ADVANCING SOCIAL WORK RESEARCH - IMPACT CASE STUDY

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Title of Case Study: UNDERSTANDING AND IMPROVING THE QUALITY OF GROUP HOME SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITIES.

1. CONTEXT

The policy shifts driven by normalisation in the early 1980s and subsequently disability rights prioritised social inclusion and community participation of people with intellectual disabilities. As institutions closed and community services developed, shared supported accommodation (group homes) accounted for the bulk of disability funding, and an estimated 17,000 people with intellectual disability now live in group homes. Despite the shift to community living and greater community presence, the evidence suggests that people with intellectual disabilities continue to be socially excluded, have low levels of participation in communities and often live in a distinct social space comprised of family, paid staff and other people with intellectual disabilities.

2. SUMMARY OF STUDY IMPACT

Professor Bigby’s program of research raised awareness about the poor and variable quality of life outcomes and staff practice in Australian group homes, particularly for people with more severe intellectual disabilities. Many organisations had adopted the internationally recognised best practice known as ‘Active Support’ and her research identified the difficulties embedding this practice in services. Prof Bigby’s team identified culture associated with better group homes and practice leadership and training as the keys to embedding Active Support in services. Working with nongovernment disability organisations, they used the research findings to drive changes to management of group homes and to design and disseminate open-access materials to make training and research findings more accessible across the disability sector. It has also been instrumental in shaping government regulatory and policy frameworks.

3. RESEARCH UNDERPINNING IMPACT

Professor Bigby leads several programs of research related to the effectiveness of practice and programs that support the social inclusion and rights of people with intellectual disabilities. This case study focusses on one of these that has investigated group homes for people with intellectual disabilities. It spans 19 years and comprises 7 broad project clusters.

1. Downsizing of Kew Cottages. 1999–2007. Evaluation of Kew Residential Services Community Relocation project, and 3 and 5 year follow up studies. Funded by the Victorian Department of Human Services. This early work focused on the move of 100 people resident in Kew Cottages to group homes in the community which were managed by nongovernment organisations. An initial study used pre and post measures to evaluate changes in the quality of life of residents. A further grant enabled a 3 and 5 year follow up of these people. Key findings were the overall improvement to quality of life but also the changing nature of group homes with house supervisor and staff turnover, the failure to develop social networks with community members and the high proportion of people who were ‘known well by no one’ which was the title of a well cited 2008 paper published by Prof Bigby.

2. Making Life Good in the Community. 2004–2008. An evaluation of the closure of Kew residential services. Funded by the Victorian Department of Human Services. Kew Cottages closed in 2008 and most of its residents moved to small group homes in the community managed by the Department of Human Services. This study included a large pre and post survey of residents moving from Kew Cottages into group homes and used ethnographic methods and action research to investigate staff practice and quality of life for residents in group homes. Additional funding was gained from the Helen McPherson Smith Trust to employ a co-researcher with intellectual disability for a sub study that looked at the homelessness of group homes. A reference group, which included senior staff involved in the closure, operational staff, an advocacy group representative and family members met regularly throughout the study. Eight research reports were produced in the Making Life Good series published the Department of Human Services, as well as peer reviewed papers and a book published by Jessica Kingsley. The findings pointed to the difficulties for staff in understanding and following through on policy intent around social inclusion and engagement in everyday activities, and the variable quality of life for residents. In depth exploration of key issues such as practice leadership, implementing active support, community participation and homelessness were undertaken.

3. Evaluating a reputed exemplary residential support service for people with severe intellectual disability and challenging behavior. 2008–2009. Funded by the Office of the Senior Practitioner in the Victorian Department of Human Services. This evaluation investigated the features of a service with a strong reputation for supporting two people with severe challenging behaviour, and developed a program logic to illustrate the practice components. It also led to a literature review project for the Office of the Senior Practitioner that examined the relationships between social inclusion and challenging behaviour.

4. Developing a theoretical framework for group home outcomes. 2009–2014. Funded by an ARC Discovery grant. This study aimed to develop a theoretical model that identified the most important factors influencing resident outcomes in group homes, and the interaction of these. Staff culture was the primary focus, including its impact and generative factors. Ethnographic data from 5 Making Life Good group homes, characterised as underperforming, were re-analysed with a cultural lens and further ethnographic work undertaken in 4 group homes identified as better performing homes. A comparative study of competencies of high performing house supervisors in Australia with those identified in a US study was conducted which illustrated the breadth of tasks and expectations of house supervisor, many of which were unrelated to ensuring and supervising staff practice. A series of published papers identified 5 common dimensions of culture in group homes, the differences, on each dimension, between under and better performing homes, and the generative factors for the enabling, motivating, respectful and cohesive culture found in better group homes. Further work included a realist review of factors influencing group home outcomes, and development of indicators of quality of life domains relevant to people with severe or profound intellectual disabilities. Subsequently, a PhD student, Humphries developed the Group Home Culture Scale from this qualitative culture work. Another PhD student, Quilliam, currently nearing completion has investigated the use of paperwork in group homes.

