Invisible Carers
Facing an Uncertain Future

A report of a study conducted with funding from
The National Health and Medical Research Council
2000-2002

Gwynnyth Llewellyn, Lindsay Gething, Hal Kendig and Rosemary Cant
Faculty of Health Sciences and Faculty of Nursing, University of Sydney

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Most importantly, we would like to thank all the parent-carer participants for their interest in the study, for their willingness to give up their time and share with us their stories and experiences, to complete questionnaires, and to answer telephone calls. Without their enthusiasm and motivation this study would not have been possible. We hope that in some small way this report repays their efforts. Their efforts will be truly rewarded if the recommendations in this report receive the considered attention they deserve.

Executive Summary and Recommendations

An estimated 3000 older parents in NSW are caring for an adult son or adult daughter with a severe or profound intellectual disability. This number will grow exponentially over the coming decade. The state relies heavily on the care these older parents provide. However these parents cannot continue caring indefinitely. Twenty, thirty or forty decades of care take a toll – physically, financially, socially and emotionally. A crisis looms.

The experiences and insights of these parent-carers have long been ignored. This study sought to understand their perspectives – critically important to any attempt to provide services that older parent-carers will use and find useful. Older parent-carers[1] begin caring as new parents and will continue to do so for five or six decades, unless prevented by death or their own disability. Their caregiving is virtually a life-long 'career' and it is a radical departure from the normal experience in which dependent children develop into independent adults. There is a wealth of knowledge in their caring careers that needs to be made publicly available to inform policy, service development and professional practice.

The study was set against the background of a rapidly ageing society. The number of people with a severe or profound handicap is increasing – and for most (82%) the main provider of assistance with self-care activities is an informal carer, usually resident in the same household[2]. People with a disability are getting older and so are their primary carers. Around 10% of the primary carers aged 65 and over (approximately 9,700 Australia wide) are older parents caring for their now adult children. Around 40% of all primary carers in Australia have been in their caring role for at least 10 years. Of these, around 13% have been in the caring role for at least 25 years. Most of these long-term carers are parents of adults with intellectual disability. Their time involvement in caring is substantial; for carers caring for 25 years or over, half (50.2%) spend no less than 20 hours a week caring and the majority of these carers (76.2%) spend over 40 hours a week devoted to caring activities. Their caring is a life long experience substantially benefiting society by caring for their family members who in previous times would have been placed in institutions.

This study, conducted by a team of researchers from the Faculty of Health Sciences and the Faculty of Nursing, University of Sydney, aimed to understand the lifetime caring experiences of older parent-carers of adults with intellectual disability and the factors which influence their patterns of service use. The study was funded under the National Medical Health and Research Council Project Grant Scheme, 2000-2002.

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[1] In policy and professional terms these older parents are referred to as caregivers. Yet their status as carers remains ambivalent. In their own minds they are parents responsible for the welfare of their disabled children who are now well into adulthood. Our preference is to refer to these ageing parents as parent-carers not caregivers. In doing so we acknowledge upfront how they regard themselves as parents first as well as recognizing the caregiving label ascribed to them by others.

[2] ABS (1999). Disability, Ageing and Carers: Summary of findings. Cat. No. 4430.0 Canberra: ABS.

Recommendation 1

That the NSW government through the Chief Executive Officers of Human Services require:

- All government and government funded services to incorporate a personal futures planning program for older parent-carers, their adult sons and daughters with a disability and other family members in their service offerings and,
- Evaluate these personal futures planning programs against agreed best practice standards.

Recommendation 2

That the NSW government through the Chief Executive Officers of Human Services urgently address:

- In the first instance the need for careful and empirically based planning to develop, in a timely fashion, the services required to support older parent-carers and,
- Secondly the funding required to ensure a more certain future (accommodation, day services, health and personal care and someone to 'look out' for them) for the adult sons and daughters of older parent-carers currently living in the community.

Recommendation 3

That the future planning needs of older parent-carers and their families are given higher priority:

- In the first instance by the Department of Ageing, Disability and Home Care giving equal policy, funding and service attention to older parent-carers currently caring for their adult so or daughter with a disability at home and,
- Secondly by establishing a consultative process with older parent-carers and organizations which represent their needs to address the consensus finding in this study that *professional workers do not seem to appreciate the problems parents face* and develop information, training and resource strategies to overcome this.

Recommendation 4

That the health needs of older parent-carers be accorded higher priority:

- By identifying these needs in general medical practice and,
- By ensuring the necessary community based interventions and supports are in place to reduce unnecessary stress on the physical and mental health status of older parent-carers.

1

Background to study and research design

Ageing of the population is one of the major social changes underway in Australia. This has a direct effect on family caregiving. First, there are more older people in the population and their number is increasing at a higher rate than other population groups[3]. Around one-third of people over 65 are primary carers for a family member or close relative. Caregiver research however has focused almost exclusively on adult children caring for ageing parents and, to a lesser extent, elderly spouse carers. Very few appreciate that many older parents continue to care for adult sons and daughters with a disability. This is particularly worrying given the increasing number of parents over 65 who are the principal carers for people with a severe and profound handicap (7,000 in 1993 to 9,000 in 2003 in Australia)[4] with a considerably larger number as principal carers for people with moderate and mild handicaps.

