

Traditional Disability Support Services Culture of Fear and Beyond Reproach

Since time immemorial, people with disabilities and their families have been seen as a burden on society... The culture of the institutions remains underlying many support services –

"Leave your family member with us, go away and don't return. We are doing you a big favour, for which you should be eternally grateful and never, ever, complain."

Whilst families seek to support, protect and obtain the best services for their family member, they are often demonised by support services and agencies, especially by government direct support services.

One of the first avenues of support sought by families, is to continue to be legal parents when their vulnerable member becomes an adult by common law at the age of 18 years.

Yet agencies such as VCAT, in Victoria, will fight parents to the bitter-end on grounds of 'need'. These pseudo government agencies very assertively question why the vulnerable person is considered in 'need' of a legal representative.

Even for a person with very high support needs, these government agencies consider the person is not in similar need of 'parental support' as that which is accepted and legal for a regular 5 year old. Whereas their 18+ year old, with very high support needs, is far more vulnerable and in need of legal parents (plenary guardians). As their young adult is most likely functioning, intellectually, at a 3 year-old level, or less.

Families with a vulnerable family member, having battled early intervention and education services, now face the really awesome task of battling adult support services and agencies who are frequently a law-unto-themselves.

These services will often do all in their power to provide as little as possible, and be as difficult and intimidating as possible. They can easily be this way, as the disability field is, and always has been captive-market where consumers have little or no service entitlement – just charity-type handouts.

Traditional charity-handout culture, with no reason for customers or customer service, was developed from, and maintained through block-funding from government general revenue. This equals a culture of fearful consumers and beyond reproach service providers.

We hear the cry, "What about ISPs within the NDIS?" The Productivity Commission considered the ISP process was the only real way to break the captive market impasse, and move support services into the market place and towards entitlement services.

Although the NDIS (DisabilityCare Australia) has yet to start funding services, the state government of Victoria are providing more and more ISPs from state funds, many of which may be funded by existing group home residents, if the state government gets its way.

In theory, ISP money in the pocket of the consumer, to directly purchase support services, puts the consumer in the driver's seat to be respected and not in-fear of speaking-out to question service provision. There are, however, many factors which will distract/negate this potential consumer power. Traditional captive market culture will not disperse overnight.

Although the NDS is working hard to encourage its CSO members to quickly develop a market-place culture, consumers and their supporters will take time to gain confidence not to fear, but to challenge the traditional power-over-people enjoyed by service providers for so many years – especially by government direct services.

A further factor reducing the ability of consumers using their ISP to shop for services, is people with high support needs do not move or settle easily. Consumer choice for people with disabilities is significantly different to shopping between supermarkets. Many service providers will take advantage of this, in an attempt to reinstate the old power over people.

Despite movement towards ISPs, with consumers, in theory, at the centre of service provision and respected, many block-funded services are expected to remain for many years to come. This is where, for years, consumer and their family are often in total fear of the repercussions of daring to speak-out. And where the service provider management and staff must be totally respected no matter what they do or don't do.

If people with disabilities, their families and other stakeholders are ever to be given the respect other consumer groups take for granted, the whole disability service system needs turning on its head, to place consumers, rather than service management and staff, at the top.

Extra 1: [State Government's Disability Tax – LISA Media Release](#)

Extra 2: [Disgusting inequity by DHS Victoria – The Age, May 23, 2013](#)

Extra 3: [People with ID very poorly represented on the new NDIS structure - says DS, SA](#)

Extra 4: [Health and Dental care for our most vulnerable citizens](#)

Note 1: Service providers need to consistently and actively show consumers that services are being provided [within acceptable standards](#), not expect consumers to prove beyond doubt they are not.

Note 2: We are finally close to completing our aged-care field work. It has been a steep learning curve, but most enlightening. Especially in comparison with the proposed large increase in fees by the state government for many people with disabilities. The final outcome should make interesting reading – Stay tuned!

Note 3: When responding to the LISA Forum/Blogs, there is no requirement to complete the information block. There is no need to identify yourself - any name is fine.

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