

# Not just more of the same, please!

The very moment parents realise their new family member is different, with special care needs, their lifetime battle with bureaucracy commences on top of this. These families, therefore, need 48 hours in every day! What they don't need is the battle for services! They need to be confident of their family member's entitlement to realistic whole of life services to properly meet their ever changing special needs.

NDIS philosophy is leading the charge towards whole of life service entitlement for those with special needs. "Will we get there, and what will life be like with NDIS?" "Let's take a futuristic ride on cloud seven" ...

Lots of government funding, lots of packages, lots of new housing, lots of respite and lots of options - This cloud seven tangible infrastructure sounds good, and is potentially very achievable. The real danger is - **"The present care philosophy will follow!"**

Parents provide quality of life care for their family member with special needs for as long as they are able. They worry what will happen when they are no longer able and will depart this world.

If parents feel they went through tough times supporting, lobbying and battling through schools years - Under most of the present post school care philosophy, the real battle has only just started!

Parents put enormous personal energy into trying to give their member with special needs the very best start in life, only to find their member's skills drop like a brick when parents are no longer able to provide or monitor support levels and service quality.

We all need to be very concerned and aware of just how easy it is for old care philosophy, old care attitudes, to follow and invade a new NDIS infrastructure. Taking the approach that, "Get a roof first, and the rest will follow", is fraught with real danger.

The recent annual reports of the Community Visitors (Victoria) and the Disability Services Commissioner (Victoria), demonstrate many of the direct care problems with present services...

## **Highlights of Community Visitors Report (Victoria) 2009/10, by LISA Inc**

### **Infrastructure (Page 10):-**

Last year, there were 484 Community Visitors compared to 335 this year. As a consequence, the number of visits which Community Visitors made was down from 5413 to 5069 visits.

**LISA Note:** *We suggest a significant reason for the reduced number of CVs, is that these volunteers are sick of the bureaucratic manoeuvring and issue avoidance, especially by the DHS. "When we were CVs, this was a major concern!"*

### **During the reporting year (page 24):-**

The program received two updated master-lists of facilities from the Disability Services Division of DHS, one in October 2009 and an update in May 2010. Both these master lists contained inaccurate information and did not reflect the information being provided at a regional level. Community Visitors are concerned that such inaccuracies mean there is the potential that facilities that should be visited may not be as these do not appear on any list. As the program has endeavoured to update the database with facilities to be visited by Community Visitors, glaring discrepancies have come to light. Some houses have the wrong service provider listed, one has been bulldozed, but is listed as operating, while another is listed as closed, but is open.

#### **Major issues raised by Community Visitors (page 24):-**

The number of issues reported by Community Visitors is a concern. Each of these issues represents a matter that is having a negative impact on the fundamental outcomes and expectations of residents in respect of their welfare, dignity and human rights and life aspirations. In many cases, issues raised have an impact on more than one resident and continued lack of resolution of such situations has far-reaching implications for everyone. It is of grave concern to Community Visitors that 45 percent of these issues remained unresolved at the end of the reporting period.

#### **At Risk (page 10):-**

The community through government is informed by the observations of Community Visitors and the people they speak up for are given a voice they might otherwise not have. It is vital that Community Visitors continue to be supported by government in their critical human rights work. Without adequate, ongoing support for the Community Visitors Program, the human rights of people with a disability living in residential facilities will be at risk.

***LISA Note:-*** Given that contained in our DHS Questionable Activities, our DHS Classics and the personal observations of our Cert 4, we very much support the views that DHS residents would be at more risk without the Community Visitors Program.

#### **Recommendation 12 (page 6) says:-**

Develop a protocol with health service providers to ensure supported accommodation residents are able to access the public health system in a timely manner.

#### **Yet, page 26 says:-**

It is rare to find any person living in shared supported accommodation that has access to private health insurance, which is every citizen's right, if affordable. In some cases, this would reduce waiting times for essential health care and procedures that have long waiting lists in the public health sector.

There has also been a lack of a preventative approach to all aspects of the health care needs of residents. While general practitioners and specialists do see the residents from time to time, this is often a reactive rather than preventative approach.

#### **Lack of attention to amenity resulting in institutional type ambience of shared supported accommodation (page 28):-**

It is important to recognise that the houses are the residents' homes and community expectation is that their homes will provide an appropriate level of comfort, ambience and

safety. It is equally important to note that residents spend a lot of their time at home so the house environment can have a major impact on the health, safety, wellbeing and dignity of residents. It is the view of many Community Visitors that the ambience or feel of a house provides a good indicator of the level of care provided to residents.

