



15 June 2012

MINISTRY OF EDUCATION

Email: SLSRTL.B.Amalgamation@minedu.govt.nz

Dear Sir/Madam

Re: PSNZ submission on the proposal to amalgamate Supplementary Learning Support with Resource Teacher of Learning Behaviour Services

Thank you for the opportunity to comment on the proposal to amalgamate Supplementary Learning Support with Resource Teacher of Learning Behaviour Services. This submission has been prepared with input from the Child Development Special Interest Group of the Paediatric Society of New Zealand. The CDSIG has a membership of 101 child health professionals including Paediatricians, Psychologists, Nurses, Speech Language Therapists, Physiotherapists and Occupational Therapists and others.

The internal organisation of Special Education Services is clearly a matter for the Ministry of Education. However there is an important and significant interface with health and decisions made in relation to Special Education have an impact on health services and vice versa.

Of particular concern to Child Health Professionals working with children and young people with disability is the group with borderline to moderate needs – “the strugglers”. Many children and young people in this group have the potential to become adults who can contribute to the economic health of the country and yet they are the group whose educational needs are most likely to be neglected. We have highlighted this in our previous submissions on Special Educational issues ^{1,2,3}. (*original documents or link provided*)

Child Health Professionals see a high level of unmet need in this group in terms of their access to current services. While we applaud the ministry’s efforts to simplify the system, any reduction in access to special educational services would be of considerable concern.

The current systems for delivering Special Education Services have evolved since the Special Education 2000 (which still forms the basis for current services) which was proposed in 1999. Services such as Supplementary Learning Support and Ongoing Resourcing Scheme Extension funding have been tacked on the system without any clarity around the processes. Parents need access to unbiased advice about educational options. Some need help to navigate a complex system. Those who need this help are often from the most disadvantaged sectors of our communities.

The concept of a hierarchy of support starting with teacher intervention at classroom level and progressing through school based interventions to increasing levels of support is appropriate. However the complexities of the system are hard for people to understand, and many confused parents turn to the Health System for advice about educational problems. As a result the advice they get is highly variable and may be incorrect or inappropriate for their child.

Educational policies impact on the health system in a number of ways. These include:

- Parents and Education requesting “a diagnosis” in the belief that this will enable them to access the educational funding that they believe a child needs. This problem has reduced over recent years with clear criteria for ORS funding on the Ministry of Education’s website.
- Inadequate education assessment of children who are not performing as expected in school. In particular, the failure of the education system to provide educational psychology assessments and clarify whether educational failure is due to intellectual disability or specific learning disability. This places huge stress on children, young people and their parents who cannot understand why they or their child is having so much more difficulty than their peers.
- Lack of recognition that children and young people have a continuous experience from home to school and back to home so that when problems occur that need professional intervention these need to be provided across these boundaries e.g. therapy and behavioural interventions. This leads to gaps and costly duplications.

Many Special Education Services are time limited or age limited. Children who have long-term disabilities will have ongoing needs and will not be “fixed” after two terms of intervention.

It is concerning to note the comment in the Discussion Document that SLS teachers are not formally required to have a specialist teaching qualification. We presume that they have a general teaching qualification but no evidence of additional training in teaching children with special needs. Clearly we support the provision of quality specialist teaching.

The discussion document does not clarify how children in rural areas are to be serviced. We are concerned that the proposed changes may mean that children in rural areas are disadvantaged in terms of access.

Yours sincerely



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On behalf of the Child Development Special Interest Group
Paediatric Society of New Zealand

References:

1. SE2000 PSNZ submission
2. Affidavit re Special Education (2003)
3. Submission by the Developmental and Community Paediatric SIGs re Review of Special Education (March 2010)

<http://www.paediatrics.org.nz/files/2010/Submission%20by%20the%20Developmental%20and%20Community%20Paediatric%20Special%20Interest%20Groups%20re%20Review%20of%20Special%20Education%20Final%2019%20March.doc>



THE PAEDIATRIC SOCIETY OF NEW ZEALAND

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15 June 2012

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Reviewer
Special Education 2000 Policy Review
NZCER
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Wellington

Dear Dr Wylie

Re Review of Special Education 2000 Policy - Submission from Paediatric Society of New Zealand

Thank you for the opportunity to present this submission which is written by the Developmental Paediatric Sub-Committee of the Paediatric Society of New Zealand on behalf of the Society. We would be happy to meet with you to discuss our concerns further if this would be of value to you. Dr Louise Porteous can be contacted at Puketiro Centre, telephone 04 237 5222; and Dr Rosemary Marks at Starship Children's Hospital, telephone 09 307 4949 ext. 6575.

