Review of child development teams

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Abstract
Since the Court report was published in 1976 there has been a consensus that the needs of children with disabilities are best met by child development teams. This study explored the structure, facilities, and organisational elements of child development teams operating in the South East Thames region by means of a structured interview with senior professionals involved with organising services for children with disabilities in 14 of 15 health districts in the region. Although all districts had a designated child development team, not all core professionals were adequately represented and four of 14 districts had no child development centre. The quality of buildings and facilities was variable. Teams that did not have a physical base in the form of a centre had fewer staff in the service and poorer facilities. There is a need for further consensus work about broad guidelines on the requirements of child development teams. These will help to inform purchasing authorities about the needs of children with disabilities living in their districts.
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The Sheldon Committee which reported in 1967 advised that children with disabilities should be assessed by a multidisciplinary team in child assessment centres. This was a new and untried concept. Since then some of the original centres created in the early 1970s have been hailed as models of excellence. The Court report in 1976 paid particular attention to services for children with disabilities and set the agenda for the future of paediatric services in the United Kingdom. The report indicated areas of overlap in service, the poor service coverage, and the generally inadequate communication links within and between services for disabled children. It recommended that each district health authority should set up a district handicap team to improve services for these children and their families. It proposed that the team should consist of the following core professionals: a consultant community paediatrician, a specialist health visitor, a social worker, a teacher, and a psychologist.

These professionals would have the appropriate expertise to determine the service needs of children with disabilities. The role of the team was further defined as clinical (dealing with patient management) and operational (carrying out evaluations, research, training, and development of services). It was envisaged that the team would act as a resource centre for other professionals and the local community.

In the years that followed, many district handicap teams and centres were established. Bax and Whitmore surveyed district handicap teams in England in 1983 and 1988 using a postal questionnaire; although 78% of districts in 1988 had either a child assessment centre or a team, or both, only 32% of districts in 1983 and 37% in 1988 were running a district handicap team as advised by the Court report. Bax and Whitmore renewed the call for a team approach with further input from relevant specialists (such as neurologists and orthopaedic surgeons), and stressed the need for developing the operational aspects of team work. They advocated that district handicap teams should be renamed child development centres, with the centre referring to the team of professionals rather than a centre building, and that they should cater for the whole spectrum of long term physical and learning disabilities up to the age of 16 years, or for those in special education to 19 years of age. Mencap (the Royal Society for Mentally Handicapped Adults and Children) promoted the views of parents about the role of child development teams. Parents preferred home visits by a member of the team before assessment to give their perspective of the child's problem. They favoured short or partial home assessments and wanted to be closely involved with the way the services were organised. Mencap proposed parental representation on child development centre management committees as a means of achieving this.

The present study reviewed the child development teams in the South East Thames region of England, which serves a total population of three and a half million in London to the south and east of the River Thames and the counties of Kent and East Sussex. We explored staffing, the mode of function, and facilities, including the existence of a child development centre building or otherwise. A further aim was to learn about the strength of individual child development teams, areas of difficulty, and to highlight examples of good practice in services for the children with special needs. Funding issues were not studied.

Methods
We contacted the senior paediatrician with responsibility for children with special needs in each of the 15 districts in the South East Thames region. Fourteen of the 15 paediatricians agreed to cooperate. We conducted a rearranged structured interview with at least one professional in these 14 districts. The interview questionnaire covered four main areas: composition of the teams; facilities at the
disposition of the teams; format of assessments and meetings; and non-clinical operational matters. Space was also given for personal comments and views on subjects not covered by the questionnaire.

Results

STAFFING OF CHILD DEVELOPMENT TEAMS

Eleven of 14 districts had at least one community consultant paediatrician (table), all of whom were involved in child development team work. In the remaining three districts, hospital paediatricians had designated sessions to coordinate such work. All teams had an input from middle grade doctors of either training or permanent grade. Ten teams had a specialist health visitor or paediatric sister. Only eight teams had a social worker but most had a clinical psychologist (9/14) and at least one teacher (10/14). Teaching staff were either funded by the education or health department and had previously worked in a variety of posts such as a nursery or an assessment centre, or as a peripatetic or home based/portage teacher. Thirteen of the teams had at least one physiotherapist, 12 a speech therapist, and 12 an occupational therapist. Most professionals worked on a sessional basis with the team and had other duties within the health authority.

FACILITIES

Centres

Ten of 14 districts had a child development centre building; these were on a variety of sites such as within a district general hospital, community hospital, or a converted school. The buildings ranged from modern purpose built through to conversions of old buildings, and a combination of the two in one instance. Several of the buildings showed signs of being in urgent need of structural repair and were poorly maintained.

