To the Productivity Commission in consideration of the proposed National Disability Insurance Scheme:

We are the management committee for Friends of Brain Injured Children (ACT) inc. Friends of Brain Injured Children (FBIC) is an organisation which seeks to foster each brain injured child's highest potential for health and independence. Our purpose is to support parents in engaging in early intensive therapies for their children with brain injuries, with the goal of giving the children the best chance possible to recover motor and cognitive function.

We have read the overview of the draft report on a proposed NDIS, and absolutely applaud the tone and intent of the proposition in terms of its flexibility, empowerment of the disabled person and of those caring for him/her, and its aim for nationwide consistency. We strongly feel that an NDIS in the proposed form would not only be a tremendous improvement on the current arrangements for people with a disability and their carers, but a very good system in its own right, regardless of comparisons. Many of the concerns we initially had about the scheme, when we first heard about it, are seriously addressed as core issues in the draft, and there is clearly a strong and focused intention to design inflexibility and bureaucracy out of the system from the start.

We have, however, two remaining concerns:

- That the proposed scheme has insufficient emphasis on early intensive therapies for children with brain injuries to produce cost-saving or effective results, and
- That the range of therapies proposed for funding will be too narrow, similarly, to yield either effects or cost-savings.

The Potential for Recovery of Function Offered by Recent Discoveries in Neuroscience

A great deal of FBIC's motive and information comes from the rapid developments in the leading edges of neuroscience, which for the last ten years or so has been making significant findings about the highly adaptable nature of the brain, including the ability of a damaged brain to re-learn its functions. This quality has been given the name 'neuroplasticity'.

Neuroplasticity is particularly pronounced in the developing brain of a child in its first eight years or so, which is the time when all childrens' brains are capable of their most vigorous development. For a child with a brain injury, these years constitute a crucially valuable resource, during which the damaged brain, given the right stimulus and support, can still learn motor control for walking, speech, eating, writing, and also develop its cognitive functions. (For an accessible summary of the current neuroscience, we would urge policy makers towards the book *The Brain That Changes Itself: Stories of Personal Triumph from the Frontiers of Brain Science,* author Norman Doidge MD, published by James H. Silberman Books.)

This means that children with brain injury have a great deal more potential for health and independence in adulthood than had previously been recognised, before these discoveries in neuroplasticity were made, and damage was generally considered to be more or less permanent.

Apart from the potential for the happiness and well-being of people with a disability, we would ask the Productivity Commission to consider the lifelong cost-savings, if every child with cerebral palsy or other brain injury-related conditions could be spared some portion of his/her health complications, or dependency on funded supports for daily living.

Emphasis on Early Intensive Intervention

One of our main concerns is that early intensive intervention is being considered with an emphasis which is too peripheral to be really helpful to children with brain injury. In the current proposed NDIS, we strongly feel that the potential for early intensive intervention to improve the condition of children with brain injury has been underestimated, and we are certain that an NDIS would reap the benefits of incorporating it as one of the core objectives of the scheme, equal in importance with, for example, the laudable aims of the 'person-centred' approach or of nationwide consistency.

The 'rewiring' described in the science which is exploring neuroplasticity does not happen lightly - it takes a great deal of stimulation to make one section of brain take over the job of another - hence our emphasis on 'intensive' as part of the 'early intervention' phrase. The therapies and treatments which FBIC parents find and employ are administered in many cases for several hours each day, including techniques which can be taught by therapists to parents for home treatment in between therapist visits. We are concerned that the intent behind the quote (p20, Overview and Recommendations document) **"...NDIS would fully fund the number of episodes of therapy appropriate to the person and which were supported by clinical evidence, with people choosing further episodes meeting their full costs"**, should be supportive of the need for quite a lot of therapy in early years, bearing in mind the future cost savings to the scheme.

Under intensive programs of treatment, many of our children escape their wheelchairs and end up walking, talking and attending mainstream schools, and all the children end up improving their condition in some way. Even if all that a child with severe brain injuries gains from the intensive therapy is the ability to breathe comfortably or feed orally, this reduces a vast range of future health complications and costs, and immeasurably improves the quality of life for that child and his/her carers.

Emphasis on a broad range of funded therapies

Our other main concern with the proposed NDIS in its current form arises from the fact that the science behind neuroplasticity is still new enough that it has not been translated into many clinically proven treatments, and that the range of therapies funded would be so narrow as to be actively counterproductive. In fact, the very existence of an NDIS could make our fundraising in the community, to support childrens', therapies more difficult, which in itself would not be of concern if the NDIS were providing adequate funding. However, if the range of therapies available to parents were little more than those listed in the second quote below, and we were unable to find the funds which we can currently make available to parents for therapies, the pressures on our families would become greater than they currently are, and the health and potential of our children would suffer.