Yours Sincerely

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REVIEW OF SPECIAL EDUCATION 2000 POLICY
SUBMISSION FROM PAEDIATRIC SOCIETY OF NEW ZEALAND

Executive Summary and Recommendations

Executive Summary

1. The current Special Education 2000 structure is inadequate to meet the needs of children with moderate and mild disability especially those who have intellectual disability and/or autistic spectrum disorder.
2. Access to the Ongoing Resourcing Scheme appears to be based on certain criteria, or labels and diagnostic categories more than on educational need.
3. There is both a lack of access to assessment services, and a philosophical bias against standardised psychometric assessment which leads to children with learning difficulties and disabilities being disadvantaged.
4. There is a need for national standards for special education/early intervention services, in line with currently accepted international practice.
5. There is lack of accountability and responsibility for children with additional educational needs.
6. The issue of provision of occupational therapy, physiotherapy and speech language therapy to children with disability and the interface between education and health with respect to this issue have never been fully explored and the ad hoc arrangements which have been put in place are failing to address therapy needs effectively.
7. Health professionals working in educational settings often experience isolation and are deprived of access to peer review and continuing education available to similarly qualified staff working in the health sector. Therapy posts in Educational settings often remain vacant for these reasons.

Recommendations

1. All children should receive quality education from appropriately skilled and trained educators.
2. Special Education funding should be based on individual need and should be flexible according to the level of need and local conditions. Funding for children with moderate and mild disability should be targeted to ensure most effective investment of resources.
3. Transition from Early Intervention Services to the school sector requires careful planning and monitoring. A longer transition period than is currently provided for is necessary.
4. Educational assessment, including appropriate psychometric assessment when and where indicated, should be freely available to all children in the school sector.
5. A comprehensive review of the issues relating to provision of occupational therapy, physiotherapy, and speech language therapy to children with disability should be undertaken. This review should consult all stakeholders and examine all options for service delivery against a background of internationally accepted best practice.
6. Parents should have easy access to free and unbiased advice on their child's educational needs and educational placement. This is especially important for families who are disadvantaged in a variety of ways.
7. There must be transparent and public accountability for all funds allocated to special education.
8. All programmes for children with disability should be designed and take into account the need for programmes to work across boundaries between home and school. This is particularly true for therapy and behavioural management programmes.
9. There must be collaborative planning and service delivery between the education sector and the health sector at all levels from service delivery focussed on the individual child through to intersectoral policy planning at ministry level. Consultation should include all relevant agencies.
10. Formal evaluation of outcomes should be made of any changes in service delivery. This requires that baseline data be obtained.
11. Transport of children with special educational needs to and from school should be as similar to their age-peers as is feasible.
12. Where children with special educational needs must be transported by taxi or bus, appropriate provision for the safety of the children, their fellow passengers, the driver, and other road-users

must be made. This includes the use of escorts for children with medical needs and challenging behaviours.

REVIEW OF SPECIAL EDUCATION 2000 POLICY
SUBMISSION FROM PAEDIATRIC SOCIETY OF NEW ZEALAND

This submission covers the following:

Background and Experience of our group
Discussion of the Prevalence of Disability in New Zealand
Comment on the Current Strands of SE2000 and our experiences of the positive and negative aspects
Issues related to Inclusion of Children with SE needs
Issues related to Fundholding
Health/Education Interface
Professional Standards and Training
Assessment including psychometric assessment and access to SE funding
Children with Moderate Needs
Children with Specific Issues
Transport
Delivery Philosophy

Background and Experience of our group

The Developmental Paediatric Sub-Committee of the Paediatric Society of New Zealand represents the views of paediatricians throughout New Zealand on issues related to child development and disability. The membership of the committee includes specialist developmental paediatricians and specialist general paediatricians with an interest in developmental and behavioural paediatrics. There is wide geographical representation with members from all of the main centres and a number of smaller centres. Members of the group have been involved in the practice of paediatrics in New Zealand since 1975. One member holds documentation of discussions around the health/education interface dating back to 1978. Most members of the group undertook part of their training outside New Zealand in Australia, the United States or the United Kingdom and bring awareness of international perspectives to their work. All members have experienced the previous as well as the current provision of special education in New Zealand.

Prior to the 1989 Education Act, paediatricians frequently found themselves advocating on behalf of children whose families had raised concern regarding special education and problems of access to education for children with severe intellectual disability. Between 1990 and 1997 it was relatively unusual for parents to want to discuss their child's provision in any depth during a paediatric consultation. However during this time some of us were involved in extensive but inconclusive discussions around provision of physical and occupational therapy and the health/education interface. Since 1998 families again commonly raise concerns about their child's educational provision. Now it is the families of those children with mild and moderate disability who are most likely to raise concerns. In addition we have seen a huge upswing in referrals from family doctors, and a range of education professionals including schools, Resource Teachers of Learning and Behaviour and Specialist Education Services, requesting a paediatric review and provision of a medical diagnosis to assist an Ongoing Resourcing Scheme application.

