

2004 DISTRICT HEALTH BOARD SCORECARD

DISABILITY ISSUES



PAEDIATRIC SOCIETY OF NEW ZEALAND

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Health of our children: Wealth of our nation
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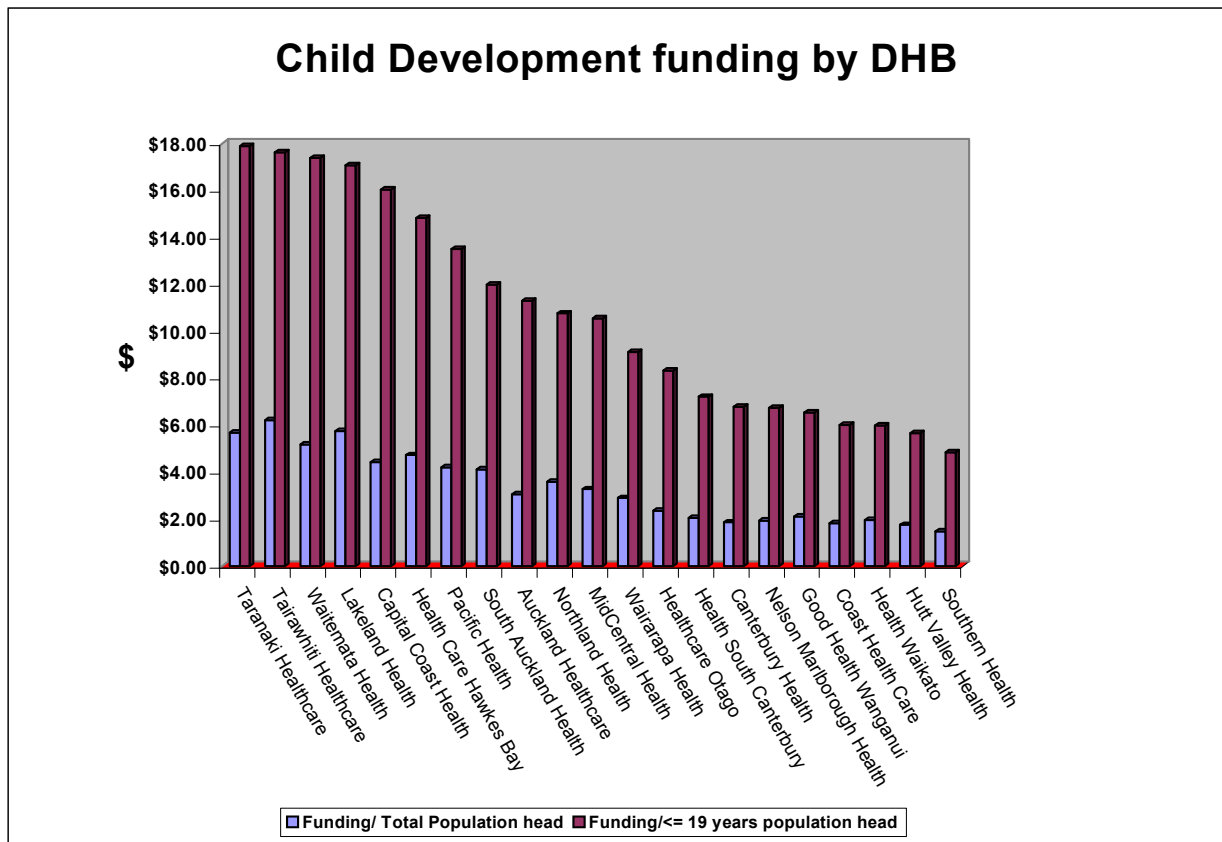
For several years the Paediatric Society of New Zealand (PSNZ) has been aware that the Disability Services Directorate (DSD) of the Ministry of Health continues to fund District Health Boards (DHBs) based on historical patterns, not on the population or on identified needs of a community. In the DHB Scorecard undertaken by PSNZ this year specific questions about disability care and support services were asked for the first time. The answers to these questions have highlighted the significant inequity in care between regions.

The following report is drawn from the findings of the scorecard and the concerns expressed by our members and the families with whom they work.

The graph below illustrates the funding per child in 2000 to DHB Child Development Services under the Ministry of Health's Child Development Service Specification, a nationally consistent contract despite the different funding levels. The graph does not include all DSD funding and in particular excludes:

- funding for respite care
- funding to various service providers e.g. conductive education, Wilson Centre, Spectrum, IHC etc
- funding of paediatric services

As far as we are aware the DSD has not changed the methods used to distribute funding since this time.



CARER SUPPORT SERVICES

From the results of the Scorecard it was pleasing to note that over the whole country it is very rare for acute inpatient beds to be used for respite care.

In every community there are a small number of children and young people with very high needs who cannot be cared for in the family homes of others. These children and young people need access to specially designed and funded facilities. In 7 DHBs one bed is available for 1:10,000 children or better, while in other DHB's one bed is available for 156,000 children. In 4 DHBs no service is available.

These concerning findings are supported by the observations of our members working in these regions who note that families are left with inadequate support.

Systems to assess the needs of families vary widely from region to region. Within a region children who may have similar needs are assessed by different organisations, depending on whether the need arises because of an intellectual disability, a mental health problem or a personal health problem. Following assessment it is possible for one child who has the same needs as another to be offered less support because of where they live, their diagnosis, or who made the diagnosis.

