

Children & Young People's  
Strategic Partnership



Outline Business Case for New Investment in  
Paediatric Therapies and to Support the  
Provision of 24 Hour Postural Management  
Equipmentv4

March 10th 2005

Children with Disabilities Steering Group

Author: Ic, Head of Strategy & Modernisation, Eastern Wakefield PCT

# Contents

Introduction
Context
National
Local
Environmental Analysis
Epidemiological Factors
Current Service Provision
Therapy Provision
Equipment Provision
The Benefits of Paediatric Therapies and 24 hour Postural Care Management
Potential Solution Options
Services for Children with needs other than DCD
DCD Services
Support to Education Services
Equipment Provision

# **1 INTRODUCTION**

This document provides an Outline Business Case for additional investment in Paediatric Therapies and the provision of 24 hour postural care management equipment. The solutions contained within the paper relate to the short-term, next twelve months and have been formulated in support of a longer term multi-agency project with the following aim and scope:

## **Aim**

The re-configuration of physical therapy services within the Wakefield District to meet the identified needs of children and their families.

## **Scope**

- To understand the current situation relating to the provision of physical therapy services for children and young people aged 0 –19 years, within the Wakefield District.
- To identify the current settings within which physical therapy services are provided.
- To describe the current need for physical therapy services
- To identify the current resource envelope within which the current service operates (staffing, budgets etc)
- Describe existing contractual arrangements for the provision of physical therapy services
- Develop a service specification and model for the future provision of therapy services within the Wakefield District.

## **2 CONTEXT**

### **National Context**

#### **Every Child Matters: Change for Children**

A range of national legislative and regulatory drivers including the proposals outlined in the Every Child Matters: Next Steps (March 2004) and Every Child Matters: Change for Children (December 2004), are shaping the actions and priorities across children and family services and our commissioning intentions and priorities.

Over the next 3 years the development of children's services will be strategically and operationally linked to the 5 outcomes for children set out in 'Every Child Matters: Change for Children'.

The 5 outcomes for children are:

- Being healthy
- Stay safe
- Enjoy achieve
- Make a positive contribution
- Achieve economic well-being

#### **National Service Framework**

The NSF establishes clear standards for promoting the health and well-being of children and young people and for providing high quality services that meet their needs.

There are eleven standards covering the following areas:

- Promoting Health and Well-being, Identifying Needs and Intervening Early
- Supporting Parents
- Child, Young Person and Family Centred Services
- Growing Up into Adulthood
- Safeguarding and Promoting the Welfare of Children and Young People
- Children and Young People who are Ill
- Hospital Standard
- Disabled Children and those with Complex Health Needs
- The Mental Health and Psychological well-being of Children and Young People
- Medicines for Children and Young People
- Maternity Services

In addition to these standards the NSF identifies ten strategic themes which must be addressed by District's in relation to children with disabilities; further supporting information is provided on those themes with a direct relevance to paediatric therapy and equipment provision.

**Theme 1: Promoting Inclusion**

**Theme 2: Partnership and Participation**

**Theme 3: Co-ordinate Multi-Agency Services**

For many disabled children, meeting their and their families' needs requires the involvement of a range of services and disciplines, which are located in a number of different statutory and voluntary agencies, and are delivered by a number of different professional groups in different settings. Finding out about dealing with services are key sources of stress for parents, and parents have long called for a single point of contact with services, such as a key worker.

Service fragmentation is a key barrier to ensuring the needs of disabled children and their families are met. The lack of a comprehensive database (at either local or national levels) pertaining to disabled children currently inhibits a needs supply analysis of current levels of provision and multi agency strategic planning of services and resources.

**Theme 4: Identification, Diagnosis and Assessment of Child's Needs within Family Context**

**Theme 5: Early Intervention**

**Theme 6: Tackling Inequalities and Family Support**

**Theme 7: Transitions (Including from Child to Adult Services)**

**Theme 8: Therapies**

Families report unmet need for therapies. Inspections and research show that there are difficulties in obtaining therapy services for children, with long waiting lists in most areas. Children can wait up to 2 years before receiving intervention. Information on the effectiveness of therapies for disabled children is lacking, as is information on the workforce in physiotherapy, occupational therapy and speech therapy and what proportion of this workforce work with disabled children. There is continuing frustration with regard to funding for therapy services and a lack of co-ordination between agencies.

**Theme 9: Equipment and Adaptations**

Regardless of the type of impairment, the great majority of disabled children and their parents have unmet needs for equipment. A lack of equipment results in stress on families, demand for services they would otherwise not need, and barriers to inclusion and family life for children.

## **Theme 10: Children with Complex and Continuing Health Needs and/or Life-Limiting Conditions**

Children with complex and continuing needs and/or a life-limiting condition are a growing population. In recent decades, the care of these children has shifted from hospital to home and schools or residential care. However, meeting the children's health, social and educational needs, and their families' support needs is a complex task if their and their families' quality of life is not to be compromised.

Severely disabled children have special care needs for them and their families. Four out of five 12 to 14 year old severely disabled children need help with self-care e.g. feeding, washing, dressing, toileting etc. A third of parents with child under two use more than three pieces of equipment daily to provide basic care. This can put great pressure on parental relationships and family life. Current evidence indicates that services for this group are often underdeveloped, fragmented and poorly co-ordinated. Parents develop considerable expertise in caring for their child, but lack support from services.

### **Local Context**

#### **Wakefield Children's Services Review 2002**

The local context for children and young people in the Wakefield District is reflected in the Children's Services Review 2002. This review was commissioned by the Wakefield Children & Young People's Strategic Partnership and was funded jointly by the Primary Care Trusts and the Council.