***LISA Note:- Many DHS houses are hostels/staff workplaces, where staff work rosters are 82% developed to meet staff needs.***

### **Lack of alternative communication strategies (page 30):-**

Are another major impediment to the capacity of people with a disability to articulate choices, and, therefore, prevent them from being involved in a preferred activity. Often, it is found that residents who do not speak are not given any other opportunity to communicate. Community Visitors routinely find that a Communication Competency Checklist (CCC) might have been completed, but no further action has been taken to identify opportunities to improve communication. Often speech pathologists are consulted for swallowing and eating issues, but not for communication issues. This omission is directly at odds with DHS policies and practice manuals, and should be addressed because of the obvious impact it has on residents behaviour, and quality of life outcomes. This is surprising given that a DHS policy on the matter exists. Section 4.10 of the *Residential Services Practice Manual*, refers to departmental standards and procedures to allow persons to communicate using alternatives to speech. In the case of the provision of communication opportunities for residents, untrained staff are required to assess a residents capability for speech, and there are no external checks to determine whether this assessment is accurate or not. It is reported that many residents, some well past middle age, have been given little or no opportunity to communicate, and struggle to be understood, with little or no support from staff, and no recognition of their rights or capacities to do so. Staff attitudes often reflect a general lack of engagement at a regional or higher level with this issue. The problem of informed consent is also an issue when considering a residents right to choose medical and other supports, and how this might be given by a nonverbal, and, otherwise, non-communicative resident. The lack of communication opportunities offered to residents means that very few have any opportunity to express a personal choice about their own health care, chosen activities, food, or degree of assistance. In other cases, residents were unable to indicate that they required medical attention, or other supports, were in pain, or could give consent for medical intervention. When questioned by Community Visitors, staff often respond that they understand what the person is trying to communicate, so that additional communication strategies are considered unnecessary. Community Visitors do not agree with this attitude. It is every persons right to speak for themselves, and, if unable to do so, they should be given the appropriate supports to achieve independent communication. It is a denial of fundamental rights in that it affects that persons ability to speak independently and freely on their own behalf.

### **Restrictive practices/locks (page 32):-**

The lack of access to the community, recreation, work opportunities, a wide range of leisure activities, and a lack of communication support cause great frustration and boredom in residents who are effectively confined to their own homes. Without any planned and meaningful activities to occupy their time effectively, many residents resort to behaviours, which cause concern to other residents and staff. Community Visitors are of the opinion that if these issues were dealt with effectively there would be fewer incidences of restrictive practices, as there would be fewer causes for the behaviours of concern in the first place.

Community Visitors are aware of the routine application of restrictive practices to control such behaviours. Often such practices are justified by staff to Community Visitors, due to the staffs fears for their own safety, or to protect the safety and the property of other residents. It is clear that where such justifications are made, there are usually very few supports for the residents with the challenging behaviours to express themselves in normal ways, or they are being prevented from achieving personal goals for various reasons. Residents who present challenging behaviours as part of their disability still deserve to be treated with the respect due to all people. They should be given all the support that is needed to live a normal and unrestricted life, as far as it is possible.

**LISA Note:** *DHS support for residents with very challenging behaviours is little more than basic minder care. The department has no proper behaviour management units with well trained, well supported and well remunerated staff to help reduce undesirable behaviours, to allow the said resident/s to have a better quality of life. Those with very challenging behaviour are often placed in any SSA vacancy, where they reduce the quality of life of the other residents and receive little or no proper behaviour management. With staff paid the same whether the work with challenging behaviour or with low support needs, there is no incentive.*

### **Capability and capacity (Page 29):-**

Community Visitors continue to be concerned that some residents are denied the opportunity of genuine participation in the community, or more challenging personal opportunities for self-development and learning. Many spend a great deal of their time waiting for staff to arrive, the bus to arrive, or sufficient staff to be present for each individual to have access to the community and activities that are meaningful to the individual rather than token. Very few activities are designed to fully engage the individual. DHS responses to repeated questions regarding a general lack of progress in this area usually refer to a lack of resources, resulting in rostering restrictions, poor transport situations, a lack of availability of day program, and no funding for staff to accompany residents on supported holidays.

**LISA Note:** *Even if residents with high support needs are taken out, it is frequently just a drive around, as consistent and meaningful Active Support both in and out of the home is not on the radar of most direct care staff. And, DHS management above house supervisor are powerless to ensure departmental care policies, standards and values are implemented within their direction, intention and spirit.*