We are aware that children with disabilities receive more support at school today than ever in the past. With philosophical and attitudinal changes in society, and with increased understanding of how to offer specific teaching programmes, of children who were previously segregated or excluded from school are now catered for in the mainstream education system. However as the value of education increases so does the pressure for the child with all levels of disability to optimise his/her educational potential.

Technological advances in medical science, and changing attitudes in the medical and wider community mean that an increasing number of children with severe and complex disability are surviving to school age. These children present new challenges to the education system as they are often medically fragile or dependent on technology such as a tracheostomy or gastrostomy feeding tube for their survival.

Prevalence of disability in New Zealand

- **Intellectual Disability**
New Zealand data show that 3.4/1000 children have a moderate-severe intellectual disability, while 26/1000 of children aged 0 to 14 years have some degree of intellectual disability or developmental delay (Vogel).
- **Autistic Spectrum Disorders**
Using even conservative estimates the prevalence of Autistic Spectrum Disorder is 1 in 1000 and of Asperger Syndrome 1 in 300 in New Zealand. (Gillberg).
- **Physical Disability**
Estimating prevalence of physical disability is difficult as incidence figures are usually derived for specific entities such as Cerebral Palsy (2.5 / 1000) or Spina Bifida (0.62-0.69/1000), and do not reflect severity or degree of need for educational or other support services.
- **Sensory disability** prevalence is fraught with similar difficulties.
- **Other Learning Difficulties**
The Warnock Report (1979) estimated that around 20% of children in the United Kingdom needed special assistance at some time during their school years. It is reasonable to suppose that these figures can be broadly extrapolated to the New Zealand situation. In 1998 between 3-4% of schoolchildren in one London Borough were receiving Special Educational Support through the process of "Statementing" put in place by the UK 1981 Education Act. (Mrs. R. McMillan; Educational Psychologist: Personal Communication) The Warnock Report was written at a time when Attention Deficit Hyperactivity Disorder was regarded as an almost exclusively North American phenomenon. Now we would conservatively estimate that 2 to 4% of New Zealand children have ADHD. It is not clear whether the Warnock report would have included this group of children. Nor is it clear whether this is a true increase or whether diagnostic thresholds have changed. The issues involved in that controversy are complex and outside the scope of this submission. What is clear is that there is a large group of children requiring additional educational support.

Comment on the current strands of SE2000 and our experiences of the positive and negative aspects

The increase in funding for educational provision for children with severe and profound intellectual disability which has resulted from the Ongoing Resourcing Scheme is very welcome. This group of children, especially those attending schools for children with severe intellectual disability, were clearly disadvantaged under the old funding system, compared with their peers attending schools and units for children with physical disability.

The Ongoing Resourcing Scheme for children with high and very high needs is reported to be allocated to approximately of 1 in 100 children in the school population. The children receiving the ORS funding are a diverse group including children with severe intellectual, physical, and sensory disability. From the prevalence data outlined above it is clear that the ORS can only meet the needs of a fraction of the total number of children requiring special educational support.

Thus it is evident that there are a large number of children with moderate to severe disabilities not receiving support through the Ongoing Resourcing Scheme to access the curriculum. While some have their needs partially met by alternative funding streams such as the Speech Language Initiative and Severe Behaviour Initiative, these schemes are not designed to give the long-term support that most of these children need. The Resource Teachers for Learning and Behaviour, the new Moderate Needs initiative for children with physical difficulties and the provisions of the Special Education Grant are inadequate to cater for children with significant disability, who fall just outside the 1% threshold. For example we have seen many children functioning at a developmental quotient of about 50 and rejected for ORS. Extrapolating from the Warnock report figures, if one in every hundred children receives ORS

funding then 19 children out of every 100 must compete for the Special Education Grant. The Special Education Grant which is to be used at schools discretion for students with “moderate” needs in reality is set at a level that cannot provide for the proper assessment let alone interventions to this low severity but high volume group. We are concerned that the level of support allocated to schools for those children with mild to moderate disabilities that do not receive ORS funding is globally inadequate. Attempts to target this by allocating differential funding according to schools historic need and decile ranking appear to have been insufficient.

It is a particular concern that those children with borderline intellectual capability and mild mental retardation, who have the capacity to join the open workforce in due course, are being seriously neglected and this is likely to increase the level of benefit dependence in the future. We consider that the findings of the Warnock report remain valid and that allocated resources should reflect the documented level of need.

There is ongoing inconsistency in obtaining ORS funding, and at times it appears to be dependent on the skills of the professional and family making the application. Schools differ in preparedness to request a review or reapply.

It is unclear why the significant numbers of children initially receive Transitional Funding although it is clear from their diagnosis that they will have ongoing needs.

There are difficulties accessing the Moderate Needs (physical difficulties) application for health professionals. Although the child may be identified as eligible for Moderate Needs, the application needs to be made by the school. As it is complex application form, many schools are not completing the applications.

