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29 September 2008

Family and Community Development Committee
Parliament House
Spring St
East Melbourne 3002

Reference: Inquiries into the Provision of Supported Accommodation for Victorians with a Disability or Mental Illness

Please find detailed below comments from the membership of the Western Region Disability Network (WRDN).

The Western Region Disability Network is a network of over 850 people with a disability, their families/carers and those who support them (i.e. service providers, government and community). The WRDN covers the 14 Local Government Areas that make up the Victorian Department of Human Services North & West Region, i.e. Brimbank, Melton, Wyndham, Melbourne, Maribyrnong, Hobsons Bay, Moonee Valley (West), Hume, Moreland, Nillumbik, Darebin, Whittlesea, Banyule and Yarra (North). It is open to all ages and all disabilities.

This submission is based on member feedback received during an open forum, plus emails and telephone calls from people who were unable to attend the forum. It incorporates feedback received in relation to a number of previous forums relating to similar issues e.g. the Federal Government Inquiry as to “Why Carers don’t plan” and “Models for accommodation”. A copy of both these submissions are attached as we believe they contain information that will inform your current Inquiry.

This submission attempts to answer each of the questions raised in the Discussion Paper. However there is much overlap from question to question so we respectfully suggest that the reader(s) recognise that responses and examples may be applied to many areas.

Italicised text is direct quotes from families, individuals or service providers.
1 What have been your experiences with supported accommodation in Victoria with regard to availability, suitability and the adequacy of care for people with a mental illness or disability?

Families only get a place in an accommodation unit when there is a dire crisis (not just a crisis – your crisis must be worse than the 1000 or more people who are on the urgent waiting list). So families end up accepting whatever is offered – even though they may recognise that the person and the environment/other residents are a mismatch. “I had turned down a place for my son 6 months earlier but this time I was so desperate I took the place even though it wasn’t the best place for him to live” – mother of a young adult living in a CRU.

Families seriously believe that people’s quality of life goes down once they move into supported accommodation. This is because funding is directed to physical care and not social interaction and emotional care. Packages cease and often people are located away from family and other community links.

There was overwhelming support for the direction of policy and legislation towards a person-centred approach and community inclusion but sadly experiences demonstrate that the funding does not allow this to happen. An example is a CRU whereby one person cannot access the disco so needs to be supported at home and staff hours need to be extended to support others to go. But the horrified response of management was “but we are over budget!”

Members clearly asked when the State Government is going to adjust the State Budget to ensure that people can enact the Person Centred Plans that they develop. Many members reported Planners actively discouraging them from putting items into a plan to keep it ‘cost realistic’ and DHS Panels saying “we won’t fund that”.

Several families who have a person in supported accommodation reported that they feel intimidated and won’t complain. One family stated that they have been told on several occasions “if you don’t like it, take him home!”

Many families said that they are welcomed at the CRU. Others feel that they are seen as being in the way and a burden. “Service providers don’t work well with our family”.

There were many comments raised about the adequacy of staffing – described as “a revolving door of management and staff” that reduces the quality of life for residents. Suggestions for improvement included a greater emphasis on staff development and offering career paths, incentives (financial and other) for people who work in CRUs with people with higher support needs and particularly “behaviours of concern”. (People related this to the danger money workers expect in other industries where they work in environments that pose a risk to health and safety).

Members were concerned that there is training – PART (Professional Assault Response Training) to deal with OH&S issues where people have behaviours of concern that focuses on safety but does not focus on supporting the individual so that the cause of the behaviours is addressed.

WRDN members felt that the recruitment of direct care staff is vital. Many managers are not trained to do this and do not do this well. There isn’t enough focus on attracting and selecting staff with the right attitude and innate skill sets. It was suggested that perhaps
recruitment could be outsourced - even on an industry wide level. Any budgetary implications would be offset by savings in recruitment if there is enhanced levels of retention and better quality of staff.

As a side issue a WRDN member raised the issue of the casualisation of the workforce. The fact she gets shifts of 1-2 hours length. This means she works for 3 agencies. But as a casual she has no sick leave or paid holidays. Planning is difficult as she doesn’t know how much work she will get each week. This does not encourage her to stay in this industry – especially as she would earn more per hour working in a supermarket packing shelves.

Members pointed out that while money should not be the only incentive to attract and retain good staff that this is an industry dominated by female staff and grossly under paid especially given the (often unrecognised) skills that people need to do it well. There was consternation that there is still a major discrepancy between Government and Non-government workers doing the same job. But it’s not just the direct care workers who are underpaid. NGO sector staff such as Case Managers and even Management receive significantly less than their peers doing similar work under other awards such as the Health sector. All these factors were recognised as being contributors to the issues of staffing.

You may be asking why families are concerned about the wages and conditions of staff. It’s because staffing selection and retention has a direct impact on the quality of care provided. People with disabilities living in CRUs need consistent approaches, care by and relationships with people who know them well. They are not well served by changing staff and the frequent use of casuals. WRDN members who are working in organisations don’t like the system either because all these issues mean more work for them to address crises big and small as they arise and the need to cover the work of peers who move on.

“Families who cannot access supported accommodation often ask/comment on why my family would be advocating so strongly for better care for our son. They think we are lucky (and compared to many of them we are!) but they don’t realise that there are things that go wrong, don’t work out, aren’t followed through and need to be addressed. And if we don’t raise it, nothing will ever change.” – Parent of a young adult in a DHS Community Residential Unit

Several people raised the issue of the need to have an independent person to support a resident to understand their Person Centred Plan, Residential statement etc. This is particularly difficult when the resident has no family and no community connections. The people who know him/her best (staff) cannot act in this role. There is no funding to pay someone. But more than that the question remains as to where to find volunteers with the skills and training to do this well.

Families believe that they are used to fill gaps in accommodation support. They were at pains to point out that they want to be involved but don’t believe that there should be a reliance on them for social/recreational activities and skill development. Here are two examples from the forum. One parent who takes her son bowling, orienteering and home for the weekends. His house can’t/won’t do these activities because of staffing, because they don’t always have access to the shared vehicle and because this persons’ interests are different to that of his co-residents. No mum – no can go! The other family have been working with their son on his behaviour at the dentist. He has gone from having a general anaesthetic every time to willingly cooperating. But it took time, effort and consistency.
Carers of young families accessing respite services are very concerned about the child/staff ratio. In one instance nine high support needs children were left unsupported when the carer sadly died on the job. Families had to fight hard to change the system.

People were disappointed to discover that they lost access to packages that supported quality of life opportunities when accessing supported accommodation. This meant they lost contact with paid and unpaid connections.

2 What is your experience of trying to access supported accommodation in terms of information, planning and decision-making?

"There are 1358 people on the urgent wait list with an average 4 year wait for accommodation. What chance have we got of planning for a life without our sons and daughters?" (Numbers quoted from the letter from Mary Wooldridge MP dated 19 August 2008)

“What happens when there’s an emergency? Someone clogs up a respite bed! What happens then? Someone is ‘bumped’ (service offer withdrawn) from receiving planned respite…. doesn’t get support… goes into crisis and clogs up another bed!!"

“There just isn’t enough facility based respite and a determination by planners that they won’t fund any more despite the stated need. Why don’t they listen to us?"

“At my kid’s specialist school there are 160 kids but only 4 have a Support & Choice package. There’s only 300 or so for the whole of Victoria. How do we plan?"

“What’s the good of getting info about the options when you know you won’t access them for 20 years?"

Accommodation was often seen as being treated as a separate rather than integral part of planning for a person – current and future plans.

Parents and service providers identified the difficulties of trying to develop a holistic Plan (One Person One Plan) that looked at all the elements of a person’s life.

Many WRDN members raised the issue of advocacy – self advocacy & advocacy, formal and informal, personal and systemic as being something that is generally under developed, overstretched, too dependent on volunteerism and not adequately supported by the State.

