Inquiry into Disability Care and Support
Productivity Commission
GPO Box 1428, Canberra City ACT 2601

Dear Commissioners

I write to represent the interests of my son with Williams Syndrome, a rare genetic condition that affects around 1 in 10-20,000 individuals. It is characterised by medical problems, including cardiovascular disease, developmental delays, and learning disabilities.

I have been on a steep learning curve about disability since my son was diagnosed, and while early intervention services are well funded, the older your child gets, the more apparent the problems with the system become.

Overall, I support the principle of a National Disability Insurance Scheme. I agree that a root and branch reform is necessary to correct the inequities that currently exist, to reform the crisis driven nature of disability services, to better target services and supports to ensure that people are able to participate in the community and to give people with disability (PWD) choice and control.

I have a few comments to make on a number of your recommendations.

I urge you to continue to recommend the inclusion of people with intellectual disability. Your report points out the ridiculous example of someone who suffers from a severe asthma attack being categorised as having a "severe or profound" disability, yet someone with a lifelong mild to moderate intellectual disability would not. Clearly, both the Productivity Commission and the Government will want to see outcomes from this scheme, including the transition of people from pensions to the workforce, and this could definitely be possible for people with intellectual disability provided they are given appropriate support.

The assessment process needs to be truly based on an assessment of individual needs. Although this is the crux of the Productivity Commission's (PC) recommendation, in some cases you do refer to some individuals being automatically entitled to support (e.g. Down Syndrome on page 5.7 and lists of groups eligible for early intervention, e.g. autism, acquired brain injury, cerebral palsy and sensory impairments). While I do not deny these individuals will require assistance, this perpetuates the continued obsession with labels and not needs. For example, people with Williams Syndrome are likely to have similar support requirements to those with Down Syndrome, both in terms of early childhood intervention and in supported living as adults.

This point also extends to therapies, services and supports being evidenced based. While I don't propose that the NDIS fund therapies that do not have a scientific basis, I do think that the cohort selected to trial therapies should be broad in scope or else the evidence outcomes be applied to people with disabilities of a similar nature. For example, the Government's Better Start program provides access to support for children with Fragile X, Down Syndrome, sight or hearing impairments and cerebral palsy because evidence shows that "that intensive early intervention in the pre-school years is effective in preparing **this cohort** of children for school." Although my son has similar needs to this cohort and would benefit from this funding he is excluded because the evidence did not cover his disability.

I suggest that one of the first studies the NDIS perform is an assessment of the effectiveness of music therapy.

I support your recommendation that the scheme be funded through a reallocation of spending priorities by the Government. The 2011-12 Budget initiatives to move people from the disability support pension into work should be offset against the costs of the scheme. What is abundantly clear in order for the system to work is for the scheme to be sufficiently well funded to genuinely meet people's assessed needs, and not a continued rationing of services. If the funding genuinely meets PWD needs, then I do not have a problem with a co payment for access to NDIS services.

I believe the scheme should include payment of family member carers, with appropriate safeguards. The whole system is about offering choice to PWD and if someone prefers to have a family member care for them rather than a stranger, then that should be an option. I do not believe the Government should take advantage of people providing natural support by not paying them for something that would cost them in the absence of people's generosity, love and compassion.

In my opinion, the reason behind the low take up rates of direct funding in the UK is because of a lack of support afforded to individuals to take up this option. People should be assisted by an independent broker to self manage their funding. Although having the money held by a service provider or disability support organisation gives individuals choice, it does not give them control. I think the NDIS should continue to subsidise the cost of independent brokerage beyond the market creation, or at least build the costs into the individual's ongoing package if they really want to encourage self management of funds. I also think there shouldn't be a limit on cashing out essential therapies, **unless** people have the opportunity to choose their own service provider.

I am concerned about the use of the words "reasonable and necessary" in that they might be used to limit the scope of services or activities the funding may be used for. Some of the activities run by day programs have the objective of community participation. If someone wants to use their package to attend a football match or join the gym, I still think this is within an acceptable definition of community participation and innovation and flexibility should be encouraged. People accessing support and activities outside the disability sector will free up access to "traditional" services, should this be what other people are seeking.

I also do not support variation between what States deem acceptable expenditure under direct funding, as this will not facilitate portability of funds.

I fully support the concept of an innovation fund as disability services are somewhat of a "wicked" problem, requiring flexible and creative solutions.

I support the proposal that the NDIS should facilitate transition of adults into public or private housing or supported accommodation. This should have an early intervention focus, so that people are assisted into independent living at an age appropriate age, e.g. in their twenties, as opposed to when their parents are on their death beds. I agree that cash out of specialist disability housing should be allowed, to encourage innovative solutions to the problem of an overburdened public housing system.

I disagree with the concept that needs assessment should not extend to domestic life and general tasks and demands. Some people may need assistance with budgeting and money, and I think it is reasonable that the Government funds this help. I also think that some people with a physical disability would need household assistance in the form of cleaning and this should be covered by the scheme.

I strongly support the concept of shared electronic records to reduce transaction costs.

Finally, I strongly support the formal governance arrangements of NDIA including the opinions of families and PWD. I do not think the model proposed in the draft report gives enough of a voice to PWD and their families, and ultimately this whole model is about giving people more choice and control, so this should extend to the formal governance arrangements.

I urge the Productivity Commission to hold the Government to its promise to respond to the final report within 25 sitting days of receiving it.