

***Finding the Collective Voice —
the role of family and community in
improving housing options for adults with
disability***

by Susan Margaret Bailey

Thesis submitted in fulfilment of the requirements for
the degree of

Doctor of Philosophy

under the supervision of
Dr Pernille H. Christensen
Professor Shankar Sankaran
Dr Michael Millington

University of Technology Sydney
Faculty of Design Architecture and Building

June 2021

CERTIFICATE OF ORIGINAL AUTHORSHIP

I, Susan Bailey, declare that this thesis is submitted in fulfillment of the requirements for the award of Doctor of Philosophy, in the Faculty of Design Architecture and Building at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

Signature:

Production Note:

Signature removed prior to publication.

Date:

27 June 2021

ACKNOWLEDGEMENTS

My sincere thanks to each parent who participated in this research. To the children who were not interviewed, this is a record of your family's achievements for you. I am grateful for the participation of the NGOs I interviewed: Supporting Independent Living Co-operative, Hartley Lifecare, JewishCare, Challenge Southern Highlands and HOME. My sincere appreciation to my three supervisors, Dr Pernille Christensen, Professor Shankar Sankaran and Dr Michael Millington. Thank you for your detailed feedback, guidance on writing and methodology, good humour and positive support. The topic for this study began with inspiration from Mike's edited collection titled *Families in Rehabilitation Counselling: A Community-based Rehabilitation Approach*. The themes of family, community, advocacy and power are ever-present. My thanks to staff with the Faculty of Design, Architecture and Building, UTS Graduate Research School, UTS Library and UTS Ethics Secretariat, who supported me with knowledge, information and training. At the beginning, Dr Nigel McCarthy was an important sounding board as a former PhD candidate. Dr Dick Bryan was generous with his time and thoughts as both parent and academic.

Parents who provided insights and information include Mary Lou Carter. There were others who motivated the research participants to keep at it: wives or husbands, siblings, grandparents, and people chosen as their extended family (both kinship and friends). My thanks to Danna Vale, a retired politician and local member, and to a former bureaucrat. Both were generous in sharing their knowledge and experience from working with some of the families who created new homes for their children. I acknowledge other local members who were determined to help families achieve new housing for their children. Andrew Allen is a colleague in the not-for-profit sector who discussed the meaning of 'consumer' with me. Anna Houston, National Institute of Dramatic Art, expressed most clearly what parents are driven to do. Ian Smith and Jonathan Harris of Harris & Co. assisted my understanding of the building classification framework, technical standards and planning framework. My friend James Lonsdale, a lawyer, Kate Mountstephens, an architect, and Doug Melloh, an accredited access consultant, kindly discussed the building classification framework with me. Melanie Southwell, CEO of the Specialist Disability Accommodation

Alliance, shared her knowledge of developments in specialist disability accommodation. In each case, any errors are mine. Shobha Nambiar is a friend who prepared tables and activity theory diagrams at the beginning. My niece, Carla Manousaridis, created vector graphics diagrams of the activity systems for each case study and subsequent publication. Danny Hui, CEO of Sameview and a friend, developed the 'person bar chart' that is used in Chapter 5. Helen Ubels provided academic editing, proofreading and formatting services before and after the examiner comments were received. Stephanie Preston, copyeditor, provided document formatting services after the examiner comments were received. Kylie Lowe provided copyediting services according to IPEd's *Guidelines for Editing Research Theses*. Thank you to each of these professionals.

STATEMENT OF THESIS BY COMPILATION FORMAT

The format of this thesis is thesis by compilation. Chapters 4, 5, 6 and 7 will be submitted for review and then publication. Chapter 5 will be re-submitted to the *Disability Studies Quarterly*. Chapter 4 will be submitted to the *Strategic Entrepreneurship Journal*. Chapter 6 will be submitted to the *Journal of Family & Economic Issues*. Chapter 7 will be submitted to the *Housing Studies* journal. Each chapter was written by the researcher with input and other feedback from examiners and her three supervisors, Dr. Pernille Christensen, Professor Shankar Sankaran and Dr. Michael Millington. These supervisors are named as co-authors and are ascribed authorship equivalent to approximately 10%, 5% and 5%, respectively.

