

**Supporting People Ageing with an Intellectual Disability:  
The Rural Perspective**

**Stuart Graham Wark  
BA (Hons) - (UNE)**

**A thesis submitted for the degree of Doctor of Philosophy  
of the University of New England  
August 2010**



# Acknowledgements

I would like to formally acknowledge the contribution of many people towards this research project.

Firstly, my sincere thanks and appreciation to my principal supervisor, Associate Professor Rafat Hussain. She has been a superb mentor, providing expert advice and guidance while allowing me the appropriate freedom to explore relevant issues, and still keeping the overall project on track.

Secondly, I am very grateful for the assistance provided by my co-supervisors: Dr Lyn Irwin who began the trip; Dr Mary Cruikshank and Dr David Briggs who helped in the middle stages; and Dr Helen Edwards who assisted me to finish the journey. Their various suggestions and support were invaluable to me reaching the stage of presenting this thesis.

Thirdly, this study could not have occurred without the willingness of disability organisations and their staff to give so generously of their time to complete the surveys in this project. It was a very time-consuming process for the participants, and I am most appreciative to the following agencies and their employees for their assistance:

- Aces
- Challenge Disability Services
- Coffs Harbour Support Services
- GlenRay Industries
- Gunnedah Support Services
- Hunter Integrated Care
- Kurrajong Waratah
- Lambing Flats Enterprises
- Mai-Wel
- Multi-Task
- On-Focus
- The Ascent Group
- The Tulgeen Group
- WestHaven

I must express my particular gratitude to the support provided to me by the CEO of The Ascent Group, Mr Kevin Mead. He encouraged me to commence this project initially, and has given ongoing assistance to see it reach completion. My thanks also go to Mr Martin Kingstone, who volunteered as the research assistant to prevent any conflict of interest issues for participating staff from my own organisation.

Finally, I must thank my family. Initially, my parents for the sacrifices they made so that their children could attend university, and currently Seonia, Emily and Matthew for their support and patience while I have undertaken this project. While my wife specifically requested not to be mentioned or acknowledged, it would be considerably remiss of me not to do so.

## Abstract

In recent years, a combination of factors has seen life expectancies for people with intellectual disabilities increase dramatically. While this improvement is naturally a very desirable outcome, it is resulting in a new crisis: How are a substantial number of people with an intellectual disability going to be supported as they start experiencing age-related issues? The majority of research so far has focussed upon the individual, but little information is available regarding how the frontline direct care staff are coping with this relatively new phenomenon. This study explores the understanding and perceptions of disability support workers in rural and remote areas of New South Wales (NSW) with respect to the most pressing issues facing them as they support people with an intellectual disability who are ageing.

A three-round Delphi research model was utilised over a period of twelve months to examine the views of disability support workers from selected rural NSW organisations regarding issues associated with ageing. The participant group (N=31) included representatives from fourteen different disability agencies covering nine of the ten Department of Ageing, Disability and Home Care designated non-metropolitan regions.

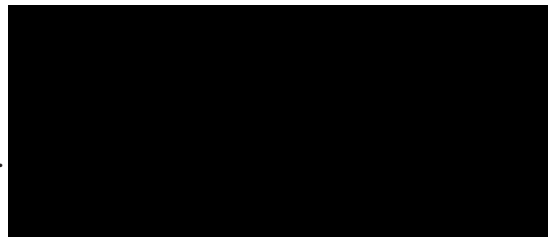
This study detailed and examined a large number of items rated as important by direct care staff in relation to the ageing of people with intellectual disabilities. A thematic analysis of these issues identified specific areas of concern including funding, inadequate or inappropriate training, access to relevant generic and specialist services, medical and health problems, time constraints and paperwork demands, and family dynamics.

On the basis of the research, eleven recommendations were made. The findings of this study have implications for government departments, disability service providers and training entities in both the delivery of services to individuals with intellectual disabilities who are ageing, and for the training of the staff who support this cohort of people. It is believed that the results have the potential to assist in the development of appropriate pathways and options to facilitate direct care staff to work successfully with people with intellectual disabilities who are ageing.

## Certification

I certify that the substance of this thesis has not already been submitted for any degree and is not currently being submitted for any other degree or qualification.

I certify that any help received in preparing this thesis, and all sources used, have been acknowledged in this thesis.



