The Personalised Residential Supports Project

A Lotterywest-funded project

Project auspice: The Developmental Disability Council of WA

Authors: Professor Errol Cocks
        Ross Boaden

Centre for Research into Disability and Society

Curtin Health Innovation Research Institute

School of Occupational Therapy and Social Work

Curtin University of Technology

May 2009

TABLE OF CONTENTS

1. INTRODUCTION

1.1 Background

The Personalised Residential Supports (PRS) project aimed to provide detailed information about the nature, purposes, and outcomes of personalised residential supports from the perspectives of key stakeholder groups, including people with a disability, family members, and service providers. By using a range of methods over an extended period of time, a set of key issues was identified and explored, including the defining characteristics of these approaches, barriers and facilitators, and perspectives on quality.

"Personalised residential supports" was coined as a term to refer to a range of individualised and personalised approaches to accommodation support for individual people with a disability, as distinct from the more traditional range of approaches in which people with a disability received accommodation support in groups. PRS approaches to accommodation support are relatively new and constitute an area of rapid development. There are many characteristics that make up PRS, most of which are associated with the central focus on the individual person and the project aimed to elucidate and elaborate these characteristics.

In the project proposal, PRS initially was conceived as having four key elements:

1. A high degree of individualisation, whereby supports are designed and arranged around the individual person with a disability that are based on clear aims for the person.

2. An emphasis on primary control over support arrangements being located in the hands of the person with a disability and/or the families, to the extent that this is feasible. This feature is frequently referred to as individual/family governance, or individual/family-directed service. A service agency may have an important, even central, role in service provision, however it does not exercise control to the exclusion of service users.

3.   An emphasis on the importance of informal relationships in the overall support arrangement.

4.   Principles that reflect the theme of person-centredness underpin the service arrangement.

This framework served as a starting point for early discussions about PRS and for the several methods of enquiry used throughout the project. By the later stages of the project, a much fuller and clearer picture of PRS had emerged, as described later in the report.

The rationale for limiting the scope of the project to adults with a developmental disability was that people in this group form the largest users of accommodation support, and generally require the assistance of others to articulate their needs and to organize support. In contrast, people with a physical disability, for example, will generally be able to speak and act on their own behalf. It was envisaged however, that the outcomes of the project would be of value to all disability groups. Similarly, children with disabilities were not included in the project due to their differing needs which are generally addressed in the context of the family home.

1.2 PRS in WA

Personalised forms of accommodation support for individuals have gradually expanded throughout WA, and indeed elsewhere in the Western world, over the past 20 years. In more recent years, interest in this area has been high, as evidenced through increasing numbers of people with disabilities taking up such options. The *WA Disability Services Commission's* (DSC) Accommodation Blueprint Steering Committee report (DSC, 2003) highlighted the need for greater innovation in support options, and *ACROD's* Think Tank on Accommodation Support Services (Croft, 2006) identified examples of innovation across the range of accommodation models. Numerous guest speakers have been brought

to WA in recent years to address innovation in accommodation support, individual/family governance, empowerment, and person-centred planning.

There has been a clear trend in WA, as elsewhere, towards increased funding and numbers of people taking up individualised supported living arrangements. This has occurred in parallel with a decreasing emphasis on grouped or congregate models of supported accommodation, reflecting the broader and long-standing trend of deinstitutionalisation (DSC, 2004; Lakin & Stancliffe, 2007; Mansell, 2006).

Supported living arrangements containing at least some elements of PRS as described above that have developed in WA include:

- arrangements that are being adopted by a growing number of service providers;
- independent family-governed arrangements;
- family-governed arrangements that are facilitated by DSC Local Area Coordinators;
- family networks with varying degrees of formality that are not primarily focused on service governance; and,
- various 'one-off' arrangements that have developed around individuals and their families.

A range of current iniviatives are concerned, at least in part, with developing personalised forms of support. *Planned Individual Networks* (PIN), based on the Canadian PLAN model, facilitates networks of support around the individual with a disability for a variety of purposes, including long term wellbeing and security. The *Microboards* model, which has been established for many years in Canada, has recently been explored and examples are emerging in WA. In the *Microboards* approach, a group of interested people provide a structure (or board) of support around an individual with a disability. This may include formal aspects of service provision. The *Shared Management Model* enables service

providers and individuals and families to negotiate a form of partnership so that service provision can be shared in a manner that suits all parties. For example, a service provider may manage recruitment and employment of support staff.

This project is timely as many families and people with a disability are considering various options for supported living arrangements that reflect individual needs and preferences. The recent adoption of the Community Living Plan by the WA Disability Services Commission provides funding support to promote high quality and individualized supported living opportunities. The descriptive framework developed in this project will provide important information to aid decision making. In addition, the framework will provide a means of evaluating aspects of existing or planned supported living arrangements.

1.3 Acknowledgement

The project was made possible through funding and support from Lotterywest.

2. ABOUT THE PROJECT

2.1 Who was involved

The auspice for the project was the *Developmental Disability Council of WA* (DDC WA), with the support of a Consortium of people with wide-ranging knowledge and experience. The Consortium provided advice and support to the work of *Curtin University's Centre for Research into Disability and Society* (CRDS), in the *School of Occupational Therapy and Social Work* which was engaged to conduct the project.

The people involved were:

- Sue Harris (Consortium Chairperson), Executive Officer, *DDC WA*.
- Heather Cassey (Consortium member), parent and Disability Officer with the *City of Gosnells*.
- Leah Ciancio (Consortium member), researcher involved in supported living for people with disabilities.
- Deirdre Croft (Consortium member), parent, researcher, and journalist.
- Monique Williamson (Consortium member), Policy Manager with *NDS WA*.
- Eddie Bartnik, Director, Metropolitan Services Coordination with the *Disability Services Commission*, who attended several Consortium meetings as Manager of the Community Living Plan.
- Professor Errol Cocks (Project Director), CRDS, *Curtin University*.
- Ross Boaden (Project Officer), CRDS, *Curtin University*.
- Lauren McKernan (Honours student), CRDS, *Curtin University*.

2.2 How the project was conducted

The project involved a wide-ranging review of PRS. It was conducted over a two and a half year period. Multiple methods were used in order to gather data from a group of key stakeholders and then to analyse that information in order to identify the elements of a framework that described PRS.

Data Collection

Four methods of data collection were used.

1. <u>Literature review</u>. A wide-ranging review of empirical and descriptive literature was conducted. The review of empirical literature entailed a systematic approach to seek evidence of outcomes associated with PRS (Appendix A). A total of 784 journal article titles were reviewed. These were narrowed down to a collection of five papers that met specific criteria for selection that addressed the topic. A separate search of descriptive literature included publications that described various aspects of PRS. These papers typically promoted such themes as community living, individualisation, home, and person-centredness, although they generally lacked the level of critical analysis contained in the empirical literature. The review of this combination of empirical and descriptive literature provided some important insights which, together with the information gathered from the following three methods, are described in Section 4.

2. <u>Case studies</u>. Using a questionnaire (Appendix B), a scoping exercise consulted a wide network that covered the WA disability field and sought information about the number and type of living arrangements that might be considered as examples of PRS. This approach cannot claim to have captured a comprehensive picture of PRS in WA, however 16 service providers and 13 parents provided information on a total of over 400 supported living arrangements that they believed met the definition of PRS provided in the survey form. This served the purpose of providing a field of PRS examples from which a sample could be chosen.

Six case studies consisting of separate, individual supported living arrangements were selected from the scoping exercise according to a set of criteria. First, each one needed clearly to fit the initial, working definition of PRS. Second, the six arrangements provided diversity on a number of dimensions: age, sex, level of support need, location, and form of governance/leadership.

A CRDS project team member maintained contact with each living arrangement for periods of up to 18 months. During this time, visits to the home of the person with a disability occurred, and interviews with the person, family members, friends, people in various support roles, and agency management were held. All interviews were recorded and transcribed.

3. Focus group. This consisted of a group discussion with ten adults with a developmental disability, and was arranged and conducted with assistance from *People With Disabilities WA*. Participants expressed their views and this yielded valuable information from this primary stakeholder group.

4. Written surveys. The Consortium identified 23 representatives from four key stakeholder groups: parents, service providers, authorities, and policy makers. A total of 18 people participated in the process. Authorities were defined as people widely regarded as having high levels of relevant knowledge and expertise, demonstrated through activities including publications, conference presentations, and consultancies. Three surveys were carried out. The first survey (*Appendix C*) sought people's views on the broad characteristics of PRS. The second and third surveys (*Appendices D* & *E*) were used to further clarify and define the themes and attributes of PRS that were generated by this method.

Data Analysis

A great deal of information was gathered from these methods. This was carefully analysed so the findings accurately reflected a consensus of stakeholders' views.

Each of three of the main methods, the case studies, focus group, and surveys, were separately analysed as follows:

1. The three CRDS personnel independently studied the written material and identified a set of key themes from each of the three methods.

2. They then convened on separate occasions for each method to conciliate their findings in order to yield three consolidated sets of key themes and sub-themes – one each to reflect the findings from the case studies, the focus group, and the surveys.

3. This group met again to consider the three sets of themes. The conciliation process resulted in a single set of themes and attributes (sub-themes) derived from all of the information gathered. The result is the PRS Framework that is described in Section 4.1.

The second and third surveys to which reference has been made were used as a form of member checking, providing an opportunity for people who participated in the process to contribute to the accuracy and further refinement of the framework of themes and attributes. The third survey asked participants to order the themes and attributes according to their relative importance and this is discussed further below.

3. THE SIX PRS ARRANGEMENTS

The 'case studies' were especially helpful as they provided a close-up and personal account of PRS in action over a period of time. The three researchers were welcomed into the homes of those involved, and the person with a disability, family members, friends, and agency management and staff involved in each arrangement met with them over a period of eighteen months. This provided an invaluable opportunity to address all of the aims of the project, and the resulting information was of a depth that only those who have been on the journey of PRS over the long haul could provide. Details of the six arrangements follow.

1. ***Rob's arrangement***. Rob is a man in his late 30s who rents an inner-city townhouse along with two non-disabled co-tenants, Ben and Julie. As such it is sometimes described as a 'co-resident model'. *Vemvane*, a non-government non-profit organisation based in Whitfords, set up this model for Rob in conjunction with his mother, Arax, 14 years ago. It has been a remarkably stable home life for Rob, with only a small handful of co-residents in that time, some of whom are still part of his friendship network. Rob was involved at the very beginning in the selection of the first two co-residents and there has never been the need to advertise for new co-residents since. His social network has grown such that people have emerged from among his friends and contacts when needed.

Rob has what are referred to as moderate support needs. His needs were much greater when the arrangement was set up, but his living arrangement has been so rich and supportive that his skills and general wellbeing have developed greatly over time. His social network has grown, initially in a planned, and then in a loose informal way, to now include some close friends and many acquaintances. A host of opportunities have also arisen, such as international and interstate travel, a range of work roles, and a warm welcome at many businesses in the inner-city area.