WRDN members considered themselves extremely fortunate to have access to the WRDN information processes (the weekly electronic updates & newsletters as well as forums and meetings) as they believed they are better linked and have a stronger voice than many other families.

3 What other approaches/models should be considered to address supported accommodation funding, planning and delivery?

WRDN members were very clear that many of their family members are not well matched in their supported accommodation. Places were accepted because they were desperately needed or from fear that they would not be offered another for a significant time. The
process of transferring to another CRU is complicated and emotionally difficult. Members would like some kind of process whereby people could apply for a transfer and have first option (rather than competing with everyone on the Needs register).

Parents said:

- "I would like to make a list of all the things we consider important and an independent advocate to ensure it happens".

- "I think I'm well informed and linked but even I'm finding it hard to get the information I need to establish the key elements for when/if we are not around".

- "Service delivery should be a whole-of-life person centred approach".

- "Families should be included in the service and not seen as an added-on".

- "Service delivery would work so much better if it wasn't always a top-down approach. Direct care staff are not included in planning".

- "There's not enough time to plan. There's not enough training in how to plan. That goes for direct care staff and families".

As stated in section 2 there is genuine and deep-seated concern by all categories of the WRDN membership about the crisis in respite care. WRDN members believe that people who are effectively homeless should NOT be placed in respite but should be placed in transitional housing models with options for skill development so there is a larger spread of permanent living options available, including people supported to live more independently in the community.

But the reality is that many people will NEVER live independently. They will always need 24 hour support. Families are willing to help but the reality is that the biggest cost is staffing and it's recurrent. Government need to recognise this and plan for realistic growth in funding.

There were many concerns raised by WRDN members (families and service providers equally) about the issue of people with disabilities who are ageing. Overall there was a genuine belief that people should be allowed to age gracefully in their own home. People should not be forced to move. Instead the service model should be funded to and expected to adjust to reflect their needs. There is this feeling that policy makers think that disability disappears miraculously if you are aged. But of course disability issues are only further compounded by ageing. Access to community contacts, disability specific supports and equipment should not disappear just because you reach the magical age of 65. Raised too were the issues of people with disabilities – also applicable to Indigenous Australians – ageing earlier than the balance of the population whereby service accessibility should be judged on need not age. Then there are the well documented needs of Young People In Nursing Homes.

One of the issues carers constantly raise is where they go when they are offered in-home respite. Perhaps consideration could be given to models of carer (or carer + the rest of the family) holidays at minimal cost.

Families with young children with disabilities and chronic ill health are dismayed to find that they are ineligible for many/most supports due to the age of the child. This includes out-of-
home overnight respite. This is even though Early Intervention is critical. “He wasn’t eligible for out-of-home care until he was over 5, even though we had a diagnosis at 9 months. As his Dad, I had 7 jobs by the time he was 5. We both lost jobs due to our caring commitments and lack of sleep”. This child’s Mother sent the WRDN email about this very issue which, in part, said “we experienced much emotional and financial hardship that we are still recovering from now. It was at this crisis point that we found, after extensive investigation, that there was no disability/crisis/health intervention that could help us e.g. Melbourne City Mission advised there was a 2 year wait for a Home First Package (a supposed support for families in crisis). We are still waitlisted as a high priority for case management with DHS and have been since November 2007.”

WRDN members believe there are some terrific models already but the problem is that the Federal, State and Local Governments do not work together to support those models. The 3 Governments need to work together – to have the same definitions, the same rules and regulations. Red tape needs to be cut to encourage innovation. New models (including cluster and facility based respite) need to be funded. There are great examples of community engagement e.g. Basecamp 3030 in Werribee but it seems because government didn’t think of it, doesn’t own it and can’t control it then no-one will fund it. And yet the model is just what the Act and State Plan say should happen.

WRDN members expressed concern that supported accommodation is being developed less in the established areas and more in the outer suburbs. This has 2 major disadvantages. Firstly it necessitates people moving out of their communities and away from their family and other established supports e.g. day program/work. Secondly they are placed in an area where transport and infrastructure reduces rather than promotes independence.

A consistent theme was that the system is crisis driven. Families want to be part of a proactive approach to planning. They are willing to be flexible, innovative and lateral thinking in their approach. It’s the system that isn’t. “Why can’t I be paid to set up my own CRU?”

One parent said “I can’t imagine what the system will look like in 10 years time, but heaven help us all when my friends and I are no longer able to care”.

4 What are the implications for individuals who need but cannot get supported accommodation? Is the alternate accommodation that is available adequate and care appropriate?

When carers cannot get adequate respite and other forms of support their health deteriorates. It is well known (refer Carers Vic submission to the Federal Government Budget 2008) that carers have poorer health outcomes than others in community.

Families said that if they were given the same supports to keep their son or daughter at home as they get in supported accommodation it would make caring so much easier e.g. the FULL cost of modifications or a wheelchair accessible vehicle.

Families said that they cannot use some forms of support due to regulation e.g. in home carers who cannot administer medication.

WRDN members were adamant that the current methods of determining accommodation needs severely underestimate (and are designed to underestimate) the level of unmet need. There were many examples of ageing and stressed carers being removed from the Needs
Register because they agreed they could hang on just a while longer. Members respectfully ask how Government can plan for the future when the wide range of planning data is not collected. Members are concerned they will NEVER be able to retire and if they do what kind of life they will have because they have sacrificed career and superannuation for many years.

Service providers supporting carers are very concerned that when a carer has a child in care they are no longer accessible for carer services such as counselling. This is even though they will in most cases remain actively involved with the child. This reduces the opportunity for children to be returned to home.

Sadly there are people with various disabilities who end up in acute hospital care because there are no suitable places available. This adds to the overall difficulties experienced by the health system.

The forum spent some time discussing the issue of accommodation for people with mental health issues and also the issue of people who have a dual disability (mental health and intellectual disability). It is appalling that there are only 2 CRUs dedicated to people with dual diagnosis. It’s also totally unacceptable that there are insufficient long term accommodation options for people with mental health issues. People end up in totally inappropriate and sometimes (in our view) abusive situations – in Boarding Houses and SRS as well as being homeless. We would like to see more resources applied to this group of people with disabilities.

5 What is your view on the provision of accommodation and care in private, government and community sector managed supported accommodation?

WRDN members do not generally care who provides the services so long as they are of high quality.

There appears to be a trend that families who have a person in a Non Government managed CRU are more positive about the quality of care provision and the way they themselves are treated than families utilising DHS managed services. However it appears to differ from CRU to CRU based on the quality and commitment of staff rather than the managing organisation.

There is however an overall concern that DHS is the funder, provider and monitor of the largest percentage of supported accommodation services. This is viewed as a distinct conflict of interest that needs to be addressed.

As stated above there are concerns about staff selection and recruitment, staff training and support and the level of direct care worker pay and career paths.

6 What issues need to be considered in the accessibility and provision of supported accommodation for people from:
  - Rural and Regional Victoria
  - Culturally and Linguistically Diverse Backgrounds
  - Indigenous Victorians?
• “Multiply each of the problems x 10<sup>xx</sup>.

• “We’ve lost something since everything’s gone mainstream”

• “It’s hard to find enough skilled staff who also have language and cultural skills”

• “We need resources to assist agencies to work in partnership with specific communities and specific agencies”.

• “We need to recognise that translations and the use of interpreters are expensive and take extra time. Planning takes longer, information exchange takes longer; people don’t always have the same sense of community engagement”.

• “People get so used to the barriers that they don’t even expect relevant services”.

Many service providers felt that the setting of priority groups by policy makers has severely disadvantaged people from other groups especially if it’s a small or rare grouping.

People from the outer suburbs/new suburbs said that they often have more in common with rural and regional communities than their city counterparts. They do not have the infrastructure and services needed. Transport is a nightmare for people who don’t drive or who need wheelchair accessible transport options.

