Curtin University

Individual supported living for people with disabilities in Australia: Policies, practices, and quality

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National Institute for Intellectual Disability, Trinity College, Dublin, 17th November, 2011

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Curtin Health Innovation Research Institute**

Some Research Work of the CRDS

1. Evaluating a community participation program for young people with high support needs.
2. Policies & practices for people with dual diagnosis of acquired brain injury & mental illness.
3. Economic & social outcomes for people with intellectual disability who complete traineeships & apprenticeships.
4. Person-centred policies & practices in services for people with disabilities, elderly people, & people with mental health issues.
5. Health disparities for adults with intellectual disability in WA.
6. Experiences of people with disability in hospitals & primary health care.
7. Evaluating quality in individual supported living arrangements for people with intellectual disabilities.

Policy Relevance for Person-Centred Development in Australia

- Australia National Disability Strategy (Council Of Australian Governments, 2010)

  "A sustainable disability support system which is person-centred & self-directed, maximising opportunities for independence & participation in the economic, social & cultural life of the community."

- WA Mental Health Commission (2010)

  "The level of service provided will be based on the needs, goals & strengths of the individual."

  A consumer-focused mental health system in which consumers: "..control their own mental health care & (are) directly involve(d) in service planning and delivery."

Policy Relevance for Person-Centred Development in Australia

▸ <u>Department of Health & Ageing</u> (2010). Introduced:

"…consumer-directed (aged) care (which) allows people to have greater control over their own lives by allowing them, to the extent that they are capable & wish to do so, to make choices about the types of care services they access & the delivery of those services, including who will deliver the services & when."

Policy Relevance for Person-Centred Development in Australia

▸ <u>Putting the public first</u> (Oct. 2009) Western Australian Economic Audit Committee Recommendation 11:

"Progressively implement pilots of self-directed service design & delivery…(by)…adapting individualised funding approaches used in the disability service sector to areas such as mental health, aged care, long-term health conditions, palliative care, job training & homelessness…"

Policy Relevance for Person-Centred Development in Ireland

▸ Report of the Disability Policy Review (2011) – Office for Disability & Mental Health

  ◦ "Full inclusion & self determination for people with disabilities."

