker or key person who will help to resolve problems
  - Someone to contact 365 days a year
  - Professional advice and support at the time of diagnosis
  - Local and national support groups or contact with other parents who have children with similar conditions
  - Respite care
  - Support for the transition to adult life and adult services.
- 3 Good information for children, young people and their families should be readily available. This should include verbal and written information that is responsive to families’ differing needs. The information should cover the child’s condition, services available, national and local support groups and contacts, and how to get help ‘between times’.
- 4 High quality health and social care should be provided by well-trained multi-disciplinary teams. Teams should be made up of specialist nurses, consultant paediatricians and paediatric neurologists, psychologists, social workers, occupational therapists, physiotherapists, diagnostic technicians and other link workers. Multi-disciplinary teams should work well together and link effectively to other services and to other levels of care.

- 5 There should be timely access to diagnostic services and to wheelchairs and adaptations.
- 6 Effective links with education and other services should be in place to ensure a timely response to the educational needs of children and young people – and to changes in their needs.
- 7 Sensitive, clear, timely communication with children, young people and their families and between professionals should take place at all times. This communication is particularly important at the time of diagnosis, during changes to the care plan and for the transition to adult life and adult services. This communication should be supported by an integrated patient record that, over time, should be electronic.
- 8 The configuration of services should allow equitable access to the variety of specialised and sub-specialty services that may be required, take account of different geographical needs and provide care closer to home whenever this is feasible. The design of these services should be appropriate for children and young people with neurological problems so that they can physically access and make full use of them.
- 9 There should be ongoing involvement of children, young people and their families in their own care and in planning and improving services as a whole.
- 10 Services should be underpinned by meaningful activity information, good training and education, audit, research and a culture of continuous improvement.

## **6 Paediatric neurology services for the PiP area**

### **6.1 Proposed service configuration**

The conference participants agreed a model for the organisation of services. This is shown in figure 1.

### **6.2 Actions to improve services**

In order to achieve the excellent services described in section 5, the conference participants developed plans for services for the PiP area. These are summarised in table 1. These plans are not exhaustive and will not cover the full range of actions needed. They are put forward as a basis for discussion with members of PiP and partner organisations. Through this discussion and the additional work that is required in several areas, a detailed plan will be developed.

## **7 Priorities**

The conference identified three priorities for action:

- 1 The development of joint clinics (paediatric neurologist, local paediatrician with an interest in paediatric neurology and specialist nurse) in all acute Trusts within the PiP area.
- 2 The appointment of someone with responsibility to drive the development of paediatric neurology services for the PiP area.
- 3 The development of detailed plans for the provision of respite and rehabilitation facilities for children and young people with neurological problems.

