Submission
No 46

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

Organisation: Greater Metropolitan Clinical Taskforce

Name: Mrs Kate Needham

Position: Executive Director

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greater metropolitan clinical taskforce

2 September 2008

The Director
General Purpose Standing Committee No. 2
Parliament House
Macquarie Street
SYDNEY NSW 2000

Dear Sir

The Greater Metropolitan Clinical Taskforce (GMCT) is pleased to submit the following summary papers on behalf of six of our clinical networks to the General Purpose Standing Committee No 2 for submission to The Program of Appliances for Disabled People (PADP) Inquiry.

- Brain Injury Rehabilitation Network
- Diabetes Network - Diabetic Foot (including supporting letter from Diabetes Australia-NSW)
- Home Enteral Nutrition Network
- Respiratory Network
- Spinal Cord Injury Service Network
- Transition Care for Young People with Chronic Disease Network

A brief background paper is also attached. Further information about GMCT can be obtained from the following website www.health.nsw.gov.au/gmct/

Should you require further information about any of the attached submissions, I can be contacted on Mb: 0412 788 818 or by email to kneedham@nsccahs.health.nsw.gov.au

Yours sincerely

K.A. Needham.

KATE NEEDHAM
Executive Director

Our Ref: GMCT Cover Letter for six submissions to GPSC No 2 PADP Inquiry - August 2008.doc

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General Purpose Standing Committee No 2
The Program of Appliances for Disabled People (PADP) Inquiry

Summary Paper
GMCT Brain Injury Rehabilitation Program

Prepared for: The Greater Metropolitan Clinical Taskforce

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1. Adequacy of funding for present and projected program demand

a. The extent to which the Specialised Equipment Set-up Fund (SESUP) will meet the ongoing needs of people with catastrophic injury is unknown because it has only been in place since July 2008 and there is a finite pool of resources in this fund. It is unclear whether the current allocation will be adequate to meet the need.

b. Follow-up and review (of those patients who received equipment) is delegated to a service provider which needs to find the resources to be able to do this. Service budgets were not designed with the inclusion of this kind of follow up. As a result it may be difficult for some BIRP services with the longer term follow-up, monitoring, and evaluation of the adequacy of equipment beyond the first 6 months that equipment is allocated to a patient.

2. Impact of client waiting lists on other health sectors

a. Long waiting lists have been related to lack of funding available to PADP to meet patient needs. For Brain Injury Rehabilitation Program (BIRP) patients this has meant that equipment has often not been available for them when they have been ready for discharge and subsequently patients have spent long periods in hospital waiting for their equipment. In some cases this has been an unreasonably long time to the extent that the health service has gone ahead and funded the equipment themselves. This has ended up being a financial drain on the health service in the past. Not long ago there was also the occasion where the GMCT - Brain Injury Rehabilitation Directorate provided funding to the metropolitan units for the purpose of purchasing specialised equipment to aid discharge of patients from hospital. While very helpful to these patients it is not a task for which GMCT - Brain Injury Rehabilitation Directorate funding is allocated. In some cases families (of BIRP patients) have bought equipment themselves rather than waiting for equipment to become available from the PADP waiting list.

b. There have examples where a patient receives equipment through PADP but was unable to secure affordable home modifications in a timely manner to support that equipment. It seems that coordination of holistic needs of patients could be improved.

We therefore recommend:

- Enable NSW Review PADP links with schemes such as the home modifications scheme.
- Enable NSW consider PADP partnerships with health providers to take joint responsibility in establishing ways patients can be reviewed and followed up after being issued with equipment. For example, seating clinics or technological aid clinics where PADP may provide some resourcing to these clinics.

3. **Effects of centralising PADP Lodgement Centres and the methods for calculating and implementing financial savings from efficiency recommendations.**
   a. The establishment of Enable NSW which now administers the PADP programme and the allocation of funding to a specialised equipment set-up fund (SESUP) has had a beneficial impact and gone some way to addressing some of the issues outlined above. The pool of dedicated funding for patients in brain injury units which can be accessed to discharge patients from hospital in a timely and efficient manner. Our experience to date is that the set-up fund has been successful in doing this. The set-up fund has been established centrally at Enable NSW and involves the expertise of clinicians who act as state-wide OT advisors to Enable NSW. We have found the centralised system has assisted with consistency in decision-making and more appropriate decision making around applications which are lodged. We have also found the decision making over applications by the set-up fund to be made rapidly and in a timely fashion. In addition we have found the set-up fund to be quite flexible around finding solutions to meet the individual needs of patients.

   b. The system of equipment procurement introduced by Enable NSW. While this may generate cost savings and efficiency there is the danger of shrinking the equipment market and reducing the number of competitive suppliers. This in turn may impact on the extent to which new equipment and developments are brought into the market. This in turn may result in reduced options available to patients, especially when trying to meet specialised, customised and individual needs.

4. **Appropriateness and equity of eligibility recommendations.**
   a. It is our understanding that clients of PADP will be required to make a contribution payment to their equipment based on an assessment of their income. This might disadvantage some patients. People with severe disability need to dedicate their financial resources to multiple things such as equipment, home modifications, therapy, etc. Therefore a person's actual income may not truly reflect a person's ability to pay. A percentage payment contribution also seems to be unfair when you consider that the more disabled person will require more equipment and thus a greater financial contribution.

      We therefore recommend
      - that a fairer system of client contribution be established.

   b. Typically people who are discharged to institutional care have been of lowest priority for PADP and there has been a lot of difficulty in succeeding in getting specialised equipment allocated to them. People with traumatic brain injury who require institutional care tend to be the most severely disabled and sometimes requiring the most specialised and complex equipment. They are in a group most at risk of secondary disability if not provided with such equipment. In our opinion they should not been seen as a low priority and should not be disadvantaged in terms of their equipment needs. Their needs are usually beyond what is reasonable to expect the nursing home to provide. We are not confident that this issue has yet been resolved with the establishment of Enable NSW and the SESUP programme. Patients going into institutional care will not be eligible for access to this programme. It is our understanding that the Young People In Nursing Homes project (YPINH) will have the responsibility of funding equipment needs for people who end up in institutional care. It is of vital importance that PADP and YPINH work closely together to ensure that people in nursing homes are not disadvantaged.

