LA TROBE
UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE

2024 RESEARCH SEMINAR SERIES

13 March

LA TROBE
UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE

A flawed model or weak implementation? A critical review of the Disability Royal Commission's approach to group homes

Professor Christine Bigby

Background – Disability Royal Commission. April 2019 - Sept 2023

DRC's Brief

- experiences and causes of harm - prevention and promoting a more inclusive society

- exploring quality services lead to a good life as well as poor services and bad things that happen

- broad focus – across the life course – across life domains – across service sectors – dedifferentiated – human rights approach

Enquiry and evidence

- Private sessions - 1,785

- Hearings - 33 - 18 Hearing reports

- Submissions – 7,944

- Commissioned research reports – 27 – Issues papers – 14

- Final report 12 Volumes

- Recommendations - 222

- Cost – $650m

LA TROBE UNIVERSITY

Focus on group homes

Aim

- critique the Commission's stance, processes, and recommendations, and where relevant, identify the links between its recommendations and those of the NDIS Review

Method

Review:

- DRC's approach to group homes

- questions asked

- evidence heard

- conclusions and recommendations

Focus

- people with intellectual disabilities, group homes and everyday life (not broader regulation or housing) [more than half of people in group homes are people with intellectual disabilities - many transferred to NDIS from state systems]

LA TROBE UNIVERSITY

DRC's approach to group homes

- Prioritised - significance of home as place to feel safe
- Recognised - barriers in engaging with the Commission – engaged advocacy groups
- Private testimonies vol. 1 approx. 204 people
- Issues paper - 9 pages cursory overview - report summarising responses
- Submissions – statements from witnesses
- Dedicated hearing **3** held 2-6 December 2019 in Melbourne - 29 witnesses
- Report of hearing
- Featured in other hearing re disability services and case studies, 13,14, 20, 26, 32
- Two primary themes
  - model itself – is it fundamentally flawed - from the outset – viability of the model and alternatives
  - way the model is implemented – ways to improve it –culture, staff skills, performance, monitoring

LA TROBE
UNIVERSITY

Evidence

- Many different perspectives – people themselves, family members, service providers, advocates, academics, govt agencies
- Many submissions and evidence drew on research
- Unlike other areas DRC did not commission any research on group homes

Most evidence – descriptive negative experiences and negative impact of various aspects

- Graphic and harrowing accounts

The home accommodated five residents including Cynthia, all non-verbal...other residents, who didn't get regular visitors, still in their pyjamas at 4:30 pm and never going out...Bruising on Cynthia's back and arms continued. Ellie said they were often unexplained or the explanations were implausible...staff forcing Cynthia to sit still against the wall for long periods. They would tape her fingers together to stop her movements and would tie her hands to the legs of the chair or behind her back...The family also learned that some staff were stealing the clothes and food Ellie bought for Cynthia. (CoA, 2023, Vol.1, p. 40)

LA TROBE UNIVERSITY

Evidence – variability over time as staff and providers changed

When the government managed the home, the families of residents were consulted when new staff were employed. …The staff that were there were absolutely fabulous…Marissa said family members helped choose new staff. If we really want people like [Brantley] … to have real say, we have to be involved in that process… the new service provider didn't seem to understand why that was important. (CoA, 2023, Vol.1, p. 410)

Evidence - problems of implementation

- part of broader systemic issues across disability services

  …violence and abuse of people with disabilities is widespread and is not confined to group homes… the problem with group homes is the 'one size fits all' approach which doesn't give people choice and control over their lives and becomes a source of disempowerment and frustration… this approach is the function of **cultural, governance and workforce issues**. (Hearing Report 3, 2020, Sept. 30, p.48)

- Failure of organisations to deliver services that ensure safety and quality support
  - Inadequacies of – staff practice, supervision, training, leadership, culture
- Wider system issues – resource scarcity, crisis placements, ill matched households

LA TROBE UNIVERSITY

Evidence – isolation of people living in group homes

- Limited social networks or access to advocacy
- Create living situations where people are more vulnerable to abuse
- Risks compounded by failure of organisations to act on complaints or investigate

Evidence - flawed model – beyond remediation – no place in disability services system

- theoretical propositions rather than empirical evidence
- segregated – impairment determines where people live – lack of alternatives
- closed environments – restricted entry and exit – service provider relationships dominate
- institutional – perceptions of self advocates and human rights lawyers

    sharing of assistants - no say who provides assistance - isolation from community - no control of day-to-day decisions - no choice who live with - rigid routines - identical activities for the group - paternalistic approach - supervision of living arrangements - disproportion in the number of persons with disability.

