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## Personalised approaches to supported accommodation

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## The Personalised Residential Supports (PRS) Project

- **Funder:** Lotterywest
- **Auspice:** Developmental Disability Council of WA (Inc)
- **Consortium:** DDC, NDS, parents, CRDS
- **Project tenure:** 30 months from December 2006
- **Aim:** Identify the nature, purposes, & outcomes of PRS for adults with developmental disabilities & develop an evaluation framework.

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## Project methodologies

- Review empirical & descriptive literature.
- Case studies of 6 personalised living arrangements over up to 30 months.
- Survey of key informants.
- Focus group with adults with developmental disabilities.

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## Literature review method: Modified systematic review

1. **Question:** What are the outcomes of residential supports that are planned & provided for individuals with developmental disabilities?
2. **Inclusion criteria:** Subjects, intervention, outcomes, design – search terms.
3. **Search strategy:** Electronic databases & hand search of journals, books, conference papers, reference lists.
4. **Process:** Initial list of 850 papers, scan of abstracts, reading of sub-set of full papers.
5. **Result:** Five papers that met inclusion criteria.

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## Literature review – key findings

- Tøssebro (1995); Stancliffe (1997); Stancliffe, Abery, & Smith (2000); Saloviita & Aberg (2000); Stancliffe (2007).
- Major emphasis on smaller size units.
- Vast majority of studies were of congregate arrangements.
- Generally better outcomes in individual/small size than congregate arrangements.
- Separate search on control/governance indicated better outcomes for individual/family control of service arrangements.

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## Case studies

- Six individuals identified through survey of local networks:
  1. Woman – mid-30s – own unit – live-in personal assistants.
  2. Woman – 50s – host family – rural area.
  3. Man – mid-40s – host family – rural area.
  4. Man – 20s – returned to parent home from group home.
  5. Woman – 20s – own villa – lives alone – drop-in support.
  6. Man – mid 30s – rents with 2 non-disabled co-tenants.
- Visits & observation/interviews with person, family, agency management, & carers over 12 months.

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## Stakeholder surveys

- Stakeholder groups (19 responded from 23): authorities (4/6), policy makers (6/6), service providers (6/7), families (3/4).
- Round One: meaning, characteristics, & issues with PRS.
- Round Two: themes rated for relevance with comments
- Round three: prioritising final themes list & attributes.

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## Focus group

- Arranged through a local advocacy group.
- 15 members of self advocacy group participated.
- Most lived in own home with various forms of support.

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## Methods for identification of themes

1. Triangulation of data sources, methods, & analysis.
2. Themes drawn separately from each of 4 methods independently by 3 researchers.
3. Conciliation & consensus of themes for each method consecutively.
4. Refined, draft list of themes & descriptors.

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## Methods for identification of themes

5. Member checking through stakeholder groups.
6. Final list of themes/clusters & attributes sent to stakeholder group for ranking in order of importance.

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## Themes ranked in order of importance

1. One person at a time
2. Leadership
3. My home
4. Support
5. Control
6. Thriving
7. Planning
8. Assumptions
9. Social inclusion

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## Development of an evaluation framework & instrument: Multi Attribute Utility (MAU)

MAU is a method to take account of multiple perspectives, i.e., the views of different stakeholders about PRS.

- The method identifies CLUSTERS/THEMES & the ATTRIBUTES/SUBTHEMES that form part of a cluster.
- Weights are assigned to:
  - individual clusters & attributes to reflect the degree of importance of each in the context of all clusters;
  - each set of attributes within each cluster.

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## Structure of a rating scale

1. THEME/CLUSTER
  - a. Brief description
    - i. First attribute description
      - Indicators – data collection via observation, interviews, documentation
      - Rating scale 1-5
        - Final score: scale score X attribute weight X cluster weight
    - ii. Second attribute description, etc.

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## Example of a rating - #1

1. THEME/CLUSTER: **One person at a time.**
  - a. **Brief description:** PRS means an intentional avoidance of grouping people with a disability. It fosters unique arrangements focussing on each person with a disability with his/her 'voice' being central. The arrangements are person-centred, based on personal knowledge of the person with a disability and are guided by those who know the person well.

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## Example of a rating - #1

- i. **First attribute description:** The person's 'voice' is central to the arrangement.
- ii. **Second attribute description:** The arrangement is designed around the unique identity of one person.
- iii. **Third attribute description:** There is an intentional avoidance of grouping people with disabilities.

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## Example of a rating - #5

5. THEME/CLUSTER: **Control**
  - a. **Brief description:** The person with a disability & the others who are close to him/her, particularly family members, have considerable influence in the arrangement. This may include governance by the person or family as appropriate. This influence occurs throughout all stages of the planning, development, & implementation of the PRS arrangement.

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## Example of a rating - #5

- i. **First attribute description:** The person &/or those in close relationships, determines his/her own lifestyle & personal affairs.
- ii. **Second attribute description:** Self-determination for the person is central to the arrangement.
- iii. **Third attribute description:** The person &/or those in close relationships, has considerable influence in governance of the arrangement.

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## Example of a rating - #8

8. THEME/CLUSTER: **Assumptions**
  - a. **Brief description:** PRS arrangements are underpinned by a set of assumptions that reflect high expectations for the person with a disability.

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### Example of a rating - #8

- i. **First attribute description:** People with complex & high support needs can live in their own home.
- ii. **Second attribute description:** It is not necessary for people with a disability to live together.
- iii. **Third attribute description:** PRS can occur without a person having to live independently or alone.

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### Example of a rating - #9

9. THEME/CLUSTER: **Social inclusion**
  - a. **Brief description:** PRS arrangements build wider community acceptance by avoiding congregation & segregation of the person with a disability. There is a focus on reduced isolation with emphasis on participation & engagement.

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### Example of a rating - #9

- i. **First attribute description:** Some relationships are close & enduring.
- ii. **Second attribute description:** The person with a disability has a rich & varied social network.
- iii. **Third attribute description:** There are opportunities for participation in a variety of community settings.

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### Next Step

- January 2009, developing the indicators for each attribute:
  - Sources of data
  - Methods of data collection
  - Questions/statements that operationalise each attribute

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### Piloting the instrument

- Small teams.
- Evaluation of both policies & examples of supported living arrangements.
- Sources of information: observation, interviews, documentation.
- Tightening up the instrument.
- Examining some of its properties including educative.

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