Submission to

Welfare Review Interim Report

On behalf of

Down Syndrome Association of NSW

Friday 8 August 2014

**DS NSW – Who we are**

The Down Syndrome Association of NSW (DS NSW) was established by parents of children with Down syndrome (Ds) 35 years ago to champion the rights of people with Ds to be fully included in all aspects of society. Our aim is the same today and we remain a parent run organization, representing the largest population of people with Down syndrome in Australia.

In preparing this response DS NSW consulted broadly with our statewide membership. We also invited a more focused cross section of members with a particular interest or expertise in the area of work and welfare to participate in formulating this submission

**Down syndrome - Background**

Down syndrome is a genetic condition which occurs due to the presence of an extra copy of the 21st chromosome. This results in a range of physical characteristics, health conditions and indications for delayed development.

Down syndrome occurs across all socio-economic and ethnic groups and to parents of all ages. It is the most common cause of intellectual disability and the most common chromosomal disorder. One of every 700-900 babies born will have Down syndrome. There is no cure and it does not go away.

*Everyone with Down syndrome will have some level of intellectual disability*. The range of intellectual capacity in people with Down syndrome will vary from individual to individual just as it does in the general community. Without exception they will require lifelong support of varying degree.

**DS NSW response to the Review**

**Overview**

DS NSW would welcome a simplification of the current system. Previous feedback from our members has shown the process of applying for supports and undertaking job capacity assessments to be unnecessarily arduous in view of the well documented and permanent nature of Down syndrome.

Accordingly DS NSW recommends any review of welfare payments to people with Ds take into account the unique lifelong needs of this section of the population. It is our understanding that all people with Ds currently in receipt of the DSP have received it as a manifest grant. The Review appears not to take this into account. DS NSW would welcome clarification of this point.

**Comments**

The main concerns arising from the recommendations are

* The Disability Support pension; Regardless of a person with Ds’ capacity to engage with income producing work at any given time in their life, the benefits currently attached to the DSP provide an integral part of the support needed to live a ‘good life’. These include health benefits and travel concessions. There is a very real concern that moving people with Ds off the DSP and on to a tiered working age payment would mean they were no longer able to access the benefits attached to the DSP. In real terms, combined with poor employment opportunities and limited earning capacity, this would mean entrenching disadvantage for people with Ds.

***Comment: Parent of a woman (26) in open employment with support 20 hrs pw***

Removing current DSP and health care card would mean poorer health outcomes as not able to afford GP and Specialists visits. It would also mean social isolation as (our daughter) would not able to afford social activities, like movies, theatre, art galleries, museums. The loss of the concession would also impact haircuts, National folk festival, intra and interstate buses, etc. The impact on (our daughter) of losing the DSP and pension card would be an increase in transport costs just to get to work from $1.28 daily add $6 min. for return trip. People need to be able to afford to live close to family, networks, services and transport.

* The Age pension; In comparison to the rest of the community people with Ds age prematurely. This curtails their capacity to participate in many ways including undertaking or continuing in paid employment. Currently the DSP supports people with Ds in this situation until they are eligible to receive the Age Pension.

***Comment: Parent of a woman (32) in supported employment 11-20 hrs pw***

Our daughter has a part time job and part pension. She has been with the one employer for 13 years and at 32 is beginning to slow up. We hope she is able to continue as long as possible, however are realistic to know when this position ceases it will be EXTREMELY difficult for her to find another position. We are ageing and if the DSP is not there for her? Is the Government willing to give her full support, eg health, accommodation, food, health and safety monitoring etc etc. all these have been and are being provided by us for now almost 33 years. Also there is NO HOUSING for her etc etc!!!

With regard to the recommendation on the Disability Support Pension (pg 51) that people with disability be divided into

1. those assessed as having no capacity to work and
2. those who have capacity now, or may have capacity in the future

We believe that such a classification, if it were to be rigidly assessed and applied, fails to take into account the fluid nature of capacity and the uncertain nature of matching capacity to the availability of support and employment opportunity at any given time.

***Comment: Parent of a woman 41-50 years working in open employment 11-20 hours pw.***

It is regrettable that the (authors of the Review) think that a person who is capable of employment does not have a disability. My daughter can only work two days per week because of health reasons, but if she had to give up that paid employment, her mental health would suffer greatly. She has plenty of reasons for receiving the DSP, but also plenty of reasons to work (on a special wage), and one does not preclude the other. However, if she did not have the DSP it would be a disaster. So we would have to end her employment.