## **8 Next Steps**

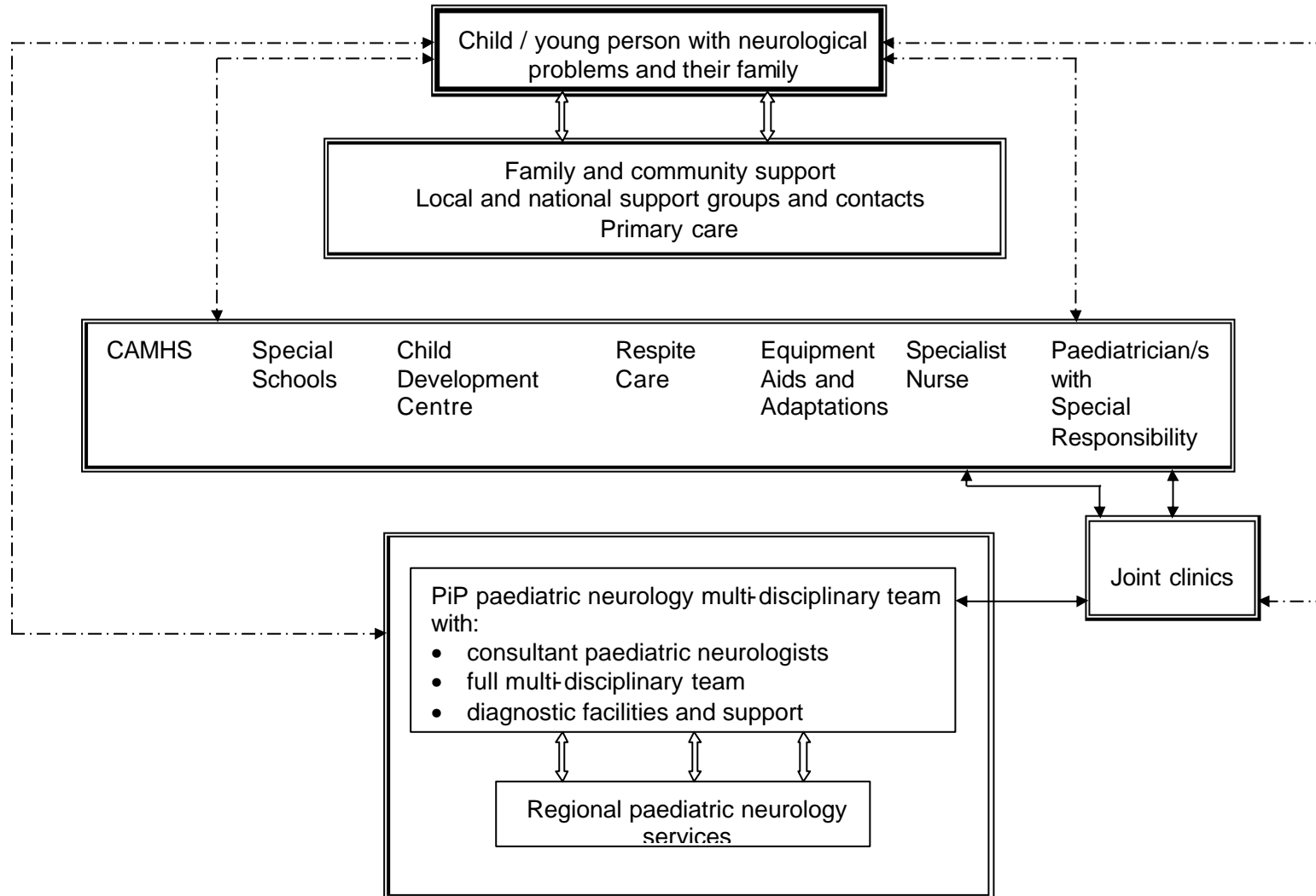
This summary of the conference proceedings will be circulated among those who attended the conference and those who were invited to attend but unable to join the day. Comments all aspects of the proceedings are welcomed and a response form for comments is given on page 2. Presentations of this report will also be made to key groups and individuals.

A detailed plan will then be developed for taking forward the development of paediatric neurology services for the PiP area. This will cover:

- Actions that can be taken without additional resources
- Preparation of business cases for additional investment where this is required
- Learning from other places and other developments
- Links to the National Service Framework for children
- Links to other work relating to children that is being coordinated through the W. Midlands Specialised Services Agency.

PiPs usual communication mechanisms will be used to keep members and partner organisations in touch with progress and developments.

**Figure 1 Proposed service configuration**



**Table 1 Proposed actions to improve services**

<b>No.</b>	<b>Proposal</b>	<b>First step</b>	<b>Longer term</b>
1	Help parents and carers develop a local network of contacts for advice and support.	<ul style="list-style-type: none"> <li>• Explore various options with parents and carers.</li> </ul>	
2	Improve the information that is available to children, young people and their families.	<ul style="list-style-type: none"> <li>• Bring together existing information from different Trusts and other sources.</li> <li>• Produce improved information.</li> <li>• Plan for further development of information for children, young people and their families.</li> </ul>	
3	<p>Ensure all children with neurological problems have a key worker.</p> <p>NB. The key worker may change over time but should not change at times of transition.</p>	<ul style="list-style-type: none"> <li>• Review existing models of key worker roles (including dedicated roles, one of team currently involved, etc).</li> <li>• Develop proposals</li> </ul>	
4	Improve children and families' experience of using services.	<ul style="list-style-type: none"> <li>• Map existing patient pathways.</li> <li>• Use continuous improvement approaches to improve choice and experience for children, young people and their families.</li> </ul> <p>NB. This will involve the development of guidelines for management of the patient's journey, for example, admission, discharge, communication, follow-up.</p>	

