Submission
No 10

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

Name: Suppressed

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NSW Health
Submission on PADP
NSW PARLIAMENTARY INQUIRY INTO PADP
STATE PARLIAMENT, SYDNEY 2001.
To Whom It May Concern

Dear sir/madam,
I am writing to highlight the difficulties and frustration I have experienced over the past eighteen years with the administration, operation and personnel of the PADP system. The constant delays in approving and supplying equipment and repairs are most unrealistic. These in my opinion are caused by insufficient funding by the NSW State Government through NSW Health and no one willing from either PADP or OT departments to take a stance about the inadequate funding that is so inherent of the failing system. Every time any of my equipment needs servicing and replacement of parts I am told that the equipment is too old and if there is no available equivalent than those items will be withdrawn, put simply, I will be without that particular equipment. When my electric bed broke down (a nylon moving part snapped) it took Mt Druitt PADP eight weeks to repair it. A new piece could have been sourced from the manufacturer or even made locally but PADP decided to replace all of the electrics on the bed and this added unnecessary time delays to a simple process and wasted much money because the part used about 50cents worth of material and would retail for about $2-$5 at most. Their policy of not fixing anything under $100 leaves clients out of pocket or out of adequate service. They did not even bother to contact the original supplier of the bed to see if availability was possible. At one stage I was told that the bed would have to be replaced in entirety, but as there were no funds available it would be at least six months before I received a new one if one was available then. When the crane (that puts the base of my wheelchair consisting of wheels, motors, computers, batteries and seat base board of my wheelchair, some 120kg weight into the rear of my Camry wagon) broke down it took Mt Druitt ten weeks to get the necessary replacement part because of their own incompetence and inflexible method of dealing with suppliers and replacement parts. The required part was always (and seemingly forever) on an overnight flight from Melbourne but PADP would not pay the part supplier the $800 for 90 – 120 days while he had to pay cash for the part and like many others have their funds tied up and can't afford to carry the lengthy PADP payment procedures. Meanwhile I was struggling trying to get my wheelchair into my car. This left me in much greater pain than usual and at greater risk of sustaining further life threatening injuries and permanent loss of the little mobility I have left but this did not phase PADP, they simply did not care to show any concern for me, my equipment, my car or my ongoing well-being; just as long as they did things their way because there was never ever going to be any alternative as far as they were/are concerned!!! Surely this incident requires some investigation. Past history has been that this crane can break down during loading or unloading leaving me without the use of the crane, the 'chair or the car; you don't need a science degree to work out how such an outcome has a detrimental impact on me. If at any time the crane should become faulty again I will have to resort to using a manual 'chair (this poses further risk to me as I have a lot of damage to my spinal column and nerves

apart from the spinal cord injury) while PADP procrastinate about repairs and more than likely I will again be under threat of having the crane withdrawn from use with no suitable replacement or method of getting my dissembled wheelchair into or out of my car. The overhead crane on the cars roof for the manual 'chair has not worked since December '06, it too needs repairing but I don't have money for it. I am really struggling with my pathetic Centrelink pension and just finding enough money to live on is nearly impossible these days. I need to replace my 20 year old car not buy something that PADP should have replaced long ago. The problem compounds; my original manual 'chair supplied in 1991 broke in 1995 and was repeatedly repaired at my cost while I was at Uni but it remains held together by bits of wire and not satisfactorily useable due to metal fatigue and breakage. PADP have refused to replace it. When the same old chair broke a front wheel fork during the Sydney Games in 2000 I had to fund the repairs myself because PADP refused to help me. Out of frustration I eventually bought a second hand 'chair that was not built to my specification and a ROHO seat twelve months ago and paid $500 for the 'chair and $300 for the ROHO seat, money that I did not have and should not have had to find but for PADP's refusal for assistance; the old 'chair was unsafe and it needed to be replaced before it broke again. I use a manual 'chair to get into my doctors surgery because my motorised 'chair is too big for the tight corners of the surgery rooms. My current electric wheelchair weighs 160kg, it is now 2 years old and when I rang for a works order number for repairs (standard practice when needed) in January this year after puncturing a tyre and ripping the tube I was confronted with more of the same rudeness as always by Mt Druitt PADP staff. It was too much bother for them to assist me, they were aggressive, said they would not email or fax the order number for repairs to the repairer, that as it was just a puncture I should be able to fix it myself, it did not need an order number and they weren't going to supply one, then it was to be repaired at my cost, when I said it was a workshop repair and not something I can fix because of the 'chair set-up and weight and that I had already driven 2kms on the damaged tyre to get home before I was able to phone them and the wheel needed assessment for damage and possible replacement this explanation meant nothing to them. They later changed their tune and said I would have to wait until the following week for an order number and the repairs would then be completed, I explained my program did not allow for that time frame nor did it allow for me to be without the use of my 'chair. They eventually relented and supplied the works order number but not before claiming I had received extra sets of tyres and tubes at the time the 'chair was supplied to me as is their current policy. However, I was never issued with additional tyres and tubes and it is now some eight months after the one and only tyre puncture I've had in 18 years of wheelchairs **AND I have still not been supplied with extra tyres and tubes for it.** PADP's hostile behaviour centred around me calling on a now old phone number originally issued as first line enquiry for assistance and now kept secret for some unknown reason and not to be used by clients; I rang them on the only phone number I could find but it was the wrong number. How pathetic and petty of them to react in this way to a request for help. Very soon I am going to need to replace the original tyres as supplied with the 'chair because they are approaching excessive wear and right now I need the air cell in my seat replaced because after five years of use it is leaking but like everything that involves PADP I put off dealing with them because of their rudeness and arrogance and I don't have time or room for that in my life, nor should I or any other person dependant on PADP. **Life is too short and not to be wasted with rudeness from PADP!!!**

