PLANNING FOR CAREGIVING OF ADULTS WITH INTELLECTUAL DISABILITY: AUSTRALIAN PERSPECTIVES

A Thesis submitted by

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For the award of

Doctor of Philosophy

2020

Abstract

Many families of adults with intellectual disability face a lifetime of caregiving, or the difficult decision of trusting their loved one in the care of another. With increased life expectancies for adults with intellectual disability, there is a growing awareness of the importance of residential care planning. Extant literature have identified a number of variables that may influence planning; external factors may include service provision and disability policy, internal factors include caregiver and care recipient characteristics. Whilst external factors highlight influences at a societal level, internal factors highlight the importance of the family system. This system may either adapt to the challenges associated with caregiving or may adopt maladaptive interaction patterns that further prevent caregiver decision-making. While existing caregiving research has investigated individual family member experiences regarding future planning, to date, little research has viewed this issue through a wider family, or social lens. Therefore, the overall aim of this program of research is to combine a macro, meso, and micro level approaches to improve understandings of planning for caregiving of adults with intellectual disability from a social context and from a family systems perspective within Australia.

Study 1 provides an evaluation of caregiving related news stories in Australian print and radio broadcast media. Using quantitative content analysis and news framing, Study 1 analysed six years of news representations of family, residential care, and disability related news stories during a time when major disability policy change was being implemented in Australia. As such, this study provides important insights into the potential impacts of such policy change at a societal level, as presented by, and filtered through, the media. Results indicated that despite Australia's paradigmatic shift in disability policy relevant media news stories were predominantly negative during the period investigated. News media also tended to present the government as culpable. Additionally, whilst news stories were inclusive of

parents as sources, these sources were presented as representative of families, whilst persons with intellectual disability continued to be overlooked.

Study 2 extends this media evaluation, by gathering further qualitative data from television broadcast media during a critical period of policy implementation. This addresses potential differences in media presentation based on modality. Furthermore, the inclusion of discursive methodology allowed for a more detailed examination of language-use in constructing roles and representations of caregivers and government bodies in relation to residential care options. Parent and sibling caregiver roles were constructed as martyred, contrasting with the construction of adults with intellectual disability as perpetual children. This has implications for how the family system may interact and approach care planning. Additionally, negative constructions of the government aligned with representations in Study 1.

Collectively, the qualitative findings from Study 1 and Study 2 highlight that media reporting of caregiving and residential care planning is dominated by a deficit model. Through this deficit-based lens media reports continue to highlight government failings in policy and funding, position persons with intellectual disability as vulnerable and at risk, and present an often singular perspective of family experiences via parent sources. Clearly such a model of presentation has potential implications on family decision making.

In order to examine this decision making, Study 3 used case study design of three family systems to collect in-depth and multiple family member experiences of caregiving and future planning for adults with intellectual disability. Findings revealed that family experiences often deviated from those reported in the media. Understandings of disability, and interactions within the family system shaped family caregiving and attitudes towards future care accommodations. Whilst identifying imperfections within services and government policy, family members did not dwell on these shortcomings as depicted in media representations in Study 1 and Study 2. Though some family members constructed

representations of adults with intellectual disability as perpetual children, others offered an alternative narrative that reflected language of current policy, emphasising the potential for growth and individual choice.

This thesis contributes to knowledge in a number of ways. Firstly, the comprehensive examination of multiple media presentations of disability related issues demonstrates that dominant and stereotypical narratives persist, even when policy change encourages more progressive and inclusive constructions of disability and those with disability. Clearly political change may alone not be enough, social forces driving acceptability of such reporting may be required to shift these deeply embedded representations. Secondly, Study 3 adds to the current literature on family caregiving and future planning by exploring the experiences of multiple family respondents. This helps to inform understandings of the family systems within a disability environment. Finally, this program of research provides support for the utility of a lifespan family systems model in advancing knowledge of, and support services for, families faced with planning for caregiving of adults with intellectual disability. Collectively the challenges and opportunities identified in this body of research may support key stakeholder relations, and inform both organisational and governmental policy designed to improve successful planning and smooth transitioning for individuals with intellectual disability and for all family members.

Keywords: intellectual disability, residential caregiving, lifespan family systems, care planning.

Certification of Thesis

This Thesis is entirely the work of Sonya Winterbotham except where otherwise acknowledged. The work is original and has not previously been submitted for any other award, except where acknowledged.

Principal Supervisor: Professor Bob Knight

Associate Supervisor: Dr Jan du Preez

Student and supervisors signatures of endorsement are held at the University.

Acknowledgements

I often tell people that I ‘fell into’ a PhD, but that is only a part truth because one does not simply ‘fall into’ such an undertaking. If I had not been surrounded by a supportive community of people these past three years would not have been possible. Though I cannot mention you all, special acknowledgements follow.

To my always flexible and calm supervisory team Bob and Jan, I thank you for your continual guidance and belief in me. You gave me direction while allowing freedom, you gave me necessary pushes, whilst accepting that I was not the best deadline keeper. I appreciate and value your invitations to collaborate and the impact such invitations have on my continually developing research abilities. You have given, and I hope will continue to give, advice not just in research but in academic life. Whilst I am still mastering the art of ‘saying no’ I am extremely appreciative of your efforts and advice. I must also pass on my thanks to so many others in the School of Psychology and Counselling, there has always been genuine enquiry and encouragement in relation to my progress through the program. A special thanks to Tanya, you have always offered your time to provide support and feedback.

To my participants, I cannot thank these families enough. Without their generosity of time and openness to share the joy, the heart ache, and the challenges of their lives I simply would not have a body of research to submit. Though they shall remain unnamed I applaud their bravery, I thank them for their honesty, and I remember each of them fondly for what they have contributed.

To my peer group at university, sharing this journey with other PhD students eases the difficulties of the process. We have shared milestones, advice, and on occasion tears. I thank you all for your encouragement, and support whether it was a friendly word or an offer to assist in some way.

To Barb, Cath, and Mortimer, you offered me sanctuary to write in your beautiful home. It was indeed a place of tranquillity that allowed me to make much-needed progress towards the completion of this thesis.

Finally, to my family, you have fed, watered, and sheltered me while I spent many of my days and nights perched in front of a computer screen. Thank you for ‘taking the load off’ and making this so much easier than it would have been had I been made solely responsible for my own well-being. You are my biggest supporters and I could not have done this without you.

This research has been supported by an Australian Government Research Training Program Scholarship.

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List of Abbreviations

ABC	Australian Broadcasting Corporation
ABS	Australian Bureau of Statistics
ACMA	Australian Communications and Media Authority
AIHW	Australian Institute of Health and Wellbeing
CA	Content Analysis
DA	Discourse Analysis
ID	Intellectual disability
ILSI	Independent Living Skills Initiative
IQ	Intelligence quotient
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
PSB	Public Service Broadcasters
SAIF	Supported Accommodation Innovations Fund
SBS	Special Broadcast Service
SDAC	Survey of Disability Ageing and Carers
SES	Socio-economic status
UK	United Kingdom
UN	United Nations
US	United States of America

Chapter 1 - Introduction

The role of family members where there is a child with an intellectual disability (ID) is non-normative. A child with ID may reduce available parental resources for other typically developing siblings (Hartling et al., 2014). Then, whilst these typically developing siblings reach milestones towards independence, the child with ID may remain highly dependent and in the care of his or her parents for an extended period of time (Haveman, van Berkum, Reijnders, & Heller, 1997). As a consequence, parents often view the caregiver role as a lifelong commitment that is exempt from retirement (Llewellyn, Gething, Kendig, & Cant, 2003). This view can lead to parental intent to care for an adult child with ID until parental death or disability restricts the role of caregiver at which point siblings may feel obligated to take on the caregiver role.

Despite several western countries including Australia, the US, and England developing assistance programs to encourage parents to engage in future care planning it is estimated that less than a third of parent-caregivers establish concrete future residential care plans for their sons or daughters with ID (Dillenburger & McKerr, 2011). Concern regarding the absence of future care planning amongst parent-caregivers is two-fold: Firstly, global increases in the life expectancy of both ageing parent-caregivers and adults with ID is likely to negatively impact on associated burden of later-life caring (Llewellyn, McConnell, Gething, Cant, & Kendig, 2010); secondly, the stability and security of the adult son's or daughter's future in regards to financial support, residential security, and social support may be less predictable (Department of Family & Community Services NSW, 2011; Heller, Caldwell, & Factor, 2007; Minnes & Woodford, 2005). Results from Dillenburger and McKerr's (2009) UK study on family caregiving highlight this issue with 48% of participants having no adequate care arrangements even in the event of an emergency (i.e., primary caregiver falling ill). This is particularly concerning for adult children with ID as their ability to self-advocate and therefore self-plan is often compromised (Bigby, 2014), relying either on siblings, or in the case of being an only child, the state, to advocate on their behalf.

Despite the likelihood that adults with ID will, at some point, require care or at least advocacy from siblings, caregiving literature tends to focus on a single perspective from within the family unit, rarely examining dyadic relationships or multiple family member experiences (Qualls, 2016). As western governments (including Australia's) continue to promote a community care model that emphasises the role of family as primary carers, a family systems approach would be advantageous in understanding family perspectives and roles in relation to caregiving and attitudes towards residential care planning. Furthermore, viewing this family system from a lifespan perspective acknowledges changing life expectancies and dynamic roles and relationships as the family ages that can influence care planning decisions, or indecision. Additionally, despite the role of governments in influencing family caregiving via policy and funding, little research has focused on how governments and caregiving issues are portrayed at a societal level, and the potential influence on family of such portrayals.

This thesis will therefore provide a micro level exploration and meso and macro level investigations of family and residential caregiving within Australia. Using a lifespan family systems perspective it builds on prior local and international research by expanding on singular caregiver perspectives, whilst simultaneously acknowledging the influence of social norms and expectations that can be present in various forms of communication such as the media. This chapter will provide further background and research rationale, followed by the presentation of research aims and objectives. Finally, it will summarise the structure of the thesis.

Background

Parent-caregivers are defined, in part, by the Australian government's *Carer Recognition Act 2010* that states:

> A carer is an individual who provides personal care, support and assistance to another individual who needs it because that other individual: (a) has a disability; or (b) has a medical condition (including a terminal or chronic illness); or (c) has a mental illness; or (d) is frail and aged. (p. 3)

Further differentiation between this role and one of an 'employed carer' comes from the use of the term 'informal'; implying that this carer role is one that is not arranged, or formally regulated by government or non-government organisations, and is unpaid (AIHW, 2004). In 2018 it was estimated that Australia had around 2.65 million informal carers (ABS, 2019); parents, spouses, children, and other family members who care for persons in need of assistance.

Parents of adults with ID account for 35% of Australia's informal carers (ABS, 2012b). Notably, according to Australian Bureau of Statistics (ABS, 2012a, 2015) data 9.5% of all primary carers in Australia had been in their caregiving role for more than 25 years. Without adequate planning, Australia's ageing parent-caregivers may remain vulnerable to the physical and psychological strains of caregiving well into their later years (e.g., Chou, Lee, Lin, Kröger, & Chang, 2009; Hammond, Weinberg, & Cummins, 2014), simultaneously placing their adult child at risk of an unknown, unplanned, and therefore unprepared future.

Persons With Intellectual Disability.

Definitions of ID have evolved over many decades to broaden the concept and understanding of this disability. Once viewed primarily as something that could be defined and categorised by IQ scores alone, emphasis is now placed on functional and environmental considerations such as the ability to carry out daily living skills including communication, socialisation, self-care, and practical skills such as meal preparation (AAIDD, 2010). Importantly definitions also include either reference to impairments manifesting during developmental periods, as in the International Classification of Disease-10 (ICD-10; WHO, 1996), or prior to the age of 18 (AAIDD, 2010). This distinguishes ID from other forms of neurological conditions such as traumatic brain injury which may also manifest in similar ways.

The Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) identifies four categories for specifying severity of ID; mild, moderate, severe, and profound (APA, 2013). Mild ID may include some social and functional limitations, whilst those with moderate ID are likely to require social and communicative support, assistance with decision making, and care with personal needs (APA, 2013). Individuals in the severe or profound categories require constant supervision and experience significant communication difficulties in that language can be limited to the use of single words or phrases in speech. Supports are therefore required for communication and all daily living tasks. In addition, those with profound ID are dependent on others for health and safety. Co-morbidity with physical and sensory impairments is common, with an increased likelihood of disorders such as cerebral palsy and epilepsy (APA, 2015). These can further limit participation in social and physical activities. Maladaptive behaviour can be present, however only within a minority of individuals.

From the above it can be seen that caregiver roles for adults with ID may vary greatly. Those with mild ID may be capable of gaining employment and living independently (APA, 2015), whereas those with severe or profound ID are dependent on a carer 24 hours a day and are less able to actively participate in areas such as employment. Whilst the caregiver role for those with mild ID may decline in adulthood as the individual works towards a goal of independent living, for parents of individuals with severe or profound ID the caregiver role may remain intensive and even become more complex throughout their child's adult life. It is estimated that out of around 668,000 Australians with ID, 62% of these experience severe or profound limitations, requiring assistance in one or more of three core daily living activities; mobility (68%), self-care (51%), and/or communication (57%; ABS, 2012b; AIHW, 2008). These complex care needs place ongoing strain on ageing parent-caregivers who, despite the difficulties of maintaining this care regime, remain reluctant to seek alternative care options outside of the family home.

Socio-Cultural Considerations.

Changes in public policy about the preferred locus of care for the person with ID impact the family system. During the era of institutionalisation, parents and family members in Australia were directed by medical experts and legislators to seek out-of-home placement, yet following the global deinstitutionalisation movement that sentiment became anti-placement (Mirfin-Veitch, Bray, & Ross, 2003). These anti-placement attitudes continue to result in the closure and privatisation of group homes in Australia as carers adjust to the introduction of a new disability model. This model, introduced in 2013 represents a significant socio-political change in disability caregiving in Australia. The National Disability Insurance Scheme (NDIS, 2012) recognises the rights of people with disability with a goal of empowering these people to exercise choice and control over support services and their future needs via individualised funding packages (Howard et al., 2015). As an actuarial insurance model, the NDIS provides no-fault insurance cover for Australians under the age of 65, meaning that theoretically the Australian government will cover disability related costs of care and support across an eligible individual's lifetime (Walsh & Johnson, 2013). Whilst many have postulated how the NDIS will affect families of, and individuals with, disability, the impact of the NDIS is unknown. For now, the NDIS rollout continues, with completion of the rollout due by mid-2020 (NDIS, 2019).

The use of language in disability policy in general has also been criticised for placing responsibility of care on parents, whilst ignoring crucial supports such as siblings (Grant, 2000; Twigg & Atkin, 1994; Waldren & Strohm, 2010). At the same time social representations of persons with ID often position these people as vulnerable, pitiful, and childlike, reinforcing the need for care, whilst failing to present alternative representations of growth, and development into adult milestones (Renwick, 2016). These public and political constructions of caregivers and care recipients is likely to increase feelings of parental obligation whilst fuelling parent's doubt that their adult child with ID will be able to successfully and safely live independently or semi-independently.

Rationale for Present Research

Families of adults with ID are clearly facing a new reality. A parent's dedication to a "lifetime of care" may no longer be sufficient to sustain the care needs of an adult with ID. Yet community care models and government policy may increase feelings of obligation (Waldren & Strohm, 20100, adding to the difficulty, or even avoidance, associated with future residential planning for these adults. How this new reality is constructed and experienced is poorly understood.

Whilst caregiver research often considers the influence that government funding and policy has on future residential care planning, little consideration has been given to the potential influence of broader social norms. The media in particular is a powerful entity in constructing representations of issues and people, including families and government policy. These representations can influence populist beliefs and behaviours. Examining such representations may therefore help explain tightly held family or individual beliefs in relation to caregiving roles, responsibilities, and available residential care options. Study 1 and Study 2 addressed this by examining how multiple modalities of media present issues relating to ID, family, and residential care.

Though existing caregiving literature acknowledges the importance of the family system (e.g., Davys, Mitchell, & Haigh, 2010; Hodapp, Burke, Finley, & Urbano, 2016), study designs continue to place emphasis on the individual rather than the family (e.g., Grey, Totsika, & Hastings, 2019). Parent and sibling roles have received much attention individually, particularly in relation to caregiver health and wellbeing, however the family system and the influence of relationships within this system on future care planning have not received the same attention. The present research addressed this gap in the literature by recruiting families of adults with ID as cases in Study 3, rather than exploring individual caregivers. By examining the family as a whole system, this has the potential to provide insights into how the functioning of family systems may act to enhance or inhibit future residential care planning.

Additionally, research, government policy, and media have all been criticised for placing little or no emphasis on the voices of those with disability. Whilst it is acknowledged that those with profound ID may experience challenges with comprehension and communication, it should not be assumed that family or government representation adequately addresses this population’s wants and needs. The absence of those most affected by policy and family decision-making will be documented and critically examined throughout this program of research.

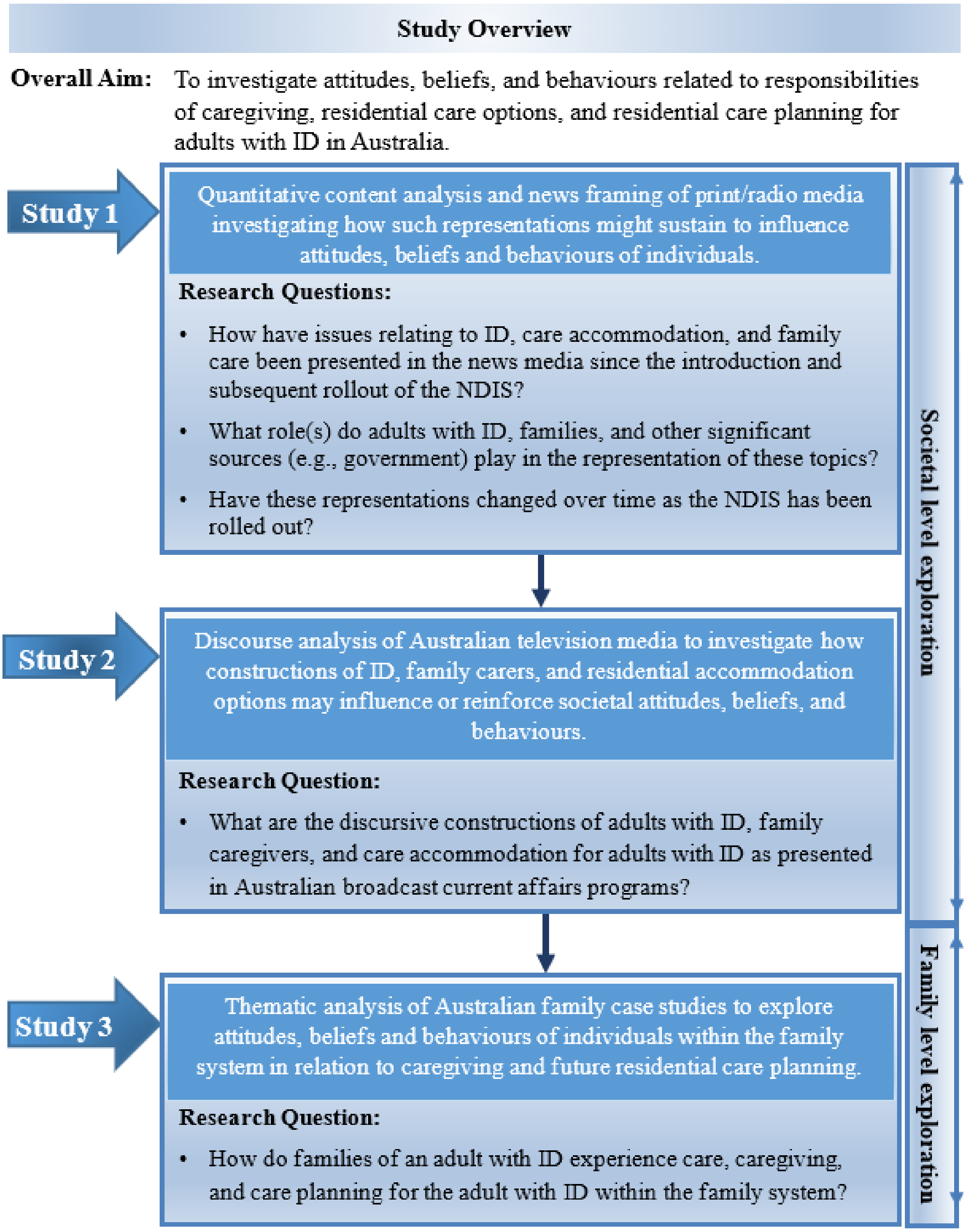
Finally, exploration of residential care planning and related challenges has typically been explored via cross-sectional survey design, and predominantly in UK and US literature. Whilst these designs have the benefit of potentially capturing large cohorts of caregivers the data collected from such designs may be insufficient for understanding the complexities and nuances of issues surrounding future residential care planning. Furthermore, validated survey instruments are rarely reported as part of the research design in caregiving literature. It is therefore possible that constructed questions may not accurately capture intended meaning thus may be open to interpretation by the caregiver, without opportunity to request or receive clarification. Even with the inclusion of open ended questions that allow for qualitative data capture, these tend to offer respondents limited space for a detailed and rich response, again with no clarification available to either participant or researcher. This research program therefore utilised qualitative methodology in Study 3 (interview and observation) to address these limitations. This methodology allowed the researcher and participants to build rapport which can assist with open and honest responses. The interview protocol encouraged rich and detailed responses absent from quantitative methods, and also provided opportunity for participants to redirect the interview to topics of importance, which may not have been established in previous research.

Aims and Research Questions

The overall aim of this thesis was to investigate attitudes, beliefs, and behaviours in relation to responsibilities of caregiving, residential care options, and residential care planning for adults with ID in Australia. This was explored at a macro/societal level (via Australian media representations), meso level (via television media directed family stories) and a family/micro level (via interviews with family members of adults with ID). Given that the literature suggests that this process has consequences for all family members, it is important that research explores more than a singular perspective. A multi-informant approach allowed for the examination of family care networks and complex family relationships, whilst the implementation of a lifespan family systems perspective illuminated how families navigated caregiving duties, external support systems, and government policy across time (Berg, Kelly, & Utz, 2019).

This research consists of three studies (refer to Figure 1.1). The key research questions in Study 1 are: (a) how have issues relating to ID, care accommodation, and family care been presented in the news media since the introduction and subsequent rollout of the

NDIS?; (b) what role(s) do adults with ID, families, and other significant sources (e.g., government) play in the representation of these topics?; and (c) have these representations changed over time as the NDIS has been rolled out? Study 2 expands on the knowledge gathered in Study 1 by asking: What are the discursive constructions of adults with ID, family caregivers, and care accommodation for adults with ID as presented in Australian broadcast current affairs programs? Study 3 explores the topic at a family level perspective, as such the key research question is: How do families of an adult with ID experience care, caregiving, and care planning for the adult with ID within the family system?



Overall Aim: To investigate attitudes, beliefs, and behaviours related to responsibilities of caregiving, residential care options, and residential care planning for adults with ID in Australia.

Quantitative content analysis and news framing of print/radio media investigating how such representations might sustain to influence attitudes, beliefs and behaviours of individuals.

Research Questions:

- How have issues relating to ID, care accommodation, and family care been presented in the news media since the introduction and subsequent rollout of the NDIS?
- What role(s) do adults with ID, families, and other significant sources (e.g., government) play in the representation of these topics?
- Have these representations changed over time as the NDIS has been rolled out?

Discourse analysis of Australian television media to investigate how constructions of ID, family carers, and residential accommodation options may influence or reinforce societal attitudes, beliefs, and behaviours.

Research Question:

- What are the discursive constructions of adults with ID, family caregivers, and care accommodation for adults with ID as presented in Australian broadcast current affairs programs?

Thematic analysis of Australian family case studies to explore attitudes, beliefs and behaviours of individuals within the family system in relation to caregiving and future residential care planning.

Research Question:

- How do families of an adult with ID experience care, caregiving, and care planning for the adult with ID within the family system?

Figure 1.1. **Flow chart of studies conducted in present research.**

Philosophical Positioning

Social Constructionism is a philosophical framework for understanding meaning and knowledge as a product of human relationships. Meaning is historically and culturally situated (Burr, 2015). Therefore, it is argued that research enquiries extend beyond individuals to consider social, political, and economic environments. The following program of research will discuss relevant historical contexts to situate the reader, and then through mixed methods enquiry explore a broad range of social constructions in relation to intellectual disability and caregiving within an Australian context.

According to social constructionism identities are constructed and negotiated through social interactions using language as a core component of such constructions (Burr, 2015). Language conventions may vary dependent on activities, objects, or settings with human motivation key to conformity of such conventions. Across the following studies, three different settings are explored; Australian print media, Australian television media, and Australian families. In all three there is a central focus on language; in Study 1’s media content analysis language was a key component of the unit of analysis, in Study 2 discourse analysis examined interactions for instances where language and talk constructed identities meaning and understanding, and in Study 3 a thematic analytic approach to the data also allowed for an exploration for how individuals build accounts of themselves, their families, disability and caregiving. Through the synthesis of such macro (Study 1) meso (Study 2) and micro (Study 3) approaches, this research can reveal how families are simultaneously positioned by discourses and how they draw on such discourses to position themselves and others (Burr, 2015; Potter & Wetherell, 1987).

Finally, the focus on social construction and interaction also highlights the significant relationships that researchers experience during such an undertaking as a thesis; for example, the relationships between researcher and the subjects of research. This thesis recognises and discusses such relationships via reflexive statements throughout each study, acknowledging the inherent challenges with objectivity and highlighting that ultimately there are different ways of understanding the world around us.

Structure of Thesis

This chapter provides an overview of the research including brief contextual information, rationale, and summary of research design. Chapter 2 presents a literature review outlining constructions of ID historically and in a post-institutionalisation era. Additionally, it discusses socio-cultural and political factors, including Australia's recent disability reform, presents a summary of caregiving research of parents, siblings, and adults with ID, and finally situates the context of family caregiving within family systems theory to provide an overview of the framework chosen for this research.

Chapter 3 presents a detailed description of the methodologies used in Study 1, including quantitative content analysis and news framing. A rationale for the selected media and search dates will be provided, along with details of search criteria and key search terms. Search results and characteristics of the Study 1 sample will be presented. Acknowledgment of the role of the researcher will be presented via statements of reflexivity. Chapter 4 will then report the results of the quantitative content analysis and news framing.

Chapter 5 describes the methodology for Study 2, which aims to expand on the knowledge gained in Study 1. The importance of exploring different media modalities will be discussed, followed by an outline of the search procedure including a rationale for inclusion/exclusion of data, and description of the final sample. This will be followed by a detailed description of the qualitative design, including analytic concepts and procedures. As per Study 1, the role and impact of the researcher will be presented via statements of reflexivity. Chapter 6 will report Study 2 findings from this qualitative analysis.

Chapter 7 provides a summary, synthesis, and discussion of Study 1 and Study 2. The aim of this chapter is to present an overview of media representations and constructions of ID, caregiving, and accommodation issues. Consideration is given to how these findings are positioned within current literature. This chapter completes the societal level exploration of the topic.

Chapter 8 describes case study methodology and its application to Study 3. A detailed description of the three cases (with family as unit) will be presented. Following this, the chapter will detail the data collection procedures with each family, including interview and observation. The six phases of thematic analysis will be outlined, as will steps taken to improve rigour and credibility. As with Study 1 and 2, the position and potential influence of the researcher will be considered via statements of reflexivity. The findings of the exploration of the three cases (families) are presented in Chapters 9 -11, with a chapter devoted to each case.

Study 3 data is revisited in Chapter 12 with consideration given to unique familial roles (i.e., parent, sibling, adult with ID). This perspective allows for the presentation of a cross-case analysis of data. This chapter will present findings with consideration given to congruence and divergence across cases.

Chapter 13 presents a summary and discussion of Study 3 data, bringing together the individual case findings and cross-case analysis. Implications for individuals, families, care agencies, and governments will be considered. Limitations of the study will also be presented.

Finally, Chapter 14 provides an overall discussion drawing on the findings from all three studies. It will consider how these studies address the overall research aims and contribute to extant knowledge. Limitations of the present research will be presented along with implications, recommendations, and future research directions.

Chapter 2 – Literature Review

Formal and informal caregiving roles for those who support individuals with intellectual disability (ID) have been influenced by medical advancement, lifespan changes, and evolving social, political, and cultural constructs of ‘disability’. This chapter will present an overview of historic global and local disability changes that have occurred, including ideological shifts from segregation to normalisation, and more recently in Australia, a drive for choice and control. Following this will be a review of international family caregiving literature in relation to future planning for adults with ID. Finally, a lifespan family systems approach to family caregiving and residential care planning will be considered.

Terminology for identifying persons with ID differs across time and region. In exploring the literature, a number of broad search terms were used to capture this range and variability, ensuring that literature featuring accepted alternative terminology such as learning disability (prominent in UK literature) and developmental disability (prominent in US literature) were not excluded. In addition to these broader terms, more specific search terms (e.g., Down syndrome) also formed part of the overall search strategy. Findings are discussed using the authors’ terminology in the original literature as acknowledgment that some terms (i.e., developmental disability) may include ID (as defined in Chapter 1) as well as additional developmental conditions such as autism spectrum disorder which may not necessarily be indicative of an ID.

A Brief Review of the History and Construction of ‘Intellectual Disability’

ID has a history of being misunderstood. In previous centuries terms such as ‘imbeciles’, ‘idiots’ and ‘natural fools’ were common descriptors of people with ID in many countries; these terms appear in abundance throughout the literature of the day, including legal documents and government policy (Goddard, 1915; Neugebauer, 1996). Idiocy was thought to originate from demons or supernatural causes and hence was deemed the domain of philosophers or priests (Neugebauer, 1996). This lack of understanding regarding the aetiology of ID gave rise to further superstitions such as the belief that idiocy was a consequence of the parental sins (Wolfensberger, 1975). To be labelled an idiot, imbecile, or fool meant dispossession; land was handed over to the custody of kings, while the intellectually disabled were left to roam the streets (Neugebauer, 1996). Dispossessed, but not yet segregated, people with ID existed in the community, yet it is poorly understood whether community based living was due to an ideology of 'community care', or rather whether this reflected community neglect. Regardless, community based living would not last with 'containment' of both those labelled fools and lunatics commencing as early as the 15th century (Foucault, 1967).

By the 17th century the rise of institutions was occurring across Europe. Conditions were appalling and few could argue that these institutions represented opportunities for treatment, but rather provided nothing more than segregation and confinement (Foucault, 1967). During this period little to no distinction was made between those with mental illness and those with ID (Neugebauer, 1996). Though society was beginning to view ID from a more medicalised model, aetiology was still poorly understood with parents believing ID was the result of antenatal or post-natal incidents such as the mother experiencing severe shock during pregnancy (Wright, 1996).

The 18th century brought about a significant shift in the understanding and treatment of people with ID. During this period ID came to be understood as an illness. This brought about a medical model of care across Europe, promoting the establishment of institutions that offered treatment and rehabilitation rather than simply containment (Drake, 2010). Despite movement for reform, change was still slow, with the terms 'idiots' and 'fools' remaining commonplace during this time. People with ID would wait another century before marked shifts in ideology and policy would occur.

Countries including the US and Australia followed in the footsteps of their European counterparts, constructing asylums and institutions for the intellectually disabled and mentally ill from the early 19th century (Swain, 2014). Yet by the 20th century language began to change and policy would soon follow. Once ‘idiots’ and ‘fools’, people with ID would be recognised as people with ‘mental retardation’ (Drake, 2010). Differentiation between those with mental illness and ID was recognised, though this was often not reflected in alternate models of care (Drake, 2010). By the early 1920’s Royal Commissions had commenced into the treatment of people with ID in British institutions (Jones, 1993, as cited in Drake, 2010). Recommendations argued for community services over institutional care, thus began the ideological shift away from segregation. Australia and the rest of the world would wait another four decades before similar enquiries and socio-political movements would occur.

It is largely acknowledged that Blatt and Kaplan’s (1966) seminal work *Christmas in Purgatory: A photographic essay on mental retardation* was instrumental in strengthening the deinstitutionalisation movement that would become an international phenomenon (Wiesel & Bigby, 2015; Young, 2003). Although their essay exposed conditions in US institutions, global discontent and outrage followed this graphic portrayal of institutional living (Wiesel & Bigby, 2015). This revelation appeared to be indicative of institutional conditions around the world, with Wiesel and Bigby (2015) describing living conditions in Australian institutions as ‘atrocious’ “characterised by overcrowding, disease, neglect, a culture of resident abuse, regimentation of daily activity and restriction of individual freedoms” (p. 182). Blatt and Kaplan’s publication occurred at a time when the ideological movement of ‘normalisation’ (Nirje, 1969) was gaining momentum, and simultaneously when civil rights was at the forefront of social consciousness; thus creating a ‘perfect storm’ for social, political, and ideological change. It is therefore no wonder that this movement went beyond addressing abuse and neglect, but would challenge discrimination, isolation, segregation, and separation (Young & Ashman, 2004).

Though one cannot ignore the ideological forces behind the normalisation movement, deinstitutionalisation also addressed a more politically practical issue – economics. Institutions were ageing, government enforced standards of care meant that that the cost of ‘humanising’ these institutions was not fiscally sound (Drake, 2010; Wiesel & Bigby, 2015). Governments could identify the economic benefits of alternative community based care, relieving the government of the financial burden in a cost-efficient manner (Drake, 2010; Twigg & Atkins, 1994). In fact, in countries such as the US the economic motivation was deemed so powerful that some argue that deinstitutionalisation had little to do with concern for the welfare of those housed in institutions, but was primarily a treasury based decision (Thomas, 1998). Thus, governments overwhelmingly conceded that change was overdue, though the speed with which they would respond did not always reflect the force behind the movement for change. Even changes unrelated to policy, such as the removal of terminology now deemed inappropriate has been slow, for example the American Association on Intellectual and Developmental Disabilities (AAIDD) only removed the term ‘mental retardation’ from its name in 2006 (Scior, 2016). It is interesting to note that through the process of deinstitutionalisation, consideration was largely given to the life quality of the person with disability, with little focus on the family members who were about to be encouraged to take sole responsibility for the care of their son, daughter, sister, or brother with ID (Cummins, 2001).

Deinstitutionalisation

Compared with other countries, Wiesel and Bigby (2015) argued that Australia’s process of deinstitutionalisation has been slow and remains incomplete. Whilst many countries commenced deinstitutionalisation in the 1960’s and 1970’s, deinstitutionalisation in

Australia commenced in the 1980's (Queensland government, 2013). Wiesel and Bigby argued that despite three decades of slowly downsizing or closing major institutions throughout Australia, by 2010 the National Disability Strategy (NDS) failed to offer any further plans for deinstitutionalisation. In 2011-2012 Australian institutions were continuing to take new admissions; most of these residents were identified as having ID (AIHW, 2013).

Perhaps what this indicates is that institutionalisation and therefore deinstitutionalisation is deeply complex, it is not simply a matter of closing doors and rehousing those who were once residents of these institutions. Parent groups have been responsible for both driving change and slowing it (Weisel & Bigby, 2015). In understanding this, one must acknowledge that institutionalisation was once an option that was at the very least encouraged, if not expected of families (Jones & Gallus, 2016; Queensland government, 2013). In the absence of home-based supports, families viewed institutions as a solution to long term caregiving, even after parents were no longer alive (Chenoweth, 2000). Parents who were once given 'permission' by community members and medical practitioners to seek out-of-home placement, therefore perceived the closing of institutions as actions that implied that parents had done something wrong (Mirfin-Veitch et al., 2003).

Parents of those housed within institutions believed that deinstitutionalisation occurred without consideration of the family (Mirfin-Veitch et al., 2003). Parents also felt that their son's or daughter's institutional history was ignored or disrespected, many of whom had lived in institutions from a very young age and therefore saw the institution as a home full of meaningful relationships with other residents and staff (Jones & Gallus, 2016). For some parents deinstitutionalisation was not welcomed; they were unprepared for change, experienced negative judgment from others, and felt pressure to conform to this new social norm (Jones & Gallus, 2016). In response to the deinstitutionalisation movement there was growing stigma attached to institutional care as those once encouraged to seek out-of-home treatment now felt ostracised, expressing feelings of guilt, remorse, fear, and worry (Jones & Gallus, 2016; Mirfin-Veitch et al., 2003).

The outcomes of deinstitutionalisation are therefore many and varied. Most parents agree that deinstitutionalisation has resulted in an increased quality of care (Jones & Gallus, 2016). It is also generally accepted that deinstitutionalisation has resulted in improved quality of life for people with ID (Young & Ashman, 2004). Studies in both Australia and the US have further indicated that specific adaptive skills that promote independent living, such as self-care, communication, and social skills, have improved significantly for those rehomed from institutional living into community care (Chenoweth, 2000; Kim, Larson, & Lakin, 2001; Young, Ashman, Sigafoos, & Grevell, 2001). The shift towards community care has also resulted in new accommodation options around supported and independent living (Drake, 2010; Queensland government, 2013; Wiesel, 2015). Despite these favourable outcomes, Felce (2017) warned that the superiority of community care may be due to the poor quality within institutions rather than an excellence in community care.

There is also evidence to suggest that deinstitutionalisation has not been beneficial for all people who have transitioned (Queensland government, 2013; Young & Ashman, 2004). In reviewing longitudinal outcomes, Young and Ashman (2004) found conflicting results; though some studies showed improved quality of life, for many relocated residents life appeared to be no better than in the institution. Young and Ashman argued that relocation did not necessarily correlate with improved outcomes and it was reckless to assume otherwise. Other reports warn of the risk of homelessness and re-institutionalisation (Simpson 2017; Queensland government, 2013). Geographical relocation is simply not enough to bring successful outcomes without appropriately supported accommodation and active community engagement (Queensland government, 2013; Young et al., 2001).

Resistance to deinstitutionalisation has at times, been as powerful as the movement in support of it. In 1996, family and public outcry led the Queensland government abandoning institutional reform (Chenoweth, 2000). By 1998, this resistance effected further change with a newly elected Labor government committing to the development of two new centres to house 30-40 former institutional residents (Chenoweth, 2000). As Chenoweth (2000) noted, those with complex needs were often left in institutions until the last wave of deinstitutionalisation, some clearly not making the move to community living at all.

Other criticisms of deinstitutionalisation have questioned whether the core goals of the movement have been achieved (Australian government, 2009; Wiesel & Bigby, 2015). Critics argue that smaller group homes are essentially ‘mini-institutions’ (Wiesel & Bigby, 2015). Others refer to a process of ‘transinstitutionalisation’ – where essentially the person has simply moved from one form of government run institution to another (nursing home, prison, shelter, hospital) where the culture is the same (Wiesel & Bigby, 2015). Furthermore, it has also been argued that whilst people with disability may live in the community, this has not progressed to meaningful community participation (Chenoweth, 2000; Simpson, 2017; Wiesel & Bigby, 2015); in fact, the following damning summary was provided in a report to the Australian government:

> Once shut in, many people with disabilities now find themselves shut out. People with disabilities may be present in our community, but too few are actually part of it. Many live desperate and lonely lives of exclusion and isolation. The institutions that once housed them may be closed, but the inequity remains. Where once they were physically segregated, many Australians with disabilities now find themselves socially, culturally and politically isolated. They are ignored, invisible and silent. They struggle to be noticed, they struggle to be seen, they struggle to have their voices heard (Australian government, 2009, p. 1).

One of the major factors in the promotion of the deinstitutionalisation movement was reports of abuse and neglect (Queensland government, 2013). Jones and Gallus (2016) highlight that parental concerns regarding their son’s or daughter’s risk and vulnerability still remains post-deinstitutionalisation. Some parents remain fearful of their son’s or daughter’s safety with exposure to the community potentially posing new risks (Fisher, Baird, Currey, & Hodapp, 2016). In 1992, Wilson and Brewer published a seminal paper on vulnerability and victimisation of adults with ID, in this paper it was found that any congregate setting (institution or group home) led to increased risk of victimisation, most likely at the hands of other individuals with ID. Fisher et al. (2016) reviewed the more recent literature concluding that the shift from institutions to community-based care had not stopped the abuse, but rather presented environments where new forms of victimisation can occur. Furthermore, outcomes for those who remain living in institutions have not been encouraging; in a 2013 Queensland advocacy report institutional conditions produced negative outcomes on the health and wellbeing of occupants which resulted in a loss of skills required to live in the community (Queensland government, 2013). Though the days of appalling conditions and neglectful treatment may be fading, a solution offering equality, security, and safety is far from being realised.

Impact of Life Expectancy

Life expectancy has increased for both the adult with ID and typically developing adults; one must therefore consider how life expectancy has altered the landscape of caregiving over the past century. In 1931 the life expectancy of an adult with an ID was 22 years (Carter & Jancar, 1983). Care, whether in-home or institutional was relatively short; family caregiving did not last for much longer beyond that of ‘normative’ parental caregiving (i.e., when in emerging adulthood it is typical for an adult child to launch into an independent lifestyle). Parents outlived their sons or daughters with ID, and therefore outlived the role of caregiver. In 2002, the life expectancy of an adult with an ID ranged from around 50 to 60 years of age for people with more severe disabilities to around 70 years of age for adults with mild to moderate disabilities (Bittles et al., 2002, Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000). Felce (2017) argued that an increase in life expectancy has a flow-on effect in that it increases pressure on funding and service budgets. In addition to economic impacts, increased longevity for adults with ID also represents a significant change for around 25% of Australia's informal caregiver population who identify as parent carers (ABS, 2015).

Life expectancy for typically developing adults has also increased. The average life expectancy for males is around 80 years of age and for females around 84 years of age (ABS, 2016). Thus the caregiving role for parents providing in-home care for a son or daughter with ID is extending for decades beyond that of 'normative' parental caregiving. In 2009 in Australia there were 218,700 adult children being cared for by their parents in the family home, for adult children aged 35 or older, 80% of parent-carers were aged 65 or older (Qu, Edwards, & Gray, 2012). For many parents, sons and daughters with ID will now outlive them, resulting in an increased need to plan for care beyond the life of the parent, or beyond the ability of the parent to provide such care.

National Disability Insurance Scheme (NDIS)

In 2009, submissions received by the Australian government in response to the National Disability Strategy consultation process, described Australia's disability service system as "chronically under-funded and under-resourced, crisis driven, struggling against a vast tide of unmet need" (Australian government, 2009, p. 4). So dire were these views, the service system was deemed fundamentally flawed "requiring a paradigm shift to deliver lasting change" (Australian government, 2009, p. 5). Four years later, the introduction of Australia's National Disability Insurance Scheme (NDIS, 2012) promised to deliver this much needed paradigm shift in disability ideology, funding, and policy.

The NDIS is also a major economic investment with projected costs of around $23.6 billion per year by 2019-2020 (Australian Government Productivity Commission, 2017). By the time the NDIS roll-out is complete and the scheme is fully operational, the NDIS is expected to cost almost double that of pre-NDIS spending on equivalent services (Buckmaster, 2017). The NDIS operates via a needs-based tiered system of funding, providing no-fault insurance to Australians under the age of 65 meeting the criteria for physical, cognitive, or psychosocial disability (Collings, Dew, & Dowse, 2016). The aim is to provide more individualised support than has been previously available; as a result funding for carer and respite support services have been subsumed under new National Disability Insurance Agency (NDIA) state funding (Kemp, King, Paleologos, Bellamy, & Mollenhauer, 2016). This major policy change may profoundly impact on current strategies for future care planning as it represents a marked change in financial and care assistance programs. Furthermore, it aims to place the person with the disability at the centre of all decision making (Howard, Blakemore, Johnston, Taylor, & Dibley, 2015). Howard et al. (2015) however suggest that the scheme raises questions regarding the role of parent-caregivers and the potential for family isolation as a result.

Though noting that it was a ‘work in progress’, Bigby (2014) warned that despite people with intellectual disabilities forming the largest group of NDIS participants (60-70%), complex issues such as how to enable choice for this group were not thoroughly addressed. Early research further suggests that this new focus on empowering care recipients has for some, left caregivers excluded from assessment and planning (Kemp et al., 2016). Twigg and Atkin (1994) have acknowledged that family caregivers play a significant role in negotiating services and contributing to the decision making, therefore any exclusion of caregivers has the potential to result in support plan deficiencies that may unintentionally increase burden of care for parents and other informal caregivers (Kemp et al., 2016).

Further concern has been raised by Dowse et al. (2016) in relation to NDIS service providers. They claim that the NDIS may not be able to deliver required support due to a workforce that lacks appropriate competencies and capacity. If NDIS support is not delivered appropriately, this could feed into parental fears and exacerbate negative experiences with service providers, which ultimately affect parent's confidence in planning future residential accommodation. This confidence may further be impacted by claims such as Laragy's (2017) that the NDIS does not have sufficient mechanisms to protect vulnerable participants.

Not all studies are reporting the potential for negative outcomes, Weisel (2015) suggests that the NDIS represents a unique opportunity to unlock new housing options for people with ID. Extensive NDIS funding will facilitate the development of new independent and shared living choices, offering people the opportunity to pool their funding for shared residential living (Wiesel, 2015). In addition to NDIS funding for alternative housing options, programs such as the Independent Living Skills Initiative (ILSI) and the Supported Accommodation Innovations Fund (SAIF) have been developed to further housing opportunities and assist adults with ID to strive for residential independence (Wiesel et al., 2015). Though Wiesel notes that financial restrictions to these new opportunities remain, the addition of these new residential placement options may provide an important impetus for change in parental attitudes toward future care planning, particularly for those who view current residential planning options as unfavourable or inadequate.

Whilst a full review of the effects of the NDIS is outside the scope of this research project, it would be timely to explore how caregiver's or care recipient's residential future planning has been impacted by the scheme thus far. For example, whether caregivers and care recipients have knowledge of any new residential options and whether these alternatives are viewed as viable in considering future planning strategies. International studies have frequently found institutional care to be deemed unacceptable by parents, though in other countries these kinds of residential facilities may be the only available options. In an environment that is beginning to offer alternatives it would be interesting to explore parent's attitudes to a range of living choices.

Changing Ideologies

The deinstitutionalisation movement went beyond physical closures of homes, to changing disability ideology, with Mirfin-Veitch et al. (2003) arguing that this resulted in disability support services becoming 'anti-placement'. Gilbert, Lankshear, and Petersen (2008) also noted that the closure of many residential facilities during the deinstitutionalisation movement created fear among parents that remaining facilities were unstable and did not represent trusted options. Mirfin-Veitch et al. further suggest that external care accommodation such as institutions are now viewed as the equivalent to 'abandonment'. If attitudes such as this persist, surely this only increases the difficulty in residential planning, especially when parents who made these decisions during a time when institutional care was socially acceptable described this as "the hardest and most painful decision of their lives" (Mirfin-Veitch et al., 2003, p. 105).

In addition to 'anti-placement' attitudes, one must not underestimate the power of government ideologies in constructing and supporting a care model that positions families as ethically, morally, economically, and affectively responsible for the care of sons and daughters with disability. Government policy increases the pressure on families to maintain in-home or at least in-family care arrangements, effectively trapping families in their caregiving role (Grant, 2000). Twigg and Atkin (1994) argued that governments view family caregivers as a resource, essentially providing free no-cost labour, allowing governments to minimise investment in social service systems. Whilst the latter half of this argument may have reflected government economics in the mid 1990's, more recent redirection of government funding, particularly in Australia, has seen an increase in both national and state committed funds to disability support programs. However, despite investment in these services this does not mean that government policies do not strongly encourage family care as a preferred care option.

Whilst it is beyond the scope of this thesis to review or debate the inherent issue of whose responsibility it is to care for disabled community members, it is never-the-less important to acknowledge that there has been a marked shift in responsibilities in many countries and over many centuries. For example, Neugebauer's (1996) research into the history of disability in England revealed; responsibility in medieval England clearly lay with the Crown to ensure protection of person and property for individuals with intellectual or mental disability. Though the language of legal documents detailed custody over person and possession, Neugebauer argued that the Crown accepted a responsibility to provide at least the bare necessities of life to the individual with the disability. Though the motivation for this responsibility was linked to royal revenue, the documentation of laws such as idiocy grants, allowing for custodial purchases of 'idiots', on the basis that individuals (labelled idiots) would be provided with bare necessities (Neugebauer, 1996).

In contrast to the language of government guardianship, today's policy documents are driven by language that essentially removes government responsibility and instils an obligation of family care. For example, a Siblings Australia report suggested that in the face of a crisis in accommodation for adults with disability, Australian government policy used language that simply expected that adult siblings would take over the care duties rather than demand out-of-home care provisions (Waldren & Strohm, 2010). Participants in this project accused the government of using carer language to exploit family guilt and promote carer expectation with families arguing that the term 'carer' was used to abdicate community or government responsibility, placing the emphasis back on family (Waldren & Strohm, 2010). This suggestion is supported by Twigg and Atkin (1994) who argued that replacing the term ‘carer’ with family friendly terms such as ‘parent’ or ‘sibling’ would not imply the same level of obligation or responsibility. Williams and Robinson (2001) further note that the term ‘care’ is not used by either parent or adult child to describe this active relationship. Yet the ‘carer’ model continues to be reinforced in the language of legislation and therefore one must be willing to adopt it in order to seek support from relevant organisations.

Waldren and Strohm (2010) also note the impact of the use of the term ‘relinquish care’ in the event that the adult with disability is placed within a government supported out-of-home accommodation service. ‘Relinquish’ is a word synonymous with terms such as ‘give up’ or ‘abandon’ which may cause further anguish and create further parental guilt. Interestingly, Bowey, McGlaughlin, and Saul (2005) suggest that terms such as ‘independence’ may also create anxiety for parents of adults with ID. Though ‘independence’ may, for many, carry positive connotations around concepts of freedom, Bowey et al. found that parent carers associated the word ‘independence’ with lack of support. This highlights the importance of language use not only in generating policy and service documentation, but in all communication between services, governments, communities, and families.

Language embedded in Australia’s NDIS may also influence ideologies of care. With a focus on addressing inequities in previous welfare policies, the NDIS uses language emphasising choice and control for people with disability (Howard et al., 2015). Wiesel and Bigby (2015) argue that with the introduction of the NDIS the language of disability policy is moving away from ‘normalisation’ to ‘individual choice’. This is an interesting shift as parents of those previously residing in institutions questioned whether ‘choice’ (a key principle underpinning the NDIS model) was taken away during the deinstitutionalisation movement, inevitably removing one’s choice to remain in an institution. Wiesel and Bigby suggest that institutions should be viewed as one of the options available to adults with ID and their families.

Disability ideologies and the mass media.

Wolfensberger, Nirje, Olshansky, Perske, and Roos (1972) argued that mass media has the power to set expectations of people by repeatedly ‘casting’ them into certain roles or portrayals, for example arguing that people with ID may be typecast as an ‘object of pity’ or ‘eternal child’. One must note that Wolfensberger et al.’s comments were published over 40 years ago, as such today’s news media has the power to either reinforce these existing ideologies or to drive change in political agendas and policy (Fraser & Llewellyn, 2015; Wilkinson & McGill, 2009). Yet despite the latter, media representations continue to be criticised for depicting people with ID in a negative and stereotypic manner (Renwick, 2016). In a review of literature on mass media representations, Renwick (2016) found that print media tended to focus on children with disabilities rather than adults, and to focus on those with less severe and less complex needs. Print media portrayals also tended to emphasise deficits with only a minority of news stories featuring affirmative stories of achievement (Renwick, 2016).

Carter, Parmenter, and Watters (1996) reviewed Australian print media representations of people with developmental disabilities, focusing predominantly on Sydney metropolitan and Sydney community-based publications with two national newspapers also included. Carter et al. found that community newspapers offered better coverage of disability related issues (on an article per paper basis) than metropolitan or national publications. In addition, metropolitan newspapers were more likely to use derogatory or questionable terms than national or community publications. Despite this, analysis of content revealed that newspaper articles were overwhelmingly positive (83%). However, interpretation of findings should consider Carter et al.’s categorisations, for example the label ‘positive’ did not necessarily represent overall tone of the article but whether the article indicated the life of the individual, or group, *could* be improved.

Since Carter et al.’s (1996) review the Australian government and sections of the Australian media have taken steps towards fair and realistic portrayals of individuals with disabilities. Australia’s commercial television industry code of practice (ACMA, 2010) outlined several terms (e.g., ‘mentally retarded’), and stereotypes (e.g., ‘object of pity’) to be avoided. However, in the most recent iteration of this code (ACMA, 2015) this detail was removed from the contents of the regulatory code, instead placed as an advisory note which is less prescriptive. For print media the Australian Press Council’s standards of practice (2011) contain no such advisory guidelines.

Though criticism remains, the media are finding novel ways of addressing the under-representation of people with ID. Reality television has attempted to offer a representation of adults with ID in shared housing. Australia’s public broadcaster the Australian Broadcast Corporation (ABC) presented a reality-TV series The Dreamhouse in 2014 as a six-part documentary/social experiment of three young Australian adults with ID experiencing a shared living environment for the first time. Though the program was highly praised for its originality and apparent innovation in housing solutions, Ellis (2017) also reported that there were some serious critiques of the documentary with claims that it provided a misleading representation of housing options, both socially, and economically. Chief executive officer of Down Syndrome Australia Catherine McApline criticised the program for only presenting a group home option rather than self-directed living options (Down Syndrome Australia, 2014). McAlpine argued that group homes represented a limited and undesirable housing option, chosen only as result of circumstance such as inadequate support and funding. One must consider whether this dislike for group housing is representative of attitudes of adults with ID or representative of broader anti-placement attitudes permeating social ideologies.

