

Joint Submission
on the proposed
**Disability Supported
Accommodation
Program**

October 07

Contact
Ross Womersley
ross.womersley@clp-sa.org.au
ph 08 8384 7866
0433 055 406
Community Living Project
111 Beach Road
CHRISTIES BEACH SA 5165

Table of Contents

| | |
|--|-----------|
| 1. Executive Summary | 5 |
| 2. Introduction | 7 |
| 3. Clarification | 8 |
| Clarification on the needs of the target group | 8 |
| Clarification of the term “supported accommodation”..... | 8 |
| Clarification on the importance of home..... | 9 |
| Clarification on housing and support..... | 9 |
| Purpose of DSAP..... | 10 |
| 4. Principles | 11 |
| Focus on the person with disability | 11 |
| Respond person by person..... | 11 |
| Allow people to grow, change and learn | 11 |
| Build on what is there..... | 11 |
| Do no harm..... | 12 |
| 5. Key Issues | 13 |
| A rich and full life will not happen without a positive vision and plan incorporating the person with disability and their family | 13 |
| There is need for the recognition of the fundamental rights of people with disability | 13 |
| “Choice” must not be the only driver | 14 |
| Paucity of person-centred planning practice | 15 |
| Many models of “supported accommodation” are unsafe for people with disability | 16 |
| Cost effectiveness is not related to size of facility..... | 17 |
| No service should have control over a person’s life..... | 18 |
| Lack of innovation and change in the established service sector | 19 |
| Duplication of effort is neither efficient nor effective..... | 19 |
| 5. Recommendations | 20 |
| Individualised funding | 20 |
| Person-centred planning..... | 20 |
| The separation of housing and support services | 22 |
| Building Capacity | 23 |
| That DSAP: establishes state-based mechanisms to assist service providers, people with disability and families to imagine better through technical assistance, information, advice and leadership development. . | 24 |
| Focus on community-based non-profit service providers..... | 24 |
| Advice and direction from people who are affected | 25 |
| Quality Assurance (QA) focuses on outcomes rather than systems | 25 |
| 6. Response to questions..... | 28 |
| What is the Disability Supported Accommodation Program (DSAP) and who will be able to use it? | 28 |
| How will DSAP link to other programs? | 29 |
| Who can provide supported accommodation?..... | 30 |
| When and where will places become available?..... | 30 |
| What will the accommodation look like? | 31 |
| How will places in DSAP be funded?..... | 32 |
| How could demand be managed? | 33 |
| Will the DSAP provide high quality supported accommodation? | 33 |
| 7. Appendix..... | 34 |

1. Executive Summary

A collective of people representing advocacy and service organisations across Australia forwards this submission for consideration. It wishes to bring to the attention of Disability Supported Accommodation Program (DSAP) that:

- the group of people with disability targeted by the Disability Supported DSAP are likely to have an established home, a loving family and a network of informal support, specific skills to manage their environment and some plans for their future.
- the term “supported accommodation” connotes an image of the for-profit homeless accommodation with a reputation for abuse and neglect. This clearly confuses what DSAP considers as best practice in supporting people with disability.

The collective proposes that FaCSIA name this program:

Disability Support and Housing Assistance Program

and the purpose be:

to assist people with disability to establish or maintain their own home within their community and to build a rich and full adult life with informal and paid supports when their families are no longer able to provide the primary care.

Principles

The collective offers the following principles for DSAP

Principle 1 - Focus on the Person with disability

DSAP will focus on the rights and needs of the person with disability and those needs of the carers that support the person to have a rich and full adult life.

Principle 2 Respond person by person

DSAP will work with people with disability, one person at a time, to develop, establish and maintain a positive future envisioned by the person and his or her family.

Principle 3 - Allow people to grow, change and learn

DSAP will support people with disability to grow, change and learn understanding that the housing and support needs provided now are likely to change over time.

Principle 4 - Build on what is there

DSAP will work with and incorporate established family, community and friends starting with the current home environment wherever possible.

Principle 5 - Do no harm

DSAP will support only those service models, which ensure people with disability receive good outcomes, based on evidence-based research.

Within a range of issues, the collective considers that rather than the arbitrary emphasis on “choice”, the DSAP works, person by person, towards his or her vision of a rich and full adult life within the person’s community. The collective is also concerned that FaCSIA will take the effortless strategy of proclaiming person-centred planning while supporting the usual service-centred practices.

Recent literature reveals a consistent pattern across service types and over time of better outcomes and lower costs where housing is integrated and ordinary compared to larger grouped facilities.

The collective offers the following recommendations:

Recommendation 1 - Individualised Planning

That DSAP delivers funding through individual support packages targeted at eligible people with disability with capacity for block funding for infrastructure.

Recommendation 2 - Person-centred planning

That DSAP ensures there is independent capacity to assist people with disability and their families to envision and plan for their future, expand and maintain their informal networks of support, maintain or establish a home of their own and direct the paid supports required.

Recommendation 3 - The separation of housing and support services

That DSAP

- funds initiatives which separate the supply and management of housing and the provision of paid support
- puts in place a range of guidelines and incentives that ensure people are able to enjoy accessible, ordinary, affordable housing that is part of the local community and which genuinely is 'home' and not 'facility'
- establishes guidelines and incentives that ensure people receive home-based support in ways that reflects the person's individuality, and which complement and build on both the person's own strengths and the support the person has from his or her family and friends.

Recommendation 4- Need to build capacity

That DSAP establishes state-based mechanisms to assist service providers, people with disability and families to imagine better through technical assistance, information, advice and leadership development.

Recommendation 5 - Focus on community-based non-profit service providers

That DSAP

- focuses on the establishment of community based non-profit services. This includes the provision of good information, adequate funding and the limiting of invasive bureaucracy. This also includes the development of a positive best practice framework that organisations can follow.
- encourages home suppliers to develop a range of housing that is accessible.

Recommendation 6 - Advice and direction from people who are affected

That DSAP

- forms a Reference Group of people skilled and experienced in supporting people with disability to live in the community to guide its implementation
- ensures that all DSAP mechanisms are 'user friendly' to people with disability and their families so that they are genuinely in control of the process as it affects them.

Recommendation 7 - Quality Assurance (QA) focuses on outcomes rather than systems

That the DSAP establishes a quality assurance system that focuses on quality outcomes for people with disability.

