



British Association for Community Child Health  
Child Development and Disability Group

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**STANDARDS FOR  
CHILD DEVELOPMENT SERVICES**

**A Guide for Commissioners and Providers**

## Introduction

These guidelines have been prepared for commissioners and providers of services for children with disabilities. There is a wide diversity of provision for these children, ranging from comprehensive family centred services encompassing all disabling conditions throughout childhood and adolescence, to clinics that cater only for under-fives with severe disorders like cerebral palsy, and then only in a fragmentary fashion.

The aims of the service specification set out here are, first, to establish a minimum standard and second, to describe the range of expertise that disabled children may need. Quality depends on the input of, and collaboration with, many other disciplines and agencies in addition to paediatric medicine. The role of parent organisations and parents support has grown rapidly in recent years and is a vital part of any disability service. Indeed, the strictly “medical” component of the care these children require is but a small part of their overall needs.

The document focuses on district or secondary level services rather than specialised tertiary neurological or neurodisability provision, but the boundary between the two is constantly shifting and can never be defined precisely. The providers’ responsibility is to ensure that children can access the expert help they need, whether within or outside their own district. The British Paediatric Neurology Association participated in developing this document and support our recommendations which are in line with those of their recent report, *A Guide for Purchasers of Tertiary Services for Children with Neurological Problems* (BPNA 1998).

Most disabling conditions affect the nervous system. The need for accurate diagnostic evaluations and for close links between acute and chronic neurology services, will be obvious. In particular, the care of children with epilepsy must be considered in the commissioning process. Epilepsy may be an isolated problem but often it co-exists with other disabilities and may itself cause major functional and educational problems. Districts differ in how they provide for children with epilepsy but there is a strong case for developing close links between epilepsy care and other services for disabled children.

There are other fast-moving subjects in neuroscience, like autism, neuro-pharmacology and neuro-psychiatry, in which rapid progress will offer new opportunities for treatment; staff at district level will need to keep up to date with all of these.

Although this document is primarily about service provision, the training implications must be remembered. Specialist registrars need to learn about disability in a centre that performs at least to the minimum standard set out here. Services that do not meet these standards should invest in staff development before undertaking to teach trainees in paediatrics or in other disciplines.

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## 1. Who needs a Child Development Service?

1.1 All children deserve access to a range of high quality services which will help them to attain optimum health and well being and to become healthy and well adjusted adults. Some children with physical or mental illness or disability or other economic or social disadvantages will need additional help, support or treatment in order to reach these goals. Although many kinds of chronic illness cause children to have special needs or disabilities, there is a substantial group (about 90% of the total) whose disabilities are caused by impaired function of the nervous system<sup>1</sup>. A proportion of children show delay or disorder in development in one or more areas, for example motor development or language development. Some have global developmental disorder. Others may have impairment of vision, hearing, communication, feeding, fine or gross motor control. A number of children have specific learning impairments, for example literacy, whereas others have behavioural difficulties, either alone or in conjunction with other impairments. About one in five children will at some stage of their education have some form of special educational need<sup>2</sup>, and about one in six children have special educational needs at any one time. Some disorders are temporary and resolve with appropriate input; others are permanent. About two percent of children have severe and ongoing difficulties. Children and young people with disabilities have a right to services and facilities which enable them to achieve the best possible social integration and individual development<sup>3</sup>. With such help children may avoid significant degrees of disadvantage.

1.2 Services for these children are best co-ordinated by a Child Development Team. According to the Court Report<sup>4</sup>, a Child Development Team should have two distinct areas of function; clinical and operational.

### Clinical:

- To assist in surveillance and management of disabled children in a locality.
- To provide investigation, assessment and to co-ordinate treatment for children with disability.
- To provide parents, teachers and others concerned in their care, with professional advice and support.
- To provide secondary and specialist child health services to special schools in the district.
- To ensure effective transition to adult care.

### Operational:

- To be involved with others at district and area level in epidemiological surveys of need; to monitor the effectiveness of the district service for disabled children; to present data and suggestions for the development of the service; and to maintain the quality of service delivery.
- To act as a source of information in the district about disability in children and the services available.
- To organise training for professional staff working in the district.

1.3 A Child Development Service includes the specialist services for assessment and management of children with disabilities including physical and learning disabilities, hearing, vision, speech and language problems. This is a multi-disciplinary team process covering the work of Child Development Centres, community based services in special and mainstream schools and nurseries, community clinics and in the child's home<sup>5</sup>. As well as working directly with the child and family, the service is required to provide advice to the local education authority and to contribute towards statements and reviews under the 1993 Education Act<sup>6</sup>, together with responsibilities relating to social services under the Children Act<sup>7</sup>.

1.4 It is important that Child Development Services have comprehensive local knowledge in order to provide the best possible packages of care. This means that good collaborative

working relationships must be built up with primary care, education, social services, parent groups and voluntary groups. The Child Development Team aims to make a diagnosis if possible and to assess the child thoroughly so that a package of ongoing treatment and care can be agreed and provided for the child and family. This management plan may involve the services of several professional groups, including paediatricians, children's nurses, physiotherapists, occupational therapists, speech and language therapists, psychologists, dieticians, orthoptists and audiologists etc. Liaison with Primary Care, Education, Social Services and voluntary groups is an important part of the package. If local services are not able to provide the very specialised packages of care required by some children, these will need to be negotiated with out of district providers. If possible, local planning for provision and purchasing of services should be joint between health, education and social services.

### 1.5 *Why is a special service needed?*

(a) This group of children requires a different kind of service from that required by most children attending hospital or other paediatric clinics. At one end of the spectrum there is the child with multiple disabilities, complex neurological problems or physical problems compounded by psychological and behavioural difficulties: most paediatricians would agree that such children need a dedicated multi-disciplinary service different from that of an ordinary paediatric consultation. At the other end of the spectrum is a group of children who will sometimes require reviews by a team of professionals with complementary skills and experience, while at other times the child and his or her family might best be dealt with by just one member of the group, often the community paediatrician with specialist experience in disability.

(b) A better understanding of **specific learning disabilities** such as dyslexia, other conditions such as attention deficit disorder, hyperactivity and emotional and behavioural disturbance has led to increasing referrals. This work requires close working relationships with educational psychologists, local child mental health services and teachers.

(c) The **pattern of school provision** is changing from special schooling to mainstream integration. The Child Development Service provides information for the statementing procedure and ongoing review and advice to schools for children with special educational needs.