Though clearly the media are willing to address specific issues relevant to those with ID, research on media representations of such topics have been scarce. For example, Wardell, Fitzgerald, Legge, and Clift (2014) conducted a quantitative content analysis on New Zealand newspaper articles on Down syndrome specifically in relation to claims of state supported eugenics, describing the print media as informing public opinion on the issue. Research has also explored media influence following representations of persons with ID competing in the Paralympic games, with findings suggesting that media representations influence public attitudes, at least in the short term (Ferrara, Burns, & Mills, 2015). However, to the researcher's knowledge no research has specifically reviewed representations of care and accommodation for persons with ID (beyond a critique of the 'Dream House'). As social norms and values are not only shaped by those directly around us, but by broader popular perceptions, including those portrayed in the media, the news media may provide important insights into the development or maintenance of potent cultural norms regarding attitudes, values, and beliefs in relation caregiving and care planning, particularly out-of-home residential care placements.

Parent-Carers

Research has shown that mothers, or in their absence, other female relatives, are more likely to take on the primary caregiving role than male family members (Grant, 2000; Seltzer, Begun, Seltzer, & Krauss, 1991). Berg et al. (2019) argued that this is simply part of gender role socialisation, in which women are expected to be responsible for care tasks in the family, whilst men are expected to be responsible for financial obligations. Caregiving figures in Australia support this with two-thirds of parent carers of individuals with ID identified as the individual's mother (ABS, 2012b). It is likely then that families may hold beliefs about the gendered norms of familial caregiving and caregiving tasks (Bigby, 2003; Bryant & Garnham, 2017; Twigg & Atkin, 1994).

Bryant and Garnham (2017) argue that the normative mothering role encompasses the tasks of caring, therefore caregiving for an adult son or daughter with ID is entrenched with maternal responsibility. It may therefore be reasonable to expect a mother to perform private personal care tasks such as bathing; however, mothers may be reluctant to suggest a nursing professional perform this same activity. For example, in the 2016 Regional Wellbeing Survey of regional Australian carers, 61% of carers reported that caring tasks were the responsibility of family members (Schirmer, 2017). Furthermore, this construction of mothering leads to discourses of a 'good mother' as a selfless and resilient caregiver (Bryant & Garnham, 2017). One can see how the acceptance of such discourses might restrict the help-seeking behaviour of the mother and limit the mother's consideration of external caregiving alternatives.

Twigg and Atkin (1994) further suggest that in addition to the construction of mothers as caregivers, cross-gender tending may be seen as taboo by parent caregivers, particularly a father tending a daughter. This may mean that in the event of a mother dying, the dynamic of the caregiving relationship may change (Bigby, 2003). The impact of perceived appropriateness of gender roles is unclear with few studies including dual parent carers in study samples. Those studies that do include dual parents suggest there may be interesting differences between parental attitudes and wishes, for example mothers are more likely to prefer that their son or daughter reside in the family home (Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012). It is possible that, in the absence of what is deemed by parents to be an appropriate gender-relationship alternative, existing stereotypes and assumptions regarding care responsibilities could further limit the development of a future care plan.

Carer health and wellbeing.

The health and wellbeing of informal caregivers has been extensively researched. Though reports have been somewhat mixed, literature tends to suggest that parent-caregivers are at increased risk of negative impacts. For example, Dillenburger and McKerr (2011) found that older parent caregivers of adult children with ID or developmental disabilities were more than twice as likely to experience psychological ill-health compared with the general population. Similarly, in a survey of more than 4,000 Australian informal carers Hammond et al. (2014) found that this sample scored significantly lower on the Personal Wellbeing Index (PWI) compared with Australia's general population. Hammond et al. further noted that the type of disability may impact on PWI, as caregivers of children with mental illness reported the lowest PWI scores. However, Hammond et al. categorised the types of disability relevant to the study as: chronic health conditions, frailty, physical disability, mental illness, or multiple disability. There was no indication whether caregivers of adults with ID were included in (and subsumed under one of these categories), or excluded from this sample.

Grant (2000) further argued that several studies have indicated that there is no linear link between caregiver stress and the characteristics of the person with the disability. Chen, Ryan-Henry, Heller, and Chen (2001) found that mothers in the US caregiving for adult children with ID reported physical and mental health that was comparative to national norms. Furthermore, characteristics of disability did not significantly influence health outcomes. Yet a more recent review of caregiving literature and parenting stress found that type of disability and behavioural problems were both linked to levels of parental stress (Pinquart, 2018). However, this review only considered chronic medical conditions such as cancer and epilepsy, not ID.

Psychological health of informal caregivers can, in extreme cases, lead to dire consequences. Brown (2012) reviewed six incidents of filicide or filicide/suicide with cases in the UK involving mothers and vulnerable adult children including those diagnosed with Down syndrome and learning disabilities. In four of the six cases, caregiver burden and stress were cited as the primary explanation for the parent's actions, with 'mercy killing' cited as an explanation in the other two. Homicidal thoughts in caregiving are not unusual, research into family caregivers of adults with dementia found that homicidal ideation was a significant phenomenon (see for example Anderson, Eppes, & O’Dwyer, 2019; O’Dwyer, Moyle, Taylor, Creese, & Zimmer-Gembeck, 2016), however it is important to note that thought does not always lead to action. Brown suggests, parents of adult children with disabilities have often been under considerable pressure for extended periods of time such that they may reach a point where the burden of care may no longer be sustained.

Most research into caregiver health has focused solely on the primary carer which, as established, in the case of parents is more likely to be the mother (Bigby, 2003). However, Rowbotham, Carroll, and Cuskelly (2011) also explored the general health of both male and female parents caring for an adult child with an ID. This study found that both mothers and fathers reported high levels of clinical stress, difficulty sleeping, anxiety, and social dysfunction. No significant differences between mothers’ and fathers’ health were found, suggesting that even for someone who is not in a primary caregiving role, such as a father who works fulltime, the negative impacts associated with caregiving may be equally significant.

Several studies have also looked at differences between younger and older family caregivers. Chou et al. (2009) grouped a sample of Taiwanese family caregivers into two age groups: younger (mean age = 43.3) and older (mean age = 66.8). Findings indicated that older family caregivers were more likely to have poorer physical and psychological health, lower quality of life, and lower family income than younger family caregivers. Whilst it could be argued that this may be indicative of an ageing cohort as opposed to an ageing caregiving cohort, the opposite was found in an Australian sample of parent caregivers of sons and daughters with ID (Llewellyn et al., 2010). Upon stratifying the sample into age groups (i.e., younger = 55-64 years of age, older = 65-74 years of age, oldest = 75 years of age and older), Llewellyn et al. (2010) found that the younger age group self-reported significantly poorer mental health than that of population norms, whilst the older groups did not differ significantly from population norms. Llewellyn et al. further pointed out that parents reported both stress and satisfaction in their caregiving role, so one must also consider the positive effects of caregiving; for example, Cairns, Tolson, Darbyshire, and Brown (2013) found that parents reported increasing selflessness and a sense of fulfilment in the caregiving role. Twigg and Atkin (1994) have also criticised both academics and lobbyists for adopting a pathologising perspective when this may not reflect the caregiver's view of their own situations.

The 2016 Regional Wellbeing Survey into Carers in regional Australia also found differences in caregiver health and wellbeing according to age (Schirmer, 2017). In this report fewer caregivers in the 65 years or over age group reported financial stress and isolation, compared with younger age groups. Further, caregivers in this age group were more likely to report good access to advice and information, as well as being financially comfortable (Schirmer, 2017). Though this report suggests that older caregivers may be better off, data were gathered from Australia's caregiver population as a whole, that is, it did not explore specific results of particular caregiving groups (e.g. parents, spouses etc.). Fifty-six percent of caregivers in the older age group identified as spousal caregivers, whilst only 19% were caring for a son or daughter. Therefore, a majority of participants in this older age group may have only commenced caregiving at an older age, this may be particularly relevant in explaining why greater financial prosperity was reported in this age group of caregivers.

Parent caregiver health and wellbeing is a complex issue. Though some findings indicate that older parent caregivers are at greater risk, clearly from the Llewellyn et al. (2010) study, long-term caregiving alone is not sufficient to create an 'at risk' environment for parents. Several other factors such as the socio-economic status (SES), physical requirements of caregiving, and social support may impact on parent carer health and wellbeing. It is important therefore to explore these factors, and to further explore whether any of these factors, including parental health and wellbeing, correlates with future care planning.

Care planning by parents.

Existing literature reveals that parents who do commence care planning are most likely to pre-arrange financial support (Heller & Factor, 1991). For example, parents might establish a trust in their son’s or daughter’s name (Davys, Mitchell, & Haigh, 2015) or leave money in a will to a relative under the arrangement that this money will assist with the future care of their son or daughter (Heller & Factor, 1991; Simpson, 2017). Indeed, government documents available to Australian caregivers to aid the development of future planning largely focus on the financial aspects of planning (e.g., DSS, 2014); this would certainly align with previously discussed fiscal motivations of the Australian government.

Yet, despite rates of financial planning improving, current interventions are having little impact on the development of residential care planning with rates for residential care planning reported in US and UK literature over the last three decades remaining steady at around 30% (Dillenburger & McKerr, 2011; Heller & Factor, 1991), whilst rates in Australia are unknown. Additionally, it should be noted that the literature does not define different types or levels of planning. Blacher (1990, as cited in Grey et al., 2019) theorised that parents move through five stages of decision-making, from not thinking about placement all the way through to actioning a process, with stages of cognitive engagement occurring in between. Parents who report to be in the lower three stages are less likely to show significant advances in planning compared with those in the latter stages (Grey et al., 2019). These earlier stages of decision making may reflect what Taggart et al. (2012) referred to as ‘aspirational’ plans rather than purposeful steps towards action. Thus, it is difficult to ascertain how various stages of planning are defined, and therefore reported; variability in operationalisation may lead to inaccurate reporting (under or over-reporting) of the number of parents who have completed explicit key succession plans for their son’s or daughter’s future residential care.

The influence of caregiver characteristics on care planning.

As has been discussed, factors such as age and SES may impact on carer health and therefore the caregiving relationship. Literature has explored whether these demographics and others, such as carer education, may also impact the likelihood of future care planning. For example, Chou et al. (2009) found that in both younger and older family carers, greater family SES was associated with a future plan to have the adult with ID cared for by a sibling. One might assume that family care minimises the cost of caring, however it might be that greater financial support increases the sibling’s willingness to accept this responsibility, whilst decreasing the parents’ concerns regarding any increased burden placed on the sibling. Chou et al. also found that older family carers who were female were less likely to have a plan in place. Considering that females are more likely to be the primary carer and more likely to be financially disadvantaged (Qu et al., 2001), the interaction of gender and SES could be important to address.

Burke, Arnold, and Owen (2018) explored demographic variables including parent’s level of education, age, and family size as potential correlates of future planning in the US. A sample of 388 parents of sons and daughters with intellectual and developmental disability was recruited across the country, with findings indicating that parents who had attended higher education were more likely to perform future planning activities than those who had completed secondary school or below (Burke, Arnold, et al., 2018). Parental exposure to disability training and support was also related to future care planning, highlighting the importance of availability to such services.

Literature focusing on age as a possible motivator for planning has reported mixed results. Hafen and Sörensen (2008) found that older parents were more likely to make concrete plans for their son’s or daughter’s future care needs than younger parents. However, results were based on a broadly worded single item measure that did not define future care needs in any detail; therefore, individual interpretation of the item may have influenced findings. Earlier research by Heller and Factor (1991) explored the relationship between age and future planning in more detail. They found that although older parents were more likely to have financial arrangements in place, age did not significantly predict whether families had made residential plans (Heller & Factor, 1991). In the Burke, Arnold, et al. (2018) study, an 11-item scale was used to measure future planning activity, including three items specifically relating to residential planning. Results indicated that age was positively related to planning, though the authors noted that only 14 participants reporting engaging in all 11 activities, whilst a majority reported 5-7 activities. Burke, Arnold et al. reported that the three residential items on the scale were amongst the four least endorsed scale items. Thus, barriers to residential planning may be distinct from other planning considerations.

Caregiver attitudes and values towards caring.

As discussed in the earlier review of deinstitutionalisation and changing disability ideology, parents have experienced a range of conflicting community, professional, and political attitudes towards disability and caregiving. This can impact on the personal expectations, values and norms that individual’s hold in relation to the task of caregiving. The 2016 Regional Wellbeing Survey found that a majority of family carers, including parents caring for sons and daughters, were motivated to care because of the belief that ‘caring is the responsibility of family members’ and because participants believed that they had an obligation to care (Schirmer, 2017). Though research by Griffiths and Unger (1994) was conducted more than two decades earlier a large proportion of their sample (80.1%) also endorsed a feeling of responsibility as a reason for caring. This is further supported by findings from the Australian Survey of Disability Ageing and Carers (SDAC) reporting that obligation and a sense of family responsibility were two of the three most common reasons for caring (ABS, 2015).

The SDAC also reported that 50.3% of primary carers believed that they could provide better care than anybody else (ABS, 2015). However, a much lower endorsement rate of this belief (only 25%) was reported in the 2016 Regional Wellbeing Survey (Schirmer, 2017). Though it is unclear why such inconsistent results were found in these two Australian surveys, recruitment strategies and questionnaire design did vary across projects. For example, SDAC data were collected by the Australian Bureau of Statistics (ABS) using multi-stage sampling techniques including random selection of private dwellings throughout urban, rural, and remote areas of Australia (ABS, 2015). In contrast the Regional Wellbeing Survey was promoted through rural and regional organisations and their networks (Schirmer, 2017). Though Schirmer (2017) did not specify what types of organisations promoted the survey, the organisations were described as ones that fostered wellbeing in local communities. It is therefore possible that these were support-based organisations that recruited participants who were more likely help-seekers and potentially less isolated from support services than the SDAC participants. Sample sizes were also vastly different with the Regional Wellbeing Survey measuring responses from almost 11,000 participants of which 15% were caregivers, whereas the SDAC data comprised a sample of over 79,000 carers.

The Adult with Intellectual Disability (ID)

In 2012, the ABS reported that around 2.9% of the Australian population, or just over 668,000 Australians had an ID (ABS, 2012b). This is consistent with prevalence estimates across developed countries of around 3-4% (Emerson, 2012). Prevalence rates for males with ID (3.3%) were slightly higher than females (2.6%; ABS, 2012b). The ABS (2012b) postulated that differences might be due to three reasons

- boys having higher rates of some conditions associated with ID (e.g., autism);

- ID is more frequently identified in boys due to more noticeable abnormal behaviour patterns during schooling; and
- increased risk of “adverse effect of maternal smoking and low birth-weight on neurological development among males” (Maulik & Harbour, 2010, p.6).

The Australian Institute of Health and Wellbeing (AIHW; 2008) reported that less than 50% of young people with an ID attended ordinary classroom schooling, 38% attended a special class within mainstream schooling, and 17% attended a special school designed for children with disability. The AIHW further highlighted the importance of two major life transitions; from family life into schooling, and again from the routine of schooling into adult life. Post-school transitioning data has tended to focus on employment rates, with participation in the labour force much lower for people with ID (AIHW, 2008). According to the ABS, a majority of adults with ID aged below 35 years of age (72%) were living in the family home, whereas most adults with ID who were living independently were over the age of 35. Only around 16% of adults with ID lived in established care (e.g., hospitals/nursing homes; ABS, 2012b).

Characteristics of the adults with ID.

Characteristics of the adult with ID influence care exchanges, and therefore may also influence the decision making involved in future residential care planning. Berg et al. (2019) identify a number of factors impacting on any caregiving relationship, including whether the disability is sudden or gradual, whether the disability involves a progressive period of decline or periods of relapse, and specific difficulties involved in the caregiving exchanges, such as levels of daily management, or cognitive and communicative challenges.

In interviews with American family caregivers, primarily mothers (75% of participants), Heller and Factor (1991) found that families caring for a son or daughter with ID who demonstrated greater maladaptive behaviour preferred out-of-home service provision to in-home care by other relatives. This finding was supported by an earlier study in which Griffiths and Unger (1994) reported that greater physical care requirements and behavioural disturbances were associated with less willingness to consider family care in future planning. However, preference does not suggest active planning. For example, Burke, Arnold, et al. (2018) reported that parents of adults with intellectual and developmental disability with fewer functional abilities were more likely to commence future planning yet they found no significant correlation between planning and maladaptive behaviours.

Behaviour and physical demands can therefore create a difficult dilemma for parent caregivers. On the one hand, difficult behaviours (e.g. physical aggression) and physical tasks make current caregiving even more challenging and burdensome for an ageing and potentially physically declining parent (Dillenburger & McKerr, 2009). On the other hand, parents may view demanding behaviours and physical tasks as a barrier to considering others such as siblings as future carers, this eliminates one option in future residential planning and may therefore make the planning process more difficult. Whilst the literature notes that behaviour and physical demands influence preferences in the decision-making process, few results indicate whether these characteristics act as a motivator or barrier to acting upon these preferences in arranging future plans. Further exploration of this would be especially salient considering that behavioural problems have been associated with increased levels of poorer health outcomes for the parent caregiver (Minnes & Woodford, 2005).

Subjective characteristics of the adult with ID may also influence caregivers’ attitudes with regards to future planning. For example, Wolfensberger et al. (1972) described perceptions of persons with ID as being depicted as ‘the eternal child’. For parents and family members who adopt this characterisation, this can lead to an absence of expectation that the adult will or is capable of being adaptive or reaching developmental advances. Williams and Robinson (2001) argue that this is part of the issue with adults with ID remaining within the family home, stating that the normative stages of development into adulthood simply do not occur. Starke, Bertilsdotter Rosqvist, and Kuosmanen (2016) refers to this as a ‘disablist’ view that can stigmatise and categorise the adult child within society in such a way that available roles are constrained. Wolfensberger et al. suggested that those who see adults with ID in this role expect to adapt their environment to ‘the child’ rather than the adult being enabled to adapt to their environment. This adult-as-child perception may therefore limit the adult’s confidence in leaving the family home as this is often seen as rite of passage into adulthood; equally the parents are likely to feel apprehensive about any separation as they would not consider the adult developmentally ready to leave. Williams and Robinson note that only upon leaving the family home can the relationship with parents develop from one of adult-child to adult-adult.

Reciprocity.

Whilst government definitions of family caregiving typically signify the unidirectional provision of a resource (i.e., care provided to the recipient; AIHW, 2016) Bibby (2013) found that reciprocity was highly prevalent in caregiving literature. Only viewing sons and daughters with ID as care-recipients, whilst labelling parents as caregivers, does not give due consideration to the complexities of this relationship. Depending on the severity of the disability, adults with ID may provide a form of functional, emotional or social support to the parent caregiver (Dillenburger & McKerr, 2009), for example Williams and Robinson (2001) found that adults with ID in the UK supported ageing parents by making meals, helping with physical tasks, housework, and gardening. The positive outcomes of this interdependency may therefore act as a barrier to future planning due to parental fears that plans for residential change may be enacted immediately leading to parents experiencing loneliness and isolation (Bowey & McGlaughlin, 2007).

It is further argued that as parents age and their own needs for support increase, the balance of caregiving may shift with a greater reliance on their adult son or daughter in supplying emotional and physical support (Bibby, 2013). Psychological reciprocity between parent and son or daughter is particularly complex, considering that the nature of the caregiving role itself can impose restrictions on the parent’s social networking outside of the caregiving relationship (Twigg & Atkin, 1994). This is also true for the sons and daughters in parental-care, with friends and social supports dominated by family (Bigby, 2003). For both parent caregivers and their adult child with ID, the demise of social connectivity and growth of interdependency often occur simultaneously over several decades and may therefore be difficult to address.

Involvement in research.

Despite the caregiving role only existing by virtue of their relationship with the care recipient, there is a scarcity of literature that explores the personal choices and wishes of this cohort in relation to future care planning. This does not suggest that research excludes people with ID, many researchers actively advocate for and conduct research with adults with ID (e.g., Abbott & McConkey, 2006; Emerson, Krnjacki, Llewellyn, Vaughan, & Kavanagh, 2016). However, within the specific topic area of future care planning inclusion of adults with ID is limited.

Current government reports in Australia clearly advocate for the active involvement of people with ID in any accommodation transition planning (Queensland government, 2013). It is therefore important that research designs should acknowledge the importance of listening to all voices, and at the very least reflect the development of human rights advocacy and legal frameworks for inclusion of people with disabilities. Kroll (2011) argued that researchers often exclude participants with disabilities simply on the basis that inclusion may require additional accommodations which may be too difficult (e.g., lengthy ethics process), too time consuming, or too expensive (e.g., purchasing alternate communication tools) to be considered for their research project. Despite developments in inclusive practice in key government policies, research appears to be lagging behind. Kroll warns excluding those with disability renders this population invisible. Given the opportunity to vocalise their opinions, and provided with the appropriate accommodations, people with ID have the capacity to self-advocate, communicate their choices, and share their stories (Atkinson, 2000).

Siblings of Adults with Intellectual Disability

Adults with ID and their parent caregivers do not exist in isolation. For siblings of a person with ID the experience of growing up in a home with disability and the non-normative development of their sibling can impact on a number of aspects including dyadic relationships within the family system. Furthermore, it has been well established that siblings are significant supports for parents and are often identified as preferred primary caregivers in the future, not only by parents but also by governments (Waldren & Strohm, 2010). As such the experience of siblings of persons with ID has been the focus of much research.

Sibling wellbeing.

Psychosocial wellbeing of siblings can be effected due to the household environment and growing up with a brother or sister with ID. Sibling identities and roles in childhood may diverge from normative child environments as siblings experience pressure to adopt the role of perfect or ‘model’ child in order to limit the stress and felt burden of the parents (Waldren & Strohm, 2010). Some studies also report siblings being exposed to bullying at school, as well as being the target of aggression by their brother or sister with ID within the family home (Davys, Mitchell, & Haigh, 2011). Siblings may also be adversely affected by restrictions placed on the home environment including not being able to have friends visit or lack of parental attention (Davys et al., 2011).

Despite a number of reported negative childhood experiences, the literature on psychosocial wellbeing of adult siblings is mixed. A large body of evidence supports positive sibling adaptation (Davys et al., 2011). In a literature review of sibling wellbeing, Heller and Arnold (2010) found a number of studies reporting lower levels of depressive symptoms in siblings of persons with ID, yet other studies reported greater distress, cognitive demands, and pessimism. Siblings also may express sorrow for the loss of a normal life for the sibling with ID (Davys et al., 2011), and experience worry and concern for their brother's or sister's future (Davys et al., 2010; Davys et al., 2011). Lee and Burke (2018) also conducted a systematic review of sibling literature in relation to caregiving and found that siblings also reported conflict with parents, specifically mothers due to poor communication and a mother's stubborn 'do-it-all' caregiving style.

Despite literature revealing a mixture of positive and negative impacts on sibling wellbeing, there is a clear need for supports for siblings of persons with ID. Arnold, Heller, and Kramer (2012) for example, found that US siblings of adults with ID were desperate to access support services that could address their specific experiences. Siblings also felt left out of family centred services that addressed the needs of parents yet ignored the needs of siblings, calling for more inclusive definitions of family. This need for support and inclusion is supported by the recommendations of the Siblings Australia report in which Waldren and Strohm (2010) recommended the development of services that would enable siblings of brother's and sister's with disability to connect. Furthermore, they also recommended that all family members be considered in family support programs and policy development.

Relationship with sibling with intellectual disability.

Sibling relationships within the family system have also been a focus of many studies. Burbidge and Minnes (2014) examined US and Canadian sibling relationships in families with siblings with developmental disability and without developmental disability (i.e., a family of three siblings or more, one of which had ID). From their study of 128 typically developing siblings (85% female), they found that the relationship between the typically developing sibling and the sibling with developmental disability involved more contact and more positive feelings than relationships between the siblings without developmental disability. Despite the positive feelings and increased contact, the relationship between the typically developing sibling and sibling with developmental disability was reported to be less intimate compared to the relationship between typically developing siblings (Burbidge & Minnes, 2014). Burbidge and Minnes hypothesised that this may be due to interactions mainly involving instrumental support, as opposed to social or emotional interactions. Heller and Arnold (2010) further note that a number of factors appear to impact the sibling relationship including degree of disability; this may provide support for Burbidge and Minnes, as those with more severe disability would require greater supports, whilst experiencing greater barriers to communication in social or emotional exchanges.

In multiple sibling families, there is usually a 'most involved' sibling (Burbidge & Minnes, 2014; Heller & Arnold, 2010). Throughout the literature this sibling is most likely to be female (Heller & Arnold, 2010; Lee & Burke, 2020). Female siblings are also more likely to become caregivers and or assist with caregiving tasks than their male siblings (Lee & Burke, 2020). Sibling research also reflects this gender bias, in that studies typically involve high percentages of female cohorts, for example Arnold et al. (2012) surveyed 130 adult siblings of brothers and sisters with developmental disabilities, 92% of whom were female (n=120), this was despite a greater percentage of siblings with developmental disability being male (60%). This further supports the notion of gendered roles relating to caregiving as previously discussed (see pp. 28-29), though may also represent a more generalised gender bias in research participation.

Attitudes Towards Residential Accommodations

Parental experiences.

Perhaps the most consistently reported barrier to future planning is parent's perceived adequacy of service provision (e.g., Bibby, 2013; Chou et al., 2009; Davys et al., 2015; Dillenburger & McKerr, 2011; Innes, McCabe, & Watchman, 2012). This makes residential care arrangements one of the most difficult and contentious to plan for (Bowey & McGlaughlin, 2007; Taggart et al., 2012) as many parents see out-of-home options for future residential care as inadequate or simply undesirable (Innes et al., 2012; Taggart et al., 2012). Australian reports suggest families view accommodation models as unsuitable with few alternatives to group homes, yet regardless of suitability, wait lists and accommodation shortages are also identified as part of the problem (Australian government, 2009). Some parents express such aversion to out-of-home care options that they consider the early death of their son or daughter (whilst in parental care) a preferable outcome (Bowey & McGlaughlin, 2007; Dillenburger & McKerr, 2011). One must consider if aversion to out-of-home residential accommodation may reflect more than genuine shortcomings in provision; it is also possible that aversion echoes social norms and attitudes to residential options that followed the deinstitutionalisation movement.

Despite such overwhelming findings as above, one study by Bowey and McGlaughlin (2007) reported that parents in the UK who had not made future care plans showed greater preference for residential care homes (large group homes). However, the study found that the opposite was true for parents who had already made future care plans, with a majority choosing sibling caregiving. As both groups of parent caregivers in this study expressed concern regarding the suitability of housing options, one may question whether the above findings represent true planning choices, or if those who showed preference for residential care homes had limited knowledge or information regarding residential choices and therefore viewed this as the sole option. This is somewhat supported by Gilbert et al. (2008) who found that UK parents viewed residential care homes as the only option for care accommodation simply because they were not aware of alternatives. Informing parents of alternative accommodation options such as supported living and small group home options may be crucial in advancing future residential planning and moving parents from a position where they feel ‘stuck’ or ‘trapped’ in the caregiving role.

Though the literature clearly demonstrates a lack of information sharing between support agencies, government bodies, and parent caregivers (Bibby, 2013; Bowey et al., 2005; Davys et al. 2015; Gilbert et al., 2008), this may not simply be a case of lack of availability of information. Bowey and McGlaughlin (2007) argue that convincing parents to consider modern accommodation options may be a challenge in itself, regardless of whether the information is highly visible or not. Bibby (2013) also noted that not only were parents unaware of accommodation options, they were also unaware of key terminology used within the service sector, and unaware of whom they might source information from. Further to this parents’ views may be influenced by negative media reports of service failure (Bowey et al. 2005), therefore any information received may be approached with suspicion or be dismissed without consideration. Further to a lack of awareness of accommodation options, research has also found that caregivers were unaware of what would happen should they become ill or die (Cairns et al., 2013); this is a significant finding as the consequences of inaction may be a critical motivator for parents to future plan.

It cannot be ignored that at the heart of every aspect of future care planning is a unique relationship between parent and child, one that is perhaps more salient than any other caregiving relationship (Bigby, 2003). In a narrative exploration of parent caregiving experiences across the lifetime, Llewellyn (2003) argued that parent caregiver’s expert knowledge of their own child was often de-emphasised by service professionals, commencing when the child was young. Bigby (2003) also maintained that due to the sporadic nature of interactions with often multiple service providers, any devaluing of parental care can destabilise the caregiving environment, rather than support it. By disregarding parent's explicit requests in relation to the caregiving of the child, service professionals may be creating long term dissatisfaction leading to parents to develop the belief that they are irreplaceable in the role of caregiver and that only they can provide appropriate and adequate care for their sons or daughters (Bibby, 2013; Bowey et al., 2005; Grant, 2000; Llewellyn, 2003). Parents' successful use of coping strategies such as self-reliance may further hinder their engagement with respite and residential services (Llewellyn, 2003).

One must also acknowledge the important distinction between caregiver and parent. As previously discussed, parents do not see their role as that of 'caregiver', theirs is a role of mother or father, often 'perpetual' in nature (Grant, 2000). This role identification and the strong sense of responsibility it carries have implications for how parents will engage with services. It is also within the context of parental responsibility that mothers and fathers begin to doubt others' capacity to provide adequate care for their children.

Views of Adults with intellectual disability.

Though there is a scarcity of literature that details attitudes towards residential planning held by adults with ID, one such study conducted by Bowey and McGlaughlin (2005) highlighted the importance of providing this population with a voice. Forty-one UK participants with mild, moderate, or severe learning disabilities were interviewed and found that adults with ID engaged in at-home-tasks to develop their own independence. Reciprocity, was therefore viewed by adults with ID as a means to personal growth. Similar findings were reported by Williams and Robinson (2001) with adults with a learning disability in their study also viewing housework as a way to cultivate independence.

Bowey and McGlaughlin (2005) also reported that 27% of those interviewed wished to move out of the family home. Furthermore, a majority of adults with ID (73%) were aware of the need for alternative future care with preferences for share housing or self-contained accommodation in a shared building over living with another relative. This suggests that parental wishes to maintain family care may not always align with personal experiences of adults with ID. This is supported by Waldren and Strohm (2010) who found that adults with ID expressed a dislike for sibling carers whose approach to caregiving was deemed to be too directive. Findings from the Waldren and Strohm study should be viewed with caution as the sample was limited to six people with ID. Furthermore, in the Bowey and McGlaughlin study participants were identified as adults with a learning disability that was either mild, moderate, or severely impaired. However, the authors did not specify how these categorisations were determined or identify the number of participants who were categorised as mild, moderate, or severe. As these categorisations reflect large differences in conceptual, social, and practical skills of the participant (APA, 2013; WHO, 1996), it would be important to identify whether particular care preferences correlate with disability level.

The desire to seek independence is further supported by Wiesel et al. (2015) who interviewed 51 Australian adults with various forms of disability about their move, or plans to move, from congregate care, group homes, or parental homes to more independent living. In this report, the most frequently described motivation for transitioning from family care was the aspiration for greater independence and choice. Parents were generally encouraging, though the authors suggested this was often underpinned by concerns about the parents own ageing (Wiesel et al., 2015). As this report aimed to explore the experiences of adults with disability, it is difficult to determine whether results specifically reflect the motivations of adults with ID. Wiesel et al. stated that 24 participants identified as having an intellectual, developmental, or cognitive impairment. However, group differences according to disability type were not explored; therefore it is difficult to ascertain whether these results adequately reflect views of adults with ID.

In some studies parents do openly acknowledge that opposition to planning options by adult sons or daughters with ID can be a barrier to future care planning (Bowey & McGlaughlin, 2007), whilst others are concerned that adults with ID do not understand the choices available and what the consequences of decisions would be (Bowey et al., 2005; Gilbert et al., 2008). However, without inclusive research designs that encourage participation by adults with ID any information of opposing wishes will be reliant on parental reports. As parents may feel justified in overriding any wishes that do not align with their own (due to a parental belief that the son or daughter does not sufficiently understand the situation) choices for adults with ID may be suppressed and decision making may default to parents.

Atkinson (2000) argues those with intellectual disabilities provide ‘a corrective view’, furthermore the inclusion of their voices and perspectives demonstrate that this is a cohort that is complex and full of capacity to care. Pryce, Tweed, Hilton, and Priest (2015) further suggest that inclusion may provide adults with ID the opportunity to develop their own ideas about an alternative future. Furthermore, it is argued that choice and inclusion in the planning process is fundamental to the physical and mental health and wellbeing of adults with ID (Australian government, 2009). A consultative approach to future care planning may therefore produce a more positive outcome for both caregiver and care recipient assisting with family cohesion, agreement, and understanding as family units work toward concrete future residential care planning.

Further to the above findings, Wiesel et al. (2015) reported that residential transition processes for adults with ID could take around 3 to 5 years. Developing living skills (e.g. meal preparation, shopping, financial management, personal care) was an essential step in the transitioning process and often involved external support or intervention (e.g., community or TAFE course, social trainer). Family and informal support was also pivotal in helping people with disability achieve independent living with both formal and informal networks playing key roles in an expanded parent's vision of accommodation options that were available (Wiesel et al., 2015).

Siblings' views of self as caregiver.

In seeking residential accommodation for sons or daughters, parents tend to look for duplication in care and protection currently provided in the family home (Bigby, 2003; Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2013). This can often mean that parents will view informal family care options such as siblings as the ideal alternative in the parent's absence (Dillenberger & McKerr, 2009). One of the difficulties with this option is that parents may either simply expect or prefer that a sibling of the adult with ID will assume caregiving responsibilities if and when the need arises (Bowey & McGlaughlin, 2007; Davys et al., 2015; Waldren & Strohm, 2010). Parental assumption without firm planning may create further turmoil in their son's or daughter's lives, and as Heller and Factor (1991) note, with no formal arrangements siblings are expected to enter into this role with no or little preparation themselves. These findings are further supported by sibling reports of a lack of adequate planning on the parent's behalf, absence of transitional planning, and little to no consultation being sought from the sibling (Coyle, Kramer, & Mutchler, 2014). Those who do indicate the existence of planning often refer to these plans as based on a 'verbal understanding' (Davys et al., 2015).

Sibling expectations in relation to their involvement in future caregiving appear to depend on a number of variables. Gender has previously been implicated in the quality of sibling relationship (see p. 43); findings also indicate that female siblings are more likely to expect they will assume caregiving duties than male siblings (Burke, Taylor, Urbano, &

Hodapp., 2012; Davys et al., 2011; Waldren & Strohm, 2010). More broadly, caregiving literature suggests that choice patterns exist for carer selection, and that these patterns are based on a combination of similarity of gender with care-recipient, emotional closeness and attitudinal congruence that determine a mother's preference for primary carers (Pillemer & Suitor, 2006).

Whilst some studies, such as Greenberg, Seltzer, Orsmond, and Krauss (1999), have found that a majority of siblings expect to assume primary caregiving tasks, other studies indicate that siblings may only anticipate a support role without intent to assume full caregiving responsibilities (Davys et al., 2015). Differences in these findings may be due to a number of reasons, firstly Greenberg et al.'s research was conducted in the US whereas Davys et al. interviewed participants in the UK, it is possible that cultural differences in regard to role expectations exist. It should further be noted that there is a 16-year difference in the collection of data, again this may reflect change in social norms at these specific times. Thirdly, sibling participants in the Greenberg et al. study were selected to participate after being identified by their mother as the sibling most involved with the disabled brother or sister, whereas in the Davy's et al. study siblings were recruited through a self-help organisation. It is possible that results are reflective of sampling bias.

Siblings not anticipating a primary caregiver role, still expect some involvement in their brother's or sister's future care. This may simply be involvement in the planning phase itself or an ongoing role in the form of financial management and advocacy (Arnold et al., 2012; Davys et al., 2015). Many siblings however remain fearful of co-residence with their brother or sister with ID; this reluctance can be due to a number of issues ranging from perceived interruptions to existing lifestyle, work commitments, or perceived appropriateness of caregiving duties according to gender (Davys et al., 2015). Furthermore, siblings are also aware that their own health and wellbeing should be considered before agreeing to take on a primary caregiver role (Davys, Mitchell, & Haigh, 2016). It is therefore relevant to explore the sibling relationship, particularly in reference to preparedness for, and willingness to assume caregiving roles in future.

Parental and sibling expectations regarding the caregiving role are not always aligned, in fact siblings may not agree with parents' approaches to the caregiving role in general. In a sample of Taiwanese family caregivers Chou et al. (2009) found that siblings were more likely than parents to use residential services when considering future care planning. Though the impact of cultural context is unknown, contrary findings have been reported in a UK study; Davys et al. (2015) found that most sibling wishes did align with parent wishes for future care planning, however in this study over half of the adults with learning disabilities were already residing outside of parental or sibling care, living in either community or independent dwellings. Considering that decision making difficulties tend to revolve around transitioning from parental care to an alternative option, this alignment of wishes may have occurred as a result of the removal of familial residential caregiving prior to the study. Furthermore, limited information is reported regarding those with disabilities; for example, the authors provided no definition of 'learning disability'. If the definition used reflects the UK Department of Health (2001) definition, it would be advantageous to report whether those with learning disabilities were diagnosed as mild, moderate, or severe, as this may have implications on the inferences made from these findings.

It is also important to note that some studies have found that parent's do not expect the primary care responsibility to shift to siblings. Gilbert et al. (2008) reported that parents' preferences were for siblings to assume an advocate role, not full-time caregiving responsibilities. Participants in the Gilbert et al. study appeared to view the role of caregiver as too burdensome for their other children. Gilbert et al. stated that the scope of their research did not allow for specific information gathering regarding the family member with ID, however, they did note that most of the adults with ID had high need requirements and attended day-centres. Similar to the previously discussed Davys et al. (2015) study, this suggests that parents were already engaged in regular use of service provision, and though it is unclear from the limited information provided, high need requirements might also indicate behavioural disturbances, which as previously noted is associated with parent's desires to seek out-of-home residential care.

A further review of literature of family caregiving of adults with Down syndrome found that between 10 and 20% of ageing adults with Down syndrome (i.e., adults in their 50's) lived with siblings (Hodapp et al., 2016). Though no literature directly compared Down syndrome with other ID, Hodapp et al. (2016) argued that the caregiving experience involving adults with Down syndrome differed from those with other ID. As a majority of adults with Down syndrome are likely to function within the mild to moderate range of ID (Lanphear & Castillo, 2007), this may further support the argument that degree of burden and the very nature of caregiving tasks are important in considering the role of siblings as caregivers.

Even in the event that siblings do not adopt the role of caregiver, Grant (2000) highlights the importance of their roles, stating that too much focus on the parent caregiver or care-recipient alone does not consider the family life cycle. Intergenerational support is significant in providing an extended network of informal support not just to the adult with ID but to older parents as well (Bigby, 2003). However, it would be erroneous to approach the sibling relationship as one that can be identified as future-caregiver and future-care-recipient. For example, siblings report feeling disconnected from organisations possessing the term 'carer' in their title (Waldren & Strohm, 2010). One must therefore consider how the use of language in study designs may impact responses provided by participant siblings.

Service provider views.

Twigg and Atkin (1994) argue that service provision occurs within a ‘context of power’; therefore, parent caregiver/service-provider relationships may be significant to the care planning advancement. Despite this, research into service provider experiences is somewhat scarce. Bowey et al. (2005) considered the views of those working in the disability and caregiving service industry by conducting focus groups with various US service professionals. Participants reported on their perceptions of family-caregivers and service-users in relation to future residential planning processes. Responses were mixed with day centre and housing association professionals advocating strongly for choice and independence for the person with ID. However, participants from a Community Learning Disability Team did not believe that adults with ID had sufficient capacity to make decisions, therefore these service providers believed that they (not parents) were justified in overriding decisions (Bowey et al., 2005). Professionals in this study further noted that adults with ID were often reluctant to verbalise their wishes when they were in direct conflict with those of their family. In some circumstances, the service professionals felt compelled to advocate for the adult with ID (Bowey et al., 2005). In such circumstances, it is easy to see how conflict between service provider and parents may arise, particularly if the service provider adopts the role of advocate when the parent believes that it is a position the parent has the right to hold.

In an Australian study with caregiver and disability service providers, Llewellyn et al. (2003) held focus groups to explore participant perceptions of parent caregivers. Participants perceived that parent caregivers were holding onto generational values and views such as the belief that asking for assistance constituted failure. Service providers also believed parents had pride in their role as an independent carer; however, this may lead to older parent caregivers being judgmental of younger parent caregivers who do choose to engage in services, with participants asserting that older parents would view this as a failure of the parent to do ‘their job’. Llewellyn et al. noted that the discourse of service providers often involved phrases such as ‘over-protective parents’ whose behaviour was viewed as obstructing the right to independence of the disabled son or daughter. Llewellyn et al. further noted that many of these service providers were younger professionals who had never seen or experienced institutional segregation and society’s ‘rejection’ of people with disability, therefore they may not understand or appreciate the older parent caregivers’ lifetime of caregiving experiences.

Quality of Life Outcomes in Residential Service Provision

Most parents of adults with ID are motivated to provide the best quality care they can with a key focus on their adult son’s or daughter’s quality of life. Though there are few papers that focus on quality of life outcomes in residential facilities, Felce (2017) conducted a review into these outcomes with potentially surprising results. Felce found that setting size (number of residents) and resource input (costs & staff-to-resident ratios) were rarely found to correlate significantly with quality of life outcome measures. It is noted that Felce emphasised this lack of association specifically in small group homes where the setting size is only between one and three residents.

Felce (2017) did however find that key indicators of quality of life outcomes were nature and location of the home (physical integration of a normative home site), and operational culture (staff attitudes, social climate etc.). Further, Glendinning et al. (2008) found psychological wellbeing was higher among people with ID living in standard accommodation arrangements versus people with ID who utilised an individual budget for accommodation. However, the reverse was true for social outcomes with people using an individual budget experiencing better outcomes. This may be particularly relevant within the Australian environment where the NDIS is focused on an individualised model of funding. Clearly, further research into this area is needed as the implications of such research findings could be widespread. Findings could instruct on the location and architecture of future residences, the operational and organisation models for staff in supported living environments, as well as the most appropriate and cost-effective funding models.

Carer Guilt and Other Emotional Experiences

Twigg and Atkin (1994) state that the obligation to care for a family member, particularly a son or daughter, is underwritten with love. Though limited studies have considered the emotional experience of parents during the process of future care planning, those that have considered this have reported that parents experienced increasing worry and guilt as they faced decisions for future care (e.g. Bowey & McLaughlin, 2007). Guilt in particular may be experienced for several reasons:

- It can stem from the need to rely on family members to support parents in their continuation of the caring role (Cairns et al., 2013);
- The very idea of ‘letting go’ of caregiving can elicit feelings of guilt (Bowey & McLaughlin, 2007); and
- Parents may feel guilty for burdening another son or daughter with the primary caregiving role in the parent’s absence (Llewellyn et al., 2003).

As previously discussed, reluctance to consider siblings as a primary choice in future accommodation plans is often associated with the behaviour of the adult with ID and concern regarding the burden of care this would place on siblings. Whilst *parental* guilt may act as a barrier, *sibling* guilt, associated with an obligation to care, may act as a motivator for siblings to take on this role and responsibility (Davys et al., 2015).

In addition to feelings of guilt, Hussain and Edwards (2009) also found that parents expressed fear for the future. As reported by Innes et al. (2012), parental fear is often associated with concern regarding the care, safety, and security of the adult with ID. However, in the Hussain and Edwards study, findings from a small cohort of Australian primary caregivers (n=11) indicated that parental fear was associated with concern that if plans were enacted and the adult with ID moved out of the family home the parent would be left lonely. As previously discussed, this fear may relate to reciprocal caring between parent and adult with ID.

Service providers have also reported on their experiences with parents and identified a number of emotional responses that they believe parents experience during caregiving and care planning (Lewellyn et al., 2003). Grief, jealousy, resentment, and remorse were all identified as common emotional experiences. Grief and remorse were associated with the sacrifices parents made in choosing the role of lifetime carer (i.e. grieving a life of missed opportunities). Service providers further warned that older parents may experience jealousy and resentment towards younger parent caregivers who more readily utilise care services to assist with caring (Lewellyn et al., 2003). As previously noted, this may reflect parent’s belief that caregiving rests firmly within a parent’s responsibility.

Though emotional experience was not a primary focus of Davys et al.’s (2016) study, during interviews of siblings of adults with ID, the parents’ emotional experience was discussed. Several sibling participants described their mothers as resentful, embarrassed, and angry toward the disabled son or daughter, whereas fathers’ emotional experience was described as shame and embarrassment. Siblings further believed that both parents experienced guilt, though this was an emotion associated more with the mother than the father. Siblings saw parents’ emotional investment as a key difference between care provided at home and care provided through external services (Davys et al., 2016), with both positive and negative experiences with external services being reported.

Clearly researchers acknowledge that family caregiving is ‘laden with emotion’ (Cummins, 2001), however very little research extends beyond superficial examination. Furthermore, though the studies referenced here have largely found that parents tend to experience negative emotions pertaining to the experiences of future planning, it should be acknowledged the caregiving experience itself can lead to positive emotional experiences such as pride (Innes et al., 2012). Exploring the thoughts and beliefs that drive both the positive and negative emotional experiences of caregiving and future planning are crucial if service providers and support organisations are to better assist families to move through the various stages of planning with minimal distress.

Systems Approach

The family as a system.

Minuchin (1974) identifies 'the family' as "society's smallest unit" (p. 47). It is a hierarchical structure, with the family system composed of smaller subsystems - these may be dyads such as husband and wife (spousal subsystem), mother and daughter (parent-child subsystem), sister and brother (sibling subsystem). Each system and subsystem contains different rules relating to power, relational roles, and boundaries (Cox & Paley, 1997; Minuchin, 1974). Minuchin describes boundaries as rules that define who can participate in the system and how the individual can participate. System and subsystem boundaries act to protect the members and the functions of the system or subsystem (Minuchin, 1974). Positive family functioning occurs when boundaries are clear, not too rigid nor too diffuse. The blurring of boundaries can lead to members performing inappropriate tasks (e.g., children performing parental tasks, or mediating spousal disputes), whereas rigid boundaries can create communication difficulties across system members and result in a lack of supportive action.

According to Minuchin (1974) family systems consist of transaction patterns that guide the rules and behaviour of family members. Within family systems, subsystems may adopt one of two transactional styles – that of enmeshment or disengagement (Minuchin, 1974). For example, a mother and young children tend to be enmeshed, yet this transactional style may shift toward disengagement as the children grow and become more independent. Minuchin argues that continuing to operate within a highly enmeshed subsystem may result in the exclusion of other family members or act to undermine the development and growth of the child’s independence and mastery of skills. On the other hand extremely disengaged members may lack loyalty and belonging to the family system, and may avoid seeking support when required.

In addition, the family system is subject to both inner pressure, from developmental changes of its members, and outer pressure from larger sociocultural systems (Minuchin, 1974). It must therefore be adaptive and transformative to these environmental changes. Adaptation therefore offers insight into how families respond to challenges and importantly how families respond to stress on the family system. Minuchin (1974) argues that stress on the family system can come from a number of sources such as stress on an individual member (e.g., workplace stress), whole family stress (e.g., economic hardship), experiences with transition points that lead to stress (e.g., child development); and stress associated with idiosyncratic problems (e.g., dealing with illness and disability). Cox and Paley (2003) emphasise the need to explore transition points (both normative and non-normative) in the family life cycle to better understand adaptive or maladaptive patterns of transactions.

Though some authors have, in part, defined ‘family’ as those who co-reside (e.g., Broderick, 1993), this limits the lifespan of the family system to a period where children remain within the family home. Others such as Fingerman and Bermann (2000) argue that the family system exists across the lifespan, providing both continuity and discontinuity that influences rules, roles, and behaviours of individual members over time (Qualls, 2016). Fingerman and Bermann highlight that across the lifespan families come together for moments of celebration and crisis. Whilst family members may default to historical transactional patterns during times of crisis, others will withdraw and distance themselves potentially splintering the family system.

Family systems and care-giving across the lifespan.

In a normative family life cycle, there are likely to be predictable patterns of caregiving. The first, usually occurs in young to middle adulthood as individuals become parents, whilst the second occurs in later adulthood as one's parents become dependent and require care (Birkel, 1991). This is not one continuous period of caregiving but rather two normative entry points into a finite period of time where one adopts a caregiving role. However, families with children born with disabilities requiring ongoing care are faced with a distorted life cycle where family members may become suspended in one particular life stage (DeMarle & le Roux, 2001).

Early experiences of caregiving within the family may influence expectations held by family members in relation to caregiving exchanges in the future (Berg et al., 2019). For example, in the case of a child with ID, a parent-child subsystem may lead to a highly enmeshed transactional style due to the ongoing needs of the child with disability. This enmeshed style may remain even after the child reaches adulthood. As previously noted, this can impact on other subsystems and may consequently result in the creation of a disengagement transactional style between parent and typically developing children due to the lack of time a parent is able to give to other family members. These transactional styles in childhood may therefore shape caregiving in the future.

As the family's developmental line continues to deviate from that of other families and the caregiving responsibilities remain or increase, the family system comes under stress (Qualls, 2016). This can necessitate changes in the family system and subsystems (DeMarle & le Roux, 2001). For example, boundaries may become permeable and roles may be renegotiated such that siblings may be promoted to co-parenting roles, whilst parents may endure ‘lifespan parenting’ rather than moving through traditional later life roles such as ‘empty nester’ (Burke, Lulinski, Jones, & Gallus, 2018: Qualls, 2016). As new roles are taken up, other roles may be untended, which may challenge family functioning. Furthermore, as the family system changes new constellations of members may arise, as with the birth of new children or grandchildren, or the welcoming of new partners (Qualls, 2016). New constellations in care may also arise, as Berg et al. (2019) note, the caregiving relationship may in time consist of a network of caregivers with the care load shared amongst family members. This can complicate the caregiving identity as those who are caregivers may hold several different roles and identities within the family, including that of parent, spouse, or sibling.

Regardless of one’s role in the family, Burke, Lulinski, et al. (2018) argue that ultimately the residential presence or absence of the individual with ID will continue to impact family interactions. The family system may need to establish new decision-making processes and new transactional patterns to communicate and negotiate issues of responsibility and decision making (Qualls, 2016). Transitioning such as launching (when adult children leave the family home) must be considered within the context of disability, within normative family lifecycles this may be viewed as a “launching and leaving stage” (Laszloffy, 2002) where parental launching is reciprocated by the young adults desire to leave, yet in families with disability it may be less likely that leaving the family home is desired. Importantly, Qualls (2016) views the family as the only continuity for the person requiring care because there is no continuity in systems and services.

Burke, Lulinski et al. (2018) state that whilst systems and supports have progressed for individuals with ID, policy and practice lag in terms of recognising family roles and needs. This argument is supported by Birkel (1991) who suggests that those in non-normative caregiving roles are likely to experience both poor social support and poor institutional supports. This is further supported by Martin (2006), who in his own reflection of life as an individual with ID, labelled his family a ‘disability family’ as social supports such as friends and extended family withdrew their presence and support. As previously noted, withdrawal of family members during times of crisis is not uncommon and can in some cases lead to disintegration of the system (Fingerman & Bermann, 2000).

Research and policy must move beyond the individual to consider social and cultural frameworks that may define who is dependent and how these dependents should be treated by society (Birkel, 2009; Burke, Lulinski et al., 2018). As noted by Qualls (2016), caregiver research has, for the most part, focused on an individual role, predominantly that of caregiver, seldom examining relationships within the family system or including the family system as a whole. In addition, and as already argued, disability policy also emphasises the role of the individual, with a focus on the person with disability (e.g., NDIS; Wiesel & Bigby, 2015). This endorsement of individualism ignores the key role of the family system over the life span of the person with disability, and especially for persons with ID.

Further to this, when viewing caregiving from a lifespan perspective, Birkel (1991) argues that caregiving for a child places emphasis on the child’s development and well-being during early developmental stages, whereas caregiving for older adults places emphasis on caregiver stress and coping. He argues that these understandings reflect, somewhat subtle social values of young versus older persons. In a family with a child with ID, even as an adult the individual often remains in care, thus progression through emerging, young, and middle adulthood may be overlooked with emphasis instead placed on caregiver burden, rather than looking for opportunities of care recipient growth or satisfaction. This is further perpetuated when families and researchers adopt the ‘eternal child’ typecast of adults with ID. Whilst the adult with ID may not develop according to typical and social milestones, it would be erroneous to suggest that across the lifespan there should be no emphasis on development.

A lifespan family systems perspective acknowledges that care and support can be ongoing and dynamic in the way that care is given and received across the life span (Berg et al., 2019). For example, as parents age, they themselves may be both caregiver for their child, and care-recipient from another family member (Berg et al., 2019). Thus, the lives of family members can be linked throughout the lifespan in complex ways, with major changes in responsibility of care (e.g., residential placement) representing significant transition points that have implications not just for the individual with disability, but for overall family functioning.

Summary

This chapter has provided a background into the social and political conceptualisations of ID from an international and Australian perspective. The chapter reviewed historical changes to government policy and public attitudes including the influence of the media on the development of policy and social norms. This chapter has also highlighted the complexities and differences in individual experiences within the family system in relation to caregiving and residential care planning. This demonstrates the importance of examining residential care planning for adults with ID through a lifespan family systems approach, emphasising the interactive and dynamic nature of caregiving and calling attention to the fact that families often do not speak with one voice. One must also acknowledge that the family system is influenced by wider community, government, and social ideology. Thus to enhance knowledge and understanding of the family system, one can look inward to family roles and interactions, as well as outward to environmental influences such as mass media and government.

Though this chapter has highlighted several limitations in the extant body of research worthy of future exploration, this program of research will focus on addressing the following limitations. To date, empirical literature has tended to reflect that of government policy, in that it has been individualised in focus, predominantly with an emphasis on parental experiences, this ignores the importance of family and other social supports that may act to encourage or discourage planning. Much of the literature has also yielded mixed results, which may further reflect the complexity of the issue, or methodological limitations. In addition, this literature draws on predominantly female samples, using survey and other quantitative methods to examine these experiences. As such, an alternative in-depth qualitative approach that explores both contextual factors such as social influences, and whole-of-family experiences is important in advancing current knowledge. A systems approach is also likely to encourage public policy and non-family care providers to consider the potential impact of decisions and of the language use in policy and programs on all family members.

