Cover Note

We appreciate the opportunity to respond to the New System for Better Employment and Social Outcomes.

Due to our extensive workload we have only skimmed through the report. This however, has led us to believe that policy makers need a reality check before they can change policies that effect millions of Australians.

Policy makers (including those who develop such reports as this New System for better Employment and Social Outcomes) need to UNDERSTAND THE SITUATION REAL PEOPLE FACE IN A REAL WORLD.

Therefore, our main emphasis in responding to this report is to share our experiences.

We are not an isolated case. Thousands of other carers are "in the same boat". Please listen to us!

Background

(Firstly about us)

We are Peter and Beverley Rubenach and we are 68 and 66 year old respectively. We live at Gray, a small rural hamlet on the East Coast of Tasmania.

We are full time carers for our 28 year old son, Tim.

Beverley has been caring for Tim since his birth as she has always been a full time at home mother and homeschooling teacher of our 6 children.

At 5 months of age Tim needed full time extreme care. When our 5 other children left home to pursue higher education/employment Peter had to give up his employment in order to help with Tim's high care/high needs. (due to his disability!)

Peter had been largely self employed for about 20 years prior to this, as a builder/cabinet maker/handy man. (He had before self employment been a miner then he became self employed as a farmer)
It was a big adjustment for our family for Peter to be give up work to care for Tim.
(Beverley only coped during those years prior to this because she had massive help from her other children)
When Tim turned 16 we found out we were eligible for carers pension and Tim was eligible for a disabilities pension. We have been receiving these payments for the past 12 years.

(Beverley's pension is approx $16,000
Peter's " " " $18,000 per year
Tim's " " " $22,00)

Our Role as FULL TIME CARERS

- Tim has been accessed by doctors etc as being a very high need/high risk person therefore requiring 2 full time carers as he cannot be left alone for more than a few seconds at a time. (Even this puts him at risk)
- Peter sleeps in the same room as Tim with a bed less than $\frac{1}{2}$ metre from Tim. Beverley sleeps in an adjoining room to help monitor Tim throughout each night.
  (This seperation for us as husband and wife causes a strain on relationships but we consider it necessary for Tim's well being.)
- Tim needs care and supervision in EVERYTHING he does (24/7)

a Bit about Tim

Tim is now 28 year old. He was born a normal, health baby but at 5 months of age he contracted menigitis. This resulted in aquired Brain Injury (ABI) causing intellectal, cognitive and physical disabilities.

- Tim's major disabilities are severe epilepsy/ABI. Tim is in what is known as a "constant seizure state" all the time ie experiencing some type of seizure or brain disruption. He can have up to 17 tonic clonic seizures in 4 hours. Tonic clonic seizures cause him to fall and loss consciousness so we need to be at hand at all times to lower him safely as possible to the ground / put him in a safe position and administer necessary / life saving help daily.
- During countless partial complex seizures Tim can present challenging behaviour eg kicking, biting, hitting, throwing things - totally unaware of his actions and the consequences of his actions.
- This challenging behaviour is also a normal part of his cognitive disability and his way of communicating as he is largely non-verbal.
- On days when Tim is having many and varied seizures one person needs to walk behind him and one in front of him to catch him at the onset of a tonic clonic seizure or a severe partial complex seizure. Tim often cannot walk at all or with difficulty assisted by its using a "Pelican Belt".
- Tim is a poor sleeper therefore we get very little sleep (3-4 hours broken sleep every night)
- We currently receive 22 hours of support workers a week which because 2 workers are needed translates to 11 hours a week.
- Tim needs special dietary requirements and alternative treatment/medication for he developed a severe toxicity to conventional anti-seizure medication over 10 years ago. Thus virtually all of Tim's disability pension is spent on treatment etc. (plus continhancy materials etc)

* We have no way or no time to earn an extra money to supplement our carers pensions and no superannuation etc on which to rely on.

NB We could both be on old age pensions but we want to be recognised as carers. (We would get about the same pension for doing nothing - as it is.

we work very hard 24/7 and a almost house bound.
We have had 3 days away from Tim as a couple in 28 years!

Having stated all thes we wish to comment on:
· Should people with a permanent impairment and no capacity to work receive a seperate payment from other working age recipients?
YES and a higher pension because of the specific needs their disability requires for their well-being (eg Tim's dietary and alternative medicine/therapies that are not subsidies by the Government) eg massage, reflexology, as it is we do these things to assist Tim but we are unqualified.

CARERS
We cannot seek any employment as our role is 24/7 caring for our loved one with high needs and high risk (we do NOT do 8 hour shifts we work 24/7)
eg we are often injured due to Tim's medical condition ABI with its challenging behaviour and during his seizures, we sustain bites, bruises, muscular strain etc.
We are under constant emotional, physecal and financial stress. In the area of financial stress Government can assist.
* Carers payments MUST be in accordance to the level of care that is provided we need some form of "space" to live a few hours a week "normal".
After all if Tim as in a group home etc he would require 2 workers 24/7. what would that cost? $200,000+ per year?

We would still be getting an aged pension.
So consider what we are saving the Goverment when we are getting approx $34,000 between us a year. Please we need more HELP!

• We need more IN HOME RESPITE.
(Tim is tramatized if he is away from home more than a few hours and must be in the company of family. In 28 years Tim has only been away from family for 48 hours in the company of support workers he likes very much. During this time he had frequent trips back home (it was to accassion of one of our daughter's wedding). When Tim is hospitalized he needs family (and an occassional break for family with support workers attending him)
" At the time of writing this Beverley is scheduled for a hernia operation (25 August) and a cataract operation (17 Nov) but these will only be possible if IN HOME Respite (with 1 worker to replace Beverley) is available. The hernia operation will need 4-6 weeks recovery time - the cataract operation 1 week) * We need a support worker for 6-7 weeks 24 hours a day 7 days a week to take over Beverley's role as carer!
(We have State politians helping us in this situation)

People everywhere need to be EDUCATED on the reality of disabilities and the needs of disabled people, their carers, families (and even support workers) stop looking just at economics and look at PEOPLE. This is good Governments responsibility!

* Come to our home and get a reality check!
BE EDUCATED.
Peter & Beverley Rukenach.

A nation's greatness is determined by the respect and nuture it gives to its most vunerable citizen.