Ben and Julie receive a part-subsidy from *Vemvane* on their rent and bills, in return for which they are basically 'there' for Rob, meaning that at least someone is home overnight and for the evening meal. They provide occasional day to day assistance to Rob as needed, but the relationships have grown into genuine friendships among the three who live in the townhouse. For the sake of security of tenure, the lease agreement is held by *Vemvane* on behalf of Rob. *Vemvane* provides support staff to come in for a few hours on weekdays in order to support Rob in a range of activities, and generally oversees the arrangement, albeit from a distance for the most part. Rob and Arax share a close relationship and spend time together often.

2. ***Andre's arrangement***. Andre is a woman in her late 30s who leases a *HomesWest* unit in her own name in the northern suburbs. A non-profit housing service provider provides assistance in regard to matters concerning the lease. Andre's support is arranged by *My Place*, a non-government, for-profit organisation. Andre's parents, Jackie and John, are very much a part of Andre's life, and have fought hard over the years for funding and services to meet Andre's needs. They are in close contact with *My Place* regarding all major aspects of Andre's living arrangement. Andre and her family have been connected with *My Place* for around 10 years, and after some early unsuccessful stints in group living arrangements, she was assisted to set up in a home of her own, and has been living in her current unit for around three years.

Andre needs very considerable support in her day to day life, as areas including communication and understanding what is going on around her can be difficult, and it takes people who know her well to be able to understand her and to respond when she needs a hand. After struggling with a range of support models to suit Andre, *My Place* now provides staffing on a live-in arrangement whereby one staff member lives in Andre's unit for one week, then a second staff member lives in for the second week, and so on with the two people alternating. Periods

in which there is no support available are generally covered by John and Jackie, and Andre's Nanna, who have Andre over to stay from time to time. With her lifestyle, general wellbeing, and support arrangements now settled, Andre's parents and *My Place* are looking to extend Andre's membership of the broader community, including a possible move from sheltered to open employment.

3. ***Geoff's arrangement.*** Geoff is in his late forties and has lived with Jackie, and her husband Brad for about six years in their home in a large town in the south of WA. Geoff has a significant developmental disability and spent his early years in special classes and then a day centre run by the *Slow Learning Children's Group* in Perth. Following disagreements between Geoff's parents and disability services in Perth, Geoff was withdrawn from services and lived with his parents for over 20 years. After his father died and his mother became too ill to care for Geoff, his brother Brian and sister-in-law Averil, who lived in the south of the state, decided that they wanted Geoff to live near them. Brian is Geoff's legal guardian. They approached the *Lower Great Southern Community Living Association (CLA)* which facilitated the current arrangement. Brian also arranged for his mother to be moved to a local nursing home where he said she was well cared for. She died a couple of years ago.

Geoff needs help with some self-care activities and has had a few health problems. Jackie is the principal carer and is supported by Brad. The *CLA* coordinates and provides support for day activities for Geoff. In addition, Geoff participates in Jackie and Brad's social and recreational life.

Jackie and Brad thought carefully about taking on the task and spent time ensuring there were common interests between Geoff and themselves. Jackie recounted: "We had to ask (Geoff) how he felt about us. We also told him about our life to give him an idea about what we're like. Told him about our pets and hobbies. Realised we had the same interests. Camping and music. (Geoff)…is a

real music lover and has music going quite often and it would be very difficult to live with people who didn't like music almost the whole time."

He has his own room, bathroom, lounge, and television. He shares an interest in music with Jackie and her husband.

    4. Jude's arrangement. Jude is in her early fifties. She is the middle of five children of Mary and John, long-time farmers in the south of WA. At nine months, Jude began having seizures that were difficult to control and were associated with a significant developmental disability. Jude's parents received support from their family, especially Jude's maternal grandmother, who enabled Jude's attendance at the (then) *Spastic Centre* in Perth. After about a year there, Jude returned home and the busy and demanding family and farm life meant further support was needed from the (then) *Slow Learning Children's Group* at a place called *Pelican*. At about this time, *Pyrton Training Centre* was established and Jude was provided with short stays. As Mary recalled,"…there was nowhere else for her to go other than *Claremont Mental Hospital*, and that was out of the question".

In the late 1980s, Local Area Coordination was initiated in the area, and Peter came on to the scene. His early contact with Jude's parents was challenging to all! When Peter suggested that Jude share a house in a nearby town, Mary described her initial response: "I threw him out of our house once!" Peter persevered and eventually prevailed. Mary went on to describe their early contact. "He was lovely. He was not *Pyrton*-minded. Made all sorts of suggestions that Judy might be able to do this and you'd never be able to know. I thought 'Oh my goodness! This is too much.' I don't think we were able to get our minds on the future. We were so busy with what was going on right then that we couldn't look to the future. We needed someone else to do our thinking for us." Initially, Jude moved into a home with another woman with a disability, but that didn't work. However: "Peter was persuasive and we became convinced that he

was on the right track. We liked him. He was good. It's hard for a mother who had the whole thing to accept that somebody else could do it." An arrangement was made through the *Lower Great Southern Community Living Association* for Jude to live with Kathy and her family in the nearby town and this arrangement continued for over 15 years. Mary was clear about her bottom line. "The main thing I said to Peter… was that we wanted to be sure that whoever looked after her loved her and respected her as a human being. That was very important. And that's what we got."

As Kathy's family situation changed, her sister Toni, who had been providing occasional care for Jude for about 13 years, took over. It is quite remarkable that Jude's circle of family and friends has been stable within these support arrangements for approaching 20 years.

Now Jude's needs are changing and thought is being given to a quieter life for her and providing more security by supporting her in her own home. Planning for this has been continuing for about 12 months and there is much consideration being given to ensuring continuity in her life. Mary reflected: "The big step was letting her come down here in the first place because I was sure no-one could look after my daughter as I would. I found out there are wonderful people in the world. They're special. And so we were able to let go of her and we knew she was being treated with respect and love and cared for – and it was a relief."

5. Lisa's arrangement. Lisa is a woman in her mid-20s who lives alone in her own villa in the northern suburbs. Lisa owns the villa, an arrangement set up by members of her family on the passing of her mother. She maintains a strong family network, and a generally active lifestyle. Lisa looks after most aspects of her day to day life, and receives drop-in support for a few hours each week to assist in areas such as diet, budgeting, mail, and any matters that pop up that Lisa needs a hand with. This support is arranged by *Baptistcare*, a non-government, not-for-profit service provider.

Baptistcare, through its then new entity 'Partners in Purpose', was amongst the first providers to embrace the 'Shared Management Model', which provides a means for people with disabilities and their families to partner with a provider in the arrangement and provision of supports, in a balance to suit all parties. In Lisa's case, a Partners in Purpose Coordinator takes care of all of the formalities such as funding and staffing. Lisa's lifestyle is quite busy, as she is able to independently travel to and from work, the shops, to visit her aunty and so on. As with Andre, a longer term goal is for Lisa to secure a job in open employment, which could add new challenges and opportunities to a lifestyle that Lisa already enjoys.

6.   *Paul's arrangement*. Paul is a young man in his early 20s who currently lives in the family home with his parents, Jenny and Leighton. Paul needs very considerable support, such as from people who know him well and can interpret his very limited means of communication. Although Paul is living at home, his 'arrangement' was included in the PRS project due to his parents' efforts over several years to plan and develop a personalised living arrangement for him. Hence there was a great deal to learn from them about issues including planning and parent leadership of an emerging arrangement.

Jenny and Leighton's journey has included contact with some people considered as international authorities on planning and community living. Their thinking and expertise has grown to the point where Paul now has a social support network in place, a *Microboard* has been established, and accommodation support funding has been secured. Crucially, Jenny and Leighton's ideas have grown into a strong determination that Paul should have a home and lifestyle that reflect the key themes of the PRS project. Apart from the people they have had contact with, these ideas have also been informed by first hand experiences of group living arrangements, which they conclude cannot provide the sort of life for Paul that they have in mind, and which they believe he wants and needs.

4. WHAT WAS LEARNT ABOUT PRS

A set of nine Themes that define and describe PRS are the main findings of the project. Each Theme has between two and six sub-themes of Attributes that make up the Theme. They represent a consensus of what people with disabilities, family members, friends, service provider management and staff, policy makers, and authorities in the area consider to be the main features of PRS.

4.1 Nine themes describing PRS

The Themes are described under two sub-sections, the first being the complete set of Themes and Attributes in a table form. This is the PRS Framework. The second sub-section contains a detailed elaboration of each Theme and Attribute. Quotations taken from the surveys, case studies, and focus group are included to illustrate the Themes and Attributes.

4.1.1 The PRS framework

PERSONALISED RESIDENTIAL SUPPORTS FRAMEWORK

THEME 1: ASSUMPTIONS
1.1 People with complex and high support needs can live in their own home.
1.2 It is not necessary for people with a disability to live together.
1.3 PRS can occur without a person having to live independently or alone.

THEME 2: LEADERSHIP
2.1 The leader/s holds and acts upon a clear vision and strong ideas.
2.2 At least one key person provides the leadership necessary for the arrangement to be created and endure.

THEME 3: MY HOME

3.1 The person has a clear personal stake, such as ownership or secure tenure, in the home.
3.2 The person engages in typical home forming practices, roles, and responsibilities.

THEME 4: ONE PERSON AT A TIME

4.1 The person's 'voice' is central to the arrangement.
4.2 The arrangement is designed around the unique identity of one person.
4.3 There is an intentional avoidance of grouping of people with disabilities.

THEME 5: PLANNING

5.1 All planning activities maintain a central focus on the person.
5.2 People in close relationships are involved appropriately.
5.3 Planning includes a long-term outlook.
5.4 Planning includes an emphasis on safeguarding positive elements and addressing areas of risk.
5.5 Considerable ongoing time and effort is spent in planning.
5.6 Ongoing processes of internal and external review occur.

THEME 6: CONTROL

6.1 The person, and/or those in close relationships, determines their own lifestyle and personal affairs.
6.2 Self-determination for the person is central to the arrangement.
6.3 The person, and/or those in close relationships, has considerable influence in governance of the arrangement.

THEME 7: SUPPORT

7.1 The overall arrangement is flexible.
7.2 The agency involved is creative and responsive.
7.3 There is a balance of formal and informal supports.

THEME 8: THRIVING

8.1 The person's lifestyle and general wellbeing are enhanced.

8.2 The person acquires a range of valued roles at home and in the community.

8.3 There are many opportunities for growth and development.

THEME 9: SOCIAL INCLUSION

9.1 Some relationships are close and enduring.

9.2 The person has a rich and varied social network.

9.3 There are opportunities for participation in a variety of community settings.

4.2.2 About the PRS Themes and Attributes

THEME 1: ASSUMPTIONS

BRIEF DESCRIPTION: PRS arrangements are underpinned by a set of assumptions that reflect high expectations for the person with a disability.

Attributes of the Theme

1.1 People with complex and high support needs can live in their own home.
1.2 It is not necessary for people with a disability to live together.
1.3 PRS can occur without a person having to live independently or alone.

Description

This Theme provides the opportunity to explore three critical assumptions based on high expectations that underpin PRS arrangements. These assumptions challenge preconceptions that people need to "qualify" in order to live in PRS

arrangements. They place the necessary conditions for success on the arrangement, not the person.

Through observation and discussion, the position taken by the PRS arrangement will be clarified. Clearly, these underpinning assumptions will be reflected in the following eight Themes. For example, the place of leadership will be clear in the challenge to preconceptions that limit the possibilities for the person with a disability. Adherence to person-centredness, flexibility, and creativity will provide arrangements for supporting people with high support needs that also challenge the preconceptions.