This program of research therefore aims to firstly examine social constructs of ID, caregiving, and residential care as presented in the Australian media; and secondly, explore Australian family caregiving experiences, giving voice to individual family members who may construct and make sense of their experiences in different and divergent ways. Given the difficulties associated with advancing future care planning in families of adults with ID, this thesis will extend the current body of knowledge and research regarding family caregiving and planning by using a family systems framework and placing this within a broader social context within Australia. The use of such a framework minimises the risk of one family member (primary carer) dominating the research perspective, whilst the use of qualitative methods provides opportunity for a level of exploration that appears to be absent from extant literature.

Study 1 (chapters 3 & 4) and Study 2 (chapters 5 & 6) will be undertaken to identify media representations of issues surrounding ID, family caregiving, and residential care planning. Synthesis of media representations will also be presented in chapter 7. Study 3 (chapters 8-13) will provide a rich exploration of family experiences with caregiving and residential planning for an adult with ID.

Chapter 3 – Study 1 Methodology

Introduction

The previous chapter provided both an historical outline of government and societal change towards persons with intellectual disability (ID) and related policy, and an overview of family beliefs and behaviours surrounding caregiving and future planning, from an international and Australian perspective. As discussed in the previous chapter, Bowey et al. (2005) suggested that much of the information being received by families is filtered through media, even information that is potentially non-factual, and that this information may influence an individual's views. For example, if parents hold implicit theories such as 'no one else can care for my son as well as I can'; these theories may be reinforced by news reports of widespread service failings. Thus, macro level explorations of media contribute to the overall aims of this program of research by adding to our understanding of the development and strength of attitudes and beliefs (and therefore subsequent behaviours) of those caregiving for adults with ID.

As previously mentioned, Australia has also welcomed significant disability policy change in the last decade. Governments rely on media representations of such policy reforms to inform and engage the public in these policies (Kang, 2013). Saunders, Landsell, Eriksson, and Bunn (2018) describe the media as being in a "powerful position" to mould attitudes, set agendas, and sway public opinion through both representations and misrepresentations of these critical political and social issues. As such the introduction of the National Disability Insurance Scheme (NDIS) in 2013 and subsequent rollout heralds a critical period for the potential shaping or reshaping of public attitudes in relation to caregiving, care planning, and residential accommodation within the context of this new political and disability landscape.

Therefore, Study 1 aims to explore the media representations of ID, caregiving, and residential care as presented in Australian print, newswires, and national radio broadcast across a 6-year period from January 2013 to December 2018. Three main research questions are being asked of the data:

- *How are the topics of ID, care accommodation, and family care presented in the news media since the introduction and subsequent rollout of the NDIS?*
- *What role do adults with ID, families, and other significant sources (e.g., government) play in the representation of this topic?*
- *Have these representations changed over time as the NDIS has been rolled out?*

Analytic Methods

To answer these questions, Study 1 utilised an augmented analytic approach drawing upon quantitative content analysis (CA) and news framing. CA more broadly falls within the umbrella term of ‘textual analysis’ described by White and Marsh (2006) as a cluster of approaches for analysing text or communication (e.g., qualitative and quantitative approaches). News framing is included within this umbrella term as it too is concentrated on the effects of communication, and similar to CA has been widely applied to media coverage of particular issues (Nelson, Oxley, & Clawson, 1997). In fact, Entman (1993) argued that CA can be strengthened by adopting a framing paradigm such as this. As it applied in this study, the addition of news framing analysis allowed for a richer contextualisation of media portrayals through detailing the issues and sources presented.

Quantitative content analysis.

Quantitative content analysis (CA) is a systematic and replicable approach to communication research (Krippendorff, 2004; Stemler, 2001). Described by Krippendorff (1989) as a methodology “indigenous” to the field of communication, CA has and continues to be strongly embedded in media content inquiry. Quantitative CA is a numerical measurement process of providing ‘counts’ of categories. Quantities are descriptive in several ways; they can describe details of the sample (e.g., circulation of a newspaper), specific characteristics of a unit within a sample (e.g., size of an individual article), or describe the size and magnitude of categories coded.

Coding decisions and thus replicability of results depend primarily on three methodological decisions; (1) identifying the unit of sampling, (2) identifying the unit of data collection, and (3) identifying the unit of analysis. A unit of sampling is the message or message component drawn from the larger population for inclusion in analysis (Neuendorf, 2017). For example, in this study the sampling units were Australian news articles (print, newswires, and radio transcripts available through searched databases) that addressed certain inclusion criteria such as publication time frames (i.e., 2013 to 2018). A unit of data collection is the level at which the data is coded. It may be the same as the unit of sampling or significantly smaller than a unit of sampling, as long as it is large enough to be considered a meaningful unit. Krippendorff (2004) notes that these units can also be described on several "levels of inclusion" (p. 100). In this study there were two levels of inclusion for data collection, at one level the newspapers and media bodies themselves were categorised (e.g., regionality of publication), however categorisation also occurred at a second level, with the unit of data collection being each article or news story. Finally, the unit of analysis relates directly back to the research question and study aims, this is the unit at which the coded data are analysed and reported (Neuendorf, 2017). In this study, the unit of analysis related to the individual news story and included the overall tone (i.e., presentation and positioning of the topic/story based on the frequency of negative, neutral, or positive words), the role of key properties (e.g., role of accommodation), geographic location, and temporal distribution.

Coding schemes and measurement details should be constructed to operationalise concepts and establish relevant and valid categories for mapping text into appropriate data language (White & Marsh, 2006). Neuendorf (2017) notes that these can be developed from existing theory, existing literature, or replicated from past research where relevant to the research question and hypotheses. Neuendorf, and White and Marsh (2006) provide a plethora of examples of studies that have fully or partially replicated existing measures and coding schemes. Furthermore, White and Marsh support the use of scale measurement to allow for all aspects of the construct to be represented. In this study, a coding template from previous research exploring disability and media representations was revised to allow for the systematic analysis of content of each article and transcript (see Wardell et al., 2014). This template was piloted, tested, and revised to ensure confidence in the coding categories.

One of the benefits of CA is that it can reveal trends, patterns, and change as it occurs across large bodies of content and across significant periods of time (Krippendorff, 1989; Neuendorf, 2017; Stemler, 2001). Thus, it is a methodology that allows for insight into media representations of issues such as disability across cultures and time. For example, Jones and Harwood (2009) conducted a quantitative CA across a decade of print media representations of autism in Australia, determining that media representations tended to create and reinforce negative stereotypes. Wardell et al. (2014) also used quantitative CA to explore media portrayals of Down syndrome in New Zealand during a critical time frame when an activist group ‘Saving Downs’ was prominent in its use of social media. A recent Australian study by Saunders et al. (2018) utilised a qualitative CA approach to explore how 30 years of media coverage shaped public perceptions of people with acquired brain injury. CA can therefore assist in exploring how topics of caregiving and residential care for adults with ID are portrayed in the media, and how these representations may shape public perceptions. More specifically, quantitative CA can reveal if these representations have changed across the course of the NDIS introduction and subsequent rollout (2013-2018).

Despite the advantages of quantitative CA, Krippendorff (2004) warned that adopting a strictly ‘count’ approach to the data is restrictive, arguing that drawing inferences from the texts should form a central part of research. Entman (1993) further argued that a count approach may misrepresent media messages by assuming that all text is equally salient. It is therefore important that in addition to quantitative CA, the research design allows for an exploration of meanings invoked by texts, as these meanings can create emotional responses, behavioural changes, or reinforce existing ideas and beliefs held by the reader (Krippendorff, 2004).

In order to address the limitations of a strict count approach to quantitative CA, the CA coding has been augmented with news framing as this allows for a more qualitative exploration of significant textual constructions of the story. In the following section news framing will be described, news framing categories will be identified, and relevant decisions relating to the analysis of news framing for Study 1 will be discussed.

News framing.

According to Entman (1993) framing refers to the specific choices made in the transfer of communication, that is, what material is selected for communication and how it is constructed to create salience. A news frame is therefore used to organise and structure meaningful information that is socially shared and persistent over time (Reese, 2009). Journalists participate in the construction of news frames by not only determining what and who is included the news frame (issue and sources presented in the frame), but also determining what or who is excluded from the news frame (absence of issues/sources in the frame). This is defined by Gamson (2001) as part of the production process, selecting certain sources to quote whilst excluding others, which can result in a marginalisation of certain perspectives. Entman further emphasises that what is absent carries just as much significance as what is present, as absence can act to reinforce judgments and elevate salience of the selected information.

In addressing the issue of absence, researchers often adopt a deductive approach to analysis, with the creation of a list of frames defined a priori so one may determine if expected news frames are present or absent (Wendorf Muhamad & Yang, 2017). However, a literature search of news framing of topics related to residential care of adults with ID revealed that this is an area that has not yet been extensively researched. Though there may be overlap with prevalent news frames found in research on disability such as autism, this may not accurately reflect the news framing of the topic in Study 1, as such an inductive-iterative approach has been adopted. Firstly, the inductive process will allow for news frames to emerge in the data and explore what or who is present or included. Secondly, with an iterative cycle of returning to those news frames and exploring other developing patterns in the data, attention can focus on the exclusion of counter-frames. This also allows for a broader scope of absence to be applied; that is, in addition to considering the absence of news frames, one may also consider the absence of voices lent to the story, for example whether adults with ID are framed as active participants in relation to care decisions or whether their voices have been silenced.

In the construction of a news frame, events, issues, and actors all characterise the subject being communicated and create the dominant text presented (Kang, 2013). Kang (2013) further suggests that news framing of people with disabilities can be thus categorised through three frames: 1) the issue presented, 2) the representative or source used in the presentation of the issue, and 3) the framing of responsibility, that is, does the news frame emphasise individual responsibility or is the issue presented from a broader social or political context? The framing of responsibility can either facilitate social/government intervention or reinforce individual problem solving. In this sense, there are frames within frames, as the source frame is not independent of the issue frame, nor is the responsibility frame. However, Gamson (2001) notes that alternative ways of extracting news frames from within the same discourse are complementary.

Through the inclusion of four framing questions (issue, source, responsibility, presence/absence?), this study can provide a more accurate analysis on media representations with specific consideration given to relationships between journalists and sources, salience placed on preferred frames, and the additional consideration of absences in these news frames. It should however be noted that whilst the description of news framing above highlights the core benefit in applying news framing to this study's analyses, the description provided is not an exhaustive one of news framing. As a major analytic approach, news framing contains many more complexities than discussed above. Whilst news framing tends to reside within a communications and media domain, many aspects of a full news framing analysis parallel with discourse analysis.

Data Collection

Articles and transcripts were sourced from the Factiva database and EBSCOhost's Australia and New Zealand Reference Centre. Database searches included Australian newspapers and news networks with articles and transcripts published or broadcast from January 2013 to December 2018. The year 2013 was chosen as it coincides with the introduction of the NDIS in Australia. A search cut date of December 31, 2018 was chosen due to the commencement of the Australian Royal Commission into Aged Care Quality and Safety in early February 2019. In Australia, there is some overlap between disability housing and aged care facilities as several young adults with disabilities reside in aged care facilities due to an apparent lack of accommodation options (see for example, Australian Senate, 2015). This is a complex and unresolved issue beyond the scope of this research program, it was therefore determined that news published directly before and after the commencement of the above-mentioned royal commission could be influenced more by issues that sit predominantly within aged care than by the NDIS, therefore December 2018 was deemed an appropriate end date. Multiple key search terms relating to disability, family care, and accommodation were used in the search. A summary of the searches is outlined in Appendix A.

Database searches yielded 646 results. Headlines and summaries of key words in context were scanned in initial database search results to determine the relevance of the articles. Relevant articles (n=235) were then downloaded and imported into the qualitative software program NVivo 12 (QRS International, 2018). All duplicate articles were removed (n=28) with remaining articles scanned to ensure inclusion criteria were met. Articles deemed to be primarily reporting on issues outside of the scope of this study were removed (e.g., news focused on law reform in disability abuse cases, sexual assault cases unrelated to accommodation, or issues of dementia). Figure 3.1 illustrates the search process that yielded the sample of articles analysed.

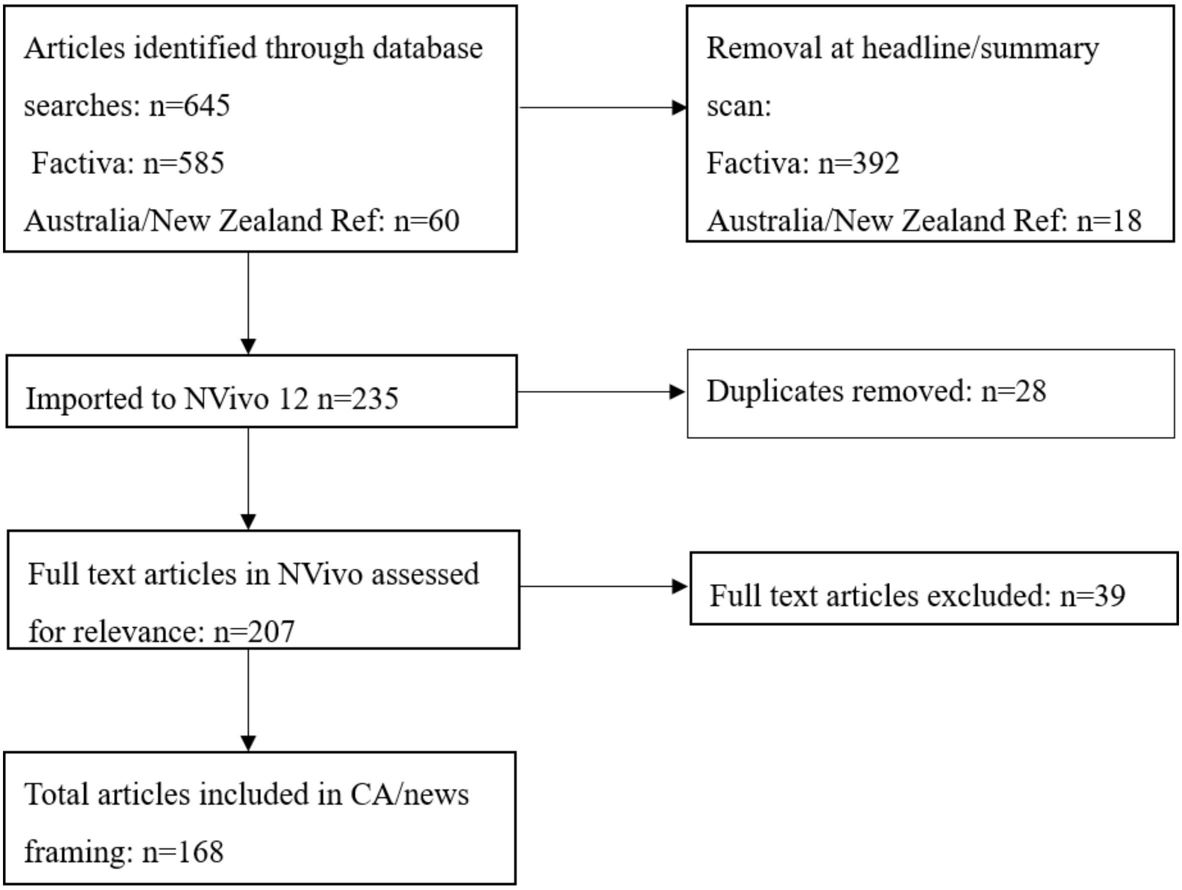


Figure 3.1. Flow chart of news content search.

Analysis

Quantitative content analysis.

According to Neuendorf (2017) a codebook or coding form with rules and guidelines for coding should be constructed prior to the commencement of the quantitative content analytic process. A coding template from previous research exploring disability and media representations (Wardell et al., 2014) was revised to fit this study's research questions, with an initial 'first draft' codebook developed. As previously stated, White and Marsh (2006) support the use of scale measurement in quantitative CA, as such the coding template for this study contained a number of category codes (e.g., what was the overall tone of the article/transcript?) with Likert scale answer options (e.g., very positive, slightly positive, neutral/balanced, slightly negative, very negative). In the initial codebook testing phase, all articles and coding template were placed in NVivo 12 (QRS International, 2018) for analysis. The following phases of coding were then undertaken by two independent coders; the researcher and a second coder.

Three articles from the total sample were randomly selected via a random number generator (https://www.random.org) for coding. Upon completion of initial coding, technical or software difficulties were corrected, and coding discrepancies were discussed with the two independent coders until agreement was reached. Revisions to codebook instructions were made to accommodate new information, these revisions were tested as follows. A further 20 articles were randomly selected and coded using the revised codebook (codebook_V2). Discrepancies revealed codebook ambiguities in relation to tone, role of ID, and role of family. Further revisions were subsequently made to the codebook in order to provide further clarity in relation to these three categories, with the goal of leading to greater consistency between the two independent coders (codebook_V3).

It should be noted that objectivity is one of the standards for quantitative CA. Whilst objectivity is desirable, Krippendorff (2004) acknowledged that the role of analyst/s who engage in quantitative CA essentially limits this goal. A researcher’s meaning making of certain counts of texts is often dependent on normative beliefs such as balanced reporting or a requirement to provide affirmative narratives (Krippendorff, 2004). As an alternative to objectivity, Neuendorf (2017) suggests that a standard of consistency among analysts must be sought, describing this as inter-subjectivity.

In seeking greater inter-subjectivity, the second phase of codebook testing incorporated a further 20 randomly selected articles for coding by the two independent coders (codebook_V3). This process revealed some discrepancies in coding the tone of the article. To explore this issue in more detail each coder revisited two selected articles where discrepancies had occurred in different directions (e.g., Article 1 was coded more positively by the researcher, whereas Article 2 was coded more negatively by the researcher). Coders were instructed to annotate article text according to codebook rules (e.g., highlight examples of positive, negative, and neutral lexicons), then use relevant sections of the codebook to justify coding outcomes.

From this process it was evident that the coding of tone into five categories (very negative, somewhat negative, neutral/balanced, somewhat positive, and very positive) was problematic. From a strict ‘count approach’ this meant that the difference between a somewhat negative and very negative story would be a single negative lexicon. As this seemed both arbitrary and potentially misleading in terms of results, coding of tone was revised to three categories; more negative (i.e., higher frequency of negative words and lower frequency of positive words), neutral/balanced (i.e., low or similar frequency of negative/positive words), and more positive (i.e., higher frequency of positive words and lower frequency of negative words).

Though the categories ‘role of family’, ‘role of person with ID’ and ‘role of accommodation’ demonstrated good consistency across coders, the process described above was repeated for all coding categories to ensure appropriate interrogation had been conducted on all codebook sections. Refinements were made to the final iteration of the codebook (codebook_V4; see Appendix B) and used to code the entire data set of 168 articles. Trends within media content and across time were explored within NVivo 12 (QRS International, 2018) and are reported in the following chapter.

News framing.

Following the quantitative content analysis (categorical coding) of each news story, the coder revisited the news story in order to answer a set of four news framing questions. This sequential analytic process was repeated across all 168 news stories. The four open ended questions were:

- What issues regarding ID and accommodation were presented in the new story?
- Who was/were the source/s in the news story?
- Was the issue framed in the news story as episodic or thematic?
- What textual frames (including sources) were absent?

Due to a lack of news framing research in this area, a list of a priori framing categories for questions such as issues could not be established, however guides from the disability sector (e.g., personal stories, policy, legal case) were provided as initial examples. Through the same pilot process as the quantitative CA coding described previously, coders were able to establish consistency in identifying dominant issues.

Sources were identified as such if (a) a person was interviewed, or (b) a person, department/organisation or document (e.g., report) was clearly cited as the source of the information presented. Coders were instructed to code news stories as episodic if the story emphasised individual episodes and responsibility, whereas news coverage of an issue placed within a frame of social responsibility was coded as thematic.

Finally, the establishment of absence of frames was an iterative process. Through coding issue, source, and responsibility for the initial testing phase of the codebook (n=43), coders were able to establish patterns in the data with attention given to both dominant frames and minor frames. Consideration was also given to government policy and standards of media practice in determining whether particular news frames that may be expected in the data were absent. This then allowed for coders to revisit each of the initial 43 news stories to establish the absence of issues and voices.

Researcher Reflexivity

Reflexivity involves an examination of the researcher's role, specifically how intersubjective elements influence the research process (Finlay, 2002a, 2002b). It is defined by Finlay (2002b) as "thoughtful, conscious self-awareness" (p. 532) through which researchers explore how knowledge is constructed. Some may argue that in a quantitative format of CA, the researcher has less influence on the research process. Yet whilst the contents of the data itself cannot be influenced by the researcher in this study, codebooks and coding manuals are designed with categories, criteria and scales all chosen by researchers, thus the influence of the researcher is ever present.

As discussed earlier in this chapter, the construction of the codebook presented challenges. Whilst the categories were established from previous research, the criteria for such categories had not been reported in previous research. The process of piloting the codebook used in this study highlighted the importance of such transparency in compiling guidelines for codes. Addressing the issue of subjectivity evident throughout the pilot phase was further complicated by the roles of the researcher (1st coder) and research assistant (2nd coder). Though encouraged to challenge discrepancies, I sensed a reluctance from the second coder to do so, rather she would refer to her coding as being wrong in some way if it did not align with my own. This process made me question whether there is a general tendency for the coder with less power, or less investment, in a research study to yield to the primary researcher, thus ‘agreement’ in essence becomes a surrender of one’s own understandings to another.

As a researcher with a lived experience in journalism and media I also found myself scrutinising the data in ways I had not experienced before. My beliefs of what constituted ‘news’ and ‘newsworthy’ content was challenged by my familiarity with what could be described as ‘sponsored news’ content. Though it is possible to examine media manipulation of the news to some degree, it is difficult to determine advertiser manipulation of the news. I found myself wondering if a number of ‘good news’ stories were endorsed for publication due to relationships between publishers and advertisers, not because they aligned with the editorial standards of the publication. I found myself feeling irritated that this content might in some way pollute the data set, and then considered whether this was not the case for all research into news content? I reminded myself that what constitutes a news story is not simply the content of one story, but the stories developing around it, for example a newspaper on a ‘quiet’ news day may be compelled to make different editorial decisions from a newspaper on a ‘busy’ news day.

Summary

This chapter has outlined the methodology for a broad exploration of media representations of ID, family, and caregiving as presented by the Australian media during the NDIS rollout period (2013-2018). Whist the use of quantitative CA allows for the systematic categorisation of news text for analysis, the addition of news framing as part of the analytic approach will address contextual factors, either present or absent, in these news representations. This acknowledges that through the journalistic process decisions to exclude sources, details, and perspectives are significant and must also be considered. A detailed presentation of the findings from Study 1 follows in Chapter 4.

Chapter 4 – Study 1 Results

Introduction

This chapter presents the quantitative content analysis (CA) and news framing results of news stories that were published or broadcast in Australia between 2013 and 2018. In total 168 news stories were identified as addressing issues relating to intellectual disability (ID), family, and residential accommodations during this time. As outlined in Chapter 3, these results aim to answer the following three research questions:

- *How are the topics of ID, care accommodation, and family care presented in the news media since the introduction and subsequent rollout of the NDIS?*
- *What role do adults with ID, families, and other significant sources (e.g., government) play in the representation of this topic?*
- *Have these representations changed over time as the NDIS has been rolled out?*

Characteristics of sample.

Publisher data from the sample were collected (e.g., ownership) to establish bias in overall media representations based on ownership and potential political affiliations. Almost 80% of the articles were published in either News Limited or Fairfax owned newspapers, this may be particularly important in relation to the representation of governments within the topic of disability as News Limited is traditionally associated politically with Australian conservative parties (right-wing), whilst Fairfax is more likely associated with the socialist parties (left-wing; Roy Morgan, 2013). Current circulation for metropolitan and inner-regional newspapers ranged from 690,000 readership for the Herald Sun, down to 35,000 readership for the Canberra Times (Roy Morgan, 2018). Almost two thirds of the articles were published in Australia’s two most populated states; Victoria (32%) and New South Wales (30%), with all other articles distributed across the remaining states, territories, or featuring in a national broadsheet/broadcast. A detailed table of media distribution can be viewed in Appendix C, an extended list of source data can be found in Appendix D.

Temporal distribution of the 168 included articles is presented in Figure 4.1. A peak in the largest number of articles per year coincided with the launch of the National Disability Insurance Scheme (NDIS) in 2013. For most other years distribution was relatively stable, however a secondary peak occurred across 2015. To the researcher’s knowledge, there were no significant events occurring in Australia in 2015 that may explain this second peak, however it did occur towards the end of the NDIS trial period (2013-2016). It is possible that this peak may be reflective of an increase in government and support service activities during this time.

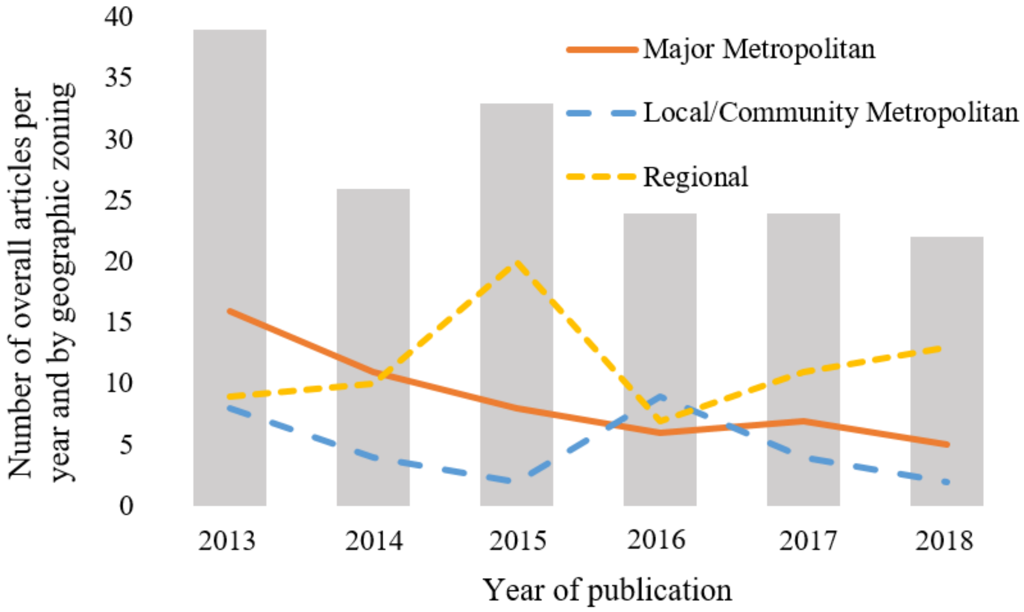


Figure 4.1. Temporal distribution of the number of articles included in analysis, and number of articles by three major geographic zones.

Distinctions were made between geographic areas of distribution (e.g., regional versus metropolitan publications) with a further distinction made between major metropolitan newspapers and local community newspapers available within a restricted metropolitan zone (e.g., suburb-focused paper). This distinction between major metropolitan, local/community newspapers, and regional newspapers reflects the Audited Media Association of Australia's (AMAA, n.d.) categories of publication type. Broadcast media and news wires were further separated out into their own categories. Consideration has been given to geographic areas of distribution when exploring each coding category.

Following is an exploration of tone of articles, role of ID, role of individuals with ID, role of family, and role of accommodation. This will be followed by news framing results identifying sources, major issues, and absence of relevant frames. A cross-analysis of role trends identified in the quantitative CA and major issues identified in the news framing will also be discussed.

Quantitative Content Analysis

The quantitative CA used a frequency count approach to the data. Consistency in coding was achieved via the use of a piloted and revised codebook to categorise the data into the following:

- tone, categorised as more positive (i.e., contained more positive words), neutral/balanced (i.e., contained neutral words or a similar frequency of positive and negative words), or more negative (i.e., contained more negative words);
- role of ID, categorised as integral, part, or incidental;
- role of individual with ID; categorised as integral, part, incidental, or absent;
- role of family (parents/siblings); categorised as integral, part, incidental, or absent; and
- role of accommodation; categorised as integral, part, incidental, or absent.

Quantitative CA results are presented as percentages; however it is noted that with a small sample size percentages can be misleading, therefore sample numbers have also been provided to aid with comparison.

Tone of news stories.

With regards to the tone of the news stories (irrespective of primary focus); 54.8% of the news stories were more negative in tone (n=92), 28% of the new stories were more positive in tone (n=47), the remaining news stories presented a neutral or balanced account of the topic. There was a consistently higher number of negative news stories in each of the six years examined, though a small decline overall in negative news stories from 2013 to 2018. Positively toned news stories increased to almost 40% in 2016, for example the story "Project houses hope for the future" (Tatman, 2016) featured positive language such as "relief", "hope", "optimism", "excitement". Despite the 2016 increase, positively toned stories have declined since (see Figure 4.2 for tone of news stories presented per year).

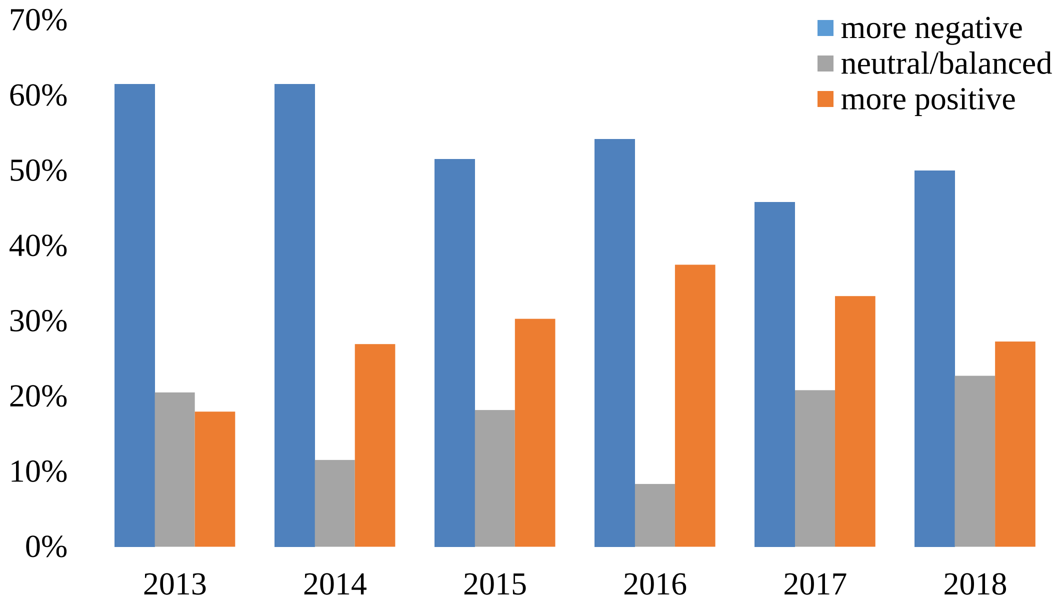


Figure 4.2. Tone of news stories presented per year.

In exploring tone of news stories by region, major metropolitan was the only area that consistently published more negative news stories across each of the six years. More than 50% of Metropolitan news stories in each year were more negatively toned such as the Sydney Morning Herald's 2018 story "Shocking abuse of disabled revealed" (Alexander, 2018), featuring a high frequency of negative language such as "state of distress", " skin rotting", and "atrocious circumstances". In comparison, there tended to be an equal number of positively toned and negatively toned news stories over time in local/community metropolitan publications. Regional publications also tended to be less skewed toward negatively toned news stories in more recent years with equal numbers of positively and negatively toned news stories in 2015, 2017, and 2018 (See Appendix E for detailed figures of tone by region).

Roles within news stories.

ID or an issue placed primarily within the context of ID was the focus of 55 news stories (32.74%). The distribution of news stories where ID was integral differed across regions and years (see Figure 4.3). Overall, regional publication featured the largest proportion of news stories focusing on ID, followed by major metropolitan publications.

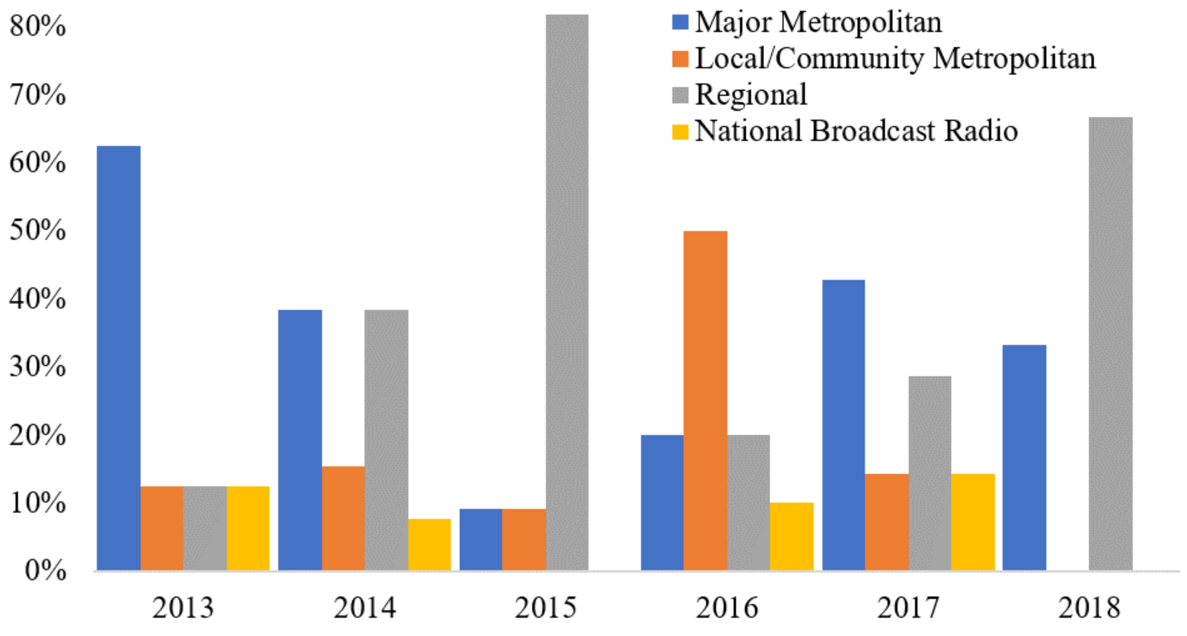


Figure 4.3. Temporal distribution of ID as integral, across regions.

Even when ID was integral to the news story, individuals with ID were not always present. Individuals with ID were only integral in 29 news stories (17.26%) and were completely absent in 36 news stories (21.43%). This contrasted with the role of family members (see Figure 4.4).

A large number of news stories focused primarily on issues surrounding accommodation (n=110), however since 2015, there has been a continuous, steady decline in accommodation focused news stories per year. Almost twice as many news stories featuring accommodation as integral appeared in regional publications compared with major metropolitan publications.

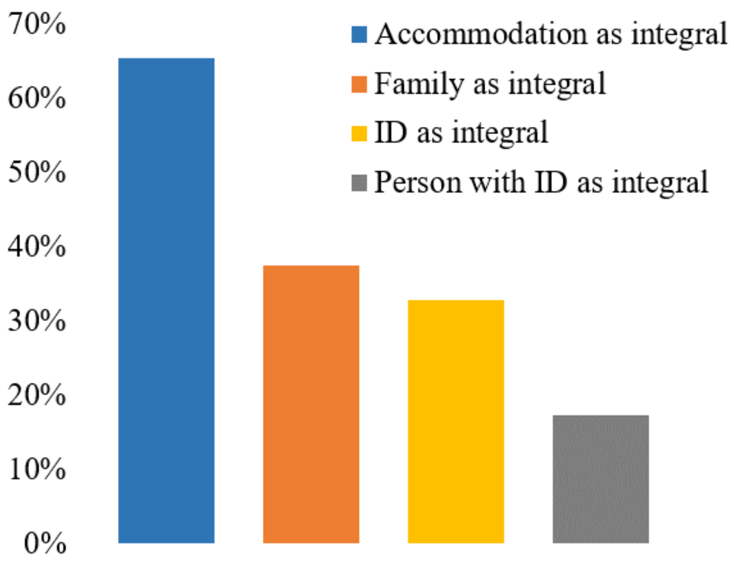


Figure 4.4. Comparison of roles as integral.

Trends across coding categories.

Table 4.1 provides a breakdown of tone of news story according to the role of ID, family, and accommodation. When ID was integral to the story (i.e., focus on ID), there was almost an even split between negatively and positively toned news stories. However, when ID formed part of a broader context such as government funding or housing, or was incidental to the story, these news stories were more likely to be presented negatively. Less than a quarter of news stories focusing on family presented the story in a positive tone, whereas almost 60% of these news stories were presented in a negative tone. News stories focusing primarily on issues surrounding accommodation were presented more negatively, whilst news stories focusing more broadly on disability issues (i.e., accommodation was incidental) were presented more positively. However, when accommodation was presented specifically within the context of ID (i.e., accommodation and ID were both integral) there were an equal number of positive (n=15) and negative (n=15) news stories.

Table 4.1

Tone Trends Across Roles

Coding category	Tone of news story (counts appear within parentheses)			Total N
	Negative	Neutral/Balanced	Positive	
ID=integral	43.64% (24)	18.18% (10)	38.18)	55
ID=part role	59.15% (42)	11.27% (8)	28.17% (20)	71
ID=incidental	61.90% (26)	23.81% (10)	14.29% (6)	42
Individual with ID=integral	37.93% (11)	24.14% (7)	34.48% (10)	29
Individual with ID=part role	64.62% (42)	12.31% (8)	23.08% (15)	65
Individual with ID=incidental	52.63% (20)	21.05% (8)	26.32% (10)	38
Family=integral	58.73% (37)	19.05% (12)	22.22% (14)	63
Family= part	54.55% (30)	12.28% (7)	32.73% (18)	55
Family = incidental	45.71% (16)	25.7% (9)	28.57% (10)	35
Accommodation as integral	55.45% (61)	16.36% (18)	28/18% (31)	110
Accommodation as part role	69.44% (25)	16.67% (6)	13.89% (5)	36
Accommodation as incidental	28.57% (6)	23.81% (5)	47.62% (10)	21

Quantitative CA Summary.

The quantitative CA revealed that overall news stories relating to issues of ID, accommodation, and family tend to be more negatively than positively toned. Though there were slight peaks across the 6-year period, a greater number of negatively toned news stories remained consistent across this time frame. However, upon categorising news stories by publication area, consistency in negative tone only held for metropolitan publications, with local/community metropolitan news stories and regional news stories either being more balanced, or more positively toned.

Most news stories placed the topic of ID within a broader context, for example accommodation for people with disabilities, including those with ID. Yet even in those stories that did focus on the topic of ID, few articles featured individuals with ID. Contrastingly, families of adults with ID were integral to a majority of news stories; however, these tended to be more negatively toned than positively toned.

Results regarding the topic of accommodation show changes over time with fewer news stories in recent years focusing on accommodation related issues, however this trend was reflected in story numbers overall. News stories that placed accommodation within a broader context tended to present the issue more positively than those predominantly focused on an accommodation related issue.

News Framing

Following on from the quantitative CA, news framing sought to answer four questions regarding the presentation of the news story. These were:

- What issues regarding ID and accommodation were presented in the news story?
- Who was/were the source/s in the news story?
- Was the issue framed in the news story as episodic or thematic?
- What textual frames (including sources) were absent?

Whilst some questions could be answered through familiarisation with the text (e.g., establishing the sources identified in the news story) identifying absence of frames involved an iterative coding process. News framing results for each of the above questions will now be presented, with consideration given to tone (as established in the quantitative CA), as well as temporal and geographic distribution of stories where relevant.

Sources.

Over twenty different categories of sources were identified throughout the news stories. These included, but were not limited to, family members, medical professionals, government and non-government representatives, financial advisors, reports and surveys, union representatives, police, and the media (see Table 4.2).

The most frequent sources cited in the news stories were family members of a person with an ID. These family members were predominantly parents, with only a small number of news stories citing siblings. Other frequent sources were politicians and government officials, government or other reports, representatives from care organisations, and advocates for people with disabilities.

While the inclusion of some sources remained relatively stable over time, in 2013 almost all news stories cited family members as sources, however in 2015 this decreased to around half of all news stories and remained around this level in 2016 through to 2018. In 2015 there was a small spike in news stories citing parent/family run respite and accommodation groups which may coincide with the opening of accommodation homes for people with ID. Persons with ID however were most likely discussed in third person with less than 6% of the news stories included the voice of the person with the ID (n=10). Persons with ID were not present as sources at all in 2015. Despite 2013 to 2018 representing a significant period of time for the trial period and subsequent rollout of the NDIS, few news stories used the NDIS or National Disability Insurance Agency (NDIA) as a source, in fact across 6 years and 168 news stories the NDIS or NDIA (including spokespeople) were only sources in nine news stories.

Table 4.2

Temporal Frequency of Sources as Percentages (Multiple allocations counted, counts appear within parentheses)

Source	2013 (n=39)	2014 (n=26)	2015 (n=33)	2016 (n=24)	2017 (n=24)	2018 (n=22)	Total N
Family of person with ID	79.49% (31)	76.92% (20)	48.48% (16)	58.33% (14)	45.83% (11)	54.54% (12)	104
Politicians/government officials	30.76%)	30.77% (8)	27.27% (9)	41.67% (10)	29.17% (7)	27.27% (6)	52
Care Agency	28.21% (11)	30.77% (8)	24.24% (8)	33.33% (8)	33.33% (8)	22.72% (5)	48
Government reports	10.27% (4)	23.07% (6)	3.03% (1)	25.00% (6)	16.67% (4)	22.73% (5)	26
Other report/survey	23.08% (9)	26.92% (7)	6.06% (2)	8.33% (2)	0.00% (0)	18.18% (4)	24
Advocates	10.27% (4)	11.54% (3)	12.12% (4)	20.83% (5)	16.67% (4)	13.64% (3)	23
Other agency representative	7.69% (3)	7.69% (2)	3.03% (1)	16.67% (4)	12.50% (3)	22.73% (5)	18
Family of (or) person with other disability	7.69% (3)	7.69% (2)	3.03% (1)	20.83% (5)	8.33% (2)	4.54% (1)	14
Parent-run Accommodation/ Respite Group	0.00% (0)	3.85% (1)	6.06% (2)	20.83% (5)	8.33% (2)	4.54% (1)	11
Adult with ID	7.69% (3)	3.85% (1)	0.00% (0)	8.33% (2)	12.5% (3)	4.54% (1)	10
NDIS/NDIA	7.69% (3)	0.00% (0)	3.03% (1)	4.17% (1)	8.33% (2)	9.09% (2)	9
Medical/hospital	0.00% (0)	0.00% (0)	9.09% (3)	8.33% (2)	0.00% (0)	13.64% (3)	8
Other	23.08% (9)	26.92% (7)	18.18% (6)	12.5% (3)	25.00% (6)	40.90% (9)	40

In reviewing sources based on areas of distribution, family members were consistently the most frequent source across all areas (see Table 4.3). Politicians and government officials were more likely to be cited as sources in local/community metropolitan and national broadcast radio. Advocates or advocacy groups were more likely to feature as sources in major metropolitan publications and national radio broadcast than other areas, as were non-government reports (other reports/surveys). Despite NDIS trial sites being based in regional areas of the country, major metropolitan publications and national broadcast were more likely to use NDIS/NDIA sources than regional areas. Almost half of all NDIS/NDIA source news stories appeared on National broadcast radio (a public service broadcaster).

Table 4.3

Frequency of Sources According to Distribution Category (Multiple Allocations Counted)

Source	Major Metropolitan (n=53)	Local/Community Metropolitan (n=29)	Regional (n=70)	National Radio B'cast (n=14)	Wires (n=2)	Total N
Family of adult with ID	64.15% (34)	55.17% (16)	61.43% (43)	71.42% (10)	33.33% (1)	104
Politicians/Government officials	24.53% (13)	44.83% (13)	24.29% (17)	64.29% (9)	0.00% (0)	52
Care Agency/Paid carer	32.08% (17)	31.03% (9)	27.14% (19)	14.29% (2)	33.33% (1)	48
Government reports	11.32% (6)	20.69% (6)	15.71% (11)	20.00% (3)	0.00% (0)	26
Other report/survey	18.87% (10)	10.34% (3)	10.00% (7)	26.67% (4)	0.00% (0)	24
Advocates	22.64% (12)	10.34% (3)	4.29% (3)	26.67% (4)	33.33% (1)	23
Other agency representative	5.66% (3)	10.34% (3)	12.86% (9)	20.00% (3)	0.00% (0)	18
Family of (or) person with other disability	9.43% (5)	10.34% (3)	5.71% (4)	14.29% (2)	0.00% (0)	14
Parent-run Accommodation/ Respite Group	0.00% (0)	10.34% (3)	8.57% (6)	14.29% (2)	0.00% (0)	11
Adult with ID	5.66% (3)	10.34% (3)	2.86% (2)	14.29% (2)	0.00% (0)	10
NDIS/NDIA	3.77% (2)	6.90% (2)	1.43% (1)	28.57% (4)	0.00% (0)	9
Medical/Hospital	34.31% (4)	3.45% (1)	4.29% (3)	0.00% (0)	0.00% (0)	8
Other	35.85% (19)	17.24% (5)	15.71% (11)	35.71% (5)	0.00% (0)	40

Issues.

Overall, topics addressed in the news stories centred around four major issues:

1. Role and responsibilities of the government (n=79). This included funding concerns, the government's abolition of the group home/institutional care model, government policy (rules/regulations), and community disability models.
2. Housing (n=63), including costs, availability, innovative and independent living options.
3. Mistreatment of persons with disability (n=29); and
4. Burden of care for families, including need for respite (n=20).

Temporal distribution of the four major issues is presented below in Table 4.4. It should be noted that often more than one major issue was present, for example availability of housing as an issue may have been presented alongside the issue of government funding.

Table 4.4

Temporal Distribution of Main Issues Present Across News Stories

Issue	2013	2014	2015	2016	2017	2018	Total
Government	19	17	18	6	11	8	79
Housing	11	10	16	12	7	7	63
Mistreatment	7	2	9	4	3	4	29
Burden of care	5	5	2	5	1	2	20

Role and responsibilities of the government.

A majority of all news stories from 2013 to 2015 focused on roles and responsibilities of the government. In comparison this focus decreased in 2016 to 2018. News stories reporting issues surrounding roles and responsibilities of the government tended to position these issues more negatively (n=51, 64.56%) and primarily used parents as sources (n=47, 60%).

Government funding was most frequently labelled inadequate, in “crisis” (e.g., Griepink, 2015; Sorensen, 2015a), or critical (“shared care funding is critical”, 2013) with families described as “fed up with government inaction” (Sorensen, 2015b). This was framed as adding to the financial burden of caring for adults with ID. Parents were also positioned as mostly sceptical of change to disability funding, including the NDIS, with one article labelling the NDIS as a way for state governments to “avoid disability funding” (“Fears NSW using NDIS deal”, 2013).

In these news stories the government was positioned as accountable, in that it was viewed as having a moral obligation to promote and maintain the well-being of persons with disability via appropriate policy and private sector regulations that would ensure the safety and security of adults with ID. Representations of the Australian government in these news stories reinforces the government’s position as a welfare state, responsible for financial aid, and access to support services.

When reviewing the data against politically affiliated publications Fairfax and News Limited, more of these stories appeared in Fairfax newspapers (50% versus 33% in News Limited). However, both publications were more likely to report negatively toned stories regarding the government. It is noted that whilst the Australian Labor Party (left-wing) initiated NDIS policy with bipartisan support, the Liberal/National Party Coalition (right-wing) were in power in Australia across the 6-year period examined.

Housing.

News stories focusing on housing issues peaked in 2015 with almost 50% of the 2015 news stories focusing on these issues (n=16). In the remaining years investigated the media focus on housing has declined. Around half of all articles in local/community metropolitan and regional publications featured housing issues, whereas housing issues only featured in a quarter of metropolitan articles across the 6-year period.

Almost half of the news stories addressing housing issues positioned these issues positively (n=28, 44.44%). A majority of these positive news stories presented new and innovative housing solutions that offered alternatives to more traditional group home options (e.g., “Innovation designed to care”, 2015). These housing options were often provided by private care organisations or not-for-profit advocacy groups (predominantly run by parents of adults with ID) who had taken it upon themselves to address housing issues facing their sons and daughters (Sorensen, 2015c). The more negative reports on housing tended to focus on a lack of availability of housing and rising costs of housing and predominantly relied on family members as sources.

Mistreatment of persons with disability.

News stories addressing the issue of mistreatment of persons with disability were more frequent in 2013 and 2015 than any other year investigated. This issue was the focus of more than half of the news stories broadcast on national radio (n=8, 57.14%), with less than a quarter of stories in other geographic areas focused on this issue.

Almost every article presenting the issue of mistreatment of persons with disability was more negatively presented (n=28, 96.55%), with one article presenting the story with a balanced or neutral tone. Abuse, neglect, and general mistreatment of persons with disability were explored within the context of government run facilities and services (“disabled woman sues carers”, 2014), private care organisations (McKenzie, 2013), and from within family homes by family members (Alexander, 2018). Despite the three different contexts, government was often positioned as responsible for the safety and security of these individuals (e.g., “who will care for our children?”, 2015).

Whilst the government were positioned as responsible in these news stories, politicians or government officials only featured as sources in nine news stories on the mistreatment of persons with disability (31.03%).

Burden of care.

Most stories relating to burden of care for families of adults with ID were published between 2014 and 2016 (n=15). Fifty percent of all ‘burden of care’ stories appeared in regional areas, with the remaining stories evenly split between major metropolitan and local/community metropolitan publications. Half of these news stories were presented more negatively in tone (n=10), with 25% presented more positively (n=5). Difficulties with respite for parents caring for persons with disabilities were often presented in these news stories. Family members were cited as sources in 75% of stories (n=15). Importantly, this was the only major issue to not feature adults with ID as a source.

Issues across tone and time.

Despite the introduction of the NDIS at trial sites in Australia in 2013, a large number of negatively toned news stories across the 6-year period focused on issues surrounding government roles and responsibilities, predominantly inadequate government funding models (see Figure 4.5). News stories on the mistreatment of persons with disability also dominated the negatively toned stories across all years.

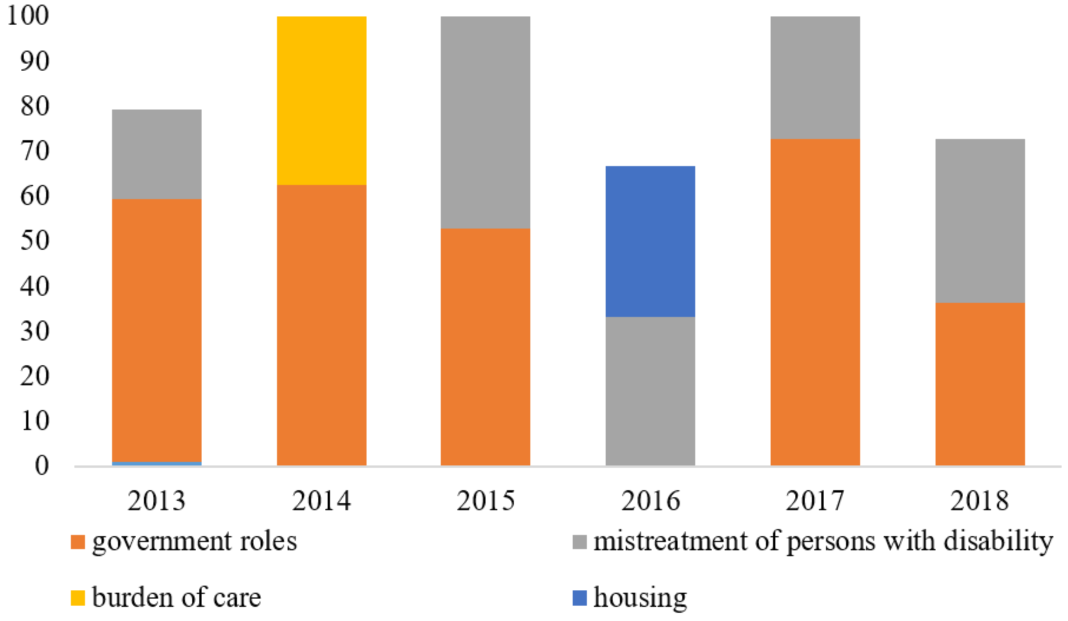


Figure 4.5. Temporal distribution of issues present in negatively toned news stories.

For the most part, positively toned news stories across the 6 years tended to focus on the issue of housing. The 2015 spike in positively toned news stories relating to housing issues (see Figure 4.6) predominantly discussed innovative housing solutions.