5. **Future departmental responsibility for the PADP**
   a. No comment

6. Other related matter

a. While the establishment of SESUP has been beneficial in providing a pool of funds and a centralised process for submitting applications there are some unintended consequences resulting from the implementation of the PADP review recommendations.

   i. Additional processes and paperwork (intended to improve services) has increased the workload for clinicians making applications. While the formal acquittal and evaluation processes and forms to be completed after equipment has been acquired will improve outcomes it has also significantly increased the amount of paperwork completed by clinicians and hence is a resource issue for BIRP Services.

   ii. The recent establishment of prescribing guidelines requires clinicians to have a certain level of skill and expertise to prescribe certain forms of equipment. While this is desirable it requires service providers to develop and implement staff training and supervision systems that did not exist before. This is having significant resource implications for some BIRP services.

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General Purpose Standing Committee No 2
The Program of Appliances for Disabled People (PADP) Inquiry

Summary Paper
GMCT Endocrine Network: Diabetic Foot

Prepared for: The Greater Metropolitan Clinical Taskforce

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Current problems with the PADP are preventing many people with diabetes at risk of amputation from obtaining suitable protective footwear. The overall number of affected individuals is small in number, however this group are high consumers of health care resources, in particular preventable hospital admissions.

Executive Summary

We propose the following improvements for the provision of footwear and orthoses for people with diabetes:

1. A separate allocation of funding under Enable NSW to provide medical grade footwear and orthoses for those at greatest risk of diabetes-related foot ulceration and amputation. This allocation would need to increase over time, in line with the increasing prevalence of type 2 diabetes.
2. A uniform system of prioritisation that negates the need to attend an outside clinic (such as the current PADP or amputee clinics) for patients who are cared for by a multidisciplinary high risk foot clinic team.
3. Simplification of the system to improve access to available funds.
4. Accreditation for suppliers and prescribers
5. Written guidelines to help prevent the dispensing of inappropriate footwear.

Background

Diabetic Foot Disease is a serious, late complication of diabetes. People with diabetes develop foot ulcers primarily as a consequence of peripheral neuropathy (nerve damage) which causes them to lose pain sensation and injure their feet. Injuries from footwear are the most common cause of ulceration.(Macfarlane and Jeffcoate 1997; McGill, Molyneaux et al. 2005) Peripheral neuropathy is also associated with the development of foot deformity.(Cavanagh, Morag et al. 1997) Once foot ulceration has occurred, the risk of infection and amputation is extremely high. Most amputations are preceded by foot ulceration, hence the need to prevent foot ulceration.(Pecoraro RE, Reiber GE et al. 1990)

In terms of its prevalence, a recent Diabcost survey of 250,000 Australians showed that foot and leg ulcers occurred in 9% of respondents, a 2.5% increase from the previous survey.(Colagiuri S 2003) This prevalence is twice that found in similar European Surveys, T^2ARDIS and Code-2UK in which other diabetic complications were generally lower than the Australian population.(Williams, Van Gaal et al. 2002; Colagiuri S 2003)

Diabetes is the fastest growing chronic disease in Australia, therefore the number of people presenting with diabetic foot complications is rising. There are substantial numbers of people in NSW suffering the complications of the disease at significant cost to themselves and the health budget. The Diabcost study found that the complications were the 'major driver' in health costs associated with Type 2 diabetes.(Colagiuri S 2003) Managing a patient with a foot complications in the Diabetes Centre- Royal Prince Alfred Hospital costs on average $ 3350/year in staff time alone, compared to $488/year for someone with diabetes and no foot ulcer. A US study estimated the cost of treating diabetic patients with foot ulceration to be 5.4 times the cost of treating their diabetic peers with no foot ulceration, with inpatient costs representing 74-77% of the total.(Ramsey SD, Newton K et al. 1999) In-patient costs are of course higher than out-patient costs. In Australia, patients admitted with diabetic foot problems stay longer than those admitted for any other diabetic complication (welfare 2002) and rank second behind Chronic Obstructive Airways Disease as the highest cause of potentially preventable admissions. These hospitalisations are considered preventable with ambulatory care. Despite this, inadequate resources are directed towards the management of diabetic foot disease.

Multidisciplinary care for people with diabetic foot disease provides the best evidence for a reduction in diabetes-related lower limb amputation.(International, Working et al. 2000) In NSW there are several hospitals multidisciplinary foot clinics offering this type of care on an outpatient basis, however the access to medical grade footwear and orthoses (MGF & O) is contributing to high rates of ulcer recurrence. The effect is that the same patients continue to present for treatment of preventable foot ulcers compounding the attendances for treatment. Within the literature, it is well recognised that diabetic foot disease requires secondary prevention strategies such as MGF & O to address recurrence.

Medical Grade Footwear is defined as footwear that meets the therapeutic needs of the patient on the basis that they provide extra depth, multiple fittings and features such as modified soles, fastening and smooth internal linings all designed to protect the foot and minimise injury. Most prescriptions are for off-the-shelf or modified off-the-shelf medical grade footwear, however some patients require custom-made footwear which are made specifically for the individual. Foot orthoses should always be custom moulded for this group of patients and aim to accommodate foot deformity and alleviate pressure over areas of bony deformity.

The International Diabetes Federation's recommendations for the management and prevention of diabetic foot problems include:

- Identification of the foot at risk
- Education of people with diabetes and health care professionals
- **Appropriate footwear**
- Rapid treatment of all foot problems

Guidelines set out by the International Working Group on the Diabetic Foot also recommend that patients with at-risk feet wear protective footwear both at home and outside and that therapeutic shoes and custom moulded orthoses can be used for preventing plantar ulceration in the at-risk diabetic foot.

Two review papers have been written on this topic.
To summarise: There is evidence from observational studies that footwear when provided as part of specialised multidisciplinary care reduces the rate of re-ulceration by 50%.(Maciejewski ML 2004; Williams 2007) This is based on comparing patients who wore their footwear and those that didn't. There is no evidence that providing footwear to low risk patients has any benefit. It is unlikely that a randomised control study can be conducted because it would be unethical to deny footwear to a group for comparison.

Edmonds et al included footwear in their descriptive study aimed at showing the effect of a specialised multidisciplinary diabetic foot clinic on limb survival. Part of the intervention included the provision of medical grade shoes. When they examined the difference between patients who wore their prescribed footwear and those who either did not receive their footwear or failed to wear them (57%), they found that 25% of patients who wore the footwear developed subsequent ulceration compared to 83% of those who didn't. (Edmonds ME 1986)

Dargis et al assessed the role of footwear as part of a multidisciplinary approach to care for people with diabetic foot disease, excluding patients with previous amputation or Charcot's arthropathy (a cause of severe deformity).(Dargis V 1999) Patients had a history of ulceration and were compared to a similar group of patients who received standard care outside the multidisciplinary clinic. The rate of re-ulceration was 30.4% in those who attend the treatment clinic and 58.4% in those receiving standard care at outside clinics.(Dargis V 1999)

In two descriptive studies by Chantelau et al the effect of footwear alone was assessed. Patients who wore their footwear were compared to patients who did not wear their shoes. Both studies found that patients who were non-compliant with their footwear had significantly high rates of re-ulceration than those who wore their shoes.(Chantelau E 1990; Chantelau E 1994)

The goal should be clear. To meet international standards, patients with diabetic foot complications require optimal treatment including footwear to prevent re-ulceration and amputations.

