SENATE STANDING COMMITTEE ON COMMUNITY AFFAIRS

REFERENCES COMMITTEE

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

SUBMISSION

SUBMISSION NUMBER: **78**

SUBMITTER

Lifestyle in Supported Accommodation (LISA) Inc

Submission to the Senate Community Affairs References Committee from Lifestyle in Supported Accommodation (LISA) Inc.

We acknowledge that on 30 September 2010 the Senate referred the following matter to the Community Affairs References Committee for inquiry and report by 31 March 2011, and that we have tailored our submission to the committee's terms of reference:

Access to options for and services to assist people with a disability and their carers to plan for the future, including:

- *(a) Inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers;*
- *(b) Ways to ensure the continued quality of life for people with a disability as they and their carers age;*
- *(c) The types of options and services that could be developed to help people with a disability and their carers to plan for the future; and*
- *(d) Any other matters which would assist carers to find an adequate and appropriate answer to the question: 'What happens when I / we can no longer care?'.*

The Mission Statement of Lifestyle in Supported Accommodation (LISA) Inc. is:

"The provision of quality of life care for all with an intellectual or multiple disability who live in supported accommodation, and that families need the support to be carers for as long as they wish to be, in the knowledge they have the right to a quality of life care accommodation and support package for their family member with a disability whenever they choose".

The Objectives, Activities and Statement of Purpose of Lifestyle in Supported Accommodation (LISA) Inc. is:

"To empower and support families with a member living in supported accommodation to better understand service provision procedures, care policies, standards and values, and thereby be better positioned to scrutinise service providers".

With reference to your terms of reference (a) ***"Inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers"***

We submit there is inadequate choice and funding options currently available to people with a disability per se, with age compounding the matter.

Although we have empathy for those families not able to secure the right service and support for their adult family member with a disability, our concerns and focus are on the quality of the services and supports, both current and future.

We are concerned that if and when funding, from wherever, becomes available to provide adequate choice and options, that this may equate to just more of the service quality problems we have at present, where service providers fail to implement the direction, intention and spirit of their, or acceptable community standards of care policies, standards and values.

<u>With reference to your terms of reference (b)</u>*"Ways to ensure the continued quality of life for people with a disability as they and their carers age"*

Ways to ensure the continued quality of life for people with a disability is a factor which is mainly that of "attitude" of service providers - their management and staff, rather than funding. As there is, at present, a general failure to set, monitor and maintain outcome expectations on funding.

Frequently, direct care staff work value expectations are not set, monitored and maintained, especially in government direct care services, to ensure service levels and quality are in accordance with the service provider's care policies. standards and values, or within good community standards to give the person with a disability a good and meaningful quality of life.

Again, we see age compounding the matter. And the failure of service providers, especially government direct care services, to pro-actively provide, implement and very regularly review meaningful action plans to ensure the person's quality of life activities are regularly reviewed and adjusted to accommodate their ability and age.

The present quality of life activities, interaction, developmental and social activities ("Active Support") is frequently inadequate, especially for those with high support needs, and especially for those in government services, for younger adults. So with the present "minder care" philosophy of many service providers, especially "Day Activity Centres", and especially government direct care services. We, therefore, see little hope for older adults with high support needs to be doing more than look at four walls

<u>With reference to your terms of reference (c)</u> "*The types of options and services that could be developed to help people with a disability and their carers to plan for the future"*

One of the major factors which limit people with a disability and their families planning for the future is the present "hand-out" services provided by service providers who have a captive market, and therefore little reason to value customers/consumers or provide meaningful customer service.

We see services in Australia for people with a disability and their families not significantly improving without "entitlement-based" services where there is "Choice of Services". Services will not significantly improve so long as people with a disability and their families are denied the basic human right of "Choice".

The NDIS has significant potential to provide “choice”. However, this will be seriously limited if the NDIS is not funded through a percentage on the Medicare Levy. As only when people pay for a service, do they have a real entitlement to that service.

This would mean that services and equipment for people with a disability would be paid for by Medicare. This would reduce the conflict of interest many government services have in being the landlord, the direct and indirect service provider, the regulator and the source of funding for direct and indirect services

Initially, there is a real need in Australia for real, meaningful and pro-active social services to work with, and support families to understand and obtain the right service and support for their adult family member with a disability.