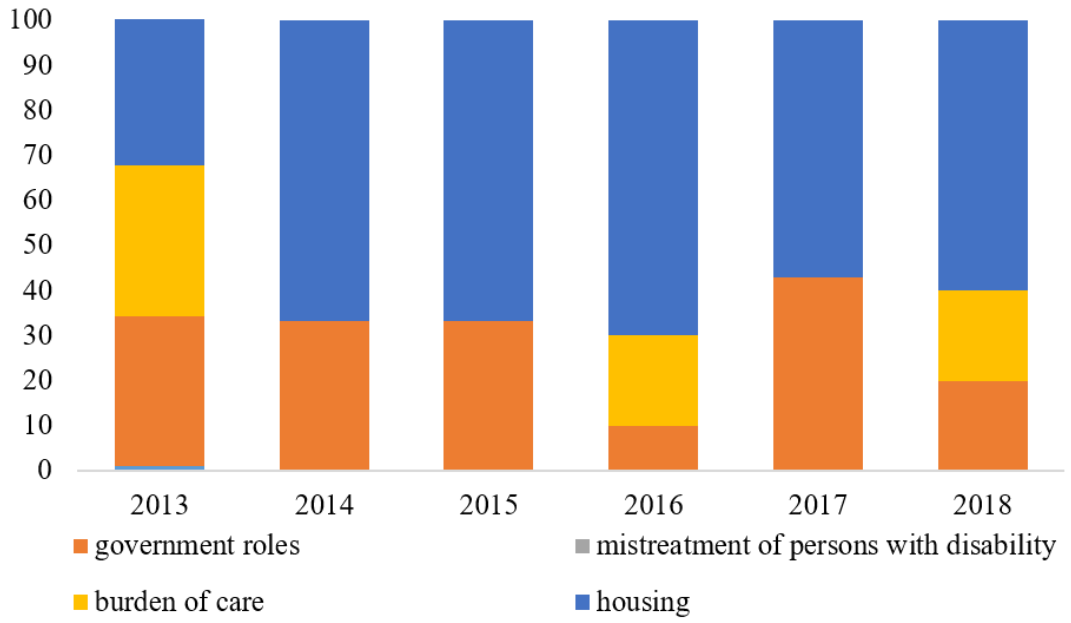


Figure 4.6. Temporal distribution of issues present in positively toned news stories

Responsibility.

A majority of issues were framed by the media as a social responsibility, one that fell predominantly on the government (n=113, 67.26%). A small number of news stories covering each of the four major issues were framed episodically (personal responsibility), however the largest number of episodic news stories focused on housing (n=8). These news stories generally presented families of adults with ID who had chosen to take steps themselves to raise money, apply for funding, build appropriate housing or locate accommodation for their sons and daughters rather than wait for the government to act (e.g., Ryan, 2017). Issues surrounding mistreatment of persons with disability was predominantly framed as a government responsibility in that the government was presented as responsible for the protection of persons with disabilities and establishing and enforcing appropriate laws to do so (e.g., "who will care for our children?", 2015). Despite burden of care revolving around family or parental burden, this issue was still largely framed as a social responsibility, in that the causes of burden of care were presented as being due to lack of appropriate supports and funding (e.g., Visentin, 2014).

Absence of frames.

There were a number of notable absences across the 168 news stories. The most frequent absence was that of individuals with ID being cited as sourced. One-hundred and forty-two news stories addressed an issue that was placed within the context of ID, a mere 10 news stories cited persons with ID directly. For the most part, parents represented sons and daughters with ID recounting their stories and presenting their wishes for the future (e.g., Nageshwar, 2015). Furthermore, siblings were also frequently absent as sources and were also absent from being acknowledged as forming part of the family system within the context of the story. This of course may reflect family systems with single children, though it is unlikely that this was always the case. In most personal stories, parents were frequent sources, with a focus on parent and adult child with ID only. Wider family contexts were rarely offered.

Despite study search dates encompassing the NDIS rollout period, the NDIS and/or NDIS/NDIA representatives were frequently absent as sources, and as a notable funding source in relevant news stories. This meant that key issues including funding, housing, and burden of care were rarely placed within the context of this new disability paradigm and political policy. Though government were often placed at the heart of the issue in terms of responsibility, government representatives or viewpoints were also frequently absent from these particular stories. This allowed reporters the opportunity to position the government negatively (e.g., Miletic, 2013) without the government offering a corrective or alternative view.

Analysis of Roles and Framing of Issues

News stories featuring both accommodation and ID — as a topic — as integral (n=37) were dominated by the issue of independent or innovative housing options for adults with ID (see Figure 4.7). These issues were almost all positive in tone. Yet when housing issues featured in news stories where family and ID were integral, almost half of these stories were negative in tone.

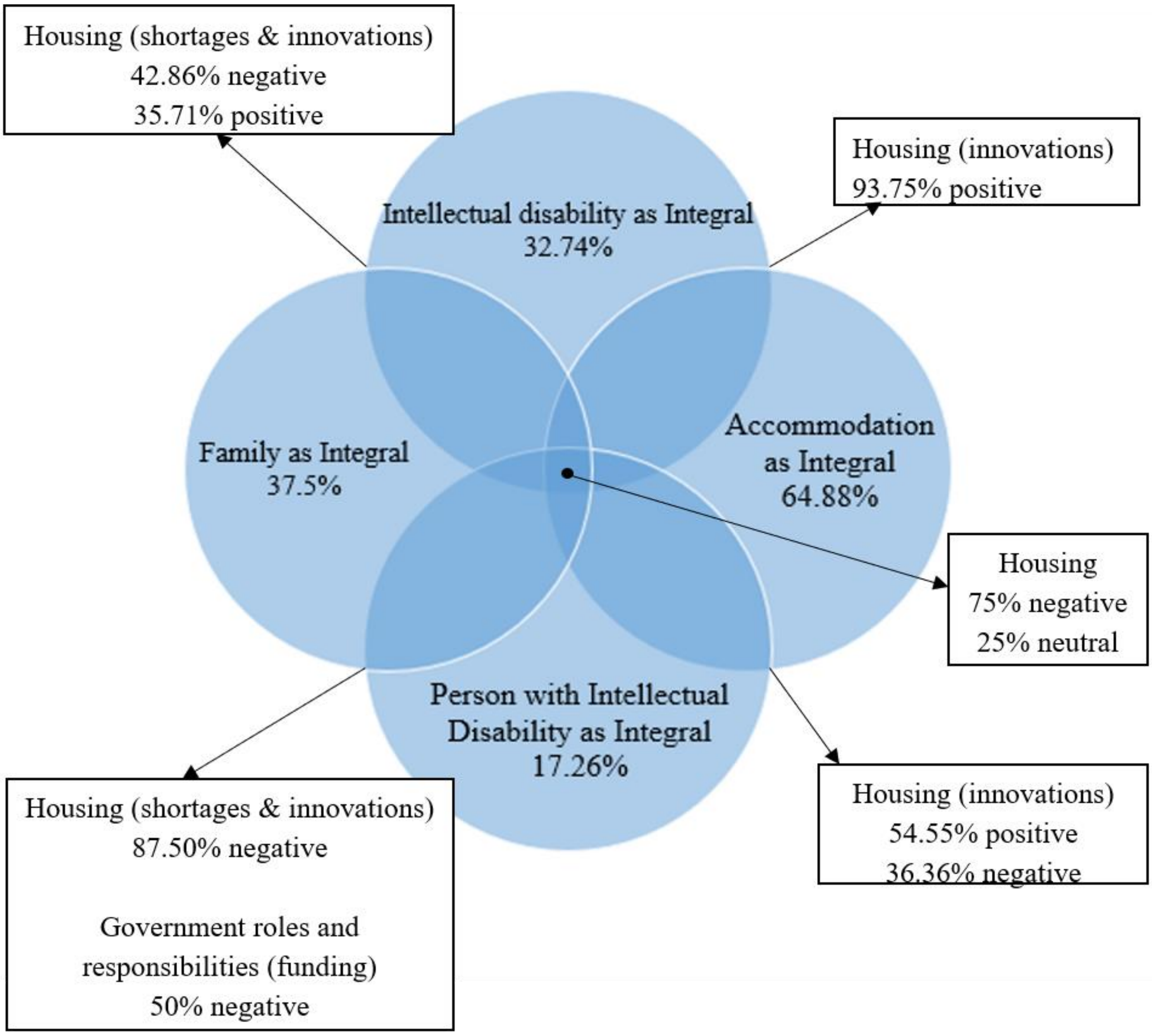


Figure 4.7. Interactions of integral roles and frequent main issue.

Fourteen news stories were coded as having both family and person with ID as integral. These stories focused on housing and government roles and responsibilities, yet only one of these stories was presented in a positive tone. News stories that were coded as having accommodation as integral and role of person with ID as integral (n=18) almost solely focused on issues relating to housing. These issues focused largely on innovative living options, which were presented slightly more positively, than negatively in tone.

Only a small number of news stories were coded with all four roles (ID, person with ID, family, and accommodation) as integral (n=8). Half of these news stories were presented negatively, half were presented with a neutral/balanced tone, none were presented positively. Six of the eight news stories were focused on housing related issues.

Summary

Study 1 addressed three research questions: (a) How were issues relating to ID, care accommodation, and family caregiving presented in the news media since the introduction and subsequent rollout of the NDIS? (b) What role(s) do adults with ID, families, and other significant sources play in the representation of these topics? (c) Have these representations changed over time as the NDIS has been rolled out?

Analysis of 168 Australian news stories published between 2013 and 2018 revealed that overall Australian media presented these news stories more negatively across the 6-year period, though regional Australia were more likely to receive positive or balanced news than metropolitan areas. Findings also suggest that the media may play an important role in shaping perceptions regarding governments and policy with government roles and responsibilities dominating the major issues across the 6-year period. These stories were predominantly presented negatively with government sources largely absent from these stories. This meant that the government were unable to provide a counter-story, as such this negative framing of the government by media bodies was often unchallenged.

Both the quantitative CA and news framing showed that adults with ID were clearly absent from most news stories. Parents were presented as representatives not just for the person with ID, but as representative for the family, with siblings also largely absent. This may have implications regarding societal expectations of caregiving if parents are positioned in the media as the primary, and often only advocate for adults with ID. Despite the frequency of family members as sources, there was a decline in family sources from 2013 to 2018.

Finally, a number of issues relating to care accommodation and housing were presented including affordability, housing stock, and advanced housing solutions. In combining the news framing analysis with the quantitative CA it was revealed that as the role of ID or individual with ID decreased, the percentage of negatively toned news stories increased. This indicates that for accommodation issues specific to adults with ID, the news has been more positive, if not somewhat promising since the inception of the NDIS, yet very few housing stories were placed explicitly within the context of the NDIS, and the number of housing related stories did decrease from 2013 to 2018.

Despite Australia being in the midst of two royal commissions into the care and treatment of vulnerable persons, including persons with ID, issues surrounding the mistreatment of persons with disability were only present in a small number of news stories as were issues of caregiver and family burden. News stories focusing on burden of care also declined from 2013 to 2018.

Study 1 results have revealed the potential influence of media in presenting ID related issues across Australia. Framing of the government was clearly controlled by the media, whilst the exclusion of adults with ID also has implications for public perceptions regarding agency of people with ID. Interestingly, those in regional areas of Australia received more positive positioning of ID related stories, which may have protective factors for these communities. Despite the rollout of such a significant policy change as the NDIS there was very little change in presentation of stories across the 6-year period which may indicate that this policy has had little impact on Australian families of those with ID, or it may suggest a reluctance from news media to present alternative news stories.

Just as this study has revealed geographic differences in news story presentation, it is also possible that modality of media may also offer differences in presentation. As broadcast media made up such a small portion of this quantitative CA and news framing, the variation in presentation via this format is worthy of further consideration. This will be investigated in Study 2.

Chapter 5 – Study 2 Methodology

Introduction

The aim of Study 2 was to explore the ways in which television current affairs programs construct intellectual disability (ID), caregiving roles, and residential care environments. Study 1 results indicated that news stories related to accommodation have been in decline since 2015, with more recent news stories on accommodation presenting the issue in a positive tone. Additionally, family sources have also declined in recent years as have news stories focused on the issue of burden of care. It is unclear if these changes represent a shift in reality for family caregivers and adults with ID, or simply a shift in media reportage. Thus, Study 2 enquiry focuses on a critical 24-month period (2017-2018) that follows the 3-year National Disability Insurance Scheme (NDIS) trial period from 2013 to 2016 (NDIA, 2016). These years coincide with a significant period of growth for the NDIS rollout across Australia, with participant numbers growing from just below 36,000 in mid-2016 (NDIA, 2016), to over 180,000 by mid-2018 (NDIA, 2018).

Literature suggests that differences in reporting of issues and use of sources are likely to occur depending on media type and format. For example, Tiffen et al. (2014) found Australian tabloid press cited fewer sources and offered fewer balancing perspectives than did television. Tiffen et al. (2014) further warn of the influence of media ownership, even in relation to assumptions of bias-free reporting by public service broadcasters (PSB), though they did find that Australian PSBs provided more source diversity than commercial broadcasters.

In addition, there has been debate about the varying degrees of influence of media depending on modality. Dijkstra, Buijtels, and van Raaij (2005) argued that largely due to the number of sensory modes stimulated, television elicits greater cognitive responses from viewers compared with newspaper. They argued that the combination of visual and auditory presentation demands more attention from viewers and therefore creates a greater impact. Due to the visual and auditory nature of television, a greater array of family and other voices may be more acceptable than an overabundance of quotes in written news stories. Finally, television formatting may also allow for greater depth in the reporting of issues due to program options such as one or two hour shows, whilst non-commercial radio stations may offer the same programming options, news stories as presented in Study 1 were likely restricted to a short five to 10 minute segment. Furthermore, the current affairs genre on Australian television is very popular, with the Australian Communications and Media Authority (ACMA, 2008) arguing that popularity strengthens these programs capacity to shape public opinion on social and political issues addressed in these programs. Thus, whilst Study 1's results presented an overview of predominantly print media representations of ID related issues in Australia during the NDIS rollout period (2013-2018), this may be a somewhat restricted or biased representation based on media type and influence.

Accordingly, Study 2 aims to add further detail to this current overview, by incorporating representations of ID, family, and accommodation across television broadcast media during a critical NDIS rollout period. As Study 1 presented predominantly quantitative results, Study 2 will uncover more nuanced constructions of relevant issues and those directly involved (e.g., family) via a discursive analysis of television transcripts. This method allows for a deeper interrogation of language by exploring how interactants use language to achieve certain goals (i.e., reinforce social norms). Thus, normalisation of stereotypes and behaviours can be deconstructed providing a richer understanding of the overall representations of ID, care, and planning related issues and potential influence of media as a whole. The resultant synthesis of mixed media data replicates a previous mixed methods approach conducted by Wardell et al. (2014). This will be discussed in Chapter 7.

The research question for Study 2 is: *What are the discursive constructions of adults with ID, family carers, and care accommodation for adults with ID as presented in Australian broadcast current affairs programs?* It will be argued that the use of DA in Study 2 provides a comprehensive and critical exploration of media discourse and its impacts on social and political perceptions of the issue of family caregiving, residential accommodation, and care options for adults with ID. This supports the overall aims of this program of research to investigate attitudes, beliefs, and behaviours in relation to caregiving and care planning for adults with ID, as it will demonstrate how attitudes, beliefs and behaviours may be formed or reinforced by such media discourse.

Procedure

In order to explore in-depth media representations of family and residential care for adults with ID national current affairs programs on Australian free-to-air television were scanned for relevant content airing 2017 or 2018. Current affairs programs, as opposed to news programs, were specifically chosen due to the likelihood that these programs would offer longer segments on relevant topics and may focus on issues that are highly relevant though may not be deemed “newsworthy” in the sense of receiving superficial reportage. Additionally, the pervasiveness of investigative journalism cannot be under-estimated in Australia or globally. This style of news reportage often keeps governments and organisations accountable, with such journalism exposing incidents such as Watergate in the U.S. (Carson & Farhall, 2018) and prompting government action on live meat exports in Australia (Petrie, 2019). Investigative journalists hold enormous power to influence both social and political change thus their presentation of ID and caregiver related stories warrants exploration.

Similar to many western democracies, television media ownership in Australia is shared between tax-funded public broadcasters and a range of private companies. The public broadcasters are the Australian Broadcasting Corporation (ABC) and Special Broadcast Service (SBS). Commercial broadcasters include Network 10, Seven Network, Channel Nine, and pay television company Foxtel. Informit database searches, and free-to-air television guides and program summaries were scanned to identify relevant programs. Programs were selected if they were described as journalistic (as opposed to entertainment based), aired nationally, and had a broad focus of content. Daily news programs, and programs with a more specific focus were excluded.

Archival episode listings of included journalistic programs were available from Informit, or either broadcaster or program specific websites. Episode and story titles and summaries were scanned for topic relevance (N=726). Episodes were retained if they addressed family caregiving, and/or residential care options and planning for persons with disability. Three episodes, and one feature story (i.e., one story appearing as part of a multi-topic episode) from four different programs were initially identified for analysis due to high content relevance. Transcripts from each of the programs were then scanned to ensure the episode or feature story addressed ID and the issue of accommodation. Upon scanning these transcripts, one episode ("Call me Harrison"), which had aired on an ABC program in 2018 was removed, as it could not be determined whether 'Harrison', an adult with autism, had an ID or was high functioning.

The three remaining transcripts were retained for in-depth discourse analysis. It was noted that there was considerable variability in story lines and program formatting. The retained transcripts were from programs airing on commercial television (Channel 9) and the public broadcast stations (ABC & SBS). Recent media reporting of political issues suggests that Channel 9 tends to adopt a right-wing conservative perspective, whilst the ABC has been accused of failing to meet their editorial standards of impartiality presenting political issues with left-wing bias. SBS is generally seen as remaining relatively impartial.

Analytic Materials

A summary of the two television program episodes and one feature story are presented in Table 5.1, variation in length of story is indicative of programming formats. One episode focused on sibling experiences and aired on television program ‘Insight’ on public broadcaster SBS. Whilst journalistic in nature, the Insight program invites the general public to participate as both audience members, and as primary focus group members on the show. This ‘focus group’ format is an hour-long show and is facilitated by a journalist (Jenny Brockie). One episode focused on group care home complaints; this was aired on public broadcaster ABC’s flagship investigative journalism program ‘Four Corners’. This program adopts a traditional investigative journalistic style (i.e., primarily a journalistic report interspersed with selected interviews), presenting one topic per week on an hour-long show. The feature story reported on the strains and stressors experienced by older parents who are caring for adults with ID. This story aired as part of Channel 9’s ’60 Minutes’ program. Similar to Four Corners, this program adopts an investigative journalistic style, however topics are presented in multi-story format, generally featuring three or four topics per hour long show. All three television stations also include paid advertising blocks throughout their programming.

All of the programs are edited by program producers prior to airing. Therefore, despite the programs featuring stories of interviewees in their own words, one cannot deny that the agenda is constructed by the media. It is the media that control the questioning directed at interviewees, the editing (inclusion/exclusion of material), and the overall construction of the program for broadcast. Examples of this control will be presented throughout the analysis.

Table 5.1

Summary of Television Current Affairs Programs Included in Discourse Analysis

Program	Episode title	Format	Broadcaster	Air date	Episode/story length
Insight	Sibling-Carers	Focus group forum – single story format	SBS (public broadcaster)	11.07.2017 8.30pm	50.28”
Four Corners	Fighting the system	Investigative reporting – single story format	ABC (public broadcaster)	27.03.2017 8.30pm	45:00”
60 Minutes	Help us before it’s too late	Investigative reporting (multi-story format)	Channel 9 (commercial broadcaster)	26.03.2018 7.30pm	14.22”

Note. Episode/story length presented in minutes and seconds.

At the time of analysis the two episodes and one feature story were publicly available for viewing from their online websites. The two episodes also provided transcripts to the general public, whilst the feature story (60 Minutes) was transcribed for analysis by the author. Though some features of interaction were added to the transcripts (e.g., interruptive speech), a Jefferson scheme used in some versions of DA was not followed as this level of micro conversation analysis did not form part of the framework of the following methodology. All transcripts were placed within NVivo 12 software (QRS International Pty Ltd, 2018) for analysis.

It is acknowledged that multimodal discourse analysis has emerged over the last two decades as a means of extending discourse analysis to encompass visual and auditory resources such as gazes, poses, and tone. Whilst there are benefits to incorporating the multiplicity of modes used in communication when analysing meaning, methodological limitations of multimodal discourse analysis have also been reported. For example, the methodology has been criticised for being too complex, laborious, and time-consuming with limited theoretical and analytical developments (O'Halloran, Podlasov, Chua, Tisse, & Lim, 2014). It is also focused on micro-interactions, with a small number of selected instances or episodes chosen as a sample of the video data to be analysed (Bezemer & Jewitt, 2010). This also requires decisions to be made regarding which sections of program are selected, and which modes are focused on, inevitably impacting the analysis. Even with the use of careful conventions in the transcription and selection of episodes, Bezemer and Jewitt (2010) note that details will still be lost. Therefore, for the purposes of this study, analysis focused on language presented in the transcripts only. Transcripts were retained in their entirety to minimise the influence of author decisions on analytic outcomes.

Analytic Concepts

Discourse analysis (DA) attempts to explore how language is used in interactions to construct social phenomenon within a social context, and what the consequences of that construction might be (Potter & Wetherell, 1987). DA recognises that language serves a variety of functions, and thus has a variety of consequences. Though these functions are not always explicit, language is action oriented, in that it is constructed in order to facilitate particular social actions such as persuading, accusing, denying, and justifying (Potter & Wetherell, 1987). In identifying these orientations, Fairclough (2003) notes that meaning-making rests as much upon implicit or ‘unsaid’ assumptions as it does on the explicit text.

The discursive analytic approach used in this study was informed by Edley (2001), Potter and Wetherell (1987), and Fairclough (2003, 2015) such that a ‘toolkit’ of DA techniques formed the basis of analysis allowing for multiple tools to assist in the understanding of discourse where appropriate. This somewhat eclectic application of DA is supported by Wetherell (1998), who argues that multiple influences can be integrated into a viable discourse analytic approach. The tools used in the following DA allow for both an understanding of how discourse is constructed (words/rhetorical devices used) and an exploration of how these constructions present a certain version of the world. A summary of these concepts and tools are discussed below.

Subject positions.

Through the use of language, presentation of self or others can be constructed in a particularly favourable or unfavourable light. Though, construction implies an active selection of what is to be included and omitted in the discourse presented, individuals are not free from influence. Reynolds and Wetherell (2003) argue that culture, history, social practices and ideology construct a set of possible identities or positions for the individual to take up. Therefore a narrative of ‘self’ as subject is developed through the use of available discursive resources, with some resources more readily available than others. In this sense, the individual's position as constructed through talk is created by others as well as by self. Edley (2001) emphasises that the importance in analysing subject positions is to investigate the 'who' that is implied by the repertoire.

Interpretative repertoires.

In order to make sense of the objects, events, people, and actions in the world around them, people draw on certain vocabularies or ways of talking as resources (Edley, 2001; Potter, 1996). This assembly of specific lexicons and metaphors provides a 'constructed version' of the person's world and assists the community to develop a shared social understanding of that object, event, person, or action. Some repertoires may be more easily drawn upon by others (dominant repertoires), this may reflect the cultural history surrounding the topic, or may highlight limitations to ways in which talk is constructed about the topic. For example, one may argue that drawing on a medical discourse or repertoire for disability may be historically favoured and widely available over other repertoires. Within the context of this study, interpretative repertoires were the vocabularies and metaphors drawn upon by journalists and interviewees to construct images of people with ID, as well as the roles and actions of others in society. The functions and consequences of these repertoires are also considered.

Ideological dilemmas.

Billig et al. (1988) argued that whilst people may hold socially shared images, representations, and values, these are not necessarily coherent or integrated, but rather contain contradiction and conflict. As such, analysis of discourse must not only consider the presence of themes, but also the presence of counter themes. Billig et al. suggested that engaging both internally and externally in argumentative debate about how one should act or be in certain contexts occurs as a result of socially and culturally embedded common-sense notions of value, community, and behaviour. It is these common-sense notions that often contain conflict; Billig et al. providing a number of examples from proverbs that offer conflicting advice such as ‘too many cooks spoil the broth’ versus ‘many hands make light work’.

Ideological dilemmas acknowledge that individuals can hold and draw upon multiple and often contrary repertoires for the same social object. In this sense rather than inhibiting a person’s thinking, ideological dilemmas can assist the person’s meaningful thinking of themselves and the world around them (Billig et al., 1988).

Extreme case formulations.

As previously noted, language is action-oriented and is often used by speakers to have fellow interactants arrive at a particular conclusion (Pomerantz, 1986). One strategy to assist in this action is to legitimise one’s claims via the use of extreme case formulations. Through the use of extreme terms of language (e.g., every, completely, absolutely, forever) the speaker can perform such tasks as: Defend against counter challenges; attribute causes to the object; indicate a speakers investment in an object or event; and position a behaviour as right/wrong, normal or abnormal, by virtue of the frequency of occurrence (Pomerantz, 1986).

Analytic Procedure

Data analysis in DA is not a prescriptive, formulaic, step-by-step process, rather it is iterative with various dimensions of analysis overlapping (Fairclough, 1992). Despite a lack of a rigid process, appreciation of and familiarity with the entire data set is an essential starting point to the analytic process. Therefore, each recording was viewed by the author twice without the transcripts, and then twice with the transcripts, checking for accuracy of detail. Following this step it became apparent that the content, and subsequent constructions of people, events, objects, and actions were largely heterogeneous, as such it was decided that each episode/feature story would be analysed independently. The Insight transcript was analysed first, followed by the Four Corners transcript, and finally the 60 Minutes transcript. The following process uses the Insight transcript as an example; this process was followed for all three transcripts.

The Insight transcript was read through with a focus on areas of interest within the text, looking for patterns within talk (shared accounts) as well as exceptional cases and variation (differences). The search for patterns within talk was guided by the analytic concepts described above with specific interest focused on talk relating to care of person's with ID, including residential care, and identity management of those involved in care. These instances of talk were broadly coded into separate files within NVivo 12 (QRS International, 2018) for ease of reference and interpretation. Description and interpretation of the data focused on how the discourse was constructed, for example by asking what lexical items and rhetorical devices were used? Consideration was also given to how this construction was situated within the interaction, and for what action or purpose.

As noted by Potter and Wetherell (1988) as part of the iterative process interpretative schemes that develop from the coding may be abandoned, or repeatedly revised. Interpretations of the coded data from the Insight program occurred over several iterations and revisions. As suggested by Potter and Wetherell, this process did not follow a strict set of rules, but rather final schemes relied on the formation of hypotheses about the patterns and uses of the repertoires.

Wiggins and Potter (2011) stated that in DA validation is "built into the process of data collection and analysis" (p. 88). For example, they argued that detailed evidence via the inclusion of transcribed data alongside the analysis allows readers to critique the analysis for coherence and credibility. This detail provides the reader with evidence of what preceded the interaction and what followed the interaction, thus a turn-by-turn account provides the reader with an opportunity to check participants' orientation. As such detailed extracts of data are provided in the following chapter as supporting evidence of the analytic claims.

Researcher Reflexivity

As a qualitative researcher I acknowledge that just as the participants in the television programs being analysed constructed their knowledge and actively selected how to present that knowledge, I do the same in my construction of interpretations. In this study, collection of existing data removed the potential biases of the researcher that can be present when interviewing individuals as part of the data collection process. Yet I was also witness to biases as presented by the journalists and production teams of the three programs included for analysis. As a researcher, witnessing these constructed versions of reality without being able to ask participants questions that would explore the key issues in depth led to frustration and irritation, particularly in the 60 Minutes program. I viewed this program as a heavily edited and coordinated account of the story. I expect that part of my frustration of this particular story was the brevity of presenting such a significant issue as attempted filial homicide in a quarter hour program, however to expect a critical exploration of the topic is unrealistic. Perhaps too the program was guided by legal obligation surrounding court proceedings, media codes of ethics, or pre-signed agreements with participants defining what would and would not be discussed. These are all elements to the story that I could not and would not know. To minimise the influence of these negative reactions on data analysis I spent time engaging in a reflexive dialogue with my supervisors to acknowledge and explore these reactions prior to returning to the transcripts.

Analysing the transcripts presented various challenges. The data did not fit neatly into the research question as it would have, had I myself constructed interview or focus group protocols. Some programs appeared to be a better 'fit' with the research question, offering richer data. Again here my lack of control over the content led to frustration. It was important to be patient and considered with the data and remind myself that this was an opportunity to explore discourse that had not been moulded by research, this was assisted by the iterative process of analysis.

Summary

This chapter discussed data collection and discursive analytic techniques adopted for Study 2. Whilst Study 1 provided a macro-level exploration across six years of Australian media, Study 2 aimed to examine more recent television broadcast media, specifically exploring how language is used in the construction of ID related issues and to what end? This methodology allows for a more detailed level of enquiry in contrast to Study 1, illuminating the intentions and actions within the media text, providing a new and different encounter with media representations as that provided in the previous study. The interactive nature of the data, and presence of voice from families allowed for a meso level exploration of the construction of identities, roles, and responsibilities. Chapter 6 presents the qualitative findings of analysis of data in Study 2.

Chapter 6 – Study 2 Analysis

Introduction

This chapter presents the analysis of three broadcast television program episodes or feature stories: Insight: Sibling-carers, Four Corners: Fighting the system, and 60-Minutes: Help us before it's too late. As discussed in Chapter 5, one program (Insight) is described as a focus-group format facilitated by a journalist, whilst the other two programs (Four Corners & 60-Minutes) reflect an investigative journalistic style. A summary of all three programs including episode focus, roles, and participants is provided in Table 6.1. Whilst the transcripts for both the Insight program and Four Corners program each reflect almost an hour long television show, the 60-Minutes transcript is reflective of the multi-story format of the program and therefore represents a quarter hour segment. Final analyses are presented in a case by case format due to the variability of program content.

Table 6.1

Characteristics of Episode and Participants Included in Discourse Analysis

Program/Episode	Focus	Roles	Participants	Relatives with disability
Insight: Sibling-Carers	Exploration of sibling experiences of persons with disability.	Facilitator	Jenny Brockie	
		Panel participants	Sarah (sibling)	Jo (sister with physical & intellectual disabilities)
			Jodi (sibling)	Andrew (brother with Down syndrome)
			Jess (sibling)	Jason (brother with Pelizaeus-Merzbacher disease)
			Yvonne (sibling)	Ashley (brother – deceased –with spastic quadriplegia & "cognitive issues"
			Luke (sibling)	Olivia (sister with severe autism)
			Trudy (parent of Luke/Olivia)	
Four Corners: Fighting the system	Investigation into allegations of abuse at an Australian disability services provider.	Reporter	Linton Besser	
		Interviewees	Jean Hislop (parent)	Andrew (son with Down syndrome)
			Maria Thomas (parent)	Matthew (son with undisclosed disability)
60-Minutes: Help us before it's too late	Expose` of hardships faced by ageing carers caring for disabled children.	Reporter	Liz Hayes	
		Interviewees	Yvette Nichol (parent)	Unnamed son with intellectual disability
			Helen Weymouth (parent)	Suzie (undisclosed disability)
			Faye Alcott (parent/wife)	Rodney (undisclosed disability)
			Wilth Alcott (parent/husband)	Rodney (undisclosed disability)
			Dan Tehan (Federal Minister for Social Services)	

Insight: Sibling-Carers (Public Broadcaster, SBS)

The focus of the Insight program included for analysis was on sibling experiences with caregiving. The focus-group participants were predominantly adult siblings of brothers or sisters with intellectual disability (ID). This analysis presents the dominant interpretative repertoires, dominant subject positions, and main ideological dilemma that participants drew upon to construct family and care roles:

- Adult as ‘eternal child’,
- Sibling as ‘good child’,
- Carer as ‘martyr’, and
- Carer obligations: Family versus other.

The first repertoire was often used as a heuristic in describing disability, whereas the two sibling subject positions presented a more complex view of the nature of caregiving and growing up as a sibling to a child with disability. Finally, an ideological dilemma regarding caregiving responsibility is presented.

Adult as ‘eternal child’.

Family members on the Insight program used an adult-as-eternal child repertoire to describe their relative (sibling or son/daughter) with ID. Rather than offer medicalised descriptions of intellectual functioning, referencing a child’s mental age was used as a ‘short-cut’ explanation of cognitive capacity. For example, Jess offered the following of her brother “he’s probably got the cognitive level of probably a four-year-old, five-year-old”. As a consequence, chronological age is minimised and at times removed from discussions whilst perceived mental age becomes a dominant descriptor.

Whilst the intention of such a metaphor may be to provide an easily understandable explanation of disability, Starke et al. (2016) argued that applying the term ‘child’ acts to remove autonomy and power, regulates the individual’s access to social identities, and reinforces dependence upon those categorised as ‘adult’. This dependent relationship between one who is categorised as ‘child’ and one who self-categorises as adult was evident in the following extract:

> Sarah: It’s like having a child again, you know, forever. When my father died of lung cancer I took over the role of caring for my sister. Life became very different from a mother of two children working a full time job. Once she’s finished her breakfast she gets up into the bathroom and brushes her teeth, I give her a shower and pull out what she’s going to wear for the day and help her get dressed. Try to keep her as independent as possible, so she does what she can on her own and I just help with the bits that she can’t do. Jo goes to a day program at Marsfield and they are awesome at engaging her in different activities. So she goes five days a week, it’s a six hour period of time through the day that she’s there which allows me to work. I work from home, I work full time, for me I need to try and be finished by the time she gets home which can be any time after 3. She’ll often sit and play on her Wii, she plays tennis and a couple of games on the Wii which she loves. She does go through clothing so there is on average a load of washing a day so again that’s like having a very young child or a baby with nappies, cleaning up after her and sweeping the floors because she is messy and that’s just the way of her disability there’s nothing you can do about that.

Here Sarah begins the above narration by constructing an image of her sister Jo as child, whilst co-constructing an image of carer as ‘parent’ by stating “It’s like having a child again”. This construction of child and parent defines roles and responsibilities for Sarah and Jo. Sarah also uses the extreme case formulation *forever* to indicate the eternal nature of Jo’s ‘childhood’ and as Sarah as carer. Sarah’s talk that she ‘took over’ from her father, further emphasises that she is not just replacing the role of carer but that of parent. This co-construction of carer-as-parent is cyclical in that it further acts to reinforce the adult-as-eternal child repertoire. This repertoire is further evident in the expression of carer duties and the portrayal of behaviours of the adult with ID. Sarah’s narrative steps through basic daily living tasks that a mother of a young child may step through; teeth brushing and bathing, highlighting that Jo’s behaviours and care needs reflect that of a young child. Sarah’s construction of her own role within the completion of daily living tasks further parallels with that of a parent of a young child who is slowly developing the child’s capacity to perform these tasks. The construction of adult-as-eternal child is even evident as Sarah describes Jo’s day program; an activity-based program that tends to replicate school hours (9-3). Sarah’s narrative again returns to the adult-as-eternal child repertoire emphasising the intensity of Sarah’s ‘parenting’ role within this caregiving relationship.

The adult-as-eternal child repertoire also acts to emphasise the adult with intellectual disability’s dependence on others and vulnerability in being taken advantage of by others due to a child-like naivety:

> Sarah: There was I with you know grown children and thinking they’re going to go and that’s what you expect to happen, but realistically that’s never going to happen for me, I’ve got a child that I will care for as long as I am physically able to do it, for much the same reasons as you mentioned, just to protect her my sister is extremely vulnerable. She trusts absolutely everybody, doesn’t really understand. It’s that thing. I can’t retire…

Here Sarah refers to the role of Jo-as-child and Sarah-as-parent as atypical, pointing out that the trajectory of this relationship does not follow expectation or norms. This talk again emphasises the permanency of the roles, minimising any counter challenges to those roles through the extreme case formulation *never* in talk regarding the growing up of the child;

‘that’s *never* going to happen for me’. In effect, the adult-as-eternal child repertoire locks carers into un-retiring roles as perpetual parents to those who are perceived to never grow up. Sarah further emphasises her sister’s child-like vulnerability with the use of the intensifying adverb ‘extremely vulnerable’, as Starke et al. (2016) note talk of vulnerability is often visible in constructions of adult-as-eternal child discourses.

Edley (2001) highlighted that objects can be constructed in a range of ways, yet interestingly, in almost all discussions there was a distinct absence of adult-as-adult discourse, even in regard to physical development in the absence of cognitive and emotion-regulation abilities reaching normative adult stages of development. Across the program’s dialogue there were only two instances of this. In the first instance, Jodi (sister of Andrew with Down syndrome) reports that her brother moved out of the family home the same time as she did, which is indicative of normative progression towards adult independence. It is perhaps the second instance that is most interesting, in that Trudy (mother of Olivia, daughter with severe autism) discusses the necessity to prevent Olivia from having menstrual cycles. In this sense a physical characteristic of female maturity is necessarily restricted, yet this restriction in turn increases Olivia’s vulnerability and ultimately reinforces the construction of adult-as-eternal child.

Sibling as ‘good child’.

Across the course of the Insight program siblings frequently understood their role within the family unit as being that of ‘the good child’. As noted by Edley and Wetherell (1997) subject positions are constructed in a relational way, so it is often through a comparison of other, or differentiation from other that people construct their own identities. Though siblings did not construct a comparative identity between themselves and other sibling per se, they did construct an image of the environment created by the needs of the sibling with ID. The desire to create an opposing environment assisted in the construction of the ‘good child’ narrative:

> Yvonne: You know it was very distressing you know thinking he [brother] was going to die all the time. So it kind of just got to a point where I couldn’t take it on board anymore it was just too much. And so I kind of became numb to it.
>
> Jenny: Could you talk to your parents about it?
>
> Yvonne: So I did talk to my parents a bit but the problem is of course they were quite stressed as well. You know I could see that my parents were just so overwhelmed with everything that I didn’t want to add to what they were already suffering through. And so I did keep it to myself quite a lot, I really wanted to be a good child for them, I wanted to make their life that little bit easier, one less thing for them to worry about it. I suppose I really wanted to do well in school and bring home good grades, and succeed in all my extra curriculars (sic) and just be something they could be happy with when they came home.

Yvonne’s construction of ‘good child’ is almost one of invisible child; one who must avoid the need for attention, and therefore be “one less thing for them [parents] to worry about”. Yvonne further differentiates self from parents who are positioned as ‘overwhelmed’ and ‘stressed’. Therefore a ‘good child’ is one who does not appear distressed, or emotional, hence her reference to becoming ‘numb’. There is an underlying notion of perfectionism in the creation of a child that does not complain, does nothing wrong, does not require attention, and does not display emotions. Adding to this is her focus on success in academic pursuits, providing a further example of differentiation between self as ‘good child’ and that of a child with ID. Though it is often implicit, the pressure to be a ‘good child’ has been previously reported amongst Australian siblings growing up with a brother or sister with disability

(Waldrem & Strohm, 2010), in some cases ‘being good’ and ‘studying’ became part of the repertoire of the siblings coping strategies.

The strategy of differentiation in the construction of ‘good child’ is also evident in the following extract:

> Luke: Like it’s this thing where your parents are so concentrated on your sibling that you’re like, I’ve got to be the good kid, I’ve got to be really good and I’ve got to make sure that I’m not being a pain for them because they don’t have time for you to be a pain and to look after that, deal with that.
>
> Jenny: Anyone else feel that kind of pressure, Sarah?
>
> Sarah: Yeah it was more a sense of you know you can’t complain because you’ve got nothing to complain about so don’t complain and if you did you were worried that people would say you know ‘why would you worry about that when your sister’s like this’ you know.

Luke’s construction of good child differentiates between the temporal aspects involved in a child with disability’s needs and a child without disability. If time is required for the disabled sibling, then a ‘good child’ must therefore require less time of his or her parents. Rather than adopting more typical cultural constructions of a child requiring parental attention as part of normative dependency, Luke’s construction of a child requiring parental attention was seen as a child being ‘a pain’. Sarah’s talk similarly offers an interesting comparison between sibling with disability and sibling without disability; if Sarah’s sister is disabled and she is not, she believes she is not justified in complaining about anything, as such she must adopt an alternative position. As reported by Waldrem and Strohm (2010) in the family system with a child with disability, a normative child that requires attention can be viewed as not being a ’good enough’ child.

Throughout these constructions of ‘the good child’ identity it is clear that the needs and concerns of ‘the good child’ are minimised as emphasis is placed on the needs of the child with ID and the impact that these needs ultimately had on the parents. As such, ‘the good child’ that is constructed here is one who internally experienced silent suffering, whilst externally presented as successful, content, and resilient.

Carer as ‘martyr’.

This repertoire emerged as Insight participants discussed the impact of the carer role on their lives as one involving self-sacrifice of health and dreams in the name of love and duty. Despite reporting knowledge of care alternatives, the ‘martyr’ repertoire persisted even in the face of potentially fatal consequences, as evident in the following extract:

> Trudy: I had two mini strokes and then what tipped it was, we hadn’t slept for 19 years, we had a baby for 19 years and I was driving one day and fell asleep at the wheel and drove off the road. Luckily for me I drove off a road that had an embankment so the car went uphill, as opposed to down, down. Then I realised ok you don’t have a choice. I hadn’t wanted to put her in because of all the horrific stories coming out about abuse in those homes and Olivia is a perfect target. She is non-verbal, because she can’t control her physical things she’s on medication to stop her periods, she’s on the pill as well, she’s a young female, and so she was absolutely vulnerable and if anything happened to her you wouldn’t know except by her behaviour. And the thought of her going in there and being abused, yeah I knew what Luke was saying but ok I need to do everything I could do so when I couldn’t do it anymore I knew I did everything.

In Trudy’s extract she does not identify multiple strokes as a justifiable reason alone to end her role as primary carer, yet a car accident is identified as the tipping point. Trudy presents an image of ‘good mother’ in that she is self-sacrificing (Sousa, 2011), but also as Broady (2015) argues, a caring persona is a ‘self-less’ identity that can lead to carers ignoring their own needs with “significant personal ramifications as a result” (Broady, 2015, p. 70). Therefore carer is constructed as an individual who is willing to accept, or even expect a degree of negative personal impact or personal sacrifice, particularly for Trudy as the alternative is perceived to be so risky and profoundly negative. In Trudy’s final comment “I need to do everything I could do so when I couldn’t do it anymore I knew I did everything”, she infers that only by exhausting all options for her to maintain the role of carer (short of her own death) could she justify the decision to seek external residential care for daughter Olivia. Broady argues that the carer is primarily concerned about how they are viewed by others, therefore by exhausting all carer options Trudy can maintain a socially desirable positive persona as parent and carer even when making the decision to place her daughter in residential care.

For other members of the Insight panel maintaining internal care options meant self-sacrificing their own dreams.

Jenny: How do you balance the rest of your life with this?

Jodi: I’ve knocked back a job with the police service to start my own business at home so I can be there for Andrew. So I’ve changed my whole career plan around-

Jenny: Well you wanted to be a police officer since you were how old?

Jodi: Four. Forever.

Jenny: What was that like for you though having to give that up?

Jodi: Yeah look it was huge but you know it’s kind of like well that’s what has to be done it has to be done.

In this extract Jodi initially indicates that her dream of becoming a police officer began at age ‘four’, then emphasises her investment in this dream by using the extreme case formulation *forever*. In taking on the role of carer for her brother, and subject position of martyr, her talk is one that is somewhat accepting of change as simply part of the role: “it has to be done”.

Commitment to change was also evident in Sarah’s talk:

Jenny: Ok so how much has your family’s life changed?

Sarah: Oh every aspect of its changed. I had two children we were living in a home in Canberra. I had a full time job, my husband had a full time job, we were doing pretty well, you know nice world. Had to pack all that up and move to Sydney. We left our daughter behind, she’s still in Canberra I you know I lost my hair because I was so stressed about leaving my daughter behind. So yeah everything changed.

Jenny: So what’s it like for you? What has that been like for you and your family?

Sarah: It’s hard. It is hard. I know you’re not supposed to say that, I know that’s not the politically correct thing but it’s a job and it’s a hard job to do sometimes.

Here Sarah lists all the elements of a ‘nice world’, including job security and family, all of which were sacrificed in order for her to adopt the role of carer. Her admission of suffering through the hardship of the role further reinforces the martyr subject position, even through her acknowledgment that ‘you’re not supposed to say that’. Sarah indicates that to voice one’s difficulties with the role is in some way breaking an unwritten code in which carers are not entitled to complain or describe their roles as difficult. Through a new positioning of the carer role as a ‘job’ Sarah allows herself to complain or talk about aspects that she dislikes or finds difficult.

Despite Sarah’s repositioning, the martyr subjection position remains dominant:

Jenny: Sarah how do you see your future?

Sarah: Living in my sister's home until I can't do it anymore basically. We talk about retirement but it's a bit of a pipe dream and we know that.

Jenny: Why is it a pipe dream?

Sarah: Well I hate to say it but for us it's she dies and then we can go on, or I physically can't do what I do anymore and then we have to look at alternative accommodations. So both of those are pretty horrendous outcomes, so it's a pipe dream really.

Jenny: So you can't see any prospect of retirement?

Sarah: Doesn't stop us talking about it, doesn't stop us dreaming about it.

The use of the word 'retirement' again positions the carer role as a 'job', as individuals generally retire from a career, however in this case she is acknowledging that the carer role is an un-retiring one, contrasting it with the normative development of a career. Similar to Trudy's talk, Sarah indicates that an end to her carer role would only be achieved by extreme and 'horrendous' outcomes, as such her talk of retirement is designated the label 'pipe dream'.

Sarah also contrasts her role as carer, with that of her mother who left the family when Sarah's sister was 8 years old:

Sarah: I genuinely don't think my mother could cope. They were children of the 50's, so I think she married the naval officer she thought she was going to travel the world and do dinner parties, and she ended up with four children which I don't think she ever wanted, and realised that children muddied the waters. But then when she had this child that wasn't a perfect child that dribble and you know you had to feed her and she took up everything. I just don't think my mother could cope which is why she was really gone by the time my sister was about eight.

By differentiating the role of carer with that of parent, a role traditionally viewed as carer, Sarah further defines the characteristics of martyr; it is a role positioned as being more difficult than that of parenting ‘normal’ children, requiring greater resilience and the ability to cope with the imperfections of life. This is emphasised with Sarah’s talk of her sister and an extreme case formulation in her statement ‘she took up *everything*’.

Carer obligations: Family versus other.

Underlying the discussion throughout the Insight program is a significant ideological dilemma: Is care a family obligation involving self-sacrifice? Or are family members entitled to live their lives free of the carer burden? In contrast to the ideals of lifelong caring held by Sarah and Jodi (as described above), Luke provides an opposing position when discussing his sister who lives in supported care:

> Luke: I have to say it was one of the best things that probably happened. I think from about the age of 16 I started telling my parents she needs to go. It wasn’t you know a spiteful thing but it was a thing where I could see how much it was not only affecting me but it was affecting my parents and I kept saying to them this can’t go on forever, why are you denying this, this is exhausting. And one of the things I made clear very early on was that I wasn’t going to be her carer. Just because I’ve seen older people that care for their siblings and their life ends in a way for some of them where their just, their sibling is the only thing that happens. And I watched that and I can’t do that. It’s, I don’t want that terror of being confined to this life forever, it’s terrifying and my parents were still going, and mum had, what was it two things, like a stroke?

Luke initially constructs external care as ‘one of the best things that probably happened’ though the beneficiaries of this decision are not identified (i.e., was it best for his sister, his parents, himself, or all family members?). However, in the remainder of his discourse there is a distinct absence of talk regarding his sister, therefore it could be implied that the positive outcomes of external care have predominantly been of benefit to Luke and his parents.

Luke also tends to construct an image of carer as not just life changing, but life ending. He emphasises the infinite nature of the role using the extreme case formulation *forever*. He also positions caregiving as all-consuming suggesting that when taking on this role the sibling with disability is “the only thing that happens”. This positions carer as a negative condition, with Luke using the words ‘terror’ and ‘terrifying’ to construct this negative image. Luke uses this construction, and the example of his mother’s ill health to justify his position as someone who does not believe care is a role for family members. Luke however was also developmentally at an age of emerging adulthood, it is therefore possible that his construction of caregiving is somewhat reflective of a period of adulthood that is characterised by identity exploration and self-focus (Arnett, 2003).

In a comparison of life with and without a sibling with ID, Yvonne constructs an image of a life free from the burden of care as a positive condition, yet not without dilemmas.

> Yvonne: yeah so obviously it’s great to actually feel like I’m succeeding because you don’t get anyone saying ‘oh yes you won best carer of the week’ it’s just a thing you do. So on that level it was really gratifying. But at the same time I couldn’t help but feel a bit guilty about it because obviously my success it feels like to me has come at the expense of my brother dying and that feels horrible. It feels horrible to say you know suddenly I can do so much and it’s because he was holding me back in a way and because he’s my brother it feels like a terrible thing to say but the reality is it’s true.

In contrast to Luke, Yvonne did not make a choice not to be a carer, yet even when the day to day burden of care tasks is removed via death, she still carries the burden of knowing success came at the cost of a life.

Summary – Insight: Sibling carers.

It was evident in the Insight program that member roles within families were constructed not just based on the tasks of the role, but how that role related to others. For example, the construction of ‘good child’ was necessary because of the existence of a sibling with disability. This role contrasted with the construction of sibling with disability as ‘eternal child’; a more stable construction that limited development of the individual across the life span. Furthermore, the tension between family carer as martyr and family member as free from care may impact the family system as members of the system negotiate such roles.

Four Corners: Fighting the System (Public Broadcaster, ABC)

The Four Corners program presented an exposé on the risks posed within care home living for adults with disabilities (including ID). Whilst there was no representation from care home providers, the dominant voices were that of parents of adults with disability. The analysis that follows discusses two interpretative repertoires present in the Four Corners episode. These are:

- Disability as vulnerability, and
- Government as failed protector.

The *vulnerability* repertoire predominantly portrays persons with disability as at risk of abuse and requiring protection, whilst the second repertoire portrays the government as the *failed protector*. These two repertoires act to reinforce the other, as failure to protect those who need protection the most places them in a more vulnerable position; those who are more vulnerable require more protection.

Disability as vulnerability.

Disability, and in particular ID have been constructed and understood in many ways throughout history including the construction of disability as deviant, defective, incompetent, and helpless (Crawford & Ostrove, 2003). Though there are those who challenge negative constructions with labels such as ‘diffability’ conceptualised as ‘differently able’ (e.g., Suharto, Kuipers, & Dorsett, 2016), negative social constructions of disability persist. In the media disability is commonly presented as vulnerability (Goggin, 2009). This construction of persons with ID as being vulnerable persons was evident in the Four Corners program in several ways across the following extracts:

> Linton: This is the group home where Andrew lives. It's run by the Victorian Department of Health and Human Services. In June 2015 the Department told Jean her son had been sexually assaulted. She asked Andrew, who has the mental age of a child, what happened?
>
> Jean: I tried to find out, you know, I questioned him then, quietly. "Did he get into bed with you? Did he push you in the back, Andrew?" You know, anything I could think of to try and see if he had been sexually assaulted. But, I mean, you can't get that out of a five-year-old, they don't know, they've no idea…
>
> Linton: Department officials told Jean the staff member had been sacked on the spot. Victoria Police interviewed Andrew but the employee wasn't charged. This happens time and time again across Australia ... where cases collapse because police and prosecutors decide people with a disability make poor witnesses in court.

As Jean is questioned about her son, the program draws on evidence from her son Andrew’s experiences to support and strengthen the vulnerability repertoire. The adult with ID is presented as ‘child’ which immediately draws on social constructions of vulnerability. Andrew’s mother Jean uses this familiar construction when reporting her son’s restricted communication skills and cognitive capacity – “I mean, you can’t get that out of a five-year-old”.

The adult with ID is not simply viewed as vulnerable because of the construction of adult-as-eternal child, but because policies facilitate the vulnerability repertoire. For example the journalist highlights that the accused abuser was not charged of committing a crime. Australia’s legal system was presented as one that fails to prosecute those who take advantage of individuals with ID, in effect increasing their vulnerability by viewing adults with ID as unreliable or unbelievable. The journalist (Linton Besser) emphasises the ongoing nature of the vulnerability with the repetition of ‘time and time again’ acting to demonstrate the regularity with which this kind of incident occurs.

The vulnerability repertoire is not just used to construct images of those with ID, in the following extract vulnerability extended to family members.

Linton: Maria Thomas and her family repeatedly warned authorities about the problem and wrote to the Department of Health and Human Services 'horrified at the sexual attacks on [Matthew] and the fact that this predator [a fellow resident] is still allowed to remain in the house'. They warned that that the man continued to show 'a great determination to get to Matthew' and that 'given half an opportunity he will strike again'.

Maria: We asked them to remove the guy because my son is in danger during that time. Our son is in danger that time. We told them.

Linton: Autism Plus[1] was equally horrified. Internal emails obtained by Four Corners show the company demanded the Department remove the man immediately. Autism Plus warned he was 'a significant and ongoing risk, in particular to Matthew as well as to the other clients' and that 'his move should have been immediate after the last attempted assault'. Despite these warnings and repeated close calls, the Victorian government insisted the man remain in the

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[1] Private disability services provider

house, until finally in April 2015, he targeted Matthew Thomas for the seventh time.

Maria: Yes. Matthew... was sexually assaulted in the shower while he's having a shower. The carer ran away because this young man who's assaulting my son, he's threatening the carer so he run away. And he leave my son in the shower. And then that's where this young man assaulting my son, how's that scenario?

The use of diverse lexicons in describing action taken to inform the government of impending danger magnifies this action. The extract informs that the government were: ‘repeatedly warned’, ‘wrote to’, ‘asked’, ‘told’, and eventually ‘demanded’ yet the response from the government was to ‘insist’ the ‘predator’ remain in the home. This discourse positions all family members as being vulnerable to the rules and policies of governments, care organisations, and other clients residing within these organisations. The ongoing threat is emphasised by the repetition of the word ‘warned’ in the families attempts to urge action from the government, though it was clear that this action was not something parents were empowered to do themselves.

Government as failed protector.

Countries identified as welfare states including Australia often have governments that are defined as having a role as ‘protector’ of minorities (da Silva & Heller, 2009). In this instance, government efforts to protect adults with ID and their families were constructed as nothing less than a ‘rank failure’ by the journalist and show producers. This was supported by narratives of families whose sons had suffered under government care, or because of government policy:

Jean: My husband was going blind and he had a heart problem. And Andrew, so outgoing, wanted to go shopping and he'd go for a walk, and I couldn't handle the two of them. So, I had to make a decision, and I thought it would be good

> for him because, he's so good with company. And I thought it would be really good for him, you know and so that's what we did. We put him in the hands of Human Services... I'm sorry I did it. I really am. I never realised things were so bad.