Second, there are many more people with a long-standing disability living into older age[5]. The 'baby boomers' are the first generation to contain a substantial proportion of people with longstanding disabilities. Advances in technology, medical care and community supports mean that many people who once would have died before reaching late adulthood now have a life expectancy that approximates that of the general population. Mid life circumstances for adults with intellectual disability such as retirement from employment or day program, chronic illness, and life changes such as developing a relationship, or seeking to move out of home may require major adjustments to the parent-adult child relationship and to the roles that the various parties perform. With increasing age, adults with intellectual disability may also experience new health problems as well as changes related to the their original disability such as depressive disorders, anxiety disorders, loss of self-esteem, forced dependency, and social isolation (Lavin & Doka, 1999).

Third, the interaction of the *increasing age* of parent-carers as their adult children with a disability also get older could be expected to place a significant strain on the parent-caring relationship. In contrast to their age peers, older parent-carers remain responsible for their adult disabled children and the typically expected changes of late middle age – retirement and children becoming independent – do not bring the same relief from caregiving duties.

[3] People aged 65 years currently make up 12% of the population and by 2016 this figure will have reached 16% (3.5 million persons) (Australian Bureau of Statistics, 1996).
[4] AIHW (1997). *Demand for Disability Support Services in Australia: Size, cost and growth*. AIHW Cat. No. DIS 8. Canberra: AIHW.
[5] The total increase between 2000 and 2006 for people with a severe or profound core activity restriction is projected to be 11.6% mainly due to the rapid increase in the age groups 45-64 (19.3% or 59,500 people) and 65 and over (15% or 76,300 people). AIHW (2000). *Disability and Ageing. Australian population patterns and implications*. Cat. No. DIS 19. Canberra: AIHW.

At all ages women are more likely to be primary caregivers and by age 65 women outnumber men 3 to 2: older parent-carers are therefore most likely to be women caring alone. A lifetime of lifting, carrying and toileting a son or daughter takes a heavy toll on these women. Retirement, moving house or city, and serious illness may also seriously affect their ability to continue caring for their adult son or daughter with intellectual disability. Older parent-carers' lives may also be particularly restricted because their life may have been constructed around the needs of their now adult son or daughter, or they share a general anxiety about how their son or daughter might fare in their absence, or because they share their homes with somebody whose behaviour disrupts daily life.

In sum, older parent-carers of adults with intellectual disability are a potentially vulnerable caregiver group. To date in Australia there has been little research attention specifically addressing this group of older parent caregivers. The study that is the subject of this report aimed to redress this oversight.

In 1998, Gwynnyth Llewellyn, Lindsay Gething, Hal Kendig and Rosemary Cant[6]sought funding from the National Health and Medical Research Council Project Grant Scheme to undertake a two-year study titled *Service pathways for ageing caregivers of adults with intellectual disability*. The study was funded by the NHMRC Ref No. 107305 for the period March 2000 to March 2002 and completed in March 2003. The study was granted ethical approval by the Human Ethics Committee, University of Sydney, Ref No. 99/06/25. Tanya Hilfstein, Julie Mastrodomenico, Rebekah Dunn and Rachel Mayes provided research assistance over the three-year study period.

Aim of the study

The overall purpose of the study was to explore the caregiving biographies of older parent-carers of adult sons and daughters with intellectual disability, factors influencing these biographies and their inter-relationship with patterns of service use.

Specifically the study aimed to:

- Identify ways in which caring relationships are influenced by personal biographies and adapt or are stressed by health status, support networks, direct care load, perception of caregiving difficulties, coping strategies and attitudes towards and willingness to engage with services.
- Document reasons why parent caregivers do or do not use services currently, their views on their service needs in the future, and reasons why parent caregiving comes to an end.
- Identify service providers' perceptions of reasons why older parent-carers do or do not use services and contrast their perspectives with those of the parent caregivers.

[6] Llewellyn, Kendig and Cant: Faculty of Health Sciences, University of Sydney; Gething: Faculty of Nursing, University of Sydney

Methods and Techniques

The central research strategy was narrative life history; a qualitative technique particularly well suited to understanding the lives of those whose experience departs from normative expectations. Derived from social constructionist theory (Blumer, 1969) and following Gergen (1994), we view narratives as products of social interchange. Conducting in-depth interviews with older parents therefore provides the opportunity for them to tell their stories (narratives) as they occur naturally in their everyday lives. Thus, studying older parent-carers' narratives offers insights into the way they portray – and understand – themselves within their ongoing relationships.

For the purposes of this study we defined older parent-carer following Schofield et al. (1998) as a person 60 years and over taking the main responsibility in caring for an adult son or daughter with intellectual disability. Intellectual disability was defined as per the 1992 American Association on Mental Retardation, 9th Edition Definition, Classification and System of Supports (AAMR, 1992) where results of previous intelligence testing are available. Alternatively, assessment was based on a history of special education placement or identification as intellectually disabled by a specialist developmental disability service.