Recommendations

The following improvements to the PADP would improve access to medical grade footwear for people at greatest need:

1. **Separate allocation of funding for people with diabetic foot disease under Enable NSW/PADP.**
   A separate allocation of funding would protect the needs of people with diabetic foot disease who require timely access to Medical Grade Footwear and Orthoses (MGF & O). The optimal window for the provision of MGF&O needs to be determined clinically but occurs around the time of ulcer healing as footwear is used primarily to prevent recurrence. Recurrence commonly occurs in the first 50 days post healing. Within the Eastern Zone of the SSWAHS, the time taken for patients to receive shoes is around 6 months at best. It is not uncommon for patients from other areas to wait 9-12 months.

   The need for footwear to this group will increase over time as the disease is becoming more prevalent.

   In terms of determining the funds required, accurate figures are not available. We estimate that 5% of the diabetic population will need footwear based on the following:

   - The Diabcost survey found 9% of respondents with type 2 diabetes had a foot or leg ulcer and hence would be at high risk of recurrence.
   - Of the patients with diabetic foot complications attending the Diabetes Centre-High Risk Foot Clinic, 60% require medical grade footwear on the basis of having a history of foot ulceration and a foot deformity that makes it unsafe for them to wear regular footwear. Some of these people would be able to pay for the footwear privately. About 60% of our patients require public funding.

2. **Uniform system of prioritisation**
The evidence suggests that NOT everyone with diabetes requires medical grade footwear. Many people can be safely accommodated in regular shoes. Prioritisation should allow for the protection of feet which are at greatest risk of ulceration and amputation.

   - The most potent predictor of ulceration is past foot ulceration. Those patients with a history of foot ulceration are considered at greatest risk and no waiting time should exist for this group as their needs are urgent. Most re-ulcerations occur within 50 days of healing so footwear need to be provided rapidly.

   - Patients with loss of sensation and foot deformity should be eligible to receive footwear. The need is less urgent for this group.

   - The threshold for determining financial disadvantage should be lower given that the cost of footwear is high and that patients are often limited in their capacity to earn an income because of their foot complications.

3. **Simplification of the system to improve access to available funds**
There is no advantage in having patients attend separate outpatient PADP clinics or separate rehabilitation specialists to determine priority. There are guidelines on the use of screening tests to identify loss of sensation which are easy to apply by a range of health professionals including doctors and podiatrists. Determining foot deformity requires clinical judgement and is best assessed by a podiatrist, preferably one with experience in the management of diabetic foot disease as part of a multidisciplinary team. Additional appointments delay access to footwear, adds to the costs in terms of clinician time and increases the complexity of the process for patients. It is not uncommon for patients to fail attendance to PADP appointments due to ill health, becoming 'lost'. These patients are often very unwell and unnecessary appointments are a burden on them and their carers.

   It would be simpler if patients could apply to the scheme for approval and once approved, be able to see the supplier directly. Included with the patients' application form should be:

   - Report from both a doctor and podiatrist indicating the evidence for their risk status on the basis of foot deformity and previous foot ulceration. It would be ideal if this was done by a multidisciplinary foot clinic.
   - The prescription should be from a podiatrist, preferably one working within a multidisciplinary foot clinic with expertise in the management of diabetic foot problems.
   - An estimate of cost from the supplier detailing costs of shoes, orthoses, time in measuring the feet and producing the casts or impressions and projected time to replacement.

   The podiatrists writing the prescription should also be required to assess the footwear prior to the patient wearing them and payment being forwarded to the supplier.

4. **Accreditation for suppliers**
This is a complex issue and one that requires further discussion with the Medical Grade Footwear Association, orthotists, prosthetists, podiatrists and pedorthists, all of whom may have the necessary skills. The Department of Veterans' Affairs and Lifetime Care and Support schemes have both produced some guidelines in this regard but we believe it is time to have a simple process for accrediting suppliers which allows for uniformity across the different schemes under Enable NSW. The accreditation process would also serve to produce a register of suppliers and their work histories. This register would also assist referrers needing to find suitable suppliers.

5. Written Guidelines

There is a large range in the level of skills and expertise within prescribers and suppliers. Some individuals have advanced skills, attained through experience and education (sometimes overseas) who need acknowledgement. Others have poor skills but are still able to accept work. With an absence of accredited courses to provide skills, guidelines need to be developed to assist referrers and prescribers. Guidelines would serve to improve communication between prescribers and suppliers leading to better products being supplied to clients. Currently, there are situations where suppliers do not follow prescriptions. The reasons for this relate to miscommunication but also differences in clinical approach. This is costly and contributes to delays.

Resources need to be allocated to the development of guidelines, disseminating this information through courses and the accrediting of suppliers.

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General Purpose Standing Committee No 2
The Program of Appliances for Disabled People (PADP) Inquiry

Summary Paper
Home Enteral Nutrition Network

Prepared for: The Greater Metropolitan Clinical Taskforce

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Why is GMCT HEN interested in PADP?

PADP provides an important function in keeping people well and independent at home. Home Enteral Nutrition (HEN) is the provision of nutrition support by mouth or feeding tube into the gastrointestinal tract in the home setting. HEN is a safe therapy which can be administered at home provided that patients are supported with clinical care and affordable access to formula and equipment.

The Greater Metropolitan Clinical Taskforce (GMCT), Home Enteral Nutrition Network would like to make a submission to the Legislative Council Inquiry into PADP for the following reasons:

- PADP provides consumables and equipment for tube feeding (but not formula) to people who meet the eligibility criteria. However, there are inequities regarding eligibility.
- People requiring nutritional support at home face a number of difficulties accessing the formula and equipment they need to survive. Patients should not have to wait for access to this equipment, without which they cannot feed themselves. For tube fed patients, this is their sole/major source of nutrition and hydration.
- No other program supports costs of HEN consumables or equipment. HEN formula, consumables and equipment are not covered by any private health fund.
- Many people who require HEN also require other disability equipment and services

Background information and more detail addressing the Inquiry's terms of reference are provided below.

Who needs Home Enteral Nutrition?