In the above extract Jean firstly positions herself as a parent with little choice but to place her son in government care, this implies parents in such a position may experience reduced freedom of choice which may then, as a consequence, act to minimise accountability. She uses language that contrasts the restrictive nature of her husband's care needs (e.g., blind/heart problem) with the needs of her son (e.g., outgoing). She then justifies her decision by stating 'I thought it would be good for him'. Her use of the figurative phrase 'we put him in the hands of' humanises her image of the government in caring for her son. Her language then shifts to a position of regret 'I'm sorry I did that. I really am'. The inclusion of the extreme case formulation *never* in the sentence 'I *never* realised things were so bad' further assists in justifying Jean's decision making and reducing personal blame by emphasising her lack of awareness of government failings. However interestingly she also uses the superlative 'so bad' which could suggest that she knew 'things' were bad, but did not realise they were 'so bad'.

Contrasting expectations with reality was also used by Maria in her experience with government supported homes:

> Maria: My opinion is they treat my son like animal. Yeah. (cries) I thought my son is really ... I thought my son is really safe. And knowingly, they had incident report. DHS[2] knows it already. Autism Plus knows already, so they should do something about that. They had incident report. Why still keeping this young

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[2] Department of Human Services

> man that he had a problem sexually? I don't understand, really. I don't understand. I try my very best but really, I don't understand.

Similar to Jean's extract, Maria justifies her decision making; "I thought my son is really safe". She likens her son's treatment to that of an 'animal' implying that he was treated by the government run home as less than human. Maria positions the government as well informed 'they had incident report. DHS knows it already', yet they failed to act. Maria then positions this inaction as something that is unexpected, unreasoned, and illogical, highlighted by the repetition of 'I don't understand'.

Summary – Four Corners: Fighting the system.

The Four Corners program highlighted the influence of government policy on constructions of ID. Vulnerability moved beyond limitations related to disability, to issues inherent in government policy that reinforce the vulnerability narrative. This was further supported by the 'government as failed protector' repertoire, which further acted to emphasise social responsibility rather than family responsibility.

60-Minutes: Help us Before it's too Late (Commercial Broadcaster, Channel 9)

The 60-Minutes program segment included in analysis focused on stories on elderly parents' caregiving for adult children with intellectual, or undisclosed, disability. Dominant voices include both parents and government officials. This analysis presents two main interpretative repertoires that the 60-Minutes program drew on to justify carer behaviour:

- Carer as 'martyr', and
- Government as accountable.

Thus the presentation of carer as one who has exhaustively sacrificed combined with the media's deliberate placement of accountability onto government bodies has the potential to reduce family carer accountability for actions taken.

Carer as 'martyr'.

Throughout the 60-Minutes segment journalist Liz Hayes positions parents who are primary carers of adults with ID as loving parents who are desperate, concerned, and willing to do anything, even die, for their child. The segment opens with this positioning of interviewee Yvette:

Liz: It's difficult to imagine a more desperate situation, or a more desperate mother. For 33 years Yvette Nichol did her very best to look after and raise her intellectually disabled son. But as they both got older she needed to know he'd be care for when she was gone. Try as she might to get help it never came. So fearing he had no reasonable future, Yvette did something shocking and deeply troubling. She decided to kill her child and herself. That decision has exposed a shameful truth about the ongoing care of disabled Australians. In essence you believed that what was best for your son was that he dies, and that you die with him.

Yvette: Oh yes we were going together. We were going together and I wasn't leaving him behind.

As the interview continues Liz Hayes reveals that Yvette had been charged with attempted murder of her son, yet this introduction and initial positioning of Yvette does not occur within typical social constructs of 'attempted murderer'. Instead, the reporter constructs notions of good mothering with the narrative "she did her very best to look after and raise her son" and "try as she might". This construction reflects traditional maternal and feminine discourses of 'good mothering' as identified by Bryant and Garnham (2017), frequently associated with the role of caring. 'Good mothering' was also evident in Yvette's justification of her decision making "I wasn't going to leave him behind". In this sense, the good mother is constructed as a martyr who was willing to make the ultimate sacrifice; to take her life and her son’s because of a deep belief that it “was best”. Liz Hayes also uses this construction of good parent and ‘martyr’ to differentiate between family carers and government roles in caring, redirecting blame for Yvette’s actions away from the parent to a ‘shameful truth’ that is identified as a broader social, or political problem. When reflecting on the turn-taking in this extract, the journalist does not ask Yvette a direct question, but rather provides Yvette with an answer and seeks confirmation. This allows Yvette to simply accept the ‘good mother’ identity without having to construct it herself.

The journalist then acts to demonstrate prevalence of such martyrs who are forced or “driven” into similar desperate situations.

> Liz: Yvette’s crisis is not an isolated one. Elderly parents are being driven to the brink because of a national shortage of accommodation for their disabled children.
>
> Helen: We feel that we have been forgotten.
>
> Faye: We’ve got to feed him we’ve got to toilet him, we cope but it’s hard.
>
> Wilth: Look the party’s over for us, we’re just about ready to die.
>
> Liz: Shockingly, 90 year old Wilth Alcott and his 80 year old wife Faye have been fighting this fight for decades.
>
> Wilth: I just hope that some miracle will happen, I just hope that something will come up. Because you get desperate.

In this extract, parents are again constructed by the journalist as being in a position of desperation, illustrated by powerful and evocative language placing parents in “crisis”, and “driven to the brink”. Interestingly, this language is contrasted against Wilth’s talk “the party’s over for us”, who uses this line as an idiom for end of life. The extract then returns to the evocative journalistic positioning of parents in a desperate situation with the term "shockingly" used to emphasise the deviation from normative age-related roles, in that Wilth and Faye find themselves in a fight-scenario at the deep old age of 90 and 80 respectively.

Government as accountable.

Throughout the course of interviewing a government representative, Liz Hayes constructs questions that enable her to position the government as responsible for the plight of the parents, often through the use of accusatory and emotive language as exemplified in the following two extracts:

Extract 1.

Liz: Minister when an elderly parent of a intellectually disabled child decides that she can no longer see a future for her child something has gone terribly wrong hasn't it?

Dan: It has something has gone wrong and we've got to make sure that we can address that and address an issue like that.

Extract 2.

Liz: So do you accept that Yvette Nichol was failed?

Dan: What I accept is that the system whereby she had to use the phone rather than have people being able to sit down with her and go through the planning process was not the right way that we should go about this.

Liz: But she never even got a reply, she didn't even get a reply and as the judge said based on that she decided 'no hope, I'm going to kill my child and myself'.

In the above exchange between journalist and Social Services Minister Dan Tehan; Dan Tehan avoids disagreement with Liz Hayes' accusation "do you accept", by replying "What I accept…", this allows him to reframe the accusation of failure by shifting the focus of the discussion onto a specific system that is identified as inadequate. This could be viewed as blame shifting from the government as a whole, to a more discrete process that exists within the government. Liz Hayes' response rebukes this attempt with "but she never even got a reply". Liz Hayes' use of the term "*never even*" acts to emphasise the extreme nature of the government's failing and counter any further challenges as she uses fact and expert opinion (i.e., the judge's) to form an implicit link between government responsibility and Yvette's behaviour (attempted murder/suicide).

The accountability discourse is present throughout the program, with Liz Hayes continuing to adopt an accusatory approach, which forces the government official into defensive responses:

> Dan: They do matter. And they matter to me, they matter to the government, they matter to the opposition, they matter to the state and territory governments. That's why we're rolling out the NDIS.
>
> Liz: For them that sounds like politics.
>
> Dan: So it's not politics, this is incredibly sincere, and housing has been an issue right through our history.
>
> Liz: So we have failed these people haven't we?

Here, Dan Tehan's repetition of "they matter" acts as magnification of the width and breadth of support and concern for this population. Dan Tehan then offers the NDIS rollout as *proof* that these parents matter claiming "that's *why* we're rolling out the NDIS". Liz Hayes evaluates his response indicating that this is not acceptable "for them that sounds like politics", essentially suggesting that his statement was spin-doctoring.

In the previous extract there was no explicit ownership of accountability, however here Liz Hayes introduces the first person pronoun "we" as the accountable ones. Clearly Liz Hayes is not inferring that she and Dan Tehan were personally responsible for failing "these people". Rather, Liz Hayes uses "we" to claim the role of a representative of society and government, and to claim Dan Tehan as a person who also forms part of society and government. As a result Dan Tehan is unable to distance himself from the Liz Hayes' "we". Liz Hayes interrogates Dan Tehan "so we have failed these people haven't we?" She is not offering Dan Tehan an opportunity to construct his own narrative but rather constraining or at least attempting to constrain his contribution by constructing a "confession" (we have failed these people) that he must either accept or deny.

Summary

Study 2 presented a detailed examination of three Australian current affairs television shows or segments airing between 2017 and 2018. Analysis revealed contrasting constructions of family members, with parents and siblings presented as martyrs whilst adults with ID were constructed as vulnerable and eternally childlike. Similarities in these constructions across all three television shows suggest that television media is inclined to present a somewhat stereotypic view of caregiving and ID which may influence the development of rules, roles, and boundaries within the family system of those caring for persons with disability. Whilst caregivers were perceived as those willing to make sacrifices, the government was portrayed as the villain, accountable yet failing in their protection of those at risk and vulnerable. These narratives create an interesting dilemma of whose responsibility it is to care for those with ID? Families, governments, or both? Perceptions of responsibility differed within family representations clearly determining individual willingness to take on the caring role. This too has implications for the longevity of the caregiving role within the family home considering the complexity of disability across the lifespan.

Chapter 7 presents a synthesis of Australian media representations, with a discussion of Study 1 and Study 2 findings.

Chapter 7 – Synthesis Discussion of Studies 1 and 2

The aim of Study 1 was to critically examine media representations of issues related to intellectual disability (ID), caregiving, and residential accommodation over time. Understandings of media representations were further examined in Study 2 with an emphasis on television media constructions of relevant roles and issues. A combination of analytic methods allowed for an exploration of both breadth and depth of mass media representations of the socio-political environment in Australia in relation to ID and housing related issues. This was particularly relevant due to the critical time frame reflecting a period of major disability policy change. Findings present both frequency of data via Study 1's quantitative CA and richness of construction as presented in Study 2's discourse analytic examination.

Following is a discussion of Study 1 and Study 2 findings in order to provide a more meaningful understanding of how various media modalities portray ID, caregiving, and residential accommodations. Through this discussion convergent constructions across all media reveal the strength of certain media representations, and how these consistent portrayals, particularly over time, can reinforce public expectations of government, family, and persons with ID. Divergent constructions will also be addressed, with an exploration of media intent and the potential for alternate constructions to create new social and political agendas. Limited instances of disability as a voice in media will also be addressed, as will limitations of the studies.

Variations in Media Representations over Time and Location

Study 1 identified variations in article tone, issue, and roles. For example, in 2015 there was a clear increase in news stories addressing disability related issues. Overall, the focus of news stories presenting issues relating to abuse and neglect increased, and in fact peaked in 2015. Additionally, news stories addressing disability and accommodation issues also peaked in regional areas during 2015. Whilst this coincides with the timing of trial sites for the National Disability Insurance Scheme (NDIS) rollout in places such as regional New South Wales, there was a distinct absence of NDIS and National Disability Insurance Agency (NDIA) sources during this period. This suggests that the media presented issues of accommodation as an unrelated issue to NDIS policy. Though Wiesel (2015) viewed the NDIS as an opportunity for new housing choices, the data do not necessarily suggest that this reflected public attitudes or the reality of family experiences. Furthermore, as housing issues addressed in these news stories focused on both lack of housing and innovative housing solutions, these representations may either act to reinforce parent concerns regarding adequacy of accommodation as previously identified (Bibby, 2013; Davys et al., 2015), or may present novel solutions to housing issues with funding provided by non-government agencies, or government funding external to the NDIS.

Regional and local/community metropolitan publications were also more likely to publish a higher percentage of positive news stories compared with metropolitan areas. This was an unexpected finding as regional areas are often considered to be lacking in access to services and supports. However, NDIS trial sites were also based within regional areas, thus it is possible that whilst the NDIS/NDIA were often absent from stories, positively toned stories may have been indirectly linked to NDIS activity in the area during the trial periods.

Personal Stories and Family Sources

Personal stories were common across both print and television media with families, primarily parents, sharing their stories. However, the focus of these personal stories was different in print/radio broadcast compared with television. The three television programs in Study 2 addressed hardships and sacrifices of family caregiving with a primary focus on the individual caregiver experience and a secondary focus on government responsibility. Despite family members being the most frequently cited source in Study 1 news stories, a majority of personal stories in print and radio broadcast media focused primarily on the impact of external factors such as government funding or housing. The Australian Communications and Media Authority (ACMA, 2008) indicates that there is a public expectation that current affairs programs aim to present stories of community interest within an affective framework, to elicit an emotional reaction from the viewer. This editorial agenda may explain the difference between the focus of issues in news stories (Study 1) as opposed to the construction of stories in television current affairs programs (Study 2). Furthermore, considering that ACMA (2008) reported that 92% of the Australian population watch current affairs programs every month, the impact of these emotional presentations on public perceptions can be immense. For example, presenting caregivers as martyrs has the potential to impact perceived pressure on families to continue in caregiving roles even if this continuation conflicts with personal needs including wellbeing.

Whilst one television program in Study 2 directly addressed sibling experiences, siblings were mostly absent from Study 1 data (less than 10% of news stories) and the remaining two television programs in Study 2. The lack of sibling voices in Study 1 may be reflective of a broad keyword search (‘family’), however it also possible that this general absence of sibling voice may reflect changing expectations of siblings in relation to assuming caregiver duties, including that of advocate. Regardless, lack of sibling representation is likely to reinforce government policy, agenda, and language that has already been criticised for ignoring the roles and importance of siblings in caregiving (Waldren & Strohm, 2010).

The presentation of siblings and sibling caregivers on the Insight program (Study 2) demonstrated the tension between the sibling role as caregiver, and sibling rights to a life independent of this responsibility. If siblings do not play a caregiving role, this has the potential to further increase demands on government for additional funding for residential accommodations. Representations of those who were sibling caregivers reinforced gendered expectations that females are more likely to expect and accept future caregiving roles (Heller

& Arnold, 2010; Lee & Burke, 2020), whilst the sole male sibling on the program presented as unwilling to assume this role, actively encouraging his parents to seek out-of-home placement. The construction of sibling as ‘good child’ evident in Study 2 also supported previous findings by Waldren and Strohm (2010) that siblings often experience pressure to adopt a role within the family system that contrasts with that of the child with disability.

Persons with Intellectual Disability

Both studies confirmed that within the media, adults with ID rarely communicate their stories in their own words. Furthermore, despite codes of practice discouraging media from typecasting persons with disability, the adult-as-child construction, and association of disability with vulnerability was evident in Study 2. It should be noted that this representation was constructed from family talk and may utilised by family members to quickly and easily communicate aspects of the individual’s disability. Though this was constructed predominantly by family talk it is acknowledged that editorial decisions can either emphasise or minimise these constructions.

Though vulnerability of persons with disability was evident in stories of mistreatment in Study 1, the primary focus in these news stories was in relation to the person’s future needs, specifically funding, care support, and housing. However, the narrative in Study 2 was more restrictive and at times contradictory, in that families adopted a view of adults with ID as childlike, yet deemed it unacceptable for the government to assume a similar position in treating adults with ID as less reliable sources (particularly as witnesses or victims of abuse). Despite parents’ rejection of this government position, dominant parental constructions of adult son or daughter as childlike may encourage paternalistic government policy rather than supporting policy that includes strategies for independence and self-advocacy. As previously noted, this narrative may also limit the adult with ID’s development and opportunity to advance to more independent living options (Starke et al., 2016; Williams & Robinson, 2001), whilst simultaneously reinforcing beliefs that parents cannot relinquish their caring role and may potentially remain in an enmeshed parent-child subsystem.

Government Roles and Responsibilities

Both studies identified a key positioning of Australia as a welfare state. Whilst a broader range of government issues were presented across the news stories examined in Study 1 (e.g., funding, abuse, care models), two of the three television shows in Study 2 focused on the government's failure to protect adults with ID in residential care homes, and failure to support family caregivers from the ongoing burden of care.

The television media's positioning of the government as accountable also acted to minimise family responsibility and freedom of choice, removing family caregiver's autonomy to initiate or drive change. Though government accountability was also present in print and radio broadcast, a small number of news stories in Study 1 presented counter-stories of parent-run accommodation and respite groups as clear exemplars of initiators and drivers of housing innovation. Private agencies were also presented in Study 1 news stories as offering new and alternative solutions for families seeking out-of-home residential care. The absence of these alternate views in current affairs programming can position government policy and strategy as a single and absolute solution to caregiving issues, with the potential to victimise families and disempower other groups (such as private corporations) to provide alternative solutions.

In general, there was little difference in the negative reportage of issues based on media ownership and related political affiliations in both Study 1 and Study 2. There were slightly more positively positioned representations in news stories appearing in conservative-News Limited (i.e., right-wing) publications in Study 1, than in the socialist (i.e., left wing) media.

Accommodation Options

Accommodation issues were present across both studies. In Study 1 a wider variety of both positive and negative issues were present, whilst in Study 2, accommodation issues of safety and security dominated. These issues were framed within a broader construction of government failings and appropriate accountability. In contrast, accommodation related news stories in Study 1 presented a variety of positively toned and negatively toned housing issues, including innovative and alternative solutions. Importantly in Study 1, when both accommodation and ID were integral to the article, there was a balance in the presentation of positive and negative news stories. Study 1 results showed that a majority of positively toned accommodation stories were published in local/community metropolitan newspapers and regional newspapers. Positive stories may be more likely to be viewed as ‘newsworthy’ in these smaller geographic areas than in major metropolitan newspapers or national broadcast television, this may explain the lack of diversity in accommodation related issues present in Study 2. Regardless, the multiple constructions present in Study 1 may provide more realistic portrayals of residential accommodation options, including examples of successful transitioning from family to out-of-home supports. Furthermore, the diversity of news stories may influence public and family attitudes towards residential care by presenting novel solutions to housing issues.

Limitations

There are a number of limitations in Study 1 and Study 2. Though the keyword search in Study 1 was broad, some stories may have been excluded for reasons that the stories used specific terminology (e.g., a specific diagnosis such as Fragile X) or non-specific language (e.g., simply referring to someone as having a disability). Secondly, despite reviewing a six-year period of news reporting, the search procedure in Study 1 only returned a relatively small number of news stories. Whilst this may be a genuine reflection of the reporting of these issues during this time frame, it may also indicate that search terms were too narrow.

Inclusion criteria for Study 2 allowed for broader disability terms to be used, however there were still difficulties with non-specific terminology as was the case with the transcript “Call Me Harrison” that was removed due to ambiguity regarding disability type. It can also be seen that a number of relatives that were referred to in the television programs selected for analysis were only identified as having a non-disclosed disability. This may simply indicate that specific disability was irrelevant to the program, or may represent assumptive thinking on behalf of program producers or the general public in terms of labelling people in certain care environments as intellectually disabled.

Beyond differences in modality, editorial differences in formatting of news and current affairs stories may complicate the synthesis of findings. Though the inclusion of these two formats and modes of media communication provide a broader understanding of media representations, there may be a number of unexplored factors relating to the divergence of media representations that have not been considered in these analyses. Whilst it is beyond the scope of this project to examine these factors, such an exploration would be informative in future research.

Summary

This chapter presented a synthesis of findings from Study 1 and Study 2. Findings demonstrated that the media presents issues relating to ID, caregiving, and accommodation in a variety of ways, and that this may depend on modality and regionality of media. Whilst overall, media are more likely to present these issues negatively, there are instances, particularly around the topic of housing, where print or radio broadcast media have adopted a more balanced or positive position. This represents an opportunity to influence public and family caregiver’s perceptions of residential care options outside of the family system.

This synthesis also revealed that despite paradigmatic changes in disability policy, the government has continued to be positioned as accountable for failings in funding and a failure to maintain the safety and security of adults with ID. By placing issues such as this as solely the responsibility of government, the media diminishes individual autonomy and power, whilst reinforcing burden of care. This supports Birkel's (1991) argument that those families of adults with ID are likely to experience poor external supports which may increase feelings of isolation, and ultimately the burden of care.

Finally, perspectives of caregiving within the family environment are almost exclusively presented through the voices of parents. Failure to acknowledge and present the perspectives of others within the family system — including siblings and adults with ID — may result in the continuation of policy and agenda that dismisses the importance of these perspectives. Furthermore, it ignores important moments of continuity and discontinuity that occurs across the lifespan of the family system. This singular representation also disregards the underlying goal of the NDIS to encourage and enable choice and control for those with disability.

Study 3 will extend this research and address the above issue by exploring caregiving and residential care planning of adults with ID within a family systems framework. The importance of an inclusive approach to research and the value of case study design will be discussed in the following chapter.

Chapter 8 – Study 3 Methodology

Introduction

In the previous studies (1 & 2) an exploration of media dominated constructions and presentations of family caregiving and residential care options of adults with intellectual disability (ID) was conducted. Though individual voices were present, the media controlled what portions of their stories were told, and what portions remained untold. Journalists, producers, and editors all constructed a version of family narratives that may or may not accurately reflect family experiences. These versions are further manipulated to fit within word counts (print media) or allotted program scheduling (broadcast media). Furthermore journalists and reporters are capable of creating questions that are likely to elicit responses that 'fit' within that organisation's expectations. Those who agree to participate may also experience pressure to conform to these expectations or present themselves and their stories in socially acceptable, or socially desirable ways. Whilst this macro level approach has been helpful in understanding this topic at a societal level, to provide further evidence for the overall aims of this program of research it is important to understand the attitudes, beliefs, and behaviours of those most affected by caregiving and care planning for adults with ID.

The aim of Study 3 is therefore to provide an in-depth exploration of the voices and experiences of members of family units in order to add strength to the findings of the previous studies. Though there is an abundance of survey data available, currently there is limited rich qualitative research available exploring the experiences of families, particularly in relation to future residential care planning. As Creswell (2013) notes, qualitative research allows for an exploration of meanings that individuals or groups assign to phenomena via collection of data "in a natural setting sensitive to the people and places under study" (Creswell, 2013, p. 44). In this way collection methods can attempt to minimise the influence of forces external to the phenomena. By moving beyond a systematic categorisation and description of participant statements, to engage in interpretation of the data, this study seeks to gain a more sophisticated understanding of caregiving experiences and future care planning from the perspective of family members (Stainton Rogers & Willig, 2017).

The research question for Study 3 is:

How do families of an adult with ID experience care, caregiving, and care planning for the adult with ID within the family system?

The following qualitative methodology will allow for an in depth exploration of individual wishes for care, personal beliefs surrounding care planning options, and the impact of significant others (partner/sibling) on the decision making process.

Design and Recruitment

Ethics approval for this study was obtained from the Human Research Ethics Committee at the University of Southern Queensland (USQ; approval no. H17REA208) before any recruitment commenced. Recruitment flyers and letters (see Appendix F) were sent to six major care organisations in a regional city situated in South East Queensland Australia, as well as a state wide support service. Local community organisations and support groups were also contacted with a request to disseminate study information to members. In addition, to reach families who were not engaged in care organisations or community groups, support was sought from local media with a newspaper story and two radio interviews promoting the study to potential participants.

These purposive sampling procedures were chosen to allow for easy access to participants who may be involved in care services or support services, and access to those participants who may not be utilising any care or support services (often missed via sampling that only utilises organisational promotion of research). Interestingly, despite support from several care organisations informing their clients of the study, the three families forming the following case studies were recruited via local media channels.

Participation was voluntary with no incentive offered for participation. Participation was however dependent on a minimum of two family members from varying roles (e.g., parent/sibling) agreeing to take part in the study. Though previous research has often included a mixture of parent and sibling participants (e.g., Griffiths & Unger, 1994; Taggart et al., 2012) very few studies have sought to sample parents and siblings from within the same family. Yet to understand how the family as a system negotiates care and future care planning exploration of this phenomenon must include multiple perspectives within the family system. Hence, a minimum of two perspectives from different roles within the family was sought. Though attempts were made via the previously discussed purposive sampling procedures to make initial contact with both parents and siblings of adults with ID, in all three cases initial interest in the project came from parents.

Case study design.

Yin (2014) suggests that case study methodology is an ideal approach for investigating phenomena in depth and within real-world context. Lack of depth has already been identified as a limitation of previous research, which has often been the result of research designs that predominantly utilised questionnaire or short answer survey designs. In contrast, the case study design adopted for this project allowed for multiple data collection points and in-depth exploration of issues with an emphasis on the participant’s real-world experiences.

Stake (1995) identifies three further relevant reasons for conducting a case study

- it satisfies an intrinsic interest in a particular case;
- examination may provide insight into a particular issue; and
- understanding the cases under investigation will lead to better understanding and or theorising of a larger set of cases.

It is argued that all three of the above reasons are relevant to the aims of this study particularly as an in-depth understanding into specific issues surrounding future care of adults with ID appears to be limited in existing literature. Therefore, the goal of investigating multiple cases was to gain further insight on the issue of residential care planning, and a better understanding of the experiences of families when faced with future residential care planning for an adult with ID.

In case study design emphasis is placed on multiple sources of evidence with Yin (2014) describing interviews as one of the important sources of evidence. Yin distinguishes between shorter interviews and prolonged case study interviews, the latter taking place over two or more hours and allowing for more extensive data to be collected on an individual's insights, explanations, and meanings related to relevant events and issues.

In addition to the in-depth data collected via interview, the 'real world' setting provided in case study design also allows researchers to gather data via direct observations. Yin (2014) specifically notes that direct observation may occur throughout fieldwork and during interviews. Yin further notes that observation may occur when a researcher takes on a 'participant observation' role; that is, a researcher is not simply a passive observer but may actively participate in the behaviours and events being studied. While the researcher did not actively participate in the issue of future residential planning or caregiving for an adult with an ID in the reported study, it would be naïve to describe the researchers' role as passive. The role of researcher provides the individual with privilege, for example being granted unique opportunities to gain access to family interactions within the family home that would ordinarily be inaccessible to those outside of this domain. In this respect the researcher has gained access to observations merely on the basis of her participation as a researcher.

As Yin (2014) points out, classic case studies have tended to focus on an individual as a case or primary unit of analysis, however Yin further indicates that a case can be an entity other than a single individual, for example many case studies have been published on small groups and communities. In this instance, Yin notes that individual cases may also contain smaller sub-units. Yin also suggests that in multiple case design (e.g., study of more than one case) it may be appropriate to analyse two or even three cases.

Defining the bounded system.

In case study design both Yin (2014) and Stake (2003) emphasise the importance of identifying the case as a bounded system. This implies that there are units that fall within the boundaries of a case and units that fall outside of it depending on the focus and scope of the research (Yin, 2014). In the present study participating families were limited to those where a) the adult with ID remained in the primary care of his or her parents (living at home), b) the parents of the adult with ID were aged 50 or older, and c) at least two members representing different roles would be willing to participate (e.g., one parent, one sibling of adult with ID).

Families were bounded by current residential circumstance (i.e., adult son/daughter living with parents) as the primary aim of the study was to explore present cognitions, emotions and behaviours of families who were about to, or yet to consider future residential care for an adult with ID. To include families who had already actioned such plans would mean asking families to recollect experiences for which accuracy may be called into question, particularly as these recollected experiences may have been influenced by outcomes that had occurred since enacting the residential accommodation plan decided upon.

Parental age was used as part of the bounded system because research indicates that parents are likely to want to care for their adult son and daughter with ID for as long as they can, often beyond normative stages of independence (e.g., Cairns et al., 2013). In exploring experiences relating to future residential care planning the researcher wanted to reach out to families for whom residential planning was a more salient subject than younger parents. In addition, there is an abundance of literature that highlights the importance of siblings in future care planning (e.g., Bowey & McGlaughlin, 2007; Waldren & Strohm, 2010). Though it may be counterintuitive, literature suggests that siblings may add further complexity to the decision-making process. Parents of a single child with ID may be more engaged with service providers and more willing to accept external care provision as this may be seen as the only option. Perspectives from families with parents and siblings may therefore provide a more complex reality of the process of residential planning when potentially more family members, and therefore more opinions may be expressed during the planning process.

Participants

Three families, totalling nine individual family members participated in the study (see Table 8.1). Age of parents ranged from 54 to 66 (n = 5; *M* = 61.2), age of siblings ranged from 26 to 41 (n = 4; *M* = 33) and represent lifespan developmental periods from emerging adulthood through to late adulthood. All participants lived within South East Queensland. Parents' length of time in the primary caregiving role ranged in years from 23 to 37 (M = 30.3), with caregiving years reflective of the age of adults with ID. All participants had a male son/brother with intellectual disabilities. All three adults with ID were also described as non-verbal. Homogeneity of gender of adult with ID may, in part, reflect overall prevalence rates of ID in Australia and globally with reports indicating that prevalence is higher in males than females (ABS, 2012b; Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Upon initial contact with all three families it was communicated that the study was designed for the inclusion of adults with ID and that provisions could be made to assist with non-verbal communication (i.e., through the use of picture boards). However, parents in all three families declined to have their son participate (refer to Chapter 13 for a more detailed discussion of this).

Table 8.1

Family Characteristics

Case	Pseudonym	Age	Family roles
1	Kylie	66	Mother/wife
1	Jess	41	Sister/daughter
1	Christian	37	Brother/son with ID
2	Gail	66	Mother/wife
2	Ken	65	Father/husband
2	Hamish	34	Brother/son
2	Cynthia	31	Sister/daughter
2	Michael	30	Brother/son with ID
3	Michelle	55	Mother/wife
3	Rob	54	Father/husband
3	Luka	26	Brother/son
3	Nathan	23	Brother/son with ID

As discussed in Chapter 2, understandings and constructions of ID have evolved along with social attitudes and government policy. In acknowledging the interplay of individuals with their environment, each case will be introduced (and findings presented) in chronological order of adult with ID, that is, dependent on the birth year of the adult with ID. As Figure 8.1 demonstrates birth order impacts on the parents' and siblings' exposure to varying socio-political constructs of disability, as well as funding models. As the figure demonstrates the earliest born adult with ID experienced over three decades of care, including at least one decade of adult care, within a state funded model. The youngest born adult with ID exited school at a socio-political tipping point; at the commencement of the National

Disability Insurance Scheme (NDIS) roll out and shift toward the federal government funding model. It should be acknowledged that exposure to these models, as well as evolving social and political climates may also impact on the individual and family narratives. The family constellation and relevant historical background will be outlined for each family/case in the section following Figure 8.1.

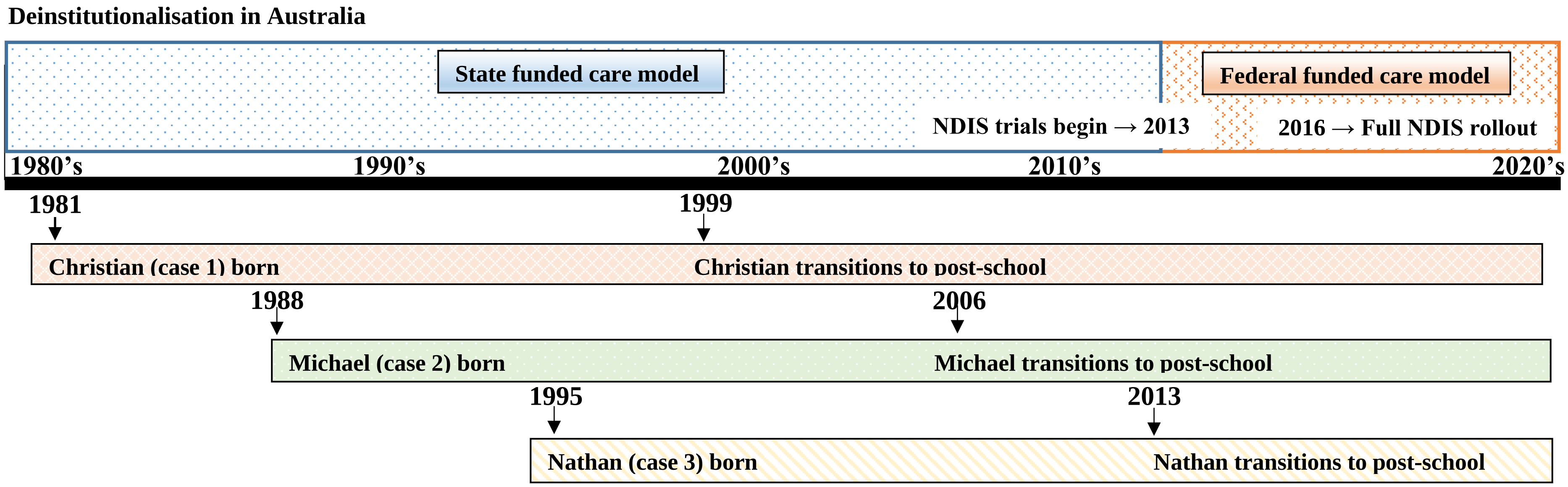

Figure 8.1. Chronology of adults with ID and co-occurrence of socio-political factors.

Case 1.

The case of interest was a family consisting of two parents, and five siblings. The parents had been in the primary caregiving role for their son with ID for 37 years. Both parents (Kylie and Matt) were aged in their mid-sixties with Matt still running his own business. Christian, the son with ID was 37 years old. He has four siblings aged between 41 and 32. Christian's siblings were all married, with two siblings living in the same city as Christian, Kylie, and Matt, one sibling resided three hours away, whilst the youngest sibling lived over 700 kilometres away in another state. The family were of particular interest as this family consisted of both male and female siblings.

Christian had been diagnosed with multiple disabilities including Down syndrome. A brief description of Christian including an overview of the impact of his disabilities follows; this description combines observation of Christian by the researcher during the informal meeting and interview, as well as information provided by his mother Kylie. Christian was in good health requiring no assistance with physical movement. Although Christian could speak some words and had been verbal in the past he was considered non-verbal with Kylie reporting that this was a result of autism. I witnessed Christian communicate greetings (when he came home during interviews) and provide yes/no answers to questions posed to him by family members. Christian required minor assistance with some personal care (i.e., showering) due to sensory issues with hot temperatures and an inability to comprehend time spent doing tasks (e.g., if not monitored he would spent too long in the shower), yet other personal care such as toileting did not require assistance. Christian did not prepare his own meals, however it was unclear whether he was unable to (noting above sensory issues) or if this was simply because of the existing living arrangements.

Christian had attended a mainstream school in his early schooling years and then a local special school until the age of 18, after which Christian commenced casual work arranged through a local care organisation. At the time of the interview Christian had two casual jobs, these jobs and other activities such as swimming were attended by Christian and a support worker five days a week. In the past twelve months prior to the interview Kylie and Matt had commenced respite services. Kylie and Matt had been accessing supports for Christian through the NDIS. One annual review of funding had been completed, which indicated that Christian was in his second year of NDIS funding.

Case 2.

The case of interest was a family consisting of two parents, and three siblings. The parents had been in the primary caregiving role for their son with ID for 30 years. Both parents (Gail and Ken) were aged in their mid-sixties and had retired from work. Michael, the son with ID, was 30 years old. His siblings were Hamish (brother, aged 34) and Cynthia (sister, aged 31). All family members resided in the same city, though Hamish and Cynthia had left home years earlier and Cynthia had recently married. The family were of particular interest because all family members were willing to participate which allowed for an exploration of both male and female experiences within both the parental and sibling role.

According to Gail and Ken, Michael had been diagnosed with multiple disabilities including severe ID. A brief description of Michael including an overview of the impact of his disabilities follows; this description combines observation of Michael by the researcher during the informal meeting, and information provided primarily by Gail and Ken. Michael is mobile and does not require assistance walking, however he does have mild spastic quadriplegia and as a result gross and fine motor skills are affected. Michael has language and speech problems including aphasia, dyspraxia, and dysarthria; although Michael can speak small utterances he is considered non-verbal with Gail and Ken reporting limited success using visual aides to assist his communication. Michael's family reported that he has no sensory awareness of hot or cold temperatures and thus needs constant monitoring when showering.

The first of Michael's disabilities was diagnosed when he was 14 months of age (mild spastic quadriplegia), all other diagnoses occurred prior to school age. Gail and Ken's caregiving tasks included assistance with all Michael's daily living tasks (e.g., preparing meals) and personal care such as bathing and toileting. This was largely due to the mild spastic quadriplegia which made it difficult for Michael perform some of these activities. Michael's older brother described Michael as not being able to understand the concept of work, and therefore not capable of being "productive like that" (referring to disability organisations that assist those with disabilities to find work). It was observed however that Michael did participate in household tasks, for example on my first visit to the family's home Michael cleared plates from the table and assembled these plates on the sink to be washed up.

Michael had attended a local special school until the age of 18, after which Gail and Ken applied for, and received, government funding for ongoing care support. Gail and Ken reported using multiple support services with Michael receiving community-based support four days per week. Gail and Ken were adjusting to Australia's NDIS system, with Michael having received his first NDIS package (a budget of his annual funding) prior to the interview.

Case 3.

The case of interest was a family consisting of two parents, and two siblings. The parents were aged mid-fifties and had been in the primary caregiving role for their son with ID for 23 years. The father (Rob) worked fulltime, whilst the mother (Michelle) had stopped working to become a full-time carer when her sons were teenagers. Nathan, the adult with ID was 23 years old, his brother Luka was 26 years old. Luka had left home around the age of sixteen, and at the time of the interview lived with his partner in a city about two hours' drive from his parents and sibling. This family were of particular interest because this family consisted only of male siblings and previous research suggests that gender may be of significance in relation to expectations regarding sibling roles in caregiving.

Parents reported that Nathan had been diagnosed with a rare congenital disorder at the age of three which resulted in severe ID. By age four Nathan experienced additional health issues including epilepsy. The impact of Nathan’s disabilities included deficits in communication (Nathan was described by family members as non-verbal), restricted behaviours, for example I witnessed difficulty with both gross and fine motor skills such as walking and opening jars or other food packaging. Parents also reported Nathan had language impairment, difficulties with motor function, balance, memory, visuospatial skills and higher order functioning. Despite Nathan being described as non-verbal, he had been taught some basic sign language, additionally I witnessed him verbalise some words such as nicknames for family members. According to a recent psychologist’s report Nathan’s level of ID was deemed to be profound. Caregiving tasks included assistance with all personal care tasks (meal preparation, bathing, toileting).

At the time of the interview Nathan received community or in-home care six days per week from at least three different care organisations. Weekly activities included swimming, horse riding, and a morning of cooking at home with his support worker. Nathan had been a client of the NDIS system for less than two years. Michelle and Rob had recently contested Nathan’s annual NDIS plan for funding.

Procedure

Data were collected by the researcher from participant observation, informal meetings (unstructured interviews), and semi-structured open ended interviewing. Information sheets and consent forms were shared with participants at initial informal meetings, or in the event that no informal meeting was set, at the time of the interview (see Appendix H). Details regarding procedures for each of these data collection methods are outlined below.

Informal meeting/observation.

Where possible, initial meetings were arranged with the families prior to formal data collection in order to explain the research, answer any questions, and develop rapport, trust, and openness for the interviewing phase. An additional reason for meeting with each family was to meet their son with ID and potentially encourage the families to consider their sons' inclusion in the research project. An important aspect of the initial research design was to include adults with ID in the data collection phase, with specific steps taken to offer visual aids or other adjustments for communication. Though ethics approval was granted to recruit adults with ID, inclusion was dependent on an individual's capacity to understand the project and the family's evaluation of the appropriateness of the project. In each case, the parents determined that their son did not have the capacity to understand the project, nor the communication skills to participate.

Case 1.

An initial meeting took place in the family home, primarily with the mother; during this time the father was also occasionally present as was the son with ID. This initial meeting lasted around two hours and consisted of general questions and answers about the project in addition to story-telling by the mother. As this was an informal meeting discussions were not recorded, however notes were made by the researcher in relation to both discussions and observations. At the conclusion of the meeting the mother agreed to continue with research participation and offered to recruit her typically developing adult children into the project.

Case 2.

An initial meeting took place in the family home with both parents and both sons present (daughter was absent). The meeting lasted almost two hours and provided the family with an opportunity to ask questions and receive answers about the project. This time also largely included story-telling by the parents about life in general with Michael. Although discussions were not recorded notes were made by the researcher in relation to both discussions and observations. At the conclusion of the meeting both parents and the typically developing son, Hamish, agreed to continue with their research participation. The parents further agreed to contact their typically developing daughter, Cynthia, and inform her of the opportunity to participate. Cynthia later contacted the researcher and agreed to be interviewed.

Case 3.

Family 3 declined an initial meeting, however both parents and the only sibling to Nathan (adult with ID) agreed to participate in the research interviews.

Interviews.

Each participant or couple took part in a semi-structured interview with probing questions used to explore responses more deeply (see Appendix G). Interviews commenced by initially asking for background information regarding family life, including diagnosis of the adult with ID. This was a broad structured question intended to allow the family members to talk openly and guide the direction of the answer (e.g., the participant could guide the discussion by talking about positives or negatives). Further questions covered topics such as the care role and responsibilities, experiences with support services, residential care planning (barriers/enablers), and experiences with or attitudes towards the NDIS. Participant answers were often paraphrased by the researcher during the course of the interview to confirm to ensure accuracy of interpretation. If any answers were unclear the researcher prompted the participant to provide further explanation. Whilst family members were entitled to discuss their interview experiences amongst themselves it was made explicit that no interview details would be shared by the researcher amongst other family members, not even in a confirmatory manner.

Following each interview a reflective diary was completed by the researcher to guide initial thoughts and to minimise the extent to which interviews were unduly influenced by the researcher's growing knowledge of family dynamics and experiences (refer to *researcher reflexivity,* p. 169).

Case 1.

During the informal interview, Kylie (the mother) had agreed to recruit her typically developing adult children into the study, and discussed an opportunity to interview them in a 'focus group' situation when they would all be at the family home during a holiday period. However, upon returning for Kylie's pre-arranged interview it was discovered by the researcher that she had recruited her second eldest daughter to join her for the interview. In this sense the mother had selected a convenient sample as the daughter, Jess, was one of only two siblings who lived locally. As Kylie had pre-arranged her daughter's participation it was agreed that they could be interviewed together. No further opportunities to interview the remaining adult children were offered.

The interview with mother and daughter lasted almost three hours, with Christian returning home from care mid-way through the interview, however this did not disrupt or impede on either questioning or responses. Interview questions were semi-structured with probing questions used to explore responses more deeply. In addition, observations and discussions drawn from the initial 'informal meeting' were explored in the interviews for further clarification or discussion whilst the daughter was present.

Case 2.

In order to gain a richer understanding of the unique experiences of each family member and to encourage honest responses and avoid suppression of conflicting views individual interview dates and locations were encouraged. The parents however requested to be interviewed together.

The first interview took place with the eldest son Hamish, (1.5 hours) on university campus grounds. One week following the son's interview, the parents (Gail and Ken) were interviewed (2 hours) in the family home. The parents asked to be interviewed at a time when Michael (son with ID) would be out of the house with community care. A further two weeks later the final interview took place with Cynthia the daughter (2 hours) on university campus grounds. All three interviews were based on the same interview guide. In addition, observations drawn from the initial 'informal meeting' were explored in the interviews with the family members who had been present; that is, the parents and eldest sibling.

Case 3.

The first interview took place with the adult sibling, Luka, via telephone (1 hour). Though each family member was encouraged to participate in an individual interview, the parents requested to be interviewed together. Two days following the interview with Luka, the parents (Michelle & Rob) were interviewed in their family home (2 hours). During the parent interview Nathan, their son with ID was present, for example wandering in and out of the interview area with food or to show the researcher his favourite possessions, however he did not participate.

Rigour and credibility of data.

Yin (2014) identifies specific principles for producing high-quality case studies, though not all principles are relevant to this particular study (e.g., exercising care in using electronic sources) consideration was given to the relevance of each principle and how this could be upheld.

Using multiple sources of evidence.

To increase confidence in the interpretation of data it is important to consider multiple sources of evidence. Whilst interviews emphasise verbal information, the additional use of observation in the following case studies provides a measurement of individual behaviour including any noted incongruence between behaviour and verbal communication (e.g., laughing when verbally expressing sadness or concern). The inclusion of multiple family members, each completing an individual (or paired) interview allowed for data source triangulation (i.e., identifying whether the narrative remained the same across family members). Though Yin (2014) notes that convergent evidence gathered via data source triangulation may strengthen a case's construct validity, it should also be noted that in exploring these case studies it was recognised that there may be multiple realities and therefore differences in the data were also explored.

Creating a case study database.

Yin (2014) differentiates between case study reporting (outcomes obtained from analysis of combined data) and case study database (a group of files collected from multiple sources and via multiple means), emphasising the need to maintain both as separate points of evidence. In this study the use of computer assisted software (NVivo 12; QRS International, 2018) was used to compile, arrange, and preserve all raw data. Yin states that the creation of such a case study database increases the reliability of the case study overall.

Maintaining a chain of evidence.

This principle highlights the importance of cross-referencing, maintaining and communicating methodological procedures to ensure there is a chain of evidence from research question through to results (Yin, 2014). Yin (2014) emphasises the need for methodology reports to contain an appropriate level of specific detail including the collection of data (when and where?) through to analytic procedures. The findings themselves should refer to specific data sources and contain actual evidence (e.g., identification of individual sources and inclusion of supporting quotes as can be seen in Chapter 4). Yin argues that “if these objectives are achieved, a case study’s evidence also should exhibit heightened construct validity, thereby increasing the overall quality of the case study.” (p. 127).

Ensuring trustworthiness.

Throughout the data collection process several steps were taken to increase trustworthiness. For example, Morrow (2005) discusses the importance of rapport in contributing to accurate understanding of participation constructions of meaning. As previously discussed, an initial step taken in the data collection phase was to meet with family members in an informal setting to discuss the research project, their involvement, and answer any questions prior to conducting any interviews. The primary goal of this meeting was to build rapport with participants.

In addition a form of member checking was carried out as part of the interview process. That is, immediate interpretation of responses was checked against the respondent to confirm that the researcher’s interpretations were correct, or if not, provide the researcher with further clarity regarding the participant’s understanding. Though Stake (1995) defines member checking as providing participants with a draft of the data (i.e., interview transcript) this definition of member checking was not considered appropriate in this study. As the interview questions were likely to elicit emotional and unfiltered responses from participants, the potential disadvantage of member checking is that participants may wish to alter their responses to a more socially desirable, or simply less emotional response (Stake, 1995). Participants were informed of this prior to commencing the interviews.

Researcher Reflexivity

As noted in previous chapters, reflexivity is the examination of self in the role of researcher (Finlay, 2002a, 2002b). As the researcher and interviewer in this study, I acknowledge that my position and presence alone during the interview phase had an influence on participant responses thereby influencing the direction of findings. For example, though I am not a part of a disability culture, I do share social context and a local and state culture with participants leading to shared meanings being negotiated throughout this process.

Finlay (2002b) noted that reflexivity should commence at the pre-research stage. At this stage a researcher must consider his or her relationship to the topic and how motives, assumptions, and interests might skew the research. In one sense, it was an advantage that I was uninvolved in disability and social work (as much of the disability literature tends to develop from the field of social work). This distancing of researcher and research topic allowed me to approach the topic with curiosity and for the research question to be guided by the literature. On the other hand, participants were likely to anticipate a certain amount of competence and knowledge relating to disability policy, services, and individual experiences, therefore I sought out advisors within the disability environment to attempt to meet expectations and avoid structuring any interview questions in a way that might offend.

During this consultation I was encouraged to acknowledge and include questioning about institutionalisation. In reflecting upon the inclusion of this line of questioning, I acknowledged a topic of importance to the advisor, an advocate for deinstitutionalisation, rather than a fundamentally significant topic for others within Australia’s ID culture. I do not deny that language once associated with Australia’s past institutional care settings remains, however the institutional framework within which it once sat was absent from participant narratives, except when responding to this very direct line of questioning.

It should further be noted that being an ‘outsider’ did not free me from assumptions. Both the literature and media representations of what could be categorised as extreme caregiving situations piqued my curiosity in certain experiences. In considering how my readings had influenced anticipated findings, I realised that I started with an assumption that families would be reluctant to source care support, and reluctant to consider residential care options. By being alert to these I was able to ensure that through data collection any discussion of such themes could be clarified with participants to minimise researcher bias. Despite starting with these assumptions, I was surprised to find two of the three families taking active steps towards transitioning into residential care, and all families heavily engaged in care services, though note that this may also represent selection bias.

Verbatim comments in the literature of parents preferencing their child's death over residential care also led me to question the underlying psychological experience of parents. Extreme cases of filial homicide reported in the media further stimulated this questioning of affective experience. Yet the exploration of caring for someone with an ID is a sensitive topic and families' experiences with government services can leave them feeling poked, prodded, microscopically observed, and critiqued; inclusion in research can be experienced as one more science experiment. It was therefore difficult to 'confront' families with questions of emotional experiences directly as I feared these may have been misinterpreted as challenging and that this may have negatively impacted on the rapport that had been achieved.

There is also a tension between being a researcher and being a representative of the field of psychology. Participants may seek or expect a therapeutic experience through the interview however the researcher role must not jeopardised, yet listening to participant stories requires sensitivity, and at appropriate times empathy and understanding. I allowed myself to adopt an empathic approach within the bounds of the researcher role, with knowledge that this may influence responses just as an apathetic approach would also influence participant responses.

From a social constructionist perspective, it is equally important to consider the impact of the participants on the researcher as it is the impact of the researcher on participants. To this end, I was mindful that I was privileged to receive accounts of family experiences from varying, and at times, contrary individual perspectives. As an interviewer I was the gatekeeper of such perspectives within each family context. It could be described as holding the keys to each individual's personal diary, which was at times an experience of uncomfortable privilege. As a researcher however my role was to consider and make sense of these perspectives combined. Yet with such a small sample, disseminating findings whilst protecting the 'secrets' of these 'personal diaries' was challenging. Consideration and respect for participant anonymity whilst staying true to the findings involved careful construction of research summaries for dissemination among participants should they request it.

Data Analysis – Individual Case Analysis

All interviews were audio-recorded and transcribed verbatim by the researcher allowing the researcher to experience detailed engagement with the data from each case. Pseudonyms were used to protect the anonymity of the participants, specific detail relating to diagnoses of each son with ID has been supressed to protect their anonymity. Verbatim transcripts and observation notes were imported into Nvivo 12 (QRS International, 2018) for data storage and coding.

Thematic analysis is described as a qualitative approach to data analysis which allows for organic and flexible coding of the data (Terry, Hayfield, Clarke, & Braun, 2017). This approach is advantageous in case study analysis as its flexibility allows for both interpretation of individual instances, and the convergence of several similar instances as outlined by Stake (1995). It is acknowledged that in case study there may be singular instances of important issues yet the relevance of this issue may warrant its inclusion, as such this particular thematic approach sought instances of categorical congruence, as well as significant individual instances of importance, even if perceived as incongruent with others (e.g., one family member raises an issue of significance for that individual yet no other family member raises this same issue).

Braun and Clarke (2006) outline six phases of thematic analysis (see Table 8.2). Phase 1 involves the researcher becoming intimately familiar with the data. As mentioned, this step began with the initial transcription of each interview being performed by the researcher. Once all transcripts were completed the researcher read and reviewed the interview transcripts, observation notes, and reflexive diary entries multiple times to become familiar with individual and case data.

The second phase of the analysis involved generating labels or codes in relation to important features in the data (Braun, Clarke, & Rance, 2014). In order to remain as consistent in the coding of each case as possible, the entire data set of each case was coded with phases 2-5 completed for case one prior to starting the coding of case two. This same process was again followed with case two prior to starting the coding of case three. At this phase of analysis, coding was both descriptive and interpretative. As the case codes and relevant data extracts were reviewed within the framework of the bounded case (e.g., family) collation of codes involved aggregating instances of congruence and incongruence, as is reflected in the Case 1 theme “Told or Involved” (a collation of opposing attitudes towards sibling involvement in future residential care planning).

Table 8.2

Phases of Thematic Analysis

Phase	Brief description
1	Data familiarisation
2	Generating initial codes
3	Searching for themes
4	Reviewing themes
5	Defining, refining, and naming themes
6	Reporting findings

(adapted from Braun & Clarke, 2006)

The third phase of the analysis involved a deeper examination of codes, including collation of codes based on broader patterns of meanings (Braun et al., 2014). This involved clustering codes into potential themes. By reviewing the coded data and developing themes, overarching themes or umbrella concepts were defined. These themes or concepts revealed both congruent and incongruent family approaches to future residential planning for an adult with ID, for example an overarching theme of Case 2 was “Care Concerns”. This theme included specific areas of concern as subthemes, for example “it’s not babysitting” which identified underlying issues with support staff and their approaches to caregiving, and “Our gentle giant could hurt someone”, referring to the parents major concern that their son would injure staff or other clients.

The fourth phase of the analysis involved reviewing the themes against the entire data set for each case to ensure that the final set of themes would tell a complete and convincing story of the family’s experiences in relation to the research aims. As noted by Braun et al. (2014) certain themes may be discarded if the themes fail to fit well together or tell a meaningful and cohesive story. In Case 2 for example, two main themes told a meaningful back story to the experiences of the family however during this reviewing phase it was determined that the story revealed in these specific themes was somewhat distinct from the study aims of understanding the family experiences in relation to future residential planning, therefore these two themes were discarded with adjustments made until an overall thematic map was finalised for each case.

