



13 July 2010

Our Ref: ACI/D10/2502

Disability Care and Support
Productivity Commission
GPO Box 1428
CANBERRA CITY ACT 2601

Re: Key questions for the Productivity Commission into Disability Care and Support

Please find attached responses from nine Clinical Networks of the Agency for Clinical Innovation (ACI). As requested I have provided a brief background about our organisation previously known as the Greater Metropolitan Clinical Taskforce (GMCT).

Background to formation of the ACI

- In 2008, Commissioner Peter Garling SC conducted a Special Commission Inquiry into Acute Care Services in NSW Public Hospitals. He proposed the establishment of a "Clinical Innovation and Enhancement Agency" that should use the GMCT's "existing clinical network model to involve clinicians and patient representations in continuous clinical redesign to deliver safer and better patient care".
- In response, the NSW Government released "Caring Together: the Health Action Plan for NSW" and the NSW Agency for Clinical Innovation (ACI) was established in late 2009.
- The ACI became a statutory body in January 2010 with the following core functions:
 - Identify, review and where appropriate, modify or enhance, or research and prepare standard evidence-based clinical protocols or models of care to reduce clinical variation and enhance and improve the effectiveness, safety and cost-effectiveness of patient care.
 - Support Area Health Services in ensuring the implementation of those standard evidence-based clinical protocols or models of care.
 - Investigate, identify, design, cost and recommend for implementation on a state-wide basis, changes in clinical practice, including the content and method of such practice to reduce inappropriate clinical variation and enhance and improve the effectiveness, safety and cost-effectiveness of patient care.
 - Support clinical networks, taskforces and clinical practice groups to assist in undertaking the Agencies functions and involve patients, carers, and other members of the community.
 - Provide advice to the Department of Health and public health organisations.
- To date, 22 Clinical Networks have been established.

- The ACI works closely with other NSW Government and non-government organisations including NSW Area Health Services, NSW Department of Health, the Bureau for Health Information (BHI), Clinical Excellence Commission (CEC), Cancer Institute NSW, Institute for Rural Clinical Services and Teaching, the Institute of Medical Education and Training (IMET) and the Ambulance Service of NSW.

Should you require further information the Network Manager's details are included in the footer of each submission.

Kind regards

HUNTER WATT
Chief Executive

Australian Government – Productivity Commission

Disability Care and Support

The Agency for Clinical Innovation (ACI) Home Enteral Nutrition (HEN) Network welcomes the Australian Government's Productivity Commission's Inquiry into long term disability care and support.

The ACI HEN Network would like to include for consideration the need for equitable access to HEN services as part of disability care and support services.

Home Enteral Nutrition (HEN) is used when adults and children cannot eat or cannot eat enough to meet their nutrition needs to survive. Specialised nutritional formula is given via a feeding tube or as a supplement drink and can be administered in the home setting.

Who is eligible?

People who require HEN are a particular group needing a more equitable system. For people requiring HEN and long term disability care and support, HEN is often required for a lifetime. HEN enables people to "eat" and "drink" at home.

What core services are needed and how should they be delivered

There is a need for equitable access to HEN services as part of disability care and support services. This includes both access to clinical care, formula and the equipment to deliver the formula eg feeding tubes and devices, consumables and feeding pumps.

Funding

Access to HEN services varies across Australia with some states providing full or partial subsidy whereas others do not. A national approach is needed for equity. HEN is currently on the Australian Health Ministers Advisory Council agenda to discuss a National HEN scheme.

A co-payment model is used in many overseas countries and in some Australian states. This co-payment is often set at the average weekly cost of food. Costs of HEN above this co-payment level are subsidised by government.

Feedback : Disability Care and Support Productivity Commission

- The National Pain Strategy, the recommendations of the National Pain Summit (March 2010) have been agreed by stakeholders in the management of chronic pain. This document primary reference for best practice, evidence based models of care for the management of chronic pain considered by the Disability Care and Support Productivity Commission. www.painsummit.org.au
- Due to the high volume of people who require the services, there is limited access for public patients in NSW to access tertiary hospital pain management clinics in NSW.
- Not all tertiary hospital pain management clinics have recurrent funding.
- There are currently no 'community care / self management programs' available for patients who have chronic pain.
- Models, like the community care program in Scotland should be explored to provide care to people with persistent pain.

Feedback: Productivity Commission Disability Care & Support Issues Paper:

- There are a great number of people with chronic diseases who do not fall within the traditional scope of Disability Care and Support Services. However, these people may be severely disabled due to conditions which progressively worsen such as heart failure, chronic obstructive pulmonary disease and osteoarthritis. As the number of elderly people in the population increases, there will be a corresponding rise in the number of people affected by chronic conditions and consideration needs to be given to this group to prevent unnecessary readmissions to acute services.
- Transport is a big issue for many patients particularly those living in rural areas. There are a number of barriers which restrict access to transport (and therefore services) including cost, service schedule and the mobility (or lack thereof) of the person.
- Disability Care and Support services need to develop strategies to address the young, long-term disabled for example people with stroke, brain and spinal injuries who may need ongoing supported accommodation for 50 years or longer. Nursing homes are not appropriate for these populations.
- There are often delays in discharge relating to obtaining equipment in a timely manner. A model which facilitates access to equipment which is adequately funded is required. There is a disparity between the provision of even basic equipment and variation in the allocation of the equipment budget between Area Health Services which results in inequity of access and potentially poorer outcomes for patients.
- In many areas of Sydney there are not enough occupational therapists to carry out home assessments.
- Families and carers often bear the burden of responsibility of caring for their disabled relatives. Without this significant, ongoing support there would be greater demand on government resources. Therefore, it is imperative to support carers in their role and provide respite on a regular basis.
- A comprehensive, web-based, state-wide information system linking both acute and community services would address some of the coordination and duplication issues that currently exist.