The collective answers the particular questions asked in the discussion paper in the light of the above principles and recommendations.

2. Introduction

The following collective of organisations (the collective) forward this submission for your consideration.

| Organisation | Contact person | Origin |
|---|-----------------------|---------------------------|
| | Dr Lorna Hallahan | Adelaide, South Australia |
| Arts Access-SA | Dr Paul Collier | Adelaide South Australia |
| Community Connection Inc | Ann Greer | Townsville Queensland |
| Community Living Program | Ross Womersley | Adelaide South Australia |
| Community Resource Unit Inc. | Lynda Shevellar | Brisbane, Queensland |
| Homes West Assoc Inc | John Groom | Brisbane Queensland |
| Include Pty Ltd | Dr Bob Jackson | Perth Western Australia |
| Independent Advocacy SA Inc. | Fiona Campbell | Adelaide, South Australia |
| Institute for Family Advocacy | Catherine Hogan | Sydney, New South Wales |
| Jane Sherwin and Associates | Jane Sherwin | Brisbane, Queensland |
| Julia Farr Association Inc | Robbi Williams | Adelaide, South Australia |
| Mamre Association Inc | Kathryn Treston | Brisbane, Queensland |
| Personalised Lifestyle Assistance Project (Melbourne) | Deb Rouget | Melbourne, Victoria |
| Queensland Advocacy Incorporated. | Kevin Cocks | Brisbane, Queensland |
| Queensland Parents for People with a Disability | Phil Tomkinson | Brisbane, Australia |
| Speaking Up for You | Di Toohey | Brisbane, Queensland |
| Uniting Care Community Options | Ronda Held | Melbourne, Victoria |

(For complete details, see Appendix)

The collective commends the Department of Families, Community Services and Indigenous Affairs (FaCSIA) for addressing the unmet needs of people with disability through its new Disability Assistance Package announced in June 2007. This submission focuses on the new **Disability Supported Accommodation Program (DSAP)** and the particular questions outlined in the document “Disability Supported Accommodation – A discussion paper” (discussion paper).

3. Clarification

The collective offers the following clarification on the terminology used, assumptions about the target group and the purpose of DSAP, all of which are not clearly defined in the discussion paper.

Clarification on the needs of the target group

The target group of people with disability are people who have lived with their families in the family home over a long period. This arrangement has been sustainable until the parents' age.

Notwithstanding the real issues, sacrifices and stresses families have experienced, the collective considers that the people with disability are likely to have:

1. a strong sense of "home", their community people in their life who love and care about them
2. developed some skills in daily living within their capacities and specific to their home and local community, supported by their loving families. (For example, people use their local shops, banks, transport and may be able to make simple meals and refreshments.)
3. established informal networks including adult brothers and sisters, nieces and nephews, church members, neighbours and local business people
4. people around them intentionally making plans about their future, including their housing tenure, alternative decision-making support, inheritance of family assets and the establishment of trusts.

| |
|---|
| <p>This group of people with disability are likely to have an established home, a loving family and a network of informal support, specific skills to manage their environment and some plans for their future.</p> |
|---|

Clarification of the term "supported accommodation"

The discussion paper uses the term "supported accommodation" as "housing or accommodation that includes support for people with disability who require assistance in a place to live and support for their care needs". This term assumes that:

- "bricks and mortar" are inherent in the solution
- housing and support are tied into the one service solution
- people will be "placed" into an already established solution.

The assumptions tied to the term "supported accommodation" are precarious in their validity and limit best practice before DSAP has even begun. The term "supported accommodation" already describes the 'private for profit' short-term accommodation targeting homeless people, many of whom have a disability. Unfortunately, this name is tarnished because of the abuse and neglect of vulnerable people that has occurred in these facilities over years, necessitating legislative safeguards and accreditation schemes to keep them in check. To align this new initiative with the name "supported accommodation" is an unfortunate and avoidable handicap towards the Government's goal of excellence.

Many people may wish to remain in the family home or have families who are interested and able to contribute to a suitable local alternative. The collective considers the DSAP should focus primarily on support and have the capacity to assist with housing options through generic housing providers if required.

The collective offers the following terms and definitions:

Supported living is a general term describing a lifestyle where formal and informal supports are required.

Informal support is support that is freely given by family, friends and community members.

Paid support is support provided by paid staff.

Home is a place where a person lives permanently¹ and has a sense of belonging.

Housing is property consisting of houses or buildings² for the purpose of establishing a permanent home.

Clarification on the importance of home

The collective knows that a "home" is much more than simply the bricks and mortar that make a house. It is also much more than a "place" or a bed in a facility somewhere. When one considers "home" it is of an unique environment which most people typically seek to create - a place that is "our own" and which gives a sense of security, a sense of pride, a place of privacy, retreat and sanctuary, and an accepted place in the community.

Clarification on housing and support

For a person who chooses and is able to move from their family home, the role of DSAP and the nominated support provider is to help that person access the same housing opportunities available to all other community members. This includes public housing, private rental, and wherever realistic, pursuing purchase options. Once obtained, the support provider's major and on-going role is to help that person create a home that reflects their life interests and personality- a home that fundamentally reflects who they are.

For a person who remains living with their family, the role of DSAP and the nominated support provider is to:

- provide the support that person needs in a manner that deeply respects the family home, traditions and customs
- enhance existing informal supports and networks and
- build on the person's existing identity and life outside of this context.

The collective proposes that FaCSIA name this program
Disability Support and Housing Assistance Program

¹ The New Shorter Oxford Dictionary 1993

² *ibid*

Purpose of DSAP

Within the aim of the new Disability Assistance Package to give practical support and peace of mind to older carers of people with disability, including “a high level of inquiry to identify alternative funding and delivery systems for disability supported accommodation”³, the collective offers the following purpose for DSAP:

Purpose of the DSAP

DSAP assists people with disability to establish or maintain their own home within their community and to build a rich and full adult life with informal and paid supports when their families are no longer able to provide the primary care.

³ Australian Government *Disability Supported Accommodation A discussion paper 2007 p7*

4. Principles

The collective offers the following principles to:

- honour the rights of people with disability
- respect the personal investment of their long-term carers
- give clear direction to the delivery of service
- avoid the mistakes of the past.