The aims of the Review were agreed as:

- To collect evidence of the needs of children and young people in the Wakefield District
- To describe current service provision
- To quantify current resource investment
- To involve all relevant stakeholders, to elicit their views
- To identify good practice existing elsewhere and consider how this can be utilized in Wakefield
- To recommend future steps including possible integrated service models.

The view of members of the Children's Services Review Project Board and the views expressed by those who attended the feedback workshop are as follows:

- Services to children and families would be enhanced through increasing integration of planning and service delivery
- There has been considerable progress on better co-ordinating and integrating planning through the Children & Young Person's Strategic Partnership
- That many of the pre-conditions for successful integration exist in Wakefield

## **Developing Our Future (2003)**

The Government has committed to producing an overarching strategy covering all services for children and young people. However it accepts that no one agency or group will be, or can be, solely responsible for delivering against the strategy. "Developing Our Future" outlines the local multi-stakeholder strategic framework for achieving this agenda in the Wakefield District. In it the following vision and overarching goals have been agreed:

### **Vision**

We want all of our children and young people to be assured of:

- The opportunity to grow up in a loving, stable environment;
- Real opportunities to achieve their full potential and contribute to a fast moving, changing and interdependent world;
- Opportunities to experience the benefits of living in a diverse multi-cultural society, where all experiences are valued and racism is not tolerated;
- The prospect of living in a safe and secure community where they are protected from harm, abuse, harassment, exploitation or neglect and have the chance to enjoy the opportunity to grow up with their peer groups and friends;
- Chances to contribute to their local communities - feeling heard and being valued as responsible citizens - shaping their lives and their futures;
- The opportunity to appreciate their environment and participate in sport, music, art, drama, and a variety of cultural activities of the society and community in which they live;
- Focussed support as they pass through the various transitions from birth to adulthood, expanding their capacity to make decisions about their identity, relationships, education, future careers and financial affairs;
- Excellent joined-up public services, which strive to meet the individual needs of children and young people and their families; and
- Our commitment to work across all sectors to end child poverty, child deprivation, disaffection and social exclusion.

### **Goals**

- Children and young people should develop healthy lifestyles and opportunities to achieve optimum health and well being, within the context of high quality preventative and treatment services - if and when they need them.
- Children and young people should have the resilience, capacity and emotional well being that allows them to play, learn, relate to other people and resolve problems in life.
- Children and young people should have the opportunity to fulfil their personal goals and ambitions, to make mature choices about their future lives, to achieve success in their academic, social and cultural development; to be recognised, to enjoy the fruits of their achievements when they begin work, and have the means to engage in constructive play and leisure pursuits for their own sake.

- Children and young people should be able to be involved in the life of their local community and economy, be active citizens with an understanding of their role and importance in democratic society. They should also be empowered to express their views about their community, and society as a whole.
- Children and young people should be brought up in a safe and secure environment; free from crime, violence, abuse and harassment at home, at school and in the community, with the skills, self-confidence and resilience to make informed choices as they mature and to seek help when they need it from accessible, dependable and comprehensive sources of support.
- Children and young people should have experienced the benefits of living within a diverse society, where experiences and attitudes of others are valued, where different races and ethnic groups including white groups live together in respect and partnership, where they have opportunities to travel and learn about communities beyond their home, and where all forms of discrimination according to different backgrounds and circumstances are not tolerated.

The Children & Young People's Strategic Partnership has agreed the following priorities for the partnership and the development of services for children in the Wakefield District over the next 3 years:

1. To increase the integration of services for children in the Wakefield District
2. To develop a comprehensive framework for the commissioning, provision and monitoring of services for children
3. To improve the experience of children, young people and their families/carers of services for children in the Wakefield District
4. To ensure the involvement of children, young people and their carers in the development and review of services

### **Children with Disabilities in School – Needs for Specialist Therapy Services (1999)**

This report was produced by a Task Group established to assess the need for Specialist Therapy Services (specifically, physiotherapy, speech and language therapy and occupational therapy) for school aged children in Wakefield, in mainstream and special schools.

The report describes and quantifies, as far as possible, the likely impact of the changing educational context.

### 3 ENVIRONMENTAL ANALYSIS

#### EPIDEMIOLOGICAL FACTORS

OPCS estimates the prevalence of some form of disability in childhood to be approximately 3%, of which 1.2% will have more severe disabilities. Extrapolating this to Wakefield gives an overall prevalence of 2400 children 0-18 years of which 900 will have more severe disabilities.

Significant conditions include epilepsy, severe learning disabilities, cerebral palsy, autistic spectrum disorders, severe hearing loss and visual defects.

**Table 1 – High Severity Low Incidence Conditions**

Condition	Incidence	Approx Prevalence Wakefield 0-17 (71,000 pop <sup>n</sup> )	Comment
Cerebral Palsies	2.5/1000	177	Many different types of aetiologies.
Spina Bifida	0.5-2/1000	35-142	Incidence varies with geography and socio-economic conditions.
Muscular Dystrophy	1 per 30000	12	Commonest muscle disorder.
Severe learning difficulties or disabilities	3.7/1000	253	Many causes including Down's Syndrome, other chromosomal defects, brain injury, foetal insults. Little social class gradient with SLD – contrast with mild/moderate L.D.
Congenital sensorineural hearing loss	1-2/1000	71-142	Multiple causes.
Severe vision defects (blind/partially sighted)	1-1.5/1000	71-106	Includes children with multi disabilities. Children with visual defect as main problem – 25-33% i.e. 18-35 in Wakefield.
Autism	0.4-2/1000	28-142	Wide variation according to spectrum of condition.
Other communication disorders (dysphasia, dysarthria, dyspraxia, severe language impairment)	Not well established ?2/1000	142	Difficulty in definition.
Epilepsy	5-7/1000	355-497	Epilepsy is inactive at any one time in about half. Disabling in only small minority.