## 2. Legislation

2.1 Current legislation lays down the responsibilities of local authorities rather than health authorities. Nevertheless, a number of principles embedded in the legislation would seem to apply equally well to health service provision, even if they are not in a strict sense legal requirements.

- The Children Act 1989<sup>7</sup>
- The Chronically Sick and Disabled Persons Act 1970 and 1986 (Services Consultation and Representation)<sup>8,9</sup>
- The Education Acts of 1988, 1991 and 1993<sup>6</sup>
- Community Care Act<sup>10</sup>

2.2 The Patient's Charter<sup>11</sup> and Children's Charter<sup>12</sup> both contain **expectations** that it will be easy for children with physical or mental disability to access NHS services of high quality. Easy access to a service providing specialist knowledge is essential. It is helpful to families if most or all of the services needed by their child are accessible through **one geographic location**, preferably a Child Development Centre. This has implications not just for access but also for quality. It is often the case at present that families are seen in a multiplicity of locations, with attendant multiplication of travel and waiting times, confusion about who is

seeing them and why, missed or late appointments and difficulty in synthesising the various assessments and treatments into a meaningful whole. A 'single front door' for most or all the services provided by health, education and social services in relation to children with special needs and a single central point of telephone contact for parents and others would help to rationalise what is often a very complex network of support for individual families.

### 2.3 Principles:

- The needs of the child are paramount.
- Partnership with parents and carers.
- Registration of children with special needs.
- Integrated joint assessments.
- Services should be needs led.
- Information on services should be publicised.
- Services should be appropriate for the child's cultural background.
- Families should have effective independent representation and complaints procedures.
- Quality control of services should be established through monitoring, inspection and review/audit/clinical governance.

## 3. Client group

3.1 The client group includes children and young people up to 19 years. Lack of appropriate adult services means that some young people may continue to access paediatric services into their twenties.

3.2 Types of disability: (see Appendix 2 for a more detailed list and population prevalence):

- Learning difficulties.
- Cerebral palsy.
- Other motor and neurological impairments including spina bifida and children with developmental co-ordination disorder, DAMP (deficits in attention motor control and perception) etc.
- Autistic spectrum disorders.
- Isolated severe language delay.
- Visual impairment.
- Hearing impairment.

A number of children have multiple disabilities. Some have additional emotional-behavioural difficulties.

3.3 The **pattern of work** for child development/disability services is changing. These are some examples:

(a) There is some evidence that an increasing proportion of children with cerebral palsy experience a **greater severity of impairment** than previously<sup>13</sup>. This will mean an increasing number of children who have severe multiple disability, e.g. whole body cerebral palsy, severe learning difficulties, cortical visual impairment and epilepsy. These children need a great deal of input from a number of professionals and may be major users of supportive technology.

(b) More **low birth weight infants** are surviving. Some have definite cerebral palsy, but many are now recognised to have less clear but still significant impairments in the realms of learning, fine motor control, emotional and behavioural well being<sup>14,15</sup>.

(c) There is increasing recognition of autistic spectrum disorders and attention deficit disorders which require expert assessment, diagnosis and subsequent advice on the educational process together with specific aspects such stimulant medication, treatment of epilepsy or depression and challenging behaviour.

(d) Working together in **partnership with parents and families** means understanding them. Professionals and parents both acknowledge the importance of parent involvement, provision of suitable information, appropriate treatment, accessible and available care, and co-ordination of care<sup>16,17</sup>. There is a considerable emotional burden and family morbidity when looking after a child with a disability, with implications for support from mental health services. Multi-agency networking also needs to be well set up, which has implications for staff training and good administrative structures.

(e) **Awareness** of the needs and status of disabled people has improved considerably (but still has some way to go). There is a consequent expectation of better services for children and more attention given to transfer into adult services, which have traditionally been poor.

(f) Increasing **scientific development** means that more interventions can be carried out: for example Botulinum Toxin treatments for children with cerebral palsy.

(g) An increasing range of complementary therapies for various conditions has increased the treatment options available to parents. Professionals involved in Child Development Services should have some understanding of these and be able to discuss them with families.

#### **4. Planning for service delivery**

4.1 Planning for services on a district basis should be under the direction of a multi-disciplinary team of experts in childhood disability working in partnership with parents and other agencies (education, social services, voluntary groups). It is highly desirable that there should be a consistent management overview and lead for all disability services in a district. This should take account of any split health trust working arrangements. Accurate information technology including a disability register is an important part of this. Suitable information technology with a data set for each child is essential for service planning, development and audit. Such a system can monitor the outcome of developmental surveillance<sup>18</sup>, log the numbers of children affected, the diagnostic categories, the areas of function affected and the degree of severity, monitor treatment input, log statements of special educational need and co-ordinate follow up arrangements. During the progression through childhood from preschool to adulthood the lead agency for planning may change. During the preschool years, child health may take the lead, but during the school years the education department may take the lead. In the transition to adult life and afterwards social services may take the lead. A consultant paediatrician with suitable training in childhood disability should take a medical lead in district level multi-agency planning and in the running of a multi-disciplinary Child Development Team. The lead clinician in a health district or in a Child Development Team is often a paediatrician but need not be as services are often successfully led by members of other professional disciplines. The district lead clinician or the local team leader roles might belong to different people and might be rotated on an agreed basis.

4.2 Close working relationships should be fostered with local education, social services and voluntary groups. Consideration should be given during planning to whether these services can be located within the Child Development Centre. Consideration should also be given to making these workers core members of the Child Development Team. Jointly funded posts between health and local authority could be explored. Parental representation is important during planning and there should be parent representation within the management structure of the Child Development Team.

4.3 Patterns of service delivery will vary according to the population characteristics of each health district. The ideal pattern of service delivery in a large conurbation will necessarily be different from that of a rural area. In larger centres of population, a centre based service is



preferable. In rural areas, this may not be practicable and a more outreach based service would be appropriate, perhaps based on local nursery or health centre provision. Some larger health districts will include regional or subregional services for aspects of childhood disability.

4.4 Children with different disabilities require different services. For example, children with moderate learning disability require less input from specialist health services than, for example, children with cerebral palsy or children with severe multiple disability.

## 5. Levels of provision

5.1 A child with significant disability may require access to several levels of health care provision. It would make sense for each district to examine the pathways of care leading through primary to secondary and on to tertiary services. For particular conditions it should be feasible to draw up integrated care pathways which should make access to appropriate services smoother for both families and professionals.