DISABILITY CARE AND SUPPORT PRODUCTIVITY COMMISSION – THE KEY QUESTIONS

SECTION	COMMENTS
<p>1. IMPROVING THE SYSTEM</p>	
<p>The features of a new long-term disability care and support scheme, based on experiences as a service provider</p>	<p>Equity of access, accessible and sustainable</p>
<p>2. WHO SHOULD BE ELIGIBLE?</p>	
<p>a) Who should be in the new scheme and how could they be practically and reliably identified? b) Which groups are most in need of additional support and help? c) What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?</p>	<p>a) Enable is currently involved in disability support. Mental Health NGOs such as Schizophrenia Fellowship of NSW, Mental Health Association of NSW, Assoc of Relatives and Friends with mental illness (ARAFMI) b) The amputees from diabetes and those who require appropriate footwear. Mental illness patients who require carers for ADLs. c) Develop a standardised needs assessment so that they can be assessed on a case by case basis.</p>
<p>3. WHO GETS THE POWER?</p>	

<p>a) How could people with disabilities or their carers have more power to make their own decisions?</p> <p>b) How should the amount of financial support and service entitlements of people be decided (and by whom)?</p>	<p>a) By being actively involved in the development of the scheme and possibly having an interactive session / forum / website in which comments can be left and answered.</p> <p>b) This should be decided by a peak body but there may be no other way than by application with a series of boxes indicating need. This of course requires a certain amount of transparency so that the forms cannot be manipulated.</p>
<p>4. WHAT SERVICES ARE NEEDED AND HOW SHOULD THEY BE DELIVERED?</p> <p>a) What kinds of services particularly need to be increased or created?</p> <p>b) How could the ways in which services are delivered be improved?</p> <p>c) Are there ways of intervening early to get improved outcomes over people's lifetimes?</p> <p>d) How could a new scheme encourage the full participation by people with disability and their carers in the community and work?</p> <p>e) How can a new system ensure that any good aspects of current approaches are preserved?</p> <p>f) What should be done in rural and remote areas where</p>	<p>a) Services for those that have been disabled by severe lower limb infection / amputation such as footwear be supplied in a quicker fashion than is currently.</p> <p>b)</p> <p>c) Screening tools for preventable disabilities such as diabetic foot disease could be completed.</p> <p>d) A new scheme could see the involvement of people from an early stage that way they could experience the advantages a new system would have.</p> <p>e) It could be possible to survey / web access the current users and see what the common themes are for the good aspects.</p> <p>f) Potentially use the National Broadband Network for rural and remote to ensure they have</p>

it is harder to get services?	access to the latest technology.
5. FUNDING	
<p>a) How should a new scheme be financed?</p> <p>b) How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?</p>	
6. ORGANISING AND IMPLEMENTING A NEW DISABILITY POLICY	
<p>a) What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?</p> <p>b) How long would be needed to start a new scheme, and what should happen in the interim?</p>	<p>a) There would obviously be a requirement for an overarching body that monitors the scheme and funding. Perhaps more consumers could be involved in this.</p>
7. OTHER IDEAS FOR A GOOD SCHEME	

DISABILITY CARE AND SUPPORT PRODUCTIVITY COMMISSION – THE KEY QUESTIONS

SECTION	COMMENTS
<p>1. IMPROVING THE SYSTEM</p> <p>The features of a new long-term disability care and support scheme, based on experiences as a service provider</p>	<p>An essential feature of a new long-term disability care and support scheme should include the development of a national disease register devoted to improving the quality of care and outcome for people affected by stroke.</p> <p>The Australian Stroke Clinical Registry (AuSCR) was established in November 2008 under the guidance of a consortium of partners, including the Stroke Society of Australasia, The National Stroke Foundation, The National Stroke Research Foundation, the George Institute of International Health.</p> <p>AUSCR is supported by an unconditional educational grant from ALLERGAN Australia and funding from the Australian Commission on Safety and Quality in Health Care. Pilot phase commenced in June 2009</p>
<p>2. WHO SHOULD BE ELIGIBLE?</p> <p>a) Who should be in the new scheme and how could they be practically and reliably identified?</p> <p>b) Which groups are most in need of additional support and help?</p>	<p>All people discharged with a diagnosis of stroke from public and private hospitals funded by state and federal health services. Utilise AuSCR to track the patients at discharge</p> <p>All people discharged with a diagnosis of stroke from public and private hospitals</p>

Agency for Clinical Innovation
Stroke Network

<p>c) What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?</p>	<p>The recognition that stroke is the greatest cause of adult disability in Australia. Approx 88 per cent of stroke survivors live at home and most have a disability. Reference AIHW: Senes S 2006. How we manage stroke in Australia.</p>
<p>3. WHO GETS THE POWER?</p>	
<p>a) How could people with disabilities or their carers have more power to make their own decisions? b) How should the amount of financial support and service entitlements of people be decided (and by whom)?</p>	<p>Being appointed as consumers on organisations (e.g. National Stroke Foundation, Stroke Recovery Association of New South Wales (NSW) and clinical networks (e.g. Agency for Clinical Innovation-Stroke Service NSW)</p>
<p>4. WHAT SERVICES ARE NEEDED AND HOW SHOULD THEY BE DELIVERED?</p>	
<p>a) What kinds of services particularly need to be increased or created? b) How could the ways in which services are delivered be improved? c) Are there ways of intervening early to get improved outcomes over people's lifetimes?</p>	<p>In NSW greater emphasis needs to be focused on the development of metropolitan stroke rehabilitation services. In rural NSW funding for allied health, medical and nursing workforce with a directed focus on outpatient and community based stroke specific services would facilitate the current network of 11 rurally based stroke services</p> <p>Audit and evaluation. The National Stroke Foundation currently undertakes a 2nd yearly cycle of national audit for acute and post acute (rehabilitation services), the results are reported to clinical networks and state health services indicating the gaps in service based on patient outcomes</p> <p>Utilise the data obtained from AuSCR to:</p> <ul style="list-style-type: none"> ➤ ensure that patients and families affected by stroke receive the best possible care