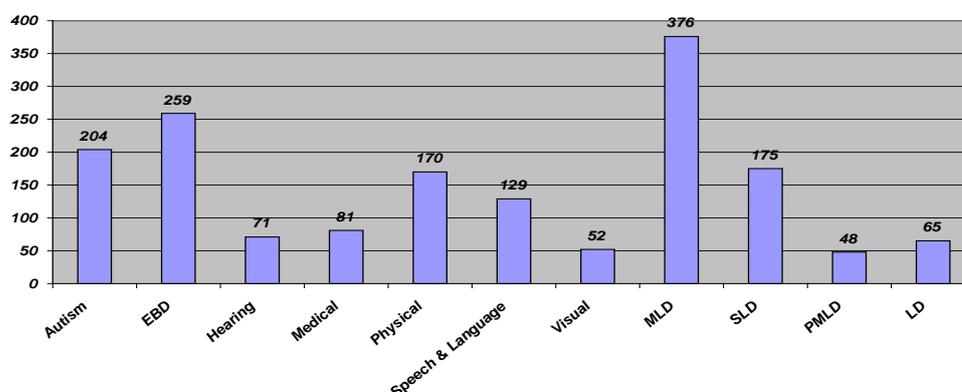
**Table 2 - Low Severity, High Prevalence Conditions**

Condition	Incidence	Approx Prevalence Wakefield 0-17 (71,000 pop <sup>n</sup> )	Comment
Delayed language development	3-10%	2130-7,100	Figure depends on definition.
General delay – mild/moderate learning disabilities	3-10%	2130-7,100	Figure depends on definition.
Developmental Co-ordination Disorder	3-7%	2130-4970	Figure depends on definition. More common in children with lower IQ.
Severe Glue Ear (Otitis Media with Effusion)	2-4%	1420-2840	
Eye defects – squint, refracture error, amblyopia	5-10%	3550-7,100	Prevalence of squint is 4-7%. Incidence of short sight increases throughout childhood and adolescence.

Difficulties arise in quantifying need locally due to the lack of an Integrated Register of Children with Disabilities and work is underway to address this.

Children with severe disabilities are often the subject of a Statement of Special Educational Needs. In January 2002 there were 1642 children and young people 0-19 years with a statement, the majority of which 1017 (63%) were being educated in mainstream settings. A further 467 (29%) were being educated in Maintained Special Schools within the District.

**Breakdown of Statements by Category Wakefield 2001**



The number of children with statements has fluctuated in recent years, reaching a peak of 1833 in 1996/97. Changes reflect a range of factors including increasing

prevalence of some conditions (e.g. autism), increasing survival of children with life limiting conditions as well as changes in educational processes.

## **4 CURRENT SERVICE PROVISION**

### **THERAPY PROVISION**

As stated in the introductory section this Business Case is concerned with two groups of Therapists; Paediatric Occupational Therapists and Paediatric Physiotherapists; the following sections give an indication of the role of these professional groupings and the current service configuration.

#### **Service Roles**

##### **Paediatric Occupational Therapy**

Paediatric OTs are specialists within their field and are trained to work with children with special needs including those with physical disability, co-ordination and specific learning difficulties, emotional and/or behavioural difficulties, learning disabilities and acute or chronic illness.

They work in a variety of settings including child development centres, nurseries, schools, at home or in clinical settings and may provide assessment and intervention in the following areas:

- Motor abilities – both in gross and fine motor skills, with particular emphasis to developing purposeful hand function, perceptuo-motor abilities and general levels of motor function to aid in daily life skills
- Sensory skills – how the child processes, interprets and modulates sensory information from the environment
- Cognitive skills – perception, concept forming, sequencing, problem solving, memory, attention and motor planning
- Visual perceptive skills – spatial relations, visual motor integration
- Play skills – exploration and encouragement of specific movement and other skills through play
- Social skills – inter-personal relationships and practice of social skills in every day situations
- Home and school – assessments and interventions can take place in either the home or school setting dependent on age and needs of the child
- Technology – aids access to curriculum and communication through technology either at home or school
- Seating – to promote an optimal seating position to aid function, management and access to the environment.
- Splinting
- Emotional/behavioural skills – interpersonal relationships, response to illness, development of self esteem, liaison and referral to other specialist services
- Aids for Daily Living – dressing/undressing, eating, drinking, bathing toileting etc. both in terms of access to and for independence skills.

## **Paediatric Physiotherapists**

The Paediatric Physiotherapist is concerned with the assessment, treatment and management of children who have a general development delay, disorder of movement, disability or illness which will be improved, controlled or alleviated by physiotherapeutic skills and/or the use of specialised equipment.

Paediatric Physiotherapists offer treatment for children with problems, caused by neuro-muscular, musculo-skeletal and cardio-vascular/respiratory conditions, Paediatric Physiotherapy covers most of the multiple pathologies which benefit from physiotherapeutic intervention e.g., cerebral palsy and developmental delay, progressive neuro-muscular disorders, elective and acute orthopaedics, burns and plastic surgery, haematology and oncology, and a wide range of respiratory conditions including intensive care and neo-natal care. The Paediatric Physiotherapist requires specialist paediatric core skills and in addition requires to develop skills particular to the specialities encountered.

The Paediatric Physiotherapist has a key role in helping to facilitate a child's maximum attainment. An in-depth knowledge of the physical, emotional, behavioural and social variables of child development is essential. The child is seen in the context of the family who has a key role to play in the team involved with the child and the Paediatric Physiotherapist is required to balance the child's needs and those of the family and offers support and teaching to families involved in the child's care.