One authority summed up how positive assumptions can be nurtured:

By continual and regular exposure to, and investment in all key stakeholders in regard to sound ideologies and practices that are life giving, non segregated/congregated, empowering, person-centred, inclusive or "normative" and promote the equality and worth of all human beings by a variety of means, e.g., formal teachings, exposure to people/families who have a proven track record, personal stories.

Attribute 1.1: People with high and complex needs can live in a PRS arrangement.

<u>Description</u>

At one end of a continuum is a "nil reject" approach which asserts that all people with a disability can live in a PRS arrangement if that arrangement is sufficiently flexible and resourced. Interpretation of resources includes much wider aspects of an arrangement than financial. At the other end of a continuum is the assertion that people with complex and high support needs require highly specialised support that cannot be provided in PRS arrangements.

An authority commented that:

Even people with complex disabilities can and often do better when they're supported to live in their own place.

Vemvane's CEO expressed this assumption in this way.

I think it doesn't matter what their disability, or level of disability is, or what they're like particularly. I think with patience, with the right support, I believe there are possibilities open to anyone. I really do believe that. If I didn't believe that, I wouldn't have attempted it with Robbie.

Attribute 1.2: People with a disability do not need to live together.

Description

People with a disability may well prefer to live with another person with a disability for reasons such as friendship. However on most occasions the assumption that 'people with a disability need to live together' is based on assertions such as that the person is lonely, needs protection, or needs to be with other people who share characteristics of disability; because of resource limitations; or simply the availability of an existing option that requires a degree of congregation. Often congregation will occur because of a crisis that does not allow sufficient timeliness of planning and preparation. These are assertions that a PRS approach challenges. This assumption may require rigorous consideration of the extent to which the arrangement reflects the real preferences and needs of the person with a disability.

Interestingly, research has established that loneliness increases as the size of the grouping of people with disabilities increases (Stancliffe et al., 2007).

Lisa lives alone in her own unit, which she says suits her very well ("*it's cool*"), as does her aunt:

Absolutely. She likes being by herself. It pleases her to be by herself. She can turn the music up. She can stay up as long as she likes. She can live life as she'd like to live it rather than be under restrictions and things.

.   21

Paul's parents had formed views about groupings that helped shape their determination for their son to have a personalised living arrangement:

> *Knowing where you gather so many people together it becomes an enclave where things can't happen normally, and I knew that in a group home it would be the same.*

Attribute 1.3: People in a PRS arrangement do not have to live alone or independently.

<u>Description</u>

A PRS arrangement may be seen as only appropriate for people who are able to, or wish to, live by themselves and are able to live independently. A PRS arrangement will be planned and provided around the needs of the individual without any requirement about the capacity to live alone or independently.

Indeed, the support needs of the people with a disability in the case studies varied widely, ranging from minimal/drop-in support, through to people who have very high support needs and require support to be on hand at all times.

An authority described:

> *That living in one's own place does not mean one has to live "independently" or on one's own. All human beings are interdependent and need company and draw on the support and guidance of others.*

Rob's co-residents sum up the benefits of his lifestyle:

> *His own space, his own private personal space, I think he really likes that. Because we don't need to have any rules or anything like that at all, Rob just fits in. We hardly have any problems at all. He gets to do his own thing. He gets to live the life that he wants to live, and still have people around who are looking out for him, just making sure that everything is ok.*

THEME 2: LEADERSHIP

BRIEF DESCRIPTION: At least one person with a clear vision or strong ideas is needed. This leadership may come from professionals or family members advocating on behalf of the person with a disability. It may also come from the person with a disability. A lack of leadership was considered to be a barrier to successful implementation of a PRS arrangement.

Attributes of the theme

2.1 The leader/s holds and acts upon a clear vision and strong ideas.
2.2 At least one key person provides the leadership necessary for the arrangement to be created and endure.

Description

PRS arrangements are shaped by a picture of how the person with a disability, and those close to the person, describe what a desirable living arrangement and lifestyle would be. Such a picture may take some years to emerge, and can entail a great deal of thought and effort, which continues when arrangements are established in order to keep them 'on track'. This often occurs in isolation, and entails trying out a set of approaches that are different to other supported accommodation arrangements.

For these efforts to be successful, strong leadership is needed. One or more persons will be prominent in terms of the clarity of their ideas on PRS-related issues, their influence on others, and their importance in bringing the PRS arrangement to reality and/or sustaining it over the longer term. Leadership here is broadly defined. It may come from a professional in a formal leadership position, but may also come from the person with a disability, a family member, or another person who has provided the major impetus. Leadership may also

come from some combination of these persons. Across each of the case studies, leadership played an important role.

A policy maker expressed that:

> *Leadership and direction is critical. Also, success is likely to be better achieved when leadership is invested in a range of people so arrangements do not fail when a person can no longer take that role.*

Attribute 2.1: The leader/s holds and acts upon a clear vision and strong ideas.

<u>Description</u>

A set of positive assumptions and an overall vision is needed to drive PRS arrangements, each one of which is designed around the identity of a single person with a disability, with standardized approaches generally not being adopted. Assumptions, including those listed at Theme 1, a clear vision for the person with a disability, a deep understanding of PRS-related issues, and a rejection of approaches that might compromise the arrangement will be evident in the leaders' thinking and conduct.

A policy maker commented on the importance of:

> *Leadership linked to values about a good life and inclusion.*

Paul's parents are clearly the leaders of his emerging arrangement. His mother described how her ideas have in turn been influenced by leaders in the broader field:

> *The best thing that happened to me was I went to hear Jeff Strully…and Heather Simmons. Just the more you listen to people who really think about how to do things in a normal way the more it helps you to just stop thinking about the problems and the problem solving and much more about what are the wonderful things and how can you facilitate that*

happening anyway? Jeff Strully was a revolution for me and I was just blown away. It was wonderful.

Leaders can provide inspiration and motivation for others. The CEO of the *Lower Great Southern Community Living Association* that provided accommodation support for two of the case studies described here spoke about the early development of their approach nearly 20 years ago and the influence and persistence of leadership.

> *I came back to get a job as a support worker here. Peter had this philosophy that we were going to set up these individual supports – I thought it was fantastic. Everything I'd been reading and learning about…I really believed this could work.*

Attribute 2.2: At least one key person provides the leadership necessary for the arrangement to be created and endure.

<u>Description</u>

While there are likely to be numerous people who have been, and remain, very important in the context of the overall arrangement, one or more persons can be identified as being the driving force. Without this person/s, the arrangement may be at risk of failing. It is likely that the leader/s will have been pro-active in building capacities in other people who are important in the arrangement.

Each of the six case studies included at least one person who was clearly recognisable as the driving force, some of whom have had an impact on the thinking of others across WA, whose actions are in turn shaped by newly formed assumptions, and so on.

An authority stated that:

> *[The leader] influences others to share the vision, and mobilizes them to do the right thing.*

THEME 3: MY HOME

BRIEF DESCRIPTION: Living in and owning one's own home is the ideal and a personal stake in your home can result in a sense of ownership, responsibility, and empowerment. By living in a 'home' and not merely 'accommodation', the person with a disability is involved in choices concerning their homes and are responsible for home forming practices such as domestic duties, privacy and routines.

Attributes of the theme

3.1 The person has a clear personal stake, such as ownership or secure tenure, in the home.
3.2 The person engages in typical home forming practices, roles, and responsibilities.

Description

The theme My Home contains two major parts. First, the word "my" conveys the idea that it is genuinely the home of the person with a disability. Having one's own home is widely regarded as being central to a balanced, secure lifestyle. It can take many forms, with outright ownership generally being most highly prized, while security of rental tenure is important for many.

Whatever form the person's stake in his or her home takes, it is real both on paper and in terms of the person's daily experience. Having one's own home entails a freedom of choice, movement, and expression beyond that which is experienced in any other setting, such as workplaces, recreational venues, and places of education. It also entails a set of expectations and responsibilities, such as those concerning paying of bills, household chores, maintenance of the garden, and relations with neighbours.

Second, the word "Home" is used here in its fullest meaning as understood by most people in our society. It can take a great many forms, such as brick and tile house, villa, or unit. Locations also vary, as do architectural styles, and furnishings and fittings. Beyond these variations of individual preference and circumstance, the notion of home can also be described by numerous characteristics that all people can relate to. As one authority commented:

> *People get their OWN home! A place of their own. A sanctuary. A place to have visitors. A place to grow and develop. A place to have ordinary and everyday experiences. Enjoyment! Personal touches. The desire and dream of most citizens – no more, no less.*

The theme 'my home' is very rich. Its expressions are diverse, yet it has a set of defining characteristics that are widely understood and agreed upon, and is distinct from the ways in which 'accommodation' is often conceived in formal human service contexts. Numerous authors, including Annison (2000), Kendrick (1993), and O'Brien (1994), have written specifically on the theme of home, and their work has been influential in the broader community living movement.

Attribute 3.1: The person has a clear personal stake, such as ownership or secure tenure, in the home.

Description

A clear personal stake entails that a formal arrangement has been established, with outright ownership generally regarded most highly. After ownership, renting is generally considered the next most desirable option and within this, the security and length of tenure impacts on the broader experience of home. The presence of specific measures, such as shared equity through a disability-specific scheme, or a head-lease arrangement through a service provider, need to be considered in terms of their relevance to the person's needs and circumstances, and impacts on the person's stake in the home.

Numerous variations of tenure were evident in the case studies, as outlined earlier, reflecting the different circumstances of each person with a disability and others close to the each arrangement.

Some focus group participants described the relative insecurity of renting compared to ownership. One person commented:

> *You've got to be careful where you move into because if they sell you're out …despite the fact we were paying rent we had to get out.. And then we got another place, like a town house. And then the owner of the property decided to sell it so yeah! You got to be careful because the person may sell. You've got to have the money to buy it.*

And a married couple:

> *I would like to have a house to myself. Buy a house. That'd be nice instead of paying rent. Yeah. We are going to buy a house in five years.*

As an authority stated:

> *Certainly ownership grants a greater level of control and a stronger sense of ownership than renting. However, renting can be a stepping stone to ownership, and provide valuable lessons in stewardship, ownership, maintenance, and carrying financial responsibilities, that pays dividends and rewards once home ownership is obtained.*

And a parent's survey response:

> *Home ownership, I believe, is an essential component of building a positive and valued life and safeguards one against being moved against their wishes or sharing with someone they would rather not.*

Attribute 3.2: The person engages in typical home forming practices, roles and responsibilities.

<u>Description</u>

The experience of home entails one's involvement in the full range of household activities, relationships, freedoms, and responsibilities. In PRS arrangements, the experience of home can be violated if the person's place in the home is compromised, such as by staff members exercising greater freedoms than the person with a disability, the agency's identity being more evident than the person's, or the agency imposing undue restrictions or routines.

Lisa described her living arrangement.

> *I get to do whatever I want. Even though I get to do what I want, I still have to do the chores.*

Comments from two focus group participants also illustrated this Attribute.