Focus on the person with disability

Given the major advocacy for DSAP stems from the voice of carers, there is a risk that the carers' needs overshadow those of the people with disability for whom DSAP is intended. People with disability, and not merely service providers, government departments and family members must be at the centre of consultations and involved in any decisions that are made.

Principle 1

DSAP will focus on the rights and needs of the person with disability and those needs of the carers that support the person to have a rich and full adult life.

Respond person by person

The DSAP's commitment to choice and person-centred service can best be met by working with people with disability, one person at a time, before any assumptions about service solutions are made.

Principle 2

DSAP will work with people with disability, one person at a time, to develop, establish and maintain a positive future envisioned by the person and his or her family.

Allow people to grow, change and learn

People with disability like other people continue to grow, change and learn. DSAP will need to be flexible, portable and structured to manage ongoing change as people with disability change, particularly as they age.

Principle 3

DSAP will support people with disability to grow, change and learn understanding that the housing and support needs provided now are likely to change over time.

Build on what is there

Most people with disability have an established home, community, family, and friends. They also have specific skills and capacities to manage their familiar home environment. People do best when they can build on these networks, skills and capacities rather than having to start again at middle age to build a new life in a foreign environment supported by strangers.

Principle 4

DSAP will work with and incorporate established family, community and friends starting with the current home environment wherever possible.

Do no harm

Over the last twenty-five years, there has been significant research and development into supported living, what works well for people and what has systemic negative consequences for people with disability.

With this evidence-based research now available, some “choices” are simply not valid, if the Australian Government is committed to “ensure that people with disability receive good outcomes”⁴.

Principle 5

DSAP will support only those service models, which ensure people with disability receive good outcomes, based on evidence based research.

⁴ FaCSIA *Disability Supported Accommodation A discussion paper* 2007 p14

5. Key Issues

A rich and full life will not happen without a positive vision and plan incorporating the person with disability and their family

DSAP are focusing on people with disability and families who may or may not have plans for life after the parents can no longer care. The collective knows that nothing much happens for people with disability unless there is deliberate and positive planning for the future.

When services plan, the outcomes are limited to the capacities of the service. The collective considers envisioning and planning what is a rich and good life for the person with disability must be driven by that person and their family, supported by people independent of service and well versed in how a good life can happen.

Where planning is done independently of service, there is a better chance of including existing informal supports and capacities. This is where the family can best contribute to the “costs”.

A range of Succession Projects (planning for the future) also exist, including those being developed by Homes West, Pave the Way, Parent to Parent, and CRU in Queensland. These projects have assisted people with disability and their families to envision, plan and build for rich and full adult lives.

There is need for the recognition of the fundamental rights of people with disability

On March 30, 2007, the Australian Government was among the first 81 countries to sign up to the Convention for the Rights of People with Disabilities (CRPD). The enactment of the Commonwealth *Disability Services Act* 1986 enshrined principles and objectives which complement the CRPD. It appears, however, the discussion paper was written with little recognition of the Commonwealth *Disability Services Act* 1986 and its principles and objectives and the CRPD articles.

Article 19 of the CRPD (Living independently and being included in the community)⁵ is an important extension of the right to liberty, which applies specifically to the living arrangements of persons with disability. The article is directed to the elimination of segregated, congregate and socially isolated environments in which people with disability have historically been forced or obliged to live. The article requires governments to ensure that persons with disability are able to live in the community with accommodation options equal to others, and that these options support the inclusion and participation of persons with disability in community life.

The article also provides that persons with disability must be able to choose with whom they live on an equal basis with others. In order to realise these freedoms, governments are obliged to ensure that persons with disability have

⁵ United Nations *Convention for the Rights of People with Disabilities* 2006.

access to the support services they require in order to live freely in the community, and avoid isolation and segregation from the community. These support services include in-home support, residential and community support services, and personal care.

The collective is concerned that the DSAP will not honour Article 19 or the principles and objectives of the *Disability Services Act* 1986, as it does not “ensure that mainstream community services and facilities are available and responsive to the needs of persons with disability to facilitate their freedom to live in and be a part of the community”⁶.

“Choice” must not be the only driver

The last twenty-five years of research, knowledge and experience within the service sector is evidence enough that people with disability do not and have never had the same opportunities as those without disability. They have limited choice at best.

As demonstrated in the consultations across Australia, people with disability are often not included in decisions that are being made about them and for them. Thus, to suggest that people with disability have choice when they are not involved in the process is untenable. Where people with disability have impaired capacity and need support to make decisions that support must be individualised and free from conflict of interest and undue influence.

As mentioned above, a large body of critique exists around many of the models of support and policies currently in place. Whilst the notion of “no one size fits all” is to be commended, and having a range of options is vital, the exaggerated emphasis currently given to choice-making is almost wholly driven by ideology rather than considered examination of its likely results.”⁷

For most people with disability:

- **Choice happens within the limitations of available information:** Choice assumes well-informed decision making where people are aware of a number of options and of the benefits and challenges of each option. Most people with disability, particularly those with high support needs, and their families have little experience of options other than large residential centres, cluster housing and group homes. There are insufficient local examples of people living in their own home, perhaps with a person without disability, with a combination of paid and freely given support.

Many families ‘choose’ a very restricted option for their family member with disability because they are unaware of the way in which other options can meet the needs of the family for reliability and security while simultaneously meeting the needs of the person with disability to develop relationships with people who care.
- **Choice is shaped by the person’s support needs:** Most models are developed for people with identified support needs and thus professionals

⁶ United Nations *Convention for the Rights of People with Disabilities* 2006

⁷ Armstrong, J. (2007). “*Making the most of autonomy and choice*”, CRUcial Times, 39, September, p. 7.

will guide any one individual to a particular service depending on their support needs. The system has developed a continuum of services in which persons with high support needs tend to be congregated at the restricted end where they are forced to trade restrictiveness (presumably of human rights) with intensity of services (needs). The continuum of care model confuses segregation with intensity of service. Whilst some people certainly need intensive supports, this does not have to relate to a type of facility.

- **Choice happens within the initiative and approval of the authorities who control their life circumstances:** People who use services are only allowed to choose between options that are currently 'on the table'. For a person living in a group home, choice might be available over which foods they prefer or which TV channel they would like to watch. The choice of leaving the group home and moving into their own home is not on offer.
- **Choice of one individual is shaped by the choices of others:** When congregate accommodation is built, significant resources will be directed to its maintenance and staffing. New people in need of supported living will be directed to the vacancy that exists since the absence of residents will be perceived as threatening the sustainability of the service.