  ◦ "Reframing provision from disability services to individualised support."
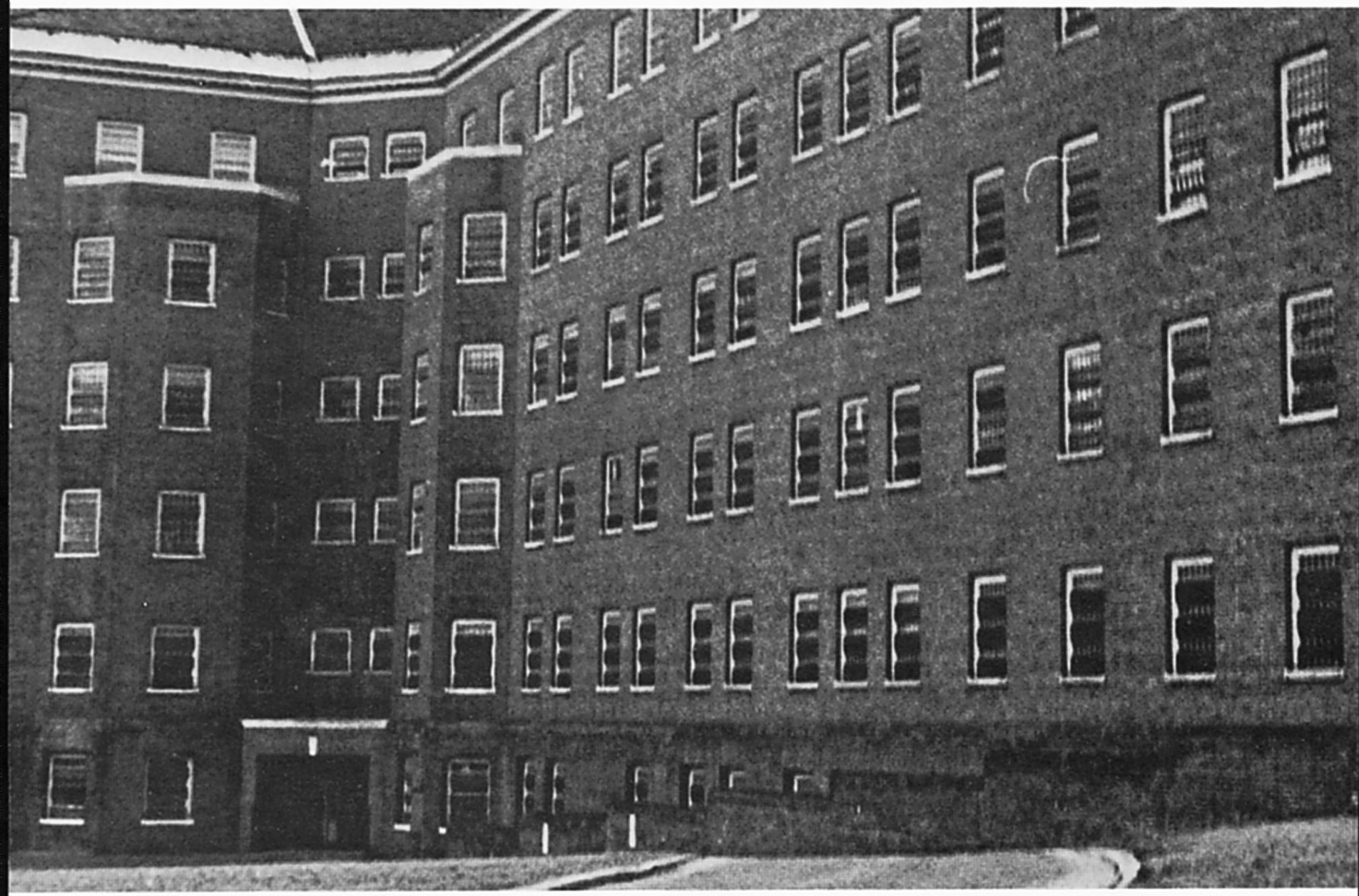
