Submission to the Disability Care and Support Inquiry - Productivity Commission Issues Paper
16 August 2010

About ARW

Australian RehabWorks ('ARW') is a recognised leading provider of Neurological Rehabilitation Services in the Australian Health Industry.

Our community-based rehabilitation practice has been operating for over 14 years in the management and treatment of neurological injuries and disabilities.

We attach our brochure which gives more information about the range of our service offerings.

We specialise in providing multi-disciplinary treatment services to those with acquired and traumatic brain injuries and spinal cord injuries who have long-term disabilities and have thus been actively involved in providing services to participants of the Lifetime Care & Support Scheme ('LTCS'). We have recently made a submission to, and given evidence on, this scheme to the New South Wales Standing Committee on Law and Justice.

Accordingly we are well-qualified to make a submission on the proposed Disability Care and Support Scheme (DCS). Our prime concern is with patient support and welfare and not with the economics of the scheme. We have therefore confined our comments to matters within our expertise and experience.

We feel that submissions from us as a service provider, and as one of the few allied health professionals to be sufficiently concerned so as to be involved in this project , should play an important role in the planning for this project.

Executive Summary

ARW has been providing treatment and rehabilitation services to patients with neurological disability for the past 14 years. Since the inception of the LTCS scheme, we have been actively involved in providing treatment services to those in the scheme with traumatic brain injury and spinal cord injury.

Even though the LTCS scheme has only been in operation for about three years, it commendably puts the participant first and enables health professionals, such as ourselves, to get on with the job of looking after the participant- without extraneous considerations. Once a satisfactory plan has been agreed upon by all relevant stakeholders, neither the participant nor their carers or service providers need be concerned with extraneous issues such as litigation or compensation claims. This frees the participant from any concern with non- health considerations. The participant and their carers and service providers are then solely concerned with medical and rehabilitation issues. The participant and their carers want proper care and support, the bills to be paid and their future secure.

The LTCS scheme is therefore a reasonable starting point for how a national scheme might operate.

We fully support extending the national scheme to all long-term serious disability sufferers particularly those who at the present time do not have any access to treatment and rehabilitation services, thus ensuring that anybody with a serious disability will have their treatment and rehabilitation needs met.

Long-term participant care, support and rehabilitation should be the sole or main objective of the scheme.

Answers to the Key Questions.

Although the Issues Paper is necessarily long and detailed the "key questions" are set out in section 2 at pages 5 -6 There are 15 key questions and we briefly comment on each of them, except question 13 which relates to "finance".

1. Who Should Be the Key Focus?

The long-term disabled and their carers should be the key focus of the new scheme, as it is of the LTCS scheme, which is a suitable model and starting point for the new scheme. As mentioned on page 11 of the Paper, the LTCS scheme is restricted to specified meeting the treatment care and rehabilitation needs of those with a catastrophic injury of major severity in New South Wales from motor vehicle accidents. It is tempting to restrict the new scheme to only those who are not covered by other schemes or systems. However this will result in further multiplying the number of schemes, sources and systems which already exist and which, by their very nature and restrictions, pose enormous problems of access – which is the subject of question 5 and a focal point of the Paper.

Inadequate attention is given to the needs of carers under existing schemes and this is recognized in the Paper at pages 9, 10, 11 & 18.

In a recent book by Dr Ken Hillman entitled "Vital Signs" the following very perceptive passage appears at pages 252 -- 253 in relation to the strain experienced by carers after their patient has been discharged from the intensive care unit (ICU), very often suffering from post traumatic stress disorder (PTSD).

"Whether or not a former patient has full-blown PTSD, the burden on the family can be overwhelming. Many are now locked into constant care for this physically damaged and emotionally disturbed person, who, even without brain damage, is significantly changed and tormented by nightmares and delusions, the source of which the victim cannot locate. Relatives, whose lives may have been put on hold while they conducted vigils at the bedside, often for weeks or months now, have to deal with a different challenge – a person different from the pre-illness one with all kinds of issues that cannot be managed with machines and drugs.

The ex-patient often needs continuous attention for reasons which are different from those arising during the hospital stay, and it is the relatives who usually have to provide that care, with little support or understanding, even from doctors – many of whom are not familiar with what happens to patients after being in an ICU.

The health system supports the infinite needs of intensive care – expensive machines and drugs, and dedicated staff 24 hours a day seven days a week; but the same system does not fund the post-hospital follow-up, relatively minor in terms of cost by comparison and just as important to the patients and their carers."