Stuart Wark

## Conference Presentations of Research Findings

**Conference:** 9th Annual ASSID Conference for Disability Support Workers  
**Date:** Wednesday 18 November 2009  
**Location:** Melbourne  
**Title:** Ageing and Intellectual Disability: The Training Needs of Disability Support Workers

**Conference:** Emerging Health Policy Research Conference  
**Date:** Wednesday 11 August 2010  
**Location:** Sydney  
**Title:** Ageing and Intellectual Disability: The Emerging Health Crisis

**Conference:** 45th ASSID Australasian Conference  
**Date:** Friday 1 October 2010  
**Location:** Brisbane  
**Title:** Ageing and Intellectual Disability: Issues for Disability Service Provision

# Table of Contents

<b>Acknowledgements</b> .....	<b>i</b>
<b>Abstract</b> .....	<b>ii</b>
<b>Certification</b> .....	<b>iii</b>
<b>Conference Presentations of Research Findings</b> .....	<b>iv</b>
<b>Table of Contents</b> .....	<b>v</b>
<b>List of Figures and Tables</b> .....	<b>x</b>
<b>List of Abbreviations</b> .....	<b>xi</b>
<b>Chapter One – Introduction</b> .....	<b>1</b>
Introduction.....	1
1.1 Background to the Study .....	1
1.2 Research Aims and Objectives .....	4
1.3 Theoretical Framework for the Current Study .....	5
1.4 Significance of the Research .....	12
1.5 Methodology .....	13
1.6 The Research Setting .....	13
1.7 Key Assumption .....	17
1.8 Key Terms .....	17
1.9 Organisation of Thesis.....	21
<b>Chapter Two - Background to the Current Research</b> .....	<b>23</b>
Introduction.....	23
2.1 Identification of Relevant Literature .....	23
2.2 Introduction to Intellectual Disability and Ageing .....	25
2.2.1 Definitions of Intellectual Disability.....	25
2.2.2 What is Ageing?.....	30
2.2.3 History of Intellectual Disability Services in New South Wales.....	36
2.2.4 Disability Legislation in Australia .....	41
2.2.5 History of Aged Care and Aged Care Standards in Australia.....	46
2.2.6 Australian Funding of Disability and Aged Care Services.....	51
2.3 The Ageing of People with Intellectual Disabilities .....	59
2.3.1 Different Factors of Ageing with an Intellectual Disability.....	62
2.4 Successful Ageing .....	66
2.4.1 Successful Ageing for a Person with an Intellectual Disability .....	69
2.4.1.1 <i>Health Issues</i> .....	70
2.4.1.2 <i>Ageing in Place</i> .....	82

2.4.1.3 Retirement for People with Intellectual Disabilities.....	87
2.4.1.4 People with an Intellectual Disability and Grief.....	89
2.5 Disability Service Provision in Rural New South Wales .....	92
2.5.1 Quality of Life .....	94
2.5.2 Quality of Life for People with an Intellectual Disability .....	98
2.5.3 Person Centred Planning .....	102
2.6 The Disability Sector Workforce .....	106
2.6.1 Training for Disability Support Staff .....	110
2.6.2 Education and Training Programs in Australia .....	116
2.6.3 Aged Care and Disability Work Training Programs in NSW .....	118
2.7 Summary.....	122
<b>Chapter Three - Methodology.....</b>	<b>124</b>
Introduction.....	124
3.1 Methodology .....	124
3.1.1 Overview of the Delphi Method .....	125
3.1.2 Strengths and Limitations of the Delphi Method .....	128
3.1.3 Justification of Delphi Method for Current Study .....	130
3.2 Ethical Issues .....	133
3.3 Setting, Sample and Recruitment .....	133
3.3.1 Population Demographics of NSW.....	133
3.3.2 NSW Government Structure for Disability Support Services .....	133
3.3.3 Recruitment of Sample .....	135
3.4 Survey Instruments .....	137
3.4.1 The Rounds of a Delphi Method Study.....	138
3.4.2 Pilot Study .....	141
3.5 Data Collection and Management .....	143
3.5.1 Contact between Researcher and Participants .....	143
3.5.2 Data Collection Procedures.....	144
3.5.2.1 First Round of the Delphi.....	145
3.5.2.2 Second Round of the Delphi .....	146
3.5.2.3 Third Round of the Delphi .....	146
3.5.2.4 Final Stage of the Research.....	147
3.5.3 Duration of the Data Collection .....	147
3.6 Determinants of Consensus and Importance.....	148
3.7 Limitations .....	150
3.8 Conclusion .....	153