5	<p>Develop a paediatric neurology service based in the PiP area and linked to the service at BCH.</p> <p>NB. This should be achieved with the BCH service and as part of strengthening and developing this service.</p>	<ul style="list-style-type: none"> <li>• With BCH and commissioners, develop a plan for future consultant staffing that combines geographical responsiveness and sub-specialty interests.</li> <li>• Develop specific proposals for the following: <ul style="list-style-type: none"> <li>➤ With BCH, appoint one consultant paediatric neurologist who has the majority of sessions at N. Staffordshire Hospitals (or other PiP hospitals). This post should be a member of the BCH team but have a specific focus on N. Staffordshire and the PiP area.</li> <li>➤ With BCH, appoint one consultant paediatric neurologist who has the majority of sessions at Oswestry and other hospitals in Shropshire. This post should be a member of the BCH team but have a specific focus on Shropshire and the PiP area.</li> <li>➤ Appoint multi-disciplinary teams to strengthen BCH service and work with new consultant posts. These teams should comprise, at least, specialist nurse, physiotherapist, speech and language therapist, occupational therapist, psychologist and social worker. (The potential for developing a team that works closely with the PiP area will be explored.)</li> <li>➤ Ensure diagnostic services are enhanced to support the work of the additional consultants</li> </ul> </li> <li>• Develop a full multi-disciplinary team, including at least 3 consultant paediatric neurologists, to serve the PiP area – while still working closely with the BCH service.</li> </ul>
6	<p>Have at least one epilepsy specialist nurse in each PiP acute Trust.</p>	<ul style="list-style-type: none"> <li>• Prepare proposals, involving BCH, acute Trusts and PCT representatives in this process.</li> <li>• Appoint / train nurses.</li> </ul>
7	<p>Have 1-2 consultant paediatrician with special responsibility for epilepsy / paediatric neurology in each PiP acute Trust.</p>	<ul style="list-style-type: none"> <li>• Prepare proposals, involving BCH, acute Trusts and PCT representatives in this process.</li> <li>• Formalise arrangements and ensure additional training / development if required.</li> </ul>

8	<p>Ensure an appropriate number of in-patient beds are available for children and young people needing hospital admission. These will include:</p> <ul style="list-style-type: none"> <li>➤ Dedicated beds at BCH</li> <li>➤ General paediatric beds at N. Staffordshire</li> <li>➤ Paediatric beds at RJAH (especially for children with gait problems)</li> </ul>	<ul style="list-style-type: none"> <li>• With BCH, specialised services commissioners, Strategic Health Authority representatives and others, review the number of beds needed at BCH and prepare proposals for expansion to an appropriate number.</li> <li>• Availability of beds at N. Staffordshire and RJAH to additional consultants as they are appointed.</li> </ul>
9	Develop rehabilitation facilities for children and young people with neurological problems.	<ul style="list-style-type: none"> <li>• Undertake further work looking at existing facilities and options for future services</li> <li>• Develop proposals</li> </ul>
10	Improve the transition from paediatric to adult services for young people with neurological problems.	<ul style="list-style-type: none"> <li>• Undertake further work looking at existing facilities and options for future services</li> <li>• Develop proposals</li> </ul>
11	Ensure services are underpinned by excellent clinical and referral guidelines	<ul style="list-style-type: none"> <li>• Review and revise original guidelines (action 4) when additional staff are in post.</li> </ul>
12	Ensure services are underpinned by multidisciplinary training, audit, research and evaluation.	<ul style="list-style-type: none"> <li>• Review arrangements for training, audit, research and evaluation when additional staff are in post.</li> </ul>

**PiP Participating Trusts**

The purpose of the partnership is to improve the quality and accessibility of services for children across the area served by the participating Trusts:

