Measuring Quality of Individual Supported Living (ISL) For Adults with Intellectual & Developmental Disabilities

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Article 19 – “…full inclusion and participation in the community…”

“Persons with disabilities have:

- the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.

- access to a range of in-home residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.”
Where do Australians with Disabilities Live?

Ref. Disability support services provided under the National Disability Agreement (NDA) 2015-16, AIHW Bulletin 140, June 2017

1. 40,000 people served by NDA in 7,474 housing “outlets” in non-govt sector (nb no data from ACT Govt provided)

2. 2013-16 9,586 people transitioned to the NDIS

3. Over $4b a year spent on “ACCOMODATION SUPPORT” for children and adults with disabilities

4. Expenditure on “COMMUNITY SUPPORT” to enable living in “non-institutional” settings was $1.4b for about 150,000 people – big increase in numbers (+10%) & funding (+27%) over past 5 years.

5. About 53% of persons with disabilities lived with their family, 24% lived with “others”, & 23% lived alone

5. Over 20,000 persons lived in congregate care:
   ◦ 1,200 in small/large institutions & hostels
   ◦ 20,000 in group homes.
Principles & Assumptions of Individual Supported Living (ISL)  (Cocks & Boaden, 2010)

1. All adults with disabilities can live in an ISL arrangement if they are provided with appropriate supports.

2. Persons with disabilities do not have to live together.

3. Persons with disabilities in an ISL arrangement do not have to live alone or independently.

4. The crucial element in ISL is the provision of appropriate support.

**ISL is not the same as “independent living”**.
The ISL Studies

1. Three project stages began in 2007 with 2 small grants from Lotterywest to develop a Manual & processes to measure quality of ISL arrangements in WA.

2. In the third stage, Curtin University received an ARC grant in partnership with Sydney & Melbourne Universities in 2014. This stage is completed.

3. A total of 130 reviews of ISL arrangements took place in WA, Victoria, NSW & the ACT.

4. A fourth project has been submitted to the ARC.
Small (3-5) trained team members, led by team leaders, visited homes & interviewed people with disabilities, their families & support staff, asking:

- How people had set up their home – Pathways interviews
- What people liked best about their home
- What could be better in their home
- The supports to enable people to stay in their home

We used measures of social participation, QoL, support need, the ISL Manual.
The people with disabilities we spoke with

• 51.5% females, 48.5% males.
• Average age 43 years, range 22-63 years.

• Of 130 reviews, 75 people (58%) lived alone in their home.

• One third had some paid work; similar number went to day centres or alternatives to employment.

• People had lived in their home between 1 month and 30 years - average 8.6 years.

• Nearly half had come from their family home to their own home.

• Self-reported level of support need was:
  15% HIGH
  40% MODERATE
  45% LOW
Some ways ISL arrangements were set up

Some arrangements were established 20+ years ago, others more recently.

1. Living alone - 58% - often occurs following living with others.

2. Co-resident - 17% - co-resident shares home, may contribute to costs, may provide some support, often students.

3. Host family - 5% - family provides accommodation & support for PWD in their own home.

4. Shared home/relationship - 18% - person with disability may share home with friends, relatives, partners…
ISL MANUAL: 8 THEMES & 21 ATTRIBUTES

A. LEADERSHIP
   1. Clear vision & strong ideas
   2. Key people involved

B. MY HOME
   3. Security of tenure
   4. Doing ordinary things at home
   5. Reflecting the person’s identity

C. ONE PERSON AT A TIME
   6. Arrangement is developed around the person
   7. No grouping of people with disability

D. PLANNING
   8. Focused on the person
   9. Involving people close to the person
  10. Focusing on the future
# ISL MANUAL: 8 THEMES & 21 ATTRIBUTES

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<tr>
<th>E. CONTROL</th>
<th>G. THRIVING</th>
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<tr>
<td>11. Control over life by person &amp;/or those who are close</td>
<td>16. Better lifestyle &amp; wellbeing</td>
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<td>12. Self determination is central</td>
<td>17. The person has VALUED ROLES</td>
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<td>13. Control over the arrangement</td>
<td>18. Many opportunities for development</td>
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<th>F. SUPPORT</th>
<th>H. SOCIAL INCLUSION</th>
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<td>15. Variety of supports including INFORMAL (unpaid)</td>
<td>20. Rich social network</td>
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<td>21. Participating in the community</td>
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Outcomes of the Reviews

**Review Scores**
- Actual range 47-97 - Possible range 21-105
- Average total score 71.6 – 68% of highest possible score

**Highest rated Themes**
- One Person at a Time
- My Home

**Lowest rated Themes**
- Social inclusion
- Planning

**Supports – Average hours/week**
- **Paid**: 29.4hrs – range 0-306
- **Unpaid**: 10.2hrs – range 0-90
Key Supports for ISL Arrangements

- Support hours came from both paid/formal & unpaid/informal support people.

- About 75% of arrangements got support from disability NGOs, especially the growing number of ISL specialist NGOs.

- Family members frequently played major roles in establishing ISL arrangements & providing continuing support.

- Financial support for arrangements came from families (around 30%) and Government funding (around 55%).

- Disability Support Pension was a key source of support.
Conclusions

1. Article 19 of the UNCRPD is explicit & very challenging.
2. Congregate options remain very strong in Australia.
3. “Independent living” & “Individual Supported Living” are different.
4. ISL arrangements are varied, sustainable, & successful across the support needs spectrum.
5. Social inclusion & participation, and planning (particularly longer-term planning) remain problematic in ISL arrangements.
6. Families played key roles & the mix of informal & formal involvement were very effective.
7. ISL principles & practices should be widely known & integral to disability policy & practice.
Next ISL Project

- Applied for a second grant from the Australian Research Council

- The new project will:
  - Focus on 60 adults with ID/DD who live in group homes or still live in the family home.
  - We are partnered with about 9 NGOs that provide support in group &/or family homes.
  - We will provide a range of training & evaluation activities over 3 years to influence changes in NGO policies & family views towards ISL.
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Partner organisations:
- Avivo Live Life (previously Perth Home Care Services)
- Integrated Living Australia
- Achieve Australia
- National Disability Services
- Inclusion Melbourne
- My Place Foundation
REFERENCES