It is also clear that those children in families who are most socially and economically disadvantaged are often least able to advocate and contest decisions and again their children are disadvantaged.

Finally once a child has been verified what services he receives vary hugely depending on geographical location in the country, whether the school is part of a cluster managing their own funds or uses SES as their provider.

We have serious concerns about the process of assessment of children for special education resources. These concerns are dealt with in the section on assessment.

Issues related to inclusion of children with Special Educational Needs

We consider that all children should receive quality education from appropriately skilled and trained educators. As parents of regular children we expect that our children will be taught by appropriately trained and qualified teachers. In addition we expect that those teachers will maintain their expertise by a process of continuing education or continuing professional development. The current funding system means that heavy reliance is placed on untrained and relatively poorly paid teacher aides. While some teacher aides provide excellent educational input for children with special needs, there are other situations where teacher aides effectively function as baby-sitters and where the educational component is minimal.

We welcome the changes to the Ongoing Resourcing Scheme, which have allocated 0.1 (high needs), or 0.2 (very high needs) FTE teacher time to children with special educational needs. It is not clear to us how much of that teacher time is spent in direct contact with children and how much in directing or training others such as teacher aides. We suspect there is a wide variation dependent on the child’s placement and the management policies of the fundholder.

For children with very high needs, for example those who require close supervision for their safety or the safety of others throughout the school day, the current level of funding does not provide a full-time support if the child is in an inclusive setting.

There is a need to recognise the tension between the parental right to choose a fully inclusive educational model in the school of their choice or their local primary school and the organisation of special education in a managed way so that most effective use of funding available to special education and educational resources such as teachers skilled in special education are used effectively. In practical terms funds may be used more effectively if children with similar needs are grouped together in special or satellite classes located within, but not necessarily administered by regular schools.

Educational assessment and advice should be freely available for all children. In particular advice on choice of educational placement should be unbiased and comprehensive.

Issues related to fundholding

It is of concern that the system of administering special education funding via fund-holders means that no impartial source of advice for parents in choosing educational options is available. Each fund-holder has a vested interest in acquiring as many Ongoing Resourcing Scheme children as possible so that services can be provided more economically and efficiently. For a child moving between schools for whatever reason, be it transition to primary to intermediate to secondary, a family moving to another area or city, or parental concern that the current educational placement is not the most appropriate for the child, there is no source of impartial advice.

It is also not clear to our group what accountability there is for fund-holders. For example if a parent wants independent advice on a behaviour management programme or other aspects of the classroom programme and the fund-holder refuses to acknowledge the need, or does not have the intellectual resource and refuses to purchase it from another provider there appears to be nothing that the parent can do. For example one special school principal stated that services would not be bought from Special Education Services (SES) because their charge out rates were too high and they (the school) had experienced teachers who could do just as good a job as any psychologist. This comment was in a school where teaching staff had failed miserably to meet the needs of one child with autistic spectrum disorder and for whom SES had provided a crucial intervention in 1998.

A further concern is the issue of teachers who do not have the appropriate set of skills for the group that they are teaching. Since SE2000 some special schools and units have grown significantly in pupil numbers, for example numbers of children with autistic spectrum disorders being enrolled in units which previously provided for children with physical disability. It is clear to us that, at times, the appropriate expertise is not necessarily available. It is also clear to us that not all parents have the knowledge to evaluate teacher skills and educational practices. We have also seen parents who are so desperate to have their child accepted, for example in a unit within a regular school rather than in a segregated special school, that they simply prefer not to look too closely at how appropriate the placement is.

We are aware of a number of instances where children who are enrolled in the Ongoing Resourcing Scheme are not receiving the physical and occupational therapies, which they require because their fund-holder has not been able to recruit an appropriate therapist. It is also of concern that the issue of professional development for physical and occupational therapists in the educational sector does not appear to have been addressed.

Health/Education Interface

Children with the most complex and severe disabilities are now funded through The Ongoing Resourcing Scheme for all their educational and therapy needs. These children are also most likely to have high health needs, which should be assessed using standardised measures, recorded and monitored.

These children often require regular, intense and specific interventions in order to maintain their health status. For example a child with cerebral palsy may require Single Event Multi Level Orthopaedic Surgery. For this surgical intervention to be effective there must be close co-operation between child and family, orthopaedic surgeon and the physiotherapist who will provide the post-operative rehabilitation.

Health and Education have a long history of philosophical differences. Special Education 2000 has however created new tensions and difficulties for a group of children with significant physical needs requiring physiotherapy and occupational therapy. With the change of therapy provision from Health to Education children in some regions receive less regular therapy, and often only an intermittent advisory service. Health therapists have close links with the hospital clinicians such as paediatricians and orthopaedic surgeons, and used to attend clinics with their clients. It has been difficult and at times impossible, to establish the same close liaison with the education therapist.