HEN patients include those who cannot swallow (eg as a result of neurological disease such as stroke, multiple sclerosis, Parkinson's Disease or head and neck cancer); those who cannot meet their nutritional requirements via their usual diet alone (eg cystic fibrosis, failure to thrive in children, short bowel syndrome), and those who require specialised formulations (eg for dialysis, metabolic conditions).

There are ~12,000 people in NSW receiving HEN (3600 tube fed, 8400 on oral nutrition supplements). The use of HEN is growing at 20% each year

Who is GMCT HEN Network?

GMCT is an advisory body to the Director General of Health and the NSW Minister for Health. The HEN network includes over 250 health professionals working in over 100 NSW public healthcare facilities. The aim of HEN Network is to improve the access and equity to HEN services for all patients across NSW – nourishing lives at home.

The GMCT HEN Network has produced a report on HEN services in NSW and recommendations to NSW Health. The report is available at www.health.nsw.gov.au/gmct. Discussions with NSW Health regarding the recommendations of this report are continuing.

What are Aids to Nutrition?

HEN consumables and equipment are listed under the PADP equipment list under the category of *Aids to Nutrition*. *Aids to Nutrition* assists the individual to maintain adequate nutrition by the provision of equipment for eating, drinking or tube-feeding. This includes nutrition aids such as, but not limited to:

- Specialised or modified equipment for eating and drinking
- All tubes, syringes, pumps, bags, feed sets and adaptors
- Naso-gastric tubing as required when replaced by the consumer's personal carer/s in the home
- Dressings for naso-gastric tubes

Addressing the Terms of Reference

1. **Adequacy of funding for present and projected program demand**
   In 2003/2004, 387 persons received Aids to Nutrition equipment from PADP (60% were children). This accounted for 3% of the PADP budget in 2003/2004 (~$300,000) (Price Waterhouse Coopers Review of PADP, 2006)

   GMCT HEN believes that present funding of PADP (Aids to Nutrition) is inadequate to meet current and future demand for the following reasons:

   - HEN has been growing at 20% per annum. This is due to advances in medicine and technology enabling people to live longer and be treated safely at home. [82% of children and 46.5% of adults receiving HEN have chronic conditions often requiring HEN for prolonged periods/permanently].
   - An audit of HEN patients in 2005 indicated that ~600 patients were receiving /eligible to receive PADP assistance. During focus group interviews, potentially eligible patients were not aware of PADP.
   - The costs of HEN consumables and equipment are expected to increase.
   - Therapeutic Goods Administration regulations recommend that single use devices (such as feeding tube giving sets and containers) should not be reused.

GMCT HEN estimates that the cost of providing HEN consumables and equipment to eligible patients would cost ~$2.5 million per annum (~$300/patient/month). Current expenditure providing 2-3 consumables/week costs ~$65/patient/month

2. **Impact of client waiting lists on other health sectors**
   The right to adequate food is an essential human right. Without affordable access to HEN consumables and equipment HEN patients cannot feed themselves. Patients cannot wait for this equipment. This is the sole source of nutrition for tube fed patients. Currently HEN is not considered a priority in some lodgement centres due to funding restrictions. This causes delays in hospital discharge and families having to pay for this equipment while they await assessment of their eligibility for PADP.

3. **Effects of centralising PADP Lodgement centres and the methods for calculating and implementing financial savings from efficiency recommendations**

GMCT HEN is in support of centralising PADP lodgement centres. Benefits include:

- Standardised criteria to assess need and prioritise access HEN equipment.
- GMCT is in discussions with Enable NSW to centralise the administrative functions for HEN supplies. This will:
    - Reduce administrative burden on clinical staff. Currently, health professionals are expending considerable time organising HEN supplies.
    - Improve contract pricing and reliability of supply for HEN patients with Enable NSW being the major customer.
    - Enable patients to access HEN formula and equipment from the one point of sale.

4. **Appropriateness and equity of eligibility requirements**
The eligibility requirements to access Aids to Nutrition via PADP exclude many HEN patients for the following reasons:

1. Criteria of permanency: Tube feeding is indicated in for patients who need prolonged nutrition support for more than 3 months For example patients receiving treatment for head and neck cancer may require tube feeding for 6-12 months while they undergo treatment. These patients would not be eligible for PADP assistance. The cost of equipment and for tube fed person requiring a feeding pump (excluding formula) is ~$300/month at contract prices (retail price ~$400-550/month).
2. Aids to Nutrition are not covered by private health funds

5. **Future departmental responsibility for PADP**
GMCT HEN believes future departmental responsibility for PADP should sit centrally in EnableNSW within NSW Health Support Services but be responsive to patients in a timely manner to ensure that their individual requirements are met and not subjected to onerous bureaucratic processes that delay access to nutrition.

6. **Any other related matter**
At present HEN formula is paid by patients. A NSW Government contract now enables patients to purchase formula at contract prices. In most other states in Australia a copayment/subsidy model exists to support patients whose formula and equipment costs are unreasonable (eg. over and above the cost of food).

GMCT has recommended that NSW Health consider a copayment model to support those who cannot afford cost of HEN formula and equipment. A single copayment across PADP would simplify the process rather than multiple copayments, as these patients often require a range of other equipment to keep them well at home. Current costs pose a potential risk with patients diluting their feeds and reusing consumables to save on costs.

General Purpose Standing Committee No 2
The Program of Appliances for Disabled People (PADP) Inquiry

Summary Paper
GMCT Respiratory Network

Prepared for: The Greater Metropolitan Clinical Taskforce

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What is the GMCT Respiratory Network?

The GMCT Respiratory Network is a collaboration of 180 members with an interest in thoracic medicine including consumers, administrators, academics and clinicians from all respiratory disciplines across NSW. The Network consists of seven working groups, including a dedicated rural respiratory group, overseen by an executive steering committee. The purpose of the Network is to promote high quality patient care and to improve equity of access to, and outcome from, respiratory medical and sleep disorder services for adult and paediatric respiratory patients across NSW. Following the amalgamation of the Respiratory Chronic Care Advisory Group into the GMCT Respiratory Steering Committee in November 2007, the Network became the principal source of advice to the NSW Department of Health on all clinical issues in the respiratory field.

Why is the GMCT Respiratory Network particularly interested in this inquiry into PADP services?

1. Respiratory clinicians and patients are particularly interested in this inquiry because, unlike many of the disability programs supported by PADP, the nature of the respiratory diseases and conditions that are supported by this scheme are often complex and critical.

2. While EnableNSW was designed to rebalance the inequities and inconsistencies in the current provision of services, no evidence has been provided to demonstrate, under the current centralisation/consolidation plan, that the situation for clients with complex respiratory care needs will improve.