5. Longitudinal study of factors associated with good Active Support and quality of life outcomes in group homes. 2009–continuing. This study initially involved 5 Victorian disability service organisations, and expanded over time to include 14 organisations across 3 states. Funded from various sources (Office of the Senior Practitioner, ARC Linkage grant) with significant contributions from partner organisations, annual data on resident outcomes, quality of staff practice, practice leadership and other organisational factors were collected and shared with organisations. The final round of collection in 2018 will include culture using the GHCS. This will enable the association between culture, staff practice and resident outcomes to be measured quantitatively. An observed measure of practice leadership has been developed. Findings demonstrate the fragile nature of good practice and the variability of levels of Active Support over time, between and within organisations and services. Key findings are the association between good Active Support, strong practice leadership, training in Active Support, homogeneity of residents, and smaller size of the group home, with little apparent influence of other staff characteristics or organisational factors.

6. Uncovering staff culture of good quality supported accommodation for people with intellectual disabilities. 2015 – continuing. Funded by National Institute for Health Research School for Social Care Research, UK. This study is still in progress and aimed to investigate the culture group homes that have demonstrable good outcomes and high levels of Active Support.
7. Developing and maintaining person centred active support: A demonstration project in supported accommodation for people with neurotrauma. 2014-2017. Funded by the Institute of Safety Compensation and Research Recovery in Victoria. This study explored the feasibility of introducing Active Support in group homes for people with neurotrauma. Findings demonstrated the feasibility and strong support from staff, found similar obstacles to embedding this practice in services to those found in group homes for people with intellectual disabilities as well as issues not previously identified such as inclusion of allied health staff in introducing and supporting direct support staff to develop skills in Active Support.

8. Adjusting group homes to people who are ageing. 2006-2012. A series of parallel studies investigating the way group homes adjust their services to people who are ageing with intellectual disabilities. Funded by two Linkage grants, and other sources more specific to dementia. Finding demonstrate the difficulties that staff and organisations have in understanding and adjusting to the changing needs as people with intellectual disabilities age, and the often premature relocation of people to residential aged care, and decision making that is driven by organisational needs.

4. DETAILS OF IMPACT

Approach to impact: This research program is marked by close collaboration with end users at all stages, including people with intellectual disabilities and their family members. Ethnographic data have been collected in small group homes using participant observation methods. This required researchers to work on shift alongside staff, use non-participant observation methods requiring unobtrusive structured observations of staff practice and their interactions with residents, interviews with practice leaders, and surveys completed by front line staff.

The program of research has relied on building strong relationships with key leaders of disability organisations and managing new relationships as change occurs as a result of the research to the structure and personnel within them. Industry partnerships have been consistently sustained through making annual research findings available to each organisation and – in all projects – either holding separate reference groups or regular meetings of representatives of each partner. These meetings have enabled partners to remain engaged in the research and to share how each organisation has applied the research to their own context. The meetings have facilitated cross-organisational exchange of how findings are disseminated within the organisation and the changes that have been made to structures and operations. Organisations such as Greystanes Disability Services, Golden City Support Services have shared revised position descriptions, proposed revised structures for practice leadership and procedures for recruitment.

The research team has been available throughout to discuss proposed ways of using research findings with organisations but has also recognised the importance of facilitating discussion between organisational leaders. These research projects have not been intervention studies, but in partnership with end users and the researchers have translated findings into easy-to-use training materials to ensure wider accessibility.

Submissions to impact on policy: Prof Bigby’s research team have made submissions to key inquiries into disability services.

For example,
- Victorian Parliament Family and Community Development Committee – Inquiry into Social Inclusion of People with Disabilities. 2014 Invited oral submission. (Prof Bigby cited in report on active support (p.3.23)
- Productivity Commission Inquiry Disability Support and Care 2011. Submissions and invited presentation.
- Parliament of Victoria. Family and Community Development Committee Inquiry into Supported Accommodation for Victorians with a Disability and/or Mental Illness. 2009. Submission

Impact on regulation and quality assurance of group homes: Prof Bigby’s work influenced the direction of quality assurance of group homes in Victoria. Through visits to group homes, the Community Visitor Program by the Office of the Public Advocate enquires into the nature of supported accommodation services. Their reports are influential at the individual service as well as the broader systemic level. Prof Bigby’s 2014 publication Identifying Better Group Homes was translated in 2015 into a guide and check list for the Program providing advice for Community Visitors about what to look for and ask about when visiting. The research team also developed and delivered a training program, which is now an embedded part of community visitor training. This has helped to change the focus of community visitors from inspecting paperwork and talking to staff to observing and asking about practice.