> *Do my own thing. Do my washing. Everything, you know. If you been to my flat, my flat's very clean.*

> *I live on me own. I do my own things. I do have a social trainer who comes over once a week. She comes over to see if I've got any letters, any mail I can't understand what it means and she explains to me. I do me own budget. Do me own shopping.*

THEME 4: ONE PERSON AT A TIME

BRIEF DESCRIPTION: PRS means an intentional avoidance of grouping of people with disabilities. It fosters unique arrangements focusing on each person with a disability with his/her 'voice' being central. The arrangements are person-centred, are based on personal knowledge of the person with a disability, and are guided by those who know the person well.

Attributes of the theme

4.1 The person's 'voice' is central to the arrangement.
4.2 The arrangement is designed around the unique identity of one person.
4.3 There is an intentional avoidance of grouping of people with disabilities.

Description

This theme is the one that most clearly differentiates PRS arrangements from the majority of supported accommodation models because arrangements are initiated, designed, and implemented around the identity of individual people with disabilities. It was assigned a clear first priority by respondents to the third survey.

The leadership and others involved will be wary of traditional, congregate-care models. Their vision will include the idea of the person with a disability having a place in society that is as full and varied as any other person of similar age, and is not restricted by the needs of other people with disabilities.

Any number of lifestyles can constitute a PRS arrangement. Depending on the person's own choices and the ideas of important others who may need to act on the person's behalf, the person might be living alone, within a marriage or with a *de facto* partner, with friends, or with some form of shared tenancy.

A person with a disability living alone does not necessarily constitute a PRS arrangement. Such situations may occur when the person has been placed into an arrangement that does not reflect their preference, and the person's experience may be characterized by isolation, loneliness, and risk of exploitation.

Situations that clearly don't meet the criteria of a PRS arrangement will include those where people with a disability have been grouped as a precondition of their living arrangement. It is important to note however that the issue of avoiding grouping does not preclude the person with a disability from exercising their choice of a living partner who has a disability, such as in intimate partner or long-time friend. For such scenarios to be considered PRS arrangements, the choice and resulting arrangement must clearly be those of the person with a disability. However, groupings that result from the ideas of other stakeholders, for reasons including the address of loneliness or pooling of resources, do not reflect this theme of PRS.

Some participants in the focus group of people with a disability were living together as marriage partners, and received various forms of support on an as-needed basis. Others lived alone, in "my own place", again with varying types of support received. Each of these living arrangements expresses the intention of this theme.

Attribute 4.1: The person's 'voice' is central to the arrangement.

Description

This attribute concerns the extent to which key people know the person well, are able to interpret the person's means of communication as need be, and respond to the person's wishes, needs, and concerns as faithfully as possible. All decisions, especially major ones, that impact on the nature of the arrangement or any aspect of the person's lifestyle or wellbeing are grounded in ongoing efforts to tune in to the person's point of view.

Paul is unable to communicate verbally, and there is difficulty in interpreting his expressions in general. His father commented that:

> Our philosophy is to try and hear as much of what Paul has got to say as we can, it's very hard to get a voice, whereas the service provider's

understandable point of view is 'we provide this service and people have got to fit in'. So I think there's a lack of compatibility there.

A policy maker commented that taking it one person at a time:

…is critical, however it requires giving the person a voice, and ability to hear that voice and interpret the person's unique strengths and needs and to match these with effective strategies.

Attribute 4.2: The arrangement is designed around the unique identity of one person.

<u>Description</u>

One person with a disability will be at the centre of the vision and ongoing efforts of the arrangement. All decisions that impact on the arrangement will take into account that person's wishes and needs. Planning and actions concerning the wishes and needs of other people with a disability that impact on the person, other than those with which the person clearly chooses to engage, run counter to this attribute.

Paul's parents became disillusioned with what group living models had to offer, and after a certain negative experience his father explained that:

Our thinking was more towards person-centred thinking. More away from the institution says: 'this is what we offer. Fit the box'. We had misgivings and this kind of crystallised them… they perceived that we were being too idealistic holding out for something that really, to make it work for Paul, is going to be extraordinarily difficult for us.

A Manager at *My Place* expressed his agency's individualized focus:

Having your own home is vital to living your own life in accordance with your own wishes. It enables the person, or an advocate, to exercise control (should they choose to) over how they conduct their life at home, how their home is furnished and laid-out, who comes into their home and

when, who they form relationships with, how they engage with their surrounding community. Once their home is shared with others, every one of those choices is compromised. When they are supported by staff and shift workers, those choices are further compromised.

Attribute 4.3: There is an intentional avoidance of grouping of people with disabilities.

Description

The thinking and actions of all involved are guided by a determination that the arrangement is and will continue to be primarily for the one person. Any form of grouping for reasons other than the person's own choices as outlined under the Theme description is avoided. Key people are conscious of the potential impacts of moving away from a PRS arrangement to any form of congregate-care model.

The research literature has long demonstrated a connection between better quality outcomes for people with disabilities and smaller grouping sizes, with the clear trend being that the smaller the better (Mansell, 2003; McConkey, 2007). Studies that have included single-person living arrangements (Saloviita & Aberg, 2000; Stancliffe, 1997, 2007; Tossebro, 1995) indicated that, relative to larger group living arrangements, these were more conducive to positive outcomes.

Paul's parents trialed group home living for their son, after which his father concluded:

Paul really went into a group home with a 'try before you buy' opportunity…he won't be going back to a group home. Simple as that!

Andre too had had negative experiences in group living, which helped form a resolve in her parents that a home of her own was to be sought. Having connected with *My Place*, an agency that consciously avoids groupings of people with disabilities in its range of living options, her mother commented:

One thing we learnt was that we didn't want Andre in a group home after our experience… And now Andre has - it's like paradise. Absolutely wonderful.

A survey response from a parent concluded:
Avoidance of groupings is a great beginning, however ongoing support is required to ensure the person is not isolated.

The advantages of an arrangement that supports just one person was expressed by a host family member.
All I can say about families, supporting someone, is that you have to build their trust. It seems to take a long time and I imagine that if there is just one person, then you can establish that a lot quicker than many people coming and going. In our situation, there is trust now, but it takes a bit of work to get there…

THEME 5: PLANNING
BRIEF DESCRIPTION: Timely planning is integral to PRS and requires a long term outlook and investment of time and effort. Planning is based on the person's uniqueness, strengths, and individual needs. People close to the person are involved in the planning process. Planning incorporates the development of safeguarding measures, including ongoing processes of review.

Attributes of the theme

5.1 All planning activities maintain a central focus on the person.
5.2 People in close relationships are involved appropriately.
5.3 Planning includes a long-term outlook.
5.4 Planning includes an emphasis on safeguarding positive elements and

addressing areas of risk.
5.5 Considerable ongoing time and effort is spent in planning.
5.6 Ongoing processes of internal and external review occur.

Description

This Theme is concerned with both the planning processes that lead up to the existing arrangement for accommodation support and also the ongoing processes of planning for the future of the person with a disability.

Planning is defined broadly to include a range of processes that contribute to decisions being made about the person's future, both immediate and long-term. These decisions may be about ordinary, day-to-day issues and decisions that may lead to changes in lifestyle. Within a PRS arrangement, planning can take many forms. These may be formal approaches that might involve meetings, documentation, and monitoring of defined outcomes. Planning can also occur in informal ways that are naturally part of the ordinary happenings of the day. Both types of processes may be used, perhaps reflecting the nature of the decisions that are required.

Attribute 5.1: All planning activities maintain a central focus on the person.
At the heart of a PRS arrangement is keeping a central focus on the person so that decisions that are made involve the person as much as possible and the person's interests take precedence over other interests, particularly those of the formal system. The emphasis is on how the arrangement can address the person's needs and preferences rather than how the person can fit into the system.

The person's presence and voice should be obvious and influential in planning processes. If there are difficulties of communication, limitations of capacity, or cultural issues, the PRS arrangement addresses these. The natural authority of the person to represent his/her own interests is respected.

Planning focuses on the person's uniqueness, strengths and capacities, as well as their needs, making it critical that others who are involved in planning know the person well.

The overall design of Rob's living arrangement was summed up by the CEO.

> *I think what makes it what it is, is the fact that we are providing an opportunity that moves with the person's expectations, wishes and desires. We're aware of what they actually want. We try to create a service for them. This service is for Rob.*

A *Baptistcare* Coordinator described some of the ongoing planning around Lisa:

> *Family is very involved so if there is anything major they're concerned about, we're concerned about, Lisa's concerned about, we just have a meeting and Lisa is always very much a focus of that and the questions and answers are directed to and from Lisa.*

Attribute 5.2: People in close relationships are involved appropriately

<u>Description</u>

It may be appropriate for the person's interests to be represented in planning processes by others who know the person well and who may have an ongoing or long-term relationship with the person. Family members, friends, advocates, and people who provide support may be able legitimately to represent the person's interests. Consideration would be given to the natural authority that in most cultures resides with family members. Planning processes are flexible and supportive of the involvement of other key people, particularly where significant decisions are being considered.

Again, the *Baptistcare* Coordinator commented:

> *She has a huge supportive network. Her grandmother, her great aunty, and there are some other family members who are really interested in Lisa. And Lisa is also very forthright and outgoing and will tell you what she wants. There's also LAC (Local Area Coordinator) involvement. Lisa says 'this is what I'd like to do, this is where I'd like to go, this is the recreation I'd like to do, this is where I want to work'. 'These are the support hours you've got Lisa, how would you like to spend those?' So that's how we support her.*

Paul's mother described the approach to planning of her son's social support network.

> *We didn't do it according to the text book. We did a very organic approach. So Jill [voluntary network facilitator] invites a few friends she knows who might be interested in doing something with Paul, and we invite a few of our friends who know Paul, relatives who know Paul, and let's just have a get together every now and then and see who turns up and what happens. So it changed over time. It was a very loose sort of thing, but we just kept at it and we kept meeting and we kept going to different things.*

Attribute 5.3: Planning includes a long-term outlook.

PRS arrangements reflect timeliness. Planning, especially for significant lifestyle changes, begins as early as possible in order to avoid a situation becoming critical. Significant changes in the nature of support include where the person lives, with whom the person lives, and how the person is supported. Effective planning processes anticipate these changes and incorporate a longer-term outlook.

PRS arrangements reflect high consciousness of, and commitment to, effective planning processes so that the person's future wellbeing remains a priority. Planning is continuous and the vision for the person's future is maintained.

An authority commented:

> *[It's important] that the person has been encouraged to imagine what a truly rich and meaningful life might look like, and is living it, or at least working towards that.*

In thinking about Rob's long term future, *Vemvane's* CEO commented:

> *I don't see the current arrangement as the be all and end all, ultimate arrangement - that this will continue till he's 60 or 70. I think if he's to live with people, they need to be people that are compatible, that share some interests, and will bring something to his life…and it raises the question that maybe Robbie should be at a different stage too as he ages. It's really going to be determined by him and his family, where they want to go with this, but we're prepared to move with them to something that is more appropriate as he ages.*

Attribute 5.4: Planning includes an emphasis on safeguarding positive elements and addressing areas of risk.

Planning processes consider how risks to the person can be addressed through safeguards that are built into the PRS arrangement. This requires awareness of the particular vulnerabilities of the person and the risks that are related to those vulnerabilities. Equally important is to safeguard the person's wellbeing by acknowledging and building on strengths and capacities. Planning will include specific strategies to address safeguards.

