SUBMISSION TO: THE AUSTRALIAN GOVERNMENT PRODUCTIVITY COMMISSION INQUIRY INTO DISABILITY CARE & SUPPORT

FROM: Ian & Heather Alcorn on behalf of our daughter Robyn Alcorn

There are two topics that we would like to draw to the attention of the Commission, namely

- 1. The lack of suitable residential options available to persons with a disability, and,
- 2. The complexity of many Centrelink forms required to be completed by persons with a disability.

Firstly some **background information** relating to our situation.

Robyn (now 26) is the youngest daughter of our four children and lives with us in our family home. She has an intellectual impairment, attended our local schools with the assistance of Special Education support and now is a permanent part-time supported employee (4 days per week) at an Australian Disability Enterprise (ADE) located in the southern suburbs of Brisbane. She is independent in many ways (personal care, planning ahead, use of public transport, minor money matters, social outings through the Lifestream Foundation) but still needs supervision & support in many areas.

We, her parents, are both in our 60s and recently retired from careers in education, involving many years involved in Special Education. We have continually had to advocate for Robyn, especially through her school years and to have her placed in an ADE. We continue to remain active advocates for Robyn and I am presently quite involved in the management of the ADE where she works. Whilst we remain in good health, Robyn is quite able to remain living at home, although our ability to participate in some activities is limited by our desire to have Robyn regularly attend work as any other young adult.

In relation to the first topic, the lack of suitable residential options available to persons with a disability, we would like to make the following observations.

On the south side of Brisbane, there are no really suitable options for young adults like Robyn. (Or, if there are, we are not aware of them.) There are group type homes for persons with higher support needs and there are some adults placed in random flats/units in the suburbs with some supervision, however Robyn needs are different as are those of many of her friends who work with her. They are independent in many ways but need to be in a safe, supported & supervised environment. A complex that provides a range of options from low support to high support – not unlike the tri level aged care homes that already exist, is a concept that should be investigated. In such a place, they would feel secure, be able to refer & confer with support persons, be with friends, cater for themselves or be catered for. They also need to be close to public transport and shopping facilities. Whilst Robyn is in a fortunate situation to be able to buy her own unit with assistance, the option of her living by herself or even with one of her friends is, in our opinion not the most favourable option. My observations of the type of support that is afforded to persons in similar situations does not provide much comfort as I feel many of these persons are left very vulnerable.

We are aware that accommodation is a State Government responsibility but unless there are extremely urgent family circumstances, no information is provided and therefore no long term planning can be done.

These concerns have been expressed by other families for many years but no initiatives seem forthcoming & no new alternative options ever seem to be considered.

With regard to the complexity of many Centrelink forms required to be completed by persons with a disability, the following comments are made.

- Some forms are required to be completed for accountability purposes and we support that requirement
- It would appear that most forms refer to "generic" persons with a disability. For
 example, some persons who are physically disabled often have good literacy &
 numeracy skills as opposed to most intellectually disabled persons who have poor
 literacy skills and rely on others (carers/parents) to complete them. Centrelink would
 have data relating to each persons disability & should be able to produce several
 different modified forms tailored to disability types.
- A good example of this is the Review of Mobility Allowance recently received. Firstly, I have no problems with the requirement to check the entitlements for this allowance but, of this 7 page review, only one (1) refers to my daughter. The data required for this review is already known to Centrelink as they already have a record of all pension payments and earnings as an ADE employee. I have raised this before with Centrelink managers but have never had a reply. I have also written to Centrelink Customer Relations but have never been provided with a reply. Copies of these letters are attached as Attachments A & B.
- The language used in the forms is such that many persons with intellectual disabilities could not read the form correctly or really understand the concepts. For example, the Privacy section on page 7 of the Review of Mobility Allowance. I accept that it is difficult to cater for every individual's need but, at present, it would appear that it is assumed that all persons with disabilities have the similar levels of intellectual ability and the same levels of literacy.
- For this Review of Mobility Allowance form, there is no reason why Centrelink could not ask simply if circumstance have changed since the last review & provide the data as they do with the Centrelink Statement for Disability Support Pension. This would be much simpler for all concerned.

Thank you for the opportunity to raise these concerns.

lan & Heather Alcorn QLD

28 June 2010

ATTACHMENT A

The Manager Centrelink PO Box 312, Sunshine VIC 3020

Dear Sir,

My letter is related to Forms & information requested by Centrelink and is specifically related to the Form MA003.0710 – Review of Mobility Allowance.

