Submission No 58

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

Name:

Mrs Alison Simpson

Date received:

6/09/2008

The Director, General Purpose Standing Committee No 2 Parliament House, Macquarie Street, Sydney NSW 2000

6 September 2008

INQUIRY INTO THE PROGRAM OF APPLICANCES FOR DISABLED PEOPLE (PADP)

Dear Sir/Madam

Apologises for this late submission into the PADP inquiry. I hope that my comments may still be considered as I have only just become aware of the inquiry.

My son Maxwell Simpson is 11 months old and unfortunately was born with two genetic abnormalities, and as such Max has a long list of complex medical problems. Due to Max's inability to orally feed he has a gastrostomy peg and we receive limited enteral feeding sets through PADP.

While we are grateful to receive some support from PADP it is also with great disappointment that we are forced to make up the 70% shortfall in supply (we currently only receive ten feeding bags a month). This shortfall is an enormous cost and adds to the financial and general stress of the household. It is a stipulation of the medical supplier (and government guidelines) that the feeding sets are only for singular use, however PADP tell us we need to wash and reuse these items to cover the gap - quite contradictive directives. My son has an immune system deficiency as part of his Velo Cardio Facial Syndrome, we do everything we possibly can to reduce contamination. Reusing a bag that has been continuously used for a 24 hour period greatly increases this risk.

Also, I am at a loss why Victorian residents receive 100% of their enteral feeding equipment and NSW residents have to be content with receiving only 33%. In addition, the response to need and level of supply greatly varies throughout NSW depending on the supply hospital/hub.

I appreciate the opportunity to be heard and look forward to hearing the outcome of the inquiry.

Please do not hesitate to contact me should you require more information.

Yours faithfully

Mrs Alison Simpson