North Staffordshire Hospital NHS Trust  
Mid Staffordshire General Hospitals NHS Trust  
Royal Shrewsbury Hospitals NHS Trust  
Princess Royal Hospital NHS Trust  
Mid Cheshire Hospitals NHS Trust  
East Cheshire Hospitals NHS Trust  
Royal Wolverhampton Hospitals NHS Trust  
Wolverhampton City Primary Care Trust  
Walsall Hospitals NHS Trust  
Burton Hospitals NHS Trust  
Telford and Wrekin Primary Care Trust  
Central Cheshire Primary Care Trust  
North Staffordshire Combined Healthcare NHS Trust  
Stoke (North) Primary Care Trust  
Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Trust  
Royal Children's Hospital NHS Trust, Alder Hey  
Royal Manchester Children's Hospital NHS Trust  
Birmingham Children's Hospital NHS Trust  
South Staffordshire Healthcare NHS Trust

## Conference Delegates

Name	Title	Organisation
Paul Carter	Consultant Paediatrician (Community)	Walsall Primary Care Trust
Paul Maubach	Head of Specialised Services	West Midlands Specialised Services Agency
Dr A Spencer	Consultant Paediatrician	North Staffordshire Hospital NHS Trust,
Dr S Green	Consultant Paediatric Neurologist	Birmingham Children's Hospital NHS Trust
Dr D Worthington	Lecturer	Lancaster University
Jane Eminson	Facilitator	
Dr S Philips	Neurology Consultant	Birmingham Children's Hospital, Steelhouse Lane, Birmingham, B4 6NH
Dr L Ingram	Consultant Paediatrician	Princess Royal Hospital NHS Trust
Dr K Reynolds	Clinical Director	North Staffordshire Hospital NHS Trust
Mrs J Powell		Shropshire and Staffordshire HA
Mrs J Greensall	Project Manager for PiP	c/o North Staffordshire Hospital NHS Trust
Mr R Appleton	Consultant Paediatric Neurologist	Alder Hey Children's Hospital, Liverpool
Ms L Lawton	Manager – Children's Outpatient Services	Leighton Hospital, Crewe
Mrs J Sherlock		Marshlands Special School, Lansdowne Way, Wildwood, Stafford
Mrs B Banks	Programme Manager	Sure Start – Stoke on Trent North
Mr P Mayhew	Headmaster	Cruckton Hall School, Cruckton, Shrewsbury
Mrs A Sweeney	Paediatric Epilepsy Nurse Specialist	Alder Hey Children's Hospital, Liverpool
Miss L Beeston	Paediatric Epilepsy Nurse Specialist	Alder Hey Children's Hospital
Dr G Cole	Consultant Community Paediatrician with special interest in paediatric neurology	Longbow House, Marlscott Lane, Shrewsbury
Dr D Bakalnova	Consultant Paediatric Radiologist	North Staffordshire Hospital NHS Trust
Ms L Garside	Conductor -Teacher Head of Early Year	Horton Lodge, Community Special School, Rudyard, Leek, Staffs
Ms J Johnson		Paediatric Physiotherapy Service
Ms E Wheeldon	Senior Physiotherapist	Horton Lodge School, Rudyard, Nr Leek, Staffs
Dr H Dent	Consultant Clinical Psychologist	380 Chellheath Road, Chellheath, Stoke on Trent
Ms H Guy	Trainee Clinical Psychologist	380 Chellheath Road, Chellheath, Stoke on Trent
Dr S Cropper	Academic Advisor for PiP	Keele University, Dept of Health Planning and Management
Dr S Derrett	Lecturer	Keele University, Dept of Health Planning and Management
Miss N Smith	PiP Coordinator	North Staffordshire Hospital NHS Trust
Mrs J Wilkinson	Parent	
Ms C Boccock	Parent	
Miss N Taylor	Parent	
Dr T Smith	Consultant Paediatrician	North Staffordshire Hospital NHS Trust

**Abbreviations**

BCH	Birmingham Children's Hospital NHS Trust
CAMHS	Child and adult mental health services
CNS	Central nervous system
DGH	District General Hospital
EEG	Electro encephalograph
MRI	Magnetic resonance imaging
PiP	Partners in Paediatrics
PCT	Primary Care Trust
PICU	Paediatric Intensive Care Unit
RCPCH	Royal College of Paediatrics and Child Health
RJAH	Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Trust
SCP	Specialist community paediatrician
wte	Whole time equivalent