7 What other issues do you think need to be considered which have not been addressed by the above questions?

Families who are not happy with the current arrangements state that there is not enough accountability. This is at all levels i.e. direct care through to management. They feel there is very little accountability to families (except for financial which was deemed as generally excellent).

Families have been very disappointed with the Office of the Disability Services Commissioner. They said that they thought the introduction of this Office would give ‘teeth’ to complaints processes. They say they are disillusioned. Here are 2 examples from the forum. Firstly a family was directed back to conciliate with the service provider with whom they had a long term impasse. They wanted someone to make a decision. Another family was told it was a “procedural issue” and the Commissioner can only address “an action or a non-delivery of service” i.e. a child of 6 years with high support needs being on a school bus for 4 hours a day (20 hours per week) was outside jurisdiction.

One parent, who also works in a CRU, has been trying to work with DHS to address the issues of numbering Incident Reports. He would like Incident Reports to be used as a proactive tool for planning and not just reactively in response to an isolated incident. DHS says they have been looking at this (for several years) and the Disability Commissioner says it is a procedural matter that he should discuss with DHS.

Families stated that their experiences are borne out by the Auditor General’s report that says processes are reactive. WRDN members would be pleased to support any initiative
that encourages the system to take a proactive approach and that seriously views complaints as tools for service improvements and complainants as 'heroes'.

Families of people with higher support needs and/or little if any functional communication would like to be allowed to advocate for their person with Community Visitors. Community Visitors can only speak to staff so adding family input may give a wider perspective on the topic (whatever it is).

Community Visitors should be able to visit Boarding Houses.

Some families thought that each CRU should have an advocate - independent of management but who would work alongside management to better support people with higher support needs.

As stated above WRDN members believe the Disability Act 2006 is a far better piece of legislation than the previous Act and supports the Victorian Disability State Plan 2002-2012, the A Fairer Victoria statement and other initiatives. But some people strongly believe it has many holes and is not friendly. It is most concerning that people with Autism Spectrum Disorder are excluded from disability services under the Act. And everyone said that all these issues would be in the open, measurable and able to be planned for if there was an entitlement to service based on need.

WRDN members at the forum were appalled to hear that there are some 2000 Behaviour Support Plans awaiting approval. In the meantime staff are expected to adhere to them.

There were many concerns raised about the issue of medication- therapeutic or chemical restraint? There are few Doctors who deal with people with a dual diagnosis or who can/are prepared to determine which is which. One parent said "On 1 July 2007 my son’s medication inexplicably changed overnight from being chemical restraint for behaviour to medication for "an unknown" medical condition."

A significant reason for these concerns was determined to be the training of the medical profession. In a society that acknowledges 1 in 5 to have some form of disability and/or a mental health issue disability is an elective rather than a core competency. The WRDN membership believes disability and mental health training should be compulsory for all medical professionals.

WRDN members believe that they are 'formed out'. Every service, every program asks for the same basic information. It is incumbent on the individual and/or family to remember all the information and to ensure that everyone is informed of changes e.g. to medication as they arise. The question was asked why not one form and one plan? The time, the duplication, the complexity, the risk of incorrect or missing information further complicated by silos of funding arrangements and directives are all a waste of valuable resources that could be directed elsewhere.

The WRDN would like to suggest that there is a senior Minister dedicated only to Disability and Mental Health issues. The current Minister has too many responsibilities and is too busy (therefore difficult) for the average person to contact.

Families ask that they stop having to consistently train staff to work in their family.
The membership of the Western Region Disability Network thank you for the opportunity to raise these issues with you. We would be more than pleased to discuss any aspect of this submission with you. Please contact our Executive Officer, Helen Adams on 9687 7066 or email helen.adams@annecto.org.au if we can be of more assistance.

Yours sincerely

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On behalf of the WRDN membership
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15th Oct 2007

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To Whom It May Concern,

Reference: Disability Supported Accommodation Program - Discussion Paper

Please find detailed below responses from the membership of the Western Region Disability Network.

The Western Region Disability Network (WRDN) is a volunteer network of people with a disability, their families/carers and those who support them (i.e. service providers, government and community). The WRDN covers 14 Local Government Areas within the North and Western Metropolitan Regions of Melbourne i.e. Brimbank, Melton, Wyndham, Melbourne, Maribyrnong, Hobsons Bay, Moonee Valley (West), Hume, Moreland, Nilumbik, Darebin, Whittlesea, Banyule and Yarra (North). It is open to all ages and all disabilities. The WRDN has a membership of 782 comprising 180 individuals with a disability, 302 carers/family members and 300 organisations, support groups, workers and community.

The WRDN held 3 forums to discuss the questions raised in the FaCSIA discussion paper. There was a range of view and ideas put forward, however there were 2 areas on which there was universal agreement:

1. The Federal Government is to be commended for recognising and addressing the area of accommodation support for people with a disability. This is an area that has been long neglected and which has reached crisis point. However the allocated funding will only scratch the surface of unmet need which is far greater than the figures suggested.

2. The majority of people who were able to respond to this paper are in fact ineligible for assistance from this package of accommodation. Less than 10% of our responding membership meets the criteria of being 65 plus caring for someone 40 years or older.
People are extremely frustrated that the “baby-boomer” generation has again been disregarded and overlooked within a planning and policy development framework. Many of the people are in fact nearing retirement age (although they clearly indicate that retirement from caring will not apply) but in fact have children well below 40. A quick calculation had members reaching mid-late 70’s before they are eligible for accommodation support under this proposal. The membership calls on the Commonwealth to allocate more funding for accommodation support or if this is not possible to broaden the criteria for this funding so that carers of all ages can be considered on the basis of need not age. As one parent said “We have a right to retire”.

In a snapshot of the participants of one forum 50% of the carers indicated they have major health issues that already impact on their ability to care. One third of the people were on (their child was on) the urgent waiting list. The time frame ranged from 6 months to 20 years.

Members do not wish to give the impression that the needs of older carers should be ignored. The issue of ageing carers is a frequent topic of concern for the WRDN. But the membership asked me to ensure that the Government is made aware that the issue of all carers requiring supported accommodation for the person they care for is a major issue wider than the ageing issue.

**Discussion Paper Key Questions:**

1 **Principles:**

The membership agreed with all the principles listed but would like to suggest the following additions:

- The person with a disability should exercise as much control as they are able over all aspects of planning and service provision
- Where this is not possible advocates (family, friends, service provider staff) should be used
- Service delivery must be independent of the processes of funding and accountability
- People with a disability and carer advocates should be an integral part of policy development, service planning and implementation as well as having an active role in ensuring quality service provision.

2 **Linkage to other programs**

The membership believes it is essential that this package is part of an integrated service system supporting people with a disability and their carers/families. Whatever is developed must work in with and have consistency with existing services and reporting requirements. This included service standards and quality frameworks, policy and procedures and linkage to accountability processes outside of disability such as the health sector and JAZ/ANZ and ISO accreditation. If this is not done well there will be confusion and some extremely good service providers may decide not to tender for service.

It was seen as extremely important that other related areas of support are also addressed as this will extend and enhance the options available to people with a disability. Areas include:

- Social support funding such as Support and Choice and Home First packages need to be increased in both number and level of funding as these are the packages that will enable people to make the widest range of choices. People will not be able to access public housing or remain in their own homes unless they have adequate support.
• HACC funding needs to be increased significantly. This package of support, usually provided by Local Government, is often the foremost point of support for families. The membership advises that as the numbers of people calling for support increases (especially in growth corridors) families are receiving reducing levels of support despite stable or increasing needs as the existing ‘pie’ is cut into ever more pieces. Along with this is the increasing practice of counting weekend and public holidays as higher usage (i.e. if it costs the service provider penalty rates, 1 hour of service is counted as 2. If you only get 8 hours per month that means 4 hours of actual respite or personal assistance).

