Supplementary Submission No 43a

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

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29th October 2008

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The Hon Robyn Parker
Chairperson
General Purpose Standing Committee Number 2
Parliament House
Macquarie Street
SYDNEY NSW 2000

Dear Ms Parker,

IRSA participated in the Legislative Council's inquiry into the Program of Appliances for Disabled People by making a formal submission and then by giving evidence at the public hearing on 2nd October 2008. We also attended the public hearing on 24th October 2008 and would like to clarify a number of issues that arose from the evidence provided by the NSW Department of Health.

1. Dr Matthews and Ms Lynch made reference to an article in the *Australian Occupational Therapy Journal* in regard to equipment abandonment rates. The Department has raised this article on various occasions and we are concerned that the data and findings are not being correctly understood or represented and could give a skewed view of the facts. Please refer to the attached explanation regarding this article.

2. In response to a question from the Chair about equipment repairs and maintenance, Dr Matthews advised the Committee of a departmental "Business Processes Working Group" that is looking into the issue. Later, the Chair asked whether suppliers, who "are a valuable source of information", were part of the working group and Dr Matthews replied that he was uncertain as to whether suppliers have a peak, representative group. IRSA is NSW's largest representative group for equipment suppliers and we estimate that more than 75% of the equipment purchased by PADP is either manufactured or supplied by our members. IRSA is constantly trying to work with the Department to assist with improving the efficiency and consumer outcomes of PADP and seek representation on this and other relevant working groups.

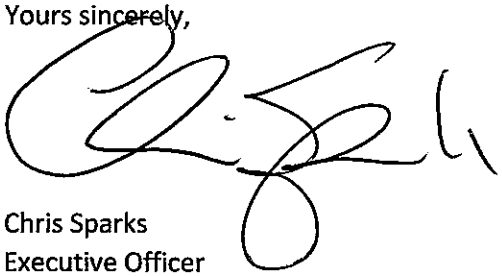
3. Mr Ian Cohen highlighted the fact that Dr Matthews' dissection of waiting lists/times into two categories (namely waiting for assessment and waiting for equipment manufacture), ignored the greatest area of delay which is waiting for funding approval. In our experience, the time taken to have funding approved is responsible for between 40% and 80% of the wait experienced by the consumer and should therefore be a critical KPI which is closely monitored and reported by the Department.

4. In response to questions about the hygienic and safe use of feeding tubes, Dr Matthews raised the role of the Therapeutic Goods Administration (TGA) in determining uniform

standards etc. We are uncertain as to whether this is actually the case and would encourage the Committee to make direct contact with the TGA to clarify the situation.

On behalf of IRSA and all of our members, I would like to thank all Committee members for taking the time to inquire into this critical public issue and we look forward to your final recommendations.

Yours sincerely,



Chris Sparks
Executive Officer
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UNDERSTANDING EQUIPMENT ABANDONMENT

In a recent "Viewpoint" article in the Australian Occupational Therapy Journal discussing the role of clinicians in prescribing Assistive Technology (AT), Waldron and Layton states -

> "Scherer (2002) cites five studies investigating non-use (of AT) which state abandonment rates ranging from 30 to 59%".

This figure has been used recently by several NSW Department of Health officials when discussing the state of PADP in NSW. However, alternative, larger research studies put the figure of non-use at between 1% and 11%.

Before using any of these figures in decision making, it is important to consider whether the figures are valid and what they really mean.

A figure of 59% non-use of Assistive Technology would certainly indicate that there is a significant amount of wastage in the reimbursement system. However, the research into this area has shown widely varied results. The rates of non-use given in the literature range from 1% up to 80%. Such a massive discrepancy between research projects indicates a lack of reliability of the results and suggests that it is difficult to generalise the data to other settings.

One of the most extensive research projects into this issue was conducted in the Netherlands, where assistive technology usage of over 2000 consumers was checked after 3-24 months of use. Dijcks et al (2006) found that less than 1% of respondents never used their equipment and that only 6% of respondents used their equipment less than expected.

Another study by Haggblom et al (2007) surveyed 649 people in an initial study and 280 of those in a follow up study ten years later and found a non use rate of assistive technology of around 11%. The most common reason for abandonment was either functional improvement or a functional change for the worse.

The differences in results between studies can be explained by the fact that the different research studies are measuring -

- Different assistive technology devices – is the study measuring non-use of walking frames, communication systems, wheelchairs, walking sticks or long handled reachers?
- Different definitions of discontinuance – is the study measuring no use at all, no frequent use, no correct use etc?
- Small sample sizes - eg Verza et al (2006), who found an initial non-usage rate of over 50%, had less than 55 subjects in their study.
- Local situations which may result in different usage levels – eg whether the consumer is involved in decision making or only standard products are supplied etc.