Older parent-carer participants

Our participants of over sixty older parent-carers were drawn from the northern region of Sydney. This geographical area was chosen because of its high concentration of late middle age to elderly people. We recruited older parents to the study by multiple methods. We approached aged care and assessment teams, developmental disability teams, home help services, non-government disability and non-government aged care agencies, general practitioners and support groups. At each entry point older people fitting the study criteria were given information about the study, and if interested to participate, their contact details were forwarded to the research team. Articles in the local media attracted additional parents by direct contact and word of mouth. In this way we attracted parents who were service and non-service users and both co-resident and non co-resident parent carers as well as those who had recently placed their son or daughter in non-familial care.

Ages of the sixty-four older parent-carers were fairly evenly spread across the sixties, seventies and eighties with an average age of 69 years[7] with six participants in their late fifties (and who had partners 60 years and older). Over three-quarters of the participants were women who identified as the primary parent-carer, which is consistent with social role expectations and an increased life span for women. The majority of participants, 61 per cent, were married and living with their partners. Thirty-nine per cent were caring alone, due to divorce (11 per cent), or being a widow (22 per cent) or widower (6 per cent). Among the adult sons and daughters with intellectual disability, over half (58 per cent) had an additional condition such as cerebral palsy, epilepsy, and other physical disabilities. The eldest adult child with intellectual disability was 74, the youngest 21 with an average age of 38 years.

We were pleased to attract participants from a range of parent-caring relationships. Almost half of the parent-carers (48 per cent) still had their adult son or daughter with intellectual disability living full time in the family home. Other arrangements included living in a residential facility or hostel (23 per cent), independent living with another disabled person or

[7] All percentages in this report are rounded to the nearest whole number.

alone (16 per cent), living in a group home (9 per cent) and, living half time with their parents and half time in a service facility (3 per cent). For those adults with intellectual disability now living away from home, around one-third (33 per cent) had moved out of home as young adults in their twenties; 14 per cent had been placed out of home during their school years (from 5 to 18 years of age), and one child had been placed prior to starting school. Demographic characteristics are included in Tables 1 and 2. Table 3 shows stratification of the study participants by age (<69 and 70>), partnered or lone carers, gender of carer and residence of adult child. Older parent-carers missing from these participants are those of Aboriginal and Torres Strait Islander descent and those from culturally and linguistically diverse backgrounds. Our recruitment strategies failed to reach and engage the interests of these older parent-carers which is a major omission awaiting redress at a later date.

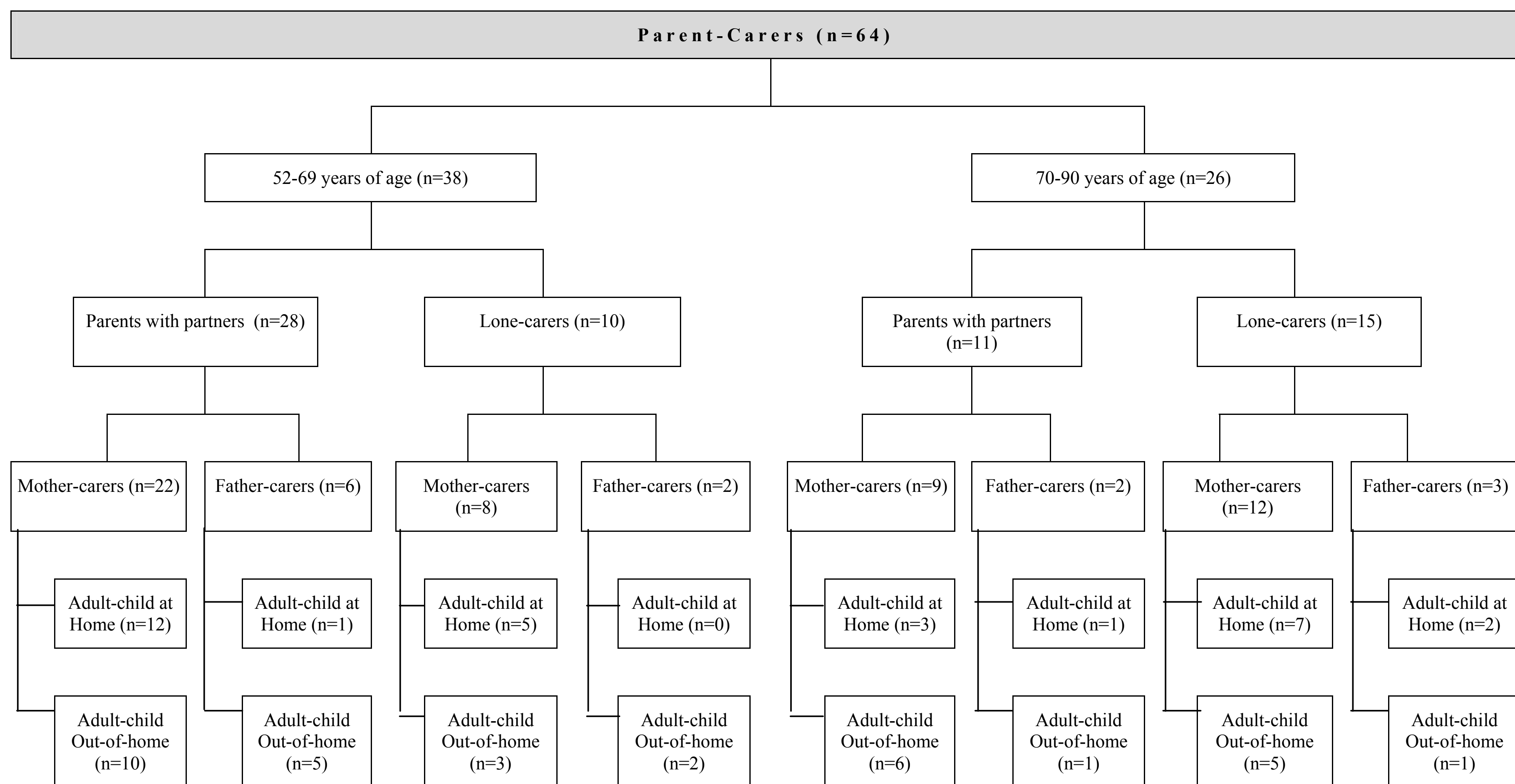
Table 1: The parent-carers (n=64)