Agency for Clinical Innovation
Stroke Network

<p>d) How could a new scheme encourage the full participation by people with disability and their carers in the community and work?</p> <p>e) How can a new system ensure that any good aspects of current approaches are preserved?</p> <p>f) What should be done in rural and remote areas where it is harder to get services?</p>	<ul style="list-style-type: none"> ➤ improve rehabilitation outcomes ➤ improve acute treatment and care in hospitals ➤ increase opportunities to prevent stroke for occurring ➤ improve the chances of recovery after stroke <p>Utilise all media processes to ensure that all communities especially those from Culturally and Linguistically Diverse (CALD) background are informed of national stroke information e.g. FAST community education program</p> <p>Audit and evaluation at a national and state health service level</p> <p>Clinical networks should be empowered by state and federal health services by appropriate funding allocations to provide community specific (e.g. indigenous, CALD) education to:</p> <ul style="list-style-type: none"> ➤ ensure that patients and families affected by stroke receive the best possible care ➤ improve rehabilitation outcomes ➤ improve acute treatment and care in hospitals ➤ increase opportunities to prevent stroke for occurring ➤ improve the chances of recovery after stroke
<p>5. FUNDING</p>	
<p>a) How should a new scheme be financed?</p> <p>b) How can it be ensured that there is enough money to deliver the services that are needed and provide greater</p>	<p>Utilise the knowledge of clinicians and consumers form clinical networks to engage with state health services to deliver and evaluate funding to ensure the sustainability of service</p>

certainty about adequate care in the future?	provision
<p>6. ORGANISING AND IMPLEMENTING A NEW DISABILITY POLICY</p> <p>a) What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?</p> <p>b) How long would be needed to start a new scheme, and what should happen in the interim?</p>	<p>Essential ingredient in the development of a disability policy is removing the state verses federal funding models that create barriers within local health services.</p>
<p>7. OTHER IDEAS FOR A GOOD SCHEME</p>	<p>Utilise knowledge from state based clinical networks to inform state health departments of gaps in service. Cross reference information across all states to inform national bodies to lobby state and federal health departments e.g. Australian Stroke Coalition www.strokefoundation.com.au</p>

**DISABILITY CARE AND SUPPORT
PRODUCTIVITY COMMISSION – THE KEY QUESTIONS**

SECTION	COMMENTS
<p>1. IMPROVING THE SYSTEM</p> <p>The features of a new long-term disability care and support scheme, based on experiences as a service provider</p>	<p>A scheme should:</p> <ul style="list-style-type: none"> • capture everyone who is eligible - school based services ensure all children are assessed and treated and is an excellent way of capturing the majority • ensure continuity of care so that young people do not fall through the gaps once they leave paediatric care – again school based services allow for planning to establish links based on trust and long term relationships • provide equity of access • be easy to understand, so that people with disabilities, parents and carers are able to follow the process • be goal orientated and evidence based • be universal so that if people move from one state to another they are able to have continuity of service • involve and respect families and have simple, clear communication processes with other services • Provide a multidisciplinary model of care
<p>2. WHO SHOULD BE ELIGIBLE?</p> <p>a) Who should be in the new scheme and how could they be practically and reliably identified?</p>	<ul style="list-style-type: none"> • People with new and existing disabilities should be able to access the scheme. • In the paediatric population all young people identified by their paediatrician or

Agency for Clinical Innovation
Transition Care Network

<p>General Practitioner as having a chronic illness / disability arising in childhood that is likely to continue into adult life should be eligible.</p> <ul style="list-style-type: none"> • Those with moderate to severe disability should have priority as they consistently miss out. It can be argued that those with mild disability should also be included as they may benefit more from support that may allow them to work productively and live independent lives but they should not be the priority as they already have better access to services. • This is frequently not the case for young adults with Autism Spectrum Disorder. Those with "normal" intelligence are not eligible for ADHC support and the majority of funding has been and continues to be allocated to early intervention in the 0-5 years of life. Those who need mental health input are particularly disadvantaged. • There could be two main stages for identification – eg paediatricians and GPs could be the main assessors for children. Young adults could be practically and reliably identified by paediatric treating teams at the time of transfer to adult health services • Young adults with severe / profound disabilities reliant on aging carers – urgent need for respite care and supported accommodation • Those who have a mental health condition as co-morbidity as few services exist who can manage behavioural issues and main stream mental health services do not accept responsibility for young people with intellectual disability. • Centralise the process and criteria – use a modified ACAT type assessment. At the moment the same departments eg ADHC offer different services depending on where you live and how well they are resourced in your area. There are too many different government departments involved and too much overlap at state and federal level. 	<p>b) Which groups are most in need of additional support and help?</p> <p>c) What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?</p>
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3. WHO GETS THE POWER?	
<p>a) How could people with disabilities or their carers have more power to make their own decisions?</p> <p>b) How should the amount of financial support and service entitlements of people be decided (and by whom)?</p>	<ul style="list-style-type: none"> • When feasible, people with mild to moderate disability should be allocated some funds to control themselves as long as there are checks and balances to ensure the vulnerable are protected and the money is spent as intended. Desire and ability to control their own funds could be part of an assessment made as part of a comprehensive transition plan prior to leaving paediatric services. • There should be the capacity for people with disabilities and their carers to change service providers and have a complaints mechanism. People stay where they are as they are afraid of making waves and losing the service that they have even when they are not happy with it. • Funding cycles for respite programs, post-school and community options disrupt service provision and create uncertainty for young people and their carers. • Provision of a designated case manager for ongoing support should be mandatory. Currently ADHC Case Management is either on an occasions of service basis or for a specific task. In reality this means that support is only available for crisis situations with the "loudest barrels" getting timely access and those who show restraint having to wait until it really is a crisis. • For those with severe/ profound disability, a designated guardian should be appointed again with checks and balances to make sure the money is spent as intended • There should be a standard scale linked to a national assessment tool (modified ACAT type form) that will determine the amount of financial support and service entitlements of people.