The collective considers that rather than the arbitrary emphasis on "choice", the DSAP works, person by person, towards his or her vision of a rich and full adult life within the person's community.

Paucity of person-centred planning practice

Person-centred planning is a process-oriented approach to empowering people with disability. It focuses on the people, their strengths, capacities, hopes and needs and puts them in charge of defining the direction for their lives.

The vast majority of services do not currently work in a person-centred framework. Obstacles to the achievement of person centred planning in the DSAP are as follows:

- current assessment processes are based on deficits in a way that undermines person-centred planning
- most services have no understanding of the process of person-centred planning
- discussion around the DSAP seems to ultimately require people with disability and their family to choose from a limited menu of accommodation options rather than designing something that is personalised and makes sense for the individual.

Currently most services develop Individual Service Plans (ISPs) in a system-centred, as against person-centred, framework⁸. The collective has concerns about current ISP practice because:

⁸ Greasley, P., *Individual planning with adults who have learning difficulties: key issues*, Disability and Society, v10 no 3, 1995

- goals are commonly set to reflect service-related aims rather than person-related aims. Since ISPs are initiated and controlled by service providers, they tend to focus on issues important to them, prescribing training goals and learning schedules that correlate with program routines. O'Brien and Lovett⁹ argue that when uniformity and predictability are primary system values, ISPs function to decrease uncertainty and variety through regulated, impersonal (objective) processes of judgment that specify people's daily routines in the pre-existing service option that best matches their disabling condition.
- the purpose and effect of individual program planning is to make the system more stable, by drawing clear boundaries between staff and client and by teaching staff and families and people with disability a way to think about people's needs that matches the system's routines.
- there is insufficient involvement of people with disability and families in the assessment and planning process, exacerbated by the unequal power status between service users and professionals. As a result, people with disability and families become passive recipients of the service.
- there is too much emphasis on personal inadequacies of people with disability relating to educational and social competencies, with too little attention to personal strengths and capabilities. This often results in a 'readiness' model where the individual is subject to endless training programs in preparation for the 'real thing' (eg work, real relationships) in the distant future and is thereby denied the valuable experience of learning in situ.

The collective considers the inclusion of the concept of person-centered planning into this policy framework demonstrates a lack of real understanding of the fundamental paradigm shift that it entails. It is another example of adopting contemporary best practice language while service practice remains the same.

The collective is concerned that FaCSIA will take the effortless strategy of proclaiming person-centred planning while supporting the usual service-centred practices.

Many models of “supported accommodation” are unsafe for people with disability

The literature clearly demonstrates that collective models and bricks and mortar responses do NOT keep people safe¹⁰. Inquiries such as the Senate Inquiry into Crime in the Community (Chapter 4)¹¹ demonstrate amply the extraordinary risks for people living in segregated and/or congregated settings.

⁹ O'Brien, J., & Lovett, H., 1992, *Finding a way toward everyday lives: the contribution of person-centred planning*, Harrisburg, PA Pennsylvania Office of Mental Retardation.

¹⁰ An excellent summary of this research exists in the Community Safeguards Coalition's (2005) position paper "Keeping People Safe"

¹¹ www.aph.gov.au/house/committee/laca/crimeinthecommunity/report/vol2chapter4.pdf

Whilst housing is a very real need, the building of group homes raises many concerns for people's safety rather than allays them. Dick Sobsey¹² identifies four factors, which may lead to the occurrence of institutional abuse: power inequities, collective lack of recognition of the deviancy of such behaviour, the 'cover-up' and environmental isolation.

As many families attest, a group home does not solve issues of loneliness and isolation but can actually accentuate people's difficulties and sense of isolation. Vacancy management, poor matches, inadequate supports and poor assessment of need can create and exacerbate a range of emotional, communicative and behavioural difficulties.

The alternative to group homes is not necessarily living alone, or living a lonely life. Instead of investing in group homes, funds need to be invested in a range of ordinary housing options, a range of alternative supports and the strengthening of the skills and knowledge of the people providing support.

Cost effectiveness is not related to size of facility

The collective considers effectiveness in achieving high quality outcomes and good quality of life is a critical factor when considering expenditure for services. Higher-cost services that deliver better outcomes ought to be supported strongly on cost effectiveness grounds.

The recent literature review by the Institute for Family Advocacy (NSW)¹³ reveals a consistent pattern across service types and over time of better outcomes and lower costs where housing is integrated and ordinary compared to larger grouped facilities.

The policy implications for DSAP from this review are:

- Effectiveness in delivering high quality outcomes for people with disability must be valued as highly as cost considerations when decisions are made to develop and fund services.
- Only models of supported living that produce positive outcomes for people with disability should be part of Australian Government policy in line with their principle that "the outcomes delivered for people with disability will be included as measures of quality"¹⁴
- Small, integrated housing and supported living schemes should be the preferred option based on the evidence that they lead to better outcomes for people with disability.
- Since people with disability and their families are only likely to understand what is possible after they see or experience good alternatives, it is critical that DSAP fund options for supported living that demonstrate best practice.

¹² Sobsey, D. (1994) *Violence and Abuse in The Lives Of People With Disabilities: The End Of Silent Acceptance?* Paul Brookes.

¹³ Family Advocacy *Presenting the Evidence*, August 2007

¹⁴ FaCSIA *Disability Supported Accommodation A discussion paper 2007* p8

This same literature review reveals that how staff provide support is a key determinant of outcome for people with disability. If staff work respectfully and creatively with families to plan, select and schedule activities and arrange the supports people have a greater chance of living a rich and full life. The more personal the home, the higher the level of engagement and the greater is the staff attention to people who live there.

The policy implications for DSAP are:

- The significance of staff in achieving positive outcomes for people with disability must be emphasised in DSAP policy
- Government funded services must provide staffing formulae based on evidence of what promotes the highest level of engagement of people with disability
- Staff working with people with disability must be trained, supported and supervised to provide effective assistance that promotes increased independence and participation in valued social roles.