### **Community Visitors are concerned (page 33 - Crises Management):-**

That, apart from the scrutiny provided by their issues reports, there is no systematic review process to monitor the unauthorised use of restrictive practices. It is a requirement of the Disability Act that this be done by service providers. Community Visitors have also reported that staff are still unaware of what constitutes a restrictive practice and continue to routinely apply these as a matter of course. Concerns remain that staff training is inadequate and restrictive practices continue to be justified by staff on OH&S grounds because of the challenging behaviours of residents or insufficient staff to resident ratios. The subtext of many issues that affect the day-to-day lives of those living in shared supported accommodation within the community, involves the impact of inappropriate placement, either in a poorly designed house, or with a mix of residents who are incompatible. Superficially, this might appear to be the result of a crisis management approach to the

location of residents, who have come into the system because they can no longer live at home, or the result of the relocation of particular residents because of behavioural issues that could not be managed appropriately in previous accommodation. However, it is evidence of a more serious failure of long-term planning processes to identify real need for appropriate accommodation for the current residents, and those in the wider community. It is of concern to Community Visitors that, in instances of incompatibility the resident, is blamed. Staff routinely report that a particular resident is responsible for upsetting a house that was previously stable, or that a persons behaviour is having a negative impact on the other residents because it is so challenging. In some instances, Community Visitors have been asked by staff to intervene with management to prevent the arrival of a particular resident at a house, which fails to identify that residents need for a safe and stable home and also highlights the lack of proper planning processes at management levels

### **Highlights of the Report of the Disability Services Commissioner (Victoria) 2009/10, by LISA Inc**

**Page 12:** The issues raised in complaints to the DSC were summarised and included themes such as access to shared supported accommodation; competing needs and compatibility of residents; quality of support issues in terms of individual needs, choice and community access; capacity to meet specific needs of residents with autism or mental illness; and the level of involvement of families with the service and decision-making.

**Page 26:** Shared supported accommodation continued to account for the greatest share of enquiries and complaints

### **Identification of systemic issues (Pages 27 & 28)**

Through the enhancement of our data base, we have been able to capture some of the emerging complaint trends and identify systemic issues underlying complaints made to DSC. In 2009/10 underlying systemic issues were identified in 123 complaints to DSC, which impacted on the level and complexity of issues and on how well these issues could be satisfactorily resolved. More than one systemic issue was identified for some complaints and were most commonly related to the following issues: The role of the family of people with a disability, including the important role that families play in raising concerns about the provision of services to service users, the dynamic of communication and relationships between families and service providers and the impact that this interaction can have on the extent to which issues arise in service provision. In several complaints, issues involved disagreement between the family and the service provider on the best way to provide services and support to the person with a disability (e.g. in relation to accommodation arrangements, activities, service planning or medication levels). In a few complaints, the wishes of the family about what they considered important for the person with a disability appeared to differ from what the person receiving the service viewed to be important to themselves. In some complaints, families and service providers differed on issues such as the capacity of the person with a disability to make choices and views about his or her support needs.

Accommodation issues, including the right to be safe and have quiet enjoyment in an accommodation service. These matters are often related to the support provisions and supervision offered in the accommodation service. Some complaints related to relocation

decisions (including decisions to move residents or close services). The planning and transition management for people with a disability, where a new person was moving into a shared supported accommodation service, was a common aspect of several complaints

Staffing issues including consistency of staff, the impact of staff turnover on people with a disability, concerns about the appropriateness and skills of staff, reliability and quality of in-home support, and alleged assaults or mistreatment by staff

Lack of person-centred planning or approaches, including services not matching the persons requirements (in some cases due to lack of flexibility in the way that services are delivered), concerns about the management of changes to the way that service is provided (particularly with regard to closure of accommodation services), perceived lack of consultation or consideration of the views of complainants and general insufficient or inappropriate planning

**LISA Note:** On Page 18, the DSC Report infers most complaints result from misunderstanding or long term and ongoing tension. Whereas, there appears no mention of the clear-cut complaints where the DHS totally fails to implement the direction, intention and spirit of its care policies, standards and values.

**LISA Comment:** There are many groups around Australia fighting for unmet needs - aging parents struggling to keep caring for their family member at home. Whilst we have the utmost sympathy for these parents, our main focus is on quality of life care, not basic minder care in supported accommodation. Parents need to depart this world in the sound knowledge their adult family member will not just have a roof over their head, but will have consistent quality of life care for the rest of their life. And that's not how it consistently is at present, especially for those with high support needs.

**Extra 1:** [Autistic Teenager's Cage..... UK Story](#)

**Extra 2:** [Siblings Australia](#)

**Extra 3:** [The Wangaratta Players play, "David's Mother"](#) - 3rd and 5th December

**Extra 4:** [Gippsland Carers Association](#) : [New website](#) - **Check it out!**

**Extra 5:** **Annie McDonald's fighting spirit and inspiration lives on** - [The Age](#)

**Extra 6:** [Political QandA](#) by [Disability Connections Victoria](#), at Moonee Valley

**Extra 7:** [Three sure steps to a fair go](#) - State Election (Victoria) - NDS

**LISA Comment:** More funding is the essence of the steps of the fair go philosophy. Yet, without funding outcome expectations and staff attitudes being set, monitored and maintained, more funding does not equal quality of life care/active support - especially in government services.

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