<ul style="list-style-type: none"> Models of care could be developed that set out the standard of care required for each person. Data from the current Third Party Compensation Scheme used to calculate projected funding costs could be a basis for this. Alternatively a formula for each condition/disability may be used to calculate funding needs. ADHC data undoubtedly contains much information about current cost of managing patients with disabilities. This would have to be done by agencies with no vested interest in provision of disability services. 	
<p>4. THE MAIN ASPECTS OF ANY SYSTEM</p> <p>a) Power: Who makes the decisions? b) Supply: Mainstream and specialist providers, people's choices c) Scope: Who gets it? What? How long for? How much? d) Financing: Financing methods?</p>	<p>a) One Gov't Department rather than many Gov't Departments? b) People's choices. Use brokerage system similar to that in the UK. c) Who: see above. How long: for life How much: \$1000000 question d) Insurance scheme similar to Medicare using a 1.5% levy on income, collected by the ATO and distributed to state body for further distribution or alternatively distributed by the Commonwealth directly to those registered for the scheme.</p>
<p>5. WHAT SERVICES ARE NEEDED AND HOW SHOULD THEY BE DELIVERED?</p>	
<p>a) What kinds of services particularly need to be increased or created?</p>	<ul style="list-style-type: none"> Transition services are needed in every Area Health Service to support young people to engage with adult services. There is also a lack of therapists, case workers and access to mental health services in adult health facilities Lifetime care programs to prepare young people with chronic illnesses and disabilities leaving paediatric care need to be created. Programs such as <i>Gillette Lifetime Care</i>, <i>Bloorview Kids rehab Good2Go Program</i> and <i>the Gateway Project</i> in Toronto Canada. There is limited focus currently in paediatric centres on encouraging independent living skills. There is an urgent need for appropriate supported living facilities for young people

<p>b) How could the ways in which services are delivered be improved?</p> <p>c) Are there ways of intervening early to get improved outcomes over people's lifetimes?</p>	<p>with disabilities who require 'nursing home' type care and palliative care facilities tailored for young people – similar to Bear Cottage at Manly in Sydney but for young adults aged 18-30.</p> <ul style="list-style-type: none"> • Urgent need for review of training and supply of Orthotists and Disability Dentistry Clinics accredited to provide treatment assisted by sedation or general anaesthetic. • Greater coordination / case management and a centralised system is needed – currently many patients receive support from numerous non-government and government agencies who all believe they are the only service providers. This leads to duplication of services and shortfall in funding for those individuals who do not know how to "shop" for services. • Delivery of a service to young people with a chronic illness or disability needs to be accessible, goal orientated and evidence based. It needs to involve and respect families and have clear communication processes with other services • Smooth transition from child centred services to adult services needs to cover all areas such as health, education, work, housing options, respite options • Delivery of care needs to be streamlined to ensure families have clearer pathways and support systems in place. • Families should play an integral role in goal setting and decision making. • All services to cover the patient from diagnosis until death. For this group of patients this may well be from birth to death. Models of care based on this principle are already being developed in NSW for those with intellectual disability. (Kogarah model) • Concerns for these families with mobility, finance, transport, time and energy are key factors in increasing the difficulty they experience accessing service delivery. • There is often a lack of knowledge about health services and lack of clarity regarding interagency management of young people
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<ul style="list-style-type: none"> • Paediatrics is well supported until the young person reaches late adolescence. The problems really start once they leave paediatric care. Transition planning is increasingly being shown to provide long term solutions for young people with chronic illnesses. Transition clinics for conditions such as diabetes, spina bifida, cerebral palsy improve health and social outcomes. The NSW GMCT/ACI Transition Care Network is a relatively low cost model (< 600K/ annum) as is the State - wide Spina Bifida Adult Resource Team (SBART) (210K/ annum) that has in one year of operation connected 185 young people to adult services who had not previously been connected or who had fallen through the gaps. This early intervention approach potentially saves hundreds of thousands per year in preventable admissions through early detection and treatment of shunt problems, renal complications and pressure areas • Allowing early planning for out-of-home care for young people with disabilities. The current system does not have the capacity for carers to plan what will happen when they no longer can care for their disabled son/daughter/relative. This is an enormous source of anxiety to families and carers. The ADHC policy preventing placement planning before it is a necessity does not allow for active involvement by carers in the decision making. • By empowering young people and their carers by increasing available options and asking families about their day to day needs • Making education, community options and employment more accessible. • Improvements with accessibility to transport, funding and support services • By looking closely at current initiatives to see if they are evidenced based and if so how strong the evidence is for continuing them. For those where evidence is lacking, carry out audits and satisfaction surveys and make decisions based on individual community needs 	<p>d) How could a new scheme encourage the full participation by people with disability and their carers in the community and work?</p> <p>e) How can a new system ensure that any good aspects of current approaches are preserved?</p>
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<p>f) What should be done in rural and remote areas where it is harder to get services?</p> <p>g) How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?</p>	<ul style="list-style-type: none"> • Fund existing services such as the rural hubs of the Spastic Centre and Northcott Disability Services to allow them to expand their intake criteria to include a broader range of disabilities. • Fund health services to broaden the number of specialist visits from metropolitan health services who visit regional centres to help monitor and maintain the health of people with chronic illness to prevent adverse incidents. Eg. No endocrinologist visit Dubbo except only for diabetes. Other diseases like thyroid, Turner Syndrome need monitoring and blood tests locally. <p>g) A new system would need to be centralised in order to stop overlapping of services. The ACI Transition Care Program uses a system of referral which requires one intake process. Active issues are addressed immediately and when a solution has been reached the patient's file is inactivated rather than discharged. This negates the need for subsequent intake calls, intake assessments and case planning meetings. Reactivation of the referral can occur at behest of the patient, their carers or the clinicians or services involved in management. Past history is not lost, assessment not duplicated and continuity ensured. Only those issues that are no longer working satisfactorily are addressed and hence the response and resolution for activated patients occur in a timely manner.</p>
<p>6. FUNDING</p>	
<p>g) How should a new scheme be financed? h) How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?</p>	<p>See above – 1.5% Disability Insurance Scheme Levy similar to Medicare The creation of a "future fund" where unspent revenue can be placed an invested for future use.</p>

<p>7. ORGANISING AND IMPLEMENTING A NEW DISABILITY POLICY</p>	
<p>i) What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically? j) How long would be needed to start a new scheme, and what should happen in the interim?</p>	<p>Pilot program should be conducted in metropolitan and rural areas to test the feasibility of the program</p>
<p>8. OTHER IDEAS FOR A GOOD SCHEME</p>	
	<p>Take the best aspects of existing schemes such as Lifetime Care, the Sydney West Community Comprehensive Assessment form and the ACAT system and apply them to meet the needs of younger age groups</p>