Access to education is important for the children and the Physiotherapists must be able to participate in this process and distinguish between a child's physiotherapy needs for home and the physiotherapeutic intervention required to enable a child to gain maximum benefit from education. The Paediatric Physiotherapist rarely works in isolation and must be able to work together with other professionals as part of a multidisciplinary and multiagency team. All children referred for physiotherapy are assessed to identify problems which may indicate that physiotherapy is appropriate. Following assessment a treatment plan is drawn up in conjunction with parents and other carers. This treatment plan should include goals, which are agreed and understood by the family and other carers. Individual treatment by the physiotherapist is a very small part of a physiotherapy programme and the management plan should reflect the need to incorporate the skills into normal daily activities carried out by carers in all environments.

Paediatric Physiotherapists can work in a variety of environments including hospitals, clinics, children's homes, schools etc. Equipment may be a fundamental part of a child's treatment and management programme. The Paediatric Physiotherapist ensures that any equipment supplied is suitable for the child and the purpose for which it has been supplied. The Paediatric Physiotherapist has a role as an advisor and educator to families, other carers and education staff who are involved in the supply and use of specialised equipment.

Physiotherapy can be both reactive and proactive. The Physiotherapist may be required to respond to an emergency or urgent situation within the hospital setting, the treatment duration being relatively short or there may be referred children who are likely to require treatment over many months or years.

### **Service Configuration**

The provision of paediatric therapies is split across two providers; Mid Yorkshire Hospitals NHS Trust who provide Paediatric Physiotherapy across the District to service users from both EW and WWPCT and Paediatric Occupational therapy to WWPCT service users, and Eastern Wakefield PCT who provide Paediatric Occupational Therapy to EWPCCT registered patients and those attending schools in their geographic area.

Both services East and West are operated in an integrated manner across the two therapy specialties being co-located although having separate management and professional accountabilities.

Staffing levels are as follows:

- Physiotherapy
  - Establishment (w.t.e.)
    - 0.83 Superintendent 3
    - 4.47 Senior I
    - 1.00 Senior II
    - 2.00 Junior
    - 1.00 Technical instructor 3
    - 0.67 Assistant
- Occupational Therapy – MYHT
  - Establishment
    - 1.00 Head IV
    - 1.00 Senior II
    - 1.00 T.I.
- Occupational Therapy - EWPCCT
  - Establishment
    - 1.00 Paediatric OT co-ordinator
    - 2.87 Senior I
    - 1.00 Technician
    - 0.48 clinical/clerical assistant

### **Service Pressures**

#### **Waiting Lists and Caseload Sizes**

All three services currently have significant numbers of children waiting for assessment and/or intervention. These are as follows:

- Physiotherapy – 130
- Occupational Therapy East – 93
- Occupational Therapy West – 125

Approximately 90% of this waiting list relates to children with coordination difficulties or developmental delays (please see below).

The British Association of Community Child Health document *Standards for Child Development Services*<sup>1</sup> suggests a mixed caseload of 30 children per w.t.e. is appropriate. A mixed caseload would comprise of equal numbers of review children (seen half-termly, termly or yearly), maintenance children (seen monthly or fortnightly), an intervention children (seen once a week or more). In addition to their caseload each w.t.e. therapist would have an average of 22 children waiting for assessment. Currently all the paediatric therapy services are operating with case loads in advance of twice this theoretical level.

Operating with caseloads and a waiting list of this size is having a number of negative effects on the services provided including:

- Staffing issues
- Clinical governance issues
- Potential medico-legal issues.

A number of issues relating to Staff exist and these include:

- potential recruitment and retention difficulties - experienced Paediatric Therapists are limited in numbers and currently the service is fully staffed, however, there is the potential for staff to leave and join other neighbouring services if pressures get much worse. Recruitment then to a service which is perceived to be in crisis would be extremely difficult.
- Front line therapists are having to choose between carrying excessive caseloads or allowing waiting lists to grow longer; to give a good service to a few or a minimum service to a lot of children and families. This means that therapists are faced with a difficult professional and morale dilemma and is resulting in significant time being spent managing service users concerns and disappointments regarding levels of intervention that can be provided consequently reducing the available time to carry out assessments and interventions..

Clinical Governance concerns identified by the service include:

- Children developing adverse consequences as a result of not receiving any therapeutic intervention often resulting in the local health community incurring 'downstream' costs on services e.g. BOTOX, surgical interventions, longer ward stays;
- Service users receiving a below optimum service which results in service users conditions deteriorating not improving.

As a result of the service, by necessity, having to take a stance balancing effectiveness with demand pressures there is an ever increasing risk of legal action will potentially damaging consequences for the local community.

### **Children with Developmental Coordination Disorder Services**

Children with developmental coordination disorder have been given many labels in the past such as clumsy, dyspraxic, having minimal brain dysfunction etc. however in 1994 it was concluded that DCD should be the diagnostic label of

choice. Children with DCD have significant difficulties with motor coordination, given their age and measured intelligence, which cannot be attributed to any other medical condition. Their poor motor coordination interferes with everyday tasks such as handwriting, dressing and learning to ride a bike. DCD can severely limit school performance, self-esteem and age appropriate activities of general living putting pressure on other elements of a holistic response to a child's needs. DCD is commonly found with other conditions such as ADHD, dyslexia and speech/language impairments and other co-morbid conditions include drug and alcohol abuse, accidents, depressive and anxiety symptoms etc.

Long term follow up studies have shown that these children do not 'grow out of it' and identified that they have health problems at a rate considerably above that of children in the general population. One community based study following up children who had been diagnosed at 7 with DCD found that at 22 individuals were more likely to be unemployed, to have had problems with breaking the law, to be alcohol or drug misusers or to have mental health difficulties. Studies of the adult prison population have shown that ADHD is common amongst inmates and with studies identifying that up to 50% of children with ADHD also have DCD it can be concluded that significant numbers in the criminal justice sector would have had a diagnosis of DCD in childhood if they had been assessed.

