Submission to the National Disability Insurance Scheme (NDIS) Costs study
Productivity Commission
GPO Box 1428
BARTON ACT 2600

Dear Commissioners',

I am writing as the mother of a now 34 year old adult male who has significant and permanent physical and mental disabilities.

He is classified as an ABI due to a benign brain tumour on the brain stem which has been resected three times – age 8, age 10, followed by radiation treatment to prevent its regrowth, and recently aged 33. He also has a VP shunt so in total has had 10 brain surgeries.

Due to his declining health, he has recently had a full mental breakdown, and as such his life has again been turned upside down. He has had to return to the family home to be supported by his father and myself as his needs are now too high for his place of residence. (We have both just retired and are now adjusting to our lives being turned upside down, again.)

I have supported the concept of the NDIS and am looking forward to our involvement but with some concerns.

The NDIS widely states that this scheme treats and respects each person as an individual and as such the formulation of their NDIS Plan will address their needs. Common sense tells me that the number of persons applying to access this scheme will far outweigh the numbers expected. Does this mean that those fortunate to access the NDIS will have limited funds available to them? i.e. more get less. Common sense also tells me that many persons needs will change over time. i.e my son.

The current ISP package that my son currently receives is no longer adequate to meet his needs and as such we are attempting to have a reassessment to address this problem. The doctors have informed us that due to his brain surgeries and the radiation treatment, his breakdown is not unexpected and

will leave him with permanent mental issues and seizures. He is also a strong candidate for early dementia. The original ISP covered his physical needs but now not his mental needs.

Will the NDIS have the flexibility to understand, address and meet such changes without exceeding the budget and/or jeopardising other participant's plans?

Each participant is an individual and many, such as my son, cannot be slotted in to any one field, as their disability covers many. Will the NDIS cover all needs with no distinctions?

My son did not ask for or deserve what life has given him, but he does have the right to have all his needs met so that he can access life to the best of his ability.

Thanking You in Anticipation,

Suzanne Read

A very proud mother.