• Social inclusion of people with disabilities into the community is essential if accommodation services are to avoid the risk of becoming ‘institutionalised’. An on-going national disability awareness campaign about the rights of people with a disability to live in and actively participate in community activities is required. There is some fantastic legislation now but members suspect most people in the community aren’t even aware of it. Community attitudes need to change from an “it’s not my problem” mentality to an “it’s all our problem” belief system.

• Social (public/welfare) housing, this will enable people to have a broader choice of housing options. This goes hand-in-hand with support packages.

• Accessible, frequent and affordable public and community transport (if you can’t get there you can’t participate).

• Access to the built environment i.e. universal planning processes that ensure all buildings are built/modified for full disability access. It should be noted that this is not only cost effective but of benefit to many people in the community including the elderly, people with young children and proactive in dealing with an ageing population.

• The rights of people with disabilities as equal citizens within Australia – in a large number of areas. The membership commended the Victorian Government for their proactive approach through initiatives such as the Victorian Charter of Rights, the “A Fairer Victoria” Statements and the Victorian State Disability Plans. A federal approach to the rights of people with disabilities would be well received.

• Changes to the taxation and related legislation - to encourage parents to leave their assets to the care and support of their adult child with a disability. Easy and free processes and supports to undertake this. Some people suggested that this would be even more viable if there was some form of compensation through the tax system for siblings if they are disadvantaged by this process.

• Transparent accounting procedures for monies left in trust towards support for the person with a disability: there was concern expressed that the money would disappear into a central pool instead of being directed to the support of the person it was left for.

• Infrastructure to new suburbs and growth corridors. Some of the membership were greatly concerned that the growth of Melbourne (and presumably other major cities) has not been matched with services and other supports.

  ➢ People in Epping for example access respite in Shepparton.
  ➢ People in Wyndham, which has grown by 40% in the last 6 years, have no funded facility based respite.
Melton Shire is expected to double in population by 2021 without the corresponding road, rail, bus, and services infrastructure to support this growth. What is planned is not disability focussed.

- Specialist services must be available to all people in supported accommodation regardless of the type of service e.g. people who live in nursing homes cannot currently access the Aids and Equipment Program.

- There is a severe shortage of specialist services in some areas (e.g. a speech therapy service in Melton has a wait list of 1.5 years after 4 months of operation!).

- More places needed at university to train the specialist providers.

- Improvements to the wages and conditions of staff working in disability services (more detail below).

- There needs to be a strengthening of the Commonwealth State and Territories Disability Agreement that enforces States to plan for and provide supported accommodation relative to need. The CSTDA needs to demonstrate clear responsibilities such as who is managing this package of supported accommodation, how it works in with current and future State provision and to ensure that the State Governments do not see this as replacing their obligations but assisting them with wait lists.

- Banks and other financial institutions could look at the way they support people with disabilities and their families to encourage families to plan for the future. They could also support government in getting best financial advantage from any assets left in Trust. Banks should be encouraged to view disability as another source of economic advantage and an untapped market. In return they could financially support some of the infrastructure of this project.

- Many of the superannuation funds invest in infrastructure. They could be encouraged/compelled to direct some of their funds towards social projects.

3 **Who can provide supported accommodation?**

The membership believes that in most cases family (usually parents) are the most used and most appropriate option for supported accommodation. However, in saying that, the membership emphasises that families should not be used as the ‘cheap option’. Families should, as a matter of right, receive whatever supports they need to enable them to care for the person with a disability and at the same time have a quality lifestyle themselves. Carers save the Government and community incredible amounts of money each and every year, money that should be redirected back into supporting them in this very important and often difficult role. Access Economics 2005 (cited by Carers Victoria 2006) estimated that Victorian carers saved the community $8 billion each and every year. Extended across Australia that must be tens of billions of $.

It should also be noted that not all carers want to be carers and that they should have the right to make that decision. Also people with a disability should have the right to independent living in the same way as their peers. It is not ‘normal’ to live with one’s family forever and if one does it is by choice not through lack of choice.

A whole range of possible providers was identified:
✓ Current service providers (many of whom were considered to be offering excellent services)
✓ Local Government
✓ Partnerships between Local Government, local communities and disability specialist services were highly favoured.

What the WRDN membership was not in favour of was:

X The provider being the funder and/or the entity to whom the provider is accountable i.e. State and Federal Government departments, as this is seen to be a conflict of interest

X The provider managing a large number of services as this was seen to be less personalised/hands-on management which in turn leads to lower levels of care, flexibility and accountability and increased bureaucracy.

The WRDN membership as a whole was not keen on the accommodation being provided by the private (for profit) sector. This reflected a genuine concern that the focus will be on ensuring profit to the shareholders rather than all possible monies being directed to supporting the residents. People pointed out that while there are many examples of excellent nursing homes (often run by for-profit organisations) there are equally as many that are not of the standard that they would use themselves.

4 Elements of Person Centred Planning

The membership feels that in many cases service providers including government do not really understand the concept of person centred planning. Members felt that services were using the right words, have excellent policies but trouble in applying them effectively. We therefore respectfully make the following suggestions:

- Person Centre Planning should always put the person at the centre of any planning and decision making processes

- The person’s choices should always be respected. People have a right to take risks, choose options that they prefer even though others may think another option is better for them, to make and learn from their mistakes.

- People have both needs and wants. Wants are important as they are about quality of life, about dreams and aspirations – many of which may be the things that the rest of the community takes for granted.

- No plan (no matter how fabulous) will work unless the resources are there to implement it.

- Supported accommodation does not mean sub-standard accommodation.

- Privacy and personal space as well as communal areas that promote interaction are needed.

- Own room also means own clothes and possessions and room to do things apart from just sleep. Members noted that in most current supported accommodation facilities the rooms are so small that options like having a double/queen bed, extra furniture, a computer desk and chair are not feasible. Own ensuite bathroom is a standard in nursing homes that could be applied to purpose built supported accommodation.
• People with disabilities should be involved with every day decision making regarding the services they receive – meaningful input into decisions large and small.

• Members felt very strongly that people with disabilities should be actively involved in the selection process for co-residents and staff. Where this is not possible then they should have access to active advocacy from people who know them well.

• The most important element is developing services to meet the needs of the individual rather than the individual having to squeeze into the available options. Parents who already have a son/daughter in supported accommodation stated that they had no choice but to take the available vacancy regardless of whether or not it was suitable/the most suitable or face going back to the bottom of the long wait list. This has resulted in people being moved away from family and social connections, and residing with people with whom they have nothing in common. It also means that quiet and gentle souls are subjected to the challenging behaviour of other residents which impinges on the overall group’s capacity, choices and independence.

• Friendships and relationships should be part of accommodation planning. Why shouldn’t people be able to share a home with people they like (which is just what the rest of us do)?

• It was also strongly noted that ability to keep in contact with one’s family is very important. As parents age they still wish to maintain contact so proximity to family and transport becomes essential over time.

5 Attracting new providers

The WRDN strongly believes that this is an opportunity to encourage the development of and/or strengthen community partnerships. It is an opportunity to bring together people who have elements of response together. This will result in local needs being met at a local level.

↓ Local individuals and their carers will identify their needs and preferences
↓ Local, State and Commonwealth governments may have land and/or buildings unused that could be redeveloped to assist with the capital expenses
↓ Many community/disability/advocacy/support groups will have an interest in developing the project for their local area in response to local need
↓ Providers will have expertise in the provision of the services
↓ The local community and business sector may be willing to contribute to the establishment and/or ongoing delivery of the service
↓ Local volunteers may be sourced to support a paid staffing model and to enhance community inclusion.

This may sound too good to be true but in Wyndham the Baptist Church, the local parent support group, the Council, the community and philanthropic grants have established a new and flexible respite service. The issue – the Victorian Department of Human Services will not fund staffing or contribute to funding costs. Why? We believe it is because they do not control the service – it’s controlled by a Committee of stakeholders. This package is an opportunity for an alternative philosophy and approach.