DCD therefore appears to be an important predictor of poor psychosocial functioning in early adulthood and it would follow that it is imperative that early intervention aimed at reducing the impact, including social exclusion, of this condition is provided to these children.

A recent survey carried out by the College of Occupational Therapists and the National Association of Paediatric Occupational Therapists found that children with DCD wait longer to be assessed and are seen as a low priority compared to children with physical disabilities.

Nationally children with DCD comprise 30.4% of children registered to caseloads and 61.7% of those waiting for assessment and treatment. This may represent a rise in referrals and/or that not all children referred with possible DCD are taken on for treatment. It may be that children are not treated because services only offer assessment and advice to these children, or that referrals are inappropriate.

Locally there are 130 children with DCD on the waiting list for Physiotherapists (cross District), 93 on the EWPCT Occupational Therapy waiting List and 88 on the MYHT Occupational Therapy waiting list (approximately 66% of their total waiting list – clinical priorities are identified within Appendix 1).

Children, young people and adults with DCD are at a significant risk of becoming socially excluded through unemployment, unlawful activity, substance misuse or mental health difficulties. Therapists play a key role in the assessment, diagnosis, treatment and management of children with DCD. They also play a key role in educating parents and professional colleagues to increase awareness and knowledge about the condition.

Early intervention to diagnose these children correctly and offer them, their families and the other professionals working with them, support and advice is crucial in preventing the known poor psychosocial outcomes. Children with DCD are doubly disadvantaged by having to compete for therapy service provision against other children with apparently more severe difficulties.

### **Current Capacity Management Initiatives**

The service has adopted a number of capacity management initiatives in an attempt to address the pressures facing it including:

- Rationalising the settings in which interventions are delivered
- Clinical Prioritisation methodologies restricting access to services

Initiatives of this kind will be difficult to sustain in the long term due to the different policy direction now expected as a result of “Every Child Matters” and have resulted in the services taking a resource led stance not one which attempts to address the needs of the children and families.

### **EQUIPMENT PROVISION**

Twenty-four hour postural management is the positioning of a child with cerebral palsy or complex needs, utilising specialist equipment throughout the day and night. This level of postural care is essential for children with neurological impairment, to promote motor function, independence and to control deformity.

The specialist equipment required may include:-

- Standing frames
- Mobility systems e.g. walking frames
- Side lying boards
- Sleep systems
- Static chairs
- Wheelchairs

The equipment could be needed in any of the environments in which the child may spend some of their time e.g. home, school, community or in transit.

The assessment, provision, funding and maintenance of equipment and adaptations for disabled children are the responsibility of several agencies. The NHS is responsible for assessing for and providing health equipment. Local Authority social work services are responsible for assessing and ensuring the provision of equipment and (temporary) adaptations for daily living – for children at home. Provision of permanent adaptations is organised according to tenure of the property.

Education departments have a responsibility to provide any aids, equipment or adaptations needed by a child to access the curriculum. Assessments for equipment and adaptations needed by children in schools are typically

undertaken by an NHS or Local Authority therapist and recommendations are made to the Education department who then purchase the equipment.

The provision of equipment to children with disabilities is currently fragmented and uncoordinated across agencies within the Wakefield District, including the NHS, Social Services and Education Department. Funding for the purchase of such equipment is limited and almost never combined to the benefit of both service user and the organisations. This has led to the situation where equipment provided by one organisation for use in a particular setting for an individual child can not be used by that child in other settings.

Locally within the NHS investment in the provision of children's equipment has been limited and increasingly the available funding is being used to purchase disposables such as feeding tubes etc as the level of complexity of care that can be delivered at home has increased.

The following table identifies the estimated cost of equipment provided through the PCT Occupational Therapy services for 2002/3.

<b>Current Equipment Issued</b>	<b>cost implication p.a.</b>
Eneurisis Alarms	£1,851.91
Bespoke Prescriptive Equipment	£657.84
Equipment requests to ADU	£30,000.00
Children's Community Nursing	£72,180.51
<b>Total</b>	<b>£104,690.26</b>

Within the wider Mid Yorkshire geographical area children with postural care management equipment needs get these needs met through a combination of resources including PCT, Education and Social Care with requests being placed. This means that within the MYHT Paediatric Therapy service there is an geographical inequity of provision.

### **Identified Unmet Need**

As part of work relating to the Integration of Community Equipment Services and the developing Children with Disabilities Service Improvement agenda, Paediatric Physiotherapist and Occupational Therapist have identified a number of individuals who have been assessed as requiring postural management equipment to assist in maintaining their independence and quality of life and who currently have little or no equipment provided to them.

The following table identifies the numbers of pieces of individual equipment required to meet this need and makes a rough estimation as to the non-recurrent costs of this equipment based on 2003/4 figures.

Equipment Needed	Number of children requiring equipment	Approximate Minimum cost of piece of equipment	Approximate Maximum cost of piece of equipment	Approximate Minimum cost implication	Approximate Maximum cost implication
Walkers	57	£600	£1,500	£34,200	£85,500
Standing Frames	80	£600	£1,200	£48,000	£96,000
Sleep Systems	51	£1,000	£1,300	£51,000	£66,300
Wedge	6	£75	£200	£450	£1,200
Side Lyer	3	£800	£1,400	£2,400	£4,200
<b>Total</b>	<b>197</b>	<b>n/a</b>	<b>n/a</b>	<b>£136,050</b>	<b>£253,200</b>

In addition to this non-recurrent investment it is recognised that approximately 10 – 15 new children would require this type of equipment prescribing to maintain independence, quality of life and support them in achieving their full development potential and it is estimated that recurrent funding in the region of £40 -45,000 per annum is required to meet this new need.