- [characterised in the institutional literature as: rigid routines, block treatment, depersonalization, social distance]

LA TROBE UNIVERSITY

Evidence about best practice

- Very little – despite declared intention to explore
- Low profile in hearings and reports – despite references to literature
- Good staff and management mentioned fleetingly amongst poorer ones

Evidence about alternatives to group homes

- Positive examples of people leaving group homes and alternatives models of housing and support
- Most were people with lower support needs and drop in support not 24 hour
- Most had been designed for people with acquired disabilities
- Some such as ILO required significant family support – low take up
- No examples people with severe or profound intellectual disabilities

  "There are limited, genuinely inclusive housing options for people with disability, particularly those with high support needs (CoA, 2023, Vol. 7, p. 629) [though later contradicted]

LA TROBE UNIVERSITY

DRC's recommendations

- Chair - both weak implementation and the inherent flaws of the group model

  …Sweeping changes are needed. Hence the many recommendations for reform …But perhaps the recommendation of greatest long-term significance is for improved access to alternative housing options. (CoA, 2023, Vol. 7, p. 649)

- Reform - practice

  - NDIS Quality and Safeguards Commission's Action plan from Own Motion Enquiry (2023) - Active Support and Practice Leadership - new standards

  - Separation of housing providers from support providers,

  - Strengthen practice models such as Active Support to create opportunities for greater social interaction and community participation and inclusion (see CoA, 2023, Rec. 7.41).

- Develop alternatives to group homes

  - Improve access to alternative housing options - expand NDIA demonstration projects, policy unit to guide development of innovative models, market research, and reform NDIS funding.

  - Access to advice, advocacy, and support to enable people to explore, decide about, and take up alternatives (see CoA, 2023, Rec. 7.42)

LA TROBE
UNIVERSITY

DRC's recommendations – split views

- Close all group homes within 15 years (4 Commissioners)
- Close within a generation (1 Commissioner)
- Retain among other alternatives –and demand will dwindle or fade away (Chair)
- All agreed priority making alternatives available

- Very little media attention compared to recommendations about closure of special schools and sheltered workshops

Critique - Uncertainty about alternatives to group homes

- Reflected existing policy directions – more powerfully stated and quicker pace

- Reflected commitment to human rights approach

- May be a good thing - how paradigmatic change happens

- From a pragmatic realist perspective- puzzling and problematic
    - Leap of faith into the unknown driven by human rights theory
    - Particularly in respect of people with more severe intellectual disabilities.
    - Lack of evidence and clarity about the alternatives to group homes
    - No clarity about what were variously named, 'inclusive housing', 'alternative housing', and 'innovative housing' options that would replace group homes
    - Australia's history of failed policy ambitions and poor implementation does not bode well for the rigorous design, evidence building, and evaluation processes the Commission suggested should be followed in developing alternative housing options

LA TROBE UNIVERSITY

Assumptions and uncertainty about alternatives to group homes

- That alternatives to group homes deliver better outcomes – by no means certain

- Danger of losing the better ones

- Earlier empirical evidence from research on new models – shows variability in each model

- **The best but not all instances of new models surpasses the best outcomes for people in earlier models** (Mansell, 2006).

- Best small group homes better than large institutions

- But worst small group homes similar or worse than institutions

- Risks empirically - some alternatives may not lead to better outcomes homes also found in human rights theory.

- Possibility of institutional features in all forms of accommodation regardless of size

  "the need to be prudent in the way support services are provided to people with disability because institutionalization can also happen in an individuals' own home" (Committee on the Rights of Persons with Disabilities, 2017).

- Examples of the situation described in the General Comment have been observed in the ongoing study of supported accommodation for people with intellectual disabilities

Little attention to support practice in alternative models

- Support practice and other disability services critical to avoiding institutional features recurring.

- Development and implementation of alternative housing models must give attention to support (albeit delivered separately by a different provider)

- Despite the mention of "housing options and support" in the intro paragraph discussion exclusively on housing on (part of Chapter 9, Volume. 7, rec 4.42).

- No consideration of how the practice reforms explained in the Own Motion Enquiry were applicable or may need to be adapted to support in new housing models (CoA, 2023, Rec. 7.41) .

- Nor how safeguards might differ in these alterative models.

- Could read into this assumptions that new models would solve all the problems of group homes, and recommendations about reforms to practice would be redundant or superseded as group homes were replaced.

- Dangers of repeating early days of the NDIS, housing models have taken precedence in policy and service development, and practice within them neglected

LA TROBE
UNIVERSITY

NDIS review holds more promise re importance of support

- NDIS Review *housing and 24/7 living supports,* explicit attention to the organisation of support in the smaller and alternative models of housing.

- Proposed when accommodation is shared specific attention must be given to the organisation and management of shared supports as well as exploring opportunities for bundling supports around each individual be explored (CoA, 2023, Dec.).

- Proposed increased focus on promoting safe and effective support for participants with 24/7 support needs.