In phase five, defining and refining of theme names occurred in order to ensure each name was appropriately informative (Braun et al., 2014). As underdevelopment of themes has been identified as a significant problem in qualitative research (see Connelly & Peltzer, 2016), this phase is a critical step in ensuring that the importance of each ‘story’ is clearly communicated with the reader. As noted by Connelly and Peltzer (2016) one issue may be a disconnect between theme names and the quotes used to support that theme. Overarching themes relied on simple descriptive titles (e.g., “Planning for others to care”). However, to ensure sub-theme names aligned with representative quotes the actual language used by participants often formed part of the theme name in order to capture the essence of that theme (e.g., “Our gentle giant could hurt someone”).

The final phase of thematic analysis identified by Braun and Clarke (2006) is the final write up of findings. To build a convincing and evidence based narrative it is imperative that the findings incorporate clear and compelling quotations to support the interpretative story of each case. Findings for each case study are provided independently in chapters 9-11.

Data Analysis – Cross Case Analysis

The above approach was similarly taken in the cross case analysis, however in this instance the emphasis was not simply placed on each individual family unit, but also exploring familial roles (e.g., role of sibling, role of parent) as a subunits in each of the three cases. To avoid repetition of the above steps in moving through each phase, this section will focus on any divergence from the phases as reported above, this begins at phase three.

For the cross case analysis coded data from all three case studies were revisited. During phase three emphasis was placed on searching for understanding and meaning across parental and sibling roles independently of family, as well as an aggregate of family findings. By returning to the codes (as established in Stage 2) new themes and umbrella concepts could develop by reframing the subunit as the roles within the family system. In this cross case analysis themes were retained if a meaningful and cohesive story for each subunit (e.g., parents/siblings), or family developed. Similar to the individual case coding these new themes revealed both congruent and incongruent experiences within families and familial roles.

During the fourth phase of analysis themes were reviewed against all subunit data (in the event of subunit comparison), and the entire data set (overall family comparison) to ensure that themes would tell a meaningful story of the role based experiences as well as broad family experiences. Just as new themes developed through the focus on subunit comparison, so too were themes that had been previously retained in the individual case study analysis, discarded due to a lack of fit within this analysis (Braun et al., 2014).

During phase five theme names were refined to ensure they were adequately descriptive of the theme content (Braun et al., 2014). Overarching themes identified both the subunit of comparison (e.g., parents, siblings, all families) and context of theme. Subthemes further ensured the essence of each theme was appropriately captured.

As previously discussed, phase six involves the final write up. This included returning to the coded data to ensure interpretation was supported by the participants own narrative. As such illustrative quotes have been provided in the theme table and written findings which are presented in chapter 12.

Summary

This chapter presented an introduction to case study design including the structure of cases and analysis of data for Study 3. Key methodological considerations including the units/cases for analyses, data collection procedures, and the six phases of thematic analysis were discussed. It has been argued in this chapter that case study design was a suitable framework for the research question as it would allow for in-depth exploration of participants real world experiences as members of a family involved in caregiving for an adult with ID. Each case presents a different type of family system that has lived through, and cared through various contextual factors (e.g., caregiving models) which has implications for the individual’s lived experience. These experiences are presented in the following chapters.

Chapter 9 – Case 1 Findings

This chapter presents the qualitative findings from Case 1 and relates to Christian, a 37 year old male adult with intellectual disability (ID), and his family. In this case study both parent (Kylie, mother) and sibling (Jess, sister/daughter) chose to be interviewed together. Despite this, the data collected in Case 1 represents over four hours of both formal and informal interviewing and observation. The findings presented below primarily focus on this single interview data, with observation data and further reflections from an informal meeting with the mother considered. The mother's narrative during the informal meeting was also compared with her interview answers to explore whether any response bias occurred due to the presence of her daughter during the formal (recorded) interview. There were no observed changes in attitudes, beliefs, or stories shared across both meetings. The daughter also appeared relaxed with no observable signs of suppression of answers. During the interview both women contributed to answering all questions asked.

Interview questions focused on exploring sibling involvement, current care plans and future residential care preferences and preparation, and experiences with the National Disability Insurance Scheme (NDIS). Where appropriate main theme titles and subtheme titles were structured around the language of the participants if this appropriately captured the essence of the family's experiences. A table of themes with representative quotes for each theme or subtheme is presented below (see Table 9.1).

Table 9.1

Case 1 Themes

Main Theme	Sub-theme	Representative quotes
'Care' is what family do		"You have a responsibility to your family… you want your family unit safe. So therefore you've got to get in there and do your part, you can't just take, take, take". (Jess)
Cautious steps to future planning	We're confident he can move forward…	"He's become so comfortable with it that we know now that we can, [his support worker] wants to take him away camping for the weekend." (Kylie)
	… But planning needs to be fluid	"Our lives have all kind of changed all the way it looks. So I mean, it might change again in a decades time…"(Jess)
NDIS – A future of opportunities		"I just have to say this is what I want, this is what his needs are, and they're there." (Kylie)

‘Care’ is What Family do

This theme revolves around the concepts of family solidarity, loyalty, and responsibility. Both Kylie, the mother, and Jess, the daughter, described the family as one which prioritised inclusion of all family members. As children all five siblings played together with toys altered to allow Christian’s involvement, and as an adult Christian was similarly “treated like everybody else” (Kylie). This inclusion was not simply about Christian taking part in all sibling and family activities, but coming together as a family to address challenges. Problems appeared to be addressed from a family perspective (“we’ll fix that”, Jess) rather than a parental responsibility to find a solution. For Jess, this was a togetherness for and because of Christian, she stated “there’s no doubt about it, the glue in the picture is Christian”, meaning that regardless of any internal family bickering the family would come together in order to support Christian.

Despite the family coming together for Christian, Jess believed that the importance that was placed on family responsibility was not directly related to disability, but was a part of “working in a family”. She recalled that sibling responsibility involving Christian had been “so normal” that she had not realised until high school that other families operated any differently. This realisation had led to the creation of a special bond with a friend who was similarly one of five children and was the only person who understood “the true meaning of responsibility to a family unit”. Kylie supported Jess’s view stating “you’ve got to be part of your family you know, you can’t sit on the outskirts of it, doesn’t work”.

This strong sense of family inclusion and togetherness appeared to relieve Kylie of any concerns relating to future planning. Jess suggested that all siblings were willing to take on the role of primary carer and have Christian move in with them. Jess displayed certainty in her siblings’ commitment even joking that the siblings were essentially fighting over who would be chosen to care for him. Kylie too expressed confidence in the siblings’ abilities and willingness to deal with the responsibility of caregiving, further indicating that she believed the siblings would make the correct decisions for Christian. This confidence in the sibling role as carer further appeared to remove any urgency related to pre-planning:

> You see that's, that's probably why I've been so laid back with the whole, I don't get stressed about that situation because I know that they all have his best interests, whichever that may be, and they'll all do it, not for them, they'll do it for him. (Kylie)

It was observed throughout the interview that the family, or at least Kylie and Jess communicated openly about Christian's current and future care. Jess was very aware of his current program and support workers, whilst they both openly discussed challenges and hopes for Christian's future. Additionally, Jess's 18 year old son was also present in the house at the time of the interview with Jess indicating that at times he was called upon to assist with caring for Christian, should her parents require assistance, this further supports the notion of family responsibility in looking after each other.

Cautious Steps to Future Planning

This theme illustrates that although planning for residential accommodations had not yet occurred, recent events had given the family cautious optimism. *We're confident he can move forward…* highlights the importance of positive experiences with current care regimes in order for families to build confidence in the system and associate successful outcomes with residential accommodation outside of the family home. Despite these positive experiences, the second subtheme, *…But planning needs to be fluid*, describes the difficulties that families face in forming concrete care plans due to unknown and often unplanned changes that occur in the lives of carers. In addition, this second subtheme extends on the first in illustrating that existing care experiences can also create change in the mindset of those who are planning for the future.

We’re confident he can move forward…

Positive outcomes from support programs were pivotal to the advancement of future care planning. In the twelve months prior to the interview Kylie had changed Christian’s primary external care provider, recognising that since then Christian had “[come] a long way”. Kylie further described the opportunities available through Christian’s care provider as “far more progressive then what he’s ever had which gives Matt and I the confidence to know he can move forward in his life”. The success of the current program simultaneously built confidence in Christian’s development whilst reducing concern relating to his future beyond the care of his parents; “we’re starting to feel like lately that Christian would be ok… it helps put our minds at ease” (Jess).

Though “progressive” was a term used to describe the nature of supports, it also aptly described the family’s involvement with supports. The family were slowly progressing Christian’s care program to commence a comfortable level of separation, or “letting go” from the family. This involved using respite for the first time in Christian’s life. Kylie described comfort in taking advice from the care provider to trial in-house respite with the provider acknowledging that this would best suit Christian’s personality. The trial proved successful with Kylie describing Christian’s second experience with respite as “pretty cruisy”. Kylie spoke positively of innovative approaches to caregiving and expressed excitement at further new experiences such as Christian spending weekends away, or camping with his support workers. It was noted that success and further development of Christian’s supports appeared somewhat dependent on one particular support worker who had been pivotal to the success of Christian’s positive development thus far.

Kylie described Christian’s care program as one that allowed Christian to be himself, and encouraged him to make his own choices. The success with Christian’s care program had given Kylie a sense of belief that Christian could continue to progress as a person and an independent adult. For example, she was hopeful that through services such as speech therapy Christian might one day be able to verbally communicate choices. This success also appeared to stimulate new ideas and hopes for Christian's future residential planning. Both Kylie and Jess spoke of options where Christian might live more independently, potentially buying his own house or unit yet living close by to where the siblings were so they could "just pop in".

Further supporting the goal for independence was the overall way in which the family viewed Christian, not as a child in need of care, but as a 37-year-old man. Throughout the course of the interview Christian was always described as a man who enjoyed an adult life. For example, Jess recounted a time when he would regularly visit another sibling and enjoy an afternoon beer with her family. In this way sibling relationships with Christian developed through a typical trajectory from childhood through to adulthood. Christian's independence was strongly respected by both Kylie and Jess, and it was acknowledged that as an adult he needed "to have his own life". This included spending time away from the family so that he could enjoy his own hobbies, with Jess admitting this may allow him the opportunity to express himself more freely; "you know we're all different with our friends then we are with our families". Jess also stressed that for Christian in particular he needed this opportunity "more than anybody else" because of him still living in the family home with her describing the option for Christian to live by himself in a house as "exciting for him". Participant awareness of the launching stage placed importance on Christian's independence, yet despite this recognition it was not discussed with urgency but rather quiet confidence that this transition would occur over time.

Despite care successes there had been notable failings with the service provision of Christian's care in the past. These failings had detrimental effects both on Christian and the family with Kylie describing a period of time when Christian's health had declined and the family's confidence in external care had waned. Difficulties revolved around transitioning

Christian from school to post-school care, during which time Kylie “saw him… really go backwards” with Christian showing signs of depression and anxiety. In facing a second major transition in Christian’s life with the advancement of residential planning, Kylie described her biggest concern as the risk of seeing Christian regress stating “I’d hate to see that happen, nobody should have to live like that”. Despite concerns remaining there was acknowledgment that support services during that time were “not as good as now” (Kylie).

…But planning needs to be fluid.

This subtheme highlights the difficulties of planning for residential care in advance of when that plan would be enacted. With sibling care identified as one of the primary care options for Christian’s future residential planning, changes within the sibling’s own family system (e.g., arrival of children or departure of partners) made it difficult for concrete plans to be established. Recent developments in Christian’s care also had the unintended impact of potentially slowing the planning process. As Christian experienced personal growth, residential options were expanded with new opportunities being considered by the family. With the potential for further personal growth in future, the family viewed Christian’s future planning as an evolving conversation.

As such, the family the approach to future planning was to continue to discuss options and opportunities without making firm plans for the future. Fluidity in planning was deemed important because individual’s lives and ideas towards planning were constantly changing. Kylie spoke of a time when her eldest daughter and husband had approached Kylie and Matt requesting to be Christian’s guardians, but since that time their marriage had broken down. Though no formal guardianship arrangements had been made, Kylie viewed this as an example, and warning, of the difficulties of enacting such plans. Jess similarly acknowledged that the siblings’ lives were rapidly changing, indicating that unless planning was deemed urgent sibling lives “might change again in a decade’s time”.

While Kylie admitted that it was likely that Christian would remain in her and Matt's care until such time as they were no longer able to continue caring she again acknowledged that "things change". As such there was a reluctance to commit to any specific pathway for Christian's future, including continued care at home, as she further acknowledged that "your ideas change over the years and I think they have to change". This evolving narrative for future care seemed to develop as a result of the changes to, and outcomes of, Christian's current care program. In addition, Kylie's complete comfort in her children's ability to support and make appropriate decision on behalf of Christian, should an emergency situation arise, also worked to create an environment where concrete future residential planning was not viewed as critical, or even necessary. Both Kylie and Jess therefore concluded that for the family it was simply important to continue to have conversations around care and to progress Christian's experiences with his care organisation without making any concrete decisions for the future.

NDIS – A Future of Opportunities

For this family the NDIS funding had provided significant change in Christian's life. The funding had provided the impetus to try a new care organisation, which ultimately led to the choice to leave a previous organisation that Christian had been a client of for 19 years. Kylie believed that the NDIS had provided support services with the opportunity to be flexible, however admitted that this still came down to the individual organisation's guidelines for how flexible they wanted to be with clients. It was this comparison of open flexibility with one organisation versus the inflexible approach of another that had led Kylie to change providers to the more flexible option.

Interestingly, Kylie described Christian's initial funding package as "ridiculous", claiming that they had been given so much money that they would never be able to spend it. During Christian's second year under the scheme his funding was reduced, to which Kylie responded “halleluiah… we couldn’t use all that money”. Even though Christian’s funding had been reduced this was still seen as a large improvement compared with the pre-NDIS era, which was seen as a period where families had to “fight your way with everything you got” (Kylie), whereas under the NDIS it was as easy as stating Christian’s needs for care and the support would be received.

Despite the positive experiences with the NDIS Kylie did acknowledge that opportunities for Christian to live independently did depend on the future of the NDIS and how it would continue to operate. Both Jess and Kylie also acknowledged that though the NDIS now meant carers were receiving “fairly good dollars” in their roles, this also led to some people choosing to become carers because they deemed it to be “easy”. These were only raised as minor concerns in comparison to the positive experiences with the opportunities provided through the NDIS. As previously noted of particular positive report was Christian’s experience with one specific carer at his new organisation.

Summary

Family and family responsibility formed the centre-piece for the experiences discussed in Case 1. This was most evident in the main theme *‘Care’ is what family do*, though notions of family responsibility were also interspersed throughout the other themes.

Findings showed that despite such strong family solidarity and expectations that sibling care was a likely next step in Christian’s residential care, this did not lead to concrete planning. Rather, specific and concrete planning was viewed as too rigid and inflexible due to the unpredictability of life. This unpredictable aspect of life was further highlighted by recent positive experiences with support workers, which gave the family new hope that Christian could live more independently than previously believed. These positive experiences together with optimistic attitudes in relation to the NDIS increased confidence and usage of service providers.

Findings from the second case study are presented in Chapter 10.

Chapter 10 – Case 2 Findings

Introduction

This chapter presents the findings from Case 2. Findings primarily focus on interview data with observation data providing support for these initial findings, or presenting an alternative explanation. This case included three interviews; the first an independent interview with the male sibling; the second, a joint interview involving both parents; and a third independent interview with the female sibling. Similar to Case 1, interview questions primarily focused on issues such as sibling involvement, planning preparation and planning preferences, current and future care plans, and experiences with the National Disability Insurance Scheme (NDIS). It was therefore unsurprising that themes revolved around the sibling role, the planning process, and attitudes towards the NDIS.

Subthemes titles were structured around the language used by the participants themselves in order to capture a true representation of the family’s experiences. For example the parents affectionately described their son with intellectual disability (ID), Michael, as a ‘gentle giant’ reflecting upon his generally passive nature and large physical size. A table of themes is presented below (see Table 10.1). A representative quote has been provided as indicative of the overall essence of each of the subthemes.

Table 10.1

Case 2 Themes

Main Theme	Sub-theme	Representative quotes
It’s not up to the siblings	Told or involved in planning	“We’re not going to know unless we need to know”
	If push came to shove: Sibs as carers	“if push came to shove I would much rather like take, just take Michael in ourselves”
Journey to external care	Almost 30 years in the making	“You’ve got to start when they’re little with a vision to the future”
	The ideal care community: We didn’t know it existed	“I couldn’t believe what I was hearing from these people”
	Institutional care: Never ever!	“A life isn’t, it isn’t a commodity… you can’t just throw it out”.
Our boy: A risk, and at risk	Our gentle giant could hurt someone	“He can get aggressive… when he has a meltdown he will attack”
	It’s not babysitting	“The whole industry could be overhauled”
NDIS: Problematic but promising		“The NDIS system itself needs a lot of re-jigging… But… The NDIS as a strategy for dealing with the issue of disability is a good one”

It’s not up to the Siblings

This main theme addresses variations in parental and sibling expectations regarding both current and future sibling roles in relation to Michael’s primary care. It highlights the tension that may exist within family systems due to differing expectations of sibling roles not just within the domain of primary care, but also within the context of future care planning. Subthemes include discussion regarding the involvement of siblings in the planning of Michael’s future residential accommodation and the impact this involvement may have on family relations. Consideration is also given to Michael’s role within the planning process. Within the *It’s not up to the Siblings* main theme there were two distinct sub-themes: *Told or Involved in Planning*, and *If Push Came to Shove: Siblings as carers*.

Told or involved in planning.

When asked about Michael’s future residential care planning, his parents Gail and Ken clearly dominated any future care planning narrative and were intent on ensuring Michael’s future was secure prior to either of them “falling off the perch” (Ken). One of the reasons this was deemed to be so important was to avoid the care responsibility falling on Michael’s siblings, Hamish and Cynthia. This avoidance of sibling responsibility extended to all aspects of future planning, which was viewed as the parents’ duty by Gail and Ken as the parents’ duty and something that they were “managing” without the need to involve Michael’s siblings. When asked directly about Hamish’s and Cynthia’s involvement they stated:

> Ken: They’re aware of what we’re doing but… they’re not involved-
>
> Gail: They’re not directly involved in that.

Each sibling however, made sense of their parents’ decision not to involve them in Michael’s future planning very differently. Hamish reflected on the decision as one that demonstrated that Gail and Ken were “being good parents”, whereas Cynthia experienced this as a barrier forcing her to feel like an “outsider” within her own family. Though Hamish admitted he “liked to live close” in case of emergency, he expressed little interest in pursuing further involvement in Michael’s care or care planning until such time as he was invited to by his parents, or needed to be involved: “We’re not going to know unless we need to know, it’s a need to know basis”. For Hamish, defining future planning as a parent’s responsibility allowed him to avoid the psychological burden of care, or as Hamish further stated it enabled him to “not think about it too much” viewing it as something he did not “need to stress about at the moment”.

In contrast, Cynthia saw Michael’s future care planning as not just a critical moment in Michael’s life, but a critical moment for the family marking a potentially pivotal change in the family dynamic. Lack of consultation was therefore a central issue for Cynthia who made direct links between this and the strained parent-sibling relationships. Whilst Hamish seemed content in his current role, Cynthia described this time as an opportunity for Michael and the family to commence a “new chapter” and for the siblings to step up to a guardianship and advocacy role:

> Hamish and I particularly will need to be quite involved in that and kind of, essentially take over. I don't like those words, but you know like relieve them I guess of this new chapter essentially. Like allow them to kind of feel as though ok well look Michael's in really good hands, we're all over it, they're all over it too, but they can kind of just take a step back.

Though noting that her parents had good intentions in wanting Cynthia and Hamish to “live their lives”, this was experienced by Cynthia as being “pushed away” every time the siblings offered to help. She expressed concern that if the family did not start “bonding” the consequences could be that “there’s always going to be this great big divide and if something does happen well no we’re not really prepared in that aspect you know”. Cynthia’s particular experience suggests that a parent’s intention to ensure their typically developing children remain burden-free and responsibility-free may have the unintended effect of isolating and alienating siblings from the caregiving family, and in turn isolating the parents from important family supports. Cynthia further indicated that a lack of involvement equated to a lack of a preparedness should the siblings be required to take on the primary care role in an emergency situation.

Family members were also asked about the involvement of Michael in his own future residential care planning. All agreed that Michael did not have the intellectual capacity to understand or be involved in the decision making. In discussing the “pointlessness” of involving Michael, Hamish reaffirmed his views regarding parental roles and responsibilities:

> He wouldn’t even have a clue what you’re talking about… there’s no point. You, you’re making a decision for someone who’s mentally four, so, it’s completely the parents’ decision, yeah, and it always has been like that, yeah.

Though Cynthia supported Hamish’s comments regarding Michael’s limited decision making capacity, she identified unique opportunities for Michael to be a part of the decision making process within his new home:

> Let’s just say he moves into accommodated care living, and he does get his own place well certainly choosing the colour of the paint and making it his home. You know like… things that he can choose so things like, you know Michael what colour curtains, you know red or blue, can guarantee he’ll say blue (laughs) guarantee, it, it’s his favourite colour. Just things like that, you know things that you can really include him in as much as possible.

This comment supports Cynthia’s inclusive family approach to the future planning process and highlights opportunities for families to recognize how choice and control can be expressed by those with severe ID as part of their involvement in their own future care planning.

If push came to shove: Siblings as carers.

The notion of siblings as primary carers also produced some varied responses from Hamish and Cynthia. Though the siblings did not tend to present themselves as a preferred primary care option for Michael’s future residential care, both siblings did indicate that they would be willing to take on the role, however this was generally positioned as a secondary or last resort preference to other accommodation options. For example, Cynthia indicated that “if push came to shove I would much rather like… just take Michael in ourselves and you know take on that role”. Cynthia’s response suggested that her willingness to adopt the role (as a last resort) reflected her need for assurance that Michael would be cared for in a safe environment, though noted that she would “still certainly continue to investigate the long term care plan”, indicating that such a situation would be temporary.

Hamish’s responses presented somewhat of a contradiction. On the one hand Hamish acknowledged that the “inherited” role of siblings as primary carer reflected “the old days”, indicating that he now believed due to a growth in supported living options “it shouldn’t have to fall on the siblings”. However, when specifically reflecting on Michael’s future residential care Hamish pondered; “at least when he’s with mum and dad… I know he’s safe. But when he’s not going to be with them, it’s almost I would rather him be with me”. Similar to Cynthia, his willingness to offer himself as primary carer centred on safety, yet this offer presents an interesting conflict; in the previous sub-theme Hamish did not wish to seek involvement in Michael’s future care planning placing responsibility firmly with the parents, yet the above statement suggests that Hamish may not feel confident with paid (non-family) carers which may lend itself to Hamish supporting a continuation of parental caring.

In discussing the carer role and caregiving duties for Michael, both siblings tended to simplify the role tasks and minimise the impact of caring compared to their parent's reflections on their primary care roles. Cynthia repeatedly identified administrative and legal paperwork as "scary" however expressed little concern for all other responsibilities: "You just turn that routine into yours and do what you need to do". For Hamish the primary caregiving task was identified as "retaining entertainment and trying to maintain a peaceful environment". Though Hamish noted that caregiving would introduce significant change into the carer's life, this was not presented as a burden or upheaval, but rather as a matter of fact:

> You wouldn't have to worry about anything, job, you'd just stop working. You'd stop doing what you're doing. Carer's pension, you'd go on that straight away. There'd be emergency funding, savings, whatever. Just, you'd move, I'd move in, sort of from there.

These narratives suggest that through the combination of relative youthfulness of Hamish and Cynthia (in comparison to their parents), and continued separation from daily caregiving tasks, the siblings have created a more manageable version of what the primary care role looks like.

When Gail and Ken were asked their opinions regarding Hamish and Cynthia's willingness and ability to take on the demands of primary care giving both confirmed that it was not an expectation that they carried. Further to this Ken indicated that primary care may not be a role that either were prepared for:

> We hope we'll have Michael settled in supported accommodation long before we fall off the perch so that we don't have to leave that responsibility with Hamish or Cynthia. Because at the moment… I don't think they would cope if we were to hit the (clicks fingers) hit it tomorrow… They would do it, but it'd be too hard on them.

During the informal meeting process both parents described Hamish as ‘germ-a-phobic’ arguing that Cynthia would be much more comfortable with intimate care tasks than Hamish. It is also interesting to note what was not discussed, for example neither sibling mentioned any experiences with sleep-overs with Michael either in the parent’s home or sibling’s home, further supporting the notion that they were predominantly removed from any involvement in care tasks. In fact sibling interaction with Michael, particularly within any care role, appeared minimal with siblings admitting that the parent’s preferred formal care organisations rather than burdening the siblings with this responsibility.

Journey to External Care

This main theme illustrates the family’s extended preparation for, and experiences with, future care planning and available options. Considered planning and early preparation are prominent in the parents’ narrative despite a lengthy wait for appropriate accommodation to become available. Responses to planning options, including attitudes towards institutional care, are also considered within the three subthemes: *Almost 30 years in the making, The ideal care community: We didn’t know it existed,* and *Institutional care: Never ever!*

Almost 30 years in the making.

Though Gail and Ken were yet to make a firm commitment to a specific residential care plan for Michael, they made it clear that they had never envisaged caring for Michael until one or both of them died. In fact, preparation for Michael’s future care had begun just years after his birth with Gail indicating that it was something that had always been in the “back of their minds”. Preparation for the launching stage within this family is unique in that it has been a long and deliberate process:

> That’s why when he was only two and a half I started getting him used to having other people in his life and spending that little bit of time away. So I’d start with just a couple of hours here, building up as he got a little bit older to half a day here. Then

> when he was four or five, a night away. The long term goal, having other people look after him you know.

The purpose of utilising care and respite organisations from such an early age was two-fold: Firstly, it was important for Michael to get used to being cared for by other people; and secondly, it helped Michael to adjust to separating from his parents and the family. Early preparation had already yielded benefits with Ken noting that Michael showed no signs of separation anxiety when staying in respite. As a result the parents held firm beliefs that successful planning required carers to start early and introduce change slowly: “That’s what you’ve got to do. You’ve got to plan, you’ve got to start when they’re little with a vision to the future. Just keep doing things gradually” (Gail). In this respect the parents showed no hesitation in introducing Michael to external sources of care.

Despite the parents’ narrative of preparedness, Hamish expressed concern for Michael’s ability to adjust to a residential care facility. One observation from the initial informal meeting with the family was that Gail maintained constant physical contact with Michael for the duration of the meeting (i.e., her hand rested on his arm). When Hamish was asked for his understanding of this observation he made sense of this as a representation of Michael’s “very close mum connection” suggesting that adapting to a new environment would be difficult and a slow process. It may be that perhaps Gail and Ken were able to focus on Michael’s progress and how far he had advanced in being comfortable with external services, whilst Hamish was focusing on the magnitude of the transition into residential care.

For Gail and Ken, consideration for Michael’s future planning also meant “keeping eyes open and ears to the ground” for information about options and opportunities. They were proactive in seeking out information, though interestingly rarely spoke of this information coming direct from government bodies. Rather, a series of both informal and formal networks provided information and support: Gail talked with other parents, attended workshops, seminars, and conferences, and utilised the knowledge of those from community based organisations. It was this approach to seeking out information themselves that led Gail to discover a promising residential care opportunity for Michael. Care planning information may therefore not be readily available through traditional or expected sources, but rather families may require a degree of dogged determination, as demonstrated by Gail and Ken, to seek this out for themselves.

A specific time frame for Michael's move into supported accommodation was not apparent and a time line did not appear to form any part of the many years of planning. Rather as the years progressed Gail and Ken tended to become more aware of the impact of caring reflecting on how long they believed they could continue to endure the primary carer roles:

> Ken: "the older we're getting, it's getting more and more… worn down. I can't see us still doing it when we're 80."
>
> Gail: "No."

As physical decline and psychological exhaustion increased, time was becoming the critical factor in planning. Both parents spoke of "depleted energy", feeling "wiped out", and increased tiredness that affected their ability to "keep absorbing all the emotional hits". It was this sense of reaching the end of their capabilities as carers that was increasing the need for a timeline and end date on these taxing roles.

The ideal care community: We didn't know it existed.

Despite all the early preparation for Michael's future residential care, locating an appropriate residence proved difficult for Gail and Ken. The family described options as limited, particularly with consideration given to Michael's high care needs and behavioural challenges. Cynthia recalled just one prior opportunity for supported accommodation in a town that was a four hour drive from Michael's home. This was immediately deemed to be "out of the question" due to distance and disruption to Michael's routine.

Difficulty in finding a suitable accommodation option for Michael initially led Gail and Ken to believe that they would be forced to consider public or self-managed housing options. The idea of pursuing either of these options left Gail "feeling a little bit overwhelmed". Yet, despite these options being deemed less favourable they were not viewed as unacceptable as a last resort. In this sense, having time to plan afforded parents greater choice in care options, whereas a narrowing timeline lessened the choice as the priority turned to actioning any available plan in order to avoid burden of care falling on other family members.

For Gail and Ken, they were seemingly saved from the 'forced option' of public or self-managed housing by a chance discovery of a new supported accommodation development via an advertisement in the local newspaper. For Gail, finding a "fit" for Michael was met with a wave of emotional relief:

> I drove home saying thank you lord, thank you, because to me, I just felt as if, I couldn't believe what I was hearing from these people…When I got home I said to Ken 'Oh my God, wait till I tell you what I've just heard' I was so excited.

Yet despite initial excitement, Ken expressed cautious optimism, demonstrating a reluctance to fully embrace the possibility of a positive outcome until it became more tangible.

Should this new community development eventuate, it would allow for Michael to live either independently or with one other person in a home that was purpose built for the client's needs. Reasons for viewing the project as an ideal option for Michael included the organisation's acknowledgement and support of the transitional process, staff training, additional on-site care (e.g., qualified registered nurse), the values of the organisation (Christian values), and community interaction.

Cynthia supported her parent’s views describing this option as “promising”. She too expressed enthusiasm towards the organisation’s approach to transitioning, and placed importance on similarities between the organisation’s core values and her family’s values, indicating that this provided “a really big comfort”. As safety had previously been highlighted as a concern held by the family it was unsurprising that Cynthia, like her parents, indicated that she was positive about the organisation’s approach to staff training, referring to this as “amazing”. She also acknowledged the role of community, though Michael may live independently his relationships with those around him was seen as a significant positive aspect of this residential option. Interestingly, though Hamish agreed that supported accommodation would be ideal, he appeared unaware of the new development, or was not forthcoming with this information at the time of the interview.

Though the importance of transitioning was a common theme throughout all interviews, one interview provided a unique perspective on viewing residential transitioning as holding much greater meaning and opportunity for Michael than a physical shift in residence. Whilst all family members positioned Michael as (or like) a child, Cynthia acknowledged that her 27-year-old sibling was simultaneously ‘an adult’ and that as such this accommodation option would provide him with “his own little bit of independence, his own place that will be Michael… with the things that he loves”. For Cynthia, Michael had witnessed his siblings develop into adulthood through typical milestones such as leaving home and marriage, it was therefore important to her for Michael to have the same opportunity to live “as an adult… having adult brother and sister kind of be around and visit and just kind of hang out”. In addition to seeing opportunities for Michael outside of the family home, Cynthia further reported that Michael was “babied” by his parents, suggesting that perhaps the home environment did not allow Michael to reach his full potential. Cynthia’s vision for both Michael’s personal growth, and a stronger bonding of sibling relationships is somewhat contrasting from Hamish's narrative that positions Michael's future as one predominantly involving maintenance of his current level of development.

Institutional care: Never ever!

All family members were firmly opposed to any sort of institutional care for Michael, often judging this option based on historical 'horror stories', whilst admitting that their knowledge of present-day institutional options was limited. Though admitting that contemporary institutional care settings "would be highly different" sibling language surrounding discussion on institutional care suggested that it was viewed as a form of abandonment and a failure of parents and families to fulfil their responsibilities. For example Hamish reflected:

> A life isn't, it isn't a commodity, it isn't like a bottle of milk that's expired. You can't just throw it out… Don't know how people can do that, they probably shouldn't be having kids yeah.

Cynthia similarly used the term "throw him in an institution", confirming that it was viewed as action taken without appropriate care and consideration for the individual. Hamish's responses further suggest that his understanding of institutions was that those in institutions were isolated from family members, he refers to these children as "never knowing a mum or dad", his language suggesting these individuals were essentially orphaned.

Parent and sibling concerns for institutional care generally reflected historic reports of neglect and abuse. Gail's and Ken's concerns were accentuated by the fact that as Michael was non-verbal he would not be able to tell anyone about any instances of abuse, and may instead react by physically hurting someone. Similarly, Hamish suggested that Michael's inability to communicate might lead an institution to "drug him up and put him in a straight-jacket". This concern regarding the misuse of medication was supported by Cynthia who reported that it was "a huge thing" in institutional care. Whilst Cynthia admitted that she was unaware if institutions still existed, she equated this kind of care to nursing homes, stating that "unsettling things [go] on in there", drawing further parallels between older adults whose communication may be impaired by dementia and her own brother's limited communication. Hamish's concerns also reflected the idea of abandonment, with Hamish further suggesting that if Michael were institutionalised he would not have someone around him who loves him. Notably Hamish remained focused on the parental decision involved in this option more so than any systemic issues, describing those who chose institutional care as "selfish" and "greedy" for wanting to live a life free of the burden of disability. This again emphasises the strength of Hamish's beliefs regarding parents' moral obligation to provide primary care.

Despite such strong opposition to institutional care, as discussion on this option developed individual views tended to demonstrate acceptance and to some extent support for institutions. Though Ken indicated "there's still a place for it", he and Gail remained firm that institutions would only be appropriate for more "extreme" cases than Michael's, those identified as "not being capable of being normalised". Gail further highlighted that rich meaning and negative evaluation were intrinsically linked to the word 'institution' and therefore such housing options should be renamed in order to create new associations and meaning making. In accepting the need for institutions Hamish again remained focused on parental care, suggesting that institutional care would be appropriate in cases where parents were incapable of caring, or where he believed that the responsibility for the pregnancy did not fall on the parents (e.g., circumstances such as rape).

Our boy: A risk and at risk

The theme *Our boy: A risk and at risk* consists of two subthemes that highlight the family's foremost concerns relating to future residential planning for Michael. The first subtheme, *Our "gentle giant" could hurt someone*, describes concern that stems from within the family (i.e., Michael's behaviour), whilst the second subtheme, *It's not babysitting*, discusses concern originating from external sources (e.g., caregiving staff).

Our "gentle giant" could hurt someone.

The primary concern for both parents in relation to Michael's current supports and future residential care was not for Michael's personal safety but rather that of others, fearing that Michael may cause harm to another person. Though Michael was described by his family as "placid", "affectionate", "easy to be around" and a "gentle giant" (reflecting his size of over six foot and 120 kilos), Gail, Ken, and Cynthia also described a history of challenging behaviours leading to violence; all of which began when Michael was an adolescent. Ken referred to these as "meltdowns" which were so aggressive that during Michael's adolescence Gail and Ken were "fearful that he could kill [them]". It is unsurprising that this discussion drew a strong emotional reaction from both parents who became visibly upset during this portion of the interview. Cynthia confirmed that there had been occasions where police had been called to assist with restraining Michael from injuring his family.

In discussing Michael's future care it became apparent that his behaviour had already impacted significantly on his existing support program. Repercussions included support workers refusing to work with Michael, the severing of a relationship with one particular respite centre, and a current community care model that required Michael to have two male support workers at all times. Though Michael's meltdowns had reduced through the combination of a medical intervention and a positive behaviour plan, this behaviour still presented challenges and possible restrictions for future planning, particularly share accommodation options. Gail and ken admitted that other clients may not want to live with Michael, or if noisy or boisterous in nature, these clients may in fact trigger Michael's meltdown.

To minimise instances of these behavioural meltdowns Gail and Ken emphasised the importance of controlling the environment, which again imposed restrictions on residential options. For example, they discussed their concerns with any future residential plan that would involve social housing provided by the government, or as Gail described it "one size fits all" housing because external stimuli such as noisy neighbours could not be controlled for and may trigger a meltdown. Hamish further emphasised the importance of Michael receiving the right care to ensure meltdowns were minimised, for example care that ensured his medication was routinely taken. Hamish tended to draw again on his historical knowledge of institutional care, concerned that if Michael hurt someone staff may react negatively, or punishingly, by "lock[ing] him in a cell or something, a padded cell".

The importance of having to control Michael's environment also added to Gail's and Ken's experience of emotional exhaustion. The metaphor of "walking on eggshells" (Gail) was used to describe the constant consideration required to maintain a calm environment at all times. Interestingly, community care (when Michael was outside of the family home) did little to ease this emotional strain, with Gail also using the metaphor of being "on tender-hooks" each time Michael was in supported care for fear that he would have a meltdown and harm someone. Ken appeared visibly distressed and almost tearful during the interview when discussing the possibility that Michael could hurt someone. Gail also appeared in a hypervigilant state and at one stage during the interview froze when an alarm went off in the house, stating "see my reaction?" as she processed whether the noise was an alarm or a potential phone call from Michael's care agency. It appeared that whilst Michael's behavioural issues increased the need for future residential care at the same time these issues added to the complexity of finding a suitable environment.

Though Michael's behavioural issues were noted by his siblings, neither sibling indicated that Michael's behaviour was a major contributing factor in finding suitable residential accommodation. In fact, Hamish tended to minimise Michaels' behaviours, describing these events as “little blow ups here and there”. As the target of many of Michael's adolescent meltdowns, Cynthia was aware of the extent of Michael's behavioural issues, yet similar to Hamish she did not identify behaviour as relevant to future planning.

It's not babysitting.

This theme highlights the family's frustrations and concerns with service providers, in particular the training of support staff, along with frustrations with government systems that require constant negotiation in order to access funding and support.

Appropriate training of support or care staff was noticeably a major concern for each family member. This concern did not reflect specific organisational standards but was identified as an industry wide issue, with Hamish suggesting “the whole industry could be overhauled”. Interestingly across all three interviews family members used the term “babysitting” to contrast the attitude of an incompetent support worker with one who was appropriately trained and understood the seriousness of the role. Though Ken emphasised the need for “basic training”, Hamish drew comparisons between support worker qualifications and other care occupations such as nursing, suggesting that if the industry wanted to attract people who took the role seriously then prerequisites needed to be increased. The family's overall concern for a standardised staff training model further explains the emphasis placed on the supported accommodation option where training was delivered in a controlled, in-house environment.

Frustrations with staffing also appeared to arise from the industry climate at the time of the interviews. The NDIS was in its fifth year of roll-out, with many in the local area (including Michael) experiencing either their first or second plan with the NDIS. Gail and Ken blamed changes associated with the NDIS for creating a “revolving door” environment where experienced support workers were leaving established organisations to pursue careers with new start-ups. Hamish also believed too many people were coming into the industry who “just needed a job”. Reasons for wanting to be a support worker were also linked to the family’s perceived quality of care. It appeared that doing the job “for the right reasons” (Ken) would equate to a client receiving “genuine care” (Hamish).

Despite staffing being a source of frustration for Gail and Ken, and a source of concern for Hamish and Cynthia, all family members acknowledged that Michael had experienced good staffing and good care. Even in recounting a life threatening incident when Michael was in respite and swallowed another client’s medication, Gail and Ken described this incidence as a “very rare occurrence”, indicating that overall they were happy with the support workers. Despite the parents’ admission that Michael’s care was positive, Hamish believed that concerns regarding Michael’s quality of care were the “black clouds rolling around in mum and dad’s head right now”.

NDIS: Problematic but Promising

This theme illustrates the contrasting experiences with Australia’s National Disability Insurance Scheme (NDIS). Despite the parent’s personal difficulties with the system, this theme reveals that overall the family remained positive to the possibility of promising outcomes under this scheme.

Across all three interviews family members aired their frustrations with the introduction of the NDIS. Far from a smooth transition, crossing over to the new NDIS system had for many families meant starting from the beginning:-

> Everyone’s spent a lifetime getting to where they are, let’s overhaul the system and get rid of [state disability support] and this one and that one. Well that’s all good and well in the long run for funding, but in the meantime we’ve now got caseworkers and interviews and friggin 50 form pages of paperwork and medical files we’ve got to submit, and that’s where families are going ‘this is bullshit’. (Hamish)

In addition to these “teething problems”, Gail and Ken also expressed concern with regards to changes in organisational focus, indicating that agencies had steered away from “a service model and moved into a financial model”. In their opinion, agencies pursuit of the “big bucks” resulted in a loss of family and client focus, overridden by the desire to make money. As previously discussed under the theme ‘*it’s not babysitting*, this new money model had created flux in the industry leading to instability with support worker staffing, an event which Gail described as “disconcerting for families”.

Yet despite their difficulties with the new NDIS system, the family viewed these issues as only temporary, holding onto hope that it could bring positive change to the disability landscape in Australia. Though Gail and Ken recognised that the NDIS had created a financial focus in organisations, the care philosophy behind the NDIS was applauded by parents and siblings alike. The family believed the NDIS had led to easier funding and greater flexibility and choice with care; some of these outcomes Gail and Ken believed they had already begun to see. The family also expressed a willingness to be patient while “the creases are ironed out”, understanding that the NDIS represented significant change requiring give and take from all involved, but ultimately believing that “in the long run… the funding will be better for everybody”. For this family in particular the success of the NDIS was inextricably linked with Michael’s new opportunity for supported accommodation. Ken viewed this opportunity as only possible “because the funding is there for it”, whereas prior to the NDIS clients such as Michael faced long waiting lists or had to rely on their own funds.

Summary

The master themes presented in Case 2 embodied congruent experiences across all family members, as well as identifying divergent experiences and understandings, as exemplified in the main theme *It’s not up to the Siblings*.

The findings highlighted some of the difficulties facing individuals in navigating family life with a child with complex disabilities. This included parent’s interactions with other typically developing children and determining the appropriate level of involvement for siblings to have in future planning. As demonstrated in these findings, there was no one-size-fits-all solution regarding appropriate levels of sibling involvement with each sibling viewing their role, and their parent’s role, differently within the family system. It was clear that despite a willingness to accept the primary care role for their brother, siblings did not consider this option likely, nor were they encouraging their parents to pursue sibling care.

Parents’ long-term dedication to planning preparation was evident. However, transitioning was complicated by availability of suitable local housing options and concern that Michael’s behavioural difficulties would lead to harm of others. All family members also expressed dissatisfaction to some degree with the current care industry with lack of appropriate staff training identified as a primary failing. Despite negative experiences and ongoing concerns with both the care industry and government funding, the family remained hopeful that the NDIS would offer improved lifestyle opportunities for individuals with disability and their families.

The following Chapter 11, presents further qualitative findings from Case 3.

Chapter 11 – Case 3 Findings

The findings from Case 3 are presented in this chapter and relate to 23 year old Nathan (adult with intellectual disability [ID]), his mother Michelle, father Rob, and only sibling Luka (aged 26). The family in Case 3 was different in structure compared with Case 1 and 2, in that Nathan had only one sibling. Nathan's sibling Luka was also the only sibling across all three cases to be interviewed over the telephone, rather than in person. Though it may be more difficult to build rapport via telephone Luka's responses appeared unfiltered (e.g., suggesting his father disagreed with his mother) and reflective. In fact, Michelle (mother) revealed that upon completion of the interview Luka had shared with his mother that during the interview, reflecting on his childhood with Nathan had been an emotional experience. Whilst this does not confirm the existence of rapport, it does suggest that Luka engaged in the interview process openly and unreservedly.

As with the previous two cases, main themes focused on the sibling role, planning process, care concerns, and experiences with the National Disability Insurance Scheme (NDIS). The largest main theme, *Initial steps to future planning*, is also the only main theme featuring sub-themes. Various stages, and approaches to Nathan's care planning dominated discussion as reflected in each of these sub-themes. Themes are presented below in Table 11.1, with representative quotes for each main theme, or subtheme.

Table 11.1

Case 3 Themes

Main Theme	Sub-theme	Representative quotes
Romanticising the Sibling-as-Carer Role		“I probably do romanticise it a lot more than I ought to” (Luka)
Initial steps to future planning	Professional encouragement	“I think, she [psychotherapist] wants to help Nath through… from an emotional perspective… She was one of the positives that came out of that” (Michelle)
	Nathan’s needs: A matter of trial and error	“Where mum's thought process is coming from like we at least need to give it a try” (Luka)
	Tossing around ideas or sole decision maker	“I think he just trusts me and if I say to him look this is what, what do you think? And he’ll either go yah or nay” (Michelle)
	Institutional care: It’s a firm “no”	“That's not something that I would allow to happen to my brother” (Luka)
Compatibility of carers		“There were times the wheels did fall off but it was just a matter of that person didn't know Nath and Nath didn't know them and it just didn't work” (Luka)
There are two sides to the NDIS- The problems and the possibilities		“at the end of the day the whole NDIS thing has changed the dynamics of that industry” (Rob)”

Romanticising the Sibling-as-Carer Role

The family constructed two ways of viewing the role of sibling as primary caregiver. This theme describes the romantic vision held by Nathan’s sibling Luka, versus the parents’ understanding of reality.

Despite Luka being at an age of transitioning from emerging adulthood (typically considered 18-25 years) to early adulthood, he admitted to “romanticising” the role of sibling as carer and expressed a desire to “give it a try”. However, Rob and Michelle indicated that Luka’s understanding of the role was an idealised version removed from the reality of what caregiving would actually involve. Michelle described any offer from Luka to take on this responsibility as a “loving gesture” however preferred Luka to adopt a role as “overseer” or advocate, rather than primary carer. Rob, suggested that a primary care role would “cramp [Luka’s] inner city lifestyle” with both Rob and Michelle joking that if Nathan went to live with Luka he would “end up in the river”[3]. It appeared that parental concerns did not centre on sibling capabilities, but rather recognition that the lifestyle chosen by Luka, or indeed the developmental period of emerging-early adulthood was not conducive to a care role.

Despite Luka “romanticising” the caregiving role, when asked if he had ever taken on this role for respite or any other short-term arrangement (e.g., for a day or weekend), he replied “not at this stage”. Luka further indicated that he felt “a bit too far removed these days from what makes him [Nathan] tick”. Luka further confessed that even during weekend visits to his family home there was more he could be doing to help with the care of his brother, but believed that this was a time for him to “have holidays” from his life, suggesting that it was not a time to be burdened by care tasks.

Regardless of the “wouldn’t it be lovely” version of Luka’s romantic notions of caring, he did not appear to be completely naive about how affected his life would be by the

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[3] Luka resided in an apartment block adjacent to the city’s river

role. He indicated that such a task "would have massive impacts", recognising that things such as regular travel "would have to stop", and in addition Luka would lose his ordered and organised lifestyle. Yet despite the anticipated upheaval, Luka indicated that taking on this role as primary carer would allow him to "feel the best" in himself because he viewed this as "making a decent effort rather than taking the easy way out and sort of going - you go over there where my life doesn't get impacted". The fact that Nathan was Luka's only sibling also seemed to heighten his desire to support his brother saying "it's only ever been the two of us… he's the only sibling I've got".

Luka did however recognise that his parents were less expectant of him to take on the primary care role. He had discussed his romantic vision of future care with his parents only to be responded to with a knowing parental "smirk" from his mother Michelle. For Rob and Michelle they respected that their son had a "good career" and enjoyed travelling, therefore did not expect or desire Luka to immerse himself in caregiving for his brother. Their main concern was that Luka would be there to monitor and control Nathan's financial wellbeing, and ensure that "everyone's doing the right thing by him".

Despite some disagreement regarding expectations of sibling care no family members reported any strain on relationships due to this disagreement. In fact, as the primary care role restricted the parents' ability to take extended or international holidays together, Luka partnered his mother on several domestic and international travel excursions. Though the parents framed this as a practical solution, Luka tended to view this as making up for holidays missed out when he was younger.

Initial Steps to Future Planning

This theme illustrates the steps taken by the family in planning for Nathan's future care. External intervention had caused the parents to consider launching with the intention to incorporate their attitudes of trial and error towards a residential plan that could adequately meet Nathan’s care needs. Though there was clear communication between both parents, decisions appeared largely driven by the mother. The steps to planning consisted of four sub-themes: *Professional encouragement, Nathan’s needs: A matter of trial and error, Tossing around ideas or sole decision maker, and Institution care: It’s a firm ‘no’.*

Professional encouragement.

The planning process for Nathan’s future residential care was in its relative infancy with family discussions occurring as recently as a week prior to the interviews. The impetus for activating discussions and research appeared to have come initially from the professional intervention of a psychotherapist. In preparing a report to the NDIS, Nathan’s psychotherapist had recommended to Michelle that planning should be approached as a 12 month goal, to which Michelle responded “no two years… that’s a mummy thing”, indicating that she needed a little longer to feel comfortable with the launching period. Rob supported this as a reasonable time frame due to practical reasons (i.e., the structure of the NDIS would require that Nathan’s goals be submitted at an annual review in order to adjust his funding package).

Though encouraged by the psychotherapist to commence planning, Rob and Michelle were also acutely aware of the dangers of not planning. Rob recounted a story of an elderly family friend who cared for a son with a disability; “You know if she departs tomorrow, you know there’s just, there’s just no preplanning or thought there, so yeah”. This demonstrates that for parents of adults with ID, launching can be a transitional period linked not only to the development of the adult with ID, but also the mortality of the parents. Rob’s involvement on the board of a local care organisation also exposed him to incidents where emergency care plans had to be enacted for individuals who could no longer be cared for within the family home, this appeared to impact upon his views regarding the importance of care planning and further act as a motivator to commence the planning process whilst both parents were still in their 50’s. Michelle also indicated that part of the importance of early planning was so that she and Rob could help Nathan “through those changes, instead of getting too old and ill that we can’t”.

In contrast to Rob and Michelle’s desire to commence planning early, Luka did not view Nathan’s future planning as something requiring urgent action. Luka saw his parents’ relative youthfulness and good health as indicators that they were capable of providing many more years of caregiving within the family home; “I mean they’re both only in their 50’s so they’ve got plenty of go left in them yet”. Thus, residential accommodation outside of the family home was not understood by Luka to be part of Nathan’s progression into adulthood, but a step taken at as necessary point in time when caregiving at home was no longer a viable option.

Nathan’s needs: A matter of trial and error.

All family members acknowledged that Nathan’s current care support had involved a period of trial and error, where support programs had been extended and then “pulled back” where necessary in response to a decline in Nathan’s wellbeing. Michelle described this as “constantly evolving” both as a result of the NDIS and in response to Nathan’s needs. The ability to adjust and change supports for Nathan seemed to reflect a general “trial and error” approach adopted by Rob and Michelle. This same approach appeared to guide their efforts for residential planning with Rob stating “at the end of the day, it’s one of those things, if it works, it works, and if it doesn’t well, rip him out”.

Previous trial and error outcomes with supports and respite also guided their understanding of what would be most successful or difficult in relation to future care planning. For example Michelle spoke of Nathan’s struggle in transitioning from the school environment to community care. Michelle acknowledged that little changes like where to place a lunch box was a big adjustment for Nathan, with his neurological health suffering due to the stress of this new environment. The level of change that Nathan would face in residential transitioning was therefore carefully considered when future planning. Rob and Michelle acknowledged that Nathan was “quite well known… around town” and it would therefore be best to “keep him in that environment” rather than “rip his whole world out from underneath him” (Rob). For Rob and Michelle this meant denying themselves a retirement by the beach in order to remain close to their son.

Both Rob and Michelle also believed that Nathan would be best sharing with one or two other people. Michelle suggested that if it was “any more than two… that would do Nathan’s head in”, suggesting that he would not cope psychologically in a group home environment. This conclusion appeared to reflect Nathan’s previous experience in both community care and respite care; Rob indicated that the group environment of certain community care organisations “was starting to stress him out big time”. Michelle also described Nathan’s experience in respite as a time “where the wheels have fallen off” due to the environment being “too busy, too noisy” for Nathan.

Luka agreed that Nathan would be best suited to living with a maximum of one or two others, but stressed that they would have to be “very, very carefully selected”. Though Luka also conceded that routine was important for Nathan and that he “likes to recognise his surroundings”, when discussing residential accommodation Luka indicated that if Rob and Michelle were no longer around he would prefer Nathan lived in the same city as him. Rather than a reflection of Nathan’s needs, this tended to reflect Luka’s self-awareness of his own behaviours stating:

> I don’t think that it would really fit very well with me having him say me living down here and him in [current town] by his own. Because reality and life gets in the way and you know for the first couple of months I’d be really, really vigilant with the visits and if he was doing ok I’d probably get slack.

Luka's vision of reality here is somewhat contrasting to his romantic notions of caring as discussed in the theme *Romanticising the Sibling-as-Carer Role*.

Tossing around ideas or sole decision maker?

Though all three family members (Rob, Michelle, and Luka) were actively engaged in discussion, it appeared that any planning would be driven by Michelle. Michelle was the self-appointed manager of Nathan's current care and clearly dominated the decision making. Even at times when Michelle had been away and Rob was primary carer, Michelle still managed Nathan's supported care from afar and dealt with any care-related issues that arose. Similarly it appeared that Michelle would manage Nathan's future care planning, with her suggesting that both parents had defined primary roles within their relationship:

> You see I, because I've handled Nathan's, a majority of Nathan's, the decision making on a day to day basis, I think Rob, it's sort of good that he is on board now, but I think he trusts my judgment a lot of the time too. And see I trust his judgment with other things in our relationship.

Michelle's dominance in the area of caregiving was supported by Luka, who described his mother as "very much the leader" whilst his father had taken on the role as "bread-winner". He further indicated that he did not believe his father "would be capable of being the primary carer for Nathan" despite Luka believing that his father would be willing to take on the role. These dynamics within the family appeared to stifle honesty in family discussions around planning. Luka for example spoke of reservations that he held in relation to the potential long term success of any residential accommodation outside of the family home:

> Just knowing what Nathan's like and all he's ever, the only home he's ever lived in is my mum and dad's house. He's, probably he is most at peace when he is in that house… That's all he's ever known. (Luka)

Luka had not discussed these reservations with his parents, but believed that his father might share his views suggesting that Rob was “just sort of resolved to like well if he has to live with us for the rest of time then so be it”. Though Rob and Michelle gave no indication of parental disagreement during their interview it was observed that Michelle tended to dominate the answering of interview questions with Rob focusing on, or at times distracted by, the arrival and departure of Nathan as he meandered into and out of the interview setting. Luka indicated he had previously had conversations with his father on subjects that Rob “wouldn’t have the balls to have [these conversations] with mum”, thus suggesting that it was unlikely disagreement or reservations about plans would be aired during the interview.