Production Note:

Signature: Signature removed prior to publication.

Name: Dr. Pernille Christensen

Date: 25. June 2021

Signature:

Name: Prof. Shankar Sankaran

Date:

Signature:

Name: Dr. Michael Millington

Date:

Production Note:

Signature: Signature removed prior to publication.

Name: Susan Bailey, Candidate

Date: 25 June 2021

STATEMENT OF THESIS BY COMPILATION FORMAT

The format of this thesis is thesis by compilation. Chapters 4, 5, 6 and 7 will be submitted for review and then publication. Chapter 5 will be re-submitted to the *Disability Studies Quarterly*. Chapter 4 will be submitted to the *Strategic Entrepreneurship Journal*. Chapter 6 will be submitted to the *Journal of Family & Economic Issues*. Chapter 7 will be submitted to the *Housing Studies* journal. Each chapter was written by the researcher with input and other feedback from examiners and her three supervisors, Dr. Pernille Christensen, Professor Shankar Sankaran and Dr. Michael Millington. These supervisors are named as co-authors and are ascribed authorship equivalent to approximately 10%, 5% and 5%, respectively.

Signature:

Name: Dr. Pernille Christensen

Date:

Production Note:

Signature: Signature removed prior to publication.

Name: Prof. Shankar Sankaran

Date: 26 - June - 2021

Signature:

Name: Dr. Michael Millington

Date:

Production Note:

Signature: Signature removed prior to publication.

Name: Susan Bailey, Candidate

Date: 25 June 2021

STATEMENT OF THESIS BY COMPILATION FORMAT

The format of this thesis is thesis by compilation. Chapters 4, 5, 6 and 7 will be submitted for review and then publication. Chapter 5 will be re-submitted to the *Disability Studies Quarterly* journal. Chapter 4 will be submitted to the *Strategic Entrepreneurship Journal*. Chapter 6 will be submitted to the *Journal of Family & Economic Issues*. Chapter 7 will be submitted to the *Housing Studies* journal. Each chapter was written by the researcher with input and other feedback from examiners and her three supervisors, Dr. Pernille Christensen, Professor Shankar Sankaran and Dr. Michael Millington. These supervisors are named as co-authors and are ascribed authorship equivalent to approximately 10%, 5% and 5%, respectively.

Signature:

Name: Dr. Pernille Christensen

Date:

Signature:

Name: Prof. Shankar Sankaran

Date:

Production Note:

Signature: Signature removed prior to publication.

Name: Dr. Michael Millington

Date:

Signature:

Name: Susan Bailey, Candidate

Date:

PREFACE

This doctorate study responds to the lack of housing for people with disability to address their needs or desires to have their own home. Governments in Australia have neither planned for nor invested in sufficient, good-quality housing for adults with a disability who are over 18 years of age and who live with family or friends but need or want to choose their own home. Some of these women and men (referred to as ‘adults’ in this thesis¹) are excluded from mainstream social housing systems and specialist disability housing such as group homes (National People with Disabilities and Carers Council 2009) because they are not considered homeless or needy enough. Yet many of them, and their families who encounter the costs associated with disability, are financially disadvantaged. This study presents 11 case studies where new homes were established for more than 44 adults. Few case study participants had the resources to purchase, build or rent the housing component to establish the adult’s own home in the communities that support them day to day. Individual funding for the paid support component to enable adults to live independently from their family caregiver was made available in New South Wales and the Australian Capital Territory in anticipation of the emerging National Disability Insurance Scheme (NDIS), which commenced in 2013.² This thesis presents the creation of the adult’s own home as a significant achievement of families — and of not-for-profit non-government organisations (NGOs). These new homes were conceived before NDIS funding was available where families and adults did not have sufficient financial means to fund paid support, housing or both. This study is relevant for adults who are not eligible for the NDIS, or who are eligible for NDIS funding for paid support but not eligible for NDIS funding for accommodation in Australia. The success of the recently established specialist disability accommodation (SDA housing) system in Australia, funded under the NDIS, is outside the scope of this study, although some of the housing in the case studies is now classified or ‘enrolled’