5.2 **Primary health care services** have a particular role to play in the detection of children with disability. The health visitor has a particular role in developmental surveillance and identifying children with potential special needs. If the child is subsequently found to have significant special needs the health visitor will have a role in supporting the child with disability and his/her family and enabling them to use services. For most families the health visitor will be the key worker in infancy and early childhood. It is important to ensure good communication with the family practice and to provide for training and support<sup>19</sup>.

5.3 **Secondary specialist children's services** are required by most children with disability<sup>18</sup>. In practice these services vary greatly between districts. This provision should be supervised by the Child Development Service using both the Child Development Centre and community based services with clear liaison pathways for all aspects of service delivery, including hospital inpatient, outpatient and community services.

5.4 **Tertiary specialist services for childhood disability** may be provided within larger teaching districts - for example paediatric neurology, specialist radiology, neurophysiology etc. (see below and Appendix 1). In smaller health districts, children needing these services should be able to access them in the nearest centre in a clearly defined pathway of service provision which includes a regional or subregional centre, usually with visiting outreach clinics by a paediatric neurologist, consultant in paediatric neurodisability or other specialities such as paediatric gastroenterology.

## 6. Identification

Children with the most severe developmental problems should be picked up early in life either because they are known to be 'at risk' (e.g. neonatal intensive care survivors) or through a combination of parental concern and pre-school child health surveillance. A third group will have learning difficulties which are not apparent until they are in school<sup>6</sup>; for these children referral will be via school medical services and education<sup>20,21</sup>.

## 7. Access and referral pathways

7.1 Easy access to a service providing specialist knowledge is essential, preferably through 'a single front door' and co-ordinated by the Child Development Service or perhaps by a larger department of community child health or combined acute and community child health. For most children with severe complex disability this will be within the organisational setting of

the Child Development Centre. Many children however, particularly the large group with moderate learning disability, may be dealt with more locally within the community but co-ordinated from within the Child Development Centre or local department of child health. It is likely that different styles and solutions will be found in different districts.

7.2 There should be an integrated mechanism for referral within the network of services for childhood disability including the Child Development Centre, other local services and services based within the special and mainstream school environment. Easy avenues of referral for parents and referring professionals may best be achieved by creating local referral protocols. The service should be responsive to cases which need to be seen urgently. Protocols should be drawn up for management of particular client groups, e.g. Down syndrome.

7.3 The Child Development Service should not be confined to a 'nine-to-five' service: arrangements for out of hours provision should be made, for example an answering machine for non urgent problems and clear information about how to contact the hospital for more acute problems, e.g. a prolonged convulsion.

## **8. Assessment and diagnosis**

8.1 This is provided by a Multi-disciplinary Team (see Appendix 1). There should be a structured multi-disciplinary assessment which:

1. Involves the parents.
2. Involves contact with the home.
3. Includes specialist assessment of hearing and vision.
4. Includes appropriate medical investigations with access to diagnostic facilities including genetic investigations, biochemical screening, neurophysiology and radiology.
5. Includes feedback to parents.
6. Produces a written report for relevant professionals which is also given to parents.
7. Includes an assessment summary containing not only the medical diagnosis but specific functional problems.
8. Includes an action plan should be produced with specific intervention goals which correlate with the problem orientated assessment.
9. Includes a process for the co-ordination of treatment plans. In most cases this will be some kind of case co-ordinating meeting of all the professionals and agencies trying to help the family. The family must be involved in this. It is also recognised that professionals often need to discuss their views and co-working without the family being present on every occasion: this may require a two tier structure for information sharing.
10. Nominates one professional, who may often be the paediatrician, to take time to provide an overview for the parents, giving them the detailed information which they require, including an attempt to answer questions about the future.\*
11. Makes genetic counselling available.
12. Includes a periodic review system.
13. Includes a named keyworker.
14. Assesses the needs of the family as a whole.

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\* Bad news should be given in private. The management of disclosure is difficult and its timing should be planned for but is not always easily predictable. Sometimes the problems are clear early in life. For other children abnormal development becomes apparent over time. Imparting information to parents will in many cases need to take place in stages too. It is important that it should be done by a professional with specialist knowledge, with both parents present if possible, in a suitable setting and with someone else present who can provide support. There should be specific training in this area<sup>22</sup>. Access to psychology, social work and child psychiatry support is important. Verbal information should be backed up by written information. Guidelines and training are also provided by the SCOPE working group 'Right from the Start'.

## 9. Treatment/management

### 9.1 *Medical/paediatric*

Depending on the degree of medical need, all children known to the Child Development Service require a paediatric review at suitable time intervals. Taking an overview of the whole child, the doctor with a special interest in child development and disability is in a good position to provide information and guidance to the parents and other professionals and should be able to provide continuity of care, e.g. between Child Development Centre, tertiary medical services and school<sup>20, 21, 23</sup>. It is important to avoid duplication of the paediatric role and desirable for one doctor to assume the lead role for a particular child's medical care. Statutory medical reports are required for education and liaison with social services over home modifications, respite care, transitional care plans and child protection issues.

### 9.2 *Nursing*

Community paediatric nurses, school nurses, health visitors and specialist health visitors working in the field of childhood disability have a vital role in the delivery of health care. They are in a particularly good position to form supportive relationships with families, to help them use services appropriately and to act as advocates and intermediaries. Community nurses who provide an outreach for a specialist service - for example the neuropathic bladder clinic, home ventilation or parenteral feeding - are very important for practical management in the community.

### 9.3 *Therapy disciplines*

(speech and language therapy, paediatric physiotherapy, paediatric occupational therapy)

(a) The therapy needs of children with disability in the U.K. have never been effectively planned for. Staffing levels compared with, for example, Scandinavia, are very low. Professional therapy organisations have produced appropriate guidelines for case loads which can be feasibly treated. The scarcity of provision motivates the more resourceful parents to seek alternative treatments, sometimes paid for by charitable fund raising to enable the child to attend specialist centres in the U.K. or abroad.

(b) *Speech and language therapists* encourage language development including the use of alternative communication i.e. signing (for example with Makaton sign language), and augmented communication (the provision of electronic devices). A number of children with disability have an ongoing need for speech and language therapy input throughout childhood. This includes at least a quarter of all children with cerebral palsy and many children with severe learning difficulties who require a speech and language programme in conjunction with their other special educational needs. Speech and language therapists are also involved with helping children with significant feeding problems. In larger health districts a specialist multi-disciplinary team is usually set up to manage this group of children.

(c) *Physiotherapy* is required to treat cerebral palsy, muscle disorders, acquired brain injury, neurodegenerative disorders and to advise on the encouragement of early development of children with learning difficulties affecting motor development.