GMCT Respiratory Network's Response to the PADP Review (June 2006) and NSW Government's Recommendations

The *Review of the Program of Appliances for Disabled People* was undertaken for the New South Wales Department of Health by PricewaterhouseCoopers (PWC) in 2005/2006. The Review and accompanying report (July 2006) appears to have provided much of the direction for the NSW Government's activity in this area in the period since its release.

Reforms to PADP services commenced with the transfer of statewide administrative functions managed by the NSW Department of Health to HealthSupport on 6 August 2007, under the new banner of EnableNSW.

The NSW Government released a response to the PWC Review in November 2007.

In December 2007 the GMCT Respiratory Network submitted a response to the Review and the recommendations contained in the NSW Government's response.

Our response made the following points, which constitute the substantive portion of this submission:

- Despite the fact that three of the five programs being recommended for amalgamation are related to respiratory care, the PADP Review focussed on the provision of general PADP services, with only cursory attention paid to programs providing domiciliary oxygen or respiratory equipment. As a consequence the specific needs, processes and difficulties encountered with home oxygen and ventilation programs were not adequately addressed in the report.

- Within the report there is no adequate description or assessment of services pertaining to the provision of domiciliary oxygen, the provision of equipment for home ventilation services (especially non-invasive ventilation) or equipment for the treatment of obstructive sleep apnoea in adults and children.

- There is no discussion of services currently provided, the criteria for referral, the cost of providing services, or any analysis of the level of support required for these services.

- We are particularly concerned about rural clients and the difficulty that they experience in accessing specialist services, assessment and equipment, and again the review has failed to address this issue adequately.

- While some consultation with the Ventilator Dependent Quadriplegic (VDQ) program and the Children's Home Ventilation (CHV) program seems to have been undertaken, it does not appear that the reviewers have appreciated the needs or problems experienced by clients with catastrophic permanent respiratory problems and ventilator dependent clients (eg: people with neuromuscular disorders) who fall outside the VDQ, spinal injuries or CHV program funding criteria.

- There is no recognition of the need to provide increasing number of CPAP machines given the strong evidence of its effectiveness in reducing sleep disorders and possibly cardiovascular disease.

- Adequate funding for respiratory equipment is not currently available, with significant numbers of clients being unable to access necessary or appropriate therapy. The cost of providing respiratory equipment, such as oxygen concentrators, ventilators, suction machines and cough assist devices, in quantities that adequately meets demand is considerable. However an adequate attempt to estimate this demand or cost has not been made.

- Following the separation in 2000-2001 of Oxygen and Respiratory Products from PADP to the various Area Health Services, there was a substantial increase in funding levels to remaining PADP services over the intervening seven year period. In contrast, funding directed to the home oxygen and ventilator programs has remained static, despite increasing level of service demand. This inequity was not addressed in the Review, nor has there been any indication that the situation would be investigated and rebalanced by EnableNSW.

- Tracheostomy

  The issue of tracheostomy equipment for both children and adults has been neglected and has not been clarified since home oxygen and related items were separated from PADP.

  A number of issues need to be addressed:

  1. The medical and financial eligibility criteria for the provision of tracheostomy equipment
  2. Who is responsible for providing this equipment (the treating hospital versus the local hospital)?
  3. An appropriate budget needs to be considered.

  Currently adults and children are being discharged from the treating hospital with very little communication to local hospitals about their on-going tracheostomy needs, but with the expectation that these needs will be met by the local "home oxygen and related equipment" program. Often this does not occur due to lack of communication and lack of resources.

  The cost of tracheostomy equipment ranges from $9,500 to $19,000 per patient per year and the cost of equipment for laryngectomy patients ranges from $5,600 to $9,500 per patient per year. The estimated annual budget required to provide this equipment to patients for the Western Zone of the Sydney South West Area Health Service (SSWAHS-WZ) has been estimated by the Department of Respiratory Medicine at Liverpool Hospital at $450,000. By extrapolation, the cost of a properly funded state-wide program providing tracheostomy equipment would be in the order of five to seven million dollars per annum. At present there is no funding for this service from within Area Health Service budgets. For example, the total budget for 'oxygen and related supplies' for SSWAHS-WZ is currently $180,000, less than half that required to fund tracheostomy equipment alone.

  In short, there is no effective financial provision for the provision of tracheostomy equipment patients who fall outside the Ventilator Dependent Quadiplegics and the Children's Home Ventilation programs. The consequence of this lack of provision is severe hardship for severely disabled people and their families and prolonged periods of hospitalisation for people who are unable to access the equipment they require for home use.

Conclusion

The GMCT Respiratory Network is extremely concerned that for such an important change in service management, appropriate and adequate consultation with the bodies that currently provide these respiratory services was not undertaken by the reviewers in the compilation of this report. Therefore, we believe that the findings of this report and its recommendations are only applicable to general disability services, and are completely inappropriate for home oxygen/ventilation programs.

While EnableNSW was designed to rebalance the inequities and inconsistencies in the current provision of services, there is no evidence that the situation for clients with complex respiratory care needs will improve.

The principles to ensure better management, administration and rationalisation of services under EnableNSW are clearly important and supported, in principle, by the GMCT Respiratory Network.

However, a crucial element missing from the Review, the Government's response, and from current EnableNSW activity, is an understanding of the critical nature of much of the respiratory equipment provided by home oxygen/ventilation programs. While PADP and the Artificial Limb Service provide equipment for disabilities with the primary aim of enhancing quality of life and independence, oxygen and related respiratory equipment provide ongoing medical therapy that is often of a life sustaining nature.

Access to specialist assessment and provision of equipment must occur in a timely and efficient manner with appropriate long term follow up. By attempting to fit oxygen and home ventilation services into the general Enable template, the unique needs and problems facing the respiratory patient, particularly those with complex care needs, will not be addressed.

The GMCT Respiratory Network feels strongly that without a proper assessment and review of the needs and issues specifically related to the provision of oxygen and related equipment, any decision by the Department to reorganise the service and incorporate it into the general Enable scheme will fail, running the risk of further compromising patient care and creating further inequalities and inconsistencies in the service, especially to clients in rural New South Wales or those with complex respiratory care needs.

Representatives from the GMCT Respiratory Network are meeting regularly with the EnableNSW to discuss our concerns and to work with NSW Health in an attempt to develop solutions to these issues.

However, in the absence of a thorough review of home oxygen and ventilation services, appreciation of the current funding inadequacies and appropriate consultation with those in the field, the Network cannot support the PWC Review, the government's response to the Review, nor the current direction of EnableNSW.

Recommendations

Recommendation 1:

That a thorough, substantive review of home oxygen and ventilation/equipment services be undertaken, in conjunction with lead personnel from respiratory departments across NSW.