- A new specific Practice Standard for 24/7 living supports should be developed. (p. 149)

LA TROBE
UNIVERSITY

Critique – dangers of demonisation

- Potentially negative consequences of signalling group homes a flawed model
  - Low priority to funding reforms as little longevity
  - Detract energy of organisations from improving existing homes, particularly those that are keen to be seen as innovators and not associated with outdated models.
- Could be avoided by linking the significance and likely similarities between good practice and leadership in group homes and alternative housing models
- Families of people with more severe intellectual disabilities in group homes concerned about the quality of group homes, particularly staff turnover, but reluctant to consider moving, thinking it would be unsettling and may not improve their person's quality of life (Bigby & Jackson, 2023).

LA TROBE
UNIVERSITY

Critique –Negative ideological stance

- From the outset DRC stance towards group homes tilted towards the negative.
- 'explore negative assertions about group homes as places conducive to violence, neglect, abuse, and exploitation'
- Stereotypical and disparaging labels applied unquestionably to group homes
- Prominence to interpretations of the UNCRPD casting group homes as inherently restrictive of human rights and in contravention of Article 19;
- Assertions about the institutional nature of group homes were not interrogated to test which if any of the 8 characteristics (CoA, 2019, Exhibit 3-033) found in Australian group
- Opportunities missed for appreciative approach
- Much might have been learned from the exceptions, such as under what conditions do some group homes work well and why?

LA TROBE
UNIVERSITY

Neglected to ask why and embedded assumptions about workforce

- Did not seek out deeper or theoretical explanations for aspects of weak implementation;
  - why do frontline support staff have such low pay and standing in the disability system;
  - why are there no mandatory qualifications;
  - why are they not tertiary trained professionals;
  - why is there no required professional accreditation for managers of group homes services?
- The absence of a professional frontline workforce is not a *sine qua non* of disability service systems
- Services systems in the Scandinavian countries and the Netherlands have 3 year university trained frontline staff.
- Commissioned research would have helped in analysing and finding solutions to some of the underlying reasons for the implementation problems identified in group homes and the wider disability services system in Australia.

LA TROBE UNIVERSITY

Clarity about meaning of 'group home' and size

- DRC used 'group home' and 'supported accommodation' interchangeably
- housing and support with a specific number of residents (usually four to six),
- with an indeterminate number of residents
- only to housing for four to five people and not support (SDA definition)
- Clarity matters
  - Conceptually challenging for readers not familiar with Australian system
- Size matters
  - SDA rules group home 4 to 5 residents
  - 6 or larger now called legacy stock - hardly mentioned but closure already firm policy
- Assumptions about size - smaller is better **No empirical evidence beyond 6 or less better**
- Repeated in NDIS Review
  - Reduce size to 3 over time as vacancies arise – no new build 4 or more
  - Assume 1: 3 shared support – with exceptions
  - This is problematic for people who need support to be engaged and can't be left alone
  - For them 5: 2 might be preferable – need for empirical evidence

LA TROBE UNIVERSITY

Priority - long term group home residents and people with severe intellectual disabilities

- Priority 'people with more profound disability and or/ more complex needs' (p. 631).

- Despite dedifferentiated approach – many references to people with intellectual disabilities, and sub-groups those with more severe intellectual disabilities belong (non verbal – high support- ex institutional- need support with decision making)

- This group also featured in NDIS review as priority for supported decision making, specialist navigators, advocacy

- But in DRC
  - Little robust data about who lives in group homes – SDA doesn't equal SIL
  - More detailed data in NDIS review

- Good data imperative to retaining focus on priority group

LA TROBE
UNIVERSITY

Conclusions

- Terminology –dispense with term 'group homes' - lack of clarity, stereotyped, demonised
- DRC could have been more rigorous, more balanced, more clarity, made better use of research.
- DRC uncovered little about group homes that was not already in the literature
- DRC said it more powerfully to wider audience
- DRC and NDIS Review highlighted a need to prioritise change for previously neglected groups long-term residents of group homes, those without family, advocates, or community connections, and people with more profound disabilities or more complex needs, or both.
- Recommendations of the DRC and the NDIS Review together could be optimistic about the future for people currently in group homes and those for whom a group home might have been their only option at some point in their life.
- The challenge will be implementation and reaching the stage in Mansell's schema where all the outcomes of alternatives to group homes are better than all group homes

LA TROBE UNIVERSITY

Bigby, C. (2024). A flawed model or weak implementation? A critical review of the approach to group homes taken the Royal Commission on Violence, Abuse, Neglect and Exploitation of People with Disabilities. *Research and Practice in Intellectual and Developmental Disabilities*

https://doi.org/10.1080/23297018.2024.2316290

LA TROBE UNIVERSITY