Therapy offered to children in the ORS appears based on a predetermined amount for each child rather than on assessed need. For many children with complex or changing needs this amount is insufficient. Therapy is mostly carried out by unregistered staff such as teachers' aides with no access to specialised equipment. This often leads to poor quality. For this group of children Occupational and Physiotherapy involvement from Health now is limited to assessment and provision of equipment for "whole of life" (e.g. wheelchairs and seating, self care equipment, walking aids). The result of this change in service provision is that a child may now have two therapists, one for therapy, one for equipment. As a therapist needs to know a child well to provide the most appropriate equipment, the Education therapist remains involved in the assessment process. Thus it takes two therapists to complete an equipment assessment, confusing and frustrating for everyone not least the child and her family.

This is further exacerbated by the confidentiality issues around accessing medical and educational files. While this is appropriate, at times it leads to poor and insufficient information across services. The Privacy Act has been misinterpreted and has become a barrier to the free passage of information that is essential to the child's welfare.

Behavioural management in the home is a further area of difficulty at the health/education interface. Provision of these services is ad hoc and depends on the type of disability and the area in which the child lives. Sometimes these services are provided through education and sometimes through health. Health funded services such as Child, Adolescent and Family services or Child Mental Health services, Child Development Services, Intellectual Disability services (for example IHC and other local providers such as The Waikato Community Living Trust in Hamilton or Spectrum Care Trust in Auckland), may all be involved in the provision of behavioural management services. Education providers such as SES or private psychology services purchased by the school may be working with the same child. In other situations no service will see the child and parents are left to struggle with challenging behaviour alone. Since challenging behaviours are rarely seen in one setting only, this impacts on educational provision.

Speech-Language Therapy for school aged children is funded by Education. Some children, especially those with severe oro-motor dysfunction and feeding difficulties would be more appropriately addressed by Health because of the multidisciplinary team approach required. These children require close liaison with Health services, including involvement from dietician, paediatrician, ENT surgeon, psychology and specialist radiology as well as Speech Language Therapy. The close relationship between Speech Language therapy and Education is a uniquely New Zealand phenomenon. Its continued relevance in the year 2000 needs to be explored.

Special Education 2000 documentation often loosely quotes 'research' supporting provision of therapy services within a school setting rather than a clinic setting, supporting the change of funding away from health to education. Despite requests, the references for this research data have not been forthcoming.

Professional Standards and Training

Special education expertise should be available in programme planning and programme execution for all children identified as having special educational needs. This should occur at three levels

- All teachers should have basic training in special education as part of their pre-service training. Existing teachers should be required to up-skill in special education. This could be part of a continuous professional development programme
- Generic special education trained educators would provide some classroom programmes and where appropriate advice to mainstream regular teachers with inclusive learners.

- ❑ Specialist special educators should act as resource teachers for an area or region for groups of children with specific or complex needs, for example
 - Autistic spectrum disorders
 - Augmented communication for children with physical disability and/or communication disorders
 - Physical disability with above average intellectual ability
- ❑ Hearing and visually impaired
 - Specific learning difficulties associated with specific syndrome, for example Fragile X syndrome, Down syndrome, Prader-Willi syndrome.
- ❑ The special education resource should include
 - Teachers at all levels of the education sector, i.e. early childhood education/early intervention; primary sector; secondary sector
 - Educational psychologists
- ❑ Health resources should include
 - Special speech language therapists
 - Physical therapists
 - Occupational therapists

We are very aware of the pitfalls of criticising professions other than our own. As observers of SE2000 we would like to know what standards of training and supervision have been defined for personnel (generally teacher aides) who carry out the hands on therapy (physiotherapy, OT, SLT) with students?

What mechanisms ensure parents are informed of visits by specialist advisors to their child, and have the opportunity to participate? The IEP process is too infrequent to ensure parents are fully informed.

It is essential that RTLBs and psychologists providing educational assessment have appropriate skills and tools to do so. Issues relevant to assessment are addressed more fully in the next section.

Assessment including psychometric assessment and access to SE funding

Assessment practices in New Zealand are at variance with international practice in this field. For many years there has been reluctance to perform psychometric testing. We believe this is driven by philosophy and attitudes rather than hard research evidence. Current research advocates a multiple assessment approach including norm referenced tests, interviews, observations and informal assessment as the best basis for making decisions about children (Sattler, 1992). The methods of information gathering have to be selected depending on the needs in each individual situation.

We do not believe that the absence of formal assessment in New Zealand results from lack of resources. Indeed the ecological assessments currently carried out are time consuming. It is not clear that such assessments are of benefit to children however.

It is our understanding that Resource Teachers of Learning and Behaviour provide the first stage in educational assessment. In our experience this assessment component is very variable and often limited with formal assessment or even a though understanding of learning difficulties being outside the expertise of the RTLB.