Parent-carers	N=64
Mother-carers	N=51
Father-carers	N=13
Age	
Range	52-90 years
Mean	68.7 years
Marital status	
Married	39
Widowed	18
Divorced	7

Table 2: The adult-children with a disability

Adult-children	N=64
Sons	N=33
Daughters	N=31
Age	
Range	21-74 years
Mean	38.4 years
Residence	
With parents	31 (48%)
Group home	6 (9%)
Independent living	10 (16%)
Residential care facility	15 (23%)
Half time parents/ half in residential service	2 (3%)

Table 3: Older parent-carers by age, marital status, gender and adult child place of residence



The interviews

Parent-carers were interviewed in their own home or at another location of their choosing. Interviews were conversational in style providing the opportunity for the older parent carer to 'tell their story'. Interviews usually began with an open-ended question such as "how are things going with you and your adult son (daughter) these days?" In the interview we sought to answer the following questions:

- What is the older parent's point of view about their life-long caring role?
- What major life events have resulted in adaptational changes or stresses on their parent-caring relationship?
- How does the older parent regard their health status and what changes in their health status would they regard as desirable?
- How does the older parent negotiate and experience support with their immediate family, extended family, friends and the wider community including health and community care services?
- What is the older parent's point of view about the likely future for themselves and for their adult son or daughter? How do they regard the place of services in their parent-caring relationship and do they anticipate that this may change in the future? What events can they foresee that may lead to their seeking help or additional assistance?
- All participants were followed up by telephone approximately one month after the initial interview to provide an opportunity to clarify or expand on the original material and for the interviewer to seek additional material based on preliminary analysis of the interview transcripts. Approximately one-fifth (n=13) of the participants, all of whom were over the age of 70, were interviewed a second time to explore and expand our thematic analysis of the parent-caring biography in later life.

Interview analysis

Textual analysis of transcribed interviews was conducted based on the narrative approach developed by Riessman (1993). A parent-caring biography was developed for each participant detailing their broader experience of parent-caring relationships and inter-relationships with family, friends, formal services and the wider community. Close attention was paid to critical events and decision points described by participants over their parent-caring career. A typical parent-caring biography was subsequently constructed. This draws attention to new phases and ongoing experiences as older parent-carers negotiate and re-negotiate their parent and carer status over their lifetime.

From in-depth analysis of each older parent-carer individual biography, we derived a typology based on older parent carers' perceptions of their parental status. This helps to explain differential patterns of negotiation and engagement employed by older parent-carers in their relationships with the service system. A participants of service providers from Northern Metropolitan region participated in focus groups. The findings from this qualitative component of the study are presented in sections 4 to 6. Prior to this in sections 2 and 3 we report quantitative data collected to assist – in the absence of any Australian data – our understanding of the health status and health service use of this group of older parent-carers, their support networks, and their assessment of caring difficulties and the strategies they employ to manage these difficulties.

Standardized self-report tools

The quantitative data was collected using four standardised self-report tools as follows.

- Health status was measured using the MOS 12-item Short Form Health Survey (SF-12) (Ware et al., 1998). This widely used self-report health survey, for which Australian norms have been published, contains 12 questions in 2 subscales. The two scores represent participants' perceived physical health and perceived mental health and their effects on daily life. These scale scores can be compared to Australian normative data from the identical scale scores on the SF-36 (the SF-12 is a shortened form of the SF-36).
- Support network was measured using the Network Assessment Instrument (Wenger, 1994). Physical distance between the respondent and their close family and friends is rated as well as involvement in community activities to generate a network type from five documented possibilities.
- Health service use was assessed using eleven questions selected from the NSW Older Person's Health Survey, 1999 (NSW Health Department, 2000).
- The Carer's Assessment of Difficulties Index (CADI)(Nolan, Grant & Keady, 1998) was used to measure older parent-carers' perceptions of the difficulties associated with caregiving. The CADI contains 30 statements to which carers respond choosing between "this statement does not apply to me" or "this statement applies to me and I find it: not stressful, stressful or very stressful".
- The Carer's Assessment of Managing Index (CAMI)(Nolan, Grant & Keady, 1998) was used to measure older parent-carer's coping strategies. The CAMI contains 37 statements about management strategies to which carers respond by choosing between "I do not use this" or "I use this and find it: not really helpful, quite helpful or very helpful". The CAMI statements are presented on cards. This allows respondents to sort their 'very helpful' strategies in priority order and also prompts carers to tell stories about their caring and coping.

