
THE PERSONALISED RESIDENTIAL SUPPORTS PROJECT

This article is an edited version of the Personalised Residential Supports Project (2009). It is included in this edition of "Thinking About the good Life" as the themes and frameworks could be usefully applied as we assist people with a disability to have a good life. The full report is available from Centre for Research into Disability and Society, Curtin Health Innovation Research Institute or School of Occupational Therapy and Social Work ,Curtin University of Technology and at www.belongingmatters.org

Professor Errol Cocks is Professor and Director of the Centre for Research into Disability and Society, Curtin Health Innovation Research Institute, and Director, Research and Graduate Studies, School of Occupational Therapy and Social Work at Curtin University.

Ross Boaden has twenty years of management experience in accommodation, open employment and recreation fields. His other experiences includes program development, evaluation and training, standards monitoring, university lecturing and research in a wide range of disability, aged-care and mental health services. He consults to a range of disability service organisations.



INTRODUCTION

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.

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

- 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.
- 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.

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

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).

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.

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.

Four methods of data collection were used. 1. Literature review. 2. Case studies. 3. Focus group. 4. Written surveys. A great deal of information was gathered from these methods. This was carefully analysed so the findings accurately reflected a consensus of

stakeholders' views. The three CRDS personnel independently studied the written material

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and identified a set of key themes from each of the three methods. The result is the PRS Framework...

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.

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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

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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.

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."

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.

and still have support workers that have been there to assist me in actively pursuing interests of different kinds which have enhanced me socially, physically and emotionally. In assisting me with these things support workers and others see me as an active person with normal wants and desires but sometimes a person who needs some assistance to achieve these tasks.

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.

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.