No service should have control over a person's life

Our history and legislation recognise the danger of one service having control over people's lives¹⁵. Consequently, investment in buildings by disability services must be the last rather than first resort. There must be a separation between the supply and management of housing and support.

Buildings last long after their original need and typically serve to limit any change or growth of those that follow. Buildings also create a number of additional problems for people including maintenance of the property, portability, mobility and flexibility of service provision.

In traditional services, it is common for the support provider to be the property owner or proprietor also. This means support in a shared house or institution is controlled by the same organisation that controls the support staff.

If the person with disability challenges the service for any reason, the support he or she receives may be withdrawn, so leaving the person without housing. Similarly, if the person wishes to change their housing, the person will also lose their support. People with disability often tolerate a mediocre, even negligent service because they don't want to risk losing their home. No single service agency should have such a level of control and influence over a person's life.

Examples of support provided wherever the person lives can be found in services such as One by One, Living Distinctive Lives, Night Life and Personalised Lifestyle Assistance Project in Melbourne, One Person at a Time (Vic), Onondaga Community Living in New York, Jay Nolan Community Services in Los Angeles, Deohaeko in Toronto, Lifestyle Options Inc, Real Life

¹⁵ *Disability Services Act 1986* Principles and Objectives

Options, Homes West, Mobile Attendant Care (Brisbane). None of these services own or manage housing.

Lack of innovation and change in the established service sector

The current situation across Australia lacks strong performance in innovation and change. Because there are few alternatives for supported living, there is little knowledge and expertise in the community about different ways of meeting people's needs. This then results in pressure to 'place' people into fixed models of support, thereby creating a so-called 'demand' for these fixed models of service. In other words, family members and people with disability themselves perceive that their only options are congregated facilities, even if they appear 'home like', and so ask for these.

Solutions that bring out the latent resources in the community are needed. People need to see that there are many other ways of having support in one's own home and of having degrees of authority over one's support arrangements.

The service system needs to adapt to find ways to work in partnership with people with disability, families and communities to evolve living arrangements that are safe, sustainable in the long term and of high quality. These partnerships must value the centrality of people with disability and families and not replicate those in which professionals tend to dominate.

Duplication of effort is neither efficient nor effective

The collective questions why this initiative requires a duplicate investment in infrastructure rather than work collaboratively through the Commonwealth State and Territory Disability Agreement (CSTDA).

Working within the CSTDA is more likely to yield real alternatives for the sector, build on existing learning, and use scarce funds in the most effective and efficient way.

5. Recommendations

Individualised funding

The collective considers that it is critical that funding is delivered through support packages targeted at eligible people with disability with capacity for block funding for infrastructure.

The two components are:

1. **core funding** for non government agencies for infrastructure costs
2. **individualised funding packages** that are:
 - targeted to named individuals;
 - transferable with the individual;
 - allocated according to a common procedure;
 - based on an assessment of the person's support needs in living in the community;
 - guaranteed on that basis and indexed to cost increases;
 - responsive to changing need;
 - able to be deployed flexibly.

For the person with disability, individualised funding:

- supports portability: being able to change services or move geographically because the resources are transferable with the individual
- supports choice and flexibility: when the resources 'belong' to individuals, their bargaining position in negotiating their support is enhanced.

For the service, individualised funding:

- creates incentives to be responsive to individuals to retain their involvement. (Many services endorse individualised funding, because it gives people with disability and their families greater control over their lives.)
- may require more complex financial and outcome acquittal processes and staff management.

Recommendation 1

That DSAP

delivers funding through individual support packages targeted at eligible people with disability with capacity for block funding for infrastructure.

Person-centred planning

Person-centered service planning is a process-oriented approach to empowering people with disability¹⁶. It should focus on the people, their strengths, capacities, hopes and their needs and put them in charge of their lives rather than focusing on the systems that may or may not be available to serve them.

¹⁶ The Person-Centred Planning Education Site <http://www.ilr.cornell.edu/ped/tsal/pcp/>

Person-centered service planning involves the development of a "toolbox" of methods and resources that enable people with disability to choose their own pathways to success. The planners simply help them to work out where they want to go and how best to get there.

Planning is the business of the person with disability and their family and will encompass a wide range of strategies. Paid supports and housing will be only one of many parts. People with disability and their families typically need assistance with planning, to imagine better and to be well informed of all the possible alternatives to meet one's needs.

When this planning is deliberate and robust, services can then more easily commit to individualised responses. Services are placed in a "come here, go away" relationship and are only required when informal networks and capacities are not sufficient to meet the person's need.

Once families take ownership of the vision building, planning and directing of the level and kind of paid service required, and paid service responds sincerely to being part of that plan, then a respectful or "right" relationship between the individual, the family and service becomes possible.

Individuals and families would also benefit from assistance to maintain and expand their informal networks. With intention and focus, these networks can make the person's life richer and safer in a way that no paid service can.

Approaches to person-centred planning

Several distinct approaches to person-centered planning have been developed over the past twenty years, including:

- 1980 - Jack Yates developed the Individual Service Design;
- 1987 - Beth Mount developed Personal Futures Planning;
- 1989 - Marsha Forest and Evelyn Lusthaus developed MAPS and Circles;
- 1992 - Michael Small and Susan Burke Harrison developed Essential Lifestyle Planning;
- 1995 - Jack Pearpoint, John O'Brien and Marsha Forest developed PATH.

Each tool has been built upon the following foundation of belief that person-centre planning:

- is a means for uncovering what is already there focusing on the essence and extraordinary gifts and capacities of a person
- assumes that the person and those who love the person are the primary authorities on the person's life direction, as such, the person is the driver of the process
- is the beginning of the journey of on-going learning through the shared action that results from participation in planning and working together.
- intends to shatter myths about people who have been given disability labels and to foster inclusive communities

- relies on skilled facilitation in developing and moving the plan forward.
- requires systems to respond in flexible and meaningful ways relative to the unique interests and needs of the focus person.

Recommendation 2

That DSAP

ensures there is independent capacity to assist people with disability and their families to envision and plan for their future, expand and maintain their informal networks of support, maintain or establish a home of their own and direct the paid supports required.

The separation of housing and support services

As stated above, services who manage both housing and support are at risk of having control over all or most of a person's life. The supply and management of housing should be separate from the management of support.