(d) *Occupational therapy* deals with hand skills, self help and daily living skills, with special responsibility for the provision of aids and appliances. The traditional ratio of one half occupational therapist to one physiotherapist is probably less than optimal. The increasing recognition of co-ordination disorders such as dyspraxia has increased the occupational therapy workload.

### 9.4 *Clinical Psychology and Child Psychiatry*

Emotional and behavioural problems are common in children and families with disability<sup>24</sup>. Problems with behaviour probably constitute the greatest burden for families of severely

disabled children. It is estimated that they occur in at least half of children with cerebral palsy and rather more than half of children with severe learning disability. The clinical psychologist is an essential member of the Child Development Team. The psychologist contributes to the specialist assessment of disability; for example administration of standardised cognitive assessment tests. The psychologist may also provide a support and counselling role for the team. Rarely, a team may have access to a psychotherapist who can work with the child or family. Links should be made with local child psychiatry services as there can be substantial overlap with these services for some client groups, for example Attention Deficit Hyperactivity Disorder and Autistic Spectrum Disorders.

#### 9.5 *Who does the hands on treatment?*

In practice this is done by the parents when the child is young but after he/she goes to school it becomes increasingly difficult for the parent to work effectively when the child comes home tired at the end of a school day. In special schools therapy is based in the school, although sometimes case loads are so large that effectiveness is limited. The increasing number of children with special needs in mainstream schools makes increasing demands on the therapy services as time has to be allowed for travelling, for educating school staff in many different schools and planning for adaptations to the school. The Child Development Team has an important role in training parents, nursery, school and other staff dealing with the child and family so that therapeutic approaches can be applied widely and consistently, not just within the Child Development Team or Centre.

#### 9.6 *Where should treatment be delivered?*

Treatment may be delivered in the Child Development Centre, the home, nursery, local clinic or school. Therapists need to be able to work in all these locations. The most effective and efficient setting for the child at various stages needs to be considered. This will include travelling time, transport costs and provision of a mobile telephone or pager. Safety of therapists working alone in the family home or in isolated locations must be considered. Junior grades should not work unsupervised. Intensive rehabilitation of children after specialist treatment is an increasing issue: for example after Botulinum Toxin injections or orthopaedic surgery for children with cerebral palsy.

#### 9.7 *Advice to Education*

All therapists are increasingly involved in contributing to statements of special educational need, to working out programmes of intervention in the school together with the teaching staff. There may also be requirements to provide information to multi-agency panels for issues of funding expensive specialist placements where several agencies share responsibility for care. There are also issues surrounding 'handover' of the primary focus of care from the Child Development Team to the Educational environment.

For further details of Child Development Centre staffing see Appendix 1.

#### 9.8 *Transition to adult services*

Adolescents with disability are often well supported by local services. Many of these teenagers are less independent than their peers and are therefore quite vulnerable if the amount of support suddenly diminishes. Services for young adults with disability are much less well developed than services for children. This is a major deficiency throughout the United Kingdom which should be remedied by appropriate strategic planning. Local disability registers which may belong to one or more agency can be helpful for both short and longer term planning. However, despite published recommendations appearing over a ten year period, little has been done in practice to remedy this situation. The *medical* services available will vary with location. Such services might include general practitioners, general physicians, adult neurologists, orthopaedic surgeons, and occasionally a young adult disabled or rehabilitation service. Young adult disabled services are not commonly available and rehabilitation services may be targeted much more towards treatment of acquired disability such as head injury or

stroke. Transitions will be smoother if local services for children and adults have established working relationships.

A structured transition to whatever services are available should occur. Child development services are in a good position to co-ordinate the handover of care to available adult services. Ideally, planning for the future should be undertaken in a multi-agency manner, with the involvement of education, social services and other services such as adult learning disability teams and voluntary services. A clear local framework for this process should be developed. Wherever possible the teenager should participate in this process. For the more able teenager issues of judging competence and of confidentiality may become important. At about 14 years old a transitional plan should be in place, which details the involvement of various agencies over the period until the end of special educational provision at 19 years. For the very physically immature some extension of this age range may be appropriate. The transitional plan should include a written summary for parents and all other relevant agencies. A staged transfer to adult medical services and further education or other provision should occur, with some degree of flexibility. Identification of a key worker can help this process. The overall aims should be to minimise disability and handicap, empowering the young adult to play as full a part in society as possible.

These issues are well discussed in the Royal College of Physicians of London publication 'Services for young people with chronic disorders in their transition from childhood to adult life'<sup>25</sup>. Although guidelines are suggested, there is little available evidence upon which to base these.

## **10. Other resources required for treatment**

10.1 These are the resources required outside the 'core' Child Development Team. Depending upon the district these may be provided locally or may require access to tertiary services for some of them. For some of these services setting up combined clinics, perhaps within the Child Development Centre, can work well.

### *10.2 Aids and appliances*

There is a bewildering array of appliances and equipment which may be expensive. Ranging from specialist footwear to wheelchairs and car seats, these should be provided in a way which is easily accessible by the disabled child, the family and the therapy team who will need to co-ordinate their aims for the child. Appliances and seating cannot be considered in isolation. An equipment library, with suitable storage space, where articles may be borrowed to try out in the home before they are ordered is useful. A seating clinic is also helpful. An equipment pool with facilities for exchange when a child outgrows certain items could save money since new equipment need not always be ordered for every child.

### *10.3 Vision team*

A team comprising an ophthalmologist, orthoptist and optometrist should provide a service to the Child Development Team not only for assessment but also for the ongoing management of squints and other visual problems which is made much easier for the parents if they can come to a special clinic. Access to diagnostic facilities including visual evoked responses is necessary. For children with visual impairment it is useful for a local developmental paediatrician to have a special interest in the pattern of development of children with poor vision, but the case for a 'stand alone' vision team is unconvincing since at least 50% of children with visual impairment have additional disabilities. Liaison should occur with the specialist teachers for the visually impaired.

### *10.4 Audiology/hearing aid service*

This service needs to be family friendly and closely linked with key agencies including



teachers and social workers for the hearing impaired and paediatric ENT services. The service needs a specific training and orientation for dealing with children, in particular children with disability. The ability to accurately assess the hearing of a child who cannot co-operate in testing is essential and access to evoked response audiology is required. A paediatrician with an interest in hearing disorders could contribute to this kind of clinic. Access to a cochlear implant programme will be necessary for a very small number of children.