¹ Daughters and sons with a disability are referred to as ‘adults’ or ‘adults with disability’ because they are over 18 years of age. This thesis also uses the terms ‘daughter’, ‘son’, ‘child’, ‘children’, ‘person’ and ‘people with a disability’ if appropriate in the particular context. In relation to NGOs, these adults may be called a ‘client’, ‘person with a disability’ or ‘people with disability’. ‘Person with a disability’ and ‘people with disability’ includes children and other people with a disability who are not adults in a case study.

² Bostock et al. (2004, p. 48 citing Lord & Hutchison 2003) described the worldwide movement towards individual funding for support paid direct to the person rather than a service provider, including the grants paid to individuals for their purchase of support services in Western Australia from 1993.

as SDA housing. The SDA housing system, as well as policy that underpins it, will need regular, independent evaluation over the coming years.

This study of activities and strategies to secure government funding for housing and paid support has five aims. First, it investigates the role of families and NGOs as advocates and change agents. Both families and NGOs acknowledged, listened and responded to the voices of adults whose housing needs had been neglected by governments. These families engaged in advocacy to meet the housing needs of these adults, as well as the housing goals and objectives of their daughter or son. Second, this study explores the activities and strategies undertaken by families and NGOs as allies of the adults (Panitch 2008). Both families and NGOs garnered broader support for the objective of establishing the adults' own home and institutional support to commit funding to achieve this objective. Third, it listens to the voice of families and NGOs who were found to create new homes in new ways, where traditional disability services and housing systems had not done so. In this thesis, these separate housing systems and the housing assets within them—both mainstream and specialist disability housing—are collectively referred to as 'social housing'.³ Fourth, this study acknowledges the lifelong service-providing and caregiving role of parents, other family members, carers and friends. It demonstrates the shifting roles of traditional institutions, whereby families became designers and/or providers of government-funded housing services and chose the key workers to deliver paid support. Parents worked within, around and across traditional service and system boundaries to secure resources and implement their designs, create more housing options and ensure better services when governments and service providers did not do so. Their volunteering, organisation, housing advocacy and home-making activities are different facets of unpaid caregiving. Fifth, this study

³ Family and Community Services (FACS), a former agency of the NSW Government, defined social housing to include public, community and Aboriginal housing in NSW, all of which are described as 'secure and affordable rental housing for people on low incomes with housing needs'. FACS and other government agencies do not include specialist disability housing, such as group homes or other NDIS-funded (SDA) housing in the description of social housing (<https://www.facs.nsw.gov.au/housing/help/ways/social-housing>, last viewed 2 October 2019). However, this thesis includes group homes and other SDA in the term 'social housing' in order to mitigate segregating housing systems in conversation, mindset and usage. The availability of capital funding for SDA does not of itself segregate that type of housing from other housing (e.g. AccessAccom's Penrith Sheffield Quarter combines SDA usage apartments with apartments for other tenants).

shares what these parents and NGOs have learned from the action they took,⁴ what worked and did not work, and the importance of the communities they supported or constructed.

Across each case study, self-determination, control and choice were highly valued. Parents frequently made decisions for or with their children. This included decisions made with and on behalf of a daughter or son with a severe or profound limitation relating to a disability. A severe or profound limitation is described by the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) as a limitation with the greatest need for help, assistance or support with activities (ABS 2018). Due to the type of disability and support needs of each adult, it was the system-level activities of parents and NGOs that attain the housing and paid support. They enabled the transition away from living with families, and they created choice, which the adults were not able to do themselves. The researcher was cognisant that the interests and priorities of adult daughters or sons and their parents can differ (Curryer, Stancliffe & Dew 2015). However, it was not the purpose of this study to identify those differences, or to study the adults' participation in system-level choice (although data were collected on individual wishes and preferences communicated by the adults to their parents). In this sense, the study is not family research. Importantly, the new homes these parents and not-for-profit NGOs established brought more people and community into the lives of each family and adult.