We note the shift in educational thinking towards the use of criterion referenced testing. We are of the opinion that norm referenced formal psychometric tests are valuable for several reasons:

- ❑ The accepted definitions of mental retardation (intellectual disability, learning disability or any other synonym) all refer to performance on norm referenced tests. We understand all the issues in relation to labelling, but note that failure to provide a clear statement that a child is intellectually disabled prevents access to a variety of support services.
- ❑ However distressing the initial diagnosis may be, provision of an explanation of why their child is different from other children is helpful to parents, enabling them to seek help and to understand

their child. It enables parents to have realistic expectations of their child rather than the pain of striving for unrealistic targets that the child cannot achieve.

- Information on the child's specific cognitive profile is important in the diagnosis of some conditions such as Fetal Alcohol Syndrome. (Astley and Clarren)

Children with moderate needs

There is no accountability in the use of the Special Education Grant. As we understand it this grant can be incorporated into the consolidated funds of the school and used for whatever purpose that school thinks fit, be it the provision of teacher aide support for children with special educational needs, the purchase of a new computer, the funding of an enrichment class for "gifted" children or to provide an in-depth assessment for one child. In addition there do not appear to be any safeguards in place to ensure that schools are accountable for decisions that are made. For example a school could decide to spend their Special Education Grant on an unproven but possibly attractive therapy such as Brain Gym.

Despite our concerns about accountability, it is our experience that many schools are in fact subsidising the Special Education Grant from their general funds to provide increased provision for children with special needs rather than the reverse.

We have already stated that the Special Education Grant is inadequate to meet the needs of children with moderate learning disability. Some parents have offered to pay out of their personal resources for teacher aide support for their child. In our experience such offers have usually been refused on the basis that it is inappropriate for parents to purchase additional resource within the public education sector. However we are also aware of some parents being pressured to apply for the WINZ Childhood Disability Allowance to fund additional help for their child at school.

We have highlighted our concern that diagnostic labels are being sought for these children in an attempt to access funding, rather than in an attempt to understand their underlying condition. (See background section)

Somewhat ironically while children with high health needs are funded through Education, children who "miss out" on assistance or with milder disabilities and specific learning disorders such as reading disorder, clumsiness, language delay, appear to no longer qualify to be seen by the education system for assessment of their difficulties. The current pressure, coming from schools themselves, is that these children be seen by paediatricians and health funded developmental and mental health services. Although these children obviously need thorough assessment including a cognitive profile to define their difficulties, this should be done by Education professionals. The paediatricians and other health professionals role in this instance is to establish if possible the aetiology of the problem assisted by the educational psychologist's assessment and manage health related issues.

Children with Specific Issues

The Preschool Child

SES Early Intervention Services see a large number of children and provide screening and curriculum based assessment. Service provision is usually "advisory" through an education Support Worker rather than through direct contact with the Early Intervention Teacher on an individual or small group basis. The issues here are similar to those for older children where provision is through teacher aides rather than qualified teachers. Funding needs to reflect an appropriate level of access to direct contact with skilled and experienced teachers and therapists. After initial assessment the Early Intervention Team often recognises the need for assistance to a child but is unable to meet that need without funding available until "next term".

Many children are discharged from Early Intervention at 5 years, because of the lack of provision for children with moderate needs in the compulsory sector. While it is usually anticipated that these children will experience difficulty in the school sector, no action is taken until the child has experienced failure. Even then it is rare for support to be forthcoming, and where it is there is significant delay in reinstating services.

Rehabilitation

There is currently no comprehensive paediatric rehabilitation Service in New Zealand. Such a service needs to be developed, and discussions regarding such a development are currently ongoing in Auckland. The management of children requiring rehabilitation is complex, and further complicated with part of this group funded by ACC, and part by health.

Rehabilitation from head injuries in particular requires close liaison with education services. Children may have mixed or subtle cognitive deficits which affect performance and behaviour profoundly. While detailed cognitive and neuropsychological assessments are provided by ACC, expertise in educational aspects of rehabilitation is required to interpret these assessments and to make specific recommendations for schools so the assessment information can be used to benefit the child. For children not funded by ACC, for example the child who has had a frontal lobe infarct following a stroke, assessment as well as educational programme advice should be provided by education. There are major inequalities between the level of support received by children with similar needs depending on whether they are entitled to ACC or not.

Expertise in educational aspects of rehabilitation is thus an essential component of any comprehensive paediatric rehabilitation service and will require collaboration between Education, Health and ACC.

The Medically Fragile Child

While there may have been some discussion between Health and Education in regard to this relatively small but increasing number of children, there has been no consultation at any systemic level with the health-based clinicians who are most involved with their care. Over the last five years there has been a rapid increase in the use of medical technology to support children who would previously have died in infancy. The absolute numbers of children with tracheostomies and gastrostomies is small, but because of their extremely high needs the impact on consumption of services is very significant.

