

## Money, Money, Money

There is a fundamental lack in the Disability Services as a whole which is money: money for many types of services, including: money to boost the scarce full-time accommodation; money for education; and money for respite, therapies, equipment and equipment repairs. Anyone reading this might comment that such a statement is glaringly obvious and that it is not easy to squeeze money from government - even though, on the 25<sup>th</sup> September 06, news was trumpeted about budget surpluses both State and Federally. It is our contention the CSTDA would have more money if it could be used more efficiently by getting rid of the overly complicated system it now has by becoming part of the Health Ministry.

Why do we have to have repeated committee meetings, which cost thousands of dollars to hold, arguing and politicking about spending, say, \$2,000 only to end up deciding that there are not enough funds in the kitty to allocate the \$2,000? The disabled person is then put on a waiting list for years and years until they die a slow, undignified death. This is disgusting, degrading and depressing. Cruel for the disabled and cruel for their families. Why do we have to have whole departments of bureaucrats deciding who is going to get funding when everyone who applies absolutely needs funding just to survive at a minimal level?

Can you imagine yourself sat permanently in a wheelchair, with involuntary movements, a very low IQ, no speech, doubly incontinent, and limited sight? Society has deemed you should live out your miserable existence at whatever cost, euthanasia is banned for you. How do you learn to signal that you're in pain, are hungry, thirsty, tired? How do you physically get to Centrelink every three months to prove you are unable to work so you can get a pension which is totally inadequate when your nappies alone cost \$240 per month and then there are taxi cost gaps, medical fund and respite gaps, expensive equipment, etc. How do you fill out seven multi-paged reviews every three months for services that are vital for your very existence?

When you are grown it takes two adults plus a hoist to change your nappy. You need someone to buy your food, prepare it and feed you, someone to put you to bed, someone to wash you and your clothes, someone to order a taxi for you when you need medical attention and to go with you, of course. Every single need has to be met by somebody else who is abled. You need this level of attention from at least one carer 24/7 with no time off for the carer – no holidays, nor sick days, nor Christmas, nor birthdays, week-ends or evenings.

Normal working hours for full-time paid work are 38 hours per week. Normal working hours for full-time family carers, usually a parent, is 168 hours per week with no time to attend meetings. It would take 4.5 full-time, paid professional carers to replace them. Where is the carers' union? Why can't the money already allocated to the Disability services to aid the disabled be used more intelligently to actually help the disabled and their families? By providing insufficient services for the

severely disabled, please realise that at least three lives are destroyed: the disabled person who is left to vegetate; the full-time carer; and the partner of the full-time carer. Many of the full-time family carers end up with ill-health caused by the stress, the constant lifting of a heavy body, and the poverty that comes from financially maintaining a disabled person for the disabled person's lifetime.

Disability is absolutely and fundamentally a health issue and we already have appropriately qualified people to decide on what facilities are required by the disabled individual. These people are called medical doctors. Why aren't the Disability services under a health banner? If this was so, a specialist could list the requirements for each disabled person when they are first diagnosed and for permanent disabilities the required facilities are allocated to that person for life. As there are very few miracles for the permanently and profoundly physically and mentally disabled, there should be no need to constantly re-apply for the services they need. An annual check-up by the specialist should be conducted in any event and it is then that the specialist would review and sign off on the continuity of services. It is possible that some individuals would require to be seen by two or three specialists because of the severity of their condition.

Because of this link to medical specialists, all the government disability departments should be under the control of the Health Minister rather than have a special Disability Minister. The Disability ministry is seen as a poisoned chalice causing a rapid turnover of ministers and a lack of continuity in policies and with initiatives constantly on hold. This has certainly been true for WA with four ministers in the past eight months. If the Disabled Ministry is not considered as important as Health, why not disband this Disabilites and put it under Health? Sections such as AIDS, Drug addiction, Alcoholism, and Mental Health all come under the overarching umbrella of Health – why are the Disability Services not under health? Is disability not ill-health of some sort?

To summarise:

1. The most significant and important vital item is more money for full-time accommodation (CAP funding). There are far too many people with this type of unmet need.
2. Re-organise the Disabilities services into a cohesive department under Health, where decisions about services and needs are made by doctors and reviewed annually by doctors. The services prescribed by doctors should be provided automatically from diagnosis of the condition according to patient needs and without multiple form-filling.
3. Education for 18 years and over should be under the Education Dept., as is anyone else in Australia. The disabled are discriminated against as their adult education is not education but merely "post-school options" under Disabilities Services and Centrelink. Without a special extension, they are not allowed back into the education system. Normally-abled people have many, many options and budgets from both Commonwealth and State governments, whereas the disabled have only one meagre fund to draw on for every single one of their needs.