⁴ They developed new, stronger tactics when their polite requests for assistance and better services failed (Panitch 2008, p. 7).

TABLE OF CONTENTS

CERTIFICATE OF ORIGINAL AUTHORSHIP	i
ACKNOWLEDGEMENTS.....	ii
STATEMENT OF THESIS BY COMPILATION FORMAT.....	iv
PREFACE	vii
TABLE OF CONTENTS.....	x
LIST OF TABLES	xv
LIST OF FIGURES.....	xvi
LIST OF APPENDICES	xvii
LIST OF ABBREVIATIONS AND ACRONYMS	xviii
GLOSSARY	xx
ABSTRACT.....	xxiii
1 INTRODUCTION.....	1
1.1 ACTION TO CREATE PATHWAYS TO NEW HOUSING	1
1.2 SUCCESSFUL CREATION OF NEW HOUSING MODELS.....	7
1.3 BARRIERS AND ENABLERS.....	9
1.3.1 Cluster of inputs and factors.....	9
1.3.2 Barriers	11
1.3.3 Enablers	12
1.3.4 Emergence of new models	12
1.4 DISABILITY MODELS AND DEFINITIONS.....	15
1.5 OTHER DEFINITIONS	16
1.6 THESIS STRUCTURE.....	20
2 LITERATURE REVIEW	23
2.1 SELF-DETERMINATION, AUTONOMY, CHOICE AND CONTROL, AND EMPOWERMENT	25
2.2 ORGANISATION AND ADVOCACY	25
2.3 VOLUNTEERING AND CAREGIVING	27
2.3.1 Volunteering	27
2.3.2 Caregiving	29
2.4 INSTITUTIONAL SUPPORT FOR PEOPLE WITH DISABILITY.....	31
2.5 HUMAN RIGHTS FRAMEWORK	33
2.6 HISTORICAL CONTRADICTIONS.....	36
2.6.1 Structural barriers within government agencies	36
2.6.2 Historical underfunding.....	37
2.6.3 Outsourcing and privatisation.....	37
2.6.4 Contracting and tendering processes.....	38
2.6.5 Who controls funding and contracting now?.....	39
2.7 HOUSING NEED AND SUPPLY	40
2.8 CONCLUSION.....	42
3 RESEARCH DESIGN	43
3.1 PHILOSOPHICAL APPROACH.....	43
3.1.1 Epistemology.....	43
3.1.2 Implications for this study	43

3.1.3 Ontology	44
3.1.4 Implications for this study	44
3.1.5 Subjectivity and objectivity in qualitative research.....	44
3.1.6 Implications for this study	44
3.2 RESEARCHER AS DATA COLLECTION INSTRUMENT.....	45
3.2.1 Implications for this study	46
3.2.2 Bias and reflexivity.....	46
3.2.3 Implications for this study	47
3.2.4 Reflection on the effect of 'self'.....	49
3.3 RESEARCH QUESTIONS.....	49
3.4 CASE STUDY AND INTERVIEW METHOD.....	51
3.5 ETHICS.....	52
3.6 SAMPLING	53
3.6.1 Selection criteria	53
3.6.2 Disability type	54
3.6.3 Characteristics of research participants	55
3.6.4 Sample	57
3.6.5 Family case studies by type	58
3.6.6 NGO case studies by service provider	60
3.7 Location	62
3.8 Interview procedure	62
3.9 DATA COLLECTION	64
3.10 DATA ANALYSIS.....	66
3.11 VALIDITY AND RELIABILITY	68
4 INSTITUTIONAL ENTREPRENEURSHIP.....	75
4.1 INTRODUCTION	76
4.2 LITERATURE REVIEW	77
4.2.1 Governance	77
4.2.2 Family governance	78
4.2.3 Institutions of governance.....	80
4.2.4 Institutional entrepreneurship	82
4.2.5 Social innovation	83
4.2.6 Activity theory of change	84
4.3 RESEARCH METHODOLOGY	85
4.3.1 Units of analysis	85
4.3.2 Research questions.....	86
4.3.3 Sample of research participants	86
4.3.4 Procedure	87
4.3.5 Backwards mapping	87
4.3.6 Activity theory for data analysis	88
4.3.7 Chronology and timeline.....	89
4.3.8 Concepts from theory	90
4.4 CASE STUDIES	90
4.5 FINDINGS.....	93
4.5.1 Control and choice and family governance	94
4.5.2 Action and transactions of parents to create new homes.....	94
4.5.3 Combination of inputs from different systems	94
4.5.4 Institutional entrepreneurship through change	95
4.6 DISCUSSION	96
4.6.1 Timeframe	96
4.6.2 Individual and collective action	97