There is also a group of children with chronic illness or sequelae of treatment who have health needs which impact on their educational setting without the child necessarily needing any curriculum support. For example children with cystic fibrosis may need physiotherapy during the school day to ensure they remain well enough to continue attending school. Children who have had surgical treatment of ano-rectal abnormalities may have severe continence issues. Often parents get called into school to clean their child after an episode of incontinence. To date some appear to be accommodated under ORS but we are not aware of specific decisions in regard to this group.

Children who are medically fragile or suffering from chronic illness may have prolonged absences from school for health reasons. If these children do not attend for more than 3 weeks, their school enrolment lapses.

The Child with Special Educational Needs and Social Disadvantage

There is a large group of children who have both special educational needs and are at a social disadvantage. Often these children are not referred to paediatric services, although many are known to Public Health Nurses. They have only mild or moderate special education needs and so get little or nothing in terms of additional educational support. Schools often find that they are in the position of providing Social Work services for these children and their families. These children include:

- ❑ Children whose parents lack resources to challenge the system; go for a medical diagnosis and manipulate the Ongoing Resourcing Scheme system to their child's advantage.
- ❑ Children who miss out on early childhood education are often diagnosed late with learning disability. In consequence the information that might lead to an Ongoing Resourcing Scheme funding application is often missing.
- ❑ Cultural differences in attitude to developmental disability may lead to different access.
- ❑ Maori or Pacific Island children with borderline cognitive ability.
- ❑ Children with low average or borderline intellectual ability and English as a second language, who may also receive little language input at home (in any language)

Transport

Children who live close to their special educational placement and who are independently mobile should be transported by their parents or encouraged to walk to school. Provisions such as the walking bus piloted for regular schoolchildren at Gladstone Primary School in Auckland have the potential to increase student fitness, provide for normal social interactions and to provide increased for both regular and special needs children.

For children transported by taxi or bus, the safety of the child and other road users must be paramount. Access to education should not be denied because the child's behaviour is difficult in the taxi. Escorts need to be provided for children with medical needs and/or challenging behaviour. No driver can be expected to monitor the health needs of a child or several children with epilepsy or other medical needs such as a tracheostomy, as well as providing full attention to driving. Children with challenging behaviour present other safety issues to their peers transported with them, to the driver and potentially to other road users. In our view it is only a matter of time before there is a serious accident resulting from distraction of a driver by a child with special needs and challenging behaviour.

All children transported by taxi or bus to special educational placements should use restraints (safety belts or seats) appropriate to their needs and developmental level. Four point harnesses may be required for some children with challenging behaviour. Children with physical disability must be provided with appropriate restraints.

Delivery Philosophy

To end our submission we would like to draw your attention to The United Nations Convention on the Rights of the Child signed by New Zealand in 1991. We would argue that currently, given the absence of adequate services and interventions for some children, there is a breach of fundamental disability rights. The Convention on the Rights of the Child contains clear guidelines of what services should be provided to children with special needs, how they should be delivered – article 23 specifically addresses children with disabilities. It states parties to recognise mentally and physically disabled children should enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community. Disabled children have the right to special care and education, rehabilitation services, and preparation for employment, in a manner conducive to achieving fullest possible social integration and individual development. Special Education 2000 in some instances is failing to provide these rights.

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**APPENDIX 1
MEMBERS OF THE DEVELOPMENTAL PAEDIATRIC SUBCOMMITTEE OF THE PAEDIATRIC
SOCIETY OF NEW ZEALAND:**

Dr Russell Austin	Christchurch Hospital
Dr Nick Baker	Nelson Hospital
Dr Giles Bates	Palmerston North Hospital
Dr Phillipa Clark	Starship Children's Hospital, Auckland
Dr John Clarkson	University of Otago
Dr Kate Hall	New Children's Hospital, Sydney
Dr Paul Heaton	Taranaki Base Hospital, New Plymouth
Dr Rosemary Marks (Convenor)	Starship Children's Hospital, Auckland
Assoc Prof Ed Mitchell	University of Auckland
Dr Johann Morreau	Rotorua Hospital
Dr David Newman	Waikato Hospital, Hamilton
Dr Louise Porteous	Puketiro Centre, Wellington
Dr Paul Shillito	Christchurch Hospital
Dr Oliver Smales	Health Care Hawkes Bay
Dr Warwick Smith	Middlemore Hospital, Auckland
Dr Louise Webster	Starship Children's Hospital
Dr Russell Wills	Royal New Zealand Plunket Society



AFFIDAVIT RE SPECIAL EDUCATION

This affidavit is presented by Dr Rosemary Marks, chair, child development committee, on behalf of the Paediatric Society of New Zealand.