Recommendation 2:

That a dedicated model of care for these services be drafted in conjunction with lead clinicians in the field and the peak clinical body in respiratory medicine in NSW, the GMCT Respiratory Network. The model should be developed with close reference to medical guidelines for the provision of home oxygen* and domiciliary non-invasive ventilation¥. The model will ultimately share some of the benefits that will be realised through the process of service centralisation and consolidation, but will be flexible enough to provide appropriate local support services at the point of service delivery to patients.

* McDonald CF, Crockett AJ and Young IH. Adult domiciliary oxygen therapy. Position statement of the Thoracic Society of Australia and New Zealand. Medical Journal of Australia 2005; 182: 621–626

¥ Guidelines currently being developed by the GMCT Respiratory Network. First draft to be released for comment in December 2008.

General Purpose Standing Committee No 2
The Program of Appliances for Disabled People (PADP) Inquiry

Summary Paper
NSW State Spinal Cord Injury Service (SSCIS)

Prepared for: The Greater Metropolitan Clinical Taskforce

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Scope and limits of the SSCIS PADP submission

Clinicians and people with a Spinal Cord Injury (SCI) have three primary gaols associated with aides required for daily living: First, to optimise community participation second, to avoid the negative health events that arise as a sequale of a SCI and third, maintenance of good health.

The SSCIS acknowledges that the issues associated with the use of high use low cost PADP items impact significantly upon the SCI population. However, for this inquiry the focus has been placed on high cost, low volume, PADP items such as wheelchairs. This approach does not discount the health issues associated with the supply of disposable items, particularly urinary catheters and continence aides.

The SSCIS clinical teams participated in the 2006 Ministerial Inquiry of PADP conducted by PricewaterhouseCoopers (PWC). This submission draws upon information obtain from specialist clinicians for the PWC review. Clinician participants are acknowledged in appendix A.

The 2006 Ministerial Review and the NSW Government's response to the review address many of the ongoing issues faced by clinical staff and consumers. Should an adequate budget be allocated to the PADP and if the recommendations of the review are implemented many, but not all, of the issues identified in this submission may be addressed.

1. Adequacy of funding for present and projected program demand

Response:

1.1 For clinicians working within the SSCIS service it is apparent that the current budget for PADP is not adequate, particularly for high cost items.

This is demonstrated by:

- Adverse health events due to inability to obtain equipment eg. pressure ulcers and deterioration in posture.
- Long wait lists for equipment reported to be between 4 – 18 months, depending on the locality of the PADP Lodgement Centre.
- High demands on already over stretched loan pools for high cost items whilst people await PADP funding.
- Discharge delays and interruption to treatment regimes due to a client's inability to access PADP funded equipment.
- The frequent inability of PADP centres to provide equipment to clients in Band 4.
- Inability of PADP to consider funding assistive technology devices as funds are overstretched in meeting the more basic equipment needs. This is an important issue for consumers as assistive technology has the potential to facilitate improved community/vocation participation and to promote independence.

1.3 SCI demand projections

SCI incidence rates per million population are currently stable, however the prevalent population will increase due to population increase and increased patient longevity.

SCI projected mean life expectancy is estimated to be 70% of the normal life expectancy for people with complete tetraplegia, 84% for people with complete paraplegia and at least 92% for those with an incomplete lesion. Currently all efforts are focused on further increasing life expectancy and quality of life. It is expected that new clients injured in their twenties and thirties will live for 45 – 50 years post injury.

Whilst a person with SCI has a permanent disability, functional ability will change over an individual's life span. Management of SCI becomes more complex as a client ages as the impact of co-morbidities, neurological decline and overuse syndromes compound existing disabilities. The reliance on higher cost equipment increases significantly as the client's functional independence decreases and disability increases, resulting in the need for PADP to supply additional items such as power wheelchairs, mattresses and hoists.

Increased utilisation of acute health resources for conditions associated with ageing and longevity: The prevalent population experience conditions that temporally alter their level of function for periods of several weeks to many months. This situation is particularly important in the treatment of pressure ulcers, fractures and overuses syndromes when a complex array of equipment is prescribed for medium-term care, community or pre and post hospital recovery. In some cases the level of equipment prescribed will be required on a permanent basis as noted in the above dot point.

Demand can be summarised as, incidence x life expectancy x functional ability x population growth as shown above three of these four factors will increase demand in the SCI population.

2. Impact of client waiting lists on other health sectors

Response: **A brief overview of SCI health issues**

2.1 For people with a spinal cord injury the appliances provided by the PADP are essential for two principal health related reasons.

1) Avoiding acute health care episodes and/or reducing the severity of disease when acute issues arise. Of particular importance are high cost customised items that treat and prevent pressure ulcers and urinary catheters to ensure good genitourinary hygiene and avoidance of urinary tract infection and sepsis.

   Once hospitalised, USA studies have demonstrated length of stays for people with a SCI range from 1.7–2.4 times longer than that of the general population, with a disproportionate burden borne by the younger members of the population particularly in the first few years post discharge. Further, once in hospital the SCI population are particularly susceptible to adverse events, it is therefore essential that all efforts are made to ensure that equipment is allocated in a timely manner to avoid hospital admissions and reduce discharge delays where ever possible.

2) Treatment and prevention of postural abnormalities associated with wheelchairs and wheeled mobility equipment is an essential component of the health care for people with SCI.

2.2 The significant delays from client assessment to the provision of equipment often requires re-assessment and adjustment of the prescription resulting in duplication of work for clinicians and discontinuity of the clinical pathway.

3. Effects of centralising PADP Lodgement Centres and the methods for calculating and implementing financial saving from efficiency recommendation

Response:

Advantages of centralisation:

- Improved equity regardless of locality.
- Improved recognition of the often more specialised nature of equipment required by clients with SCI.
- Utilisation of clinical expertise, which at present is centralised at the three Spinal Cord Injury Units.

Disadvantages of centralisation:

- Potential to disconnect the prescribing process from clinicians and consumers
- If not correctly resourced reduce the responsiveness to clinical needs.
- Difficulty in managing clinical issues, particularly in remote communities.
- A potential to allow business decisions to override clinical priorities,

4. Appropriateness and equity of eligibility requirements

Response:

4.1 Equity would be improved by all clients having to make a reasonable co-payment per annum, regardless of when they started accessing the PADP scheme (clients accessing the scheme prior to 2001 are currently exempt from the co-payment).

Anecdotally it is the experience of clinicians that band 4 clients are disadvantage, and remain on waiting lists for an inappropriate period or do not receive equipment. This situation is made worse by the lack of transparency in the application processes.