4.6.3 Philosophies and values.....	100
4.6.4 Co-operative values and principles	102
4.6.5 Action and transactions: family governance and innovations.....	103
4.6.6 Others who empowered parents to combine inputs from different systems	104
4.6.7 Inputs from different systems	106
4.6.8 Scalable innovation	108
4.7 CONCLUSION.....	111
5 POWER.....	114
5.1 INTRODUCTION	114
5.2 LITERATURE REVIEW	116
5.2.1 Barriers to housing with paid support	116
5.2.2 Challenging the status quo	121
5.2.3 Three-dimensional power	122
5.2.4 Power-within, power-to and power-with.....	124
5.2.5 Synthesis of power literature	124
5.2.6 Entrepreneurial bricolage	127
5.3 RESEARCH METHODOLOGY	128
5.3.1 Units of analysis	128
5.3.2 Procedure	129
5.3.3 Activity theory for data analysis.....	130
5.3.4 Chronology and timeline.....	131
5.4 CASE STUDIES	131
5.5 FINDINGS.....	132
5.6 POLITICIANS, PARENTS AND THEIR COMMUNITY	134
5.6.1 Role of politicians	134
5.6.2 Role of parent advocates.....	137
5.6.3 Role of community support.....	138
5.7 DISCUSSION	140
5.7.1 Power-over: barriers to housing	140
5.7.2 Power-to: define the problem and the solution.....	142
5.7.3 Power-to, power-within and power-with: bricolage.....	143
5.7.4 Power-over: new barriers	154
5.8 CONCLUSION.....	160
6 SOCIAL ENTREPRENEURSHIP AND SOCIAL INNOVATION.....	163
6.1 INTRODUCTION	163
6.2 LITERATURE REVIEW	165
6.2.1 Entrepreneurship v. social entrepreneurship.....	166
6.2.2 Innovation v. social innovation.....	171
6.3 CASE STUDIES	175
6.4 RESEARCH METHODOLOGY	177
6.4.1 Units of analysis	177
6.4.2 Procedure	177
6.4.3 Exploratory study.....	178
6.4.4 Ethics approval.....	180
6.4.5 Activity theory for data analysis.....	180
6.4.6 Concepts from theory	183
6.5 DISCUSSION	183
6.6 FINDINGS.....	184
6.6.1 Cross-sectoral	185
6.6.2 Open and collaborative.....	185