#### 10.5 *Specialist communication aids*

This complex technology was originally provided in a small number of national centres but is increasingly devolved to districts. It is important within a district to have a speech therapist specialising in the communication problems of children who will mostly have cerebral palsy and who has knowledge of electronic communication aids<sup>26</sup>. Technicians provided within the district, perhaps jointly with education, can lessen the dependence on remote services for the maintenance of this equipment.

#### 10.6 *Dietetic advice*

Many children with disability require dietary advice and dietary supplements up to and including in some cases artificial feeding. This advice should form part of the service.

#### 10.7 *Clinic for severe neurological feeding impairment*

Increasingly regarded as the best way of assessing and making decisions on the variety of treatment approaches required by these children in order to ensure adequate nutrition. The professionals involved may include a specialist speech and language therapist, a dietician, a developmental paediatrician, a paediatric gastroenterologist, a paediatric surgeon and a radiologist with experience of videofluoroscopy, together with the community children's nurse who carries on the work of the team within the child's home and helps manage naso-gastric or gastrostomy tube feeding.

#### 10.8 *Paediatric dentistry*

Dental treatment is difficult in children with severe disability. Children with a variety of disorders have particular abnormalities of development of teeth, jaws and facial structure. Advice on dental hygiene and specialist dentistry should be part of the Child Development Service.

#### 10.9 *Orthopaedic surgery*

Should be a long term process of involvement rather than a brief time-limited episode of care. For the best decision making and timing of intervention an orthopaedic surgeon specialising in cerebral palsy needs to have long term involvement with the child and the therapeutic teams. Combined clinics can be very useful for this. There should be access to a spinal unit for children who develop scoliosis. Good orthotic support is also essential. A Gait Analysis Laboratory enables objective assessment of the effectiveness of orthotic appliances and Botulinum toxin. Recordings may be made over time which should aid and improve decision making in orthopaedic surgery for cerebral palsy. A Child Development Service should have a budget allocated in order to access a gait laboratory for children with cerebral palsy and other disorders. However it is not just a question of sending out a request and getting a paper report back; there should be a working relationship between the local team treating the child, the orthopaedic surgeon and the gait analysis laboratory.

#### 10.10 *Specialist Radiology*

An essential requirement. At a basic level this is a need for good quality hip and spinal X rays. More specialist radiological investigations are increasingly expected in order to diagnose the cause of the child's disability, for example brain MRI.

#### 10.11 *Chiropody/podiatry*

This resource is needed particularly by children with cerebral palsy and spina bifida.

#### 10.12 *A neuropathic bladder service*

Particularly important for children with spina bifida and should include input into the home by a community children's nurse.

#### 10.13 *Child psychiatry*

A very important resource for helping families deal with the bad news of the diagnosis, ongoing emotional adjustment, and behaviour problems. In many Child Development Services this work is carried out by clinical psychologists. However, the extra resources provided by child psychiatry and by child psychotherapy can be very valuable. For children with disability this provision is most effective and accessible if child psychiatry can be part of the Child Development Centre service. This is much easier for families than the separate provision of a child psychiatry/child guidance service. Input for children with challenging behaviour is important, but currently substantially under provided in terms of both inpatient provision and expertise in management, for example psychotropic medication. Some conditions require services which create an overlap between Child Development Services and Child and Adolescent Mental health services, for example Attention Deficit Hyperactivity Disorder, Autistic spectrum Disorders and the disturbed adolescent with severe learning disability. Local solutions for efficient combined service delivery should be thought out.

#### 10.14 *Inpatient admissions to acute services*

There should be a system to train and inform ward staff on how to care for and communicate with the disabled child. It is useful to have a ward proforma containing information about the child's special needs. 'Seamless' management structures for acute and community services greatly help this exchange of information and provide suitable continuity of care. Combined protocols for management could be useful. Advice to other departments in the hospital can be an important issue; e.g. how do accident and emergency staff deal with an autistic child who is injured? Children's wards may be reluctant to admit teenagers. However, teenagers and young adults with disability, especially significant levels of learning disability, may not be appropriately placed on adult wards. This strengthens the case for all units to develop adolescent ward provision. Part of the population served by such units would then be teenagers and young adults with disability. Acute mental health problems, for example the psychotic adolescent with autism, requires specialist adolescent mental health inpatient provision, which is very scarce throughout the country, but needs considerable further development.

### **11. The organisational setting**

11.1 In 1968 the Sheldon working party<sup>27</sup> suggested that Child Assessment Centres should be created and the Court report<sup>4</sup> described the multi-professional nature of the work, suggesting that District Handicap Teams should be formed. In health terms these are now called Child Development Teams<sup>28</sup>. Most children with significant and/or complex conditions benefit from assessment by a multi-disciplinary team and need a wide range of support services. In the majority of districts these children are assessed and often treated in a Child Development Centre. Co-ordination of assessment and therapeutic services from one centre offers a number of benefits<sup>29, 30</sup>.

11.2 A Child Development Centre building gives professionals an essential base and a meeting point where they can exchange views and experiences. A coherent team provides a better service to families. The success of a Child Development Centre depends upon its ability to motivate parents, to be a source of information and help, and to provide a warm and hopeful environment<sup>5</sup>.

11.3 Both parents and professionals view close parental involvement, education and

information, treatment, accessible and available care and co-ordination of effort as important aspects of service delivery. Parents also view continuity/consistency and family-centred care as being particularly important to them<sup>16,31</sup>. Children even with the same disorder are individuals and the capacity to tailor flexible care packages for different families is desirable.

11.4 It is Department of Health policy supported by the Royal College of Paediatrics and Child Health and most other concerned professional bodies, that children's services should be managed on a unified basis combining hospital with community services<sup>21, 31, 32</sup>.

## **12. Support for the child and family**

### *12.1 Child Development Centre*

This can be a focus of family support. Families need to feel that this is a special place for them and their children. The centre should be available for all kinds of disability and all age groups: 'we want to have some sort of knowledgeable unit which we can contact easily for advice and support'<sup>33</sup>.

### *12.2 Support groups*

Extremely valuable to families and often benefit from some professional input. If a parent representative or representatives are involved in planning Child Development Centre policy, it might be helpful if one of these representatives were to co-ordinate parent groups active at the centre.

### *12.3 Respite care*

An essential requirement for families whose children have severe disability. It should not only provide relief for the family but a positive experience for the child. In some districts there is a small provision of respite care by health services. This is usually a fairly minor proportion of the total respite care services of the district, most of which will be provided by social services. Health professionals are required to advise respite carers and provide support for the child when staying in respite care. Health service respite care can be particularly appropriate for children with complex multiple disability or children with challenging behaviour. However, suitable mental health provision for children with severe challenging behaviour remains hard to find<sup>34</sup>.