Our concern on this count is sparked by the intent behind the following two quotes from the Overview and Recommendations document:

p20 **"...funded therapies would have to be in keeping with current clinical practice, evidence based practice and/or clinical guidelines."**

p21 Box 2 **"Therapies such as occupational and physiotherapy, counselling and specialist behavioural interventions"** (named as early intervention therapies which would be funded under the NDIS)

The rapidly-evolving science which is beginning to understand how the brain relearns to operate its body and itself after injury and especially in the first few years of life, is far ahead of current clinical practices such as those listed above. Established clinical practices strongly tend to privilege programs of lifelong palliation and supportive care, assuming a relatively static set of disabilities, and therefore only anticipating complications or deterioration in the condition of the person with the disability. Certainly they have not yet had time to incorporate a full response to the opportunities for improvements in health or motility discovered with neuroplasticity.

Our organisation encourages parents to experiment with a wide range of therapies and treatments whose entire focus is that of improvement in their child's condition, and to cultivate a critical attitude towards their efficacy. Our parents use scientific findings, existing empirical evidence, careful experimentation and attention to detail to develop programs of care for their child with a brain injury, which combine a number of therapies, aids and other treatments.

Some of the more commonly used therapies and treatments that our parents have found effective include: hydrotherapy, a wide range of remedial massage techniques, Advanced Biomechanical Rehabilitation, Conductive Education, Point Percussion Therapy, as well as aids such as nutritional supplements or the Second Skin body splint. All of these treatments have in common methods which stimulate and support the brain to recognise and connect with parts of the body which had been abandoned by the damaged sections of the brain. They stimulate the remaining functioning parts of the brain into 'rewiring', to learn how to do the jobs that the damaged parts are unable to do. Many of these are also beginning to be supported by a growing body of empirical evidence.

To present some rather simplified examples, by way of illustration of our concerns about our children accessing a range of therapies too narrow to help them;

- A child may present with an overly-tight muscle which is causing pain or discomfort, and distortion of a limb: a physiotherapist may recommend the use of botox, alleviating the pain but weakening the muscle in the long term, where a tuina massage therapist will find (and teach the parent) a technique which simultaneously relaxes the muscle and in the longer term stimulates the brain's recognition of it.
- A child may present with difficulties in sleeping: the paediatrician will tend to seek out a drug which will best suit the child with as few possible side-effects, whereas a body splint may relieve the breathing difficulties that the child is having while lying down.

Given that the current developments in the science which understands neuroplasticity seem to be pointing in the direction of therapies such as these for their stimulative and corrective qualities, we feel it crucially important that parents of children with brain injury should have funded access to such therapies.

We have read with particular interest Chapter 11: *Early Intervention,* of the full Draft Report, and have noted that there does seem to be an opening in the debate to permit consideration of a wider range of therapies funded, namely, the proposition in which the NDIS would use the experience of its clients to build its own evidence base where existing research and evidence is patchy. Because the science is young, conclusive evidence for the efficacy of particular therapies in this area is incomplete, but growing. We would suggest that the kinds of therapies that our parents are using are excellent candidates for such observation:

- a certain amount of empirical evidence is already available, as well as a great deal of anecdotal evidence from people who have experienced the benefits,
- their potential for cost-savings and life-improvements is tremendous,
- the scientific community would be very supportive of research into this area,

- the therapies are relatively low-cost and therefore low-risk to the NDIS budget. This is particularly the case if large portions of them can be administered by parents using their ‘vouchers’ to buy housekeeping support which frees up time to perform the therapies,
- they are quite common-sense in their approaches - any therapy offered that looks like a time-waster tends to get pretty short shrift from parents, given the preciousness of the developmental opportunities available to their child.

We of course recognise the validity of the Productivity Commission’s caution that funding must not turn into a free-for-all, and that ineffective therapies must not end up funded by the scheme, and we very much respect the quality of the debate which was presented in Chapter 11 of the Draft Report. With that in mind, we are confident that funding for a wide range of the therapies and aids such as those listed above would be a highly cost-effective and worthwhile use of the public funds.

We thank you for your attention to our submission, and for the very thorough work which the Productivity Commission has performed so far in considering an NDIS.

Sincerely,

Libby Steeper,
President, Management Committee for
Friends of Brain Injured Children (ACT) inc.