We suggest the inquiry should look at the social services of the UK, Holland and Denmark, as a starting point. And also look at how these countries cater for the factors under the inquiry’s mission statement

With reference to your terms of reference (d): “*Any other matters which would assist carers to find an adequate and appropriate answer to the question: 'What happens when I / we can no longer care?”*

Families of people with a disability, no matter if they are hands-on carers or families who’s family member is living/being supported outside of the family, they need assurance their family member will receive quality of life care for the rest of their lives.

Achieving this is not just that of providing a whole heap of funding – this is the relatively easy part. The hard part is ensuring the infrastructure provides a meaningful outcome.

There needs to be a very independent complaints process where the board members are from commerce and industries totally outside the disability field. Most industrial and commercial organisations would be happy to provide pro-bono community support through the provision of a executive or manager to sit on a complaints review panel.

There needs to be a far more effective service inspection process than the present “Community Visitor’s Program”. And it needs to be totally independent of government and pseudo government.

It should also be noted that the same state government minister is responsible for both the DHS group home service, and the community visitor program which inspects that service.

In Addition:

1. We consider there is a real need to fund the community service organisations (CSOs) who provide services for people with a disability and their families from sources independent of government departments like the Department of Human Services in Victoria.

2. As this government department has a massive conflict of interest, being the landlord, the direct and indirect service provider, the regulator and the source of funding for direct and

indirect services they take, they take a difficult line with CSO, expecting them to, "Do as they say, not as they do" - Expecting the CSOs to provide quality services whilst not fully funded, as they are expected to fund raise and charge their residents a higher service fee than similar DHS services. Whilst DHS equivalent services are fully funded, and with adequate finance overrun.

3. Whilst CSO services can be made accountable for fully implementing care, policies, standards and values, government direct care service cannot.

   We have proven that public service management are unable to provide proper business management of direct care services for the residents of its group homes as a direct result of the traditional public service culture that public servants have safe employment almost no matter what they do or don't do. Therefore, it is difficult for people with a disability and their families to expect true quality of life care, especially for those residents with high support needs.

<u>Some of our key points are:-</u>

- Government direct care services for people with a disability are run by captive market public servants who have little reason for customers or customer service. These services are like Telecom before Telstra!

- Government services buy, not manage their way! They therefore chew up funding, whilst non government services are under-funded but expected to provide good services.

- Government direct care services rely on the integrity of direct care staff, not the direction of management to provide services within the direction, intention and spirit of their care policies, standards and values. Therefore services fluctuate dramatically! As the Victorian Auditor General said, "Services are inconsistent". With ineffective management, direct care services are by staff lore, staff peer pressure and staff intimidation of management, staff, clients and families.

- Supported Accommodation Group Homes where government is the direct service provider, the residents have few rights in the home for which they pay rent. They cannot choose their service provider or their staff, as they have no residential tenancy rights or right to individualised funding. Direct care staff cannot be moved from the house if they don't wish to be. So the group homes in the community are HOSTELS not HOMES!

- As almost all services in Victoria for people with a disability are government funded through DHS. The DHS has, therefore, total control. There are therefore no rights based services! All people with a disability and their families must have a begging bowl. They must crawl, beg and lick DHS bureaucratic boots for even the most simple things. "We have to bang on their door, they never come to us!" This is why we desperately need the NDIS to allow more service providers to allow choice to achieve customer value and customer service.

- There is no effective complaints process in Victoria! Any complaints process has been biased towards government departments, and against consumers. Nevertheless, no one but the Minister can direct the DHS. So this department can thumb its nose at anyone who questions it, and it does!

- We say the way to an independent complaints process is by having the panel/s from outside industry…… BHP, Motorola, Myer, David Jones, etc, etc. These organisations are usually happy to provide an executive or manager to sit on a complaints panel as a community service.

- Governments should not provide direct services, as traditional public servants see their jobs as safe and secure no matter what they do or don't do. They see their job as little more than appearance employment.

- The provision of quality of life care for people with a disability requires a real commitment. Direct care staff need to see clients/residents as their second family. Not as, "We are just here for the beer"!

- We have wall to wall documented evidence of the public service take the pay and look the other way attitude. And Heather saw heaps of it when she worked in the field.

- "Not Rocket Science!" The provision of quality of life care for people with a disability is not rocket science, it is mainly common sense.

- The main reason care policies, standards and values are not implemented at service points within their direction, intention and spirit, is service provider management and staff attitude (especially DHS), not lack of training and funding.

In Conclusion:

People with a disability and their families need the NDIS to provide choice. So long as people have no choice of service providers, service providers and their staff will have power over already disadvantaged and vulnerable people – people with a disability and their families.

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