### *12.4 Parent information*

It is essential that parents have information about their child, about the child's condition and about services available both statutory and voluntary. One component of this is the parent held child health record. A special health record for disabled children enables parents to know exactly what services and which health professionals are involved, where they can be reached, and gives them information about their child's special needs<sup>35</sup>. The written report produced as part of the assessment process is another source of information for parents. Increasingly paediatricians are sending parents a copy of the letter written at every clinic visit. This should be seen as good practice<sup>36</sup>. Collated reports from many different professionals could make up a portfolio for the family.

### *12.5 Information/library service for parents and professionals*

This resource is most effectively located in the Child Development Centre and if a part time librarian or parent can establish and co-ordinate this service it will be most effective. A useful starting point is the *Contact A Family* directory<sup>37</sup>. Internet and Web access are desirable.

### *12.6 Benefits*

Advice on benefits for families which contain a disabled child, for example Disability Living Allowance and the Family Fund, should be readily available. If the Disabled Children's Social Work Team is based or has a representative at the Child Development Centre, benefits advice



is made much easier.

#### 12.7 *Special support for ethnic and cultural minorities*

This may be necessary to ensure that families from ethnic and cultural minorities are able to use services fully.

#### 12.8 *Child protection*

Children with disability are at risk of abuse. There should be clear local policies drawn up by child health and social services, which include information about communication between the child development and child protection services.

## **SUMMARY**

1. Although many kinds of chronic illness cause children to have special needs or disabilities, there is a substantial group (about 90% of the total) whose disabilities are caused by impaired function of the nervous system. These children require a different kind of approach from that provided by hospital paediatric services. Children and young people with disabilities have the right to facilities which enable them to achieve the fullest possible social integration and individual development. With such help children may avoid significant degrees of disadvantage. These facilities are best provided on a district basis by a Child Development Service.

2. A Child Development Service includes specialist services for assessment and management of children with disabilities including physical, learning, hearing, vision, speech and language problems. This is a multi-disciplinary team process functioning in the Child Development Centre, in special and mainstream schools and nurseries, in community clinics and in the child's home.

3. Access to services via 'a single front door' is important. For many, although not all, children with complex or severe disability this will be within the organisational setting of a Child Development Centre, which should have a single geographic location. Many other children, for example the large group with moderate learning disability, may be dealt with more appropriately within the community. In larger districts there is a need to provide an equitable and accessible service. Consideration should be given in addition to providing locality based assessment and treatment services (outreach) delivering a service within the quality standards of the Child Development Service. A single organisational and information base for all children with special needs is preferable in order to provide an integrated service. There should be provision for out of hours contact arrangements, for example an answering machine for non urgent matters and clear referral arrangements to the hospital service for more acute medical problems.

4. It is important that the Child Development Services develop comprehensive local knowledge and networking in order to provide the best possible packages of care. Good collaborative working relationships must be built up with primary care, education, social services, parent groups and voluntary agencies, including joint planning arrangements. Consideration should be given to inclusion of representatives from education and social services (and sometimes voluntary groups) within the Child Development Team and to jointly funded posts. A suitable information base for planning should exist for health purchasers and providers is essential. Single trust management arrangements are ideal. Split trust responsibilities can make planning difficult. Parental representatives should be involved in planning and in the running of Child Development Services.

5. The majority of children seen by the Child Development Centre are 0-5 years old. However, there is an important ongoing commitment for review and treatment of a number of children with special educational needs in mainstream or special schools in collaboration with

the Education Department. Continuity of care from pre-school to school age is important. The client group includes children and young people with developmental disability up to the age of 19 years. Handover arrangements should be made for transfer to adult services (where available) during the teenage years. A transitional care plan should be drawn up in collaboration between health, social services and education, including the resource team for adults with learning difficulties.

6. Primary health care (including general practitioners and health visitors) has a particular role to play in the detection and ascertainment of children with disability. Liaison should be close, with provision of support, training, clear referral criteria and lines of communication.
7. Supporting hospital paediatric services should be available at a convenient location, with established lines of communication and referral criteria. Inpatient admissions to acute services should use a system to inform the ward staff on how to care for and communicate with the disabled child. 'Seamless' models of service provision are to be encouraged. Combined protocols for management could be devised. The needs of adolescents and young adults for appropriate inpatient accommodation should be considered both for medical needs and acute mental health issues.
8. Tertiary specialist services for childhood disability may be provided within larger teaching districts. In smaller health districts, children needing these services should be able to easily access them in the nearest centre. Combined outreach clinics may also be set up.
9. Children and their families should receive flexible service provision according to their requirements.
10. Assessment and treatment is provided by the Specialist Multi-disciplinary Team. The family must be fully involved in the assessment process and subsequent treatment. After the initial multi-disciplinary assessment a treatment package should be drawn up in agreement with the family.
11. Management of disclosure should be carefully planned. It is important that it should be done by professionals with specialist knowledge, with both parents, in a suitable setting, preferably with someone who will be able to support the parents afterwards. Access to psychology, social work and child psychiatry support is important for families, but also for team support.
12. It is desirable for one professional to take on the role of keyworker in order to provide a single point of contact and co-ordination for the family's care package. Initially this likely to be the team health visitor, however the family will often make this selection for themselves. Specialist health visitors working in the field of childhood disability have a vital role in service delivery. They are in a particularly good position to form supportive relationships with families, to help them use services appropriately and to act as advocates and intermediaries for the family. The role may pass to different professionals either inside or outside the Child Development Team as the child grows.
13. Whilst some children require very regular medical supervision, most require a paediatric review at less frequent intervals. Taking an overview of the whole child, the doctor specialising in developmental paediatrics and childhood disability is in a good position to provide information and guidance to the parents and other professionals and should be able to provide continuity of care.
14. The therapy needs of children with disability in the U.K. should be effectively planned for, with appropriate staffing levels, following guidelines from professional therapy

associations. Treatment may be delivered in the Child Development Centre, the home, nursery or school. Other individuals (care assistants, parents, siblings) will also be involved in the delivery of therapy and the Child Development Team has an important role in training them.

15. Clinical Psychology and Child Psychiatry are important for emotional and behavioural problems, cognitive assessment, counselling and team support. Ideally, child psychiatry should be part of the Child Development Service rather than being supplied from a different unit since a number of conditions benefit from combined input.