An authority recommended:

> *Firstly, get clear about <u>what</u> needs to be safeguarded. I would suggest that there are things like the person's absolute safety and security, their*

authority over their home space, their authority over their lifestyle, freely given relationships, developmental opportunities, having decent, respectful skilled staff, having equal and ethical partnering between the individual and the service.

Secondly, get clear about what the nightmares would be, such as high turnover of staff, poor service culture, using someone's home for respite or as an office base; unequal unethical power relationships.

Talking about the benefits of Geoff's arrangement, a support worker remarked:

I think for him to know that he's coming home to a safe place. I'm sure there are some people who have been abused and they don't know what's going to happen from week-to-week or who's coming into their lives. When they trust the person they're with – that's how I would feel.

Attribute 5.5: Considerable ongoing time and effort is spent in planning.

<u>Description</u>

Planning is considered to be an essential element of the process of providing residential support. Resources including time and financial support, if necessary, are used to support ongoing planning.

The planning around Paul has been ongoing for several years, as described by Jill, Paul's social network facilitator*:*

It's been a combination of everything. It's been a journey that started about 4 or 5 years ago with the PLAN model. It's never been a formalized plan. It's been organic, and it's been educational.

And Paul's mother:

It's people we knew, who knew Paul. We invited them to get to know other people who know Paul. And it started with grandparents, a school teacher, a few people. Then it grew to other family friends, and then their children. Then recently we've been trying to invite along people more Paul's age.

As described above, Jude's arrangement is in the process of change as her needs have changed. Those involved in the planning are not rushing the process and are taking great care that continuity of her relationships is maintained.

Attribute 5.6: Ongoing processes of internal and external review occur.

Description

Review addresses the question of the ongoing suitability of the PRS arrangement. What is working? What isn't working? What else is needed? Review occurs both within the arrangement, for example, in conjunction with the support that is provided. It also has external involvement from people who have a more objective, critical capacity. Review may take various levels of formality, with ongoing involvement of interested people likely to be as effective as formal external review.

An authority recommended:

> …continual and regular <u>independent</u> monitoring, guidance/advice and mentoring by those who have a proven track record.

A service provider suggested:

> Having a process of regular review and appraisal at all levels to ensure that decisions about supports provided and model of service delivery continue to be made in full consciousness of all implications.

THEME 6: CONTROL

BRIEF DESCRIPTION: People who are the primary concern of a PRS arrangement and the others who are close to them, particularly family members, have considerable influence in the arrangement. This may include direct governance by the person or the family as appropriate. This influence occurs through all stages of the planning, development, and implementation of a PRS arrangement.

Attributes of the theme

6.1 The person, and/or those in close relationships, determines their own lifestyle and personal affairs.
6.2 Self-determination for the person is central to the arrangement.
6.3 The person, and/or those in close relationships, has considerable influence in governance of the arrangement.

Description

A PRS approach is characterized by the person, and those closed to him/her, having and exercising extensive influence over the planning for, and ongoing efforts regarding, the arrangement. They might be in control of all aspects of the arrangement, delegating only specific responsibilities to others as they choose.

It may also be legitimate for other stakeholders to have and exercise varying levels of influence. This may include a formal agency holding primary responsibility for such formalities as funding arrangements and staffing. This will entail some form of partnership based on trusting relationships. The person with a disability and those close to him/her will have vested responsibility for certain areas. Other stakeholders who have responsibilities communicate openly and regularly about all aspects in which they have authority. For example, a person who wishes an agency to handle all aspects of funding and related formalities will have an open and trusting relationship with agency personnel who, in turn, will communicate openly, and collaborate about all aspects of funding as the person may wish.

A person may be severely impaired in their ability to contribute directly to aspects of the arrangement and have no people in family or other close relationships. In

this case, the other stakeholders, such as agency management and staff, will make extensive efforts to know and understand the person, to exercise authority in a manner faithful to the person's identity and preferences, and to facilitate the process of introducing others into the person's life who might in time speak and act on his or her behalf.

Research evidence (Caldwell & Heller, 2003; Haggland, Clark, Farmer, & Sherman, 2004; Benjamin, Matthias, & Franke, 2000) indicated that more positive outcomes are associated with individual/family controlled funding and support than with agency controlled arrangements. Such outcomes include increased choice, flexibility and control; greater community involvement; and greater satisfaction with support arrangements.

Attribute 6.1: The person, and/or those in close relationships, determines their own lifestyle and personal affairs.

<u>Description</u>

In regard to day to day affairs, the same arrangements outlined under the Attribute 5.2 apply here. These may concern, among many other possibilities, matters regarding the running of the household, relations with neighbours, or pursuing new ideas such as for a new hobby or form of employment. In these areas, the person is assisted by others in support roles as need be, and is not unduly constrained by such things as rigid agency rules, regulations, or practices.

A *My Place* Coordinator conveyed a deep respect for the importance of the parents in regard to Andre and her affairs.

> *Her parents are very upfront about anything they would want for their daughter. They are very, very supportive of their daughter…They're very strong advocates. It works really well.*

Numerous focus group participants valued the freedom that came with having their own home:

> Good because for one, you haven't got anyone telling you what to do. Two, you can go to bed when you want to.

> You can watch what programs you want to watch.

> And you come home when you want to come home.

> It's wonderful to be married and go away on holidays when you want to.

A carer acknowledged the importance of sensitivity to families.

> Everybody respecting the situation and also understanding that the family are within their rights to be worried and I've had to reassure the family for quite a long time. I've understood it, but it's been hard work too.

Attribute 6.2: Self-determination for the person is central to the arrangement.

Description

In addition to the exercise of authority in the areas outlined above, there is an overall emphasis throughout the arrangement on the person's capacities to determine their own priorities and handle their own affairs. This may be in the form of efforts to get to know the person better, assisting the person to express themselves more clearly, and for key people to be as responsive as possible to the wishes of the person. The person's own outlook and prospects for the future are enriched, rather than constrained, by those in support positions. Therefore, capacity building is ongoing in regard to the person's development, and in the ability of relevant others to listen and respond.

The *Baptistcare* Coordinator was clear that Lisa should be in charge of her own affairs as much as possible:

There is never a meeting we have with Lisa not there. She chooses whether we sit outside and she arranges the table…It's her home, she invites who she wants.

Progress regarding Andre's control of her own time at home has required careful attention to small steps, as a *My Place* Coordinator described:

Initially Andre wouldn't even use her key and let herself into the unit… but now she does it and staff are turning up half an hour later. She is letting herself in, having a cup of coffee and spending some time by herself, whereas previously that wasn't happening at all. She has high support needs and I believe there is room for independence. She helps run her house. She does her own washing, washing the dishes, makes her lunch, making her bed, choosing furniture, choosing things to wear, really making a choice in as many things as possible.

This approach reflected Andre's parents' intentions about life for Andre outside of the family home. Her father commented:

I looked at both our girls, bearing in mind how difficult Andre's behaviour was, but even with that in mind, my attitude was that Andre, like Melanie, deserved to one day leave home and live independent lives. I believe that was really what we wanted. We wanted Andre to live independent of mum and dad. We'd seen examples of aged parents who had an adult that lived at home and their biggest fear was, and perhaps our biggest fear, what's going to happen to Andre when we die?

Attribute 6.3: The person, and/or those in close relationships, has considerable influence in governance of the arrangement.

Description

Major elements that characterise the arrangement, such as the ownership or tenancy structure, funding processes, and staffing, will either be governed directly by the person and/or those in close relationships, or in partnership with

another stakeholder (usually a service provider) in which responsibilities are divided to the satisfaction of all concerned. If agency personnel are the only ones able to speak directly for the person with a disability, they proceed as outlined under the Theme description.

In the case studies that were primarily agency-governed, extensive efforts to engage constructively and respectfully with family members was evident. Family members had varying degrees of control over specific areas, such as the person's finances or major decision making, to a degree that best suited them.

An authority commented:

> *A home needs to be crafted with a person, not by others, i.e., the person (and their family) has influence or say over where they live, with whom, and all design features including how resources are used and all support features.*

On the other hand, Lisa's aunt is elderly and happy to leave the formalities to the agency:

> *Everything's left up to Baptistcare. They've been very, very good.*

THEME 7: SUPPORT

BRIEF DESCRIPTION: Support to people in PRS arrangements comes from many different informal and formal sources including family, friends, neighbours, advocates, and paid workers through organisations. There is a conscious balance between informal and formal supports. Support is flexible and responsive to changing needs.

Attributes of the theme

7.1 The overall arrangement is flexible.

7.2 The agency involved is creative and responsive.
7.3 There is a balance of formal and informal supports.

Description

PRS arrangements provide support in ways that respond flexibly to the needs and preferences of the person. Support includes direct support from formal workers, informal support from friends and family, and indirect support such as through advocacy. It also includes other people who may live within the support arrangement and the location and nature of the physical environment that is part of the arrangement.

Attribute 7.1: The overall arrangement is flexible

PRS arrangements are open to different possibilities and may be adapted as they go. There is consciousness of the limitations of formal accommodation support models that rely on rostered, paid staff and this is avoided where possible. The arrangement is highly conscious and respectful of the notion of "home". There is flexibility in terms of the amount and type of support and necessary contingency plans and back-up are in place should some aspect of the arrangement require it.

An authority described the importance of flexibility.

> *Whatever is crafted needs to be flexible enough to be changed when a person's desires, needs, or circumstances change. A person should not have to shift just because their needs increase. However if a person wishes to move then this is possible (like all other citizens).*

Rob's living arrangement has been very stable, and when there is a need for a new co-resident to be found, the arrangement is flexible enough for this to happen with ease, as described by Ben, a current co-resident.

It's always been word of mouth. There's never been any advertising or anything. It's been friends. Like originally I was in a band, and the singer from the band was actually living with Rob for about three years, then she wanted to move out, and I was overseas and came back and was looking for somewhere to live and this opportunity came up and I said 'oh ok'.

Attribute 7.2: The agency involved is creative and responsive

Various formal requirements such as regulation and funding are addressed creatively, based on awareness of how these may undermine some PRS principles. Rules and regulations are minimised. PRS arrangements are responsive to the changing needs and preferences of the person and also to the changing external environment. The arrangement carefully considers the need for changes in the location and type of physical environment, people with whom the person may share accommodation, those who provide support, and any other aspects of the PRS arrangement.

A Local Area Coordinator emphasised the importance of:

> *Funding that is flexible and open to experimentation, [and] agencies that are willing to be creative and responsive.*

The role of *Vemvane* in Rob's life has evolved along with his lifestyle and development, as the CEO described.

> *The fact that when the network is expanded it's got its own life. It means we're able to step back as coordinating people. The practical interventions are far less than they were at the start of the co-residency and I think the co-residents could tell you themselves that we interfere very minimally…they are three adults living together, sharing a place. I hope that they perceive it that way, but behind it there's still thought, structure, direction, but it's more subtle than it was at the beginning.*

Attribute 7.3: There is a balance of formal and informal supports

The balance between formal, paid support and informal, unpaid support is a delicate one. PRS arrangements acknowledge the importance of both. The arrangement is outward-looking and actively pursues the involvement of informal support and understands that this may be undermined by paid support.