Firstly, let me explain the reason for this. My wife & I are the carers of our daughter, Robyn, who has an intellectual disability and is in receipt of the Disability Support Pension. Whilst Robyn is reasonably independent in many living skills, she is very limited in literacy and numeracy skills and consequently any decision making that relates to financial matters is made by us. We, as is the case for many parents in a similar situation, become the persons responsible for the completion of all Centrelink forms. In relation to this, I would like to raise the following issues:

- 1. There is considerable repetition in the information required. For instance, the Review of Mobility Allowance, which is a 7 page document, requires us to provide you, once more, with considerable information that you already know. All the information you seek in reference to personal details, hours of work, payments and the employer are already known as you provide it to us when we receive the Disability Support Pension Account Statement every three months. Why is it not possible to refer to this data in relation to the Mobility Allowance Review?
- 2. In relation to the **Mobility Allowance Review**, why is it not possible to provide us with the information you already have and request that it be updated, if necessary, as this would be the same format as required with the **Disability Support Pension Account Statement?**
- 3. The format of this form (Mobility Allowance Review), is cumbersome. In our situation, only one page of seven is relevant and again with information from other sources, why is it not possible to individualise these forms. I accept that information requires to be updated but it could be collected in a much more simplified manner.
- 4. Related to the above issue, is the form designed for the person receiving the allowance or for the carers/parents completing the information? It would seem that these forms are designed generically for persons with a disability and do not, in many respects, consider the person's disability. In our situation, Robyn would be unable to read or comprehend very much at all on the Mobility Allowance Review. Therefore, for persons with an intellectual disability or learning difficulty, this form is totally inappropriate. It would be a different matter for a person who has a physical or hearing disability and has competent literacy skills, as they would be able to read and understand what is required. So, if it is required that carers/parents complete the form, why design it differently from any other form?
- **5.** Another consideration is who actually signs the form (Question 19). One presumes it is signed by the person to whom it is addressed (in our case, me as a parent), as I am the person providing the information & therefore the accountable person. This needs some clarification on the form as the recipient (the person receiving the support) may sign it with a very limited understanding of the implications.

- **6.** This consideration also applies to some of the additional information given on the forms, for example, the Privacy & your personal information paragraphs on page 7. My daughter would not be able to read or understand this material. Others, with non-intellectual difficulties may, but why confuse those who don't understand?
- 7. The purpose of this form needs further clarification and a simple explanation. It is obvious that the data is necessary if the **Mobility Allowance** is going to be continued to be paid and again, who is this explanation aimed at, the carers/parents or the recipient? What is not stated is under what circumstances is the allowance changed? I have tried on many occasions to understand this, but it is never made clear why the allowance is varied, especially if the recipient has not altered their employment circumstances. If there is to be a change in the amount payment, suitable explanations should be provided.

I would hope that you consider these concerns appropriately. My daughter is fortunate in that she has two parents who are able to advocate for her, while there are many adults receiving this financial support, who are not so fortunate. Many become totally confused by the accountability requirements imposed by Centrelink and whilst I totally support the need to distribute these funds in an equitable manner, I consider it could be achieved in a far more user friendly way. The majority of persons with intellectual disabilities do not deliberately set out to defraud anyone (unless they have been instructed by some other person); in many cases they simply do not understand what is required of them. Therefore, as a carer/parent, who seems to be frequently supplying similar sets of information to your department, I urge you to consider data collection systems that are for the betterment of all concerned. Yours sincerely.

lan Alcorn QLD

14 January 2008

Copies to:

- 1. Ms Kerry Rea MP, Member for Bonner.
- 2. Ms Helen Bedford, Branch Manager, Disability Policy & Coordination Branch, Department of Families, Housing, Community Services & Indigenous Affairs

ATTACHMENT B

The Manager Centrelink Customer Relations Reply Paid 7788 Canberra BC, ACT 2610

Dear Sir

I am requesting your assistance in a matter involving the **Mobility Team located in the Centrelink Office**, **Sunshine**, **Victoria**.

On 14 January, 2008, I wrote to the Manager of the Sunshine Office in relation to a number of matters about Mobility Allowance information & forms (a copy of this letter is attached). As I have indicated in the letter, I am the parent of a young adult who receives this allowance and I believe that the matters I have raised are legitimate concerns. As of the 25 March, 2008, no acknowledgement or response had been received. I phoned the office of the Area Manager, Ms Lees & spoke to her assistant who followed through my concern very promptly and after calls from several staff, I was called by Jacquie, the Mobility Team Leader. Nobody was aware of my original letter and at the time of the phone call I did not have a copy with me, however I explained in general terms some of my concerns. I was asked to forward a copy of the letter and did so on 28 March. This was sent directly to the Mobility Team Leader. **To date, I have still have had no reply.** Several issues concern me about this matter:

- 1. Whilst, I don't expect policies & procedures to change overnight, I do expect some acknowledgement of correspondence.
- 2. I also expect that if there are legitimate concerns, then Centrelink staff, at all levels, advocate for appropriate change.
- 3. If my concerns, as an advocate are ignored, are those disabled clients who have limited abilities and communication difficulties, treated in a similar manner?

I look forward to your assistance in this matter, as all I am really requesting is that the appropriate staff are aware of these issues and are really considering the needs of disabled people and their carers.

Yours sincerely

lan Alcorn QLD

1 May 2008