Submission to the Productivity Commission's Draft Report on Disability Care and Support (4.5.11)

Del and Kevin Smith

- 1. We are very happy to see these reforms being suggested. We are optimistic of a better future for our boys and family with this new scheme.
- 2. Life with 2 children with autism has been very difficult physically, emotionally and financially. We still have a long journey ahead. As "caring" does not end when the child leaves home, if the child leaves home, our second income is unlikely to return easily. We have had only one income available during the largest portion of our boy's lives (currently almost 15 and 11years) it has been a huge struggle. The second income available would have been approximately \$85,000 as a Level 3 Had of Learning Area in a Senior High School.
- 3. In addition to 2 boys with autism, wife is the primary carer for her elderly mother. This multiplies the difficulties associated with being a carer, accessing respite, etc. This does not qualify wife for the Carer Payment, only the Carer Allowance and is not a replacement for the income she has lost. Partial payment for the caring time required would enable this caring to continue at home for a much longer term and at much les cost to the taxpayer.
- 4. We are not at all happy with a "fixed upfront contribution" as is being suggested on some services. We have paid and continue to pay taxes. We did not choose to have children with disability and are struggling along on one income. This is unfair, as it makes it a user (STILL) pays system, still disadvantaging the individual and carers. People will have to or chose not to access those services as it will be a bigger burden financially. It must be made clear IF "SIGNIFICANT UNPAID CARE" would allow for a waiver of this contribution.
- 5. Really appreciate if assessments will only occur periodically, rather than as they are now.
- 6. Consider what is "reasonably and willingly" provided by families and unpaid carers. This is not sitting well with us due to the circumstances we find ourselves in. Perhaps packages should be evaluated without this encumbrance. Having family, friends and volunteers truly willing and able to take on part of the caring and decision making role is a bonus this statement makes it sound like an expectation.
- 7. The Commission should provide guidelines for charges for "Case Management and Coordination" this is one of the biggest rorts of the current system.
- 8. We believe this scheme should be funded from consolidated revenue, not a levy or new tax.
- 9. Choice is a big positive with this proposed scheme.
- 10. We believe Carer Payments, Carer Allowances and Disability Pensions should all come under the umbrella of this scheme and require a major review also.

- 11. All along our journey we have and met many others who have found it very frustrating to access the information they require about the diagnosis process, the disability, the services, the therapies, school options, and the respite funding options available. I'm sure we will continue to have these frustrations as our boys head into post-school options and accommodation options and eventually becoming an elderly person with a disability. This new scheme should provide a one-stop-shop/National Registry for all of this so that this frustration and stress could be greatly reduced.
- 12. In Western Australia we have Disability Services Commission Local Area Coordination ~ although our experience of this service has been generally successful it is a bit hit and miss. Well managed, this would be an excellent model for the local support for a NDIS.
- 13. We have concern that the examples given appear to have a focus on Intellectual and physical disabilities only autism and mental illness must be included for this to be a comprehensive scheme.

Thank you for the opportunity to make a submission after the draft report.