Accountability for service quality is imperative

There should be sanctions available and used (like in the nursing home sector) when standards are not met.
Service providers should not be managing large numbers of units (whatever model or mix of models they are). Members were quite scathing of the Victorian Department of Human Services North & West that manages 197 Community Residential Units (about 1000 beds) in our region. The feeling was that where non-government agencies manage smaller numbers there is greater opportunity for management to be involved and a more personalised and efficient system.

However the WRDN recognises economies of scale and believes the maximum amount of finding should be directed to on-the-ground service delivery and administration kept to a minimum. This is a dilemma but there are many examples of agencies successfully managing 6-20 units (30-100 beds) as part of their overall service delivery.

The membership would like to see people with disabilities and carers actively involved in service design and management.

6 Advantages of having different types of providers?

- Different providers should mean a range of options from which people can choose.
- This should enable specialist providers to offer services appropriate to their target group.
- This would allow community groups to develop services (independently or in partnership with current providers).
- The issue with only using current providers is that they may only offer the options they currently provide. New providers may think laterally, outside the square, offering innovative and differing models and ways of doing things. However as there are many examples of local providers who demonstrate a commitment to innovative and inclusive service delivery, the membership wants to emphasise that this is raised as a potential issue rather than a firm belief. In saying that a number of the WRDN members thought quite strongly that Government departments are far more rigid in their approach than the not-for-profit sector agencies.

7 What are the pros and cons of separating housing and support?

7.1 Advantages
- Support follows the person regardless of housing options
- Widens the housing options
- Some housing options e.g. Victorian Disability Housing Trust will only provide housing if support is organised
- Flexible options such as sharing with friends becomes viable
- The level and delivery of support can be changed according to the needs at hand

7.2 Disadvantages
- Another layer of bureaucracy – and the costs of this
- Potential for conflict and confusion
- May lessen accountability (passing the buck)
- It will never work unless the support is adequate.

8 What is needed to make the roll-out viable?
The WRDN was very strong on the following advice:

Listen to the people who are going into accommodation and if they are not capable of giving input listen to the people who know them best - the carers and the service providers who are currently supporting them.

Apply a whole of government, whole of community, whole of family, whole person approach at all levels and stages.

Other comments were:

- A commitment to on-going funding that has built in CPI and wages costs increases. Failure to do this will decrease the involvement of some potential providers/partners. Local Government was particularly strong on this issue based on past experiences.

- A clear definition of eligibility (e.g. what is severe or profound disability?)

- A clear picture of need. In November 2006 Victoria had 1606 people on the urgent or high priority lists but during that year the Victorian Department of Human Services changed the way it was collecting accommodation data. Basically anyone not in need of a service at time of contact was removed from the list. Within the WRDN there were elderly carers removed despite the fact that they were frail and on the brink of a crisis.

- A process for determining what options people want BEFORE the models and the service providers are selected (see our example of the closure of Caloola below).

- A process for selecting the package recipients based on level of need and a MATCHING of participants.

- Opportunities for people to remain in their local communities and to retain relationships.

- Management with a commitment to innovation and listening to people.

- People with disabilities and carers as active consultants to the process at all stages.

9 What criteria should determine where places are located?

First Determine who will be eligible and in what order of priority
Then Determine what those people want
And only then determine where they are going to be and seek potential providers

(Our experience is that this is NOT the way the process has worked in the past e.g. when Caloola institution closed there was a ‘Client Consultation on Relocation’ process undertaken that identified over 200 people wanting to stay in the local area as they either had family living close by or had lived all/most of their lives in that community. But houses had already been built across the State with only 18 places available in the area. This resulted in many friendships and relationships being broken up and many people dislocated from everything and everyone they knew.)

However priority of eligibility should include areas where there are few options, suitability of current options, needs of the carer, and needs of the individual.
10 How can we ensure places are available when needed?

- Keep up-to-date and detailed records of need.
- Pre-planning. Anticipate need as it is inevitable that people will need services given the carer age criteria. One can reasonably pre-empt that a carer of 80 will go into crisis at some point.
- Update the record on a regular basis (a family may be managing very well and then there is a crisis of some kind and the capacity to manage changes dramatically e.g. two parents cope but one on their own struggles).
- Increase availability of supported accommodation as an on-going commitment – there will never be enough supply to meet demand.
- Service providers should be able to adapt model(s) to meet changing needs. Additional resources should be available to assist with this as required.
- Develop partnerships with parents/families, community, providers, Local and Sate Government to ensure the most effective use of resources.
- Increase access to the service models that support carers and that prepare the individual with a disability to live away from the family i.e. transition. This is an often overlooked positive arising from regular use of respite care.

11 What would providers require to be able to bring places on line as necessary?

- Assistance with planning and building regulations (especially if the building is ‘different’).
- Linkage to other stakeholders/potential partners.
- Access to the needs analysis data to allow for pre-planning.
- Families and individuals need time to explore options so they can make informed decisions.
- Skilled staff to undertake the various aspects of the project.
- Support from an Advisory Board of people with disabilities and family members (preferably including people who are going to be using the service but also people with skills in other areas – there are many people with much to offer). This should be paid/renumerated consultancy.
- A commitment to adequate funding.
- Cut the red tape and apply the KISS principle.
- Transition timelines.

12 What key features would people like to see?

- Individualised
- Homely
- Person centred
- Safe (acknowledge that some people are best supported in a more secure environment – but that does not mean locked away and isolated)
- Good quality staff who are committed to meeting the needs of the residents
- Flexibility
- Quality buildings and fixtures
- As ‘normal’ as possible – not standing out
- Commitment to skill development, to decision making at all levels
- Active involvement of family (or people with disabilities and carers as advocates) including at a management level
- Integrated services
- Access to specialist services where required
- Ageing in place (lifelong placement – no need to move if your needs change)
Residents have input into co-resident and staff selection (or where not possible advocates independent of service provider)

Close to people’s family and current community/activities/work

Vehicles for each unit to encourage and assist with community involvement

This funding safeguarded for the target group and not redirected to other needs e.g. the homeless

Rights-based service delivery

Tenancy rights and safeguards

13 What are the strengths and weaknesses of existing models (Cost-benefit)?

13.1 Strengths

- Its cheaper and more effective to support 4/5/6 people together than an individual especially if you need specialist equipment or services e.g. active nights

- WRDN members believe that the non-government sector provides a higher quality of service provision than the government sector

- WRDN members believe that the not-for-profit sector provides services at a lower cost than the government sector as the government sector tends to be administratively heavy and high cost

13.2 Weaknesses

- Often poor matching of residents can result in issues of worker stress and Occupational Health and Safety

- This sector is not well paid. There is a genuine concern that (to coin a phrase) ”when you pay peanuts you get monkeys”. There appears to be a belief within Centrelink and the Job Network Agencies that just anyone can work in the residential field. It does not have a high profile as a skilled job. There is a large discrepancy between the wages and conditions of government and non-government sector that needs to be addressed urgently

- Inconsistency of care caused by the high turnover of staff and inability to attract people to the industry (see point above). Every service provider indicated a difficulty in attracting and retaining quality staff.

- Many WRDN members are concerned about the cost associated with the Commonwealth/State funding arrangements. There is a generalised belief that direct funding will ensure that administration costs are kept to a minimum especially at a government level. One family pointed out that the $11,000 support package allocation from the Commonwealth (amount of $ divided by number of people to be assisted) equates to only $3000 worth of direct hours of support to his daughter once the various levels of bureaucracy have taken a percentage.

14 What innovative supported community living models should be considered?

WRDN members wanted to state that in most cases they believe that the current Community Residential Unit (CRU) model is very good. It could be improved by addressing issues such as resident matching, improving staffing reliability, minimising staff turnover and improving decision-making for residents. Of course there are examples where this works better than others. But the WRDN believes it important to state that some people need this model. Please don’t throw out the baby with the bath water!