## **5 THE BENEFITS OF APPROPRIATE PAEDIATRIC THERAPY INTERVENTION AND TWENTY- FOUR HOUR POSTURAL MANAGEMENT**

The benefits of appropriate paediatric therapy intervention and twenty-four hour postural management are numerous and include benefits to the patient as well as the therapy services. Therapy services are designed, and aim, to maximise the potential of service users including their educational attainment as well as physical development.

The following sections identify a range of benefits which will be realised through the operation of an appropriate service response.

### **Benefits to the Child:**

Paediatric Therapies and twenty-four hour postural management will have benefits for the child directly and in their overall quality of life. The following list highlights some of the benefits in outcome for the child.

#### Physical

- Controlling deformities: Therapeutic interventions and Postural management allows alignment of the joints and may act to stretch tendons and muscles. Twenty four hour postural management delays muscle contractures and the need for further intervention and subsequently orthopaedic surgery. Regular

standing in a standing frame will promote development of the hip joint and improve bone density, facilitating prevention of hip dislocation and subsequently arthritis.

- Improved and earlier acquisition of motor skills e.g. head and trunk control, and walking
- Allowing a child to experience a variety of different positions in a supported manner will stimulate the functioning of their sensory systems, improving their perception, response to gravitational movements and sensory awareness.

### Communication

- Comfortable postural positioning will assist in listening skills and allow the child to track with their eyes, enhancing reading skills. Positioning a child so that he / she is at eye level with peers will facilitate communication and increase self-confidence. Upright positioning may also assist in voice projection.

### Learning

- Improved comfort for the child when positioned, resulting in increase in concentration and attention level, reduced tiredness and therefore increased arousal level for learning
- At school, postural management allows the child to access the curriculum more readily. For example, appropriate positioning of trunk and lower limbs will result in better hand function. Positioning may also allow a child to participate in PE and to integrate more fully into the school curriculum.

### Associated health benefits:

- Nutrition - postural management in an upright position will facilitate the child's swallow and thus assist in feeding and absorption of food
- Providing a variety of different positions will promote efficiency of the systems i.e. respiratory / digestion / circulatory and thus result in decreased risk of pressure sores and aid general health
- Promotion of good quality sleep for the child directly and thus indirectly to the parent, as their sleep is not disturbed when re-positioning the uncomfortable child in bed

### Independence

- Enabling the child to increase independence through mobility, for example a moulded seating system in an electric wheelchair will give the child who is unable to walk independent mobility
- A child is encouraged to be mobile and to practise walking at the appropriate time i.e. 'window of opportunity'.

### Emotional

- By providing all the previously mentioned benefits a child's emotional well being may be improved.

### **Benefits to the Parent / Carer:**

The parent / carer may benefit from appropriate therapeutic intervention and postural management of the child by the following.

- Improved functioning of family life, due to child's gaining of independence, mobility and less reliance on 1:1 handling of the child
- Improved overall satisfaction with child's care and consequently reduced anxiety to the parent / carer
- Less risk of physical injury due to handling of child as they are positioned correctly
- Facilitation of relationship between child / parent due to all of the above

Provision of postural equipment must address the inequality which currently exists between the families who can and cannot self-fund pieces of equipment.

### **Benefits to the Service:**

The maintenance of patient function and the reduction in progression of deformities has a number of positive outcomes.

- Delaying or preventing surgical intervention with its associated
  - costly in-patient stays
  - cost of medication – both anti-spasticity and pain relieving drugs
  - intensive post-operative therapy management
  - need for specialist post-operative equipment with consequent increase in the demands on resources
- Effective pressure area management reducing risk of pressure sores and need for medical intervention, medication or in severe cases admission to hospital
- Easier handling of patients leading to reduced risk with moving and handling issues and consequent reduced physical risk to therapists and carers
- With earlier intervention with postural management patients would have less need for specialist wheelchairs with individual moulded seats.

### **Positive Effect on Therapy Time:**

The provision and use of specialist equipment to position children to achieve stretching of muscles and other soft tissue structures would benefit therapists in a number of ways.

Although therapists would use their specialist skills in assessment and analysis of movements to identify the postural needs of the children within equipment, time previously used to manually and routinely stretch soft tissues and muscles could be used more effectively.

Timely and efficient provision of postural equipment would therefore increase the effectiveness of the Physiotherapy Service with increased savings by:-

- Decreased travel and travel expenses
- Decreased time needed in attaining resources for equipment
- Decreased number of physiotherapy sessions i.e. the earlier a child walks, the less therapy the child needs
- Decreased number of acute, high intensity therapy sessions e.g. post-surgery

## **6 POTENTIAL SOLUTION OPTIONS**

The complexity of pressures facing the Paediatric Therapy Service are multi-factorial in nature and therefore require a similar approach to be taken to the solutions available to the local health economy. The following options therefore need to be considered as a whole and not individually with the decision in one area of service delivery having potential impacts in others. Wherever possible the consequences of each option have been identified. In addition, and supportive of these solutions, it is proposed that a concerted communications programme be carried out both informing service users and their families/carers but also relevant professionals and partner organisations about the solution options decided upon and the impacts this may have on them. This support from the Commissioners should also include an agreement to deal with any complaints regarding the levels of service provided by the provider agencies.

### **Services for Children with needs other than DCD**

As identified within the section relating to the roles of both paediatric occupational therapists and physiotherapists there are significant demands placed on the service. In order to meet the pressures this demand places on the local service the following options have been identified:

- Option 1 – Do nothing
- Option 2 – Minimal Additional Investment to address Clinical Governance /Caseload Concerns and maintain support to educational inclusion
- Option 3 – Significant additional investment to provide “Gold Standard” Service

#### **Option 1 – Do nothing**

This option maintains the status quo i.e. carry out an assessment and provide the current level of interventions even though there are concerns as to the clinical governance risk.