<b>Chapter Four - Results .....</b>	<b>154</b>
Introduction.....	154
4.1 Demographic Characteristics of Study Participants .....	154
4.2 First Round of the Delphi .....	156
4.2.1 Issues Identified for Question One .....	157
4.2.2 Issues Identified for Question Two.....	159
4.2.3 Issues Identified for Question Three .....	160
4.2.4 Issues Identified for Question Four .....	162
4.2.5 Issues Identified for Question Five .....	164
4.2.6 Issues Identified for Question Six .....	166
4.2.7 Summary of Round One of the Delphi.....	168
4.3 Second Round of the Delphi.....	169
4.3.1 Additional Items for Question Three .....	169
4.3.2 Additional Items for Question Four .....	169
4.3.3 Additional Items for Question Five .....	170
4.3.4 Summary of Round Two of the Delphi .....	170
4.4 Third Round of the Delphi .....	170
4.4.1 Analysis of Data for Question One Responses .....	172
4.4.2 Analysis of Data for Question Two Responses .....	176
4.4.3 Analysis of Data for Question Three Responses .....	179
4.4.4 Analysis of Data for Question Four Responses .....	183
4.4.5 Analysis of Data for Question Five Responses.....	187
4.4.6 Analysis of Data for Question Six Responses.....	190
4.4.7 Summary of Round Three of the Delphi.....	193
4.5 Final Round of the Delphi .....	193
4.5.1 Analysis of Data for the Final Round .....	194
4.6 Senior Managers' Views.....	195
4.7 Conclusion .....	198
<b>Chapter Five - Discussion of Results.....</b>	<b>199</b>
Introduction.....	199
5.1 Disability Sector Workforce Demographics .....	199
5.1.1 Demographic Issues in Current Study .....	201
5.2 Discussion of Question One Issues.....	203
5.2.1 Funding.....	204
5.2.2 Training Needs .....	208

5.2.3 Access to Services .....	210
5.2.4 Individual Health .....	214
5.3 Discussion of Question Two Issues .....	214
5.3.1 Generic Health and Support Needs .....	215
5.3.2 Mental Functioning .....	215
5.3.3 Physical Issues .....	217
5.3.4 Emotional or Personality Issues .....	218
5.4 Discussion of Question Three Issues .....	220
5.4.1 Time Constraints .....	221
5.4.2 Family Issues .....	223
5.5 Discussion of Question Four Issues .....	225
5.5.1 Ageing Parents .....	225
5.5.2 Understanding and Coping with Ageing .....	227
5.5.3 Increasing Care Needs .....	228
5.6 Discussion of Question Five Issues .....	231
5.6.1 Training and Staff Development .....	231
5.6.2 Funding .....	234
5.6.3 Access to Services .....	237
5.7 Discussion of Question Six Issues .....	239
5.7.1 Quality of Life .....	240
5.7.2 Medical Issues .....	241
5.7.3 Personal Care Issues .....	243
5.7.4 Counselling Support .....	245
5.7.5 Generic Training Issues .....	246
5.8 Conclusion .....	251

**Chapter Six - Recommendations and Summary.....253**

Introduction .....	253
6.1 Discussion of Training Priorities .....	253
6.1.1 Accredited Disability and Aged Care Training .....	253
6.1.2 Collaborative Training Opportunities .....	257
6.1.3 Local Training Opportunities .....	259
6.1.4 Specific Mental Health Training Opportunities .....	260
6.1.5 Emerging Needs Training Opportunities .....	263
6.1.6 Quality of Life Training .....	264
6.1.7 Family Support Training Opportunities .....	267
6.1.8 Medical Practitioner Training .....	269

6.2 Recommendations from the Study .....	270
6.2.1 Key Recommendation 1 – Mandatory Minimum Qualifications.....	270
6.2.2 Key Recommendation 2 – Appropriate Accredited Training Options .....	271
6.2.3 Key Recommendation 3 – Funded Disability Work Skill Set .....	271
6.2.4 Key Recommendation 4 – Joint Training Agenda .....	271
6.2.5 Key Recommendation 5 – Better Networking.....	271
6.2.6 Key Recommendation 6 – Greater Collaboration .....	272
6.2.7 Key Recommendation 7 – Mental Health First Aid.....	272
6.2.8 Key Recommendation 8 – Accidental Counsellor Training .....	272
6.2.9 Key Recommendation 9 – Mandatory Annual Training.....	272
6.2.10 Key Recommendation 10 – Future Planning Workshops.....	272
6.2.11 Key Recommendation 11 – Quality of Life Training.....	273
6.3 Implications for Future Research.....	273
6.3.1 Large Scale Study of the Rural Disability Workforce.....	273
6.3.1.1 <i>Demographics</i> .....	273
6.3.1.2 <i>Training and Qualifications</i> .....	274
6.3.1.3 <i>Comparative Study of Rural and Metropolitan Service Provision</i> .....	275
6.3.2 Training of Doctors and Allied Health Professionals.....	276
6.3.3 Family and Community Needs .....	277
6.3.4 Research on Emerging Needs.....	278
6.4 Conclusion of the Present Study .....	279
<b>Reference List.....</b>	<b>282</b>
<b>Appendix Contents Page.....</b>	<b>334</b>
Appendix 1 - Letter of Invitation, Information Sheet and Consent Form .....	335
Appendix 2 - Introductory Letter and First Round Questionnaire .....	339
Appendix 3 - Letter of Invitation, Information Sheet and Consent Form for The Ascent Group Staff only .....	343
Appendix 4 - Introductory Letter and First Round Questionnaire for The Ascent Group staff only .....	348
Appendix 5 - Confidentiality Agreement between Principal Researcher and the Research Assistant .....	353
Appendix 6 - Second Round of Delphi Questionnaire .....	355
Appendix 7 - Third Round of Delphi Questionnaire .....	362
Appendix 8 - Final Round of Delphi Questionnaire .....	375
Appendix 9 – Ethics Approval .....	382