6.6.3 Grassroots and bottom-up.....	186
6.6.4 Pro-sumption and co-production	188
6.6.5 Mutualism	189
6.6.6 Creates new roles and relationships	190
6.6.7 Better use of assets and resources	191
6.6.8 Develop assets and capabilities	194
6.7 CONCLUSION	196
7 BUILDING PERSON-CENTRED HOMES	198
7.1 INTRODUCTION	198
7.2 LITERATURE REVIEW	201
7.2.1 Lack of choice.....	204
7.2.2 Institution as structure or function.....	206
7.2.3 Negative attitudes, practices and rules.....	208
7.2.4 Building rules in Australia	209
7.2.5 Livable Housing Design Guidelines.....	211
7.2.6 NDIS SDA Design Standard.....	212
7.3 METHODOLOGY	213
7.3.1 Units of analysis	213
7.3.2 Research questions.....	214
7.3.3 Sample of research participants	214
7.3.4 Procedure	215
7.3.5 Activity theory for data analysis.....	215
7.3.6 Concepts from theory	215
7.4 FINDINGS.....	216
7.5 DISCUSSION	219
7.5.1 Contradictory objectives	219
7.5.2 Implementation of the model	221
7.5.3 Community within a community.....	224
7.5.4 Individual choice	224
7.6 DESIRED OUTCOMES	226
7.7 UNEXPECTED OUTCOMES	227
7.8 CONCLUSION.....	228
8 CONCLUSION, CONTRIBUTION AND RECOMMENDATIONS	231
8.1 STRUCTURE OF THIS CHAPTER	232
8.2 CONTRIBUTIONS TO THE DISCIPLINE OF INSTITUTIONAL ENTREPRENEURSHIP	232
8.3 CONTRIBUTIONS TO THE FIELD OF POWER	234
8.4 CONTRIBUTIONS TO THE DISCIPLINE OF SOCIAL ENTREPRENEURSHIP	235
8.5 CONTRIBUTIONS TO INNOVATION IN BUILDING PERSON- CENTRED HOMES	236
8.6 EXPLANATION OF BARRIERS AND SUCCESSES	237
8.6.1 Housing as a barrier	237
8.6.2 Limited involvement of NGO service providers	238
8.6.3 Determination and persistence of parents.....	240
8.6.4 Least cost to government	241
8.7 CONTRIBUTIONS AND RECOMMENDATIONS	242
8.7.1 Theory contribution.....	242
8.7.2 Practice contribution	243
8.7.3 Policy recommendations	245

8.8 LIMITATIONS	248
8.9 ACHIEVEMENT OF STUDY AIMS	249
8.10 FUTURE RESEARCH	251
8.11 CONCLUSION	252
REFERENCES	254
APPENDICES	285

LIST OF TABLES

Table 1: Replacing unpaid caregiving with paid support.....	31
Table 2: Activity system framework to support control and choice.....	35
Table 3: Levels of reflexivity	47
Table 4: Types of disability.....	55
Table 5: Case study sample.....	57
Table 6: Family case studies by type	59
Table 7: NGO case studies by service provider	61
Table 8: Criteria comparison for judging quantitative and qualitative research.....	68
Table 9: Philosophies, values and partnerships.....	106
Table 10: Resulting theoretical framework	126
Table 11: Powerful NSW politicians	135
Table 12: Strategies to develop power.....	159
Table 13: Defining social entrepreneurship (Dees 1998).....	168
Table 14: EMES social enterprise indicators.....	170
Table 15: Five types of social innovations (TEPSIE 2014, p. 10)	173
Table 16: Definitions of social enterprise, social entrepreneurship and social innovations.....	175
Table 17: Key differences between the models	194
Table 18: Types of housing.....	233

LIST OF FIGURES

Figure 1: Activity system as analytical tool.....	10
Figure 2: Activity theory identifies resolved contradictions.....	67
Figure 3: Connected, interdependent activity systems.....	89
Figure 4: Benambra Intentional Community inputs	92
Figure 5: Karen Connaughton’s individual timeline (Case #2)	98
Figure 6: Cross-case comparison of source of housing (#1, #2, #3).....	107
Figure 7: SILC’s family governed models are individual and scalable	110
Figure 8: Timeline Case #3	147
Figure 9: Timeline Case #2	150
Figure 10: Timeline Case #1	153
Figure 11: Spatial and temporal activity Case #3.....	158
Figure 12: Enabled Housing Model #1	182
Figure 13: Co-resident Support Model #2	193
Figure 14: RASAIID contradictions.....	218
Figure 15: Three elements of home — pre-NDIS.....	233
Figure 16: Housing pathway elements — post NDIS	245

LIST OF APPENDICES

APPENDIX A: STUDIES OF UNPAID CAREGIVING	286
APPENDIX B: ETHICS APPROVAL UTS HREC REF NO. ETH17-1412.....	288
APPENDIX C: FAMILY CASE STUDY INTERVIEW QUESTIONS	289
APPENDIX D: NGO CASE STUDY INTERVIEW QUESTIONS	292
APPENDIX E: NOTE OF MEETINGS OF S. RICHARDS, CASE #2	294

The thesis is written in Australian English. The spelling and terminology in Chapters 4–7 will be changed to their US equivalent when submitted to US journals.