Ease of access to the centre and building

Access to the centre by public transport was good or adequate in eight and fairly difficult in the remaining two centres; only six centres had parking facilities for parents. Four of the 10 centres presented definite difficulties for disabled wheelchair users in terms of access to the building, such as stairs without lifts and narrow entrances.

There was no designated private space suitable for grieving parents or breastfeeding mothers in nine centres. Nine centres had a reception area staffed with a clerk to welcome visitors, with an attractive play area for waiting families in eight centres and toy libraries in six centres.

Facilities for children

Nine centres had a nursery and several ran therapeutic playgroups for children with problems such as Down's syndrome.

CLINICAL FUNCTION OF THE TEAMS

Assessments

Three teams conducted joint assessments by the relevant team members during an assessment period in the centre nursery, followed by a joint feedback session to the family during which problems were discussed and services for the child were planned. Usually, however, assessments were performed at different times by individual team members. All the teams assessed children on a variety of sites outside the centre, including local nurseries, educational units, and the home. Medical staff in 11 districts had on occasion assessed children at home.

Team meetings

Most teams met regularly to discuss the children on their case loads. There was a wide spectrum in the frequency of review (from weekly to every two months) and the number of children reviewed (problem cases only or review of the whole case load on a six monthly or annual basis). New referrals were discussed by some teams in a separate meeting. Only three teams limited their reviews to preschool children.

Many school age children attending special schools were discussed in multidisciplinary school meetings. Parents were present at the review in a minority of district team meetings, and two teams regularly sent copies of all assessments to the parents. The remaining
teams sent reports occasionally but not as a matter of policy.

AUDIT AND OPERATIONAL ROLE

Information technology
Half of the teams held their case records on a computer; only three teams used functional as well as diagnostic coding. It was not practical, or often possible, within the time limits of the interview to determine the precise number of children on the special needs register and the breakdown of their working diagnoses. A regional subgroup of community paediatricians has been meeting to plan the implementation of the special needs module of the child health computing program for the region as a whole.

Planning meetings
There was a separate forum for discussion of non-clinical child development team matters in 12 districts. In many instances clinical managers (who may or may not be members of the child development team) attended these meetings instead of actual team members.

Training
All teams provided individual training to some junior professional staff, but it was difficult to establish whether they organised any training or teaching for the team as a whole. A ‘day retreat’ was organised by one team every six months offering in part training and in part an operational discussion forum for its members. One of the teams provided an annual report of its activities.

Discussion
Districts in the South East Thames region vary greatly in the way they run their services for children with disabilities, reflecting differences in historical practice, manpower, funding, and facilities. They all, however, have an identifiable child development team even if the members are not attached on a full time basis to the team. A shortage of professional staff, especially therapists due to recruitment problems, was commonly reported. There were similar shortages of key professionals in non-health service departments, especially social workers in some teams, resulting in cross cover and excessively large case loads. Many of the buildings were in a shabby state and appeared to need physical repair and upgrading.

All four teams which did not have a designated child development centre building saw this as an important shortfall and gave a long term lack of finance rather than local policy as the cause. It became clear that an identified child development centre building not only provides a physical place for team members to meet, both formally and informally, but also facilitates team building and thus the easy discussion of clinical and organisational matters; it acts as a base for in-service training and provides a headquarters for coordinating therapeutic services. The buildings are a community resource and information centre for children and their families. Three of the four teams with no centre building had neither administrative nor secretarial back up, as opposed to one of 10 teams based in a building; the same three teams did not include representation from three or more key professional groups as opposed to two of 10 centre based teams (table). Where a building was available, a lack of proper facilities such as equipment storage, office space, parking, security, and access was common.

Some centre based staff were keen, however, that their building was not regarded as the only place where children with special needs living in the district should be seen. A flexibility of venues for assessments and treatment was also regarded as important by parents, as expressed in the Mencap report. Most of the teams do not hold a preliminary planning session with parents, nor do they assess children in a truly multidisciplinary way during set assessment periods. This mode of function requires strong administrative back-up, a commitment to joint work, adequate time, and a suitable and convenient venue. It is likely that the absence of some of these factors prevented most of the teams from fully carrying out multidisciplinary assessments.

Many consultants spontaneously expressed concern over the lack of provision for the young disabled adult. This study did not inquire further into the exact provision provided by the provision was addressed by the Royal College of Physicians in 1986 and their report recommended a strengthening of services for this group of subjects. A survey of more than 100 physically disabled young people by Thomas et al further illustrates the severe deficiency of all services provided. This evidence supports our conclusion that teams should retain young people on their case loads until school leaving age.

The implementation of the special needs module of the child health computing system throughout the region in 1993 should facilitate the operational and audit roles of child development teams and provide standard information for epidemiological surveys.