DISABILITY CARE AND SUPPORT PRODUCTIVITY COMMISSION – THE KEY QUESTIONS

SECTION	COMMENTS
<p>1. IMPROVING THE SYSTEM</p> <p>The features of a new long-term disability care and support scheme, based on experiences as a service provider</p>	<p>The ACI Respiratory Network is pleased to submit the attached proposal, A New Model of Care for patients requiring Home Non-Invasive Ventilation (NIV) Services in NSW, the product of broad consultation with respiratory clinicians and clinical teams with an interest in this field across NSW.</p> <p>The proposal addresses the current inadequacies and inequities in home NIV services in NSW and provides recommendations on efficient and sustainable improvements to those services.</p> <p>The proposal describes a model of care involving one 'Centralised Agency' (EnableNSW) responsible for the provision of:</p> <ul style="list-style-type: none"> a) all government funded domiciliary ventilation equipment, and b) a state-wide database and information management system including capacity for the management of both equipment and clinical/patient-related data. <p>Operating in conjunction with the Central Agency is a hub and spoke network of clinical services featuring:</p> <ul style="list-style-type: none"> a) 'Specialised Hubs' with adequate resources, expertise and sufficient critical mass to assess and commence patients with complex disease on non-invasive ventilation, b) 'Level 2 Agencies' with resources, expertise and critical mass to commence less complex patients on NIV and share in the continued management of complex patients, and c) 'Level 3 Assessment' and monitoring nodes providing regular monitoring services for patients who have difficulty accessing medical services due to their medical condition or geographical isolation.

2. WHO SHOULD BE ELIGIBLE?	
<p>a) Who should be in the new scheme and how could they be practically and reliably identified?</p>	<p>See Recommendation 42 in attached Model of Care proposal (p.39)</p> <p>The following process for obtaining government funded domiciliary NIV equipment in NSW is recommended:</p> <ul style="list-style-type: none"> i) If, based on standardised clinical and eligibility guidelines, a patient appears to satisfy requirements and is deemed potentially eligible for publicly funded equipment, the Central Agency should give tentative approval for the provision of equipment for an initial, short-term (usually 2 - 3 months) compliance period. Tentative approval should be obtainable via telephone discussion between a senior clinician (or recognised local support officer) and Central Agency staff. Equipment should be delivered to the patient within 24 hours of such approval. [The patient is responsible for the purchase of ventilator tubing and masks]. ii) The prescribing clinician (through the local support officer) would then use standardised forms on the online information management system to lodge a formal application for long term equipment provision. iii) The prescribing clinician would use the online information management system to document standard patient clinical information and equipment prescription information. iv) On receipt of the loan equipment the prescribing clinician would commence the patient on NIV. Equipment settings would be recorded in the online information management system. v) Review appointments are made, based on standardised guidelines, and recorded in the information management system. vi) A review of the patient's clinical condition, equipment needs and machine compliance is conducted at the first review appointment. Data form review is entered into the information management system. vii) If the patient demonstrates adequate compliance, and approval for long term ventilation is given by the Central Agency, the patient continues to use their current

	<p>loan machine.</p> <p>[Should the patient require a less sophisticated machine, a more appropriate machine is ordered and provided. All details are recorded in the information management system.]</p>
<p>b) Which groups are most in need of additional support and help?</p>	<p>See attached Model of Care proposal - Section 1.1.2 (p.3): Why is non-invasive ventilation required?</p> <p>There are many conditions which can cause a patient to under-breathe to the point where their oxygen levels fall and carbon dioxide levels rise, causing respiratory failure. This can be the result of respiratory muscle weakness, alterations in the chemical control of the breathing centres or abnormalities of the chest wall and lungs. General examples of disorders include patients with neuromuscular disorders (such as Duchene Muscular Dystrophy, Spinal Muscular Atrophy, Motor Neurone Disease), spinal cord injury, chest wall deformities, lung disease (such as cystic fibrosis or chronic obstructive pulmonary disease (COPD)), obesity hypoventilation syndrome, congenital breathing abnormalities and breathing problems resulting from catastrophic illness (such as brainstem tumours or trauma).</p> <p>To ameliorate the patient's under-breathing the most common and cost effective way is to treat the patient with an external mechanical breathing machine (ventilator), either through an invasive route (e.g. tube placed in their windpipe) or non-invasive route (e.g. mask placed firmly over the patient's nose and/or mouth). Although long term invasive ventilation is the only solution in certain circumstances, where ventilation can be safely managed non-invasively, this should be encouraged as it is preferred over invasive ventilation for safety, reducing infections and airway trauma, convenience, comfort, speech, swallowing, sleep, appearance and cost^(3, 4). Non-invasive ventilation (NIV), the provision of ventilatory assistance without an invasive airway, has assumed an important role in the therapy of respiratory failure in both acute and chronic settings⁽⁶⁾.</p>
<p>c) What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?</p>	<p>See attached Model of Care proposal</p>

<p>3. WHO GETS THE POWER?</p>	<p>a) How could people with disabilities or their carers have more power to make their own decisions?</p> <p>b) How should the amount of financial support and service entitlements of people be decided (and by whom)?</p>	<ul style="list-style-type: none"> • Provision of a comprehensive, web-based, patient information management and medical records system. The system would be available to the patient and all in the patient's multi-disciplinary team, via a secure password-protected portal. • Provision of clear and concise patient information sheets.
<p>4. WHAT SERVICES ARE NEEDED AND HOW SHOULD THEY BE DELIVERED?</p>	<p>a) What kinds of services particularly need to be increased or created?</p> <p>b) How could the ways in which services are delivered be improved?</p> <p>c) Are there ways of intervening early to get improved outcomes over people's lifetimes?</p> <p>d) How could a new scheme encourage the full participation by people with disability and their carers in the community and work?</p> <p>e) How can a new system ensure that any good aspects of current approaches are preserved?</p>	<ul style="list-style-type: none"> • Home Non-Invasive Ventilation Services • Services for oxygen and related equipment <p>See attached model of care proposal</p>

