SUBMISSION TO THE AUSTRALIAN PRODUCTIVITY COMMISSION
DISABILITY CARE AND SUPPORT DRAFT INQUIRY REPORT 2011 (Canberra)

SUBMISSION: ***-At all times one recognises that most proposed changes and improvements are dependent upon the implementation of the proposed NIDS Scheme's provision of increased funding, but that there should and could also be some immediate changes to existing practice and that the following life-saving changes additional to those already recommended and which would not require additional funding, be immediately implemented in the existing legislation:-***

(a) That the option of detailed self-funding be immediately implemented in order to permit choice of Providers, Carers and Case Managers.

(b) That the suggested provisions do little to ensure desperately needed requirements for improvements in the standard and quality of care received.

(c) That existing legislation be changed to recognise both the environmental and medical status of both disabled and intellectually disabled persons who may suffer as many as 8 other co-existing illnesses and disabilities and that these persons should be entitled to all necessary and desirable forms of therapeutic and medical supervision and treatments equivalent to those received by all other Australians, incoming migrants and asylum seekers.

(d) That the existing legislation prohibiting severely disabled persons under the age of 75 from entry into hostels and nursing homes or from receiving necessary high level nursing care or from receiving in-home care by someone of higher qualifications than Certificate 3 (School Certificate Level) when cared for at home or in a Group Home be abolished, and entry into higher care be permitted at any age deemed necessary, especially if family members are willing to contribute a proportion of the cost of this care. (In my youth I was involved in the establishment of a Nursing Home specifically for younger people.) Clinical nurses should be appointed to routinely check all existing Group Home patients.

(e) That administration of simple basic medical treatments such as specialist-prescribed blindness-preventing eye-drops and of allergy-prevention creams should become an integral permissible part of all personal care duties. At present many carers blatantly refuse to perform these simple duties, even for clients with fractured limbs, seem to consider the situation amusing and claim they cannot legally perform such duties.

(f) That detailed self-funding should permit the introduction of innovative programmes likely to benefit the client (eg appropriate music therapy, physiotherapy, speech therapy etc or lip-reading programmes to benefit hearing-loss clients and foster confidence and acceptance of disability)Currently these services are funded only for those resident in a Group Home.

(g) That there should be enforcement of the provision that only adequately trained persons able to speak and understand English clearly should be allowed to undertake the position of Carer.

(h) That there should be necessity for improved training and experience of Case Managers and Carers, many of whom have been appointed to the position with minimal experience of disability issues.

(i) That application processes be democratised and the culture of requiring subservience to carers from reasonable family members be eliminated and that there should be immediate re-wording and decriminalisation of NSW DADHC Application Forms for Supported Accommodation which currently implicate the disabled applicant in and assess on a basis of criminal, dangerous or troublesome behaviour rather than on the basis of need.
(j) That provision should be made for the employment and remuneration of suitable family members to be employed as Carers as an alternative to government selected personnel.

RATIONALE: -

I would like to present a submission on behalf of myself and other Ageing Parent Carers regarding funding changes which, with the exception of clause (f), could improve quality of services without necessitating additional expenditure.

I am 82 years old and still care for a 59 year old intellectually disabled son (recent DADHC assessment tests place him in the lowest percentile of the population). To the best of his ability he is helpful, cooperative and affectionate, but we have a serious problem in that I suffer spinal stenosis which restricts my mobility to a wheelchair, in addition to an inoperable severely fractured shoulder from a fall. This is coupled with other medical conditions such as occasional renal failure, diabetes, cellulitis and glaucoma. My son was asphyxiated at birth and suffers from a unilateral vestibular lesion, central nervous system injuries, abnormal nystagmus etc and suffers from epilepsy, diabetes, hearing loss, tinnitus and orthopaedic problems. Although he reads and writes well, this means he experiences difficulty finding his way around and is at times confused, repetitive, dizzy and worried.

My son happily attends both a Sheltered Workshop and a Leisure Centre one day per week. He works very slowly, earns $2.50 an hour and also receives a two-hour domestic assistance package per week for which he pays a reduced fee. I am now 82 with a fractured disabled shoulder and can no longer perform these cleaning duties. His Provider has offloaded this domestic assistance to a secondary provider and this is proving a tremendous problem. Permissible duties (frequently poorly performed) are predetermined from central office many months in advance and there is no flexibility whatsoever to substitute an activity which may not be really necessary for an acutely necessary one such as cleaning the laundry (my son is scrupulously clean but incontinent and the domestic assistant is not allowed perform this task.) Even though I may sometimes be really ill, there is no possibility that I could substitute a weekly cleaning duty for any other form of personal care.

I am now 82 and am frequently admitted to hospital and this presents problems with the care of my son who requires daily medication, occasional PRN medications and clinical supervision of his permissible daily activities (no TV, access to diabetic diet, reduced travel, avoidance of situations involving much flickering or strong light, excessive movement etc.)