Financial and commissioning issues lie at the heart of the proper provision of tertiary prevention services for children with disabilities. There is a need for establishing substantive guidelines and protocols that would define desirable clinical and operational practices for child development teams. These should avoid being over prescriptive while addressing the crucial commissioning and financial issues in providing tertiary prevention services for disabled children. In March 1993 a childhood disability subgroup was convened with proposed links with the British Association for Community Child Health and the British Paediatric Neurology Association. This group may prove to be an appropriate forum to carry out such work and to help paediatricians inform commissioning authorities about the true costs of providing child development teams for their child population.
We thank all the professionals interviewed for their time and patience as well as Professor N Noah and Dr D Smyth for their valuable advice, Professor E Ross for suggesting the project, and Dr L Davidson for epidemiological advice.


Commentary

A quarter of a century after the Sheldon report was published, we learn that in South East Thames, one of the most densely populated parts of Britain, four out of 14 health districts still lack an identifiable base from which to care for their disabled children. This is a depressing statistic. Of course, the absence of a child development centre does not necessarily mean that the disabled child receives second rate care, any more than the existence of a beautiful purpose built centre guarantees that care will be excellent. This study did not attempt to assess whether the absence of a child development centre made any difference to the quality of care, but the need for a 'single front door', a place where all the necessary professional help can be found, is repeatedly emphasised by individual parents and voluntary organisations.

The authors have not told us much about the operational policies of the child development centres in their study, but for me one point stood out – the extraordinary finding that just two teams regularly copy their reports to parents. Two out of 14! I wonder what reasons would be given by the remaining 12 for not following this practice. Perhaps they have forgotten that parents may in any case exercise their right to read their child's notes? Perhaps the members of these teams have not read the evidence that parents want and value the information contained in assessment reports.1,2

How can a team claim to regard parents as partners (as doubtless they all do) if they copy their reports to all the relevant professionals but not to the people with the greatest need and right to know. Evidently, these teams have not considered the implications of social sciences research on the relationships between professional and family within child development centre structures.3,4

The evaluation described in this paper addresses only the first two of the three stages of audit; it focuses on structure and looks briefly at process, but ignores outcome. Although the authors presumably feel that the standard of service for disabled children in many districts leaves much to be desired, they do not provide any direct evidence for this. The assessment of long term outcomes in the management of disabled children is of course very difficult, because severely disabled children rarely show a dramatic gain in development or function and very few can ever be said to have been 'cured'.

Nevertheless, there are short term outcomes such as parental adjustment and satisfaction, and effective service utilisation, which could be assessed by each child development centre team. After all, the aim of the child development centre is not merely to accelerate developmental progress. An equally important role is helping the parents to comprehend what it means to have a handicapped child and to deal with their grief and anger. The extent to which parents and professionals are able to collaborate to help the child is itself a measure of good care.

DistRICTS WHERE THE PROFESSIONALS HAVE LEARNT TO WORK AS A CHILD DEVELOPMENT TEAM AND ARE BASED IN A CHILD DEVELOPMENT CENTRE WILL PROBABLY FULFIL THIS WIDER ROLE MORE EFFECTIVELY THAN THOSE IN MORE AFFLUENT AND Densely Populated districts. Nevertheless, parents cannot be expected to be any more interested in concepts like 'multidisciplinary working' or 'district handicap team' than in who holds the contract for cleaning the child development centre toilets! The key question is not whether we have a particular structure in our child development team or centre, but how the service looks to the consumer – 'what is the experience like, for a parent in our district, who is concerned about a suspected disability in their child?'

In our own district audit, which will be reported in detail elsewhere, we asked parents this question. Three main themes emerged in their answers. Firstly, the way in which the news breaking process was handled was immensely important, as so many other authors have found.5 Secondly, problems with 'boundary disputes' and poor information transfer between health, education, and social services caused considerable irritation (in spite of our immense efforts, which we believed had been successful, to overcome these problems). Clearly we had not yet achieved the single front door as effectively as we had thought. Thirdly, we learnt that our notion of the multidisciplinary team was a somewhat artificial construct, as every family had built their own particular and unique team of professionals to cater for their child's needs. Sometimes this team did not include any of the 'core members' of the child development centre. Indeed, it did not always include health professionals at all. The parents were interested in their whole network of support and how it had worked from the beginning, not just in the child development centre.

We called our audit 'Can we do better?'. There can be few child development teams who could not do better, even without additional resources. The first task is for the team to consider some operational issues – so it is perhaps surprising that in the Zahir and Bennett study very few teams had 'awaydays'. Secondly, clinicians must be involved in management within their provider unit. If we have already clarified our own objectives in the care of the disabled child, it