  ◦ Person-centred support
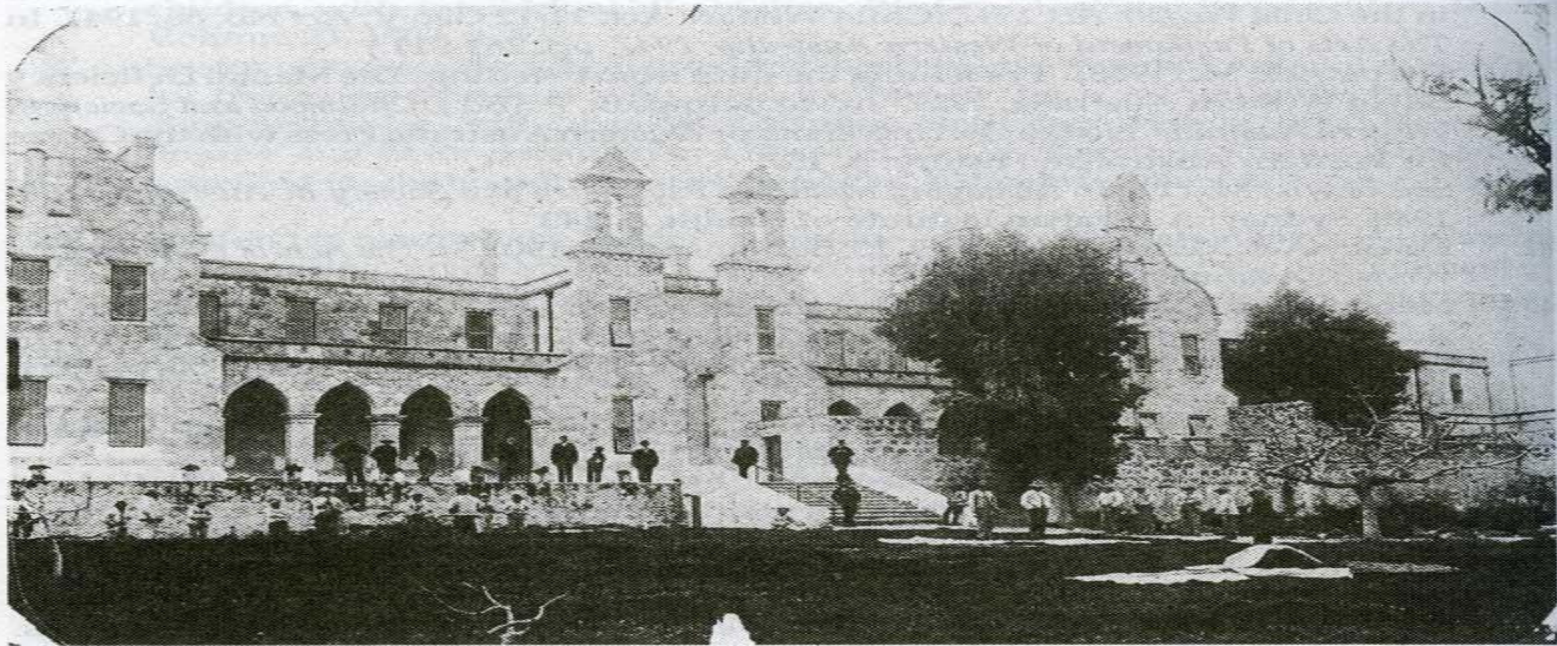
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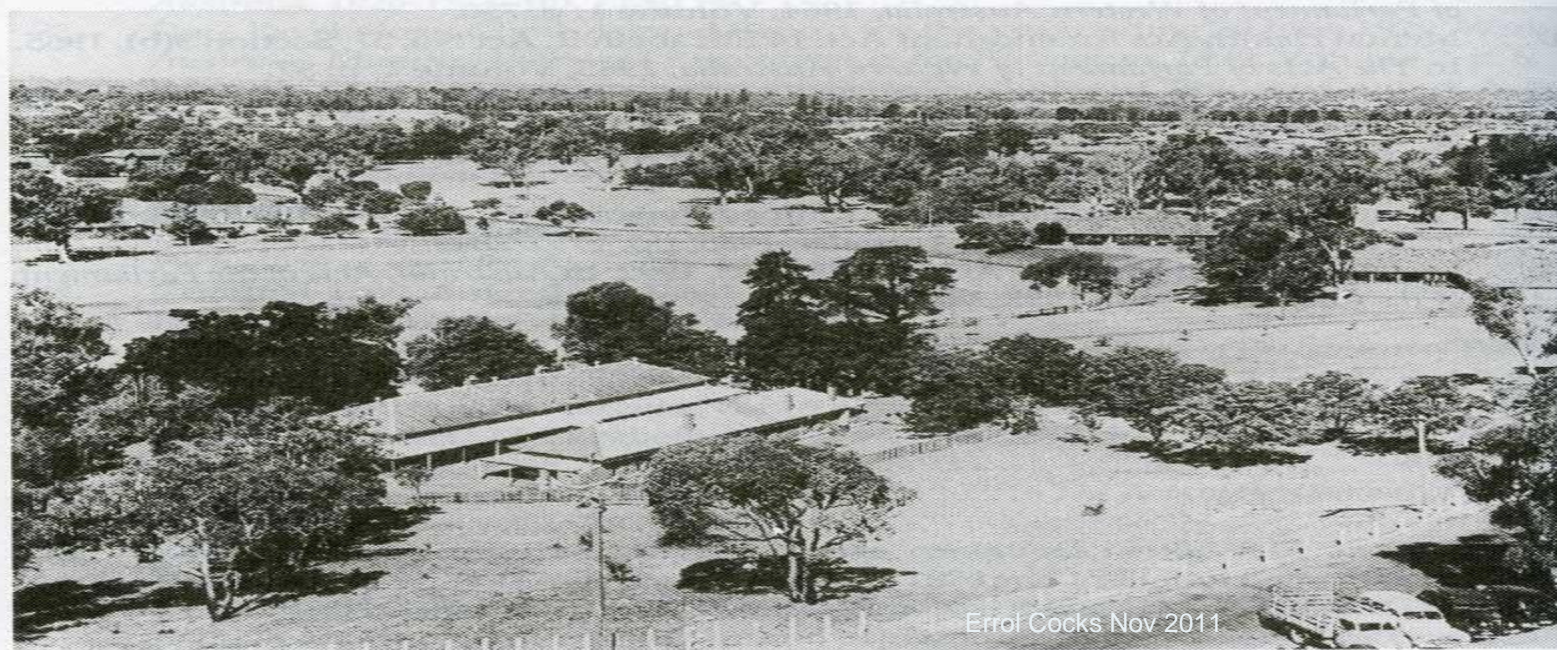