Discontinued, abandoned or just not being used?

A further question that must be considered is what does abandonment of devices really mean? Consider some examples -

- James is a 6 year old boy with cerebral palsy. When he was 4, he was prescribed a buggy to meet his mobility and postural needs. The buggy has worked very well in his family and pre-school environment, but now he is attending school, he needs a wheelchair that better meets his needs for school.
- Philip is a 14 year old boy with Duchenne muscular dystrophy. Because she knew funds were tight in PADP, his therapist only asked for a standard powered wheelchair, rather than one with tilt in space. But now, 18 months later, Philip cannot sit in the chair he was prescribed and a new request is being submitted to PADP.
- Edna is an 85 year old woman, with severe arthritis, who lives with her husband. She requires a shower commode for showering. As a low cost item, this was ordered through a bulk supplier (eg OfficeMax). It was delivered in a box on the front porch 3 months ago, and has been left there ever since as neither Edna nor her husband can physically manage getting it out of the box.
- John is a 50 year old man who had a stroke ten years ago. Two years ago, his therapist put in an application through PADP for a scripted manual wheelchair to allow him to independently self propel. The wheelchair funding has just been approved and sent through to the supplier. The therapist no longer works in the service, so the supplier ordered the chair without reassessing the client. Unfortunately, John has since put on 25 kilos, and the chair no longer fits.
- Cathy is a 45 year old woman who had a traumatic brain injury following a fall from a balcony 2 years ago. Following discharge, she was prescribed a manual wheelchair, but 2 years later, following intensive therapy, she can now walk independently, and the wheelchair is no longer required.
- Julia is a 50 year old woman with multiple sclerosis. Her therapist insisted that Julia required a powered wheelchair for mobility. Julia felt that using a powered wheelchair would be "giving up" and she preferred to stick with a manual wheelchair, even though it means less mobility and independence. But the therapist went ahead and prescribed the powered wheelchair, which sits unused in the garage.

All of these people might fall into the category of "abandoning" their equipment - some of them for positive reasons, some for negative reasons. Without understanding the reasons why the equipment is no longer being used, the statistics have very little relevance. In fact, the Assistive Technology Outcomes Measurement Systems Centre (ATOMS) recommend abandoning the term "abandonment" in favour of discontinuance, to avoid the negative connotation and highlight the need to discover why the equipment is no longer in use.

So what is the situation in NSW?

Given the large variation in results in overseas studies, is discontinuance a problem for PADP? Unfortunately, there are no published statistics on the rate of discontinuance in NSW for equipment funded by PADP. Without this data, it is impossible to ascertain whether there is significant wastage in the PADP system due to discontinuance. Anecdotal feedback from the MASS program in QLD suggests that non-use of equipment following poor prescription is relatively uncommon, and that the main cause for return of equipment is a change in functional needs, a change in size or the equipment being due for replacement.

What can be done to reduce the rates of discontinuance?

Djicks et al (2006) found that one of the key reasons for discontinuance was that the product didn't meet the consumers needs, but had been chosen because it was the "easiest" product to obtain under the insurance/funding guidelines. Phillips and Zhao (1993) found that where consumers were not involved in decision making regarding assistive technology that they were less likely to accept the equipment. Verza et al (2006), in the study mentioned above, found that non-use of assistive technology dropped from over 50% to under 10% where a multi disciplinary team were involved in the prescription process.

Based on these studies, as well as our own experience, there are several steps which can be taken by PADP NSW to reduce discontinuance of assistive technology devices -

1. Involve consumers in decision making and provide them with choices regarding the type of equipment prescribed (Phillips & Zhao, 1993).
2. Ensure that the focus of equipment prescription remains on meeting consumer needs, rather than trying to fit consumers into a standard product to avoid inappropriate prescription of easy to fund items (Djicks et al 2006).
3. Have a multidisciplinary team involved in equipment prescription (Verza, 2006, Waldron and Layton, 2008).
4. Reduce the waiting time between prescription of equipment and approval of funding to ensure prescriptions are as accurate as possible.
5. Keep statistics on the discontinuance of equipment use, the type of equipment being discontinued and the reasons for the discontinuance, in order to address specific problem areas.
6. Have a clear recycling procedure, including costs allocated for servicing of products and ensuring that inappropriate equipment is not supplied to consumers.

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