**QUEENSLAND PAEDIATRIC REHABILITATION SERVICE**

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Queensland Government

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Communities, Disability Services,
and Domestic Violence Prevention Committee.
Parliament House
Brisbane.4000

Dear Committee Members,

**Re: Inquiry into a suitable model for the implementation of the National Injury Insurance Scheme (NIIS)**

Thank you for the opportunity to respond to the parliamentary inquiry into a suitable model for the implementation of the National Injury Insurance Scheme in Queensland. Queensland Paediatric Rehabilitation Service (QPRS) is the state-wide service for acute and long term care of children with Acquired Brain or Spinal Cord Injuries, Limb Deficiencies and Congenital Spinal Cord impairments. Our client group include children who have suffered catastrophic Traumatic Brain Injuries and Spinal Cord Injuries in the course of road traffic accidents (RTA')s. QPRS is based at the Lady Cilento Children's Hospital at which site acute Rehabilitation Services are provided as well as outpatient specialist rehabilitation services. QPRS also provides outreach services to major regional centres within Queensland to support both families and health care providers within their local communities. QPRS was established in 1995 and currently has approximately 100 patients receiving inpatient or outpatient care for their RTA related brain injury. There are a further 180 patients with Traumatic Brain Injury due to other mechanisms who are currently receiving care from QPRS. It is our practice that QPRS teams provide ongoing support for the child and family until such time that they leave formal education. The patients are then supported through the transition process to adult services. QPRS teams are allocated for each patient with a severe or catastrophic injury who liaises closely with local community providers including staff from health, education and social services to optimise outcomes for the child following discharge from hospital. We therefore are well positioned to address the question of how best to support young people with "Severe or Profound core activity limitation" as described in the National Disability Strategy.

We therefore, as significant stakeholders in the provision of services for this patient group are grateful for the opportunity to document our thoughts and concerns with regards to these very important changes.

Firstly QPRS fully supports the implementation of a no-fault Lifetime Care and Support Scheme (LTCSS) for all people catastrophically injured in road traffic accidents (RTA) in Queensland. A support scheme that provides individualised lifelong funding such as currently in place in Victoria will enable the providers to focus on optimising outcomes for the catastrophically injured individual over the course of their life time. The overarching goals of the rehabilitation process include optimising independence, supporting opportunities for participation particularly in developmentally/age appropriate activities such as school attendance and vocational placements whilst also putting in place required environmental modifications. We, at QPRS recognise that the current resource rationing approach in place in Queensland is associated with significant barriers to achieving optimal outcomes in a timely fashion for our severely injured patients. This is very evident during the phase of home modification, school liaison and equipment purchase as the patient and their families are undergoing enormous upheaval and psychosocial adjustment. QPRS submit the view that it is highly preferable that unspecified hybrid common law claims do not impact on the provision of the Lifetime Care provision. Under the TAC scheme, seriously injured persons are entitled to pursue a lump sum settlement for economic loss and pain and suffering, but not future care, as care and support are funded on a lifelong basis by the TAC. Additionally, those unable to establish another's fault in causation of their injury are entitled to receive a 'no-fault' lump sum impairment benefit up to the value of $333,630. Whereas adoption of similar entitlements in Queensland would enhance opportunities for choice and control for seriously injured persons, there are many complicating issues to consider when deliberating whether lump-sum payments are beneficial.

QPRS have several concerns regarding the retention of "one-off" lump sum payments for patients with catastrophic brain injuries. These concerns include:

- Prior to settlement for patients with a CTP claim in the current Queensland system, the provision of services for clients is based on an "as needed" basis with the recommendations provided by specialist clinicians in conjunction with the CTP case manager. As there is a process of continual review in place the service provision is optimised and cost effective. The process of clinical review and justification of ongoing provision of services prevents misuse of available funds whilst ensuring the needs of the child are being met in spite of financial or psycho-social challenges faced by the family. The families of the clients are supported in their decision making by QPRS team members and their CTP case manager whilst being confident that their child's essential health, psychosocial and educational needs will be met.

  The importance of supported decision making during childhood, adolescence and the young adult years cannot be underestimated as many families have great difficulty in adjusting their family function in order to promote independence in the young person who has sustained a catastrophic brain injury. These patients are often non-verbal or have severe communication impairments that impact on their ability to express their wishes to be more independent. It is frequently only with multidisciplinary support that their wishes can be identified and addressed. *Families who have been provided with a lump sum* in our experience are less likely to recognise the needs and desires of an adolescent or young adult to socialise with age appropriate peers, explore leisure activities and as much as possible be independent with their activities of daily living which in the case of a profound impairment may be basic personal self-cares such as having choice when to have a shower.

- Additionally there is a significantly increased vulnerability to mental health issues including anxiety, depression and substance abuse following Traumatic Brain Injury which is evident both in the adolescent population and well documented in the adult population. In our experience where families have settled early, (thus receiving a lump sum payment) programs to support the child with socialisation, recreation, respite and counselling are often ceased, resulting in increased potential for diminished independence and subsequently mental health problems. Further, for young people with executive dysfunction (impulsivity, poor attention, poor insight) and mental health issues (majority of catastrophic TBI patients) capacity to manage finances and their health is diminished therefore requiring the lump sum to be managed by others (trustee, family). QPRS submit the view that "one-off" financial settlements, although theoretically allowing independence and flexibility, in fact, are not the best way to achieve optimal long term outcomes for vulnerable patients with potentially long term adjustment and mental health issues.