Institutional Care – It’s a firm no!

Considering that past experiences had indicated to the family that Nathan’s wellbeing is best suited to smaller groups or one on one care it is no surprise that no one in the family supported institutional care as an option for Nathan. Though the group environment formed part of this argument, the historical aspect of institutional care was also raised.

Rob had a personal connection to past institutional care admitting that his father had been a male nurse at a psychiatric institution. He referred to institutions as being a place where historically patients were “just fed drugs” and exposed to bullying, manipulation, and abuse. Michelle likened group homes to “small institutions” referring to these homes as having the same “institution mentality” and hence reinforced her opposition to large congregate living options. Luka acknowledging that he could not comment on current institutional policy, but that his views were formed by stories from the past stating “that’s not something that I would allow to happen to my brother”.

Compatibility of Carers

The family acknowledged that in the past Nathan had experienced difficulty with finding compatible carers and this was a primary concern with future care planning. Though the family indicated that there had been several issues with carers and care organisations in the past, the blame was not singularly placed on the organisation. All family members admitted that Nathan could be challenging with Rob describing him as “obnoxious” at times. Luka further indicated that if things did not go Nathan’s way “he’s definitely got a funny way of showing it”. The family tended to take a light-hearted approach to this, embracing Nathan’s personality. Luka for example reported finding Nathan’s actions “hilarious”, though he described occasions when Michelle had to be called in to “referee the situation”. Whilst the family found it difficult to articulate what would make a carer compatible with Nathan, Michelle described incompatibility with staff and fellow clients as her “biggest fear” in transitioning Nathan into residential care outside of the family home.

Problems with care organisations however did not simply stem from compatibility issues, reliability was also another major factor. Michelle recounted that staffing issues could have a significant impact on her day if she received a last minute phone call from a care organisation to inform her “can’t get any staff to fill the shift today”. She believed that this was a common issue amongst families and found it frustrating that staff were not reliable and not always of a standard she expected:

> You know I’ve had guys come here … and they haven’t even been able to speak English. And I’ve had to write down now you go, I’ve had to write his schedule … And Nathan looks at them as though …

Michelle uses this last line of narrative to emphasise the paradox of sending her non-verbal son out in the community with a non-English speaking carer.

Additionally, Rob also told of a time when Nathan had become separated from his carer whilst in community care. Though troubling for the parents that this had occurred, the resulting actions of Nathan, who located a shop assistant and identified his father by way of a business card in his back pocket, demonstrated that Nathan had a level of awareness that Rob and Michelle may not have previously recognised. Thus, the outcome provided Rob and Michelle with confidence in Nathan's ability to problem solve in that situation, yet also confirmed for them the importance of Nathan remaining in a familiar environment.

The ongoing issue of finding and keeping reliable staff appeared to be an industry wide issue with Rob indicating that organisations were "struggling to get staff to fill shoes". In discussing the options of Nathan moving into housing run by a care organisation versus private housing (e.g., Nathan purchasing his own home), the ongoing battle to find and keep staff was identified as a "catch" to parents managing the care, whereas if the care was run by the organisation staffing becomes "their problem". The decision whether to "take a step back" or remain the primary decision makers in relation to all aspects of Nathan's care appeared unresolved at the time of the interviews.

There are two Sides to the NDIS: The Problems and the Possibilities

Nathan had been receiving funding through the NDIS for almost two years. This theme illustrates the family's experiences of frustrations and difficulties, as well as direct benefits to Nathan's care across the two years of NDIS involvement.

Initially, Nathan's transition to the NDIS model was described by his parents as easy, leading to a fantastic first year funding package. However, in the second year Nathan's funding was cut resulting in Michelle and Rob appealing the package. Both parents remained confused over why this had occurred:

> This was the thing that really annoyed me was nothing had changed, absolutely nothing had changed except for, I believe the people who handled the second one need a good swift kick in the arse. (Rob)

Michelle suggested that there were instances of “trickery” with the way the NDIS made enquiries into care and reported that NDIS staff had admitted “they had L-plates on”[4]. Luka admitted knowing little about the NDIS simply because it did not interest him, however from his parents he had gained the impression that the NDIS had been “quite tedious, stressful, and draining”.

Despite these difficulties Rob and Michelle also acknowledged that NDIS funding had provided the opportunity to change Nathan’s routine to a larger amount of one on one care, and also become more goal focused in his development. Whilst an individual’s NDIS funding is often managed by a third party care organisation, Michelle had decided to manage Nathan’s funding herself. She described this as the equivalent of “running a small business”, however this gave her the freedom to change and “tweak” Nathan’s care hours and routine at a pace that suited Nathan. In addition Rob and Michelle were able to discuss future possibilities for Nathan such as going on a two night supported holiday. NDIS funding was also pivotal in relation to Nathan’s future residential care. Funding for Nathan’s care would come from the NDIS, in this respect planning had to be linked with Nathan’s package which meant pre-planning to ensure the funding would be included in their annual review.

For Rob and Michelle, the NDIS was clearly a mixture of problems and possibilities. The impact of the NDIS went beyond the individual with Rob admitting that it had “changed the dynamics of the industry”. Rob believed this resulted in professionals viewing caregiving as a “money making venture” which led to the industry being flooded by “new players” all trying to attract staff. Rob and Michelle indicated that this had increased staffing issues with the established care organisations that they were using at the time of the interview. Yet

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[4] L-Plates is a reference to ‘learner’ plates as in the initial license given to someone who has just obtained a driver’s license and is learning the process.

despite these issues, Rob and Michelle were willing to view these as difficulties that would "settle down" with time and patience.

Summary

This chapter presented qualitative findings from Case 3. Uniquely, parents in this family were the only parents across all three cases to indicate a specific time frame for the residential care planning of their son (2 years). Parents were also the first to indicate that an external source (i.e., professional psychotherapist) had encouraged them to set care planning deadlines. As such themes tended to revolve around the steps involved in, and concerns for, locating suitable accommodation outside of the family home.

Similar to Case 2 there was also a degree of conflict between Luka's romantic views of becoming his brother's primary carer, versus the parents' understanding of reality. However, in contrast to Case 2 these conflicting expectations did not appear to impact upon family relationships.

In this family the primary care role was clearly dominated by Michelle who had taken control of Nathan's care package and made a majority of decisions surrounding his day to day care. Current approaches would also be adopted in future care, that is, Michelle would dominate the decision making with acceptance that a trial and error approach would be needed. Past experiences also influenced future care planning with recognition that group environments negatively impacted Nathan's psychological wellbeing. His vibrant and yet sometimes "obnoxious" demeanour also created some difficulty in finding a good-fit with carers, as did the quality and reliability of staff in general.

Experiences with the NDIS were varied, with a disappointing second year funding package leading the parents launching an appeal. Upheaval within the industry had also created instability and frustration, yet despite experienced difficulties, the NDIS provided

Nathan with new possibilities for goal setting, including the opportunity for his residential care to be funded exclusively by the NDIS.

Chapter 12, presents a cross case analysis of data gathered from all three case studies.

Chapter 12 - Findings From Cross-Case Analysis

When reporting multiple cases, Yin (2014) indicates that a cross-case analysis can improve robustness of findings. This chapter provides an opportunity to review coded data from the three case studies within a family systems framework to explore congruence and divergence within specific family roles (e.g., parent/sibling) as experienced by members in each case study. As such, attention turns to the familial role as a sub-unit within each case, in addition to the overall family unit (Yin, 2014). For the convenience of the reader, previously presented information about the families and individual roles within the family system is repeated in this chapter (see Table 12.1). A table of roles and themes associated within each sub-unit (role) follows with representative quotes for each theme (see Table 12.2).

Table 12.1

Family Characteristics for Each Case

Case	Pseudonym	Age	Family roles
1	Kylie	66	Mother/wife
1	Jess	41	Sister/daughter
1	Christian	37	Brother/son with ID
2	Gail	66	Mother/wife
2	Ken	65	Father/husband
2	Hamish	34	Brother/son
2	Cynthia	31	Sister/daughter
2	Michael	30	Brother/son with ID
3	Michelle	55	Mother/wife
3	Rob	54	Father/husband
3	Luka	26	Brother/son
3	Nathan	23	Brother/son with ID

Table 12.2

Themes of Cross-Case Analysis

Roles	Themes	Representative quotes
Parent	Trauma of post-school transitioning	“That was a very traumatic time for him… because he left school just the day before he was eighteen. And we just didn't realise when, when they're non-verbal it's really hard to… get a handle on exactly what's wrong”. (Kylie)
	Respite, what respite?	Ken: What the issue is all about is the fact that a parent cannot go away- Gail: To get total respite Ken: Well cannot go away being fully freed of anxiety about what's happening.
	A lifetime of change	“Oh we’ve seen, yeah we’ve seen quite a lot of changes in terms of things improving”. (Gail)
	This is our lot!	“You got to take the positive out of every situation that you're in.” (Kylie)
Sibling	Expectations of future care	“I'll just build a granny flat he'll just live out the back”. (Jess)
	Gendered understandings	“At least Michael is easily entertained. You can put something on and he’s happy.” (Hamish)
Family	Care versus babysitting	“He was a mature man that was being babysat and he knew it.” (Kylie)
Family member with ID	No two disabilities are the same	“He's quite small, so he's a lot easier to handle.” (Luka)

Parent Roles

Parent’s perspectives describe the impact of past experiences on current decision making and future planning by parents. Parents highlight the importance of these experiences in shaping their beliefs, attitudes, and emotional responses to transitioning and residential care options. Each theme addresses a particular type of experience and considers the associations made between each past experience and the future residential care planning of their sons.

Trauma of post-school transitioning.

For adults with intellectual disability (ID) living with their parents, one of the most significant life transitions is that of moving from a school environment to post school work or care. Though experiences with this transitioning process were not a major theme within individual families, the parents of each family raised the subject of post-school transitioning without being probed. The end of their sons’ schooling itself was seen as an anxiety provoking time for parents as they themselves potentially faced a significant change to their carer role should funding for external care not be readily available. Parents also lost all support from the education system and government in respect to their sons’ future education and care with Gail stating:

> Once your children finish at this school and walk out that gate we are no longer responsible for having any input into your child's educational future or programs or anything. You walk out of that school and you go to agencies.

In the event that funding for external care was readily available, adjusting to this major change from a structured and controlled school environment to a community care environment was also difficult for the sons to manage. In particular, Michelle and Kylie indicated that this process led to severe psychological distress for their sons.

Despite schools and community care organisations offering some form of transitional support, the gap between a structured schooling system and a less structured community care environment presented significant challenges with transition deemed overwhelming for Nathan and Christian. In the year following Nathan's senior year at secondary school, Michelle described the impact on Nathan's wellbeing:

> Neurologically he was a mess… Nathan's neurologist was quite concerned about Nathan because he thought that he was borderline anorexic and also he felt that there was too many staff changes, too many changes.

Similarly, Kylie discussed Christian's difficulties in dealing with a life of less structure:

> I don't know if anybody's ever written it or anything but a lot of our parents say that when they leave school, they can go to school until they're 18 right. Because they've had such structure, and they're lost, and that's where Christian's depression and anxiety started to slowly kick off … We were so lucky that we were approved for this post-school options.

Families' negative experiences with post-school transitioning were clearly powerful and impactful memories. Parents discussed this content without any direct questioning, recalling funding and wellbeing concerns both leading into and out of the transitioning process. As such, parents tended to emphasise routine, familiar surrounds, minimal change, and a very slow and measured transitioning process that could be adjusted in the event that psychological distress was encountered.

As this shift from school to post-school was the only major transitional event prior to discussing future plans for residential transitioning these past experiences appeared to have a significant impact on the parents' emotional associations. Parents lacked confidence in how their sons would adjust to this major transition, particular in the event that they could not control for environmental stressors.

Respite, what respite?

Two of the three families had years of experience with out-of-home local respite facilities, whilst Kylie (Case 1) reported only recently trialling in-home respite, with positive outcomes. For the parents of Case 2 and 3 however respite had paradoxically provided anything but respite. Major difficulties with respite services were two-fold, parents and sons had experienced issues with staffing, as exemplified in the story of Michael consuming another client's medication (see Chapter 10, *It's not babysitting*), and secondly sons had been exposed to an array of environmental stimuli (e.g., noise, client behaviours etc.) generally controlled for in their own home environment.

Ken described respite as a time when you were expected to "put your absolute trust in somebody else", the resulting experience was one where parents could not be "fully freed of anxiety" (Ken). Good staff were considered to be not just those who knew how to care for the parent's son, but those who had the skills to maintain a calm and controlled environment, that is, an environment where all clients display appropriate behaviour.

Failure to maintain a calm environment led to problematic behaviour of other clients resulting in negative outcomes (including meltdowns) for Nathan and Michael. Michelle described the noise of other clients as sensory overstimulation at a time when clients were likely to behaviour poorly because "they know they're not at home", further highlighting the importance of respite staff needing the skills to manage these situations. These environmental stressors led to Nathan experiencing peak periods of anxiety, with one particular time described by Michelle as follows: "We did hit a really, really bad speed bump and I said I think it's best if we just don't expose him to that for a little while".

The type of disability of the son and other clients also impacted the sons' experiences in respite. In particular the non-verbal nature of these sons further complicated their communication between son and staff, making it even more difficult to avoid potential triggers as highlighted in the following narrative from Gail and Ken:

> Ken: [Michael] couldn’t tell him what he’s upset about… see the trigger could have been caused by another client, but the other client may not have been able to tell them.
>
> Gail: And they had some clients up there at the time who were very, very loud… Like on top note, and perseverating over and over and over… That would have driven him crazy, and then he’d react to that sort of thing. Because he’s so big and strong he might… They were worried that the more physically disabled clients were vulnerable.

The outcome in this scenario was the discontinuation of respite for Michael at this particular facility, further emphasising the severity of impact of these negative experiences. Rob also noted that although Nathan was non-verbal, due to his “social” personality he preferred an environment where he was surrounded with verbal people, thus being able to match their sons with compatible clients was important to ensure a successful environment.

It was evident that these previous past experiences with respite had directly influenced parents’ perceptions of group home accommodation options. Neither Gail and Ken, nor Michelle and Rob viewed group homes as an appropriate option for their son. In considering a hypothetical offer for Nathan to move into a 10 bedroom house run by a support agency Rob responded “Well you’d sit there and go well no I don’t think that’s the right place”. For Gail and Ken, Michael’s behaviour created a further complication when considering a home environment with other clients: “So there’s a lot of, a lot of considerations involved. And it’s not only how it’d affect Michael, but it’s also how Michael could affect others, you know, got to look at it from both sides”.

A lifetime of change.

Parents from each of the three families had witnessed significant change throughout their lives, and throughout the lives of their adult son with ID. Parents were able to recall times when institutional care was prominent and when disability was treated differently as highlighted in the following excerpt from Gail's and Ken's interview:

"Many years ago, children like Michael would have been put in institutions and left to vegetate. They would have been, they were" (Gail). However, across decades of caregiving parents witnessed many instances of positive change. They had seen an evolution in institutional care, in disability and inclusion policy, in medical support, in social norms, and of course were now part of the first wave of clients experiencing the countries new reforms in disability funding via the National Disability Insurance Scheme (NDIS).

Parents themselves had been involved with, and at times drivers of change. For example, Kylie started the first Down syndrome support group in her region and remained involved in this support group for decades. Rob had also taken a position on the board of a local care organisation as his way of "giving back". There was a sense of personal ownership, of membership to a disability society in which everyone was responsible for contributing to and producing better outcomes; parents, organisations, and governments alike.

It is perhaps being a part of this change that has led these parents to embrace available care supports and remain positive about the future. Despite reported negative experiences with care organisations and individual staff, no parents had stopped using external support services, on the contrary in Case 1 and Case 3 there was a tendency to increase their use of services, and explore new opportunities instead. For parents, negative experiences simply meant that the care needed to be adjusted, or changed, not removed. Negative experiences were not perceived as major failings in the system, but rather instances of a) human error, or b) 'poor fit' between son and care. Though there was recognition that the current care models and care organisations were not perfect, parents persevered with confidence that positive change would continue to benefit their sons.

This is our lot!

In summarising their experiences, most of the parents tended to be accepting of their circumstances and worked towards creating a positive environment for themselves and their son. Rob for example, described their experiences as “pretty lucky” and tended to view difficulties as a “speed bump”. Similarly, Gail reflected on moments of difficulties with the following imagery “sometimes you’ve got to ride the waves”. As such an attitude of just getting on with it tended to permeate parents’ experiences. Parents also expressed the importance of adopting such an attitude, recognising that existing within any other approach would be difficult:

> You know like, and I think probably you've got to treat it like a positive. You know you can't, nobody can live with the negative. I don't care who you are, you can't live with a, it, it'll do your head in. So, you got to take the positive out of every situation that you're in. (Kylie)

Michelle and Rob identified that there were others worse off than them, with Michelle pausing to reflect on Nathan’s school mates who were no longer living.

It is possible that this positive attitude reflects the functioning of the subsystems. For example, in Case 2 and Case 3, where both spouses were present husband and wife operated as a team and appeared to provide each other with refuge from external stresses. Ken emphasised the supportive nature of the subsystem; “I don’t know how single parents do it, I really don’t”. Within the parent subsystem, lines of differentiation were clear, the mother’s role was that of primary caregiver whilst the father was ‘breadwinner’. In Case 2 and Case 3 instances of accommodations to these roles were evident with mothers in both families giving up work to perform caregiving duties that lasted beyond the normative launching period of children into adulthood. In reference to Michelle not working, Rob stated more than once “so we weren’t the richest people in the street” revealing the financial implications of the ongoing caregiving situation.

Despite restraints caused by the role of caregiving, part of the ‘just getting on’ attitude for Michelle and Rob meant not denying themselves opportunities to do things they have always wanted to do. Rob, for example indicated that both he and Michelle had commenced international travel though with limitations, or as Michelle described it “we play tag-team”. Due to Nathan’s care Michelle and Rob travelled independently, or with Luka, though Rob admitted “it’s not ideal” he further noted that “if we want to go it’s the only way we can do it”. In this example, the spouse subsystem adapted to the ongoing care situation through flexible boundaries that allowed for a modified parent-child subsystem with Luka to provide unique supports without intruding into the functioning of the spouse subsystem. Interestingly, something Michelle did admit to “putting off” was her own mental health. She described an earlier opportunity to see a counsellor as “not fair because if I lose the plot I’ve got to go home to Nath and he will pick up on… that sort of thing”. In this sense ‘just getting on’ meant keeping it together for Nathan’s sake.

Contrary to Michelle’s and Rob’s experiences with travel, Gail and Ken described a lifetime of self-sacrifice and missing out. Gail admitted “we haven’t had a holiday since our honeymoon”, with Ken emphasising that similar to Michelle and Rob “[we] have to do a lot of things on our own”. Ken differentiated between situations in which a family member might care for an elderly parent, or child who is terminal, referring to this care scenario as one in which you are “going to be released…from that commitment” whereas for a parent of a child with an ID such as Michael, the parent was “stuck with that situation until you die”.

Sibling Roles

Sibling perspectives illustrate the varied ways in which siblings make sense of their roles, relationships, and express expectations relating to future care. Both within cases and across cases there were examples of divergence in the way siblings viewed planning for their brother, including the level of involvement that each sibling sought to have in this (refer to theme *Expectations of future care*). In spite of the small sample, there were also indications that gender may impact an individual's understanding of roles and responsibilities as identified in the theme *Gendered understandings.*

Expectations of future care.

This theme illustrates the varied ways in which siblings make sense of their roles and express expectations relating to future care. For example, despite siblings in Case 2 and 3 indicating a willingness to take on the primary care role, this was secondary to either parental care or alternative residential care options. In contrast Jess (Case 1) viewed future residential care as inherently linked to siblings' responsibility to family, regarding either sharing residential accommodation with Christian or living within close proximity to his accommodation as preferred options. This is exemplified in the following quote:

> But you know [eldest sister] goes oh no I'll just build a granny flat he'll just live out the back. And then I'll go no, no, no, I'll just build the granny flat and he'll just live out the back.

For Jess, Christian's care was understood to be something that should be approached together as a family, whilst decisions may have been made by Kylie, Jess and her other elder sibling in particular tended to be aware of Christian's care routine and plans for the future.

Involvement of siblings was less apparent in Case 2 and Case 3. Though conversations were taking place between family members in Case 3, Luka was less interested in current aspects of Nathan's care (e.g., the NDIS) and indicated that he experienced some distance in understanding Nathan as he had aged (see Chapter 11, *Romanticising the sibling-as-carer role*). Despite this potential void in relationship, Luka made sense of his future role within the context of being an only sibling which seemed to compel him to want to have

Nathan close and safe. This desire to be a primary caregiver in future however contrasted with his lack of caregiving involvement.

Case 2 was quite unique as it allowed for comparison of two siblings, both of whom desired different levels of involvement in the future care of Michael. On the one hand Hamish expressed no desire to be involved in the process of future planning believing that this as strictly a parental decision: “See mum and dad have always been very proactive in trying not to involve us too much... they’re being good parents like that”. However, Cynthia craved involvement and saw sibling roles as important in the planning process: “We're wanting to get involved. Like and this is something we're going to need to do one day anyway”.

Gendered understandings.

Though only a small sample, the two female siblings (Case 1 and Case 2) displayed a greater desire for involvement in their brothers residential planning than the male siblings. Both Hamish and Luka appeared content with their parents planning for their brothers’ residential future and did not see the need to be involved in this process. Furthermore the male siblings tended to prefer that their brother remained in the primary care of their parents for as long as possible as this allowed them to avoid experiencing negative feelings such as worry. In this respect there was less consideration given to their parents needs for respite from care but rather an emphasis placed on their own needs and experiences. As Hamish and Luka’s parents tended to express a desire to minimise burden on siblings, this may inadvertently encourage parents to remain in the care role so to avoid siblings carrying the emotional burden of worry as may occur if their brothers were placed in external care.

A further potential gendered difference was in the siblings’ understanding of their brother. The female siblings tended to discuss their brother with ID in terms of potential; that is viewing their brothers as adults who could continue to develop and experience personal growth. For example, in discussing the possibility of Michael moving into a residential community environment Cynthia said, “If there's other people living there too like that's a good social aspect for him too and to learn some new skills”. In contrast the male siblings tended to highlight the childlike behaviour of their brothers, for example Luka referred to Nathan as “very much a toddler”, and Hamish repeatedly referred to Michael as a “4 year old”.

Male siblings also discussed their brothers in terms of managing their care needs rather than the potential for personal growth. Luka described Nathan as “set and forget” in relation to his interests in children’s television shows and colouring-in. Similarly, Hamish described Michael as simply requiring entertainment, rather than emphasising activities that could lead to growth, socialisation, or the development of new skills.

Family Roles

The below theme discusses a common concern that permeated across families and roles with striking similarity in the use of terminology. *Care versus babysitting* highlights a potential shortcoming of external care services when complacency creeps into the role of caregiver, thus replacing an interactive and engaged support worker with a passive and disengaged minder.

Care versus babysitting.

In almost every interview the term ‘babysitting’ was used in a derogatory sense to describe an incompetent approach to caregiving. “Babysitting” tended to describe a support worker who did not engage or interact with the client, failed to provide adequate care and safety to the client, failed to demonstrate respect for and understanding of clients, or tended to act selfishly (e.g., on their mobile phones) whilst out in public with clients. Yet despite most participants framing this term within a derogatory context, Hamish described instances when he was caring for his brother as “we babysit when we can”.

It was clear that for all families a major aspect of a successful care model was a positive, secure relationship between carer and support worker. This was often hindered by constant staffing changes in organisations which were then poorly communicated with families. For example, on the day of Case 2's parent interview, Michael had been expecting the arrival of two familiar support workers for his community care outing, however unexpectedly another staff member had been rostered on to his community care for that day. This appeared to create anxiety for both Michael and his parents:

> Gail: He was frowning a lot and when one of the support workers said hello to him he turned-
>
> Ken: (talking over the top of Gail) And we're just hoping he can get through the whole four hours without us getting a phone call while we're talking to you.

Family Member with ID

As parents decided not to include their sons with ID in the interviews, the following theme, *No two disabilities are the same,* reflects primarily on interview observations of the three adult men with ID. Though time spent with these men was limited, the researcher was able to meet each of the men, spend time in their homes with them, observing their interactions with family, their physical appearance, and visible physical disabilities in complex cases (i.e., Case 2 and Case 3). Throughout these observations and the interviews it became apparent that although all three men fitted a similar diagnosis category their disabilities and thus care needs differed dramatically.

No two disabilities are the same.

Though all three adults with ID were male, non-verbal, and had been given a diagnosis of severe or profound impairment, there appeared to be distinct differences in the functioning of each individual. Christian for example was the only adult who worked in the community with his family commenting on his positive physical health, including his regular swimming sessions. As an observer I noticed that Christian displayed no physical impairments or observable health concerns, for example he did not appear overweight as can be common among adults with Down syndrome (Baynard, Pitetti, Guerra, & Fernall, 2004). Both Nathan and Michael however displayed more obvious physical limitations. As identified by Gail and Ken, and observed during the informal family meeting, Michael's fine motor skills were impacted by his cerebral palsy. It was also observed that Nathan experienced difficulties with some fine motor skills as well as walking, and was noticeably smaller in stature than an average male of his age.

Nathan's size was also referred to by Luka and his parents, as it was believed that due to his diminutive size he was easier to physically restrain during outbursts or meltdowns. This contrasted with the difficulties in pacifying Michael in Case 2 who was large and physically powerful. Environmental factors also appeared to impact upon these two individuals with parents emphasising calm, peaceful environments and the avoidance of overstimulation. These added to the list of considerations when planning for future residential care.

Christian appeared to spend more time with his siblings in the absence of his parents. In addition to time spent together, it was also the quality of the time spent together that differed; this was particularly evident when comparing the sibling discussions in Case 1 with Case 2. Though Case 2 mentioned instances where the siblings were called upon to provide some care for Michael this was described as rare and only during times when the parents were unable to receive support from professional care organisations. Case 1 however discussed periods of time when Christian wanted to, and was encouraged to, visit his siblings in a social aspect, as opposed to the sibling adopting a caring role for their parents. This was identified as spending time together, sharing typical sibling moments as exemplified in the following narrative from Jess; "He would… sit out here, in the barbecue area with me and we're going to have a chat and we're going to have a beer together". Jess's use of normative language “we’re going to have a chat” is particularly interesting considering that Christian was described as non-verbal. It should be noted that the researcher observed that Christian was able to respond, and therefore participate in conversation, albeit with single word responses. This contrasted Case 2’s descriptions of spending time with their sibling which was described within a role of caring and monitoring. The sibling involvement in Christian’s daily life tended to reflect their approach to family inclusion that developed throughout childhood.

Summary

This chapter presented findings from the cross-case analysis of Case 1, 2, and 3. Whereas ‘family’ was the unit of analysis in Chapters 9-11, findings discussed in this chapter focused primarily on familial roles as a sub-unit of analysis. That is congruence and divergence between parental, sibling, and adult with ID experiences across all three cases.

Whilst the individual case findings discussed in previous chapters emphasised the importance of current experiences with care organisations, this cross-case analysis highlighted that past experiences, particular major transitional moments, may lead to cautious approaches toward future planning. Yet parental attitudes were generally optimistic as they spoke of witnessing decades of political and ideological change. Acceptance of responsibility as a caregiver may also lead family members to delay their own care needs in favour of caring for their loved one.

Future care planning may also be affected by the unique needs of the individual with disability, findings clearly indicate that categories for severity of ID do not categorise a homogenous group, as emphasised in the theme *No two disabilities are the same.* Finally, family understandings of appropriate care were contrasted against the adopted term “baby-sitting”. Across all three cases there existed a vision of what appropriate care looked like, though it was not always easy to achieve due to certain service system barriers such as poor communication.

A discussion of Study 3 follows in Chapter 13. This includes synthesis of findings from Chapters 9-12. Implications for policy and practice will also be considered.

Chapter 13 –Discussion of Study 3

The aim of Study 3 was to gather critical information regarding similarities and differences within the family unit, and between family roles in relation to residential care planning as expressed by three families, each with a son with intellectual disability (ID). Though research has shown that residential care planning is clearly a difficult and complex process for parents and families, as previously noted, studies reporting the depth of understanding of these experiences are currently absent from the literature. Through rich detailed narrative and observation, each case study aimed to explore individual wishes and behaviours in relation to residential care planning, personal beliefs surrounding residential care planning options, and the role and impact of significant others on the decision making of residential care. The data were analysed and interpreted using thematic analysis with families defined as the bounded system. Data from each family were therefore grouped and analysed according to Braun and Clarke’s (2006) six phases of analysis. Coded data were then revisited for the cross-case comparison with an emphasis on individual family roles and the three family systems.

This chapter presents a discussion of the findings of Study 3 with consideration given to implications for individuals, families, care organisations, and potentially for services provided by state and federal governments. Discussion is presented for each case (within case), followed by a discussion of the cross-case comparison. Limitations are also discussed.

Case 1

Family system.

This case study examined the experiences of a parent and sibling of an adult with ID within a larger family structure (i.e., two parents, five siblings). At the heart of this narrative was the family system and definitive understandings of family responsibility. Whilst characteristics of the family such as expected loyalty and strong cohesiveness could be signs of an enmeshed system, family members also spoke of shared leadership and recognised the importance of Christian’s own space and own friends. According to Olson’s circumplex model, this would suggest a structurally connected family system in which there is high cohesion, loyalty, interdependency, and in which family roles and rules are relatively stable (Olson, 2000).

Despite shared understandings of familial responsibilities, this appeared to act as a barrier to future residential planning for Christian (adult with ID). Sibling willingness to become Christian’s primary caregivers created an environment of safety and security for the parents who were at the time of the interview relying on this informal family understanding. This is supported in the literature with Davys’ et al. (2015) reporting that plans between parents and siblings may be based primarily or exclusively on verbal understandings.

One of the difficulties in establishing a concrete care plan for this family was the variability in the life of the siblings. Changing family structures such as the birth of children, marriage, and divorce made formal planning arrangements difficult to enact. Although factors such as lifestyle and work commitments have previously been associated with the perceived appropriateness of sibling care roles (Davys et al., 2015), in this case study it did not appear to be the factor itself that determined the siblings’ willingness to care, but the risk of change that made the parent reluctant to commit. As Qualls (2016) previously noted, changing constellations within the family can alter roles, for example divorce can mean a shift in role from partner and co-parent to that of single parent, a transition that can lead to increased stress and greater difficulty in adopting a caregiving role for a sibling with ID. Therefore, being able to work within a fluid care plan that could be evolved to fit changing family structures was imperative.

Care planning experiences.

Previous research reported that self-reliance could act as a barrier to engaging in care services, including residential services (Llewellyn, 2003). In this instance it was not any one individual's self-reliance but rather reliance on the larger family system that created a support network of informal carers reducing the family's need for external support. This meant that over the years there had been little need to explore any range of services as the family simply adapted to the care requirements of its members.

The significance of existing care experiences and outcomes was highlighted in this study. Had it not been for a recent change in service provider which led to observed growth in Christian over time with his carers, the family's beliefs regarding his care options would have remained limited. This highlights the importance of positive and progressive care experiences, and also suggests that although change can be challenging for individuals with ID, it can also provide opportunity for individual growth and development.

The NDIS solution?

Though families across all three cases viewed the National Disability Insurance Scheme (NDIS) as a positive advancement in care and government support, this family tended to show unrestrained optimism. This may be reflective of a family who were previously more self-reliant regarding care for Christian, therefore the NDIS may have represented the greatest amount of positive change for this family. Kylie (mother) viewed funding changes between their first and second years under the scheme as a correction rather than a reduction. Additionally, rather than identifying any major issues with the delivery of services, Kylie perceived the NDIS as the impetus for more flexible, innovative care options for Christian.

Case 2

Family system.

Michael, the son with ID in Case 2 was non-verbal and described as requiring a substantial amount of care including toileting, bathing, and daily living tasks such as meal preparation. It was also reported by Ken and Gail (parents), and Cynthia (sister) that Michael displayed maladaptive behaviours (i.e., physically aggressive meltdowns) which had at times required police intervention. The future care planning narrative of Gail and Ken, who were determined to secure out of home care for Michael, supports previous findings by Heller and Factor (1991) and Griffiths and Unger (1994); these authors note that parents with children with high physical care needs and behavioural disturbances prefer out-of-home service provision to that of other relatives, specifically siblings. The emotional demands associated with caring for an adult with high needs can lead parents to experience guilt about leaving caregiving tasks to typically-developing children (Lee & Burke, 2020). Furthermore, Ken's and Gail's self-reported states of physical and mental exhaustion also provide some support for Minnes and Woodford's (2005) findings that suggested that behavioural issues in adults with ID may be associated with poorer health outcomes for parent carers.

Though Coyle et al. (2014) reported a lack of sibling consultation during future planning, this study extends the literature by exploring the impact of this on the family system. This sibling role within the framework of caregiving and future care planning was clearly a complex and divisive issue in this family. Ken's and Gail's strategy to maintain sole responsibility for care planning in order to ensure their typically developing children were not burdened with this responsibility exemplifies strict role boundaries that in this instance may have had the unintended effect of isolating the siblings from the caregiving family, and isolating the parents from important family supports. Lack of consultation was clearly a central issue for daughter Cynthia who made direct links between this and the strained parent-sibling relationships. Minuchin (1974) previously identified that rigid boundaries such as imposed in this family often creates communications difficulties with outcomes such as this resulting from maladaptive patterns of interaction.

Cynthia also had a unique perspective of the parent-child-with-ID relationship, highlighting her parents "babying" of her brother Michael, suggesting that she believed that this relationship should have progressed through similar adaptations within the family system as her own relationship with her parents did. This is similar to Williams and Robinson's (2001) argument that adults with ID living in the family home continue to be viewed by the parents as children long into adulthood. For Cynthia, the different treatment of her brother was seen as limiting his growth into maturity and independence.

For Hamish (brother) however the parent-child role was understood very differently. By his own admission Hamish did not view the sibling role as one that was bound by obligation and duty to provide assistance. He appeared comfortable in his parents decision to not seek sibling consultation as this allowed him to avoid the psychological burden of care, that is by defining future planning as a parent's responsibility he was able to avoid negative emotions such as worry. This avoidance however has the potential to impact on sibling preparedness should the parents no longer be able to care for their adult child with ID. The issue of preparedness is somewhat circular, in that the parents acknowledge that siblings would not be ready to care, and so do not involve them in planning. This non-inclusive approach however further exacerbates the lack of preparedness by failing to provide the siblings with opportunities to explore the roles of carers and the requirements for planning.

It was clear from this case that within family differences existed in the understanding and expectation of roles, and that these differences impacted on family functioning. To encourage cohesive family relationships, these expectations and understandings must be communicated and discussed with all family members in order to clarify roles and reduce the potential for isolation. It cannot be assumed by parents, or siblings alike, that a lack of expectation in relation to the caring role will be interpreted positively, or incur the same meaning making. In this case two siblings had created very different meanings of their lack of involvement, which then affected their respective relationships with their parents in different ways. As noted by Fingerman and Bermann (2000) "families are continuous entities with rules, beliefs, and values that shape and are shaped by individual members over time" (p. 6), thus family systems extend across the spectrum of adult development. Such a framework may have value in exploring the unique functions of families who are faced with non-normative periods of caregiving for a family member, and consequently impacting on the unique dyadic relationships across the lifespan.

Care planning experiences.

Contrary to previous findings (e.g., Bowey & McGlaughlin, 2007; Dillenburger & McKerr, 2011) the parents in Case 2 displayed no concrete aversion to out of home care options; by contrast, they had been explicitly preparing Michael for this scenario since he was a toddler. Such early intention and long term preparation for accommodation and care outside of the family home has not been previously reported. It is also perhaps a reflection of accommodation shortages and lack of suitable options in Australia, as reported by the Australian Government (2009), that after almost 30 years of preparation Gail and Ken were still in primary caring roles. This scenario indicates that preparation and intention may not necessarily lead to appropriate and timely action if there are systemic barriers to planning, such as the suitability and availability of accommodation. In this case parents must consider how sustainable it is for them to continue in the care role, whether care intentions are aspirational or realistic, and what, if any, compromises they are willing to accept.

Though previous studies have emphasised parents' lack of knowledge of care options (Bibby, 2013; Davys et al. 2015; Gilbert et al., 2008), or lack of understanding in seeking out this information (Bibby, 2013), this was not an issue for the parents in Case 2. Gail and Ken were particularly proactive in seeking information from a variety of sources, and it was this dogged determination that had led them to discover a suitable accommodation option. However, the fact that this accommodation option was discovered in a small newspaper advertisement suggests that communication of critical information is not systematically available to families and may require time and energy on the family's behalf to seek out this information. Devoting time on a daily basis to reading available media and online sites may not be realistic considering how time poor many families already are due to the commitments of caring. The Australian government already supports the existence of a national carer gateway designed to collect and collate relevant and digestible information for family carers (see https://www.carergateway.gov.au). However, although this gateway offers respite information for carers, support regarding residential accommodation is focused on the client remaining in the family home (e.g., assistance with home modifications). This does little to support time-poor families in seeking relevant information for those who wish, or need, to explore out-of-home residential care options. Available information may instead act to encourage parents to sustain the caregiving role themselves beyond what is reasonable or what they are capable of.

Previous research has reported that out-of-home options for residential care are often viewed as inadequate and undesirable (see Innes et al., 2012; Taggart et al., 2012). Family members in this case study had similar negative reactions to institutional care. The family's narrative was encased in historical and often extreme negative accounts of institutional living, however family members reported little knowledge of current institutional care facilities. The narrative also suggested that opting for institutional care was a socially unacceptable decision for responsible families to make. In difficult situations where choice is restricted, this may make future care planning an almost impossible task if the only option available is a modernised version of institutional care, or viewed as the equivalent of institutional care. Further, it would be interesting to explore families' perceptions of group homes to understand if a clear differentiation is made between group homes and institutionalisation. Education may also be required to develop families' understanding of modern day accommodation options, for example, the siblings in this family tended to believe that once a person resided in an institution the family had little to no contact with the resident. Educational programs debunking such myths may be required to change beliefs associated with this or similar styles of accommodation options.

This case study also highlights the complex emotional experience that families face with residential care planning. Though previous reports (e.g., Innes et al., 2012) found that fear is often associated with concern for the care of the adult with ID, Gail and Ken expressed a deep fear associated with the wellbeing of others and the unintentional physical impact their son may have on others. The need to minimise the risk of harmful behaviours further limited the suitability of residential options with several types of environmental stimuli identified as possible triggers. Community housing and group home options may therefore be less suitable for families with adult children who have complex behavioural issues. Residential care options specifically addressing sensory and environmental stimuli, and offering proven transitioning or behavioural intervention programs with relevant professional staffing (e.g., psychiatrists/psychologists) may be required in order for families to feel confident in placing their adult child into a new residential environment.

The NDIS solution?

This case study does raise concerns regarding the suitability of support workers and the lack of formal requirements for those working with adults with ID. This is particularly concerning as an increase in untrained and unsuitable staff appeared to be associated with the NDIS. This finding supports concerns previously raised by Dowse et al. (2016) and Laragy

(2017) that the NDIS has not appropriately addressed job skill competencies for the roles required to meet the needs of clients. Despite such a powerful paradigm shift in disability ideology, perhaps the policy of the NDIS has not gone far enough in defining standards of care, and identifying minimum knowledge, skills, attitudes, and abilities required for those working in what has become a booming disability industry. This lack of clarity surrounding job roles and competencies may unintentionally allow those entering disability services to diminish the significance of the support worker role and consider it to be little more than that of babysitting.

Despite staffing concerns linked to the NDIS and noted “teething problems”, the ideology underpinning the NDIS was applauded by the family and provided them with optimism for the future. Funding and choice were the most significant changes provided by the NDIS, leading to greater opportunities for residential accommodation options. Wiesel (2015) previously suggested that NDIS funding would facilitate new and innovative housing options for adults with ID. Yet despite having located a suitable alternative for Michael, the parents’ cautious optimism was perhaps demonstrative of the continued shortfall, particularly in innovative housing options available at the time of the research.

Case 3

Family system.

The family structure in Case 3 consisted of two parents and two siblings, one typically developing sibling and one sibling with ID. This structure led to an interesting narrative by Luka (brother) in which the felt obligation of being an “only sibling” was expressed through his romanticising the caregiving role. Obligation as a motivation to care has often been reported in the literature (e.g., ABS, 2015; Schirmer, 2017), however Luka’s narrative was also laden with contradiction, with his current involvement suggesting a lack of interest in caregiving duties, care related issues such as the NDIS, and in the involvement with Nathan’s future care planning. This contradiction may be somewhat indicative of a young adult transitioning from emerging to early adulthood as Luka was at the time of the interview or perhaps indicates that his description of ‘romanticising’ a future role as primary carer is no more than a whimsical notion with little expectation that it will ever become a reality.

Care Planning Experiences.

Previous research has shown that relationships between service providers and parents of adults with ID can be easily strained, with power struggles often occurring as a result of conflicting beliefs regarding what is in the best interest of the adult with ID (see Bowey et al., 2005). However, this case highlights how a cohesive parent-professional relationship can work to assist in the progression of future planning. In this instance, professional assistance via a psychotherapist initially employed to assess Nathan’s needs for the NDIS funding appeal, had clearly created the conversation of launching and steps towards future residential planning within the family. Rather than viewing the psychotherapist as an advocate for their son, the parents tended to view the psychotherapist as an advocate for the family. By respecting family roles and listening to parental concerns an environment was created in which parents and professional could work together towards a mutual goal. It should be noted that the parents in Case 3 were around 10 years younger than the parents in Cases 1 and 2, yet despite their relative youth, progress towards planning had commenced with a definitive timeline established. This progress appeared to be directly related to the influence of the psychotherapist. Since this relationship only existed between parents and psychotherapist, with no sibling involvement, it would be interesting to explore the impact on the family system if the relationship were to be extended to include all direct family members.

It is interesting that this family displayed a trial and error approach to Nathan’s care needs. Previous research suggests that dissatisfaction with care organisations may lead to strategies of self-reliance and withdrawal from services, sustaining the belief by parents that they are irreplaceable in the care role (Lewellyn, 2003), however this was not the response adopted by the family in Case 3. The family were openly prepared to view Nathan’s care (including future residential care) as an ongoing, adjustable model that worked within a feedback loop. Based on signals received from Nathan, negative feedback would prompt change, whilst a positive reaction would indicate that the model was working successfully. By utilising feedback and adjusting external care accordingly the parents were able to build confidence in their son’s model of care. Residential care was also viewed as a model that would work within a feedback loop, it may therefore be important to consider the flexibility in commitments required from families in making decisions regarding residential care. Though some residential facilities may offer opportunities to ‘trial’ residential placements, other options such as a client purchasing their own home may be less flexible. As such these options may potentially lock families into long term financial commitments, forcing them to make an educated guess as to the outcomes of such a model, or alternatively a rigid and long term commitment may act as a barrier to enacting such a plan. This may result in families avoiding such commitments or choosing more conservative or flexible options that may not be as appropriate for their son or daughter.

Carer and client relationships with Nathan were a clear concern in considering future residential care. This partially supports previous research that identified fear and concern associated with the care, safety, and security of the adult with ID (Innes et al., 2012). Concerns for the family tended to reflect negative past experiences with service providers, this experience also impacted on how the family framed options for future residential care. For example, staffing difficulties associated with the self-management model were viewed as barriers to choosing a self-managed residential care option. With the NDIS placing so much emphasis on self-advocacy and self-management via individualised choice and control it is imperative that these values reflect a realistic care model for families to work within. If it does not, families may find that the complexities of managing care staff would on the one hand release parents from the physical burden of care, only to replace it with the daily strains of managing a care agency.

The NDIS solution?

It has been previously suggested that the NDIS could create both difficulties and opportunities for families. This variation in positive and negative outcomes was reflected in the parents' narrative. In 2014, Bigby described the NDIS as a 'work in progress', this was similar to the description held by the parents four years following Bigby's original depiction. Considering that the NDIS commenced in trial sites around Australia in 2013, and is currently in its fifth year of roll-out, experiences such as this raise serious questions regarding the scheme's functionality, efficiency, and effectiveness.

However, this family also observed that in some aspects the NDIS may be meeting its core goals. One of those goals was to provide individuals with greater choice regarding their disability needs and care (Howard et al., 2015). It is clear from this case-study that greater freedom of choice in relation to day care services and new innovative opportunities for future care, including residential care options was directly associated with the NDIS. Though no longer a work in progress, but rather a work in action, it is still considerably early in the NDIS lifecycle, too early to determine if the NDIS can genuinely deliver on the promises that are creating hope for clients and their families. For a scheme that appears to be experiencing continued difficulties with funding and functionality it may be challenging for the NDIS to continue to deliver hope as clients wait for change.

Cross-Case Comparison

Past experiences impact on future plans.

Within each of the cases were stories of distressing experiences associated with the major transition period between school and post-school care. This was a time of upheaval not just for the adult with ID but also for the parents who faced dramatic changes in their role as primary carer as the fixed routine of schooling came to an end.

It is interesting that governments, whether willingly or via socio-political pressure, offer families of individuals with ID a system of schooling which structurally parallels the normative schooling system for typically developing children. Yet despite the non-normative development of individuals with ID, there is no adjustment or extension of this structure beyond the conclusion of year 12. As indicated by Gail (mother of Michael), any provision for post school support is clearly not an education department concern, year 12 therefore appears to represent a sharp and definitive end to any kind of structured systemic support within a government run educational or care-based organisation. This further places the onus of care back on families who are faced with the task of approaching care organisations whose offerings may not reflect the same structured environment that the individuals have been surrounded by for the majority of their lives.

It should be noted that in Australia there exist many practical tools to assist families with transitioning. These tools however tend to guide parents to non-psychological services and supports that offer assistance with the care and/or community inclusion of the individual. Whilst these guides focus on practical support, for example funding and community-based care, they include little about the impact that such a major environmental change can have on the psychological health of the individual and family system. From these case studies it is clear that parents are ill-prepared for the psychological impact of change. A need for programs or indeed psychological services that work with families to address these issues and assist parents in preparation for this change has been identified by the present study. Services may include assistance in choosing a care environment that is a psychological fit for their son or daughter, thereby minimising the experienced distress and potentially creating a transition that is experienced positively.

Respite accommodation was also identified as an experience that may be crucial in the development of family attitudes towards future accommodation offerings. Whilst in-home respite appeared successful in Case 1, with new beliefs created regarding Christian's ability to live somewhat independently, out of home respite was clearly more difficult in Cases 2 and 3. The emphasis on negative experiences within an environment of multi-client accommodation settings appeared to impact on family views regarding group home settings. Whilst a client-environment fit may promote positive respite experiences, it is difficult to conceive how such an approach could be developed whilst respite accommodation remains in short supply.

Past experiences with ID in a broader societal and political sense also impacted attitudes and beliefs regarding the future. Positive attitudes and beliefs may be reflective of a generation of parents and siblings who have witnessed significant events such as deinstitutionalisation and the introduction of the NDIS. However, across these cases, parent's often active roles in driving positive change may indicate a bias in the sample, in that those who responded to recruitment information may be more engaged with care organisations and supports, and be more proactive within the disability community than those who did not respond.

Understanding sibling experiences.

Sibling experiences more so than parent narratives tended to highlight the complexities of family relationships and role expectations. Individual understandings of family, obligation, disability, and appropriate parenting all formed the basis of meaning making in regards to relationships, roles, and future residential care planning. As was evident with Case 2, even within a single family unit there may be varied and opposing ways of understanding each other's roles and responsibilities. As such one person's protective strategies (i.e., parent not wishing to burden their child) may be perceived as isolating by other family members. This case highlighted the importance of continued and open communication between family members in order to clarify expectations and understanding.

It was further evident across the cases that an understanding of the sibling role may not be easy to articulate. Siblings themselves may wrestle with competing responsibilities and desires; on the one hand they may feel obligated to ensure the safety of their sibling (which may mean providing primary care), yet on the other hand they have, often with their parents encouragement and blessing, built a life free of obligation and care. The distancing of siblings from the caring role may also allow them to create a false fantasy of what the caregiving role involves and therefore fail to prepare them for the realities of the role.

Furthermore adding to the complexities of sibling meanings of care may be additional factors such as gender, and understandings of disability. For example, in these case studies sisters indicated greater interest in being involved in the care planning process, whereas the males preferred to avoid care planning altogether as this allowed them to escape unpleasant feelings of worry and uneasiness. Despite their brothers' disability, the sisters' narratives were laden with talk of potential growth, whereas the typically developing brothers were more likely to discuss disability within the context of limitations. It would be advantageous for future research to explore these variables across a larger sample.

Quality of care.

The responsibility of support workers to care, protect, respect, and facilitate the growth and development of individuals with ID cannot be underestimated. Families expressed reasonable expectations that their son/brother would be cared for by someone who was competent, reliable, and actively engaged in their role as support worker, whether that be in daily community care, respite, or a residential care environment. Clearly though the industry is replete with both those who meet these standards and those who do not. This again raises questions regarding minimum standards for support workers within Australia's care industry. In addition, the potential rise of a cash-for-care competition laden industry also has consequences for families, particularly in relation to the stability and longevity of support workers. Support workers are ultimately the face of the care organisations, by assuming a 'babysitting' style approach to caring this can reinforce family fears that external services devalue individuals with ID.

Limitations

There are several limitations in Study 3. Firstly, one of the goals of the study was to actively include participants with ID so that their voices may be heard. Although care-organisations with direct contact with individuals with ID were used as a recruitment channel, all initial respondents were parents. As such, parents essentially acted as gatekeepers in determining whether or not their sons could participate. Despite offering alternative communication tools such as visual aids, parents were reluctant to allow their sons to participate and were of the opinion that their sons had very little to offer the research project. Parents cited lack of verbal communication skills, and lack of capacity to understand the concept of the research as reasons to not allow participation. However, this reasoning was at times contradictory to the family's own meaning-making of their son's or brother's intellectual capacity. For example, Jess (sister) stated that the family maintained Christian's intellect was "in some sense" higher than the rest of the family and that he was always listening. Jess and Kylie (mother), as well as Rob and Michelle (parents) were comfortable having their sons or siblings present during the interview, albeit not participate directly. Not being able to interview the individuals most impacted by future residential planning has significant impacts on the interpretation of findings. Parent and sibling views may present a bias that may not accurately reflect the opinions of adults with ID. As previously discovered by Waldren and Strohm (2010) parent and adult-child wishes for future residential care environments do not always align, this must be considered when interpreting the case study results.

The sample of families for the study was also small (n=3), with those interviewed being white, middle class Australians. The experiences of such a small sample cannot be extrapolated as representative of the wider population of families of adults with ID. In addition, whilst the heterogeneity of the family system (i.e., single sibling environments to five mixed-gendered sibling environments) provided interesting insights into differences across these systems, the lack of participation from family members, other than mother and female sibling, in Case 1 may have impacted the family narrative and limits the conclusions that can be drawn from Case 1. Additionally, whilst all parents had been caring for their sons for more than 20 years, the age range of parents was limited to those in mid to older age, but not deep old age. Parents in Case 2 described decline associated with caring (e.g., physical and emotional strains), however based on observation and parent narrative none of the parents appeared to be significantly affected by age related decline or impairment. It would be important to consider how the additional pressures of caring into deeper old age may impact on the decision-making process for residential accommodation.

All three families had a non-verbal son/brother with ID, with a level of impairment categorised as either severe or profound. The experiences of these families may therefore differ from those with a daughter/sister with ID, and those whose child/sibling has a mild or moderate ID. It would be informative to explore whether adults with a milder form of ID than the one’s recruited in this study may be more likely to enact residential care planning earlier in the adult’s life if a form of independent living is a more practicable option. Further research could involve families with female adults with ID and explore differences in residential care planning for those with different levels of disability.

Though participants were offered to be interviewed individually, they mostly chose to be interviewed together. This decision may represent a unity in attitudes and opinions relating to care, or may simply have been chosen for convenience. It is possible that in these dual-person interview environments disagreements or divergent views relating to future residential care may have been suppressed by individuals to avoid conflict or confrontation, particularly within the spouse subsystem. Future studies should consider ways to explore individual experiences within dual parent care environments. As indicated in Study 1 carer roles are often varied with some parents sharing this role more equally whilst in other families, one parent adopts the role of primary carer and primary decision maker.

Summary

This chapter presented a discussion of the qualitative findings of Study 3. Findings showed that each family system was unique in their interactions, relationships, and understandings of caregiving and future care planning. Whilst sibling involvement was encouraged in Case 1 and appeared imperative to the future care of Christian, this was not a shared vision in Cases 2 and 3. What was particularly interesting was how strict subsystem boundaries in Case 2, likely enacted to protect siblings, led to a distancing of siblings. This had implications for the support systems of both parents and siblings and could lead to potential conflict in the development of a future care plan.

Interviews also revealed that there were multiple ways of understanding disability, it could be normalised (e.g., Case 1), viewed as a limitation (e.g., male siblings), or seen as something that may still allow the individual to develop via personal growth (e.g., female siblings). These understandings helped shape beliefs about accommodations which impacted on the housing opportunities and choices deemed appropriate for adults with ID.