The consequences of this option include:

- The present deterioration of health and loss of skills/potential skills of the children will continue
- Staff will be unable to operate within safer boundaries and their low morale/stress of balancing the potential unsafe working practices will continue and potentially exacerbated with a negative impact on staff retention
- An ever increasing potential for complaints etc against the organisations and the staff themselves potentially resulting in costly negligence/malpractice claims.
- The continuation of operating a service on priorities rather than patient need

#### Cost implications

By definition this has no direct cost implications however as identified above there may be significant cost implications downstream as a result of future health care and social interventions.

#### **Option 2 - Minimal Additional Investment to address Clinical Governance /Caseload Concerns and maintain support to educational inclusion**

This option allows for the recruitment of a small number of additional staff across each therapy speciality to address immediate caseload/clinical governance issues. Work with the service has identified a bare minimum requirement for an additional staffing establishment of 2 w.t.e. Physiotherapists (1 Senior I and 1 Senior II) on each site at PGH and PGI and 2 w.t.e. Senior II Occupational Therapists.

The consequences of this option include:

- The present deterioration of health and loss of skills/potential skills of the children will be reduced
- Staff will be able to operate within safer boundaries and their low morale/stress of balancing the potential unsafe working practices could be reduced which in turn could improve retention
- A slight reduction in the potential for complaints etc against the organisations and the staff themselves
- The continuation of operating a service on priorities rather than patient need

#### Cost implications

This option would require additional investment in Paediatric therapies as identified below.

- Salary costs - £205,000
- Non-salary costs - £15,000 (estimated value)

### **Option 3 - Significant additional investment to provide “Gold Standard” Service**

This option would require the setting up of a comprehensive paediatric therapy service which includes the assessment and management of children with conditions other than DCD

#### Cost implications

The British Association of Community Child Health document *Standards for Child Development Services (2000)* suggests a mixed caseload of 30 children per w.t.e. is appropriate. A mixed caseload would comprise of equal numbers of review children (seen half-termly, termly or yearly), maintenance children (seen monthly or fortnightly), an intervention children (seen once a week or more). In addition to their caseload each w.t.e. therapist would have an average of 22 children waiting for assessment. The adoption of this service to the suggested caseload size would require significant investment in paediatric therapy services which by necessity in terms of recruitment ability would need to be spread over a number of years.

Using the minimum incidence figures for those conditions identified in the Epidemiological analysis and using the following ratio of 40% awaiting assessment and 60% receiving interventions a fully functioning service operating to suggested caseloads would have 686 children on active caseload requiring 22.8 w.t.e. therapists (across a range of skill mixes and grades).

### **DCD Services**

This document identifies the following options to address pressures relating to this particular service area:

- Option 1 – Do nothing i.e. maintain the status quo, not carry out assessments and place service users on a waiting list which is not addressed due to other more urgent needs.,
- Option 2 – Do not allow referrals to Paediatric Therapies from GPs and other professionals
- Option 3 - Provide an assessment only service with no follow up intervention other than provision of written information and guidance,
- Option 4 – Provide a comprehensive assessment and management service

#### **Option 1 – Do nothing**

This option maintains the status quo i.e. continue with referrals, don't carry out an assessment and place service users on a waiting list which is not addressed due to other more urgent needs.

The consequences of this option include:

- Morbidity of condition results in the children having difficulties with gross/fine motor, behaviour and self esteem problems

- Failure to achieve full potential as a child and with consequences into adulthood
- Continuation of growing waiting list
- Potential for a negative public response and an increase in complaints regarding waiting times
- Failure to comply with the Government's waiting time pledges
- Exacerbation of low staff morale and stress due to conflict when making decisions

#### Cost implications

By definition this has no direct cost implications however as identified above there may be significant cost implications downstream as a result of future social interventions.

### **Option 2 – Do not allow referrals to Paediatric Therapies from GPs and other professionals**

This option means that GPs and other professionals have no referral route through to specialist services when faced with children whom they feel may have DCD.

The consequences of this option include:

- Disquiet amongst those currently referring to the service who will perceive a service reduction
- Concern amongst parents who again would perceive a service reduction
- Increased pressure on other parts of the local health, social care and education communities

#### Cost implications

By definition this has no direct cost implications however as identified above there may be significant cost implications downstream as a result of future social and educational interventions.

### **Option 3 - Provide an assessment only service with no follow up intervention other than provision of written information and guidance**

This option would mean that service users are assessed and following diagnosis would receive written information and guidance material as a substitute for therapeutic intervention, additionally information would be sent to teachers etc.

A service of this nature is provided in the North Kirklees locality and therefore would provide equity of service across the three PCT localities if employed within Wakefield.

Currently there are limited numbers of assessments carried out as and when capacity allows although these are becoming less and less frequent. In order to provide an equal service for both old and new referrals some level of waiting list

initiative would be required to clear the backlog and in the long term additional staffing resources to meet new referrals.

The consequences of this option include:

- Locum staffing would be required during the timeframe of the waiting list initiative to backfill experienced and specialist staff to carry out the assessments
- The recruitment of additional staff with appropriate skills and experience would be difficult but not impossible
- Completion of assessments may result in the identification of needs requiring support from other sectors of the local health, social care and education community putting additional pressures on these already stretched resources. However, it is accepted that these children will probably already been in receipt of some level of support over and above that received universally.

#### Cost implications

This option does have some cost implication as service users would be assessed prior to information being issued however at this time a full quantification of these implications cannot be identified. As identified above there may be significant cost implications downstream as a result of future social interventions. The production of appropriate written information and guidance material will require some additional printing/production budget the magnitude of which has yet to be determined.