The data from each of these instruments was entered into SPSS v.10 along with data on direct care load (amount of time adult child spends at home and help needed with activities of daily living) and residence of adult child (parental home, group home, independent living, residential care facilities). The statistical procedures used are reported along with the findings in the following two sections on health status and caring and coping. In the interests of brevity in this report only summary findings are presented here. Detailed reports of each section including tables of results are either in press, submitted or in preparation. Information about accessing these additional reports is provided in the relevant footnote in each section.

2

Older parent-caring biography[8]

The following brief overview of the typical older parent-carer biography developed from analysis of the interview material needs to be understood as a narrative. This narrative reflects the commonalities of older parent-carers' lives while not necessarily capturing the particularities of each participant's individual life story. We have organised this biographical summary around five critical events and decision points as follows: finding out and declaring parental responsibility; seeking help; developing expertise; life challenges; and, changing policy and practice.

Finding out and declaring parental responsibility

Older parent-carer's biographies begin with finding out that their child has an impairment. Although devastating the 'news' was rarely unexpected. Mothers in particular reported a sixth sense that they knew something was wrong before their child was born, immediately after, or in the early months. Acknowledging and accepting their child's impairments was often made more difficult by others' negative reactions and rejection of their child. This caused unimaginable hurt but also a declaration of parental responsibility: their child would be loved and cared for as one of their own. This declaration was often reinforced by the contrasting advice coming from others. For example, while typically being advised to place their children in institutional care, none appreciated being given this 'opportunity'. Feeling angry and hurt at this suggestion, many developed feelings of resistance and defiance and became extremely determined to raise their child at home.

Seeking help

Without exception, older parent-carers struggled to get information or to locate somebody who would help their child and provide some hope of a more positive future. Many parents were left in a state of limbo by the ambiguity and uncertainty surrounding diagnosis and predictions for the future. Would their child be better than they dared hoped? Was the outcome likely to be worse? Some frustrated by the perceived rejection of their child decided to go it alone, rely on their own resources and have no more contact with formal services, often for some time. Others became 'locked into' a cycle of visits and searching for answers and multiple opinions.

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[8] Llewellyn, G. (in press). Family decision-making in later life. In Nolan, M., Lundh, U., Grant, G., & Keady, J. (Eds.). *Partnerships in Family Care: Understanding the caregiving career*. Open University Press.

Developing expertise

Over time, parent-carers became experts on their child: they understood their likes and dislikes, activities which pacified their child and the activities to avoid, and tasks that their child could not or would not do. However they also came to realize that their 'lay' knowledge had a secondary status (if any at all) compared to the 'expert' knowledge of professionals. As well, parents most distrusted the 'distanced' stand taken by workers. Parents knowing their children well were able to anticipate their needs and offer appropriate and dignified preventative action. Without intimacy, workers relied on solutions typically formulated after an event. Adding insult to injury, 'professionals' came and went while parents and children remained, getting on as best they knew how with their family lives. 'Decreasing' worker wisdom is seen here to contrast sharply with the parent-carers accumulating and deepening knowledge of their child over time.

Life challenges

Relative to life stages, everyday events threw up particular challenges at different times in their child's life. So, for example, in the early years the significant challenge was seeking out an education and finding a school willing to accept their child when little thought was given to educating disabled children. Parents faced significant barriers to be overcome; the notion and knowledge of special education was just beginning four or five decades ago. Leaving school presented another challenge. With nowhere to go and nothing to do, young adult men and women sat at home with their mothers (and with those fathers who were by now retired). Daily isolation, loneliness and lack of stimulation created significant stresses for parents and their young adult sons and daughters at this time. This is a time when these parent-carers spent many hours desperately searching for any alternative to achieve and maintain meaningful activity in their adult child's life.

Changing policy and practice

Current government policy promotes community living away from the parental home. This is in direct contrast to the policy existing when the now adult children where born. Some older parent-carers were able to work with services to set up small group or independent living situations for their child. Other parents, after years of disappointment or disgust at 'the system', decided to keep their children at home, often 'soldiering on' as lifetime carers now and as well as parents. Others searched for security in knowing someone or an organization who would 'take a keen interest' in their adult child's welfare once they were no longer able to do so. Whatever the case, facing the inevitable future in an uncertain policy climate presented older parent-carers with an emotionally wrenching challenge. Equally worrisome was the lack of meaningful activity available for adults with intellectual disability once too old to work or attend a day centre. With little thought apparently given to retirement activities for disabled people, and particularly for those living in the community, parent concerns focused on their adult child's likely isolation, loneliness and depression.