- A further significant concern related to lump sum pay-outs is the increasing costs and complexity of organising and providing modified equipment and aides. It is extremely difficult for families to predict their needs and therefore manage funds for a child (who may be 30kg and easily manageable with one parent for dressing and transfers) in comparison to an adult who may be 80kg in weight with unpredictable movements and or behaviour. Another example is the funding of communication devices: there has been a great deal of progress in recent years with Augmentative Communication Devices, which require specialist Speech Pathology support, a prolonged integrated learning/training program as well as ongoing maintenance and updates of the devise. Given that optimising communication and thereby participation in patients with severe or profound core impairments is central to National Disability Strategy, rising funding costs in this rapidly developing area of technology and devices need to be anticipated. This type of planning cannot be expected of families dealing with day to day care needs of catastrophically injured children or young adults.

- Lump sum payments for children and young adults who may have cognitive and communication issues make them vulnerable in the sense of financial exploitation by family members or carers. This situation is much less likely when a structured lifetime care and support service/program and multidisciplinary specialist rehabilitation service is in place who are able to provide guidance, assessment and planning to ensure that the client's needs are being appropriately met. Frequent cognitive issues recognised following Traumatic Brain Injury include impulsivity, poor decision making and poor memory all of which increase the likelihood that the client will require support with their financial, health, living and vocational decision making.

- It is our experience that even when a lump sum payout has been received most of the cares for the catastrophically impaired young person is delivered by family members. This occurs because family are worried about future financial sustainability, and also because they find it difficult to 'hand over' care to professional agencies. This gratuitous care is usually at the cost of their own working lives and certainly at the cost of their time to pursue personal interests and maintain their own health. It is definitely our experience that siblings of a catastrophically injured child become enmeshed in the daily cares, hospital visits secondary mental health issues frequent in highly stressed families. Family holidays frequently become impossible due to greatly increased expenses and the family always being "time poor" due to a vastly increased domestic workload and constant strain. Although respite services have been addressing this need for some time the key provision to prevent the stress, exhaustion and mental health issues is for adequate and continued provision of domestic and attendant care.

In the administration of the Lifetime Care and Support Scheme, QPRS support adoption of the *Clinical Framework for the Delivery of Health Services* to guide funding decisions. The scheme should promote the core principles underpinning the clinical framework, including:

- measurement and demonstration of the effectiveness of treatment
- adoption of a biopsychosocial approach
- empowering the injured person to manage their injury
- implementing goals focused on optimising function, participation and return to work
- basing treatment on best available research evidence

Additional recommendations include:

1. Care needs to be <u>clinically justifiable and goal centred</u>: The scheme will need to employ and train highly skilled case managers who adopt evidence based practice and are aware of the full range of entitlements under the scheme. Service providers need to justify their recommendations and all ongoing services should be subject to intermittent review. The case management role is frequently the critical working relationship for the patient and their family and also needs to be subject to review to optimise the outcomes for the individual.

2. Access to funding to provide one-to-one teacher aid assistance to children in schools, one-to-one support for young adults attending educational and vocational training, and on-the-job support for those entering the workforce is recommended. Development of specialist pre-vocational/vocational rehabilitation services for people with brain injury is also recommended. Ongoing funding for communication technology with specialist training and support as required is recommended to optimise participation of the child or adult in their learning or working environment.

3. The legislation needs to reflect opportunities for social participation in addition to employment and education. The scheme needs to support leisure and recreation access. Access to leisure and recreation is important for a child's holistic development, providing opportunity to develop social skills, everyday living skills and executive skills such as

decision making and problem solving. This is particularly important for children as they transition to adulthood as part of their journey to be independent from their parents. Many may also have limited time in employment, further necessitating the need for these young adults to be able to engage in meaningful activities.

4. In accordance with the UN Convention on Rights of People with Disability, LTCSS participants should be able to choose their place of residence and where and with whom they live on an equal basis with others in the community. Although existing lifetime care schemes will fund 24 hour in-home care to support an individual's move into an independent living environment, access to affordable modified housing is not covered under existing entitlements.

5. The scheme needs to support the sustainability of informal supports, and in the case of children, their care-givers by funding access to counselling for family members, respite and family support and education programs. Recognition of the importance of parenting in a child's development should be reflected in funding of parenting programs and counselling for parents/care-givers of the catastrophically injured child.

6. Ongoing monitoring of care and support needs is required to promote individual opportunities for choice and increasing independence over time. In respect to children there needs to be provision for responding to the child's preferences and goals within the context of their insight and capacity to engage in goal setting and planning for the future. For young people nearing adulthood (16-18 years), case managers need to tactfully and respectfully manage the teen/parent dynamic, in accordance with the Rights of the Child.

7. Current approaches to determining what is reasonable and necessary care after catastrophic injury are inconsistent across Queensland's multiple private CTP insurers. A centralised government body, established under the NIIS, should promote equitable responses to all people with catastrophic injury and help to deliver integrated care over each individual's lifetime. The presence of a centralised body in other Australian jurisdictions has promoted the development of specialist services focused on optimising function, social and recreational participation and return to work for those with serious injuries. The experience of no-fault jurisdictions is that integrated service delivery and the availability of specialist rehabilitation services has improved participant outcomes and reduced the lifetime cost of injury (Productivity Commission, 2011).

8. Provision of funds for the lifetime care and support authority to oversee research to develop best practice guidelines and professional development and training opportunities for health, disability, education and social services.

QPRS values the opportunity to contribute to this important reform, which has the potential to significantly improve the long term health and wellbeing of people who experience catastrophic injury and their families in Queensland. We would be pleased to provide further information to support the committee's deliberation on the most suitable model for implementation of the NIIS.

Kind Regards,

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