#### **Option 4 – Provide a comprehensive assessment and management service**

This option would require the setting up of a comprehensive DCD service which includes the assessment and management of children with DCD on a multi-agency basis delivering interventions through a range of mechanisms and settings including group sessions and the use of settings such as sports centres etc.

#### Cost implications

It is estimated that a gold standard service could be provided within the District with 8 therapists and 2 assistants across physiotherapy & OT dedicated to DCD services.

The development of such a service would need to be undertaken jointly with the local education authority and a broader range of organisational partners than currently provides funding for therapy services in order to support an integrated multi-agency approach. This approach would require the input of paediatricians, therapists, educational and clinical psychologists to ensure a holistic approach to diagnosis and treatment and it is expected that a consideration of this service will be included in the longer term modernisation programme for paediatric therapies.

## **Support to Education Services**

As identified above the Therapy service provides support to children who attend Streethouse School, this service was funded through Joint Funding arrangements which the two PCTs committed to support through to the end of March 2005. The options relating to this service therefore are:

- Option 1 – Do not provide funding support
- Option 2 – Provide funding support of an equivalent magnitude

### **Option 1 – Do not provide funding support**

This option would mean a reduction in the level of service provided to children attending this facility.

The consequences of this option include:

- A reduction in services provided to support the inclusion in mainstream education for children with disabilities in the school
- Additional staffing resources have been recruited and paid for with this funding, removal of the funding with therefore either increase the cost pressures facing the service or require staff to be redeployed elsewhere
- Additional pressures on the service as the children receiving support in the school setting would still require some level of intervention to maintain their independence levels.

#### Cost implications

An immediate cost-saving of £35,000 would be achieved however as can be seen from the above consequences this is likely to be incurred through a range of 'downstream' interventions.

### **Option 2 - Provide funding support of an equivalent magnitude**

This option would require continuation of the current funding levels.

#### Cost implications

Currently a funding contribution of £35,000 (2004/5) is made by the two PCTs.

## **Paediatric Equipment Provision**

Solutions relating to improving the provision of paediatric equipment i.e. postural care management equipment are purely reliant upon the ability to secure additional investment in this area of service delivery.

This document identifies three potential options:

- Option 1 – do nothing
- Option 2 – provide recurrent funding for new service users only

- Option 3 – provide additional investment to meet the historical unmet need and recurrent funding for new service users

### **Option 1 – Do Nothing**

This option maintains the status quo position relating to the provision of paediatric equipment i.e. provision as and when possible from the limited funding available, reuse where possible of equipment and/or use of charitable funds by service users families to meet the gap in service.

The consequences of this option are numerous and include:

- The present deterioration of health and loss of skills/potential skills of the children will continue
- Staff will be unable to operate within safer boundaries and their low morale/stress of balancing the potential unsafe working practices will continue and potentially exacerbated with a negative impact on staff retention
- An ever increasing potential for complaints etc against the organisations and the staff themselves potentially resulting in costly negligence/malpractice claims.

#### Cost implications

By definition this has no direct cost implications however as identified above there may be significant cost implications downstream as a result of future clinical and social interventions.

### **Option 2 – Provide recurrent funding to be used to meet priority needs as identified by therapists**

This option requires the provision of a limited and capped recurrent funding provision to meet the postural care management needs of those children identified as having priority needs following appropriate assessment

The identified consequences of this option include:

- Inequitable service provision across the MYHT geographical area
- Inequitable provision within the local service as once the monies had been spent no further equipment could be provided
- Increased pressure on the Integrated Community Equipment Service provided by WWPCT, however the amount requested does include an element of ICES support costs
- The majority of children still requiring increased hands on intervention and downstream interventions e.g. surgery.

#### Cost implications

It is estimated that recurrent funding in the region of £55 -70,000 per annum be provided as a starting point with a year on year increase to eventually provide a comprehensive equipment provision..

### **Option 3 – Provide Additional Investment to meet historical unmet need and recurrent funding for new service users**

This option requires the provision of recurrent funding to meet the postural care management needs of newly diagnosed/identified service users plus a significant non-recurrent investment to meet an historic under funding of equipment provision.

The identified consequences of this option are:

- Increased pressure on the Integrated Community Equipment Service provided by WWPCT, however the amount requested does include an element of ICES support costs

#### Cost implications

It is estimated that recurrent funding in the region of £55 -70,000 per annum is required to meet new need based on projected prevalence figures with a non-recurrent investment of between £135,000 – 250,000 based on a minimum and maximum impact identified in Table 2 above.

## Appendix 1

### PAEDIATRIC OCCUPATIONAL THERAPY SERVICE AT P.G.H. - PRIORITISATION OF REFERRALS

**PAEDIATRIC OCCUPATIONAL THERAPY SERVICE AT P.G.H.  
PRIORITISATION OF REFERRALS**

**Priority A**

- Child requires in-patient rehabilitation at PGH
- Child requires a splint - acute situation
- Child protection case; equipment issues
- Child has debilitating condition; would deteriorate without immediate intervention e.g. equipment
- Child has a recent diagnosis of a neurological condition and has an acute/deteriorating/fluctuating condition
- Child requires equipment (safety or feeding/swallowing issues)

**Priority B**

- Child is 0-2 years and has a diagnosis e.g. cerebral palsy (CP); child due for a phase transfer at school
- Child is 3-5 years has diagnosis of CP
- Child is 6-19 years with a CP diagnosis
- Assessment requested to assist diagnosis e.g. Autism Spectrum Disorder

**Priority C**

- Child is 3-4 years of age with developmental delay or co-ordination difficulties

**Priority D**

- Child is 5-8 years of age and referred for co-ordination difficulties; developmental delay

**Priority E**

- Child is 9 years of age or older and has learning and/or co-ordination difficulties but is not due for phase transfer