Confronting their own disability or impending death, a few parents made financial and/ or guardianship plans. Some enlisted the help of others such as siblings with the promise of resources to assist care for their brother or sister in the future. Others hoped, without overtly discussing this with their family, that siblings or other family members would fulfill their

‘responsibilities’. Many continued to put aside thoughts of no longer being able to care for their son or daughter and wished them to die before their own death thus avoiding the painful task of confronting the finality of their parenting career.

Discussion

Older parent-carers in this study reacted strongly against attitudes of rejection, segregation and institutionalization of their young disabled children and developed strong protective parental responses. Our view is that this protective response in the early years later expanded and consolidated into a significantly enhanced sense of parental responsibility. In turn and not surprisingly, this fuelled and continues to fuel older parent-carers’ continuing desire to retain parental control as protectors of their children.

Later life, with the potential adverse changes associated with their own ageing, their children’s ageing and the inevitable realization of life nearing its end, destabilizes this deeply embedded sense of parental control. As parents reach this phase in their parent-caring career they are confronted by many events over which they feel little sense of control. Their diminishing energy, potential ill health, and possible additional caring responsibilities undermine their sense of parental control and drive the growing realization that some or all of this control over their adult son or daughter’s life will need to be relinquished.

In contrast to their confident appraisals in earlier years where they could rely on their parental expertise they are now faced with an entirely new situation without prior experience to draw upon. This situation provokes anxiety because in essence it is about the remainder of their child’s life. At the most fundamental level this anxiety focuses on their adult child receiving a similar standard of physical care to that which they have provided over a lifetime, a concern noted by many authors (e.g., Bigby, 2000; Smith, Fulmer & Tobin, 1994). The greater worry for older parent-carers however is the uncertainty about who *might* or *could* or *will* take their place in making sure their son or daughter is happy and busy and enjoying their lives, a feature also noted by Brubaker and Brubaker (1993).

There is now good evidence from several countries that a substantial proportion of older parents of adults with intellectual disability – in some cases at least half – do not use the family support services that are available to them (Delaney, 1994; Janicki et al., 1999; Pierce, 1991 cited in Bigby, 2000; Smith, 1997; Twigg and Atkin, 1994). A number of reasons have been advanced for this somewhat surprising finding given the potential vulnerability of older parent-carers with increasing age. These include mothers not perceiving a need for many of the services on offer (Smith, 1997); mothers of this generation, without access to services, had to develop coping strategies which in turn, effectively negated their need to seek outside support (Hayden & Heller, 1997); and, feelings of personal responsibility for their child (now an adult), embarrassment and a desire to keep ‘ones’ troubles to oneself’ (Twigg & Atkin, 1994).

As the parent-caring biography illustrates, our participants reflected these generational effects – they felt they had no choice but to manage alone – without services, without support and in many instances, without understanding of their situation. Missing from the literature however is a central theme evident in our older parent-carer biography of their satisfaction with a job well done. The converse of this however is that the area of greatest worry for many of the older parent-carers is the safety, health and well-being of their adult children when they are

not directly under their care. Dissatisfaction with the standards maintained by residential care providers or fear of inadequate attention to basic health needs reinforces for many older parent-carers their view that they are the only ones who can provide appropriate and adequate care.

Negative experiences with services can and do drive caregivers away often for extended periods of time and beyond the time when re-engagement would be in the best interests of the caregiver and the cared-for person. A poorly understood component is the invasion felt by families when medical and other professionals entered their lives and how this permeated all aspects of their everyday lives. In a practical sense, older parent-carers in this study reported being required to alter their preferred daily routines to fit the time schedules of service providers, often traveling long distances and waiting for extended periods to suit the professionals and not the families' convenience.

At a personal level, older parent carers reported feeling all aspects of their family lives open to scrutiny by an ever-changing parade of 'strangers'. Their intimate relationship with their partner, their family values, beliefs and goals for their children, their financial status and many other areas of family life were frequently examined. Whilst recognizing that questioners may have offered the opportunity not to divulge information, our participants frequently reported feeling under 'pressure' to comply for fear of loosing out on a potential service or backlash against their child. Parent-carers' protective responses built up over many decades of caring, coupled with their belief in their ability to provide the best care for their adult children and their desire to do so within the privacy of their family lives, all help to shape their reluctance to look beyond their present situations to a likely uncertain future.

Uncertain policy and practice directions

In one lifetime older parent-carers have experienced the full range of advice on what they should do and how this should be done with their (now adult) children. For example, in relation to where their child should live at birth or in their early years, the 'best' advice was to place their child in an institution and to go home and forget about them. Community attitudes reinforced rejection of disabled children by segregation in institutional care and special schooling at the same time as promoting a sense of protectiveness born out of pity for these 'poor unfortunate' children. Organizations founded by parents at this time worked hard to accumulate bricks and mortar to ensure secure 'birth to death' care for their disabled children.

