Dear Commissioner,

Firstly I must apologise for the late arrival of this correspondence, however as indicated to Ineke Redmond of your office a few minutes ago in our phone conversation, I was unaware of the April deadline for submissions relating to the proposed NDIS. In fact, at the NDS Congress held in Melbourne in May ’11, I was led to believe that further submissions were to be accepted up until the final report was due to be submitted to the Government in July ’11.

I will attempt to be as succinct as possible with the matters I wish to raise. Our organisation caters for the needs of over 300 South Australians whom are affected by either Spina Bifida or Hydrocephalus. As you may be aware, Spina Bifida is a physiological condition, and Hydrocephalus (which occurs in 90% of cases with Spina Bifida) is a neurological condition relating to fluid on the brain.

I was very pleased to hear at the NDS Congress of proposed additional Government funding and the initiative to make disability core business for the Federal Government. My concerns however centre around the individual funding model and self management of services for people such as our clients/members with Hydrocephalus. Our organisational purpose is to improve the quality of life for our members and whilst additional funding will greatly assist in that regard, there are significant concerns about the ability of many to be able to manage their financial affairs and to even make discerning choices about who best to source their services from. Hydrocephalus gives rise to cognitive, memory, behavioural and personality disorders and these issues will inevitably limit their ability to ensure the best outcomes for themselves.

Many of our members rely on our organisation quite heavily. We offer Outreach Nursing Services, medical (and other) subsidies, social inclusion programs, advice and information about the conditions as well as a range of other issues where our members need assistance. An example of this is in situation where for example, members have come to us with excessive and overdue utilities accounts due (ie phone, power, gas etc) which are about to be disconnected. In these cases we mediate and negotiate on their behalf to assist them to avoid having essential services cut off.

These issues are a function of the cognitive problems associated with Hydrocephalus, and are not restricted to only accounts due to be paid. Sometimes the issue may relate to co-ordination of medical and specialist services provided by others, since many of our members are not in a position to be able to make decisions in their own best interest. This being the case, we have significant concerns about the proposed self funded and self managed service model for many of our members, which appears to be a key feature of the NDIS. Many of our members will continue to rely on our own services once an NDIS is introduced, however there will be proportion who are likely to be influenced by the last person who they spoke to and if that happens to be an unscrupulous service provider then the possibility for squandering or mismanaging their own finances will exist. Not to mention the risk of making the wrong decisions about who best to cater for their many and complex needs.

Our organisation was formed over 40 years ago by parents of children with SB & H who were seeking the best care and support for their young ones. In spite of our exceptional reputation, sound governance and ability to deliver excellent services, we currently receive less than 4% of our annual revenue from our own State Government – even though we have tried to secure an increase to that figure. We receive no Federal Government funding at all and as such, must fund the majority of our services through our own Call Centre and Doorknock Appeal programs and other fundraising activities. Contrary to common perception, Disability SA (our State Government’s department established to deliver services) does not meet the needs of many people with a disability such as SB & H in this state. A number of our members prefer not to deal with DSA due to past experiences. As such, the role we play within the sector for our members is vital. Disability SA (DSA) staff often contact us for assistance and advice about SB & H and in relation to our own members that they may be in contact with, because they do not have the knowledge or resources needed. On one occasion we had a call from DSA staff member who wanted us to provide a nurse to change bandages twice a day one of our members who was in country hospital (Murray Bridge – 80 kms away) for a period of seven days. We have only one nurse to accommodate the needs of our 300+ members, yet DSA and the SA Health Commission are well funded to care for their own patients/clients.

When the time comes I would welcome discussions and involvement in developing a structure to best accommodate the needs of our members in relation to the NDIS. For the reasons I have stated above however, careful consideration must occur in relation to how are members and their carers are provided with funding and assistance, otherwise the new system may well create more problems than it solves.

Please feel free to contact the undersigned if I can be of assistance.

Regards

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