The collective supports the coherent and sustained application of the following objectives:

- people with disability are well informed about the breadth of possible support arrangements and have well informed choice and control over their housing arrangements
- no service has control over multiple aspects of a person's life. That means housing is the responsibility of the person, the family or housing agency, not the responsibility of the support service
- no person loses their home because of dissatisfaction with their support provider.

We encourage the DSAP to achieve the following:

- avoid any planned or future supported housing initiatives where the landlord is also the support provider
- establish a timeframe for the separation of roles in all existing supported housing arrangements
- establish mechanisms that give people with disability the opportunity to take an equity stake in their home through purchase plans.

In the provision of paid support, the collective supports the coherent and sustained application of the following approach:

- assume that people with disability have the capacity to take control and responsibility in their lives
- focus on what it takes to create a genuine sense of 'home', rather than creating facilities that might 'house people who have a disability'
- support within people's homes should always happen in ways that support and honour the person's individuality and autonomy, customs and history

- support within people's homes should be developmental in nature, so that instead of being passive recipients of 'care', people are growing their capacity to take control of more and more things in their lives.

Recommendation 3

That DSAP:

1. funds initiatives which separate the supply and management of housing and the provision of paid support.
2. put in place a range of guidelines and incentives that help ensure that people are able to enjoy accessible, ordinary, affordable housing that is part of the local community and which genuinely is 'home' and not 'facility'
3. establishes guidelines and incentives that help ensure that people receive home-based support in ways that reflects the person's individuality, and which complement and build on both the person's own strengths and the support the person has from his or her family and friends.

Building Capacity

Capacity Building mechanisms are required to:

1. bring about a wider range of supported living options than is currently available.
2. increase participation of people with disability and their families in decision-making over the kinds of support they need.

One such strategy is the establishment of state-based community agencies, which will focus on providing technical support and building the capacity of people with disability, families, members of the community, and Government and non-Government service-providing agencies.

The role of the proposed agencies would be similar to that of the Community Resource Unit Inc (CRU) in Queensland. CRU was established in the late 1980s, following the introduction of the Commonwealth *Disability Services Act* 1986. CRU has established itself as a vital contributor to grassroots social change by providing information, education, leadership development and innovative projects to families, people with disability and community organisations.

The proposed state-based technical support would assist in developing support alternatives for individuals through:

- working with individuals and their families to identify the kinds of supported living which will suit them
- helping identify what people with disability and their families have to offer in relation to the supports needed
- providing tailored technical support to families, people with disability and service providers in order to develop the support options needed
- assisting communities to establish new services
- assisting existing services to find better ways of supporting people with disability.

The proposed state-based technical support would offer leadership development, information and expertise by:

- documenting and sharing information on alternative and innovative methods of support;
- networking people who are wanting to create more flexible options;
- providing training and development to people with disability, families, service workers (generic and disability specific) and members of the wider community
- strengthening and developing individual families, people with disability, and professionals to provide 'technical' support to others.

Recommendation 4

That DSAP:

establishes state-based mechanisms to assist service providers, people with disability and families to imagine better through technical assistance, information, advice and leadership development.

Focus on community-based non-profit service providers

The collective calls for DSAP to consider the motivations with which any providers of social endeavour enter the marketplace. Non-profit organisations tend to be driven by the motive to build social capital so that communities are successful and inclusive, and to deliver tangible lifestyle benefits to their target group. As such, it is people with disability who are the primary consideration of the non-profit organisation, and whose interests should drive the organisation's work.

When for-profit organisations enter the arena of disability support and the provision of supported living, it is probable that the interests of the shareholders will be at odds with the interests of the people to whom the organisation is providing a service. In these situations, the shareholders by definition take priority, and this can lead to decisions and actions that do not serve people with disability. The collective calls for the coherent and sustained application of the following principles:

- government should focus on attracting non-profit organisations to the marketplace, so that there is a clear focus on social gain rather than financial gain
- new organisations entering the marketplace should have a clear understanding of, and commitment to, building social capital
- new organisations entering the marketplace should have clear accountability to a membership base whose interests are well-aligned with people with disability
- the emergence of new organisations should reflect grass-roots community development, where common interests combine to form a movement for change.

Recommendation 5

That DSAP:

1. focuses on the establishment of community based non-profit services. This includes the provision of good information, adequate funding and the limiting of invasive bureaucracy. This also includes the development of a positive best practice framework that organisations can follow.
2. encourages home suppliers to develop a range of housing that is accessible.

Advice and direction from people who are affected

FaCSIA has no experience in supported living programs, yet is committed to best practice in the implementation of DSAP. Advice and direction will be necessary from people with disability whose lives will be affected, their families and the community based services that have a track record of best practice.

Recommendation 6

That DSAP:

1. forms a Reference Group of people skilled and experienced in supporting people with disability to live in the community to guide the implementation of DSAP
2. ensures that all DSAP mechanisms are 'user friendly' to people with disability and their families so that they are genuinely in control of the process as it affects them.

Quality Assurance (QA) focuses on outcomes rather than systems

Any measurements of quality in DSAP must be focused on outcomes in the lives of people with disability rather than service systems. This means that monitoring and measurement must be of the improvement that occurs in people's lives because of DSAP.

This would include, but not be limited to the following:

- the number of valued roles that the person authentically has. These could include but are not limited to tenant, homemaker, host, cook, gardener, pet owner, neighbour
- the degree of skill development that has occurred within each role;
- the number of unpaid relationships in the person's life at the level of acquaintance
- the number of unpaid relationships in the person's life at the level of friend
- the number of unpaid relationships in the person's life at the level of intimate partner
- the number of unpaid relationships in the person's life at the level of family member

- the degree to which the home is the person's own home, has their personality expressed through furnishings, and has control over who enters and what occurs there
- the level of harmony within the person's home and between the people living with the person
- the percentage of funds that is directed to support compared to funds for administration and co-ordination expenses.

The collective is aware this is in sharp contrast to most of the current QA processes which focus on the compliance and regularity of service systems. In terms of monitoring of outcomes for supported living, then the following would be considered:

- how people came to live in their home, and the degree of involvement they had in that decision
- how compatible the person is with others (including family) sharing the home
- how support workers are recruited, supervised, inducted and trained, and the degree of involvement by the person being supported
- the potency and usefulness of the support, including the degree of flexibility of support in terms of when it is provided and how it is spent;
- how freely given relationships are supported and maintained
- how each person is supported to develop their own skills in home-related roles
- the discretion of bureaucratic processes, that is, the degree of presence (or absence) of "office-related" paraphernalia for service staff, notices pertaining to service staff
- the location of the home and its proximity to the person's family, established community and to local services and facilities.