Though parents were willing to embrace the use of day-care service options, there appeared to be many more serious considerations required when planning residential accommodation. Some of these considerations were unique to the individual (e.g., environmental stimuli), whilst others appeared more universal (e.g., quality of care). Considerations may also involve challenging strongly held beliefs relating to care itself; for example individual understandings of parental obligation and the belief in ‘lifespan parenting’ may be challenged by professionals such as psychologists, allowing for parents to step back from these roles to take up more traditional or normative later life roles with minimal guilt.

Family experiences with disability at both at an individual level, and more globally provided an interesting context for future planning. This mixture of often positive (e.g., global changes towards disability) and negative experiences (e.g., individual respite) created cautious optimism toward planning, with a preference for fluid rather than concrete options in order to address ongoing changes in the family system highlighting the significance of a lifespan approach. Finally, there was a strong reliance on the NDIS to deliver change and innovation in the disability sector, particularly in relation to the funding of residential accommodation options in the future.

Following in chapter 14, is a synthesis of findings from all three studies in this research program, with consideration given to clinical, practical, and research implications of these integrated findings.

Chapter 14 – Conclusions and Recommendations

The purpose of the present research was to explore residential care planning for adults with ID in Australia from both a broad societal perspective (as determined by media representations) and family systems perspective. Existing literature demonstrates that residential care planning is a complex and difficult task for families, yet whilst the importance of the family system has been emphasised, little research has simultaneously explored multiple perspectives from within the same family system. Additionally, the influence of social norms such as those presented in the media have not been explored in relation to intellectual disability (ID) and residential care planning. The broad aim of the research was to investigate family attitudes, beliefs, and behaviours in relation to caregiving and residential care planning for adults with ID. A further objective of the research was to shed some light on the potential role of the media in forming or shaping both government and societal perspectives on caregiving.

Study 1 aimed to address three research questions: (1) How were issues relating to ID, care accommodation, and family caregiving presented in the Australian print and radio news media during the National Disability Insurance Scheme (NDIS) rollout period (2013-2018)? (2) What role do adults with ID, their families, and other significant sources play in the representation of these issues? (3) Have these representations changed over time as the NDIS has been rolled out? To answer these questions the methodological approach incorporated two analytic methods, quantitative content analysis to examine counts relating to tone and roles, temporal distribution, and geographic distribution of news stories, and news framing to explore issues presented, sources included, the framing of responsibility, and importantly what counter-frames were absent in these stories.

Study 2 expanded on the findings in Study 1, by presenting an exploration of constructions of relevant issues as presented in television current affairs programs. This study aimed to answer the following research question: What is the discursive construction of adults with ID, family carers and care accommodation for adults with ID as presented in Australian television current affairs programs? The examination of more nuanced media constructions was achieved via discourse analysis of three current affairs programs than aired across three different television stations between 2017 and 2018 (a peak period for NDIS growth during the rollout period).

In Study 3 the focus shifted from societal representations to an exploration of Australian families’ experiences with caregiving and care planning. The research question addressed in this study was: How do families of an adult with ID experience care, caregiving, and residential care planning for the adult with ID within the family system? This was achieved through case study design, with each family defined as the unit of exploration. Thematic analysis of each case, followed by a cross-case comparison added further depth to the examination and understanding of the phenomena.

Given the potential impact of changes such as increasing life expectancy of both caregivers and care recipients, and the introduction of a new disability model in Australia, it is important that key stakeholders understand factors influencing residential care planning for adults with ID, both those factors that progress plans and those that act as barriers to planning. This chapter will present implications for media, government, family, and service providers, highlight unique contributions to knowledge along with key recommendations, discuss limitations and future research directions, and overall conclusions.

Study findings and implications

Perhaps one of the more surprising findings in Study 1 was the greater likelihood of positive news stories in regional areas, with a stronger focus on ID or persons with ID. This is somewhat unexpected as persons residing in regional and remote areas of Australia are often viewed as ‘at risk’ with reports of poorer health outcomes and poorer access to primary health care services than those living in metropolitan areas (AIHW, 2019). Three potential reasons for this finding are briefly discussed below.

Firstly, whilst those in regional and remote areas of Australia have poorer health outcomes, they also report greater life satisfaction and community connectedness compared to those living in major cities (Wilkins, 2015; Ziersch, Baum, Darmawan, Kavanagh, & Bentley, 2009), therefore a larger number of positive news stories may reflect the positive impact of this connectedness and potential presence of associated informal supports. Secondly, Kirkpatrick (2001) argued that metropolitan and regional newspapers perform different roles, each with audiences that hold different values and have different needs. For example, Hess and Waller (2012), suggest that regional newspapers are more likely to address "low threshold" issues and that one of the roles of small newspapers (e.g., those in regional and community metropolitan areas) is to combat negative representations of the community. This unique role of smaller newspapers in generating community togetherness may lead journalists to either seek out or favour positive news stories or reposition news reports in a more positive light. If this is indeed the case, then perhaps the adoption of a similar function by metropolitan media would mitigate negative reporting bias. Thirdly, whilst the NDIS/NDIA were frequently absent from explicit news reporting on topics of disability, initial NDIS trials occurred in regional areas of Australia. It is possible that due to these trials, financial interest and progressive service management was directed towards these locations resulting in an increase in positive and newsworthy outcomes.

Media presentations in Study 1 and Study 2 somewhat contrasted with family narratives in Study 3 relating to government responsibility. Media presentations emphasised the role of the government as a welfare state through terminology that was at times scathing, denouncing the government for its apparent failures in this area. Despite the promises of an improved disability support system via the NDIS, these news and current affairs reports suggested that little had changed for adults with ID and their families who were in some accounts laden with burden. Though media representations of governments as negative is not uncommon (Rölle, 2017), ongoing ‘bureaucracy-bashing’ that proposes government funding and policy are the panacea to care-related issues is problematic. Existing literature as well as the current research program suggests challenges are more complex; family systems, service system experiences, and uniqueness of disability are all additional factors that influence the caregiving experience and care planning. To present issues of such complexity may be difficult for the media due to restrictions of space in print, and time in broadcast, yet to overlook these complexities is to misrepresent and oversimplify the issue. It also has the potential to create demand for policy and funding changes when assistance may be best placed elsewhere.

Contrasting with the above representation was the optimism and acceptance of imperfections in government policy and provision present in family narratives in Study 3. Participants here tended to place the government in more of a partnership role, though clearly the government wielded power that could affect positive social, economic, and ideological change. Parents in particular had lived through deinstitutionalisation and other major shifts towards inclusion and value of persons with disability. They had been immersed in systemic challenges often inherent in dealing with government services therefore accepted ‘teething problems’ with the NDIS as part of the journey to a better disability system. Whether it is simply a journalistic bias towards negative news stories, or deeper political agenda setting on behalf of the media owners, this alternative family narrative did not line the pages of newspapers nor feature on the screens of Australia’s television networks. Yet without this narrative governments will continue to be under constant pressure to recreate disability policy, whilst families may become reluctant to acknowledge improvement when the media continue to emphasise current failings.

Interestingly, the voices behind these one-dimensional media representations were most frequently parents of persons with disability. Why then are the family narratives in Study 3 so different? The possibility of selection bias must be acknowledged, these three families self-selected into the study and thus strength of comparison between Australian family perspectives and media presentations is limited. Yet as discussed in Study 2, the framing of questions and editing of voices in the creation of news and current affairs also allows the media to control the narrative. This may strengthen media influence as the media can essentially recreate a family's narrative using their own words, such distorted representations have the potential to override a family's own experience.

Media also relied primarily on parent narratives. This restricted view of family may act to reinforce caregiver roles of parents whilst offering few alternative voices of those who may provide informal supports and hold important alternative views about the engagement of external supports (e.g., siblings). Similar to Burke, Lulinski et al.'s (2018) criticism of policy and practice in failing to recognise the roles of others, it would appear that the media also deserve such criticism.

The importance of considering the family as a system was demonstrated in Study 3. The three case studies revealed that throughout the lifespan families can be highly interconnected (as in Case 1), or alternatively become disconnected (as demonstrated in Case 2). Parents' intention to protect or shield siblings from the burden of caregiving as present in Case 2, may lead to a disengaged transactional style between parent and sibling as the parents hold onto rigid boundaries around the role of caring. As previously discussed, Minuchin (1974) warns that this disengagement can lead to an avoidance in support seeking within the family, leaving caregivers and potential care advocates isolated from other family members. This isolation was evident in Case 2, with the female sibling interpreting this rigid caregiving boundary as symbolic of pushing siblings away from their position within the family system to the role of ‘outsider’. Whilst research has indicated that children experience resource depletion from parents when there is a child with disability in the household (Hartling et al., 2014), siblings may continue to receive limited psychological resources from parents even throughout adulthood.

Siblings may also view caregiving through a different lens than their parents. A single incident in Study 2, where parent and son were both present, highlighted the tension between the martyred repertoire of the mother and the wishes held by the son (that the family be free from the burden of care). This demonstrated that the question of responsibility (i.e., whose responsibility is it to provide care?) is not easily answered and that those within the family system may have different views and justifications for such answers. In this instance for example, the sibling appeared to view caregiving through a lifespan lens, acknowledging ongoing challenges associated with care, and identifying long term impacts on the family members (including marriage breakdown and health problems) whereas the parent’s experience was reflectiveness of the ‘stuck-ness’ described by Case 2 parents in Study 3. A lifespan approach may have significant benefits for families in making appropriate choices for residential care as consideration is given to the various stages of adulthood for both caregivers and care recipients, including consideration given to potential increases in future care needs for both.

Sibling willingness to take on the caregiving role was mixed. There were a number of siblings present in Study 2 who assumed this role and adopted the martyr repertoire, yet in Study 3 only Case 1 considered siblings as caregivers in future residential care. Despite numerous transition points (e.g., typically developing siblings transitioning through emerging adulthood, marrying, having children) the family remained interconnected with new family members contributing to a growing network of carers for the adult with ID. Though the sample from this family was small, neither mother nor daughter spoke of the adult with ID through an ‘adult as child’ metaphor, rather the adult with ID was treated similar to other family members, he was encouraged to take part in normative events (e.g., barbecuing with siblings), and was able to engage in some form of regular work.

Though it may be argued that sibship size may be one reason for this interconnectedness, research does not support this, with one study reporting that larger numbers of siblings relates to weaker inter and intra-generational closeness and intimacy (Hank & Steinbach, 2018). It may be more likely that the sibship gender composition (largely female) may explain sibling willingness to adopt caregiving roles or it may be that a combination of family structures (e.g., sibship size, sibship gender composition, sibling age/age gaps) as well as family roles and transactions over time support a functioning family system that embraces connectedness and family cohesion.

One other difference with this family’s experience was that Case 1 received a diagnosis of disability within days of Christian’s birth, so that when the parents brought their child home from hospital they knew they were bringing home a child with ID. Whereas parents in Case 2 and Case 3 reporting knowing something was wrong with their sons, but not receiving a diagnosis until their sons were older. One might speculate that this early diagnosis in Case 1 allowed the parents and siblings to normalise Christian’s needs from the moment he arrived into the family. In contrast, other family environments may have been filled with worry and fear in the absence of diagnosis producing prolonged inner pressure and stress within the family system that may have resulted in maladaptive transactional patterns.

Interactions between the adult with ID and his or her parents is also likely to influence residential care planning. The ‘adult as child’ metaphor observed in Study 2, was also evident in Case 2 and Case 3 narratives in Study 3. Family members may initially start using such a metaphor to communicate aspects of disability to others, however the continued use of such a metaphor in the absence of alternative or adult perspectives may result in a lack of autonomy for the adult with ID who, through this metaphor, may be seen as incapable of engaging in adult activities such as sexual relationships (Björnsdóttir, Stefánsdóttir, & Stefánstdóttir, 2017; Lam, Yau, Franklin, & Leggat, 2019). Adults with ID have themselves reported that this metaphor can lead to patronising practices and bring into question their identity in adulthood (Björnsdóttir, 2010). Viewing an adult with ID as only a child, may act on some level as a barrier to residential planning and certain residential options as it denies potential achievement of normative life transitions such as launching. This 'adult as child' metaphor might also position the adult as 'ageless', which is perhaps why a lifespan approach to care or care planning was not always evident particularly in parent narratives. Furthermore continuing to view the adult only as child ignores the principles of both the NDIS (choice and control), and article 12 in the UN Convention of Rights of persons with Disabilities (autonomy of decision making for persons with ID), a developmental lifespan approach supports these principles and may be invaluable in framing (or reframing) future residential care planning.

Adults with ID were also grossly under-represented both in the media and in the case studies. Furthermore, parents, and at times siblings, were accepted by the media (presumably unquestionably) to be appropriate and sufficient advocates and voices for those with ID. It should also be noted that in Study 3, all parents declined opportunities for their sons to be involved in the current research program, despite accommodations and communication tools being made available. In Australia at least, there appears to be social acceptance that those with ID must be spoken *for* but not spoken *with*. Though it must be acknowledged that ID can be complex and may limit an individual's ability to communicate their experiences and preferences, intellectual disability groups themselves argue that those with ID who can advocate, should act as voices for those with ID who cannot (Simpson & Chan, 2019). This appears poorly understood by the media who continue to provide stereotypic depictions of adults with ID as vulnerable children. This does little to progress disability policy that emphasises the inclusion of persons with ID if they are often excluded from their own personal stories and denied opportunities to be seen, and listened to, as adults with equal rights within our society.

All families in Study 3 had different approaches to future residential planning, yet none of the three cases were averse to some form of care that would result in transitioning to outside the family home, or in developmental terms, launching. On the contrary, family members were considering either some form of shared housing, independent living, or supported living close to, or with siblings. In Case 1 and Case 3 being able to trial, adjust, withdraw, or pursue new and dynamic options was important for these families. Adjusting such plans based on the adult with ID's feedback was also essential. This suggests that to improve service use and satisfaction, and to further family planning a more flexible approach to service provision and government funding would be welcomed.

Though the family in Case 2 had spent 30 years preparing for the launching stage, this family was less open to a 'trial' approach to future care strategies. Enduring concern for others safety appeared to be driving parents' decision making, highlighting that the stress associated with this transitional period (one considered a stressor even in normative life cycles; Laszloffy, 2002) may be heightened by the complexity of disability. This reinforces existing knowledge that care recipient characteristics such as challenging behaviour can be a major factor in future residential care planning (Griffiths & Unger, 1994; Heller & Factor, 1991). In more complex cases such as this it may be that care accommodations with the flexibility and capacity to either create or integrate positive behavioural support may assist those with more challenging behaviours to locate suitable accommodation.

Despite a general optimism amongst Study 3 participants, the primary concern in relation to future residential care planning held by all participants related to quality of care.

Though Study 1 clearly demarcated this as a government responsibility, those in Study 3 deemed it the responsibility of individual support workers and service providers alike. Though poor quality care was easy to define (e.g., babysitting), appropriate care was more difficult to communicate. The ideal support worker was one that went beyond expected standards of practice to show genuine interest in, and build a genuine bond with, the adult with ID. Therefore standards of practice that focus solely on administrative and reporting processes rather than the human interaction do not appear to be aligned with family concerns and expectations.

Contributions to Knowledge

The unique contributions to knowledge developed through this research will be discussed here. News media is an important vehicle for understanding experiences as it can act to reinforce dominant narratives and stereotypes or generate alternative perspectives by reflecting changes in policy and evolving social values. This thesis has explored the influence of journalistic and media representations of issues such as disability, and has, to my knowledge, provided the first exploration of Australian media constructions of issues relevant to ID, families, and residential accommodation during the NDIS rollout period. By exploring three media modalities (print, radio, and television) the present research provides a broad framework for understanding the shaping of public perceptions regarding these issues. Additionally, this research suggests that despite significant policy change, dominant narratives appear embedded in the media and may be difficult to change.

This thesis aimed to understand the family, not from an individual’s perspective, but as a collective and whole family system. Though the importance of family and various roles within the family have long been acknowledged in the literature, a family systems perspective has rarely been applied to the issue of family caregiving and future residential planning for adults with ID. As has been demonstrated in Study 3, family interactions and transactional styles may, in part, account for the involvement of family members, the preferences for, and actions towards future residential planning. Whilst acknowledging the exploratory nature of the study, evidence has been presented that the adoption of a lifespan family systems approach to both research and practice could be beneficial in advancing planning practices of parents, and more broadly, families.

Collectively, this program of research has highlighted interesting areas of divergence between family experiences and broader representations of such experiences. An important contribution to existing knowledge is the ‘alternative story’ presented here. Despite the generally negative and problem focused media representations, Study 3 provided an alternative and positive position. These Australian families were proactive, engaged with services, and flexible in their thinking about the future. They were open to external housing options and held optimistic views of what was acknowledged to be an imperfect government disability policy. Importantly, parents did not necessarily view their role as carer as a lifelong obligation, parents, family members, or professional supports gave them permission to plan residential placement early in their son’s adult life and reframe this as allowing for their son’s own development and growth. This research challenges both existing literature and media representations that position parents as being at the mercy of the system and expected to remain as primary carers into old age. As such this finding has implications for policy, funding, and support programs. One such area of opportunity is in the early development of independent living skills which may challenge current funding models that tend to reward dependency on service providers.

Additionally, the richness of the data collected via case study design combined with the inclusion of multiple family respondents has provided a depth of knowledge that is seldom present in existing literature. The case study design recognizes the uniqueness of the family systems in each of the three cases, yet patterns and linkages between cases allow for the creation of propositions that may be applicable and transferable to a broader demographic of caregiver families.

Key Recommendations

Despite the existing body of knowledge identifying challenges and opportunities related to residential care planning for adults with ID, current interventions appear to be doing little to increase planning rates. In considering the findings collectively, a number of recommendations can be made that impact various stake holders:

1. A lifespan developmental approach to the planning needs of adults with ID to be adopted. This approach repositions the adult as ‘adult’ reducing the existing ‘adult as child’ metaphor. As such, a lifespan approach allows for growth, opportunity, and brings attention to the potential for decline in middle to late adulthood for the adult with ID. Furthermore, provision for life after caring for the parent or other primary carer is also considered under this approach.
2. The issue of caregiving to be presented as a collective responsibility that brings together support networks inherent in families, services, communities, and governments. A presentation of collective responsibility may act to minimise individual isolation that may be experienced as a result of current singular-responsibility narratives.
3. Life transition points, including school to post-school, and family care to residential care to proceed with the assistance of professional and independent supports such as psychologists. This will a) assist with family preparation, b) address psychological stressors brought on by environmental changes, and c) ensure the inclusion of adults with ID in decision making and feedback processes.
4. Planning to be positioned within a family systems framework. Such a framework would require that information and assistance programs acknowledge and encourage

the involvement of all family members, allowing for communication of multiple and at times opposing perspectives on care.

5. Future residential planning to be broken down into smaller scaffolded steps that can be trialled and adjusted as required over time.
6. Housemate ‘match and trial’ opportunities to be presented through service providers. These flexible, short stay or holiday options could replace traditional respite group home accommodations and should be supported by NDIS funding as part of individual goals.
7. Housing associations and advocate groups to work with multidisciplinary teams to further understand the needs of adults with ID to ensure complex issues such as behavioural challenges and sensory issues are addressed at a housing design phase where possible.
8. Current service standards to be re-evaluated with a focus on the human interaction side of service delivery. This should ensure that support workers and other professionals engaging with adults with ID are appropriately trained and that they support the advocacy and growth of the person with ID, rather than simply focusing on minimising safety risks and maintaining routine.
9. All approaches to residential planning to acknowledge the fundamental rights of adults with ID to assert choice and control over their lives. This includes preferences in decision-making, or where necessary ensuring access to supported decision-making related to residential planning.
10. Psychologists have a key role to play in facilitating the above recommendation. Collaborating with families can ensure the adult with ID is understood, tensions between opposing family perspectives are appropriately managed, and risk aversive family attitudes are respectfully challenged to encourage implementation of

preferences expressed by the adult with ID. Training for such facilitation to be provided via professional development.

Limitations and Future Directions

Conducting research into family caregiving and future planning for adults with ID is not without challenges. As mentioned in Chapter 7, various terminologies and groupings of disabilities may have impacted on the media searches conducted in Study 1 and Study 2. Even in the previous literature language tends to group ID with other developmental or learning disabilities despite the unique challenges associated with each, for example there is often no division between autism and ID despite each term representing separate developmental disorders. Additionally, the variability within a diagnosis of ID is immense, yet this variability is frequently unreported. This does not just impact on the accuracy of media reporting but raises questions regarding the heterogeneity of research samples. For example, in this research program no comparison could be made between disability categorisation of the adults with ID in Study 3, and adults with ID discussed in news stories and current affairs programs in Study 1 and Study 2 due to the limited reporting of disability information in these news and current affairs stories. Thus future research would benefit from the collection and sharing of specific information relating to disability diagnosis (including comorbidities) as provided in this thesis in Study 3.

Furthermore, Study 1 data suggested that the tone of media reports differed between metropolitan Australia and regional Australia, with regional Australian media presenting more positive news stories. In Study 3 all three families lived in the same regional location. It is possible that available services and support networks within the region influenced the family experiences and proactive behaviours. Thus it would be beneficial if future research considered the influence of geographic diversity on family experiences. Whilst those living in more rural and remote areas may have less access to services, those in metropolitan areas may have less access to the community connectedness of a smaller community. Thus exploring and comparing these experiences may be valuable in understanding the needs of families based on geography.

Study 3 presented its own unique challenges and limitations. Primary caregivers are often time poor, and family members may be living in geographically diverse regions. Thus, obtaining full participation from all family members, particularly with the larger family size, proved difficult. Overall the sample size in Study 3 was small, though the data were rich. Whilst the family structure differed across all three cases, all cases were White, middle class families, with financial and social capital, and all with sons or brothers with ID. Additionally, all families engaged in services to support their son/brother with severe or profound disabilities. To extend on the findings in this thesis, future research will need to recruit families of adults with milder forms of ID, including families of adult females with ID. It is possible that families of adults with milder forms of ID, and families of females with ID hold different concerns regarding external accommodation than families of males with more severe forms of ID.

Findings from the present research suggest family structure may influence family interactions and thus future residential care planning. By expanding the research to include a greater range of family structures (e.g., single parents, single child families, and multiple children with disabilities) a greater understanding of the role of family structures may be obtained. Expansion of the definition of ‘family’ may also assist, particularly in culturally diverse families where extended family members (e.g., grandparents, grandchildren, aunts, uncles) may be more likely to be sharing the caregiving roles.

All families in Study 3 were engaged with support services to different degrees. Each son spent weekly scheduled time out of the home with support workers which enabled the parents to have a break, albeit often a short one. Case 2 and Case 3 also had experience with out-of-home respite accommodations in the past. The parents in Case 2 were extremely active in researching and identifying available accommodation options, whilst the father in Case 3 was at the time of the interview a board member of a local service provider. All three adults with ID were also receiving NDIS funding, with Case 1 and Case 3 in their second year of the NDIS model. This suggests that the families in the Study 3 were proactive and competent in negotiating external services and the NDIS system, yet this may not accurately reflect many family experiences within Australia. For example, by the revised 2020 rollout completion date, the NDIS is estimated to be assisting 460,000 Australians (NDIS, 2019), as of January 2019 the NDIS was supporting 250,000 Australians. With persons with ID accounting for approximately 60% of all eligible persons with disability on the NDIS, this suggests that over 125,000 eligible persons with ID are not receiving NDIS funding. Advocates continue to argue that the scheme remains problematic with insufficient outreach and engagement with people who may not know how to navigate the scheme, inconsistent or poor planning, and discouragement of families to pursue self-managed planning (CID, 2019). Data collected from the three cases may therefore not be representative of those who are less engaged with funding and support services.

Inclusion of adults with ID was also challenging. Study 3 demonstrated that inclusion is not necessarily limited by research design, but even when designs consist of provisions for adults with ID, those who speak on behalf of, or make decisions on behalf of, adults with ID may be reluctant to allow persons with ID participate. This may further explain the lack of voice for people with ID in Study 1 and Study 2. Perhaps it is not a deliberate decision on behalf of the media to exclude these voices, but a reluctance from family members to allow the inclusion of such voices, or acknowledgment by families that for some profoundly disabled adults with ID, communication is not possible. Though steps were taken in Study 3 to encourage the participation of all family members this was unsuccessful. Perhaps the involvement of family members and adults with ID at an earlier stage in the research design would combat some barriers to participation. Researchers should consider how family members and adults with ID can act as co-researchers. Co-researcher involvement would allow for input at multiple levels from the development of research questions, to study design, and advice on inclusions strategies. This strategy would align with inclusive disability research philosophies and practices.

Study 3 presented a history of family experiences and snapshot of future residential planning from one brief moment time. Whilst all case studies suggested that Australian families may be proactive in pursuing future residential care planning, none of the families had actioned a plan. One can only speculate as to whether plans have been followed through or if further challenges have arisen since the time of the interviews. As such, whether expressed thoughts towards planning leads to actionable outcomes remains unclear. Future research would therefore benefit from longitudinal studies that follow families across a number of years to determine if and how they progress towards residential outcomes for the adult with ID. This would increase current knowledge regarding involvement of family members, external services, and professional supports in the planning process.

Finally, this research program explored the issue of future residential planning for adults with ID within an Australian context. The influence of Australian cultural and social values must therefore be considered. Additionally, though many countries are moving toward disability policy similar to that of the NDIS, each country may have specific aspects of disability and housing related policy that may further influence family perspectives in relation to residential planning, thus limiting the generalisability of claims made in this program of research.

Conclusion

As Australia's largest disability reform, the NDIS, edges towards the completion of a countrywide rollout, this research program has presented a timely and highly relevant exploration of caregiving and future residential care planning for adults with ID. This thesis has contributed important insights into media representations of ID, family, and caregiving related issues during this significant period of policy change. This thesis reveals that policy change does not necessarily parallel with social change as long-held stereotypes of persons with ID continued to be presented in the media along with stereotyped positioning of the government as one of failure, despite progressive policy such as the NDIS. This research program also suggests that media representations may not offer an accurate reflection of lived experience.

Australian families of adults with ID, particularly parents, have lived through significant periods of disability change. Most likely born in an era of institutionalisation, parents were witnesses to the deinstitutionalisation movement, before knowing the effect this would have on their adult and family life. Families have lived through disability policy changes, the advancement of inclusive education and workplace practices, and in the coming months will be exposed to the likely horrors that will be reported in Australia's Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This report will almost certainly prompt further change in the lives of families of adults with ID. Perhaps it should come as little surprise then that Australian families of adults with ID present as resilient and accepting of change as it would appear to be the constant throughout their lives.

Family systems however are complex and represent patterns of transactions and interactions that have become embedded over the lifespan. As demonstrated in the present research program, there is value in applying a family systems perspective in order to shed light on the lived experience of families and the often complicated relationships that occur within the family system, ultimately impacting on caregiving roles and future care planning. This perspective may also offer an effective framework for constructing formal supports for families as they engage in the lengthy and emotional process of planning for the future residential care of a loved one.

Just as the family system is crucial in understanding future residential care planning, the person at the heart of planning should not be forgotten. Persons with ID deserve to be supported, to be understood, and to be respected. Each person with ID is a crucial member of the family system and as such deserves to be involved in research, in practice, in policy, and importantly in his or her own future residential planning. If the vision of the NDIS is to be recognised, obstacles to full inclusion must be challenged and overcome. It is only through inclusion that we, the researchers, the family members, the community members, and the politicians can be confident that the wishes of those most impacted by these decisions are being realized.

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Appendix A

Table A1

Australia/New Zealand Reference Centre Search Summary for Study 1

Data type	Search summary
Text	(disability OR impairment OR disabled OR impaired OR autism) AND (intellectual OR intellectually OR “down syndrome” OR “down’s syndrome” OR “fragile X”) AND (accommodation OR resid* OR housing) AND care AND (parent* OR sibling* OR family)
Dates Searched	01/01/2013 – 31/12/2018
Source	Newspapers (Domestic): The Age, Newcastle Herald, ABC Premium News, AAP Australian National news wire, Herald Sun, Canberra Times, ABC Regional News, Illawarra Mercury, Sunday Star-Times, Frankston Weekly, Peninsula Weekly, Sunday Age, Western Advocate, The Australian, Border Mail, Brimbank Weekly, Maribyrnong Weekly, Port Macquarie News, The Sunday Times, Sun-Herald, Sydney Morning Herald, The Advertiser, The Courier Mail, Bendigo Advertiser, Greater Dandenong Weekly, Gold Coast Bulletin, Townsville Bulletin, The Weekly Times.

Table A2

Factiva Search Summary for Study 1

Data type	Search summary
Text	(disability OR impairment OR disabled OR impaired OR autism) AND (intellectual OR intellectually OR “down syndrome” OR “down’s syndrome” OR “fragile X”) AND (accommodation OR resid* OR housing) AND care AND (parent* OR sibling* OR family) AND re=Australia
Dates Searched	01/01/2013 – 31/12/2018
Source	“Major news and business sources” OR “news digest sources” OR “Newspapers: All” OR “Transcripts: All”
Region	Australia

Appendix B

Table B1

Coding Template for Content Analysis (Codebook_V4)

Variables (category code)	Coded answers
What was the overall tone of the article/transcript?	1 = more negative, 2 = neutral/balanced, 3 = more positive
What was the role of intellectual disability in the article/transcript?	1 = integral, 2 = part, 3 = incidental, 4 = absent
What was the role of the individual with ID in the article/transcript?	1 = integral, 2 = part, 3 = incidental, 4 = absent
What was the role of family (parents/siblings) in the article/transcript?	1 = integral, 2 = part, 3 = incidental, 4 = absent
What was the role of accommodation in the article/transcript?	1 = integral, 2 = part, 3 = incidental, 4 = absent
Was the issue framed in the article/transcript as episodic (individual responsibility) or thematic (social responsibility)?	1 = episodic, 2 = thematic, 3 = not identified
What issues regarding intellectual disability and accommodation were presented in the article/transcript?	Examples include personal stories, abuse, accommodation shortages, family distress.
Who was/were the source/s in the article/transcript?	Examples include parents, care providers, politicians.
What textual frames were present/absent?	Examples include a gain/loss frame, human interest frame.

Appendix C

Table C1

Media Ownership and Distribution of Stories

Ownership	Metro	Local metro	Regional	National/wires	Total
News Limited	12	22	10	10	54
Fairfax	28	5	46	-	79
Australian Broadcasting Corporation (ABC)	-	-	-	14	14
Australian Provincial Newspapers (APN)	-	-	10	-	10
Seven West Media	3	-	-	-	3
Australian Associated Press (AAP)	-	-	-	2	2
McPherson Media Group	-	-	3	-	3
Independent	-	3	-	-	3
Total	43	30	69	26	168

Appendix D

Table D1

Full List of Media Sources Included in Final CA

Media source	Media ownership	Location	Total articles
AAP-news wires	AAP	news wires	2
ABC transcript	ABC	broadcast	14
Ballarat Courier	Fairfax	regional	1
Bendigo Advertiser	Fairfax	regional	15
Border Mail	Fairfax	regional	1
Brimbank Weekly	Fairfax	Local metro	1
Cairns Post	News Limited	Regional	1
Comment News	News Limited	Local metro	1
District Northern News	News Limited	regional	1
Geelong Advertiser	News Limited	regional	4
Gold Coast Sun	News Limited	regional	1
Goondiwindi Argus	Fairfax	regional	1
Herald Sun	News Limited	metropolitan	2
Hobsons Bay leader	News Limited	regional	1
Illawarra Mercury	Fairfax	regional	7
Leader Messenger	News Limited	Local metro	1
Macarthur Chronicle	News Limited	Local metro	1
Maribyrnong Weekly	independent	Local metro	1
Maroondah Leader	News Limited	Local metro	1
Melton and Moorabool Star Weekly	Fairfax	Local metro	1
Merimbula News	Fairfax	regional	1
Moonee Valley leader	News Limited	local metro	2
Mornington Peninsula Leader	News Limited	Local metro	3
Newcastle Herald	Fairfax	regional	15
Newsmail	APN Newspapers	regional	1
Northern District Times	News Limited	Local metro	1
Parramatta Advertiser	News Limited	Local metro	1
Peninsula Weekly,	Independent	Local metro	2

Media source	Media ownership	Location	Total articles
Mornington			
Penrith Press	News Limited	local metro	2
Port Curtis Post	APN Newspapers	regional	4
Riverine Herald	McPherson Media Group	regional	2
Shepparton News	McPherson Media Group	regional	1
Southern Highlands news	Fairfax	regional	1
St George Leader	Fairfax	regional	1
St Mary's Star	Fairfax	Local metro	1
Stirling Times	News Limited	Local metro	1
Sunbury Leader	News Limited	Local metro	1
The Advertiser	News Limited	metropolitan	2
The Age	Fairfax	metropolitan	13
The Australian	News Limited	metropolitan	10
The Canberra Times	Fairfax	metropolitan	6
The Courier Mail	News Limited	metropolitan	4
The Daily Telegraph	News Limited	metropolitan	1
The Inner West Courier	News Limited	Local metro	1
The Maitland Mercury	Fairfax	Regional	1
The Mercury	News Limited	metropolitan	2
The Morning Bulletin	APN Newspapers	regional	1
The Northern Star	APN Newspapers	regional	1
The Parramatta Sun	Fairfax	local metro	1
The Queensland Times	APN Newspapers	regional	2
The Sunday Times	News Limited	metropolitan	1
The Sun-Herald	Fairfax	metropolitan	1
The Sydney Morning Herald	Fairfax	metropolitan	8
The Warrnambool Standard	Fairfax	regional	2
The Warwick Daily news	APN Newspapers	regional	1
The West Australian	Seven West Media	metropolitan	3
Townsville Bulletin	News Limited	regional	1
Townsville Sun	News Limited	regional	1

Media source	Media ownership	Location	Total articles
WA Today	Fairfax	local metro	1
Waverley leader	News Limited	Local metro	2
Western suburbs weekly	News Limited	local metro	1
Whittlesea Leader	News Limited	Local metro	3

Appendix E

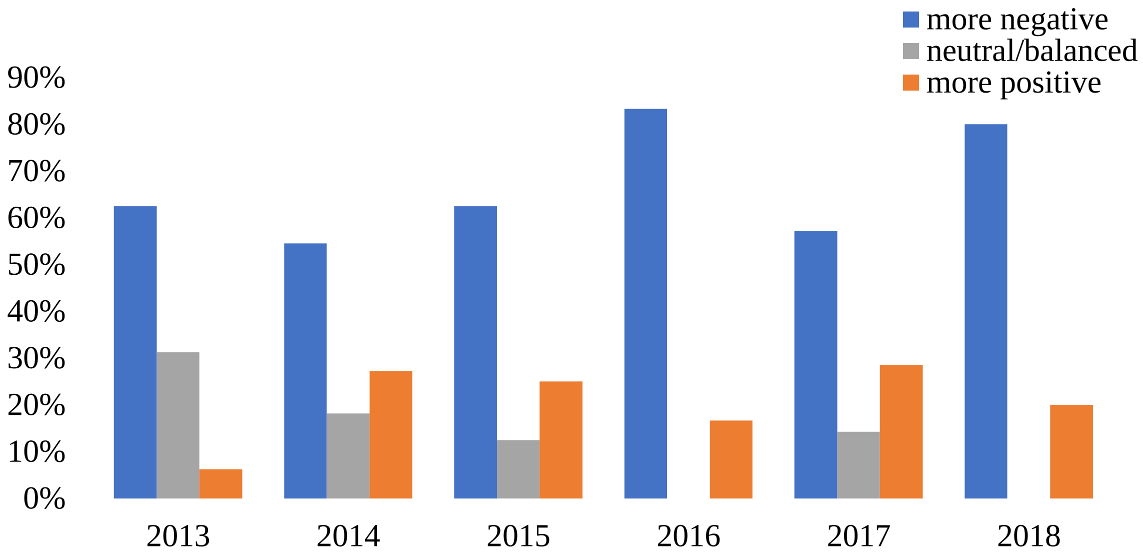

Figure E1. Tone of major metropolitan news stories presented per year.

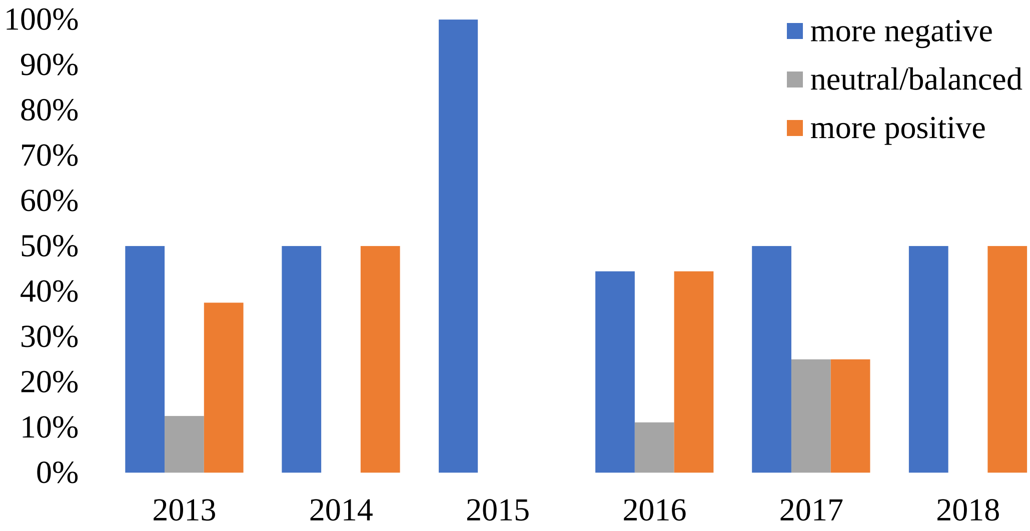

Figure E2. Tone of local/community metropolitan news stories presented per year.

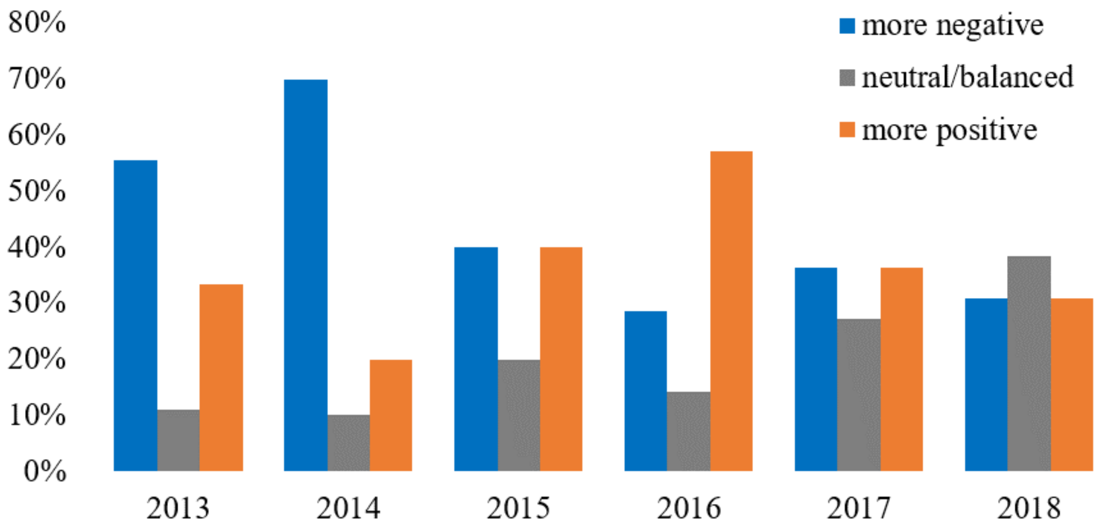

Figure E3. Tone of regional news stories presented per year.

Appendix F

Study 3 Recruitment Flyers and Emails/Letters.

UNIVERSITY OF SOUTHERN QUEENSLAND

Future Planning
in Family Caregiving
of Adults with Intellectual Disability

All family members deserve to be heard.

The University of Southern Queensland is conducting a study aimed at better understanding the experiences of families faced with future planning for a son or daughter with an intellectual disability.

This study gives all family members (parents, sibling, adults with intellectual disability) an equal opportunity to share their attitudes, beliefs, dreams and challenges for the future.

We're looking for families with **parents who are long term carers of an adult son/daughter with an intellectual disability.** Parents must be aged 65 or older. We would like to speak with at least three family members (that is, a parent, a son or daughter with intellectual disability, and a sibling of the son or daughter). Your participation would involve being interviewed by a USQ PhD student, as part of her PhD thesis.

We would love to hear from you
and listen to your stories!

If you would like more information or would like to get involved, please contact Ms Sonya Winterbotham:

Phone: 07 46312898

Email: sonya.winterbotham@usq.edu.au

E-mail/letter content:

Ms Sonya Winterbotham, PhD candidate at the University of Southern Queensland is inviting families of an adult with an intellectual disability to take part in a study about future planning residential care accommodation for people with intellectual disability. Participating families will consist of at least one parent, their adult son or daughter with an intellectual disability, and at least one sibling of the son or daughter. Parents must be 65 years of age or older and be the primary carer of their adult son or daughter with an intellectual disability.

It is NOT necessary for families to have discussed or made any concrete plans for their son or daughter, we are simply interested in the family's views on available options and how they might approach planning in future. It is hoped that results can be used to draw attention to the extraordinary experiences of family caring and the unique challenges that face families when planning future care. It is hoped this information will assist support services and other bodies to become more relevant and considerate of the complexities of family planning.

We are writing to see if you would be willing to share details of this study with members of your group via newsletters, emails, community noticeboards et cetera.

Participating family members are asked to take part in individual interviews with a researcher. These interviews are expected to take between one to one and a half hours to complete, or for adults with intellectual disability these interviews may be shortened to avoid fatigue. We also invite participants with intellectual disability to have a support person present if they wish. Furthermore, we recognise that not all family members live in the same geographical location, therefore interviews may be conducted over the phone if required.

If you would like to discuss the details of this research further, please contact Ms Sonya Winterbotham at sonya.winterbotham@usq.edu.au or 07 4631 2898.

Appendix G

Participant Information Sheet and Consent Form

University of Southern Queensland

Parent and sibling participant Information for USQ Research Project Interview

Project Details

Title of Project:	Future Planning in Family Caregiving of Adults with Intellectual Disability
Human Research Ethics Approval Number:	H17REA208

Research Team Contact Details

Principal Investigator Details
Ms Sonya Winterbotham
Email: sonya.winterbotham@usq.edu.au
Telephone: (07) 4631 2898
Mobile: 0418 185 177

Supervisor Details
Professor Bob Knight, PhD
Email: bob.knight@usq.edu.au
Telephone: (07) 4631 1480
Mobile: 0448 082 946

Dr Jan Du Preez
Email: jan.dupreez@usq.edu.au
Telephone: (07) 4631 1672

Description

This project is being undertaken as part of a PhD project.

The purpose of this project is to gain further knowledge of individual experiences of future care planning for adults with intellectual disability. This includes better understanding individual wishes for future care planning, personal beliefs surrounding future care planning options, and significant others' impact on parent/sibling decision making.

The research team requests your assistance because in order to improve support services for families faced with establishing concrete future care plans we need to hear from those most affected. By talking with families we can gain further understanding of barriers/enablers to future care planning which can assist with the development of more appropriate support services addressing relevant needs.

Participation

Participation would involve at least three members of your family being interviewed (a parent aged 65 or older, an adult son or daughter with an intellectual disability, and at least one sibling of the adult with the intellectual disability). Each family member will be interviewed individually by a USQ researcher. This interview will take approximately 60 minutes in duration.

The interview will take place at a time and venue that is convenient for you (this may include an interview via telephone). Questions will be based around exploring your wishes, opinions and experiences with future care planning options. Following are two example questions:

- What have your experiences with support services been like?
- When thinking about future care planning, specifically residential planning, what do you believe are the options for parents with an adult son/daughter with an intellectual disability?

The interview will be recorded on an audio recording device. The audio of the interview will be transcribed and, should clarification be required, you will be contacted to verify any responses at this time. The audio recording and subsequent transcript will be kept confidential with any identifiable data obtained from the interview removed before publication of research so you (or others you might mention) may not be personally identified.

Your participation in this project is entirely voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. You may also request that any data collected about you be destroyed. If you do wish to withdraw from this project or withdraw data collected about you, please contact the Research Team (contact details at the top of this form). If a family member wishes to withdraw from the project after the interviews have taken place, data from the remaining family members may be retained in the project. If all family members specify that they wish to withdraw from the project, all family data will be removed.

Your decision whether you take part, do not take part, or to take part and then withdraw, will in no way impact your current or future relationship with the University of Southern Queensland.

Expected Benefits

It is expected that this project will not directly benefit you. Though your involvement may promote further family communication surrounding the future care planning of a loved one. In the long term, your participation in this project may benefit other families of adults with intellectual disability by providing important information that may help address planning issues and deficits in current support services.

Risks

As this interview involves the discussion of some sensitive topics the risks involved include emotional distress as well as the imposition on your time whilst you participate in the interview.

Sometimes thinking about the sorts of issues raised in the interview can create some uncomfortable or distressing feelings. If you need to talk to someone about this immediately, please contact Lifeline on 13 11 14. You may also wish to consider consulting your General Practitioner (GP) for additional support.

Privacy and Confidentiality

All comments and responses will be treated confidentially unless required by law.

You should feel free to express your opinions and views openly and honestly in the interview. Any identifying information provided will be removed at the time of transcription. This includes your name and any other names that you may provide in your answers.

Any data collected as a part of this project will be stored securely as per University of Southern Queensland's Research Data Management policy.

Only the research team identified above, and if required a professional transcription agency, will have access to your audio recording. Professional transcription agencies are only supplied with audio, no other identifiable information, and have signed confidentiality agreements with the university.

Consent to Participate

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate in this project. Please return your signed consent form to a member of the Research Team prior to participating in your interview.

Questions or Further Information about the Project

Please refer to the Research Team Contact Details at the top of the form to have any questions answered or to request further information about this project.

Concerns or Complaints Regarding the Conduct of the Project

If you have any concerns or complaints about the ethical conduct of the project you may contact the University of Southern Queensland Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au. The Ethics Coordinator is not connected with the research project and can facilitate a resolution to your concern in an unbiased manner.

Thank you for taking the time to help with this research project. Please keep this sheet for your information.

University of Southern Queensland

Consent Form for USQ Research Project Interview

Project Details

Title of Project:	Future Planning in Family Caregiving of Adults with Intellectual Disability
Human Research Ethics Approval Number:	H17REA208

Research Team Contact Details

Principal Investigator Details

Ms Sonya Winterbotham
Email: sonya.winterbotham@usq.edu.au
Telephone: (07) 4631 2898
Mobile: 0418 185 177

Supervisor Details

Professor Bob Knight, PhD
Email: bob.knight@usq.edu.au
Telephone: (07) 4631 1480
Mobile: 0448 082 946

Dr Jan Du Preez
Email: jan.dupreez@usq.edu.au
Telephone: (07) 4631 1672

Statement of Consent

By signing below, you are indicating that you:

- Have read and understood the information document regarding this project.
- Have had any questions answered to your satisfaction.
- Understand that if you have any additional questions you can contact the research team.
- Understand that the interview will be audio recorded.
- Understand that you will not be provided with a copy of the transcript of the interview for my perusal and endorsement prior to inclusion of this data in the project.
- Understand that you are free to withdraw at any time, without comment or penalty.
- Understand that you can contact the University of Southern Queensland Ethics Coordinator on (07) 4631 2690 or email ethics@usq.edu.au if you do have any concern or complaint about the ethical conduct of this project.
- Have been caring for your adult son or daughter with an intellectual disability for a minimum of 20 years.
- Are caring for your adult son or daughter with an intellectual disability in the family home.
- Agree to participate in the project.

Participant Name	
Participant Signature	
Date	

Please return this sheet to a Research Team member prior to undertaking the interview

Appendix H

Draft Interview Schedules for Parents and Siblings

Parent Interviews:

Interviewer will need to gather basic demographic questions before commencing:

Participant age.

Gender.

Marital status.

Current living situation.

Scene setting

o Today's interview will focus on your experiences, beliefs, and perceptions of caring for your son/daughter and planning for his/her future.

o Our discussion is being audio recorded. The transcription of our discussion will be used for analysis at a later date.

o As a participant, your role is to discuss as openly as possible, your thoughts, beliefs and experiences.

o I acknowledge that today's topic is a very personal and sensitive one. If at any time you wish to stop the interview, if you feel upset or distressed and would like a break, please let me know.

o Before we start, I would like to discuss a couple of terms that I might use in our discussions and questioning.

Background information

- Can we start with a little background about your son/daughter – a little summary of what life has been like with him/her, what caring has been like for you?
- What does a normal day look like for you?
- What does a normal day look like for your son/daughter?
- What kinds of tasks do you perform in the day to day care of your son/daughter?
- Are there other family and friends that support you with the care of your son/daughter? *how would you rate your social support?

- Do you use support services?
- What have your experiences with these services been like?

(What was the process like in order to access this service?

has it been easy to access this service?)

- If the answer is “no”, have you used support services in the past? Why don’t you use services?
- What services are you aware of that are available? (are current services sufficient? What services do you believe you need that you aren’t getting?)

Institutional Care.

- In the past, formal support services in Australia largely involved that of institutional care.

o How would you describe institutional care?

o What thoughts and emotions do you experience in relation to institutional care?

Future care Planning.

- Have you considered, talked about, or arranged for any future care plans to be put in place for a time when you may no longer be able to continue to perform the caring tasks you are currently performing for your son/daughter?

o If ‘no’ do you intend to? If ‘no’ is there something that is preventing you from discussing it? What are your thoughts on future care plans?

o What emotions do you experience when you contemplate future care planning for your son/daughter.

- When thinking about future care planning, specifically residential planning, what do you believe are the options for parents with an adult son/daughter with an intellectual disability?

(for each option identified ask the following questions)

- How do you feel about this option?

- If you were to arrange this option for your son/daughter what do you believe it would be like for your son/daughter? (what would the positive outcomes be?, what could potential negative outcomes be?)

- With these options in mind, which one do you believe is the best option? (Is this the option you intend to plan for? When? Or why not?)

- Are there other people that you need to consider when making future care plans for your son/daughter?

- What other considerations are there?

Offspring experience

- How do you think your son/daughter would feel about these options?

- What option do you think your son/daughter would choose?

- If you and your son/daughter disagree, how do you think this will be resolved?

Siblings.

- What do you think your son's/daughter's siblings expectations are in relation to the future care planning of your son/daughter?

- How do you think these sibling/s would feel about residential options previously discussed?

- What option do you think the siblings would choose?

- If you and your son/daughter's siblings disagree, how do you think this will be resolved? (why do you think disagreements exist?)

NDIS.

- How do you think the NDIS will impact on future care planning for your son/daughter? (do you think any current services issues/concerns will be improved upon through the NDIS? Which ones? How?)

Thank you for your contribution to this study, is there anything else you would like to add? Anything that you believe is important that has not be asked today?

Sibling Interviews:

Interviewer will need to gather basic demographic questions before commencing:
Participant age.
Gender.
Marital status.
Current living situation.

Scene setting

- Today's interview will focus on your experiences, beliefs, and perceptions of caring for your brother/sister and planning for his/her future.
- Our discussion is being audio recorded. The transcription of our discussion will be used for analysis at a later date.
- As a participant, your role is to discuss as openly as possible, your thoughts, beliefs and experiences.
- I acknowledge that today's topic is a very personal and sensitive one. If at any time you wish to stop the interview, if you feel upset or distressed and would like a break, please let me know.

Background information

- Can we start with a little background about your brother/sister – a little summary of what life has been like growing up with him/her?
    - What does a normal day look like for you?
    - What does a normal day look like for your brother/sister?
    - What kinds of tasks do your parents perform in the day to day care of your brother/sister?

- Do you or other family and friends support your parents with the care of your brother/sister? *how would you rate their social support?

- Do you or your parents use support services?
    - What have your experiences with these services been like? (what was the process like in order to access this service? What has been easy/challenging in accessing this service?
    - If the answer is "no", have you or your parents used support services in the past? Why don't you or your parents use services?
    - What services are you aware of that are available? (are current services sufficient? What services do you believe you need that you are not getting?)

Institutional care.

- In the past, formal support services in Australia largely involved that of institutional care. Can you share with me your thoughts on institutional care?

  - How would you describe institutional care?
- Many institutions in Australia have been closed down, and residents have been re-homed in group home accommodation. What are your thoughts on group homes?

Future care Planning.

- Have you or your parents considered, talked about, or arranged for any future care plans to be put in place for a time when your parents may no longer be able to continue to perform the caring tasks they are currently performing for your brother/sister?
  - If ‘no’ do you intend to? If ‘no’ is there something that is preventing you from discussing it? What are your thoughts on future care plans?
  - What emotions do you experience when you contemplate future care planning for your brother/sister.

- When thinking about future care planning, specifically residential planning, what do you believe are the options for parents with an adult son/daughter with an intellectual disability?

  - How do you feel about each of these options?
  - If these options were arranged for your brother/sister what do you believe it would be like for him/her? (what would the outcomes be?)
  - With these options in mind, which one do you believe is the best option? (What option would you plan for? What do you think your parents would prefer to plan for? When? Or why not?)
  - If you disagree with your parents decision regarding future care planning how do you think this will be resolved? (why do you think disagreements exist?)

- Who do you think should be considered in the decision making for future care plans for your brother/sister?
  - What other considerations are there?

Brother/sister experience

- How do you think your brother/sister would feel about these options?

  - What option do you think your brother/sister would choose?
  - If you and your brother/sister disagree, how do you think this will be resolved?

NDIS.

- How do you think the NDIS will impact on future care planning for your brother/sister? (*do you think any current services issues/concerns will be improved upon through the NDIS? Which ones? How?)*

Thank you for your contribution to this study, is there anything else you would like to add? Anything that you believe is important that has not be asked today?