The reality for people with Ds in Australia today is that whatever their capacity for work, people with Ds will never have the prospects of career advancement that their peers without intellectual disability have. They will never progress up the pay scale to any significant degree. They will always be reliant on other support systems to maintain a basic and reasonable standard of living.

***Comment: Parent of a woman 21-30 years old in supported employment 6-10 hrs pw***

It actually costs my daughter more to get to her workplace, than she earns ie; she earns $52 a fortnight and it costs her $80.80 a fortnight on top of her taxi vouchers, and subsiding by local business and fundraising, to travel to and from work. Of course we know that the benefits of participating in such a workplace are well worth the extra costs each week. The LOSS of the DSP would financially cripple her. The loss of benefits would seriously affect her well-being, quality of life and ability to access and participate in services and events.

The lived reality of people with Ds is that the opportunity for open employment is rare. Employment in Australian Disability Enterprises (ADEs) does not deliver a living wage. The option for full time employment in either system is almost non-existent.

***Comment:******Parent of a woman 21-30 years old in open employment 6-10 hours pw***

My daughter would happily work more hours (if available) and we are very pleased to support her in achieving an independent life, but we believe she should be given at least a fighting chance of not being condemned to a lifetime below the poverty line. The current DSP allows her to live with some dignity (with family and friends support) in our rural community. Until opportunities in employment and accommodation are more equitable across the community she cannot function in society without regular financial assistance to provide the most basic requirements for an independent life.

The recommendation states that,

*To align Disability Support Pension with contemporary disability policy the payment needs to better differentiate between permanent and temporary incapacity. At present the definition of permanent incapacity used to access the Disability Support Pension relies on the disability persisting for two years. This definition is outmoded as it disregards modern advances in working with people with disability to improve their employment capacity.* Pg 47

**DS NSW believes that employment capacity can only be truly improved when employment opportunities are truly available.** A recent survey of DS NSW members shows that just over half of people with Ds (54%) were not in employment of any kind. Of the remaining 46% the majority were employed in ADEs.

DS NSW is concerned that ‘capacity to work’ is not clearly defined and that the treatment or service plans to develop capacity, and provide ongoing support to maintain capacity is not stated.

Ninety two per cent of our members surveyed say the person with Ds in their care receives the Disability Support Pension. Ninety eight percent stated that the loss of the DSP would affect the well being of their person with Down syndrome.

**Conclusion**

Contrary to the perception aired in the recommendation by the Productivity Commission report (pg 47) that *‘ the current design of the Disability Support pension arrangement and the way people perceive them , discourage the social and economic engagement of people with a disability. . . ‘* the overwhelming majority of people with Ds want to work. Their families are aware of the many benefits other than financial that arise from being in the workplace and wish to support their person with Ds to engage with the community in this way.

**In our extensive experience, the availability of the DSP in no way discourages people with Down syndrome from pursuing participation in the workforce.** Rather it provides an essential support for the individual in maintaining a reasonable degree of health, wellbeing and livelihood during their life span.

The potential loss of the DSP, the security it provides and the associated benefits would severely and adversely affect the wellbeing of all people with Ds regardless of their capacity to work now or in the future.

***Comment: Parent of a young woman working 4 hours per week in open employment.***

I am concerned that, as my daughter works 4 hours a week, she will be put onto something like Newstart and does not have the skills to cope with this. Concerned that, as usual, more organizing and paperwork will fall on my hands even though I don't receive any career payment anymore.

Regarding the Recommendations as they stand there is a very real concern that

* capacity to work is not clearly defined
* income and benefits would not be flexible enough to reflect the unique lifelong requirements of people with Down syndrome
* the burden of providing adequate support to people with Ds will fall to family members, particularly aging parents as the life expectancy of people with Ds reaches parity with their peers
* people with Ds will be excluded from attempting to join the workforce in any capacity if they are assessed, with no review mechanism, as having no capacity to work at any point in time

DS NSW welcomes the opportunity to make a submission to the Review and hopes to become on ongoing member of the consultative group.