Seven months ago I requested my son be placed **on a waiting list** for entry into a suitable and compatible Group Home. I have been repeatedly requested to provide the same documentation by a number of Case Managers, who have little familiarity with disabled persons or issues. After all this time two Case Managers still have him listed as “Down’s Syndrome” rather than “Brain Injury with Complex Audiological Issues” and cannot accurately record the names of his doctors together with many other salient facts and cannot admit he might require some supervision of his medical conditions from a clinical nurse. They have also advised me that there is no possibility that I could be given the opportunity to preview any suitable Group Homes where he might be placed. This is a return to the Dark Ages. They are completely content with the fact that he could be placed in a Group Home supervised solely by a Certificate 3 or 4 Carer who could refuse to administer life-saving treatments as has happened to me with my specialist-prescribed eye-drops or allergy creams. (I have a fractured right shoulder and cannot lift my arm above my wrist.) This is not good enough. The sole function of these highly-paid executives seems to be to advise that there are no vacancies and certainly no skilled treatments available.

As a person who has 50 years experience in the disability field and who has been cited in Who’s Who in the World for my voluntary work and contribution to disability issues, I strongly object to disabled persons being categorised by a minority of Members of Parliament as ‘economic vandals’. I also object to the format of DADHC NSW Application for Entry into Supported Accommodation Form, which is based on the premise that all disabled persons are violent and disruptive and need to be classified as a threat to society with their danger risk factor categorised as either red, amber or green. This is slanderous and unjust – If some disabled present such problems, it is frequently because they have been exposed to inappropriate environments and company, inappropriate trigger factors or have received insufficient supervision and have been left to roam the streets.

There are many excellent and dedicated carers who are to be highly commended. I could not have managed without the assistance of such persons. I am also deeply appreciative of having had to pay reduced fees for the services provided. However there are also far too many non-committed, short-term providers who never get to meet the clients for whom they provide care and who provide minimal uncaring poor quality assistance. In many cases the monies already allocated to ageing and disability could be better used by eliminating a great deal of duplication involving expense in our current system of providers, travel rosters etc. Too many of the carers appointed lack sufficient language and basic education skills (at best School Certificate) and perhaps enter the system as a way of obtaining permanent residency in Australia. Non-compliant Providers should be immediately deregistered.

I understand that in UK, USA, Western Australia and Victoria that package money is successfully allocated to non dementia clients who desire the option to employ staff of their choice. My disabled son lives at home with me .When I was working for several years he was disoriented and ill with a severely poisoned foot but I managed to go to work and keep my job by employing at my own expense part-time nursing aids and nurses. Apart from the massive expense this worked very well and solved our problems. This system could work well for those who desired it and would entail no additional expense to Government. Are you able to implement detailed funding for this? In my son's case, we would commence with a personal care/domestic assistant of our choice. There are many willing and able to offer this service for less than $45 per hour. For acting as a full-time Carer 24 x 7 x 365 the Commonwealth Government pays me approx. 25 cents per hour.

Many suggested changes such as re- planning of travel routes and task schedules could be implemented prior to the suggested date of 2014. Fewer supervisors would be required, communication times reduced and the client would be empowered to obtain the type of assistance most urgent. It might even mean that care-workers could be provided with a higher wage and an incentive to undertake further training.

CONCLUSION:-

I am now 82. I could easily be dead before the proposed date of 2015 when the National Disability Insurance Scheme has been debated and possibly implemented. I have now spent almost 60 years of involvement in disability issues and positions, including vast amounts of voluntary work in hospitals, schools, nursing homes and other organisations and including participation in the establishment of a special school, nursing home and sheltered workshop. I now have to provide massive amounts of documentation, paperwork and effort in order to obtain any certainty regarding my son's future care. This is not good enough. Older Parent Carers who have done their share should be provided with more certainty than this. Many would be prepared to provide some financial provision towards the aftercare of their offspring if this could be facilitated.

DON'T SHELVE THE PROBLEMS.

NOW IS THE TIME TO ACT!

Yours faithfully,

Judith A. Douglas
BA (Qld) (1950), Master of Disability Studies with Merit (Newcastle) (2006)
Member New York Academy of Sciences

ADDENDUM: - I myself currently receive EACH assistance from two different Providers and am grateful for reduced charges. My doctor has provided a certificate stating that I require administration of specialist prescribed the eye-drops to prevent blindness and that I require a carer trained to administer these and my allergy creams. My primary Provider has trained its workers to administer these three days per week. The other Agency refuses to do this and this is creating worsening medical problems for me. I cannot lift my

right arm above the waist and take very strong pain-killers six times a day to provide some relief. Many of the carers are helpful and excellent but in the past, too many have provided abysmal services, refusing the lightest duty such as carrying a cup to the kitchen and are unable even to speak English. I have volunteered to provide the necessary 15 minutes training for drops and creams free of charge to care workers but have been rejected. I have been a Registered First Aid Officer, a teacher to HSC, have worked in hospitals, nursing homes, sheltered workshops, group homes etc, have 15 or 16 Post Graduate Extension Subjects (Masters Level)(UNSW) in Paramedical subjects (Linguistics Today, Vision Development, OH and S, Speech and Hearing, Music in Communication, Psychology, Clinical Counselling, Pharmacology, Neurology, Medical and Paramedical Law etc.) Additionally I have a Master of Disability Studies with Merit (Newcastle 2006.) I would willingly do more if I physically could but am physically unable. On occasions I have even been subjected to verbal vilification and abuse regarding these matters and I find this very upsetting.

COPY TO: - The Hon. A. Constance MP, NSW Minister for Ageing and Disability