LIST OF ABBREVIATIONS AND ACRONYMS

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
ADHC	Ageing, Disability & Home Care, a Department of Family and Community Services (NSW)
CDLS	Cornelia de Lange syndrome
CHP	Community housing provider
CRA	Commonwealth Rent Assistance
DADHC	Department of Ageing, Disability & Home Care (NSW)
DSP	Disability Support Pension
EMES	European Research Network (named after the emergence of social enterprises in Europe research program)
FACS	NSW Department of Family and Community Services
HILDA	Household, Income and Labour Dynamics in Australia
HOME	Home Owners Mutual Enterprise
HREC	Human Research Ethics Committee
ISL	Individual supported living arrangements
ILO	Individual living options
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NFP	Not-for-profit
NGO	Non-government organisation
NSW	New South Wales
PaRA	Parent-assisted residential accommodation
PwD	People with disability
RASAID	Ryde Area Supported Accommodation for Intellectually Disabled Inc.
SAIF	Supported Accommodation Innovation Fund
SDA	Specialist Disability Accommodation
SDAC	The Survey of Disability, Ageing and Carers
SIL	Supported Independent Living
SILC	Supporting Independent Living Co-operative
SRV	Social Role Valorisation

SSDAAG	Sutherland Shire Disability Accommodation Action Group
TEPSIE	Theoretical, Empirical and Policy Foundations for Building Social Innovation in Europe
UK	United Kingdom
US	United States of America

GLOSSARY

ACT Housing	The agency of the ACT Government that manages public housing in the ACT.
Ageing, Disability & Home Care (NSW)	Formerly a division of the NSW Department of Family and Community Services that funded or provided disability services and support accommodation including group homes.
Benambra Intentional Community	The public housing development in which the intentional community is located in Canberra.
Carer and caregiver	A person who provides care, support and other assistance to a person with a disability. Caregiver is a term used to refer to unpaid parent caregivers.
Community housing	Community housing is a type of social housing rented by a community housing provider to people who need housing. Some of the properties rented out by community housing providers are owned by or subject to the interests of a government agency or government-owned statutory corporation of a state or territory government.
Community housing provider	A community housing provider is a company or co-operative registered as a community housing provider under the <i>Community Housing Providers (Adoption of National Law) Act 2012</i> (NSW) and the National Regulatory System for Community Housing. It is a non-government organisation that provides a type of social housing on behalf of a state or territory government.
Commonwealth Rent Assistance	A non-taxable income supplement paid by the Australian Government to eligible people to help them pay rent, excluding rent for public housing.
Disability ACT	Disability ACT was the ACT Government agency that funded disability services in the ACT before the NDIS commenced.
Disability Royal Commission	Australia's Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.
Disability Support Pension	An Australian Government payment to help cover rental costs for eligible people.

Family and Community Services (FACS)	FACS was a department of the NSW government until its functions and responsibilities were transferred in 2019 to a newly formed cluster agency called the Department of Community and Justice.
Group home	A dwelling where a number of people with disability live together in a domestic setting with or without paid support whether or not payment for board and lodging is required.
HILDA survey	The Household, Income and Labour Dynamics in Australia (HILDA) survey is a household-based panel study conducted annually since 2001. It collects information about economic and subjective wellbeing, labour market dynamics and family dynamics. It is funded through the Department of Social Services. The Melbourne Institute at the University of Melbourne designs and manages the study.
Housing NSW	A division of the NSW Department of Family and Community Services.
Housing Pathways NSW	Housing assistance system in NSW for the management and administration of applications for government-funded mainstream housing.
National Disability Insurance Agency (NDIA)	The statutory agency that implements the NDIS and administers the allocation of NDIS funding.
National Disability Insurance Scheme (NDIS)	The Australian Scheme that provides individual funding for paid support and SDA housing in Australia.
NSW Housing Register	A single list of people approved as eligible to wait for social housing and remain on that list. The NSW Housing Register is an element of the Housing Pathways NSW system for the management and administration of housing assistance.
Pathway or housing pathway	A person's experience of housing over time. The term can also refer to a policy pathway to ensure people can access housing, and the system that provides policies, processes and other tools to assist people into housing or, conversely, restrict access.