The other point the WRDN membership was clear on is that because people are different, with different needs - no one model is better than another. It’s about appropriate meeting of needs:
• CRUs as currently offered (usually 4-5 residents)
• People supported on a 1:1 or even 1:2 basis should be considered
• Cluster housing – several houses within a village or community with some communal space but where each house has residents with different needs and responses.
• Village concepts where parents/carers, extended family (ies), people with disabilities and community members could live in the same village but in different houses. Support provided to each person as required. If necessary the village could include a nursing home.
• Secure housing segregated from the wider community due to the needs of the individual(s). (But although the building is secure there is still community access and integration)
• The Neighbour-ring concept – people living independently but in contact with each other through a formalised process (comes from the UK)
• Nursing homes for people with high physical support needs/complex care issues but age appropriate services and matched residents (no more young people living in aged care facilities).
• Family homes opened up to friends – support being provided in the home on an individual and/or group basis
• ‘Granny flat’ type accommodation
• Lead tenant models
• Nursing homes willing to support both the ageing carer and the person with a disability (but planning needs to ensure that this remains the most viable option for the person with a disability once parent has died)
• Private rental (public, Housing Trust, private rental market) housing with support packages
• Members said that they had visited some innovative models in Adelaide and Queensland whereby the village or ‘institution’ model was softened by incorporating community facilities such as a dental service, swimming pool, library, recreation services within the complex. So even if people with a disability could not access the community, the community was accessing and including them.
• There is a model currently run in our Region (by annecto-the people network) whereby care is shared by the service provider and the family. 4 people live in the unit one week and swap over with 4 others the next week (i.e. each group of 4 spends 1 week supported in an agency house and 1 at home). In this model 8 families are supported. While this particular service is for children WRDN members thought this might serve as a “transition” model to support families awaiting permanent placement or who are not ready to relinquish total care, for whatever reason. It may also support extended family to retain some of the caring responsibility.

15 What should be considered when designing supported accommodation for certain disability ‘types’?

• People with a physical or sensory disability are more than capable of being active partners in the development of the services they will use
• People with cognitive disabilities are capable of having a role in the development of the services they may wish to access
• Individual plus parent/advocate involvement at all times
• Specialist agencies may be the right provider e.g. ARBIAS for people with ABI or SCOPE for people with high physical support needs
• It’s easier and considerably cheaper to build in the practical supports that may be needed rather than pay for modifications down the track e.g. ramps, framing for hoists, wide doorways and corridors i.e. apply the highest possible standard of universal access to any building project.
• Universally accessible buildings means no-one will need to be excluded from an option on the basis of the building not being suitable
• People with dual disabilities (especially cognitive and psychiatric) often fall between the cracks due to ‘buck-passing’ between government departments and service delivery agencies. A whole of person approach is needed
• Aids such as strobe lighting fire alarms for people with hearing impairment, thought to colour contrasting in home decoration for people with vision impairment and other Australian Standards considerations
• Options for people to be married/in a relationship
• Keeping the carer and person together with support if this is what they want
• Please remember not everyone wants to be placed with others with the same disability
• There were mixed ideas as to whether it is a good idea to support several people together who have challenging behaviours but everyone agreed that no model will ever work effectively unless there are adequate supports including the staffing model and a recognition that some people may need a more secure environment of some kind.

16 Funding Models:

The WRDN believes that there are many innovative ways for individuals, families and the wider community to input into the funding of supported accommodation.

• Family homes used as accommodation
• Family homes bequeathed - rent or sale of property being used to augment support costs (with a proviso that there is a transparent process for ensuring that the funds support the person they are left for, unless otherwise stated)
• Local, State and Commonwealth owned land could be utilised or unused buildings redeveloped
• Partnerships with private providers such as builders
• There were mixed responses to the idea that people might ‘buy’ a place in a service – in a similar way to which aged people access nursing homes at the moment. It wasn’t so much the concept of payment but a genuine concern that access would be prioritised towards those with a capacity to pay.
• Members also believed that there should be an equity of costs across providers and models
• Some families thought that a brokerage model of support may be appropriate especially where people are living in a more independent option. i.e. a number of families combine and purchase the services of an independent advocate to manage the packages of support.

17 Range of costs:

• This will obviously change according to the needs of the individuals.

• The balance is to have sufficient funding to allow for support provision at all levels.

18 Main costs:

• The WRDN identified staffing as the highest cost of any supported accommodation, followed by aids and equipment.

• Staffing costs can be minimised by utilising volunteers, maintaining family and other relationships and keeping/linking people into their existing and community networks. (This also adds to positive quality of life outcomes).
19 How can the funding model ensure flexibility, choice and viability?

- Listening to people
- Proactive planning (avoiding a system based on crisis management)
- Good matching
- Portability of funding
- Funding reviewed on a regular basis
- Using partnership approaches
- Minimise the red tape

20 Contributions by stakeholders

- The WRDN agreed that people with a disability should contribute to their daily living expenses e.g. pay rent, pay bills, buy food.

- The WRDN agreed that where people have the capacity and are willing to do so they should make a contribution towards capital and support costs.

- And of course people must have the right to purchase accommodation options over and beyond DASP programs if that is what they wish to do.

- BUT ACCESS MUST BE ON THE BASIS OF NEED NOT CAPACITY TO PAY. WRDN members pointed out that in most cases carers have made significant contributions to society through their caring role, saving the community incredible amounts of money over the years, very often at the expense of their own income building capacity.

- It was noted that without a clear understanding of the needs of the people eligible for the DASP that it is not possible for the Government to determine whether or not the allocated funds are sufficient to meet demand. The Government must be prepared to allocate additional funds – based on meeting individual need rather than fitting people into pre-determined funding boxes. However it was also pointed out that if the Government is skilful in managing this project that the majority of funding can be spent on direct service provision.

- The WRDN believes this should be a fully funded model. It is not acceptable to expect a $ for $ contribution or even an in-kind contribution from providers as the membership believes this must restrict opportunities for innovation and flexibility.

- The community is a stakeholder therefore community institutions such as banks, superannuation funds, local government, philanthropic organisations should all make a contribution.

21 What will people with a disability and carers need to know and do whilst waiting for a placement?

- Support to enable the carer to continue caring will be essential – increased access to HACC and respite services (possibly for both individual and carer).

- Planning – exploring the options (some members of the WRDN had difficulty in looking past the CRU or nursing home models as they are the only models of which they are aware).
• Planning – what needs to be done to prepare the person for the supported accommodation of their choice and separation from carer.

• Planning – contingency planning in case of crisis.

• If financial contributions are to be made, putting this into place.

• Determining issues such as Guardianship should the carer be unable to make these decisions and practical assistance to do this (including financial assistance to cover costs as this can be very expensive).

• Transition planning .

• Regular contact and updates with stable planning personnel were seen as essential as needs will change during the waiting period.

• Having a time frame to work towards (or ‘hang in’ for).

22 Examples of good assessment frameworks

The WRDN membership was not able to identify any specific examples of best practice but were able to identify a number of issues/challenges

• Involvement of the person with a disability (regardless of level of disability) at all times

• Independent advocacy for the individual may be required because experience indicates the wishes of the carer may be quite different to the wishes of the person with a disability (e.g. individual wants a less restrictive environment)

• Don’t trim the service delivery to meet funding (as happens with the Support and Choice Packages) but fund to need.

• Include the views of a wide range of people who have a relationship with the person. In many cases this would mean involving staff from current providers such as day placements and HACC.

• Many people with disabilities and carers express consternation at yet another assessment process and respectfully suggest that an integrated assessment process be used. It was thought there is one used within Health services.

23 Assessments should include all manner of information:

• Medical needs
• Skills analysis
• Likes/dislikes
• Behaviour support
• Relationships
• Community and social connections
• Other services accessed
• Cultural and language needs were not seen as so important as it was believed that best practice service delivery should be flexible enough to incorporate these. It was noted, however, that it is
well known that as people age they lose their second language skills and as people with disabilities tend to age quicker than their peers that this may be an issue at an earlier life stage than in aged care.