A Photographic Essay on Mental Retardation
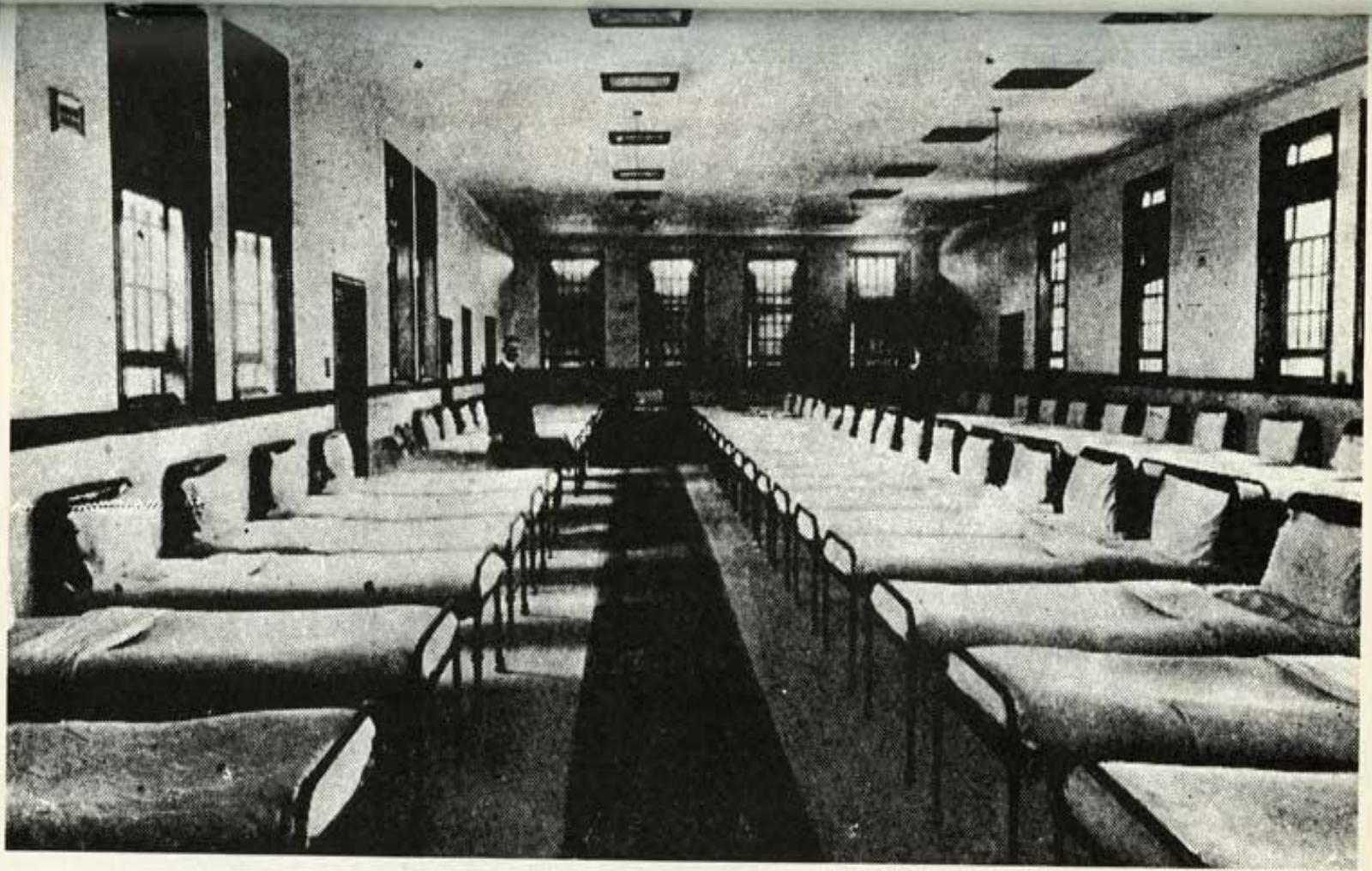
BURTON BLATT   FRED KAPLAN