Many survey respondents, in addition to those involved in the case studies stressed the importance of this attribute. For example, a service provider commented:

> *[Our service] favours freely given devotions over paid support. Paid*
> *supports will always give-way to freely given devotions and opportunities.*
> *This is both cost effective and the best way to promote real friendships.*

Rob's co-residents could be considered as both informal and formal support people. They receive some reimbursement for their presence and back-up support, but the friendship and shared experiences between the three residents, Ben, Julie, and Rob, goes far beyond formal boundaries, as described by Ben.

> *He loves his music, loves having a sing and dance, loves coming out. I*
> *play a few shows here and there around town, I've got a band, and Rob*
> *comes along.*

And Julie.

> *I think we're really lucky, we love Rob to bits. Both of us just think the*
> *world of him, and we want to look out for him anyway, and we do consider*
> *him our mate.*

A married couple who participated in the focus group expressed their satisfaction with the support received from a live-in, co-tenant/support person, who contributed to rental costs and provided a range of supports:

> *Husband: We have a lady that lives with us. Wife: But that's all right.*
> *H: She do herself what she do. I'm not stopping her doing anything*

and she's not stopping me doing anything. W: We get on really good.
And she helps us with the shopping and everything. It's wonderful.

Lisa receives assistance from a support worker on a drop-in basis. Her aunt commented on some aspects of this.

> *The thing was learning, teaching her, decent dressing and things like that.*
> *The one thing we were apprehensive about was her being able to keep*
> *herself clean but she, with the help of her carers, has been able to do that*
> *really well.*
>
> *Heidi [a former support worker] used to help her cook a meal and then*
> *they'd invite me down and she'd have to lay the table down which was*
> *really good.*

THEME 8: THRIVING

BRIEF DESCRIPTION: PRS facilitates growth and development through opportunities with an increased likelihood of an enhanced lifestyle and general well-being. There are opportunities in PRS for personal growth in the areas of independence, self-determination, and competencies, and fostering valued roles in the home and in the community.

Attributes of the theme

8.1 The person's lifestyle and general wellbeing are enhanced.
8.2 The person acquires a range of valued roles at home and in the community.
8.3 There are many opportunities for growth and development.

Description

This theme concerns the outcomes of PRS arrangements, which are associated with a range of positive outcomes in terms of the person's wellbeing, and their lifestyle at home and in the broader community.

In terms of wellbeing, benefits occur in such areas as skills, motivation, spontaneity, confidence, and contentment. When PRS arrangements are established and operating in line with the expectations of those involved, the person with a disability is often described as thriving and generally doing well as a result. Key people who have been involved for an extended time can often describe substantial positive changes in the person.

PRS arrangements are also associated with a high level of engagement in the typical range of routines and responsibilities associated with home and enhanced opportunities to engage with people in settings throughout the broader community.

For arrangements that are in the planning stages, the leadership and other key people will have identified outcomes such as these as being part of their vision, and a major reason for working towards a PRS arrangement over other models of support.

It has been mentioned that the research literature provided ample evidence of positive outcomes being associated with small scale living arrangements, with some evidence supporting the highest quality outcomes in arrangements that do not involve any grouping of people with disabilities. Positive outcomes described include self-determination, personal control, and choice making.

Attribute 8.1: The person's lifestyle and general wellbeing are enhanced.

Description

From a review of the overall arrangement, a range of benefits associated with the person's lifestyle and wellbeing should be evident. Barriers to the person's wellbeing will be known to key people and actively addressed in order to maximize the person's prospects to thrive.

Andre's mother summed up the benefits of her living arrangement.

I think that is one of the biggest bonuses of living independently - having your own life.

Rob's mother commented on the benefits of her son's co-resident lifestyle.

He doesn't have a disability when he's with them. It's hard to explain. He's got his problems and the rest of it, but I'm sure that he feels that he's just one of them. In fact on Saturday night Ben took him to a gig. He plays in a band, and Rob loves it. He loves his music. Give him that any day.

Attribute 8.2: The person acquires a range of valued roles at home and in the community.

Description

Resulting from the range of opportunities and appropriate support as outlined above should be a range of outcomes in the form of valued roles. These are potentially very varied, but can be identified under the broad categories of home (such as home owner/renter, partner/friend, cook, decorator, gardener) and community (such as neighbour, valued employee, helper, companion). Support should be provided as needed to assist the person to fulfill these roles, and to enhance the range and depth of their valued roles.

Reflecting the research evidence, the people with a disability in each of the case studies had a range of home, community, and relationship roles in greater variety and number than appears to be evident for many people in other types of

supported accommodation arrangements. The key people in the arrangements are highly conscious of this and determined to safeguard the progress made.

Rob has a rapport with many in people in his neighborhood, as described by one of his carers.

> *A lot of the businesses around Northbridge know Rob, which is very good because he can be quite vulnerable, especially as far as finances and things like that go. A lot of the business owners keep a bit of an eye out for Rob.*

Jackie, in response to what happens with Geoff on the weekends said:

> *We (usually) stay at home on the weekend here. Geoff can do what we normally do. Help out with the gardening or cleaning. Shopping. A movie. Cooking. Going out….loves a drive. Walking around here often in the evening. Fishing and camping.*

Attribute 8.3: There are many opportunities for growth and development.

<u>Description</u>

Having one's own home entails a vast range of opportunities that are naturally conducive to personal growth and development. The arrangement should capitalise on this, with the person fully engaged in all aspects of planning and actions regarding household freedoms, roles, and responsibilities, and in the typical range of neighbourhood and broader community roles that citizenship affords. The person's support needs are addressed in a developmental manner, with support people maintaining and enhancing the person's engagements in their home and community, rather than acting for the person unnecessarily.

Andre's mother summed up Andre's growth and the style of support that has facilitated this.

> *In herself, she feels really good because she's not under our roof. She's improved heaps. Her development. We thought she'd get to a certain*

stage and wouldn't improve at all. She's absolutely, sort of blossomed basically since she's been in independent living. I think it's the best thing really. All they need is a bit of support. Guidance. One of the coordinators, I think one of the best things he described was the supports should basically be like a shadow and just be there to guide them but allow them to do most of the things themselves. I think that's the greatest thing in independent living, is that you have life. Like so called normal children get their own flat and do their shopping and go to work. And basically Andre does that but just has someone with her.

THEME 9: SOCIAL INCLUSION

BRIEF DESCRIPTION: PRS arrangements involve building wider community acceptance by avoiding congregation and segregation of the person with the disability. There is an outcome of reduced isolation and there is a focus on participation and engagement resulting in social inclusion.

Attributes of the theme

9.1 Some relationships are close and enduring.
9.2 The person has a rich and varied social network.
9.3 There are opportunities for participation in a variety of community settings.

Description

This Theme is concerned with how the PRS arrangement contributes to the person's inclusion in the community. Social inclusion means being involved in the life of the person's community, particularly through relationships with people. It means spending time physically in community settings and participating in those settings through relationships and activities. It is about the valued roles that become available through valued membership of communities.

Attribute 9.1: Some relationships are close and enduring

The PRS arrangement is particularly supportive of relationships that are close and relationships that are enduring. This consists of both a keen awareness of the importance of those relationships as well as enabling and facilitating them through the way the support arrangements work. Attention is given to sustaining existing important relationships and also to seeking opportunities for the development of new relationships.

One person involved in a host family arrangement described how she had known Jude for a long time.

> *Yes. A long time. And with Kathy (also involved in the arrangement) being my sister, she's been part of the family for 15 years – she's like family. Fits in and loves the kids…she loves it and it's great for the kids.*

Jackie spoke about the importance of knowing the person.

> *And you get more protective too. It feels like it's a person who's part of the family. But one of the beauties of (the current arrangement) is that we're living with Geoff and we can learn more about him. It's true.*

Attribute 9.2: The person has a rich and varied social network

Social networks refer to the range of relationships that are facilitated and supported by the PRS arrangement. Relationships vary in terms of closeness, for example, from family and friends through to casual acquaintances. Associated roles will vary, for example, from brother or sister, to shopper. The extent of reciprocity in relationships will also vary. The person may give and/or receive in different relationships. A person in a PRS arrangement will have developing social networks both within the home setting and outside it.

A *Vemvane* Coordinator described how:

> *Many opportunities arise where people want to spend time with Rob. We haven't formally structured or planned them. They've happened because the service design has allowed it to happen. He mixes with some interesting characters. We don't know many of them. We don't scrutinize them. We don't have police clearances for them. They're not paid by us. That's life.*

A co-resident named numerous people in close and long-standing friendships with Rob. In addition to these, there was a wide range of acquaintances.

> *I was always inquisitive of where Rob actually goes during the day, so one day we just jumped in the car and I said 'ok Rob, I want you to take me around to all the places where you go'. I was just curious. And sure enough, I introduced myself to a lot of these people. Rob knows his sense of direction really well. He said, 'this is where I go'. We'd go into a shop and everyone would say, 'hey Robbie, how you going?', and I introduced myself, 'hi I'm Ben. I live with Rob. Just wondering if you ever see him, and it was, 'oh yeah Rob comes in a couple of times a day and makes a coffee and does this'. It's just good to know he's got all these friends around the place. Then we went to another little shop up in Mt Lawley, there were these girls who work there and they know Robbie as well.*
> *He goes in and gets a coffee. It's just great to know there's all these people around the place. They know who he is. Everyone sort of looks out for you don't they?*

For Paul's parents, the building of a social network for their son has brought some results and remains a work in progress, as his father explained.

> *Paul needs reciprocal relationships. We need to find people who can contribute something to Paul and his life, but equally can open their eyes and see that they can receive something from Paul.*

The advantages of being part of a host family arrangement were described as connecting with a social network.

> *I think the social aspect would have to be the biggest. She shops. She has so many friends – like our friends – and Jude's friends as well – who come and visit her.*

And neighbours are important too.

> *Neighbours here always make the effort to say 'Hi!' and Geoff is invited with us when they have a barbecue. He gets to know more people through us.*

Attribute 9.3: There are opportunities for participation in a variety of community settings.

PRS arrangements enable the person to participate in a wide variety of activities in communities. Community participation refers to the valued social roles that the person may fulfill through those activities, such as traveler, consumer, member, student, worker, friend, etc. Participation occurs in different communities such as the neighbourhood, work, leisure/recreation, education, etc. It will reflect the particular interests, preferences, and capacities of the person.

Rob has had the opportunity to travel overseas in the company of several co-residents who have sought no payment in return. Likewise, he has travelled interstate with a co-resident, who described how:

> *He actually came on tour with my band, around Australia, Sydney, Melbourne and Adelaide. Rob came along. Why not?*

As an authority concluded:

> *Living in one's own place is not enough. All people need company, relationships, friends, neighbours, and to be well connected and valued by their local community and contribute in meaningful ways to the life of the community.*

4.2 Other findings

Beyond the PRS Framework, a number of issues of interest emerged during the project.

PRS arrangements are often viewed with some doubt about their longer term viability, and indeed long term security was considered very important by those with whom we spoke and corresponded. Safeguarding against risk was an issue of importance to many. Among the arrangements were some that have been very stable and secure, with very low levels of turnover of key support people. This suggests that PRS arrangements can be as secure and stable, and potentially more so, than other models of supported accommodation. This would be a worthwhile issue to investigate in greater detail.