The information gathered should have one goal in mind – what do we need to know to ensure that this person/family receives the most appropriate service, at the right time, in the right place and with the right people.

24 How often should assessments be undertaken?

- An in-depth assessment needs to be undertaken to assess eligibility and priority of access.

- Due to ageing and other issues, reviews need to be undertaken on a regular basis (6 monthly at least) to ensure the information is up-to-date and to determine if a change of priority is required.

- It was pointed out that most parents are unaware (or frightened) of options outside of the CRU or nursing home models but as they become more involved in the service determination processes they may become aware of wider options that they could consider.

- As stated above any plan/assessment should include a contingency plan in case of crisis because that turns crisis management (panic) into planned response.

25 The most appropriate way to handle emergency placements?

The WRDN membership was unanimous in saying that facility based respite services should NOT be used for emergency placements. In the West of Melbourne at any time there is a number of people living long term in respite houses – not for a couple of weeks but for months, even years. This only creates blockages and prevents families from accessing the planned respite which is so essential to supporting them in their caring role. Lack of respite leads to crisis and so the circle continues.

The WRDN proposes that each region should have a “Transition” or “Interim” service for people who are in crisis and in need of longer term accommodation until there is either an appropriate supported accommodation place available or until the family is able to resume care. Specialist, experienced and most importantly a stable staffing model is essential. Individualised or family access to counselling would need to be available. Behaviour intervention services would most probably be required (experience indicates that a deterioration in behaviour is common in crisis situations but particularly if cognitive issues prevent the person from understanding what is happening or they feel disempowered. Transport support is essential so that individuals may continue as many of their daily activities as possible as this minimises the trauma. This “service” needs to be able to cater for people with a range of needs and disabilities.

Where the person with a disability has complex care/nursing home level medical needs there should be designated beds available within/attached to the local nursing homes or better still a regional designated nursing home with emergency beds.

As many crises occur out of business hours the WRDN suggested that there should be a central point of access. It was suggested that perhaps an extension of the Victorian EARS (After Hours Emergency Response Service managed by annecto-the people network) might be a model to be considered.

Specialist “Crisis Management Case Managers” would then work with the individual and family to ensure the transition from home to the “Transition house” and later from the “Transition house” to the
permanent accommodation goes smoothly and any emerging issues are dealt with in a timely and efficient manner. This is cost effective as well as best practice on an individual level.

26 What outcomes should be used to determine quality in disability supported accommodation?

The membership believes that quality is measured in both qualitative and quantitative ways and that both are equally important.

26.1 Qualitative

- What all the stakeholders (people living in the accommodation, their families, front-line staff, service provider, community, related service providers, local community) think of the services provided.
- If residents get on well together – is there interaction and friendships or conflict/resignation.
- How involved are people with disabilities in their daily lives? (independent living skills)
- How involved are residents in decision making that affects their lives – large and small decisions?
- Are people encouraged and supported in their independence?
- How connected are people to their community and a life outside the service?
- What would people change if they could?

26.2 Quantitative.

- Is the ‘unit’ clean, tidy and well maintained?
- Regular health reviews?
- Individualised planning and support in place?
- Records as appropriate e.g. case notes, medication administration.
- Type, quantity and appropriateness of food
- Are the supports and resources appropriate to the needs
- Staffing quality – turnover, qualifications, training, appraisal etc

It was noted that these forms of ‘quality reviews’ will not be appropriate to all accommodation types. E.g. if a person is living in their own home

27 How can people with a disability actively participate in the quality assurance process?

- Ask them.
- Use open questions phrased in a way relevant to the individual.
- If people with disabilities are actively engaged in their accommodation service they will be directing the service on a day to day basis.
- If the provider and funder are willing to listen and encourage self advocacy then it will be easy to identify areas for improvement.
- House meetings for residents and for parents/advocates.
• A commitment by the Board of Management or equivalent to linking complaints/feedback to quality improvement is a necessity.

• If advocates with disabilities and carer advocates are active partners in the service provision there will always be people around to insist on best practice at all times.

• External scrutiny from schemes such as the Victorian Community Visitors program was seen as positive but people who live in/have a family member already living in supported accommodation said that these ‘volunteers’ need to be well trained, paid (so there’s more time and greater frequency of contact) and should have “teeth” i.e. their reports should be taken very seriously.

28 What are the most important features of a complaints resolution process?

• People need to know there is one!
• Accessibility of information i.e. differing formats
• Self advocacy training
• Being heard and taken seriously
• A clear process including recording
• A speedy outcome
• Staff trained in conflict resolution and complaints resolution
• An organisational culture that sees complaints as feedback that can only enhance service delivery
• An independent umpire (Commissioner or similar to make a final imposable decision)
• Being able to see a tangible outcome (something happens, or changes etc)
• Advocacy support throughout the process

29 What are the important elements of an official Volunteers program?

• As stated above: well trained, paid (so there’s more time and greater frequency of contact) and should have “teeth” i.e. their reports should be taken very seriously.
• People with disabilities and carers should be encouraged to take on these roles.
• The office that supports the program should be independent of both the provider and the funder e.g. members felt that the Victorian Community Visitors Program lost strength and integrity when it moved from the Department of Justice to the Department of Human Services. It can be hard to “bite the hand that feeds you”.

The WRDN membership thanks the Commonwealth Government for the opportunity to input into the development of this initiative. We would be more than pleased to expand on any of the points above.

The WRDN membership is keen to support the development of services in the North and West of metropolitan Melbourne.

Yours sincerely,

Helen Adams
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Western Region Disability Network

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13th December 2006

Succession Planning for Carers
Carer Policy Section
FaCSIA
Box 7788
Canberra Mail Centre
ACT 2600

To Whom It May Concern,

I am writing on behalf of the Western Region Disability Network (WRDN) to forward the views of the WRDN membership regarding succession planning for Carers.

The WRDN is a network of people with disabilities, their carers/family members, service providers, State and Local Government and community based in the Western Suburbs of Metropolitan Melbourne. The Region consists of the 7 Local Government Areas of Melbourne, Melton, Brimbank, Maribyrnong, Moonee Valley, Hobsons Bay and Wyndham. The WRDN has been operating since 1993 and has a membership of over 600. The main roles of the WRDN are information dissemination and systemic advocacy.

The WRDN held 2 forums regarding this issue. The response was phenomenal, drawing responses by email and phone as well as discussion.

Feedback was as follows. All italicised type are direct quotes from the membership:

Firstly the membership applauds the Federal Government for recognising this complex and often distressing issue. The membership found it hard to believe that the Government is not aware of carer needs and sincerely hopes that this and other research projects will confirm Carer needs and result in action. However the membership also recognised that it may be difficult to have detailed information about carer needs for 2 reasons. The first being that the Victorian Department of Human Services has recently changed its recording processes and now only records needs that are required TODAY. There is no forward planning. The
second is that there are many Carers in the community who are not linked into formal programs either directly or via the person they care for. The WRDN includes many people with a disability and carers who are among ‘the invisible’.

There were many concerns raised about the introduction of the $500,000 donation to the Special Disability Trust. Not that people thought this a bad thing. Several carers said that they had received confusing complex and expensive advice about what they could and could not do to financially support their son or daughter on their death. The concern is for the future of those people whose families do not have the capacity to provide financially for the future.

One parent who has a son and a daughter living in supported accommodation has been advised by the Victorian State Trustees that they cannot leave their home (i.e. their only asset) to the organisations that care for their children but must leave it to their children. Due to the severity of their disabilities their children do not have the capacity to make a will and therefore the property will go to extended family (who have little if any contact with them). They have been told they may challenge this in the High Court at $5000 each but wonder why they can’t leave the property to provide the caring agency with income from the sale or rent. “After all, doesn’t it belong to us? So why can’t we decide what to do with it”

The other concern about the Special Disability Trust is how that money will be expended. Is it lumped together and shared around? Is it only used to support my person? What will it be used for – everyday expenses or quality of life extras e.g. recreation? What happens when it runs out? Several carers said that they also have to consider the rights and needs of their other children and cannot commit all their money to just one member of the family.