The Paediatric Society of New Zealand represents paediatricians and child health professionals, working in New Zealand. The society has an active child development committee. The membership of the Paediatric Society has been consulted in the preparation of this affidavit.

1. The Paediatric Society has previously expressed concern over the provision of special education.
2. Copies of our submissions to the "Wylie report", and to Special Education – what do you say? are attached.
3. We remain very concerned about the level of special educational support provided to children with mild and moderate intellectual and other disabilities. That is, those children who have significant special educational needs but fall outside the threshold for ORRS funding.
4. We see these children presenting, and often re-presenting to developmental and general paediatric clinics throughout the country, with concerns from parents, primary health care workers and educators about their educational provision. Often we are asked to provide a medical assessment in the hope that the provision of a medical diagnosis or label will improve the child's chance of obtaining ORRS funding. We are fully aware that the provision of funding is intended to reflect educational need, and to be unbiased by any diagnostic label. However we have observed that a child with a developmental quotient of 55 who looks physically normal and has no "diagnosis" other than intellectual disability is unlikely to receive funding while a child with, for example, Down syndrome and the same DQ does.
5. A child may present at age 5 years, with cognitive and academic skills equivalent to a 3.6 to 4 year old. That is, functioning in the borderline to mild mental retardation range. It is now common to see the same child referred back for further medical evaluation as to why the child is not learning. Often, by the age of 11 years, the child is still only functioning at a 6 year level. The child remains outside the threshold for ORRS funding and yet has clearly lost ground compared with their peers. The reason for the child's poor performance is not medical, but lack of access to appropriate educational intervention. As one paediatrician from a small North Island centre described the situation "kids with moderate learning needs are abandoned by the present system".
6. A further concern is children with a specific diagnosis such as an autism spectrum disorder or cerebral palsy. These children maybe functioning academically outside the ORRS threshold but still have special learning needs which need to be addressed.
7. We estimate that, currently in New Zealand, about 2% of children in the compulsory education sector do not receive adequate educational input to remediate or ameliorate their special educational needs. We are deeply concerned that the failure of our country to invest in the education of this group of young people will have a significant impact in the future. It is the opinion of our membership, that, with appropriate support and intervention through the education system, many of these children and young people have the potential to become independent, self-supporting, and perhaps tax-paying adults. However, without support, we envisage a substantial group of adults, who remain dependent on others and, worse, may be at risk of criminal offending as a result of being marginalised.
8. The issue of special needs units is a complex and contentious one. As a national organisation we are aware that there are many children for whom attendance at any SNU is not a viable option on grounds of geographical access. However we would also point out that there is a tension between meeting special needs in mainstream education and meeting special needs in special education facilities. In mainstream education, the child with special needs has access to their non-disabled

age peers who can model appropriate behaviours and learning (we hope!). However, that child must also compete with those peers for teacher time and attention. Inevitably teachers must pitch their teaching at the majority of average performers in the class. While some teacher aide support may be provided to those who have ORRS funding, or a school management team who use their SEG and other funds creatively, the teacher aide will be poorly paid and usually untrained if not unskilled. In a special school or SNU, the child with special needs has access to teaching expertise in special education, but also has the disadvantage of a classroom peer group who may model inappropriate behaviours or learning styles. Neither option is ideal.

9. Our opinion is that the provision of special education needs to be adequately funded.
10. Provision should be needs based and tagged to the child. The use of funding formulas which do not take into account the needs of individual children are unfair and inequitable.
11. In order for an assessment of educational needs to take place, the child must have free access to an individualised educational assessment. This includes the provision of quantitative as well as qualitative assessment of the child's learning potential and needs, to guide the provision of appropriately targeted educational intervention.
12. The role of health services is to provide paediatric and other child health assessments, according to individual need. It is not the role of child health services to fill the gaps in educational provision.
13. Communication about special education provision by the Ministry of Education needs to be clear. Communication with Health Care Professionals has been minimal, and often dependent on individual and personal contacts. Parents and schools often do not appear to have any idea how to use the systems that have been set up.
14. A range of educational models should be provided. These would include mainstream provision with appropriate paraprofessional support and itinerant special educational expertise, special needs units in regular schools, and special provision.
15. Parental choice remains important but should be guided by informed evidence based provision of advice by appropriately qualified educators. Educational resources should be managed effectively and efficiently. At times this will mean that grouping children with similar educational needs together in an SNU is the most effective use of scarce financial resources and expertise. Ongoing evaluation of the effectiveness of different models of service delivery is essential, to ensure future decisions on service provision are made appropriately.
16. Lastly, we note on the Ministry of Education's own letterhead the statement "Nothing else provides people with a better capability to FULFIL THEIR LIVES, leap the fences of background and situation, and benefit those around them." "Ministry of Education, Raising Achievement, Reducing Disparity" It is our grave concern that this worthy statement is simply not true for children with moderate learning difficulties and disability.

7 May 2003