1 *Fremantle Asylum showing inmates and warders, 1897. Courtesy Battye Library, Perth.*

Male Dormitory, Claremont, 1912 *Courtesy Western Mail*

From Large Institutions to…

- Smaller institutions.
- Hostels.
- Group homes.
- Cluster housing.

- All are characterised by congregate care/living.
- Congregated on specific "shared" criteria, i.e., DISABILITY.
- Separated from various aspects of life.

Personal Involvements

- Movement of children & adults from Swanbourne Hospital in Western Australia (1970–85) to:
  - Pyrton Training Centre (160 residents)
  - Hostels (18–40 residents)
- Victoria, Australia: St Nicholas Hospital closure (120 residents) (1981)
  - Anne MacDonald & Rosemary Crossley ("Annie's Coming Out")
- Nulsen Haven Association previously Mentally Incurable Children's Assoc. (40 residents)

- Achieving better lives? Closing institutions?

Snapshot of Disability in Australia in 2009–10 (ABS & AIHW)

- Prevalence 18.5% (4m).
- 295,000 Australians receive specialist disability services provided by all Australian governments.
- 28% have intellectual disability.
- 2,300 agencies via 11,900 service "outlets" – 80% NGOs, most not-for-profit.
- $5.8b on specialist services by Commonwealth & State Governments.
- 36% increase in expenditure 2005–2010 & 50% increase in service users.
- $16b on income support (Disability Support Pensions by C'W)
- Not inclusive of aged services, health, education, and transport.

Accommodation Support

- Enables people to remain in existing/move to more appropriate accommodation, e.g., attendant/personal care, in-home support. *Independent of housing support.

- 40,000 service users.

- 4,700 "outlets" (37%).

- $2.6b (45%) of expenditure.

Community Support

- Enables people to live in non-institutional settings, e.g., therapy, early intervention, behavioural intervention, counselling, *local coordination*.

- 128,000 service users.

- 1,585 "outlets".

- $832m expenditure (14%)

Living Support

▸ 40,000 persons received Accommodation Support

◦ Institutional (over 7 people in large-small institutions & hostels): 4,174 (11%)

◦ Group homes (<7 people): 13, 435 (34%)

◦ Other (individuals) (e.g., attendant care, in-home, emergency): 23,024 (57%)

Living Support (295 service users)

Living alone   65,000 (19%)
   Accommodation support   7,500
   Community support   11,000

With Family   147,000 (48%)
   Accommodation support   8,600
   Community support   90,000

Other   78,000 (29%)
   Accommodation support   22,000
   Community support   20,000

Pathways to Individual Supported Living in Western Australia

1. Mental Deficiency Division (c1969); Authority for Intellectually Handicapped Persons (AIH) (c1980); and Disability Services Commission (DSC) (c1986)
2. Local Area Coordination and Community Living Associations (c1990)
3. Person centred principles
4. Combined Access Process (c2000)
5. Community Living Initiative (c2008)
6. Individual Supported Living

1. Creating a Dedicated Government Agency (AIHP/DSC) (1980/1986)

- Based on a social model of disability rather than a clinical/medical model.

- Strong representation by key stakeholders in governance.

- Minimising direct service provision.

- Focusing on policy development and funding of services in the non-government sector.

2. Local Area Coordination (LAC)/Community Living Associations (CLA) (1990)

- Strong values base around family support.

- Working directly with families.

- Local focus.

- Advocacy role.

- Community development role (CLAs).

- "Discretionary funding".

- Supporting families to access funding/services across departments.

3. Person-Centred Principles

- Key policy development in disability, mental health (WA Mental Health Commission), and aged services.

- A focus on respecting the PERSON that emphasises:
  1. Providing support to the individual that closely reflects the person's needs and preferences.

  2. Responding to the person by acknowledging and working through his/her strengths.

  3. Enabling the person and/or those close to the person to have a strong influence over that support.

  4. Promoting informal relationships as much as possible.

4. Combined Access Process (CAP) (c2000)

- Three times a year individuals/families apply for individualised funding for 3 services – based on critical need:
  ◦ Accommodation support
  ◦ Intensive family support
  ◦ Alternatives to employment

- Highly competitive.

- Decisions re funding made by the Independent Priority Assessment Panel

CAP 2010/2011 Fiscal Year

	Applied	Success	$s
Accom. Support	733	289	$26.4m
Intensive Family Support	251	119	$4m
Alternatives to Employment	323	95	$1.9m

5. Community Living Initiative (2008)

1. Positive planning, not critical need.

2. Promotes flexible, person-centred, innovative community-living approaches.

3. Based on a "community living plan".

4. Supported by LACs and "Community & Family Living Facilitators".

5. $20,000 annual recurrent funding.

