THE PAEDIATRIC SOCIETY OF NEW ZEALAND

Secretariat: Denise Tringham
P O Box 22 234
Wellington
Tel: (04) 938 4827
Fax: (04) 976 4827

Email: psnz@paradise.net.nz

POSITION STATEMENT

Meeting the Care and Support Needs of Young People with Complex and Chronic Health and Disability Needs as they Approach Adulthood

STATEMENT ENDORSED BY:

- Office of the Commissioner for Children
- UNICEF New Zealand
- Council for Medical Colleges
- Royal New Zealand College of General Practitioners
- Cardiac Society
- Paediatric Dentistry, University of Otago
- Group Special Education
- Epilepsy New Zealand
- Heart Children New Zealand
- Cerebral Palsy Society
- Parent to Parent New Zealand
- New Zealand Organisation for Rare Disorders

March 2003
Nick Baker
Review: March 2005

THE PAEDIATRIC SOCIETY OF NEW ZEALAND

Secretariat: Denise Tringham
P O Box 22 234
Wellington
Tel: (04) 938 4827
Fax: (04) 976 4827
Email: psnz@paradise.net.nz

POSITION STATEMENT

Meeting the Care and Support Needs of Young People with Complex and Chronic Health and Disability Needs as they Approach Adulthood

The Paediatric Society of New Zealand believes:

1. Special provisions need to be made for young people with complex and chronic health and disability needs, particularly with regard to their health care after the age of 12 years.

2. Young people with complex and chronic health and disability needs require a single local individual who has a role as a point of first contact and co-ordinator of a team of care.

3. Young people with complex and chronic health and disability needs require access to the best available national or international expert medical advice to direct their health care.

4. Young people with complex and chronic health and disability needs require access to habilitation and rehabilitation services appropriate to their age and developmental level

The Paediatric Society of New Zealand notes

1. That many young people with complex and chronic health and disability needs often have problems that are complex and/or rare and require input from a range of health providers and services

2. That many young people with complex and chronic health and disability needs have difficulty accessing coordinated care and expertise in rare disorders

3. That parents frequently report that apart from within General Practice it is hard to access inclusive holistic care within adult specialist medical services.

4. Many young people with complex and chronic health and disability needs have problems that are too complex or rare to be adequately managed by a General Practitioner alone.

March 2003
Nick Baker
Review: March 2005

5. When transferred from paediatric care the process of access to specialist services by General Practitioner referral is procedurally complex and time consuming

6. Significant financial barriers frequently prevent young people with complex and chronic health and disability needs from adequately accessing General Practice and this often means transferring costs to individuals and families

The Paediatric Society of New Zealand recommends:

1. Development of systems for funding and implementation for a system of care that meets the needs of these children and young people.

2. That as systems of capitation or population based funding are developed care is taken to avoid any incentives that might discourage care for individuals with complex and chronic health and disability needs. Special recognition of the high cost of providing care for these people such as funding attached to the individual may be required.

3. Funding of care for young people with needs should support the best local solutions for continuity of holistic care. These might include:

   - Development of adolescent transition services
   - Initiatives within primary care
   - Funding for Paediatric Services to extend to young people up until their 18th birthday, (consistent with Paediatric Specialties Review (PSSR) and the United Nations Convention on the Rights of a Child (UNCROC)
   - Development of adult medicine and adult rehabilitation services with a special interest in young people with high health and disability needs

4. National networks need to be developed to support the complicated needs of young people with complex and chronic health and disability conditions which are frequently rare.

The Paediatric Society of New Zealand recommends to its members:

1. They encourage the establishment of developmentally appropriate systems to support the continuity of holistic care after age of 12 eg: develop adolescent services that focus on the transition to adult services

2. Support networking both nationally and internationally to deliver the best available services for young people with high health and disability support needs.

3. Young people with complex and chronic health and disability needs require a transition plan clearly providing for continuity of care when they have reached the age at which they would otherwise leave Paediatric care: the plan should clearly identify which option is chosen for ongoing holistic care

4. Discharge from paediatrics should not occur until the plan is agreed and operational.

March 2003
Nick Baker
Review: March 2005