

INQUIRY INTO TRANSITION SUPPORT FOR STUDENTS WITH ADDITIONAL OR COMPLEX NEEDS AND THEIR FAMILIES

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Department of Rehabilitation Medicine

Dr. Helen Somerville

Adult Developmental Disability Services

Provider No: 458024F

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Submission from Developmental Disability Clinic Services – Westmead Hospital

The issue of transition for young people with Intellectual Disability and complex health needs has been on the Health and Education agenda for some time.

A transition committee of Agency for Clinical Innovation (ACI – previously GMCT) has been active and the largest group needing additional support at the time of transition is young people with a disability. Survival has very significantly increased in the past two decades so hitherto unseen conditions are now encountered in adult medicine.

Transition co-ordinators in Area Health Services (now local health networks) have greatly assisted with transition to Adult Health Services. However, the adult health system has had significant difficulty responding adequately to the needs of this group. Often adult clinicians have had no exposure during training to many rare disorders of childhood. There is a strong need for specialised and out patient health services to be developed at Adult hospitals. Equally a great deal of liaison, support and training is needed for General Practitioners who have often been underutilised in the paediatric system with the model of case management done by the paediatrician.

Exposure of adult clinicians (medical, nursing, allied health and psychosocial professionals) is still infrequent, so experience may need to be concentrated in a small number of areas with outreach facilities..

Centres of multidisciplinary care for these young people, who often have rare and complex disorders underlying their disability are supported. Further development of school based education, disability and health based clinics is urgently needed. Appropriate supported employment is urgently needed in NSW. Training and support in open employment is scarce. Models of care need to be responsive to new technology (including use of video conferencing for consultations), the increased mobility of young people and the sophisticated (and costly) equipment required.

Western Sydney Local Health Network
ABN 48 702 394 764

Dept Rehabilitation Medicine
Dr. Helen Somerville
Adult Developmental Disability Services
Westmead Hospital
PO Box 533, Wentworthville 2145
Tel (02) 9845 9710 Fax 9633 5952

Access to satisfying work or daily activity and recreational programs remains scarce.

Appropriate accommodation options and financial support to foster independence from the family (when appropriate) and to enhance quality of life are increasingly needed.

A number of interdisciplinary health care models are being developed in Western Sydney and further information can be given if required.

We would be happy to discuss further with the standing Committee.

Helen Somerville
Disability Physician

Jann Capizzi
Clinical Nurse Consultant

A/Prof Ben Marosszeky
Director Area Rehabilitation Medicine.