<p>f) What should be done in rural and remote areas where it is harder to get services?</p>	<p>See attached Model of Care proposal. Particular attention has been given to the requirements of patients who have difficulty accessing medical services due to their medical condition or geographical isolation.</p>
<p>5. FUNDING</p>	
<p>a) How should a new scheme be financed?</p>	
<p>b) How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?</p>	
<p>6. ORGANISING AND IMPLEMENTING A NEW DISABILITY POLICY</p>	
<p>a) What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?</p>	
<p>b) How long would be needed to start a new scheme, and what should happen in the interim?</p>	
<p>7. OTHER IDEAS FOR A GOOD SCHEME</p>	

DISABILITY CARE AND SUPPORT PRODUCTIVITY COMMISSION – THE KEY QUESTIONS

SECTION	COMMENTS
<p>1. IMPROVING THE SYSTEM</p> <p>The features of a new long-term disability care and support scheme, based on experiences as a service provider</p>	<p>1. The Brain injury Rehabilitation Directorate (BIRD) has experience working with the Life Time Care and Support Authority (LTCS A) for treatment, rehabilitation and care of people injured in a motor vehicle accident (MVA). NSW Health has a fee for service arrangement for payment of services provided to LTCS participants that applies to the NSW Brain Injury Rehabilitation Program (BIRP). This is a network of 14 units providing inpatient specialist rehabilitation, transitional living and community outreach services for children, young people and adults with severe traumatic brain injury (TBI). MVAs account for approximately 60% of statewide admissions.</p> <ul style="list-style-type: none"> • The LTCS provides a structure that could potentially be adapted for a broader range of people with acquired disability • The fee for service arrangement has limitations <ul style="list-style-type: none"> ○ Not all of the services being provided are included in the fees schedule ○ There is no flow back arrangement of revenue to the service provider (eg NSW BIRP) to ensure sustainability and growth of service delivery ○ There has been no growth of the specialist TBI health sector to meet participant needs (eg alternatives to employment, initiatives for addressing social inclusion problems, management of behaviour that cannot be met within existing networks etc) ○ There is no pathway for support of non clinical services (eg research, education, service development) by access to capital funds or seeding grants to establish new service initiatives until they can be included on a fee for service basis ○ The disability service sector is not included in the fee for service arrangement. ○ There is limited awareness of fee recovery for private paying participants and how this may achieve service delivery growth

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- The LTCSA has established a goal based planning approach for approving intervention that does not readily adapt to maintaining rehabilitation outcomes for those living with a disability. People with severe disability are more likely to be Centrelink recipients and have less income to manage the financial burden of disability in addition to cost of living eg gym membership for cognitive and psychosocial benefits
- The LTCS does not include provision or payment of accommodation as there is an underlying assumption that people have their own place to live (own or rent) that can be modified. Peak incidence for TBI is children and adults 15-24yrs so the result is increased burden on family to provide accommodation. Applications for Department of Housing can be delayed as properties are not available even when priority has been established. Challenging behaviours can develop for people with TBI / Acquired Brain Injury (ABI) while living in inappropriate housing and/or away from social networks.
- The LTCS limits financial and service support to families (eg counselling services, residential respite, family holidays, wage) who choose to provide family care instead of seeking external care arrangements for the LTCS participant

2. Until recently, people in NSW with acquired brain injury were not a target group for service delivery in the disability sector. The Stronger Together Disability Plan is providing a framework for improving access and equity of service delivery.

However there remains a lack of appropriate service delivery models and there is limited flexibility in how services are provided and funded to meet individual needs for children, young people and adults after an ABI/TBI. Service delivery is not planned and provided based on client need. Instead a provider is funded to provide a type of service that will suit the majority of people/ target group. There are limited programs to bridge these gaps (eg brokerage funds) which could provide more flexible client centred models of service delivery.

3. Other issues include a lack of supported accommodation with peers and a lack of recurrent support hours for a person with high care and support needs who wishes to live in the community either alone or with family. Care and support needs above 35 hours per week generally require informal support from family or admission to a shared living arrangement. This is usually to an aged care facility and sometimes to an ADHC funded or supported

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	<p>accommodation service that is not ABI aware and might be located away from the social networks of the person.</p> <p>4. The NSW BIRP has opportunity for clients to be readmitted at times of changing needs over the life span of the client. This enables health and community services to work together.</p>
<p>2. WHO SHOULD BE ELIGIBLE?</p> <p>a) Who should be in the new scheme and how could they be practically and reliably identified?</p> <p>b) Which groups are most in need of additional support and help?</p>	<p>a) Members of the NSW BIRP support equity of access for people with traumatic and acquired brain injury with and without compensation to access the services they need at the level of assessed need for the length of time it is required.</p> <ul style="list-style-type: none"> • The LTCS operates with interim and permanent participants. A permanent participant meets entry criteria for injury severity (for TBI, Spinal, burns, complex amputation/loss of sight) and permanent disability) at 2 years post injury assessed on standardised measures of outcome. People who exit the LTCS have generally improved or have a level of disability that does not require daily care (i.e. can be managed within generic health and disability services). • NSW Health would generally be involved with all disabled children young people and adults at the initial exit point and referral to the disability service system. The LTCS has an application form that could form the basis of entry to the scheme. Information could be provided to NSW Health discharge planners (etc) and speciality services (eg NSW BIRP) to develop a pathway into the Scheme. <p>b) In the NSW BIRP the clients who are in most need of additional support and help are those who</p> <ul style="list-style-type: none"> • Live in rural and remote areas of NSW and are unable to access the services they need in their local community • Have challenging behaviour that cannot be managed within current resources and who require increased hours for support staff, education and training of family, carers and community to manage behaviour appropriately over time. Inappropriate living arrangements may promote challenging behaviour and alternative positive community living arrangements are often not available • People with ABI/TBI who are not working and have no meaningful alternatives are often socially isolated and vulnerable .They may be at risk of involvement with the