The key to active involvement of people with disability and family members begins with strong ethics held by the service that involvement is important and valuable. People should be involved from the start of any decision-making, and to the degree that they can and wish to be, in the creating of visions in their own lives and in the future of the organisation, in shaping the broad direction of a service, in shaping the broad principles of service delivery, and in monitoring the delivery.

Some people with disability and their families will wish to have authority over the management of the service and most will expect authority over the design and management of their own support arrangements. People with disability and families will only support quality assurance processes when their involvement is authentic and valued, and not token.

One such process is the Council on Quality and Leadership (CQL) based in the United States of America. More information about CQL and the work they do is outlined on their website www.thecouncil.org

Recommendation 7

That the DSAP:

establishes a quality assurance system that focuses on quality outcomes for people with disability.

6. Response to questions

What is the Disability Supported Accommodation Program (DSAP) and who will be able to use it?

- *Are these principles appropriate?*
- *Are there any other principles that should be included?*

The DSAP identifies a very narrow target group by definition.

This group of people with disability is likely to have an established home, a loving family and a network of informal support, as well as many specific skills to manage their environment and some plans for their own futures. They may well be seeking to have more of a life of their own – some while remaining living in the family home and others who would dearly like a home of their own.

This group of parents/carers are likely to have been very resourceful in resolving the support needs of their son/daughters. Many may be very comfortable living with their son/daughter although quite reasonably, may be seeking to have more of a life of their own and may well fear for the future “when I am not here to look out for my son/daughter”.

The collective proposes that for all the reasons outlined earlier in this paper FaCSIA rename this program

Disability Support and Housing Assistance Program

Furthermore the collective recommends that the primary purpose of DSAP be re-considered and in its place adopt the following purpose:

DSAP assists people with disability to establish or maintain their own home within their community and to build a rich and full adult life with informal and paid supports when their families are no longer able to provide the primary care.

The collective proposes the following additional principles

Principle 1

DSAP will focus on the rights and needs of the person with disability as well as those needs of the carers that support the person having a rich and full adult life.

Principle 2

DSAP will work with people with disability, one person at a time, to develop, establish and maintain a positive future envisioned by the person and his or her family.

Principle 3

DSAP will support people with disability to grow, change and learn understanding that the housing and support needs provided now are likely to change over time.

Principle 4

DSAP will work with and incorporate established family, community and friends starting with the current home environment wherever possible.

Principle 5

DSAP will support only service models, which ensure people with disability receive good lifestyle outcomes, based on evidence based research.

How will DSAP link to other programs?

- *Are there any other programs that will complement DSAP?*

Under the terms of the CSTDA State and Territory Governments have had responsibility for funding accommodation support/supported living services. There are a number of these services spread throughout the states and territories that have been seriously pursuing ways in which to strengthen the capacity of people with disability to have a home in the enriched sense of this word.

The collective believes that these services - many of which are quite small – should become prime partners in DSAP because of their record and the quality of their support to people with disability and their families.

- *Are there programs that should be linked with the new DSAP to ensure better outcomes for people with disability and their carers?*

It will be imperative that DSAP link closely to State and Territory governments so as to ensure complementary efforts at both levels of government.

It will also be imperative that the Commonwealth seeks to invest in infrastructure and social housing initiatives which release opportunities for people with disability to live alongside other people in communities which are accessible and in housing which is built using lifetime or universal access principles. In cities and large population clusters it is recommended that investments be made in infrastructure which is central rather than remote suburban and located on multiple major transport routes within easy access to most relevant community services and facilities.

The Australian Government should use all its powers to ensure all future infrastructure development (i.e. housing, office premises, shopping centres, suburban housing developments, entertainment etc) is constructed with a clear requirement that these enhance the capacity of people with disability to actively participate in the life of the community.

Who can provide supported accommodation?

- *What are the elements of a person centred approach to supported accommodation?*

The collective has detailed some of the key elements of what it believes a genuinely person-centred support service would look like earlier in this paper. Furthermore the collective recommends that the function of assisting people and their families to envision and plan for their future, as well as maintain and expand their informal networks of support, be separated from the delivery of day to day support for the person in their home.

- *How can we attract new providers into the supported accommodation sector?*

As noted elsewhere there are a wide range of existing providers that have been actively working to structure services in a way which supports people with disability to have good homes and lifestyles in their local communities. The collective believes that it is crucial to grow some new capacity within local communities in order to ensure the needs of local people with disability and their families are addressed. In doing so any developments should capitalise on the wisdom and knowledge of existing providers and ensure the needs of people with disability and their families are the primary driving motivation for any provider. Providers should not be motivated by profit.

- *What are the advantages of having different types of accommodation providers?*
- *What are the pros and cons of separating housing and support?*

The collective believes that there little problem with separating housing from support services and in fact earlier in this paper has argued strongly that there is a wide body of evidence which identifies many benefits which flow from such a clear separation – not the least of which is that no one service has control over all the life spheres of a person with disability.

When and where will places become available?

- *What would be needed to make the roll out of DSAP achievable?*

Assuming that in many instances the people targeted by DSAP are not necessarily likely to need alternative housing in the first instance, it should be reasonably straightforward to commence the development of good personal plans and implementing supports which enhance the capacity of the people targeted by DSAP (both carers and the person cared for) to lead better lifestyles.

Due to the general shortage of well located, good quality affordable housing especially housing that is either already adapted or indeed could easily be adapted to make living in the property feasible and enjoyable for a person with disability, DSAP will need to cultivate some of these investments in order to make it achievable.

- *What criteria should determine where places are located?*

The collective believes that a key criterion should be the presence in a region of an existing provider with extremely good credentials in working closely with people with disability and their families to plan and work towards people having good lives as valued members of their local community.

Where there is no such provider in a region, priority should be given to nurturing and enhancing the capacity of people to come together and develop capacity to respond with assistance from an existing provider with experience and knowledge as described above.