Within a decade or so, the tide had turned and including people with disabilities in the mainstream of society had become the catch cry of policy makers and professionals. Now children were to be integrated and to take their place in their local school. Parent-carers were expected to give up the special support offered by segregated schooling and welcome this 'mainstreamed' opportunity. Parent organizations providing cradle to the grave care found themselves out of step with policy directives and funding opportunities yet were forced by financial imperatives to take on board, however reluctantly, the fragmentation of their whole of life services. A lifetime of parenting a disabled child leaves older parent-carers with superior knowledge of the 'changing fashion' in disability policy and service provision but without acceptable or adequate solutions to a safe, healthy and meaningful future for their adult son or daughter with intellectual disability.

There is evidence from a number of studies that a significant proportion of older parent-carers, generally around one half to two thirds, do not make plans regarding future financial, residential or guardianship arrangements for their adult sons and daughters (Freedman et al., 1997; Grant, 1986; Heller and Factor, 1991; Kaufmann et al., 1991). This is of serious concern given that one likely outcome is the need for an emergency placement that may be unsuitable and uncertain financial and guardianship status for offspring who survive their parents when no future plans have been put in place.

The desire of service providers that older parent-carers make concrete and detailed plans appears logical in the face of their increasing parental age. Making plans for adults with intellectual disability to live outside the family home also sits comfortably with current service philosophies about the meaning of adulthood, independence and quality of life for adults with intellectual disability. There is a strong financial imperative for policy makers and service providers to consider who will pay for the care of the adult with intellectual disability once their parents are no longer able to do so. In contrast, the interests of older parent-carers in the uncertain future are rooted in their strong parental identities established in response to earlier rejections of their children, their traditions of independence and personal responsibility and their experiences having their parental expertise overlooked or denied. Simply put, for older parent-carers the question is *who* will look after my child and *in the way* that I have done?

The caregiving careers of older parent-carers of adult children with intellectual disability began – and continue - in a different time and place. Confronting the immediate presence of an uncertain future will need to be a central component of case management underpinned by recognition of older parent-carers' lifetime experiences brought to any talk of the future. Successful case management may well hinge on acceptance and affirmation of the unique characteristics of their caring careers in tandem with giving full rein to their strong parental identities. The challenge for policy and practice is to initiate (and then evaluate) family care partnerships that create a more certain future acceptable to both older parent-carers and their adult sons and daughters with intellectual disability.

3

Caring and coping[9]

This section describes the most common difficulties experienced by older parent-carers and the coping strategies they most frequently use and/or find helpful.

Data analysis

Cronbach Alpha coefficients were computed to assess the internal consistency of items comprising each sub-scale of the Carers' Assessment of Difficulties Index (CADI) and Carers' Assessment of Managing Index (CAMI). The alpha coefficients for the five sub-scales that make up the CADI exceeded 0.7, and were generally consistent with previously reported findings (Nolan, Grant & Keady, 1998). Little internal consistency was found for the sub-scales 'poor family support' (-.05) and 'poor professional support' (.60). For the CAMI, the alpha coefficients for each of the three theoretically derived sub-scales were deemed low but acceptable, ranging from 0.64 to 0.69 however no comparable data has been published.

Simple descriptive statistics were used to generate a participants profile, and frequency counts were computed to determine which difficulties were most common and stressful and which coping strategies were most often used and perceived to be helpful. Response rates for all statements comprising the CADI and CAMI are shown in tables 4 and 5. Confidence intervals (95%) for the mean CADI and CAMI subscale scores were computed and compared to determine if any areas of difficulty or coping strategies were more common among the study participants.

Multiple regression analysis was employed to determine the extent to which participants variation on the CADI and CAMI sub-scales could be explained by parent-carer age and gender, lone-carer status, the amount of time the adult child spends at home, and, the level of help the adult child needs with everyday personal care tasks. For each analysis, all independent variables were entered simultaneously. Note that the distribution of data on each CADI sub-scale was visibly skewed. Transformation of the data by computing the square root offered little redress. Cautious interpretation of regression findings is therefore warranted. By contrast, a graphic display of CAMI sub-scale scores revealed a normal distribution.

[9] Llewellyn, McConnell, Mayes, Gething, Kendig and Cant (in preparation). Caring and coping in older parent-carers of adults with intellectual disability

Table 4: Carer Difficulties

	Response %			
	Item-total correlation	Stressful*	Not Stressful	Does not apply
Carer-dependent relationships (Alpha .72)				
The behaviour of the person I care for is a problem	.57	31	6	63
The person I care for can demand too much of me	.55	31	11	58
The person I care for can play me up	.46	27	23	50
The person I care for does not always help as much as they could	.54	17	23	59
I no longer have a meaningful relationship with the person I care for	.11	6	0	94
The person I care for does not always appreciate what I do	.45	5	33	63
There is no satisfaction to be gained from caring	.39	3	6	91
Reactions to caregiving (Alpha .75)				
I can feel helpless/not in control of the situation	.48	45	6	48.
My emotional well-being suffers	.60	35	10	56
It can put a strain an family relationships	.43	31	16	53
I can't relax because of worry about caring	.53	30	3	67
I don't have enough private time for myself	.39	28	20	52
I can't devote enough time to other family members	.45	24	6	70
I feel angry about the situation	.41	14	3	83
I feel guilty about the situation	.30	13	2	86
Physical demands of caring (Alpha .83)				
It is physically tiring	.67	53	14	33
The person I care for is immobile/has problems getting about	.66	33	3	64
My physical health has suffered	.57	31	5	64
The person I care for needs a lot of help with personal care	.79	30	19	52
My sleep is affected	.59	27	6	67
The person I care for is incontinent	.36	16	11	73

* 'stressful' or 'very stressful'

Table 4: cont….