6. New category for homeshare flatmates.

7. 118 funded plans to date.

6. Individual Supported Living (ISL) Project: Purposes

- To explore the nature, purposes & outcomes of individual supported living (ISL) for adults with developmental disabilities.

- To develop a quality framework for ISL (Stage One, 2007-2009).

- To develop & pilot an instrument for evaluating the *fidelity* of ISL arrangements (Stage Two, 2010-2011).

- To examine the relationship between the quality of ISL arrangements & outcomes for persons with disabilities (Stage Three, 2012-2013).

Methodologies

Stage One

1. Literature review.
2. Following six ISL arrangements over two years.
3. Surveys of key stakeholders (Delphi method).
4. Focus groups.

Outcome

Descriptive framework of nine Themes & 28 Attributes.

Stage Two

5. Development of attribute *indicators* & *evidence*.
6. Two sets of reviews of five ISL arrangements with modifications of the instrument.

Outcome

Evaluation instrument of 8 Themes, 21 Attributes & Manual.

The Literature

Empirical literature
- 784 articles published from 1982 reviewed.

- 104 abstracts selected.

- 5 papers met criteria of focus on ISL.

- Most focused on congregate arrangements, comparing sizes, movement from institutions.

Descriptive literature
- Concept of "home".

- Person centred principles.

- Self-determination.

- Community living.

Stories of 6 adults with developmental disability

Rob is a man in his late 30s who rents an inner-city townhouse along with two non-disabled co-tenants, Ben and Laura. 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.

Andree is a woman in her late 30s who leases a *HomesWest* unit in her own name in the northern suburbs of Perth. A non-profit housing service agency provides assistance in regard to matters concerning the lease. Andree's support is arranged by *My Place*, a non-government, for-profit organization.

Stories of 6 adults with developmental disability

- Geoff is in his late forties and has lived with Jackie, and her husband Brad for about six years in a "host family" arrangement, in their home in a large town in the south of WA.

- 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. ." 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.

Stories of 6 adults with developmental disability

LUKE'S ARRANGEMENT

- Lisa is a woman in her mid-20s who lives alone in her own villa in the northern suburbs of Perth. Lisa owns the villa, an arrangement set up by members of her family on the passing of her mother. This support is arranged by *Baptistcare*, a non-government, not-for-profit service provider.

- Luke is a young man in his early 20s who currently lives in the family home with his parents. Although Luke is living at home, his 'arrangement' was included in the PRS project due to his parents' efforts over several years to plan and develop an individualised living arrangement for him.

Assessing the Quality of Individual Supported Living Arrangements

- 1. LEADERSHIP
  - Clear vision & strong ideas
  - Key people
- 2. MY HOME
  - Security of tenure
  - Doing things at home
  - Reflection of person's identity
- 3. ONE PERSON AT A TIME
  - Developed around the person
  - No grouping of disability
- 4. PLANNING
  - Focused on the person
  - Involving people who are close
  - Focus on the future

Assessing the Quality of Individual Supported Living Arrangements

- **5. CONTROL**
  - Control over life by the person &/or those who are close
  - Self-determination is central
  - Control over arrangement by person &/or those who are close
- **6. SUPPORT**
  - Flexible & responsive
  - Variety of supports including informal
- **7. THRIVING**
  - Better lifestyle & wellbeing
  - Many opportunities for development
- **8. SOCIAL INCLUSION**
  - Close & lasting relationships
  - Rich social network
  - Participating in the community

Assessing Attributes

1. Reviews can be internal or external.

2. They can apply to existing or planned arrangements.

3. Persons with disabilities & families can carry out reviews.

4. Attributes are scored on a 5-point scale from (1) the Attribute not being addressed, to (5) the Attribute is optimal.

5. The framework has potential for learning through workshops & training evaluations.

Third Stage (2012-2013)

▸ Examining the relationship between Attributes and outcomes:
  ◦ Quality of life

  ◦ Social participation

  ◦ Access to, & cost of, support services

  ◦ Pathways to ISL

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2. Parsons, L., Cocks, E., & Williamson, M. (2009). *A review of best practice in individual needs planning*. CRDS.

3. Cocks, E., & Boaden, R. (2011). A quality framework for personalised residential supports for adults with developmental disabilities. *Journal of Intellectual Disability Research*, 55(8), 720-731.

CRDS link: *http://otsw.curtin.edu.au/research/*