- *How can we ensure that places are available when people with disability need them?*

There is a well documented vast unmet need for supports so that people with disability can be assisted to have a home and to lead good lives as valued members of their local communities. Please note that in fact no-one needs a "place". A place is not far from a bed and both are usually found in a facility. This would seem to be the very antithesis of the intent behind DSAP.

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

In the first instance people with disability and their families need the opportunity to make sense of what will strengthen and enhance their capacity to live well in the world. If as previously suggested DSAP targets specific regions on the basis of the presence on well credentialed experienced and adaptable providers there may be the need to establish good planning support first.

What will the accommodation look like?

- *What key features would people with disability, carers and service providers want to see in supported accommodation (physical, clinical, social, cultural, and other)?*

As noted earlier the accommodation would reflect the normal range of housing most individuals, couples and families might choose to live in. A key test might be its genuine appeal to most valued citizens as a place to call home.

- *What are the strengths and weaknesses (cost-benefits) of existing models of supported accommodation for people with disability?*
- *What innovative supported community living models may be emerging and should be considered as options for the DSAP?*

See previous discussions

- *What should be considered when designing supported accommodation options for people with certain types of disability such as intellectual disability, physical disability, or multiple disabilities?*

One of the primary issues facing people with disability is locating housing built in a manner that can be adapted to their own specific needs which might arise as a result of their disability. In practice designers should be mindful of the concept of universal housing design which meets all people's housing needs at any time.

How will places in DSAP be funded?

- *What types of funding model(s) should be considered for the DSAP?*

The collective strongly recommends a funding model that makes it possible for each person to have a clear understanding of the resources which are available to them for their support. This also increases his or her capacity to direct how those resources can be used to best advantage.

- *What is the range of estimated costs of establishing disability supported accommodation for people with severe or profound disability?*

As noted earlier in this submission the costs involved in supporting people with disability to have a home in their local community generally correlate to the costs involved in providing people with places in institutional and mini-institutional arrangements.

With individualised support, there is greater opportunity to work with and involve informal networks who can provide freely given support.

- *What are the estimated costs of the main cost drivers for different models of accommodation and different levels of support provided?*

The primary cost driver for most services is the cost of support staff and the degree to which a service invests in cultivating and promoting the presence of a person's family and informal network as additional supports to the person.

- *How could the funding model ensure both greater individual flexibility and choice of support and viability of the service provider?*

See earlier conversation re individualized funding mechanisms.

- *How would you ensure equity in allocating funding across different types of support for people with disability?*
- *What contribution should be made by Government, providers and residents to the cost of support?*

In most instances where providers support people with disability to live in their own homes in the community, people themselves assume responsibility for

payment of all the costs relating to their daily living. Providers generally only meet the costs of salaries and related costs for support workers.

- *What contribution should residents and families make if they wish to choose accommodation and support options beyond the capacity of DSAP?*
- *Are particular funding models more appropriate for certain types of accommodation support, and less appropriate for other models of support?*
- *Are there innovative funding models in other sectors which could be used for accommodation services and support?*

See earlier discussion on individualised funding mechanisms.

How could demand be managed?

- *What is the best way to manage access to places within DSAP for people with disability, their carers and providers?*
- *What will people with disability and their older carers want to know and do while waiting for a place to become available?*
- *What determines a good assessment framework and what are best current examples of assessment frameworks?*

See earlier discussion on person-centred planning mechanisms.

- *What should be included in the assessment – for example, should it be based on functional, medical, social and cultural needs?*
- *Who should be involved in the assessment?*
- *How often should assessments be undertaken?*
- *What is the most appropriate way to manage emergency placements?*

Will the DSAP provide high quality supported accommodation?

- *What outcomes for people with disability should be used to measure quality in disability supported accommodation?*
- *How can people with disability actively participate in the quality assurance process?*
- *What needs to be considered in developing a regulatory framework?*

See earlier discussion on quality assurance mechanisms.

- *What are the most important features of a complaints resolution service?*
- *What are the important elements of an Official Visitors program?*

7. Appendix

Details of contributing organisations

| Organisation | Contact person | Position and email | Origin |
|---|-------------------|---|---------------------------|
| | Dr Lorna Hallahan | Lecturer, School of Social Administration and Social Work. Chair, Minister's Disability Advisory Council (South Australia) lorna.hallahan@flinders.edu.au | Adelaide, South Australia |
| Arts Access-SA | Dr Paul Collier | Chair chair@artsaccess-sa.org.au | Adelaide South Australia |
| Community Connection Inc | Ann Greer | Manager agreer@communityconnection.org.au | Townsville Queensland |
| Community Living Program | Ross Womersley | Co-ordinator ross.womersley@clp-sa.org.au | Adelaide South Australia |
| Community Resource Unit Inc. | Lynda Shevellar | Director lyndashevellar@cru.org.au | Brisbane, Queensland |
| Homes West Assoc Inc | John Groom | Chairman helend@homeswest.org.au | Brisbane Queensland |
| Include Pty Ltd | Dr Bob Jackson | Director bobjackson@include.com.au | Perth Western Australia |
| Independent Advocacy SA Inc. | Fiona Campbell | Program Coordinator indepadv5@internode.on.net | Adelaide, South Australia |
| Institute for Family Advocacy | Catherine Hogan | Director catherine@family-advocacy.com | Sydney, New South Wales |
| Jane Sherwin and Associates | Jane Sherwin | Director sherwinconsulting@gmail.com | Brisbane, Queensland |
| Julia Farr Association Inc | Robbi Williams | Chief Executive Officer robbiw@juliafarr.org.au | Adelaide, South Australia |
| Mamre Association Inc | Kathryn Treston | Director mamre@mamre.org.au | Brisbane, Queensland |
| Personalised Lifestyle Assistance Project | Deb Rouget | Project Manager debrouget@netspace.net.au | Melbourne, Victoria |

| | | | |
|---|----------------|---|----------------------|
| Queensland Advocacy Incorporated. | Kevin Cocks | Director Kevin@qai.org.au | Brisbane, Queensland |
| Queensland Parents for People with a Disability | Phil Tomkinson | President gppd@gppd.org | Brisbane, Australia |
| Speaking Up for You | Di Toohey | Co-ordinator sufy@sufy.org.au | Brisbane, Queensland |
| Uniting Care Community Options | Ronda Held | Chief Executive Officer ronda.held@ucco.org.au | Melbourne, Victoria |