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<p>c) What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?</p>	<p>criminal justice system</p> <ul style="list-style-type: none"> • People with ABI/TBI and co-morbidities (mental health and drug and alcohol most evident) • People with ABI who are working age and are unable to access specialist rehabilitation to maximise recovery and establish service networks to meet changing needs (eg stroke, brain cancer patients, people with hypoxia, infections) • People with ABI/TBI and their families who have no insight into service needs. <p>c) The insurance model (eg LTCS) provides a framework for assessing level of disability, promoting early intervention and individual planning for determining access to services and support including regular reviews at times of change/development.</p> <p>There would be a number of key characteristics common to all people with disability that can be addressed through interagency collaboration eg access to rehabilitation, access to housing and support, access to education and employment and availability of a range of service types to meet different/changing needs. This may require MoU's and service level agreements.</p> <p>There would need to be involvement of the client and family/extended family and clinicians in decision making to ensure that there is a match between what is desired and what is reasonable for the planned outcomes</p> <p>There would need to be an open and accountable process with an independent dispute management process</p> <p>There would need to be education about the Scheme (implementation and recurrent) and information for new participants/families/service providers.</p> <p>The NSW BIRP and LTCS utilise the Care and Needs Scale (CANS) to provide a profile for understanding level of need (area of disability) and level of support (type of assistance and intensity). Different government and non government agencies use different standardised measures. This knowledge then needs to be translated into client service plans or be used by the agency to assess admission criteria or program entry.</p>
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3. WHO GETS THE POWER?	
<p>a) How could people with disabilities or their carers have more power to make their own decisions?</p>	<ul style="list-style-type: none"> • Utilise a client centred approach to planning services that involves family/friends. The client is the central decision maker (parents for a child, person responsible or a formal guardian if capacity an issue or conflict arises). • Split the planning of services from the approving of services (eg LTCS has a de facto role in overriding a client's decision because LTCS approves payment). This would help to avoid the situation where the client only requests what they know will be approved rather than what they feel they really need. • Provide support/alternative options for decisions that fall outside the scheme eg where the family would prefer to manage care and support without the intrusiveness of paid carers in their home. • Assess the family's ability to provide a positive environment for the client and ask what they need to achieve this goal. • Provide a range of different service delivery options so people have choices about what services they use and can move between services if they are unhappy for any reason.
<p>b) How should the amount of financial support and service entitlements of people be decided (and by whom)?</p>	<p>Australia has adopted international obligations on the rights of people with disability. These would form the core entitlements and be established and funded by the Commonwealth for implementation by the State.</p> <p>The operation of how each State manages may remain part of COAG or be separate. It may have some aspect/s additional to COAG. The fee for service arrangement for insurance is an example. Disability insurance funds could be used for specific aspects of care arrangements while the COAG agreement provides baseline funding across different service types.</p> <p>There could be a Commonwealth allowance made for reducing the additional financial burden of different aspects of disability (replace single programs such as an incontinence program or transport allowance) so the Centrelink payment is made at a, base rate then uses a sliding scale of disability costs eg 1-7 where 7 is for people with 24/7 care and support needs.</p> <p>NSW currently has a service system in place that identifies needs and provides options for</p>

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	<p>program access. However, many of these services lack capacity for new clients or clients with different needs.</p>
<p>4. WHAT SERVICES ARE NEEDED AND HOW SHOULD THEY BE DELIVERED?</p> <p>a) What kinds of services particularly need to be increased or created?</p> <p>b) How could the ways in which services are delivered be improved?</p> <p>c) Are there ways of intervening early to get improved outcomes over people's lifetimes?</p> <p>d) How could a new scheme encourage the full participation by people with disability and their carers in the community and work?</p> <p>e) How can a new system ensure that any good aspects of current approaches are preserved?</p>	<p>a) There are a number of models of care and service types that are appropriate. The issue is availability and lack of options while waiting for services to be available. Waiting lists are not encouraged so the size of unmet need is not evident.</p> <p>b) Increased coordination and a consistent approach across different services are required. More information is needed for consumers about what is available (eg NSW ADHC moving towards a single service access point). Service types are in silos so there is a lack of knowledge about what others provide. Services are generally block funded and not individual client funded so there is a barrier to movement between services/ changing services to meet changing needs as clients can't take the program \$'s with them. Services with individual \$'s usually can't be managed by the client/family but require an agency to be involved. The \$ value is reduced by agency management fees. Knowledge of the agency about the disability and what is needed / wanted can be limited when they are not familiar with the target group.</p> <p>c) The NSW BIRP has early intervention as a key principal to maximise spontaneous recovery and the multi/intra disciplinary approach to the client, their family and environment reduces activity limitations and achieves social participation.</p> <p>d)</p> <p>e)</p>

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<p>f) What should be done in rural and remote areas where it is harder to get services?</p>	<p>f) The BIRD remote and indigenous ABI service delivery project has identified that building on existing local networks and developing trust with aboriginal people and their communities is important for improving service access. Developing interagency collaboration, improving community awareness, communication and liaison as part of an identified service can build service capacity and improve client outcomes. Access to brokerage funds and flexibility in use can reduce barriers for the individual (eg transport, paying client and carer for travel)</p>
<p>5. FUNDING</p>	
<p>a) How should a new scheme be financed? b) How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?</p>	<p>It is really exciting that disability services is moving from a charity or welfare culture to the integration of the needs of people with disability into a rights based framework with statutory entitlements and accountability. A number of options are reasonable.</p> <ul style="list-style-type: none"> • % of GDP • A Medicare levy • An industry levy • Insurance policies eg attached to private health maternity benefits, home insurance policies, extension of the no fault motor vehicle accident insurance to off road/sports injuries etc <p>Identification of funding strategies is integral to meeting the needs of people with disability. Quarantining all or some of funds generated for this purpose would require the establishment of special committees or Authorities (eg LTCS). It is important that these committees are independent with actuarial services and financial advisors that involve clinicians, consumers and service providers. It is important that these committees have a reporting role across government and treasury.</p>