Parents are really concerned about the Victorian Government policy that says they will not be building any more supported residential units. There are currently over 900 people on the Victorian DHS urgent list for supported housing (please refer to table below from the DHS website). Recognising that some of these people can be supported in the community and that some residential places are being created by encouraging people to move from residential care to more independent options it still leaves a huge number of people in need. If you look further at the table DHS acknowledges over 1100 people waiting for Home First packages – the support that most people need if they are to be supported in the community either independently or with their families.

The number of requests for services on the Disability Support Register on 30 June 2006.

<table>
<thead>
<tr>
<th></th>
<th>Urgent</th>
<th>High</th>
<th>Low</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared Supported Accommodation</td>
<td>924</td>
<td>487</td>
<td>953</td>
<td>2,364</td>
</tr>
<tr>
<td>Day Programs</td>
<td>417</td>
<td>111</td>
<td>17</td>
<td>545</td>
</tr>
<tr>
<td>HomeFirst</td>
<td>1,197</td>
<td>247</td>
<td>83</td>
<td>1,527</td>
</tr>
</tbody>
</table>

Total 4,436 requests for services.
One parent said “I have been on the urgent list for years. My son is 33 and very strong. When his dad was taken ill we discovered we were only on the bottom of the list”. Another asked “Where will my son go if I drop dead tomorrow – the streets?”

Several carers raised the issue of preparation. They see using respite as not only respite but also as a way of preparing their son or daughter for a different form of accommodation in the future. “But we can’t get any, because the respite beds are all taken up with people in crisis waiting for permanent accommodation.”

Another parent said “Getting the house is the easy part. But where does the support come from?”. Another parent said “I’ve been on the Home First Waiting List for years, still waiting! Is there even a list? How can we plan when we have no idea of timelines, resources and options available?”

The writer asked the membership how many had made plans for the future. About 60% said they had a clear idea of what needs to happen but sadly most of these said that there was little chance of those needs being met. “Thinking about the bigger picture is hard when we cannot get today’s needs met”. There was a general agreement that planning for the future is both ‘scary’ and ‘time consuming’. Some people just can’t bring themselves to think about the future. “Even talking about this makes my wife anxious”.

Sadly 3 out of the 40 participants at one forum clearly believed that the best option for their son or daughter was euthanasia. These ageing parents really believe that the trauma of losing parents and being moved from the family home would be so unfair and distressing that they have made a pact to take him or her with them. This is not seen as murder but as a final act of caring and love. These parents refuse to let their other children take on the caring role. They believe that their other children should not be burdened as they have been. Sometimes the siblings refuse to agree to take on the caring role, even though this would be the parent’s first choice. One daughter said “We’ve seen what Mum goes through – no way”.

One parent, who has a daughter aged 18 with severe disabilities, is struggling to keep going until her daughter dies soon. She said her daughter needs nursing level care but she refuses to put her in a nursing home with old people. This same person also raised an interesting spin-off for future caring issues. She said she has told her parents that when X dies her caring days are over and she will definitely not care for them in their old age – she’s burned out. Nursing home for them! (and the parents agree she’s done her fair share).

It was amazing the number of people who are actually carers of 2 generations. As an example one lady cares for her daughter with intellectual disabilities at home plus sick and elderly parents and elderly parents-in-law who live in different parts of the city. Another parent was looking after her 37 year old son and her ailing husband.

A number of respondents said that they believe it is the Government’s (at all levels) responsibility to plan. “The government is just relinquishing delegation of duty...” Expecting families to take on this responsibility was seen as another way of deflecting that responsibility onto families. “I want to be involved but I don’t want or need the work. After all if X was in care it would cost a fortune. We carers save the government millions every year. Why isn’t this directed to helping us?” Several people said that they thought decision
makers see the provision of a case manager as half the problem solved whereas families only see this as a support and one small step in a long process.

Those who had not started to plan said that it was difficult, that they had enough difficulty surviving through each day to worry about the future and that they are so depressed and busy there is not time.

When asked about what supports people need to plan the answers included –

- Information – what are my options?
- Timeframes – when will those options be available?
- Seeing the options would help people to make choices as they don’t really know what it is they are opting for. “It would reduce our anxiety if we could actually go to a residential unit and see what it looks like, how it operates, see that people are cared for properly”
- Someone to help the family through the process – but with 2 major differences to the way planning is currently undertaken. Firstly “it needs to be someone with whom you have a relationship and who you can trust. Trust takes time to develop. A lot of the information that needs to be discussed is personal, it’s hard. You need to be able to trust the person not to judge you and not to push you to make decisions”. This all takes time. Secondly is the time factor. It can’t be done in 20 hours or 3 months but must be a ‘work in progress’ that develops as people feel more in control and ready to make those decisions.
- Legal advice “need a Philadelphian lawyer to wade through it all”
- Free and “in my time space”
- Someone to follow up and report back their findings
- “Someone who will respect our decisions, even if they don’t like our choices.”
- Someone who can be my advocate – that people like Centrelink will talk to on my behalf.
- Someone who will address the issues
- “A good communicator”
- Early planning – don’t wait until we’re in crisis to do something.

There was support for a well organised and well publicised process for parents to raise ideas. “You don’t know who to speak to”. “It’s so frustrating when the goal posts keep changing”. There was a strong feeling that decision makers don’t like people in receipt of service to have any ideas other than what’s currently available. People said that they had heard about different options. They want information about things that others have tried. “Don’t reinvent the wheel but don’t assume that because it worked overseas it will work here” “What about individual needs, one size does not fit all. I’m an individual and so is my son. He’d hate living with other people. He has most of our house to himself as it is”.

People felt that organisations were prevented from being more lateral thinking and individualised in their approach to people with a disability by three main factors. The first is red-tape and the inability of funding bodies to fund creative ideas. The second is that because it is all-too-difficult to get funding for new options that agencies have given up trying. The third is that agencies are turning down offers of money and assets because of the legal complexities that arise. “The processes that would enable our organisation to accept offers and use them flexibly and creatively are just not in place” said one CEO.

Other barriers to planning that were identified were language and cultural issues.
Members believe that the Federal Government must fund and strengthen the disability advocacy sector including ‘different’ and ‘unique’ organisations such as the WRDN. “I cannot read in my own language so how am I expected to understand papers like this? Thank goodness you (the WRDN) are telling me what the paper says and will tell the Government what I think”

Members also pointed out that it is important to remember that many people with a disability are capable of making their own decisions or at least being an active participant in the process. Self advocacy support was seen as crucial to supporting this concept.

An interesting point raised was the concern that parents have regarding the on-going advocacy and support role that they currently have or would assume if their person was living in alternative accommodation. “Who is going to ensure that he is cared for properly when I’m gone?” asked one parent. ”As it happens I’m the only one who takes him out on his own”

There were many other comments and concerns raised by the WRDN membership. They related to the frustrations that people feel every day – lack of resources, lack of information or misinformation, the increasing cost of keeping their person at home, inflexible options that push ‘a square peg into the round hole’. People are concerned they can’t get access to essential equipment, to respite, to recreation, that services are poor quality, stretched to the limit and reducing hours when extra hours are needed. And they are tired. Tired of the demands, tired of not being supported, tired of not being listened to. The membership applauded when someone said "Not another survey! Where is the action? “

I would be pleased to expand on the above at any time or more importantly to organise for you to meet the carers of the WRDN who would be only too pleased to discuss the issue of planning for the future with you personally.

Yours sincerely,

Helen Adams
Executive Officer, WRDN