16. A Child Development Centre is essential in order to give professionals a base. There should be adequate secretarial and administrative support; a suitable waiting area for families with play and information facilities; and rooms which are suitable for assessment and treatment. The success of a Child Development Centre depends upon its ability to be a source of information and help, and to provide a warm and hopeful environment. A Child Development Centre may provide a home for services such as a seating clinic, an equipment library, a toy library, parent groups, an information service for both professionals and parents.

17. Other professionals who are not core members of the Child Development Team provide important additional services and combined clinics can work well for a number of these services. These include: a paediatric ophthalmologist, orthoptist and peripatetic teacher for the visually impaired; audiology, hearing aid service, peripatetic teacher for the hearing impaired; dietician; a clinic for severe neurological feeding impairment; specialist dentistry; orthopaedic surgery, with access to gait analysis and to a spinal unit, good orthotic support; specialist radiology (X ray, CT, MRI, videofluoroscopy); specialist neurophysiology (EEG, auditory and visual evoked responses); podiatry; a neuropathic bladder service.

18. Parent support groups are extremely valuable to families and often benefit from professional support.

19. Respite care is an essential requirement of families whose children have severe disability. In some health districts there is provision of respite care by health. This is usually a minor proportion of the total respite care services of the district, most of which will be provided by social services.

20. Written information for the family is essential. A special health record for disabled children enables parents to know exactly what services and which health professionals are involved, where they can be reached and to give them information about their child's special needs.

21. Advice about benefits should be readily available.

22. Special support should be provided for ethnic and cultural minorities.

23. Clear guidelines should exist for the management of child protection issues.

## Appendix 1: Staffing

All staff working directly with special needs children should have specialist training and qualifications in this field. Much remains to be done to achieve this for all disciplines.

### Medical

As described by Neville<sup>23</sup> in his paper on regional and district services for children with disability, a district Child Development Service per 100,000 total population would require: Consultant Paediatrician with specialist training in development and disability, at least one per 100,000 population with 2 full-time equivalents of other paediatricians, some of whom may be non-consultants or trainees.

Access to:

- Paediatric Neurologist
- Paediatric Neurosurgeon
- Paediatric Surgeons specialising in neuropathic bladder
- Paediatric Orthopaedic Surgeon
- Paediatric Ophthalmologist and orthoptist (may include optometrist)
- Paediatric Dentist
- Child Psychiatrist
- Clinical Geneticist
- Radiology
- Neurophysiology
- Physiotherapists specialising in childhood disability

The Association of Chartered Physiotherapists has made clear recommendations for staffing levels<sup>38</sup>. Three levels of physiotherapy input are defined:

#### 1. *Review*

Frequency ½ termly, termly, yearly. These are occasional reviews to ascertain possible changes of need or levels of intervention.

#### 2. *Maintenance*

Frequency once a month or fortnightly. This is regular intervention in the form of treatment or review of advice to carers, which also enables identification of change of need.

#### 3. *Intervention*

Frequency once a week or more. This may range from once a week to daily. A further breakdown might be needed in this category, e.g. high/medium/low to suit local need.

Detailed calculations for direct and indirect patient contact time and non-patient-related working time are made.

A whole time physiotherapist managing a caseload in the review category could review 352 children 3 times a year or 176 children 6 times a year. In the maintenance category this falls to 88 children seen once a month or 44 seen once a fortnight. In the intervention category 25 children could be seen once a week or 8 children 3 times a week.

The recommendation is made that all children on a caseload should be allocated a category. The resulting number of hours from each category defines the service need. This figure is then divided by the available indirect/direct contact hours from 1 whole time equivalent (1058 hours/year) to give the number of whole time equivalents (wte's) required to meet the service need.

For example:

Review

12 children (3 hours/year) = 36 hours

12 children (6 hours/year) = 72 hours

Maintenance

12 children (12 hours/year) = 144 hours

12 children (24 hours/year) = 288 hours

Intervention

12 children (42 hours/year) = 504 hours

12 children (126 hours/year) = 1512 hours

Therefore a total of 72 children on the caseload requires 2556 hours of direct and indirect patient contact time. This calculation refers to a typical non-acute community caseload. This gives an approximate mixed caseload of 30 children per 1 wte.

$$\frac{2556}{1058} = 2.4 \text{ wte's}$$

- *Paediatric Occupational Therapists*

Traditionally it is thought that the required number of occupational therapists is about half the number of physiotherapists. This is unlikely to remain true in the current climate where there is an increasing workload involving children who have subtle motor control disorders such as developmental co-ordination disorder and dyspraxia. Although the National Association of Paediatric Occupational Therapists makes no specific recommendations for Child Development Centre staffing, similar recommendations to those made for physiotherapy could be made for occupational therapy staffing levels.

- *Speech Therapists*

The Royal College of Speech and Language Therapists makes no specific recommendation for staffing Child Development Services at a national level. However, at local level, a number of studies in providing speech and language input to a mixed caseload have been carried out in order to provide local solutions.

- *Clinical Psychologists*

The British Psychological Society recommends at least one full time clinical psychologist working with children and families per 75,000 general population to cover a variety of aspects of clinical psychology assessment and treatment<sup>39</sup>. There is no specific recommendation for Child Development Services but is recommended that additional posts are necessary in order to provide specialist services. These might include those for childhood disability. A more specific recommendation is made for acquired neurological disorders such as head injury: one whole time clinical psychologist specialising in neuropsychology linked between 2 or 3 health districts<sup>40</sup>.