<p>6. ORGANISING AND IMPLEMENTING A NEW DISABILITY POLICY</p>	
<p>a) What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?</p> <p>b) How long would be needed to start a new scheme, and what should happen in the interim?</p>	<p>a) There is a need to establish the organisational and financial structures before implementing a scheme. Having a start date for a new scheme provides time to prepare and educate the public, recruit workers and lease office space etc. The LTCS may have lessons learned that could assist implementation.</p> <ul style="list-style-type: none"> • There would be a need to identify if people currently living with disability and their carers will be included or excluded from the new scheme and if they will have transition arrangements to provide equity with new scheme participants. • The new scheme would need a positive community image to minimise sensationalist reporting. LTCS may have lessons learned for how this can be achieved. <p>b) The establishment of governance to manage the process, state based implementation committees and working parties and a timeframe for transition change management are required.</p> <p>The LTCS operated for some time before introducing the scheme for children in 2006 and for adults in 2007. Some adjustments to the legislation were subsequently required and obtained. Consultation about the changes took place as internal systems were introduced.</p> <p>Given the number of branches of government and non government agencies currently involved in the disability sector it would be hard to identify all programs, plan for new services, provide infrastructure for new services and implement all changes at the same time. A staged approach would be required.</p> <p>Questions about building on existing state disability networks or establishing a separate service system need to be answered. Will existing service providers be part of the Scheme? What new professions if any will be required to staff new/additional disability services? How will funding be provided to services and will there be individual funding opportunities?</p>

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7. OTHER IDEAS FOR A GOOD SCHEME	
Initial implementation funds to upgrade current service systems	<p>In NSW the BIRP was initially provided with capital funds to build the infrastructure required for the new program. Recurrent funds were initially quarantined for service development. This did not occur with the introduction of the LTCS. The increased demands were added to the existing network with fee for service only. NSW BIRP funds were no longer quarantined and no revenue flow back arrangement was in place to manage the increasing demand. It would be a similar situation for a new disability scheme if capital funds were not introduced into the ailing sector. A strategy to manage infrastructure development should be considered as part of the implementation and reorganisation of services</p>

DISABILITY CARE AND SUPPORT PRODUCTIVITY COMMISSION – THE KEY QUESTIONS

SECTION	COMMENTS
<p>1. IMPROVING THE SYSTEM</p> <p>The features of a new long-term disability care and support scheme, based on experiences as a service provider</p>	<p>The scheme should have a method of undertaking objective assessments of impairment / core activity limitations, eligibility criteria that is not too restrictive nor discriminatory, not means tested but with ability for co-payments, should allow income, incentives for participation in work, community participation and recreation, have a periodic review/reassessment.</p>
<p>2. WHO SHOULD BE ELIGIBLE?</p> <p>a) Who should be in the new scheme and how could they be practically and reliably identified?</p> <p>b) Which groups are most in need of additional support and help?</p> <p>c) What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?</p>	<p>Those with core activity limitations, especially those with severe or profound core activity limitations.</p> <p>Those with long term disability. An interim eligibility period eg 2 years, would be supported with a reassessment every 2 years for a period, eg 10yrs and then at longer intervals.</p> <p>Have an objective and valid method of assessing impairment (eg Functional Independence Measure, FIM) with other recognised tools to assess ability to participate in domestic and community activities.</p>
<p>3. WHO GETS THE POWER?</p>	

<p>a) How could people with disabilities or their carers have more power to make their own decisions?</p> <p>b) How should the amount of financial support and service entitlements of people be decided (and by whom)?</p>	<p>The Scheme Authority should make decisions regarding eligibility but there must also be an appeals process.</p> <p>Support (financial and other) needs should be based on the outcome / findings of the objective assessment of impairment.</p>
<p>4. WHAT SERVICES ARE NEEDED AND HOW SHOULD THEY BE DELIVERED?</p>	
<p>a) What kinds of services particularly need to be increased or created?</p>	<p>Services which provide timely response to the eligible client's needs. Currently those in need are placed on a waiting list, often waiting for extended periods to receive the service.</p>
<p>b) How could the ways in which services are delivered be improved?</p>	<p>Reduction in extensive waiting times for specialised equipment and assistive technology which is currently the case in the state-based services. Timely prescription and supply of the equipment once the person is deemed eligible is essential.</p>
<p>c) Are there ways of intervening early to get improved outcomes over people's lifetimes?</p>	<p>Timely and objective assessment of their abilities & capabilities, followed by support, and vocational and education advice services to help guide the person with a disability of the options and opportunities available to them. The underlying philosophy should be that of encouraging independence and community participation. General community education focussing on acceptance and inclusion of people with disabilities and recognition & support of their abilities rather than their disabilities</p>
<p>d) How could a new scheme encourage the full participation by people with disability and their carers in the community and work?</p>	<p>Evaluation of current services prior to implementation of new services / program.</p>
<p>e) How can a new system ensure that any good aspects of current approaches are preserved?</p>	<p>Implementation of specialist outreach program such as the NSW Spinal Outreach Service</p>
<p>f) What should be done in rural and remote areas where</p>	

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<p>it is harder to get services?</p>	<p>with local contact person / representative (eg Spinal Cord Injury Rural Service), possibly funded similarly to the Medical Specialist Outreach Assistance Program (MSOAP)</p>
<p>5. FUNDING</p>	
<p>a) How should a new scheme be financed?</p>	<p>Through an increase in the Medicare levy.</p>
<p>b) How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?</p>	<p>Costing models similar to those used for the NSW Lifetime Care Support Scheme could be used. The funding and support needs for individuals would need to include their unique needs for equipment, support, care determined through the objective assessments of impairment, and ability to participate in domestic and community activities. Entitlements should be needs based with service provision based on available resources. However, these resources need to be adequate to provide timely services.</p>
<p>6. ORGANISING AND IMPLEMENTING A NEW DISABILITY POLICY</p>	
<p>a) What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?</p>	<p>Much could be modelled on the implementation of the NSW Lifetime Care Support Scheme in NSW.</p>
<p>b) How long would be needed to start a new scheme, and what should happen in the interim?</p>	<p>The scheme should commence with people with new profound activity limitations, then to all people with profound activity limitations and finally those with severe limitations if / when resources become available.</p>
<p>7. OTHER IDEAS FOR A GOOD SCHEME</p>	