Participant	Person eligible for NDIS. Not all participants will be eligible for SDA housing or SIL support in an SDA house.
Productivity Commission	The Australian Government's advisory body on microeconomic policy and regulation relating to social and environmental issues.
Public housing	Rental housing owned and managed by FACS or another government agency.
Quality and Safeguards Commission	An independent agency that regulates, audits and enforces quality and safety of NDIS supports and services.
Specialist disability accommodation (SDA)	NDIS housing payments for specialist disability accommodation and the SDA housing itself.
SDA Design Standard	The SDA Design Standard (edn 1.1 issue date 25 October 2019) applies to specialist disability accommodation (SDA) where an application for enrolment is made from 1 July 2021 (https://www.ndis.gov.au/providers/housing-and-living-supports-and-services/specialist-disability-accommodation/sda-design-standard).
SDA housing	Specialist disability accommodation funded by SDA under a rental model.
Social housing	Government-funded subsidised housing for people on a low income — particularly people who receive Australia's Disability Support Pension, Newstart or Job Seeker. This thesis uses the term to include group homes and other SDA as well as public housing and community housing.
Supported Independent Living (SIL)	Individual funding for independent living supports under the NDIS.
Survey of Disability, Ageing and Carers (SDAC)	A survey undertaken and published by the Australian Bureau of Statistics semi-regularly. SDAC surveys were conducted in 2012, 2015 and 2018.

ABSTRACT

This study explored the activities, strategies and transactions of parents and not-for-profit non-governmental organisations (NGOs) that acquired resources and created the power to establish new homes for adults with a disability. The study used theories of institutional entrepreneurship, power, social entrepreneurship and social innovation to explain the interaction between families, the state (as provider of individual funding for paid support or housing) and NGOs to create more housing for adults with a disability. These families and NGOs took action when traditional specialist and mainstream housing systems were constrained and difficult to access. Innovative models of housing, support and community were created or supported by these families and NGOs working with other people, organisations and institutions. These initiatives, which combined resources and inputs from different sectors and systems to meet housing needs in new ways, are presented in this thesis.

Qualitative data collection involved semi-structured interviews and document analysis in 11 case studies where new homes were established for more than 44 adults. In six family case studies and five NGO case studies, parents and NGOs were economic actors and bricoleurs who became innovators who refused to accept limited financial resources as a reason why these adults could not have their own home. Cross-case analysis using Engeström's (2001) cultural-historical activity theory revealed the importance of: family advocacy, empowerment through collective action with other families, allies and resources drawn from the parent or NGO's community or network; institutional entrepreneurship through organisation forming, new models of housing with paid support and governance models; institutional support from like-minded politicians, bureaucrats and NGOs; and bricolage, where families and NGOs combined bits and pieces of resources and other inputs to establish housing and deliver paid support in new ways. Families and NGOs in the case studies were empowered to attain new homes through their persistence, individual funding received from government, and capital funding where needed.

The study demonstrated that the institutions of family, the state (through government and politicians) and the not-for-profit sector (through NGOs) can achieve new models of housing and support when they collaborate, combine

resources and act together without regard for sector boundaries. In short, these actors achieve more together than they could achieve alone. To encapsulate their efforts, this study presented the development of their organised action, purposeful networks, collaboration and shifting power relationships, giving effect to the voice of parent advocacy, collective action and family groups.