Impact on service delivery: People with intellectual disabilities, particularly those with more severe or profound disabilities, need support to be engaged, express their needs and exercise choice and control over their lives. They consistently experience poorer quality support than their peers with milder disabilities. Active Support is an enabling relationship between staff and a person with intellectual disability that supports engagement in meaningful activities or social relationships. Consistently used Active Support is associated with increased quality of life, greater choice and control, skill development and emotional well-being – no matter how profound a person’s disability. This research has improved the capacity of organisations to deliver Active Support by identifying poor implementation of Active Support, two key elements associated with good Active Support, and the culture in better performing group homes, as well as by producing open access training resources. This has led to changes to organisational structures and increased likelihood that support staff will be trained in and implement this internationally recognised best practice. By taking an approach uncompromising in its assertion that group home residents have a fundamental right to respectful, high-quality, person-centred support, this research has had a profound impact not only on the quality of support people receive, but also on the very way many group homes are managed.

Impact on practice leadership in disability organisations: The research findings show that practice leadership was integral to high-quality staff support and consistent levels of Active Support. The focus of front line managers as practice leaders on quality of life outcomes and modelling of Active Support, together with their capacity to coach staff in situ, lead team meetings and undertake individual supervision institutes an enabling culture leading to the engagement of residents in everyday activities. The observational measure of practice leadership developed by the research team has enabled practice leadership to be measured, and the Group Culture Scale will enable measurement of culture.

The 14 organisations involved in study 4, the longitudinal study, manage over 134 group homes delivering services to 1112 people across five states. As a result of discussion of the annual research findings, partner organisations have started to rethink staff roles and responsibilities and refocus leadership roles. Some moved from a single supervisor role with multiple roles to a service manager across several houses, removing and centralising the administrative tasks to enable greater focus on the elements of practice leadership. As one senior manager said, “this… research has offered that keen sharpened light into the dark corners of the role of a team leader embedded at the site driving Active Support. We didn’t get for the first four years or five years of us actually saying we were using Active Support”.

Development of training resources: The research team developed a free online resource Every Moment has Potential as an introduction to Active Support and Practice Leadership in 2014. This was in collaboration with Greystanes Disability Services and funded by the Department of Industry Innovation, Climate Change, Science, Research and Tertiary Education. The resource is used extensively by disability and training organisations in Australia and overseas. For example, it is used in TAFE certificate 3 courses, and embedded in learning systems of large providers such as Actv in Australia, and Mosaic in the US which supports over 3500 people with intellectual disabilities across 10 states. The resource had more than 10,804 page views between its release in February 2015 to the end of November that year, and visits to the site have remained consistent at an average of 100 a day. Some organisations such as Unisson and ‘House with No Steps’ require its completion as part of staff induction. As one manager said about their policies for new staff, “in their first month, they need to do the Every Moment has Potential modules.”
Every Moment Has Potential is an online learning resource developed specifically for disability support workers. The resource provides an introduction to Person Centred Active Support – a way of working that enables everyone, no matter what their level of intellectual or physical disability, to make choices and participate in meaningful activities and social relationships. [http://www.activesupportresource.net.au/](http://www.activesupportresource.net.au/). A second online training resource was produced as part of a parallel program of research more tightly focused on social inclusion work of support workers. It has proved however to be useful resource in training support workers about using Active Support in community settings.

Supporting Inclusion is an online learning program which has been developed for support workers. It can also be used by trainers or teachers to support their teaching. The purpose of this program is to create a space where disability support workers can think about what social inclusion means for people with intellectual disability, and learn or refresh some useful tools and strategies to support people with intellectual disability in ways that will promote their social inclusion.

A guide to good group homes, which brought together the research findings, was produced in 2017 with support from National Disability Services. This guide is in straightforward English and is accessible to families, people with disabilities and service providers, highlighting what to look for in a good group home. It is accessible online through the NDS Centre of Applied Disability Research.

Impact on the quality of life of people with intellectual disabilities in group homes: Annual data presented to partner organisations during the study demonstrate an upward trajectory of Active Support, though it remains variable between services. Even so, evidence of the impact of this research on the quality of support is compelling: the organisation with one of the strongest upward trajectories in quality of practice is Greystanes Disability Services, which exclusively supports people with severe and profound intellectual disabilities. By implementing recommendations from the research, this service showed an increased score on the Active Support measure from 28 in 2011 to 55 in 2016, as detailed in its Annual Report 2016. Data about increasingly levels of Active Support were published in 2017, and further analysis is underway.

5. ENGAGEMENT

The leaders of this program have taken every opportunity to disseminate their findings through invitations to present at many different types of forums. They have spoken at conferences organised by the peak disability agency, National Disability Services, and by individual organisations and advocacy groups. They have drawn attention to issues relating to the poor quality of staff support in group homes and the need to give more attention to front line staff practice and practice leadership through radio and other media.