The current bands for income tiers require review generally and specifically, examination of the disincentive to employment that significant co-payments has on people who are already disadvantaged in finding employment.

4.2 Access to PADP by people transferred to aged care facilities

From an operational perspective and regardless of current policy, clients with a SCI discharged from the two specialty spinal rehabilitation units to a residential aged care facility such as a nursing home are not provided with their equipment through the Spinal Set-up fund or PADP. This is a significant equity and quality issue and has resulted in regular cases of clients being readmitted to the acute sector with complex and highly expensive complications directly attributable to the lack of suitable equipment. Whilst this issue is associated with a small number of patients it is a clear example of cost shifting between sectors that results in significant cost implications for the NSW Health. Currently the number of SCI clients discharged to aged care facility is less than 5 per annum, as the population ages and experiences more falls resulting in SCI it is anticipated the problem will worsen.

The issues facing people with SCI who are living in aged care facilities can be summarised as follows:

- A person with a SCI may enter an aged care facility at a relatively young age in comparison to the aged population in general. This is due in part to the lack of NSW Government funded personal care packages for those people over 55 years. Generally[1] 65% of the aged care population is older than 80 yrs at the time of admission, with 65% of residents discharged from aged care facilities after 3 years.

[1] http://www.aihw.gov.au/publications/age/raca03-04/raca03-04.pdf web site accessed 6/12/2005 14.00 hours

- People in their late fifties and sixties with a SCI can expect to live for many years, particularly if the injury is incomplete.
- Older people have good rehabilitation outcomes after a SCI.
- Rehabilitation goals will not be maintained without appropriate equipment
- They are not generally cognitively impaired.
- Acute health issues will emerge if equipment for the management of mobility and pressure care is not available.
- People with a SCI residing in aged care facilities will be transferred to a public hospital setting for the management of acute conditions e.g. sepsis, pressure ulcers and for further rehabilitation.

A case example is a nursing home client who developed severe pressure ulcers requiring extensive acute care interventions, involving multiple inpatient admissions, costing an estimated $50,000–$60, 000, due to the lack of a basic initial equipment set up package costing $11,000. Even when nursing home management accepted the need for high cost specialised equipment, funds were sourced from the charitable arm of the organization rather than core budget allocations. This process whilst commendable is tenuous at best.

5. Future departmental Responsibility for the PADP

Given the multiple programs and schemes for the supply of equipment in NSW an important goal is to move to a single point of responsibility and where schemes are administered by different bodies close alignment of eligibility and business processes is important eg. eligibility, prescribing standards and clinical documentation requirements. It the opinion of the SSCIS that the majority of clinicians prescribing equipment are employed by NSW Health and retention and enhancement of NSW Health's responsibility for PADP is logical. Further NSW Health has the capacity, established clinical networks and the operational experience to address important workforce issues, see dot point 6.3.

6. Any other related matters

6.1 It is important to note that whilst an efficiently managed PADP is desirable there is the potential to move costs from the PADP to other sectors of the health budget and this would be counter productive. The lack of timely access to equipment often leads to discharge delays or importantly admissions to hospital. A potential solution is the utilisation of lending pools and lease arrangements with vendors to meet medium term needs or to bridge the gap between the provision of PADP equipment and immediate clinical needs, adding flexibility to the program. The management and funding of equipment loan pools (ELP) needs to be carefully considered to maximise their potential.

6.2 Whilst Area Health Services have ELPs it is the experience of the SSCIS that these services are very variable and are poorly functioning in many Areas. It is also not reasonable, nor possible for an ELP to carry a full range of complex and high cost equipment for the SCI population. This is a significant equity issue for the SSCIS when attempting to provide a statewide service and various methodologies have been tried to address this issue such as utilising equipment provided through donations and fund raising. This situation has been found to be unsustainable and generally unsatisfactory.

Currently when equipment is sourced through alternative methods, such as a hospital loan pool a client's priority on the PADP waiting list may be reduced, as it is perceived that the clinical need has been met and therefore the priority is lower. This is an ineffective strategy as it only delays the need for equipment and reduces the capacity of the lending pool to meet its objectives of timely discharge and prevention of admissions. If an effective ELP were to be considered it would need a strict policy framework including the setting of very clear objectives.

6.3 Workforce issues

Given the cost clinician to conduct client assessments, trials, prescription and acquittal of PADP equipment, workforce issues must be addressed as an integrated component of the PADP.

Currently there are few resources allocated to maximise client and system outcomes through workforce development and there are significant barriers and few enablers for clinicians to attain clinical competency. There is little or no education in undergraduate or post graduate curricula for allied health professionals in NSW for the prescription of wheeled mobility and complex disability equipment. At times this leads to incorrect or repeated prescriptions, increased cost for the system and less than optimal outcomes for consumers. The GMCT State Spinal Cord Injury Service is currently piloting web based education for wheeled mobility topics and developing experiential workshop modules.

Given that many generalist allied health practitioners will infrequently prescribe high cost equipment, attainment of clinical competency is difficult. Creation of a tiered level of prescriber and service, with provision of services occurring in the community, generalist clinics or specialist clinics, determined by the client's needs as assessed against agreed criteria could be an option. This would require a move by allied health staff to a workforce model of sub-specialisation that does not currently exist. Each tier of staff would have access to appropriate education and competency criteria and work within safe boundaries that promote quality decision making (see figure 1).

Client complexity / Need	Community Services	Generalist Clinic Services	Specialist Clinic Services
Simpler	√√√	Consultation	
Intermediate	√ Shared care with generalist	√√√	consultation
Specialised / Complex		√ Shared care with specialist	√√√
Education provider		√	√√√

Figure one: an example of tired model for education and capacity building
(modified from The Scottish Government Health Policy and Strategy Directorate Wheelchair and Seating Modernisation: an Action Plan 2007)

6.4 The development of prescriber guidelines to support clinicians in making efficient prescriptions would be welcomed, as would consideration of accredited prescribers. Including the development of competencies, education and assessment processes essential to ensure high cost equipment prescriptions are clinically valid and prescribed in a cost effective manner.

For rural clients and health professionals access to appropriately qualified practitioners as close to home as possible is an important consideration.

6.5 An appeals mechanism

An independent and transparent appeal mechanism to assess contested applications is required by both consumers and health professionals.

6.6 High cost equipment repair and maintenance

A noted in the 2006 Ministerial Review this is a very important aspect for the PAPD. For people with a SCI a broken wheelchair or other equipment may place them at risk of adverse health events eg. bed rest due to having a broken wheelchair places the consumer at risk of a pressure ulcer and a system to provide timely repair is essential.