It also became clear that 'doing PRS' takes very considerable time and effort on the part of many people. Arrangements take considerable time to come into being, responsibilities are typically shared around, and those involved are engaged in something quite different to the majority of supported accommodation models that are funded in W.A. As *Vemvane's* CEO stated, "it's not for everyone", and went on to describe that it takes sufficient people with shared ideas, with sufficient time and energy, to bring a PRS arrangement into being.

Terms such as 'community living', 'supported living', 'independent living', and 'individual options' among others are frequently used interchangeably and without an agreed definition or understanding. Often, the use of such terms is misleading. The literature review revealed that these terms may refer to relatively large, congregate care arrangements that may be described in terms of number of beds and not people. This is especially the case in the empirical literature. It is also almost universal that the empirical literature will identify the number of beds or number of people in an arrangement as the key independent variable when

examining outcomes of accommodation support. Rarely are the aspects of PRS that are described here the subject of empirical research.

PRS arrangements can occur in many forms, just as every person's home in the wider community is in some way different to everybody else's. The nine themes describe what stakeholders believed to be the most important characteristics of personalised residential supports. As such, we propose that they be used to define and describe the many possible arrangements that can be termed PRS.

Among the project's initial aims was to identify barriers and facilitators, strategies, and outcomes, concerning the implementation of PRS. Our findings on these are not separately described, as they are contained within the PRS Framework. For example, much of the information gathered on the first Theme, Assumptions, was conveyed in terms including the importance of positive assumptions and high expectations for people with a disability as a facilitator. The absence of such assumptions was described as a major barrier. It follows that strategies for the implementation of PRS, some of which were identified by various stakeholders, should include the involvement of people with positive assumptions, and forms of awareness-raising that will serve to raise people's expectations for what is desirable and achievable.

Likewise the second Theme, Leadership, was often expressed in terms including strong, values-based leadership as a key facilitator of PRS. Conversely, the lack of such leadership was expressed as a barrier. In terms of strategies for creating a PRS arrangement then, the presence of, and investment in, leadership are vital.

Themes 8 and 9, Thriving and Social Inclusion, convey the key outcomes associated with PRS. Like all of the Themes, these contain a number of attributes, each of which constitutes an outcome that PRS arrangements are designed to bring about.

It follows that the PRS framework can be used not only as a definition and description of the key characteristics of PRS, but also for the identification of key barriers, facilitators, strategies, and outcomes.

5. Conclusions

The Personalised Residential Supports Project set out to explore personalised forms of supporting adults with developmental disabilities. A great many people with a vast array of knowledge and experiences contributed to this task, the results of which have provided a useful descriptive framework. All those involved in the project acknowledged that this pooling of expertise into a consensus view of the key ingredients of PRS provided an invaluable source of knowledge.

It was not the intention of the project to examine other, group-living support models. A great many studies of group-living arrangements have been conducted over many years and no doubt more will follow. It is the case that for many of the people who contributed to this project, their experience of other support models contributed to their motivation to pursue PRS approaches. We anticipate that people who benefit from the findings of the project will include many who are involved in group living arrangements in one capacity or another. The themes expressed in the PRS Framework have relevance to many aspects of all forms of supported accommodation. While the project focused on adults with developmental disability, the project's findings will be of value to those involved in supports for people of various ages and with other disabilities.

Among the possible next steps beyond this project is the potential for the PRS Framework to form the basis of new material to be developed for the purposes of program evaluation, and education and training. Early work on this task is underway.

.

6. References

Annison, J. (2000). Towards a clearer understanding of the meaning of "home". *Journal of Intellectual & Developmental Disabilities, 25*(4), 251-262.

Benjamin, A., Matthias, R., & Franke, T. (2000). Comparing consumer-directed and agency models for providing supportive services at home. *Health Services Research, 35*(1), 351-366.

Caldwell, J., & Heller, T. (2003). Management of respite and personal assistance services in a consumer-directed family support program. *Journal of Intellectual Disability Research, 47*(4-5), 352-367.

Croft, D. (2006). *Innovation in the provision of accommodation support services for Western Australians with disabilities – case studies.* Perth: ACROD.

Disability Services Commission. (2004). *Annual Report 2003-2004.* Perth: Author.

Disability Services Commission. (2003). *Accommodation Blueprint Steering Committee – Final report and recommendations.* Perth: Author.

Haggland, K., Clark, M., Farmer, J., & Sherman, A. (2004). A comparison of consumer-directed and agency-directed personal assistance services programs. *Disability & Rehabilitation, 26*(9), 518-527.

Kendrick, M. (1993). The choice between a real home and a program. *Progress, 2*(1).

Lakin, C., & Stancliffe, R. (2007). Residential supports for persons with intellectual and developmental disabilities. *Mental Retardation and Intellectual Disabilities Research Reviews 13*, 151-159.

Mansell, J. (2006). Deinstitutionalisation and community living: Progress, problems and priorities. *Journal of Intellectual & Developmental Disabilities, 31*(2), 65-76.

McConkey, J. (2007). Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Journal of Intellectual Disability Research, 51*(3), 207-217.

O'Brien, J. (1994). Down stairs that are never your own: Supporting people with developmental disabilities in their own homes. *Mental Retardation, 32*(1), 1-6.

Saloviita, T., & Aberg, M. (2000). Self-determination in hospital, community group homes, and apartments. *The British Journal of Developmental Disabilities, 46*(1), 23-29.

Stancliffe, R. (1997). Community living-unit size, staff presence, and residents' choice-making. *Mental Retardation, 35*(1), 1-9.

Stancliffe, R., Abery, B., & Smith, J. (2000). Personal control and ecology of community living settings: Beyond living-unit size and type. *American Journal on Mental Retardation, 105*(6), 431-454.

Stancliffe, R. J., Lakin, C. K., Doljanac, R., Byun, S., Taub, S., & Chiri, G. (2007). Loneliness and living arrangements. *Intellectual and Developmental Disabilities, 45*(6), 380-390.

.

Tossebro, J. (1995). Impact of size revisited: Relation of number of residents to self-determination and deprivation. *American Journal on Mental Retardation, 100*(1), 59-67.

7. Contributors to the project

The contributions of the many people involved in the various aspects of this project are gratefully acknowledged, and we thank all of the following people:

Rob's arrangement: Rob and his mother, his co-residents, and the management of *Vemvane*.

Andre's arrangement: Andre and her parents, and the staff and management of *My Place*.

Geoff's arrangement: Geoff and his brother and sister-in-law, Jackie, and the staff and management of the *Lower Great Southern Community Living Association*.

Jude's arrangement: Jude and her parents, Kathy and Toni, and the staff and management of the *Lower Great Southern Community Living Association*.

Lisa's arrangement: Lisa and her aunt, and the staff and management of *Baptistcare*.

Paul's arrangement: Paul and his parents, and Paul's network facilitator.

Focus group: The members of the *People With Disabilities WA* (PWD WA) self-advocacy group, and the staff and management of PWD WA.

Surveys: The many families and service providers who contributed to the scoping questionnaire, and/or to the round of three surveys.

Consortium Members**:** Sue, Deirdre, Heather, Leah, Eddie, and Lauren and the staff and management of DDC WA.

8. Resources

A number of groups and initiatives have been referred to in this report, web site details for which are provided below.

Community Living Plan

http://www.disability.wa.gov.au/newsevents/home_news.html?svNews_TYPE=Detail,svMLI_ID=120074

Microboards

In Australia: http://www.microboard.org.au/page/Home

In Canada: www.microboard.org

PIN (Planned Individual Networks)

www.pin.org.au

PLAN (Planned Lifetime Advocacy Network)

www.plan.ca

Shared Management Model

http://www.disability.wa.gov.au/dscwr/_assets/main/promotional/documents/doc/smm_brochure.doc

9. Appendices

Appendix A: Empirical research search strategy.

Appendix B: Scoping exercise questionnaire form.

Appendix C: Survey 1.

Appendix D: Survey 2.

Appendix E: Survey 3.

RESEARCH QUESTION

What are the outcomes of individualised residential supports for adults with developmental disabilities?

Components of the research question:

SUBJECTS	INTERVENTION	OUTCOMES	DESIGNS
Adult people with a developmental disability. Adult = $\geq$ 18. Developmental disability = onset $\leq$ 18 and is life-long: includes intellectual disability, cerebral palsy, sensory impairments, autism and acquired brain injury.	Residential supports planned and provided for individuals. Some form of support in addition to immediate family members must be in place. Any form of support is included. Support must be provided primarily in a residential context. Employment, educational and	Outcomes of the intervention in the following categories will be considered: • Quality of life • Subjective and objective wellbeing • Choice • Self-determination • Service satisfaction • Engagement in home and community roles • Personal development • Social inclusion • Other	All studies reporting outcome data will be reviewed.

	other non-home based supports are excluded. Individual = one person with a disability within the residence.		

SEARCH STRATEGY

1. Search of databases.

Databases: Cochrane library; CCC, PsychINFO, Cinahl.

Search terms:

1. (disabilit$ OR impairment OR handicap$ OR retard$); AND 2. (accommodation OR residen$ OR home OR living OR facility OR house OR apartment).	Combined with: (individual$ OR person$); (community OR independ$ OR inclus$ OR integrat$); (size OR single OR group OR congregat$).

2. Hand-search of all available studies: additional web-searching, journals, books, conference papers, reference lists.

3. Contact key researchers for access to additional material.

THE PERSONALISED RESIDENTIAL SUPPORTS PROJECT

Questionnaire

Your name:_____

Agency (if applicable):_____

BACKGROUND TO THE QUESTIONS

Personalised residential supports (PRS) can be thought of as: *supports that are planned for and provided around an individual person with a disability in their own home, in which that person, and/or that person's family, have a central role in the planning and delivery of the support.*

Congregate-care arrangements, such as group homes, hostels and cluster developments, or residences that are owned and governed primarily by a formal service provider, are not included in this definition.

We are seeking information on examples of PRS that involve an *adult who has a developmental disability (i.e. intellectual disability, cerebral palsy, sensory impairments, autism and acquired brain injury).*

1. Are there examples of PRS in which you and/or your agency have an involvement?

    Yes/No

2. If YES, how many are there? _____

3. What is the location (broad area only, e.g. south metro, Pilbara) of these examples?

_____

3. Please provide a brief description of one arrangement (existing or proposed) that might constitute an example of personalised residential supports as described above (please do not include any identifying information such as names and addresses):

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

4. We will be seeking to follow up with some people for further information. If you are agreeable to being contacted, please provide your phone and/or email contacts: _____

Please return this form in the enclosed envelope.

THANK YOU

Personalised Residential Supports Survey- First Round

One of the aims of the personalised residential supports (PRS) project is to develop an explanation of PRS or individualised living for adults with developmental disabilities. This survey is to determine how key stakeholders who are involved in accommodation services for people with developmental disabilities view personalised and individualised living. This will help to create a comprehensive description and definition of personalised living that can be utilised by families, service providers and authorities.