My OT use to tell me that there might be other equipment on the list of supplies from PADP that I should look into with a view of them being supplied but every time an application goes in it waits up to 12 sometimes 18 months before it goes to committee for basic approval and then the 'system' takes up to 2 years to provide approved items; that's if the equipment is considered a number 1 priority, if it's not number 1 but is perhaps a lower priority it may never be provided even if it has been assessed and approved by an OT and seen as highly needed or beneficial to the patient. Bear in mind that OT's and doctors are reluctant to say what is needed for patients these days for fear that lengthy delays or 'no supply' situations will leave them red faced and ridiculed, it's considered to be bad for business.

Wheelchair suppliers are asked to requote on approved purchases 2 and 3 years after initial patient measuring. After the need for the new wheelchair had been established, the OT took 3 months to make an appointment for measuring and the quote was supplied and submitted to the PADP committee, approved for priority 1 and sat for two years before it saw the light of day again; then it had to be re-quoted and re-assessed on the new price scale and then it waited for the next government budget injection of funds before it was ordered from the supplier; and with other orders ahead of it then took 4 months in production time. PADP constantly adds unnecessary, lengthy delays in equipment procurement and hang on to funds when items of equipment are seen as essential and necessary for patient rehabilitation and to restore quality of life and freedom of mobility and the chance to participate with family, friends and community. These things just mentioned should be treated with the utmost urgency not shoved into the bottomless pit of inability to supply.

Before leaving paid employment and before I needed a wheelchair I was involved in material procurement, manpower requirement and workforce distribution, machinery allocation, scheduling, dealing with contractors, media publishers, pricing policy, product training and problem solving of engineering projects. For 16 of the last 18 years that I have been in a wheelchair I have sat on many committees and participated in advising 3 levels of government (sometimes directly) on disability access issues related to buildings and transport. I have been effective in town planning in the Blacktown CBD and surrounding areas and I have received two Australia Day Awards from Local Government and other awards for my community work being overall winner in category in 1996 and nominated for Citizen Of The Year; I believe I could make a worthwhile contribution as a community representative on any PADP local committee should an invitation be extended to me but it grieves me greatly to see so much time wasted in procrastination and poor decision process as experienced with PADP. I am not convinced that one big centralised PADP will make all the present problems disappear and solve all the inherent bungling of a neglected, under-funded, and ill managed scheme that PADP has become. It will almost certainly end in one almighty bottleneck with even less equipment and repairs filtering through the system and longer delays in supply. It's simply unacceptable that clients of the system are so disadvantaged and inconvenienced when it comes to equipment supply and repair of what is essential mobility aids and meant to give some quality of life and increased participation with family and community. PADP personnel are at best glorified clerks with seemingly little or no mechanical aptitude or knowledge of how mechanical things work and they show complete contempt for anyone that does have that knowledge and experience. PADP should be about more than just supply of equipment, it should embody empathy for the lives it touches, it should have and be seen to have concern for its clients welfare, after all, is it not an extension of government for the people? or have I got something confused or wrong here?

I'm guessing by now you have sensed my frustration with the present system is very high. Living with progressive disabilities is really difficult enough without having a government body that is there for support and help adding to that frustration. Since St Joseph's Auburn, Westmead, Blacktown, Mt Druitt, Nepean and Hawkesbury were combined into one body the service aspect has gone noticeably downhill and rife with patient abuse and lengthy delays a regular occurrence. Am I dissatisfied with outcomes from PADP? You can bet I am. My only remaining concern now is will I be further disadvantaged with future supplies from them and suffer recriminations for speaking out so openly? I hope not. I hope that my criticism is seen as constructive with the possibility of improving this service for the benefit of those who through no fault of their own need to avail themselves of the equipment on offer. With regard to the $100 contribution from patrons/recipients this is far too disadvantaging to a single person on a pension of just $269 per week and should be reduced in such cases to not more than $30 maximum which in itself is extremely difficult to find these days. The only way forward for this under resourced facility is to have more suppliers of similar types of equipment thus providing increased competition and lower prices at the other end. It cannot be expected to improve on supply times without more funds being provided to it from the Governments budget. When dealing with and planning for disability and ageing in the community it should be remembered that the cost is far greater than the sum of its individual parts in terms of supply of goods and services and also in terms of suffering and the experience of the affected parties involved. In other words, the hidden cost of disability has greater impact as a person ages; I'm talking about the social isolation by being cut-off from family, friends and the community. Having suitable equipment is essential in any attempt of maintaining established relationships and building new friendships.

I sincerely hope that the information I have provided here is put to good use in re-constructing a properly managed PADP system.

Yours sincerely,