- Social Worker
- Specialist Health Visitors or Nurses specialising in childhood disability with commitment to liaison with generic health visitors
- Podiatrist/Chiroprapist
- Orthotist
- Audiologist
- Bioengineer
- Technicians
- Nurses qualified in the care of ill children and nursery nurses are required to staff the Child Development Centre and may outreach to other clinics and special schools. The school nurse in the special school has a vital role

- Paediatric Dieticians
- Information Officer/Librarian
- Secretarial and clerical staff to provide support for all the multi-disciplinary team and to administer and organise clinics

## Appendix 2: Client group

### *Learning impairments*

1. Severe learning disability - prevalence 3.5 per 1000
2. Moderate learning difficulties IQ 50-70 - prevalence 1.8%<sup>41</sup>
3. Specific learning difficulty including dyslexia - prevalence underestimated at 2%
4. Down syndrome - prevalence 1 in 1000

### *Motor Impairments*

1. Cerebral palsy - prevalence 2.5 per 1000  
Hemiplegia - 30%  
Diplegia - 20%  
Other types - 50%
2. Clumsy Child syndrome  
Developmental Co-ordination Disorder - estimated prevalence 5%  
Deficits in Attention, Motor control and Perception - estimated prevalence 1-3%  
(overlaps with attention deficit disorder with hyperactivity)
3. Neural tube defects - prevalence 1 in 1000
4. Hydrocephalus - prevalence 0.1 per 1000

### *Neuromuscular Disorders*

1. Duchenne muscular dystrophy - prevalence 3 in 100,000
2. Other neuromuscular disorders

### *Other chronic neurological disorders*

1. Neurodegenerative disorders
2. Other chronic neurological disorders
  - survivors of brain infections, such as meningitis or encephalitis
  - damaged survivors of head injury
  - brain malformations
3. Epilepsy - prevalence 0.8% (usually associated with other disorders to require Child Development Service)

### *Speech, Language and Communication disorders*

1. Isolated speech delay - prevalence 1 per 1000 at school entry
2. Severe language disorder - prevalence 5 per 1000
3. Autistic spectrum disorders (including Asperger syndrome) - estimated prevalence 4 per 1000

### *Visual Impairment*

1. Partially sighted - prevalence 0.4 per 1000
2. Blind - prevalence 0.3 per 1000

### *Hearing Impairment*

Significant impairment (>50dB loss in better ear) - prevalence 1.5 per 1000

N.B. Many children will have two or more co-existing disorders.

### *Associated Problems*

1. Behaviour (up to 30%)
2. Nutrition/gastro-oesophageal reflux/constipation
3. Recurrent respiratory infection
4. Orthopaedic deformities
5. Other medical problems, e.g. asthma
6. Social and family problems

## Appendix 3: Accommodation

The following facilities are recommended for Child Development Centres:

- Several **consulting rooms**.
- A **play room**.
- A suitably equipped room for **ophthalmology**.
- A sound-treated room for **audiology and speech therapy**
- Space for **physiotherapy**.
- Facilities for **occupational therapy**.
- **Waiting areas** for parents and children with soft play facilities, information area, quiet room for discussion between staff and with parents, proper kitchen facilities and adequate toilet facilities including a changing area.
- An adequate **meeting/teaching room** for staff meetings and for training purposes.
- **Specialised facilities** for assessment and treatment: video camera and playback equipment, observation facility using a one way mirror and sound transmission equipment.
- Suitable **office space** for various professionals and trainees.
- Facilities to **store equipment**.
- Facilities for **office staff** and case record storage.
- Centre **library**.
- Adequate **computing** with internet access.
- Parent resource room with printed information and internet access.

The centre should have sufficient space for trainees in various disciplines to see patients under supervision. Ideally, some of the consulting rooms should be set up with observation facilities. Consulting and observation rooms should be of sufficient size since multi-disciplinary assessments by definition involve a number of people.



## Appendix 4: A charter for disabled children and their families

(From Milner, J., Bungay, C., Jellinek, D., Hall, D.M., Needs of disabled children and their families. *Archives of Disease in Childhood*, 75(5): 399-404. Reproduced with permission from the B.M.J. Publishing Group)

*Principles:* The family should feel that they have been listened to and heard, and that their concerns and aspirations have been taken seriously, and that their responsibility to their child is respected

There should be a prompt response to the first referral (within one week) and the degree of urgency and parental anxiety should be considered when arranging the first appointment

The process of news breaking should follow established guidelines, whichever professional undertakes the task. Where necessary training should be provided. There should be arrangements for an early follow up appointment or home visit, and telephone support should be made available

The child should receive either regular medical follow up or open access to the consultant in the event of new problems

There should be arrangements for children with complex medical needs to be seen urgently on request. The family should know who to contact in the event of new problems

The child's future needs (for example, for care in adolescence and adult life, or for terminal care in the case of progressive disease) should be discussed with the parents and child as soon as possible

There should be planned handover to a relevant, co-ordinated adult service, in line with the requirements of current legislation

*Diagnosis and disability* The parents and child should know the correct name, label or description for the child's Condition, and its prognosis and functional implications

Investigations should be carried out according to current best professional practice; even if no exact diagnosis can be made, the family should know what tests have been performed and what the results mean. If the situation changes, any new investigations should be explained

Every family should receive a written report in language that they can understand or an audiotape of the consultation(s) or both. Their views should be sought and respected regarding the circulation of this report to other professionals. They should have access to professional advice at the time that the report is received, to explain anything that is not clear in the report. Preferably, reports should be delivered, not posted. They should not be posted to arrive when no professional is available

*Treatment and therapy* If the child takes any medication, the parent should know what, why, for how long and how much. They should have a medication card to summarise complex drug or multiple therapy

The family should know what sort of therapy or teaching that the child is

receiving, what it is intended to achieve, and how they can help. There should be defined and achievable goals. Parents and the child should understand what system of prioritising need is used by therapists and the reasons for delays in commencing a treatment programme

The family should know what other methods might be offered by others for treating the child's condition (including both orthodox and controversial therapies, and alternative medicine) and why the team/therapists are not using them for the child; they should be aware that some treatments of dubious efficacy can be disturbing and distressing to children. Families who try other methods should continue to receive support

*Information* Every family should be offered: full information about the child's condition including implications and prognosis; a meeting with another parent whose child has the same problem; the name and phone number of the organisation for children with this condition

Every family should be offered expert information about the genetic aspects of the child's condition, by either a clinical geneticist or a well informed paediatrician. This information should not be omitted when the condition is thought to be non-genetic by the professionals

*Medical care and support* Each child should be offered hearing and vision assessments as appropriate

Every parent should know about: day care (day nurseries etc.); respite care (short breaks). There should be a range of respite provision and other relevant local support services

Each child should be offered prophylactic dental advice and access to dental specialist services if needed

Each parent should know about benefits and the Family Fund

Each child with cerebral palsy associated with a risk of hip dislocation should receive regular orthopaedic checks and hip radiography as appropriate

Each child should be offered a full immunisation programme unless there are recognised contraindications

The growth of each child should be monitored

Every parent should know about preschool educational help (home teachers, Portage etc.); their rights under the Education Act. Limitations in resource provision should be explained. There should be an impartial source of advice on services

The family should be given all equipment and aids appropriate to the child's needs

There should not be undue delays in providing or repairing equipment; if delay is unavoidable, the family should be kept informed

The family should be invited and encouraged to identify other important service needs

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