The survey has been sent to you via email in a word document that can be emailed back once completed to Ross Boaden at the address below. We will send you a gentle reminder in two weeks. We encourage you to be expansive in your answers. The survey consists of four sections. Each of these has some guideline questions which can be used to answer the sections.

Section One: Description of PRS
- What are the key features or characteristics of individualised or personalised accommodation support for adults with developmental disabilities?

Section Two: Quality in PRS
- How can the quality of individualised or personalised accommodation support be safeguarded?

Section Three: Outcomes of PRS
- What range of outcomes are associated with PRS?

Section Four: Barriers and facilitators to PRS
- What are the barriers to successful implementation of PRS?
- What are the facilitators to PRS?

If you have any questions regarding the survey please contact either:
Ross Boaden (Project Officer)
        (08) 9266 1787
        r.boaden@curtin.edu.au
Professor Errol Cocks
        (08) 9266 3659
        e.cocks@curtin.edu.au
Lauren McKernan
        (08) 9332 3636
        lauren.mckernan@student.curtin.edu.au

NAME:

Confirmation of PRS Themes

The aim of the personalised residential supports (PRS) project is to develop an understanding of PRS or individualised living for adults with developmental disabilities. Research has been conducted to determine how key stakeholders in accommodation for people with developmental disabilities view personalised and individualised living. This has involved a written survey, case studies of six PRS arrangements, and a focus group with adults with developmental disabilities. A set of 14 themes has been drawn from all of the information gathered. The aim of this survey is for you to tell us how relevant you believe the themes are to PRS.

The themes are presented in no particular order of importance. At the end of each theme narrative is a scale from one, strongly disagree, to five, strongly agree, asking if this is a relevant and valid PRS theme. Below the scale is a space for comments relevant to the theme. At the end of the survey is a space for any final comments.

We will adjust the themes according to the information received from this survey. The next step will then be to send the final list of themes back to you for prioritizing.

Please send the completed survey to Ross Boaden by return email.

1. My Home
Living in and owning one's own home is the ideal and a personal stake in your home can result in a sense of ownership, responsibility and empowerment. By living in a 'home' and not merely 'accommodation', the person with a disability is involved in choices concerning their homes and are responsible for home forming practices such as domestic duties, privacy and routines.

1---------------------2------------------------3------------------------4-----------------------5
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree

Comments

2. Leadership
At least one person with a clear vision or strong ideas is needed. This leadership may come from professionals or family members advocating on behalf of the person with a disability. It may also come from the person with a disability. A lack of leadership was considered a barrier to successful implementation of a PRS arrangement.

1---------------------2-----------------------3-----------------------4-----------------------5
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree

<u>Comments</u>

3. One Person at a Time

PRS means an intentional avoidance of grouping of people with disabilities. It fosters unique arrangements focusing on each person with a disability with his/her 'voice' being central. The arrangements are person-centred, are based on personal knowledge of the person with a disability and are guided by those who know the person well.

1---------------------2-----------------------3-----------------------4-----------------------5
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree

<u>Comments</u>

4. Thriving

PRS facilitates growth and development through opportunities with an increased likelihood of an enhanced lifestyle and general well-being. There are opportunities in PRS for personal growth in the areas of independence, self-determination and competencies and fosters valued roles in the home and in the community.

1---------------------2-----------------------3-----------------------4--------------------5
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree

<u>Comments</u>

5. Continuity

Continuity means stability in relationships, where and with whom a person lives, and the lifestyle each person prefers. There is a sense of stability in the arrangements with continuity of support workers. There are enduring relationships with family, friends and neighbours.

1---------------------2-----------------------3-----------------------4-----------------------5
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree
<u>Comments</u>

6. Safeguarding

PRS includes awareness and identification of risks and the planning and implementation of safeguards. Some risks associated with PRS include instability of arrangements including funding and support, demands on primary carers, tenancy issues, and loneliness and vulnerability if living alone. Many of the characteristics of PRS, such as continuity of relationships constitute safeguards in themselves.

```
1--------------------2-----------------------3-----------------------4-----------------------5
```
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree

Comments

7. Relationships

The person has, or is supported to achieve, a rich social network, including family, friends, acquaintances, and support workers. There are some relationships that are very close and enduring.

```
1--------------------2-----------------------3-----------------------4-----------------------5
```
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree

Comments

8. Qualities and Characteristics of the PRS Arrangement

Some qualities that make PRS unique are flexibility, informality and personalised support. Successful arrangements are monitored by agencies that are creative, responsive to possibilities and open to change.

```
1--------------------2-----------------------3-----------------------4-----------------------5
```
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree

Comments

9. Support

Support to people in PRS arrangements comes from many different informal and formal sources including family, friends, neighbours, advocates, and paid workers through organisations. There is a conscious balance between informal and formal supports. Support is flexible and responsive to changing needs.

1--------------------2-----------------------3-----------------------4-----------------------5
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree

<u>Comments</u>

10. Control

People who are the primary concern of a PRS arrangement and the others who are close to them, particularly family members, have considerable influence in the arrangement. This may include direct governance by the person or the family as appropriate. This influence occurs through all stages of the planning, development, and implementation of a PRS arrangement.

1--------------------2-----------------------3-----------------------4-----------------------5
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree

<u>Comments</u>

11. Assumptions

Some key assumptions that underpin PRS arrangements include:
- It is not necessary for people with a disability to live together;
- PRS can occur without a person having to live independently or alone;
- People with complex and high support needs can live in their own home;
- PRS are associated with increased expectations for people with a disability.

1--------------------2-----------------------3-----------------------4---------------------5
        Strongly Disagree   Disagree   Uncertain   Agree Strongly Agree

<u>Comments</u>

12. Planning

Timely planning is integral to PRS and requires a long term outlook and investment of time and effort. Planning is based on the person's uniqueness, strengths and individual needs. People close to the person are involved in the planning process.

1--------------------2-----------------------3-----------------------4-----------------------5
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree

Comments

13. Social Inclusion

PRS arrangements involve building wider community acceptance by avoiding congregation and segregation of the person with the disability. There is an outcome of reduced isolation and there is a focus on participation and engagement resulting in social inclusion.

1----------------------2------------------------3------------------------4------------------------5
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree

Comments

14. Self-Determination

PRS arrangements enable people to exercise choice and decision-making and be more independent.

1----------------------2------------------------3------------------------4------------------------5
  Strongly Disagree Disagree   Uncertain   Agree   Strongly
Agree

Comments

Any Final Comments

Thank you for your participation. If you have any questions regarding the survey please contact:
Ross Boaden (Project Officer)
        (08) 9266 1787
        R.Boaden@curtin.edu.au

Survey 3: PRS Themes and Attributes

THEME 1: MY HOME   **Relative importance (1-9):_____**
BRIEF DESCRIPTION: Living in and owning one's own home is the ideal and a personal stake in your home can result in a sense of ownership, responsibility and empowerment. By living in a 'home' and not merely 'accommodation', the person with a disability is involved in choices concerning their homes and are responsible for home forming practices such as domestic duties, privacy and routines.

Attributes of the theme	Relative importance (1-2)
The person has a clear personal stake, such as ownership or secure tenure, in the home.	
The person engages in typical home forming practices, roles and responsibilities.	

THEME 2: LEADERSHIP   **Relative importance (1-9):_____**
BRIEF DESCRIPTION: At least one person with a clear vision or strong ideas is needed. This leadership may come from professionals or family members advocating on behalf of the person with a disability. It may also come from the person with a disability. A lack of leadership was considered a barrier to successful implementation of a PRS arrangement.

Attributes of the theme	Relative importance (1-2)
At least one key person provides the leadership necessary for the arrangement to be created and endure.	
The leader/s holds and acts upon a clear vision and strong ideas.	

THEME 3: ONE PERSON AT A TIME   **Relative importance (1-9):_____**
BRIEF DESCRIPTION: PRS means an intentional avoidance of grouping of people with disabilities. It fosters unique arrangements focusing on each person with a disability with his/her 'voice' being central. The arrangements are person-centred, are based on personal knowledge of the person with a disability and are guided by those who know the person well.

Attributes of the theme	Relative importance (1-3)
The arrangement is designed around the unique identity of one person.	
The person's 'voice' is central to the arrangement.	
There is an intentional avoidance of grouping of people	

with disabilities.	

THEME 4: THRIVING **Relative importance (1-9):_____**

BRIEF DESCRIPTION: PRS facilitates growth and development through opportunities with an increased likelihood of an enhanced lifestyle and general well-being. There are opportunities in PRS for personal growth in the areas of independence, self-determination and competencies and fosters valued roles in the home and in the community.

Attributes of the theme	Relative importance (1-3)
The person's lifestyle and general wellbeing are enhanced.	
There are many opportunities for growth and development.	
The person acquires a range of valued roles at home and in the community.	

THEME 5: CONTROL **Relative importance (1-9):_____**

BRIEF DESCRIPTION: People who are the primary concern of a PRS arrangement and the others who are close to them, particularly family members, have considerable influence in the arrangement. This may include direct governance by the person or the family as appropriate. This influence occurs through all stages of the planning, development, and implementation of a PRS arrangement.

Attributes of the theme	Relative importance (1-3)
The person, and/or those in close relationships, has considerable influence in governance of the arrangement.	
The person, and/or those in close relationships, determines their own lifestyle and personal affairs.	
Self-determination for the person is central to the arrangement.	

THEME 6: PLANNING **Relative importance (1-9):_____**

BRIEF DESCRIPTION: Timely planning is integral to PRS and requires a long term outlook and investment of time and effort. Planning is based on the person's uniqueness, strengths and individual needs. People close to the person are involved in the planning process. Planning incorporates the development of safeguarding measures, including ongoing processes of review.

Attributes of the theme **Relative importance (1-6)**

Planning includes a long-term outlook.	
Considerable ongoing time and effort is spent in planning.	
All planning activities maintain a central focus on the person.	
People in close relationships are involved appropriately.	
Planning includes an emphasis on safeguarding positive elements and addressing areas of risk.	
Ongoing processes of internal and external review occur.	

THEME 7: SOCIAL INCLUSION   **Relative importance (1-9):_____**
BRIEF DESCRIPTION: PRS arrangements involve building wider community acceptance by avoiding congregation and segregation of the person with the disability. There is an outcome of reduced isolation and there is a focus on participation and engagement resulting in social inclusion.

Attributes of the theme	Relative importance (1-3)
The person has a rich and varied social network.	
Some relationships are close and enduring.	
There are opportunities for participation in a variety of community settings.	

THEME 8: SUPPORT   **Relative importance (1-9):_____**
BRIEF DESCRIPTION: Support to people in PRS arrangements comes from many different informal and formal sources including family, friends, neighbours, advocates, and paid workers through organisations. There is a conscious balance between informal and formal supports. Support is flexible and responsive to changing needs.

Attributes of the theme	Relative importance (1-3)
The overall arrangement is flexible.	
The agency involved is creative and responsive.	
There is a balance of formal and informal supports.	

THEME 9: ASSUMPTIONS   **Relative importance (1-9):_____**
BRIEF DESCRIPTION: PRS arrangements are underpinned by a set of assumptions that reflect high expectations for the person with a disability.

It is not necessary for people with a disability to live together.	
PRS can occur without a person having to live independently or alone.	
People with complex and high support needs can live in their own home.	