An effective information system should enable funding bodies and clinicians to track equipment for the purposes of routine maintenance.

6.7 Reuse of equipment

The reuse of equipment has capacity to improve the amount of equipment available in the Program and an option to link this category of equipment to the ELP. For specialised and customised equipment particularly wheelchairs, there is significant skill required to assess, make good and adapt used equipment for another client and generally this would beyond the scope of all but a specialised service or provider. In many cases the costs of modifying used equipment for another client is finely balance between reuse and replacement and again requires expertise that resides largely with specialist engineers and suppliers working in partnership with allied health practitioners. It is important that the resources allocated to refurbishment do not impede client assessment and prescription.

6.8 The issue of tendering for certain PADP items has been considered in previous PADP reviews. It is reasonable to think there are opportunities for the tendering of items such as electric hoist and electric beds. Limitation exists due to the highly specialised nature of many of the items such as manual wheelchairs, postural supports, power wheelchairs and commode chairs. Further as the market for high cost specialist spinal items is small there is limited scope for vendors to provide the complete range of equipment required in a competitive manner.

Utilisation of service contracts or agreements and business processes such as volume discounts, or preferred suppliers may provide opportunities for efficiencies outside the tender framework. It is also important to note that good relationships exist with existing suppliers of highly specialised goods with significant pro bono arrangements in place that benefit patients, moving to a tender relationship may jeopardise these arrangements to the overall cost of the program. For example very expensive electric wheelchairs are often left on semi permanent loan to the spinal units for trialling by patients. Whilst there is some obvious commercial advantage for the supplier in these arrangements there are also significant clinical benefits associated with the arrangements.

Appendix A

Clinician participation in the 2006 PADP Ministerial Review.
Debbie Croll SSCIS Spinal Outreach Service OT
Michelle Ellis NRAHS OT
Suzanne Johnston GWAHS OT
Dr Bill Fisher NSCCAHS Manager / Biomedical Engineer
Jenny Nicholls SSCIS SPCC POWH OT
Anne Thompson RRCS OT
Sally Oates POWH OT
Dr Stella Engel SSCIS Director, Spinal Staff Specialist & Director Spinal Medicine POWH
Louise McGlade SSCIS SPC RNSH OT
Bronwyn Dalton Hunter rehabilitation Service OT
Jillian Eyles, RRCS /RNSH, PT

greater metropolitan clinical taskforce

GMCT TRANSITION

General Purpose Standing Committee No 2
The Program of Appliances for Disabled People (PADP) Inquiry

Summary Paper
Implications for Young People with Chronic Disease Transitioning from Paediatric to Adult Health Services

Prepared for: The Greater Metropolitan Clinical Taskforce

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Young people with chronic illnesses and disabilities arising in childhood and their parents / carers face many challenges when they transition to adult health services. Accessing equipment through PADP is consistently mentioned by these families as a major hurdle. The majority of these patients have for many years, been cared for by clinicians at one of the three NSW tertiary paediatric hospitals. In most cases, their equipment needs have been expertly determined and provided free of cost and the changes they face when they enter the adult health system comes as a shock when they suddenly face problems both accessing and paying for equipment and services. Many find that they are no longer eligible for much needed equipment that they've been receiving for years. And those who are eligible are competing with a large numbers of adults.

Much of the onus continues to fall on parents and carers as many of the young people are not able to advocate for their own needs. However the adult health system is very much focused on the individual. Parents and carers express a great deal of frustration with the systems and processes they face which tends to sideline their role.

Young people who are referred to the GMCT Transition Network Coordinators for help with the move to adult health services include young people who currently access equipment needs through PADP, those living in group homes who access equipment via DADHC and a small number of compensable patients who are provided for under the new Motor Accidents Authority Lifetime Care and Support Scheme.

The young people most affected by inequity of access to equipment are those with the following needs:

- home ventilation and home oxygen
- enteral nutrition
- wound dressings, particularly young people with epidermylosis bullosa
- those requiring pumps for eg young people with cerebral palsy on intrathecal baclofen and diabetics requiring insulin pumps
- wheelchairs and seating needs
- artificial limbs
- orthotics
- continence aids

Implementation of proposed changes outlined in the Price Waterhouse Coopers 2006 Review document and NSW Health's 2007 response should significantly address many of the concerns expressed to date over inequity in access to equipment, lack of consumer information, difficulties in maintaining and replacing equipment and bureaucracy around application for equipment and referrals when changes are required.

GMCT Background

GMCT has been established to promote clinician and consumer involvement in planning and health service delivery.

We are a relatively autonomous organisation working actively with Area Health Services and reporting to the NSW Minister for Health and to the Director-General of the NSW Department of Health.

The ongoing commitment of GMCT is to improve health care in NSW is based upon the principles of clinical governance with a focus on:

- Developing services based on clinical need
- Quality of care and safety for patients
- Equity of access and equity of outcome within the Hospital System
- Clinician / Consumer driven planning

Through the twenty clinical networks chaired by clinicians and involving doctors, nurses, allied health professionals, scientists, managers, and consumers we identify how and where improvements can be made in the particular specialty and implement these changes in association with NSW Health and the Area Health Services.

These networks have annual recurrent funding with a full time or part time Network Manager. Some of the Networks are well established, having received funding from as early as 2002, and employ a number of staff to carry out the objectives of the Network.

The clinical networks achievements are numerous and significant, and have:

- Brought together clinicians from facilities across the greater metropolitan region and beyond to identify the key issues in that specialty
- Established working groups to develop consensus documents to guide next steps
- Developed collaborative approaches, e.g. standardised assessment and treatment protocols, models of care, benchmarks for services
- Shared staffing and resources across facilities to improve patient access
- Utilised consumers to keep thinking patient-focussed
- Provided staff training in various forms – conferences, seminars, webcasts, study groups and courses in conjunction with tertiary education institutions, opportunities to work in other facilities etc.
- Introduced uniform data collection systems to provide clinicians with data to guide changes in practice
- Facilitated clinical research and the dissemination of results
- Developed patient resources such as booklets, websites, directories, fact sheets, DVDs etc. to ensure that patients and their carers have a good understanding of the issues they face at diagnosis, during treatment and afterwards.

Main concerns

The two main concerns that have been voiced to the Transition network by both clinicians and consumers are:

- Concern that the new eligibility guidelines might exclude many young people with chronic illnesses/disabilities.
- There may not be access to all equipment needed eg pumps, dressings
- There needs to be a system for prioritisation of equipment.

The GMCT Transition Executive would be happy for the above comments to be submitted at the Parliamentary Inquiry and would also be happy to provide more specific information if required.