## List of Figures and Tables

Figure 1 – Map of NSW .....	14
Figure 2 – Australian Qualifications Framework.....	117
Figure 3 – Map of DADHC Regions .....	135
Figure 4 – Delphi Study Process.....	144
Figure 5 – Age of Panel Members .....	155
Figure 6 – Years of Experience Working with People with Disabilities.....	155
Figure 7 – Highest Education Level Achieved .....	156
Table 1 – Issues Identified for Question One.....	158
Table 2 – Issues Identified for Question Two .....	160
Table 3 – Issues Identified for Question Three .....	162
Table 4 – Issues Identified for Question Four .....	164
Table 5 – Issues Identified for Question Five.....	166
Table 6 – Issues Identified for Question Six.....	168
Table 7 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) for Question One.....	175
Table 8 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) for Question Two .....	178
Table 9 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) for Question Three.....	182
Table 10 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) for Question Four.....	186
Table 11 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) for Question Five.....	189
Table 12 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) for Question Six.....	192
Table 13 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) of the lists for Questions One to Six.....	195
Table 14 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) of the lists for Questions One to Six as Scored by the CEOs .....	198

## List of Abbreviations

Throughout this text, some standard abbreviations are used. These terms are presented in full in the first occurrence in each section, as this will assist the reader to have a clear understanding of the ideas being presented without having to refer back to check on the terminology. The abbreviations are presented below in their alphabetical sequence, not in order of either importance or occurrence within the text.

- Aged Care Assessment Team (ACAT)
- American Association on Mental Retardation (AAMR)
- American Psychiatric Association (APA)
- Australian Bureau of Statistics (ABS)
- Australian Institute of Health and Welfare (AIHW)
- Australian Qualifications Framework (AQF)
- Australian Standard Geographical Classification – Remoteness Areas (ASGC - RA)
- Chief Executive Officer (CEO)
- Chronic Disease Management (CDM)
- Community Aged Care Package (CACP)
- Consumer Price Index (CPI)
- Department of Ageing, Disability and Home Care (DADHC) – NSW Government<sup>1</sup>
- Department of Education and Training (DET) – NSW Government
- Department of Education, Employment and Workplace Relations (DEEWR) – Commonwealth Government

---

<sup>1</sup> In July 2009, a restructure by the NSW Government created the Department of Human Services. This change saw the abolishment of the Department of Ageing, Disability and Home Care (DADHC), with these functions included as a section within the newly created department. The agency is now called 'Ageing, Disability and Home Care, Department of Human Services NSW' (ADHC). As the majority of information cited in this thesis is prior to July 2009, and to prevent unnecessary confusion through changing terminology, the name DADHC is used throughout the document.

- Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) – Commonwealth Government
- Department of Health and Ageing (DoHA) – Commonwealth Government
- Diagnostic and Statistical Manual of Mental Disorders Version IV Text Revision (DSM-IV-TR)
- Disability Professionals Australasia (DPA)
- Disability Professionals New South Wales (DPNSW)
- Disability Services Act (DSA)
- Extended Aged Care Package (EACH)
- Extended Aged Care Package Dementia (EACHD)
- General Manager (GM)
- Home and Community Care (HACC)
- Intelligence Quotient (IQ)
- International Statistical Classification of Diseases and Related Health Problems Tenth Revision Australian Modification (ICD-10-AM).
- Million (m)
- National Disability Services (NDS)
- New South Wales (NSW)
- Non-Government Organisation (NGO)
- Not-for-Profit (NFP)
- Person Centred Planning (PCP)
- Quality of Life (QoL)
- Registered Training Organisation (RTO)
- Rural, Remote and Metropolitan Areas system (RRMA)
- World Health Organization (WHO)