

To: Committee Secretary
Senate Standing Committee on Community Affairs
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From: Val Pawagi

Inquiry into Planning Options and Services for People Ageing
with a Disability

My contact with the state disability services system dates back to the early 1990s when the Commonwealth transferred responsibility for the Attendant Care Scheme to the states and territories under the first Commonwealth State Disability Agreement. I continue to receive the same assistance today under the guise of an Adult Lifestyle Support Package through the Queensland Department of Communities (Disability Services).

As a person with a lifelong physical disability who is of mature age (over 45 years), I found myself in need of additional support earlier in the year when I was diagnosed with ovarian cancer. I applied for additional support through Disability Services upon my discharge from hospital.

My contact with Disability Services during this difficult time was disappointing to say the least. They presented as generally uninterested in my situation. They did not go out of their way to visit me, nor did they see the need to officially review my support needs. Instead, Disability Services asked me to complete one of their standard forms, which I found unnecessarily lengthy and unclear, and posted it within a week of being discharged from hospital.

I received a letter from Disability Services about two weeks later stating that I had completed the incorrect form. They had formed this view as the service area processing my form had no record of me as a current service user. I had indeed completed the correct form. It had not occurred to them to contact me as to my reasons for completing the form I did.

After sorting out that matter, it was only when I was half-way through my chemotherapy treatment (May to August) that I received a phone call from Disability Services telling me that an extra 40 hours of support had been approved. To this date, I still have nothing in writing about this decision.

Equally as disappointing was that my then service provider also did not see the need to visit me to reassess my support needs. They, too, mentioned

nothing to me about any additional support being approved by Disability Services. My service provider did, however, provide me with some additional support (around 1 hour a day) at my request through their rostering area. I knew that this additional support could not be sustained over a lengthy period as my Adult Lifestyle Support Package would not cover these extra costs.

Thankfully, soon after being discharged from hospital, my employer put me in contact with Carers Queensland, who in turn put me in contact with Carers of Disabled Adults (CODA). CODA was able to provide me with the additional support I needed during this difficult time. I was advised that this additional support was funded through the Home and Community Care (HACC) program and not Disability Services. That support ceased at the end of September.

After my positive dealings with CODA, I asked Disability Services to transfer responsibility for my Adult Lifestyle Support Package to them, which has since occurred. I returned to work in early October.

In telling you my story, I was hoping to highlight the significant gaps in the planning and availability of additional services for older people with disability already known to the state disability services system and whose support needs have changed. It seems that, once funding has been allocated in respect of a person with disability, it is assumed that their support needs will remain the same or static over the life course. This is simply not the case. My support needs today are certainly greater now than what they were some 20 years ago, and no doubt will increase even further as I get older. My primary carer meets my additional support needs at present.

From my experience, formal reviews of the support needs of older service users are not conducted on a regular basis by the state disability department responsible for funding service providers. In the last 20 years, I have had three such reviews – one by the Commonwealth in 1990 when they had responsibility for the Attendant Care Scheme, one by Disability ACT under portability arrangements and one by Disability Services in Queensland under portability arrangements. Such reviews, therefore, have not been routinely undertaken and have been precipitated by administrative changes rather than a genuine interest in whether my support needs are being adequately met.

Even though procedures are in place to apply for additional support through the completion of a standard form, I have my doubts as to whether there is any policy framework in place for dealing with older service users whose support needs have changed. It is safe to assume that the support needs of older people with disability will increase with age. Hence, the importance of such a policy.

There also seems to be a heavy reliance on the service provider to relay changes in the support needs of older people with disability to the state disability department. Even when the service provider does relay this information, the response from the state disability department is generally unfavourable. In these situations, the older person with disability is faced with 'under-met demand' and, as a consequence, their overall health and well-being is likely to suffer.

These administrative inadequacies – a lack of policy, commitment, planning and services on the part of the states and territories to address the changing support needs of older service users – need to be addressed through whole-of-government fora. What is needed here is fundamental state disability services system changes, not more of the same.

(Electronically signed)

Val Pawagi

Thursday, 3 December 2009