Significant industry appointments, memberships and awards

- Community member of Intellectual Disability Review Panel 2001–2007
- Member of the Victorian Disability Advisory Council. 2000–2003
- Member of the The Project Reference Group for Future Planning provisions, Careers Branch Department of Families, Housing, Community Services & Indigenous Affairs 2008
- National Research Award of the Australian Society for the Study of Intellectual Disability 1993
- National Research Award of the Australian Society for the Study of Intellectual Disability, 2010

Professional development and training

Prof Bigby’s team have consistently used professional networks and industry partnerships disseminate research findings, translate findings into accessible formats, raise awareness of poor quality group homes and draw attention to the importance of practice leadership in designing and funding services. This has included an annual Roundtable on Intellectual Disability Policy and Practice since 2006, which has brought together academics, policy makers, and senior staff from disability service providers around key issues. The collected published papers from the early Roundtables were an important source of commentary and research for the disability sector which until the advent of the NDIS in 2013 attracted little public debate or media attention.

Prof Bigby has delivered keynote addresses and invited presentations at industry events, conferences, workshops and Annual general Meetings. Examples include:

- 2012 invited to convene workshops for WA Disability Services Commission on the future of group homes, practice in group homes and support for aging people with intellectual disability.
- 2015 invited by Endeavour, Qld. to host a workshop — Embedding Person Centred Active Support – Research Findings and Implications for Endeavour and NDIS Readiness.
- 2016 invited by Bayley House as an AGM Guest Speaker to inform their active support model. Uploaded by Bayley House [https://www.youtube.com/watch?v=xcfO9M2C5n0](https://www.youtube.com/watch?v=xcfO9M2C5n0)

The regular attendance at events and conferences by Prof Bigby has prompted robust debate and plans for future service models in various States. In 2016 Prof Bigby presented 16 conference papers on topics related to her research program.

Prof Bigby is also engaged with international organisations. She has been a visiting Professor of Disability Research at Halmstad University in Sweden, and continues to be a visiting Professor at the Tizard Centre at the University of Kent, a Fellow of the International Association for the Scientific Study of Intellectual Disability, Past chair of the IASSID Special Interest Group on Ageing and Intellectual Disability, a National Board member of ASID – Research to Practice, founding Editor of Research and Practice in Intellectual Disability (RAPIDD), and a Foundation Fellow of the Australian College of Social Work.

Engagement with people with intellectual disabilities

Prof Bigby and her colleagues have ensured the perspectives of people with more severe or profound intellectual disabilities are incorporated into their research through observational methods, given this group’s difficulty of communication and the representation of their perspectives by people with milder intellectual disabilities. Earlier studies used the ethnographic methods (observation over a long-term) and later studies structured observations of staff practice. Where reference groups have been formed they have included representatives of advocacy groups and family members of people with more severe intellectual disabilities.

Engagement with media

Where opportunities arise, the team has used the media to promote the research findings and raise broader issues relevant to adults with more severe intellectual disabilities. For example,

- NDIS 5 years on — Bold Thinking Series, LaTrobe University, 28 March 2018 [https://www.youtube.com/watch?v=2hDMGB8-2ySU](https://www.youtube.com/watch?v=2hDMGB8-2ySU)

Opinion piece. Let’s wise up on housing options for people with intellectual disabilities The Conversation. August 2 (This article preceded the seminar presentation by Prof Bigby organised by Advocacy group Fighting Chance Supported Accommodation Models for People with Disabilities: The past, the present – and the future? Sydney).

Research supervision and teaching

Two doctoral students have been involved specifically in this program of research.
6. RESEARCH INCOME

For this research program, the total research grant income has been $3,291,000, comprising 8 national or international competitive grants ($1,261,194), 16 industry grants or grants as a result of tenders ($2,014,820) and 2 internal University grants ($15,000). Prof Bigby also received significant infrastructure support for La Trobe University with the formation of the Living with Disability Research Centre in late 2015.

Category 1 (international and national competitive)
4. Webber, R., Bigby, C., Bowers, B. Increasing organisational capacity of community residential units to facilitate ageing in place for people with intellectual disability, 2010-2012. ARC Linkage $172,000 plus $135,000 cash industry partners.
7. Webber, R., Bigby, C., & Bowers, B. Accommodating the needs of people with lifelong intellectual disability in residential aged care, 2007-2009. ARC Linkage $93,000 plus $48,000 cash industry partners.

Category 2 (government)

Category 3 (Other industry)

Other
22. Bigby, C. Group homes for people with intellectual disabilities, 2008. Faculty of Health Sciences Project grant $5000.

7. RESEARCH OUTPUTS

There are over 41 publications including books; book chapters, refereed articles, and research reports related to this research program. Selected publications are:

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