We do not believe the over 65's should be excluded from this scheme given that the population in Australia is aging, people are living longer and there is high prevalence of stroke and other disabling diseases that occur in the over 65's.

2. Groups in Need of Additional Support?

The main groups we feel that are in need of additional support are those patients and their carers not currently covered by any third party scheme or program, thus relying on self-funding (if able) or public services which are, in our experience, over-burdened and have long waiting lists, to have their needs met.

3. Kinds of Services to Be Increased or Created?

We believe based on our extensive experience as allied health professionals that treatment, care and rehabilitation services need to be provided early on following an injury or disability as well as funding for equipment, home modifications, respite services and most importantly, community access and leisure activities.

4. Early Intervention?

Early intervention for treatment and rehabilitation services is shown to be the most effective in reducing long-term disability. Therefore, we strongly support that treatment and rehabilitative services commence either just prior to a person's discharge if they have been hospitalised or once they return back to their home and community to ensure the best possible long-term outcomes.

General practitioners and other medical and community institutions should be educated as to how and where to refer their patients for early intervention treatment.

5. Participation?

In our experience the main problem with all current systems is a lack of knowledge and information about them. Patients and their carers will be only too happy to rush in for help once they become aware of what services and systems are available.

Education to the major hospitals and secondary medical facilities will increase the awareness of what services are available.

In addition, general practitioners and community health centres should also be provided with knowledge and education about how to access treatment and rehabilitation services for their clients.

6. **Power**?

The system must be patient oriented and put the patient first. This can be achieved by legislating priorities and/or by a code of conduct.

The patient and their families should be given wide powers to appeal against any unacceptable decision as is possible under the LTCS scheme where there is a system for handling disputes that can be initiated by any party.

The relevant principles of administrative law and of independent mediation are well-known and well established. They should be implemented, once priorities have been established and clearly defined.

7. **Improved Service Delivery**?

Our experience has been that the LTCS scheme has come a long way since it started due to their open and consultative approach to information sharing as well as continuous improvement activities such as free workshops, education sessions and working parties to ensure that all of their systems and processes are time-efficient, user-friendly and environmentally conscious. Lessons can be learnt from the progress and success of that scheme in relation to all relevant factors such as coordination, cost, timeliness and innovation.

8. **How Much Support?**

In dealing with the LTCS scheme, the coordinator is in consultation with the case manager who we believe should be the primary decision-maker, but subject to rights of appeal to independent persons as referred to in question 6 above.

9. **Preserve the Good**?

All current successful schemes such as LTCS, Transport Accident Commission ('TAC') in Victoria and the New Zealand system should be examined in detail and the best features of each system should be incorporated into the new scheme to ensure that appropriate lessons are learnt.

10. **Rural and Remote Areas**?

Obviously more money and resources will need to be spent on rural and remote areas particularly resources for training and education as well as mentoring to increase the skill-base of local health professionals.

Funding for these activities will need to be factored into the national scheme.

11. **Reducing Unfairness?**

As indicated above, this is of the very essence of the new national scheme. The best features of all current schemes, such as LTCS, the TAC and the New Zealand system should be taken up and made available to all those who presently miss out.

12. Reducing Waste?

As the LTCS scheme has evolved, unnecessary paperwork and duplication have been reduced by all necessary forms being delivered and submitted electronically, thus reducing the necessity for paper.

Any new national scheme should pick up the best of all current schemes and try to avoid some of the problems of the past.

CONCLUSION

ARW has been fortunate to work closely and extensively in providing treatment and rehabilitation services to participants of the LTCS scheme. In addition we have been fortunate to provide treatment and rehabilitation services to other third party schemes, including the CTP and Workers Compensation system in New South Wales.

We believe the model of the LTCS scheme provides the best possible platform for provision of services to those included in the criteria, being traumatic brain injury and spinal cord injury.

We would like to see a national scheme that would take the best parts of schemes that have been proven to be effective, such as LTCS, the TAC and the New Zealand scheme to include coverage for those with many forms of disability within Australia.

We support early intervention for treatment and rehabilitation services as well as funding for home modifications, equipment, leisure and respite services.

We are happy to elaborate on any aspect of this submission and to present at any public hearing and give evidence, when appropriate.

Yours sincerely,
Australian RehabWorks P/L

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