In some parts of the country after funding has been allocated families can approach an agency that has actively recruited, screened for suitability and trained families for shared care. That agency can then develop individual plans for children and young people (taking into account evolving needs and school holidays) to set up appropriate routine care to reduce the risk of crises and to optimise the wellbeing of all family members.

Unfortunately in many DHBs this comprehensive service is not available. Families are expected to find and train their own caregivers. As these families are already often under major stress the process can be compared with asking a drowning man to build his own lifeboat. The result is continuing stress, as families do not have suitable caregivers.

Carer support services are chaotic and inequitable. Children and young people with the highest need have the greatest difficulty getting services, especially if they cannot be cared for in a family home because of their very high needs or extreme medical fragility. In some parts of the country no residential facilities are available for these children or young people.

The subsidy allocated for carer support is also inequitable: it appears to be based on the historical allocation paid by Regional Health Authorities. We are aware that in one DHB area it is paid at \$74 per day and in a neighbouring DHB, \$64 per day. For a child or young person with complex needs requiring 24 hour care, this equates to as little as \$3 per hour.

To attract the high skills base required for this care this payment needs to be addressed.

The Paediatric Society believes that the provision of carer support and respite care throughout New Zealand must be based on the right of families with similar needs to be entitled to similar services. We have anecdotal evidence that families are relocating to areas where they perceive more services are available.

THE PAEDIATRIC SOCIETY RECOMMENDS:-

- Funding should be equitable based on population or number of cases in a region as the first step towards national equity of access.
- A model of care based on assessment of family need, regardless of diagnosis or causality, should be explored. It is likely to reduce inequity and improve quality of care.
- Successful care incorporates adequate service co-ordination, guarantees adequate training and ensures accountability and monitoring related to the impact of interventions.
- That in some regions the spectrum of alternative carer support accommodation needs to be increased.

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- The burden of finding their own carer is removed from parents.
- Existing respite care facilities are audited according to SNZ HB 8134.4:2004 to ensure their suitability for children and young people.

CHILD DEVELOPMENT SERVICES

Questions were asked in the DHB Scorecard about the availability of health funded psychologists and family support social workers to Early Intervention Teams. Both these components of care are listed as key inputs in the Child Development Service Specification. A wide regional variation in access to these services occurs across the country. In five DHBs these services are not available.

One significant discrepancy is the funding stream for Child Development services. In some DHB's this is shared in various allocations between disability and personal health funding and in others it is solely disability funding. The funding stream appears to have a direct impact on the level of service provided by each DHB.

Autism Spectrum Disorder (ASD) is an example of a disabling condition which results in children and young people having very high needs. To plan and offer appropriate co-ordinated care it is important to know something about needs in a community. DHBs were therefore asked for basic information about the numbers of children with this condition in their community together with elements related to audit of care. It was very disappointing that almost universally DHBs were unable to answer these questions.

Disability support systems rely heavily on interdisciplinary and interagency working with systems offering holistic case management. Too often the responsibility for organising and working across these organisations falls solely on the shoulders of a parent who is already having difficulty coping because of the additional needs of their child.

The involvement of therapists is crucial in the effective delivery of child development services. The contract for child development services is a national contract but within the contract there is freedom for individual DHB's to choose what is included. Some DHB's personal health and disability services overlap and are melded together, this may be advantageous for the client but does not give a clear indication of the demand. Some DHB's are more rigid in their application and service boundaries are clear, wait listing is the way CDT's manage the demand when it is greater than the resource and wait listing gives a clear indication to the MoH that resources are tight.

What has not been considered is that the Memorandum of understanding between Health and Education drawn up in the SE2000 situation. The MoU contradicts the CDT contract.

The CDT contract has been in roll over mode since 2000, service specs seem to be varied with some services operating on 2000 documents and others on later documents – this becomes a significant issue when the route to disability services is theoretically through the needs assessment process and the same documents are not being used to base decisions – families get inappropriate expectations.

The changing population has not been considered – immigrant and refugee families have significant needs requiring intense input to be engaged in services. Complex cases have increased – unless there is collaboration between services there is little resolve in these cases.

In addition there are difficulties in recruiting allied health professional with Dieticians being the most difficult, Speech Language and Physiotherapists next followed by Social Workers and Occupational therapists. This is further complicated through the differing remunerations offered by health, SES and ACC.

A question was asked of DHBs so they could describe how they resolved these issues. The answers contained considerable information about how this is being achieved but the differences in models of care made comparison impossible. A theme that emerged however, which is supported by the experience of families, is that care from a multidisciplinary team that links the health and education sectors is likely to be better organised in the pre-school than school age years.

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Overall systems for effective case management and service co-ordination to support carers are inconsistent or absent in some regions. This is in stark contrast to the recommendations of the "Implementation Plan - Autism Services Interdepartmental Working Group" (MOH June1999) <http://www.moh.govt.nz/moh.nsf/ea6005dc347e7bd44c2566a40079ae6f/e03b8b339e8825094c25678400819d20?OpenDocument>),

The information from the DHB scorecard would be valuable to people developing these services and contains some exciting initiatives, especially joint working between the health and education sector in a few places.

THE PAEDIATRIC SOCIETY RECOMMENDS:-

- Funding should be equitable based on population (or number of cases) in a region as the first step towards national equity of access.
- Disability Support Directorate works with DHBs to offer services in accordance with service specifications.
- Development of systems to record information about children and young people with disabilities and special needs.
- Holistic co-ordinated care with collaborative working and active case management is an intrinsic component of all services to improve efficiency and adequacy of support services.
- Existing services are audited according to SNZ HB 8134.4:2004