	Response %			
	Item-total correlation	Stressful*	Not Stressful	Does not apply
Restricted social life (Alpha .73)				
It restricts my social life/outside interests	.62	30	23.	47
I can't have a break or take a holiday	.55	27	13	61
I can't see friends as often as I'd like	.51	14	9	77
Poor family support (Alpha -.05)				
Relatives don't keep in touch as often as I'd like	-.02	19	8	73
Some family members don't help as much as they could	-.02	11	14	75
Poor professional support (Alpha .60)				
Professional workers don't seem to appreciate the problems carers face	0.42	41	9	50.
I don't get enough help from the health and social services	0.42	27	6	67
Financial consequences (Alpha .76)				
It causes financial difficulties	0.61	17	5	78.
My standard of living has fallen	0.61	16	0	84

* 'stressful' or 'very stressful'

Table 5: Coping strategies

	Response %			
	Item-total correlation	***Helpful****	***Not really helpful***	***Don't use***
Managing events/problem solving (Alpha .69)				
Relying on your own experience and the expertise you have built up	.24	97	2	2
Finding out as much information as you can about the problem	.58	83	6	11
Establishing a regular routine and sticking to it	.12	78	6	16
Thinking about the problem and finding a way to overcome it	.38	77	5	19
Keeping one step ahead of things by planning in advance	.47	73	2	25
Keeping the person you care for as active as possible	.45	70	6	24
Establishing priorities and concentrating on them	.39	69	5	27
Talking over your problems with someone you trust	.19	66	6	28
Being firm and pointing out to the person you care for what you expect of them	.16	66	6	28
Preventing problems before they happen	.38	59	13	28
Getting as much help as you can from professionals and other service providers	.21	58	17	25
Trying out a number of solutions until you find one that works	.35	48	3.	48
Getting as much practical help as you can from your family	.21	48	3	48
Altering your home environment to make things as easy as possible	.32	31	14	55
Managing meanings (Alpha .65)				
Believing in yourself and your ability to handle the situation	.26	88	6	6
Realising there's always someone worse off than yourself	.27	83	9	8
Taking life one day at a time	.23	83	6	11
Seeing the funny side of the situation	.30	84	3	13
Realising that the person you care for is not to blame for the way they are	.20	78	6	14
Looking for the positive things in each situation	.50	77	9	14
Gritting your teeth and just getting on with it	.19	74	9	17
Accepting the situation as it is	.34	74	14	11
Drawing on strong personal or religious beliefs	.34	69	5	27
Realising that no one is to blame for things	.48	65	10	25
Realising that things are better now than they used to be	.24	48	6.	45
Keeping your emotions and feelings tightly under control	.16	44	27	28
Forgetting about your problems for a short while by day-dreaming or the like	.30	30	3	67
Ignoring the problem and hoping it will go away	-.08	2	6	92

Table 5: cont…

	Response %			
	Item-total correlation	Helpful*	Not really helpful	Don't use
Managing/alleviating stress (Alpha .64)				
Maintaining interests outside caring	.41	81.	2	17
Keeping a little free time for yourself	.29	72	0	28
Taking your mind off things in some way	.47	66	5	30
Getting rid of excess energy and feelings by walking, swimming or other exercise	.44	58	3	55
By having a good cry	.26	38	17	45
Using relaxation techniques, meditation or the like	.36	27	3	70
Letting off steam in some way (e.g. shouting, yelling and the like)	.18	23	20	56
Trying to cheer yourself up by eating, having a drink, smoking or the like	.19	20	9.	70
Attending a self-help group	.22	17	3	80

* 'quite helpful' or 'very helpful'.

Research question 1: What are the most common and stressful difficulties experienced by older parent-carers of adult-sons and adult-daughters with intellectual disability?

- The most frequently cited difficulties were 'It is physically tiring', 'I can feel helpless/not in control of the situation' and 'Professional workers don't seem to appreciate the problems carers face', with 53%, 45% and 41% of participants respectively identifying these difficulties as stressful.
- A substantial proportion, at least 30% of study participants, indicated that 'problematic behaviour and the excessive demands of their adult child, the effects of caring on their emotional well-being and family relationships, and the effects on their physical health and the mobility and personal care demands of their adult child were a source of stress.
- These sources of stress however did not seem to be reflected in the participants' feelings about their relationship with their adult son or daughter or the satisfaction gained from caring. For example, the majority of the study participants (97%) indicated that the statement 'There is no satisfaction to be gained from caring' either *did not apply* to them or was *not stressful*. Similarly, 94% and 95% of parent-carers respectively indicated that the statements 'I no longer have a meaningful relationship with the person I care for' and 'the person I care for does not always appreciate what I do' *did not apply* to them or were not sources of stress.
- The large majority of participants did not feel angry (86%) or guilty (88%) about their situations. However as noted above, a substantial proportion (45%) found that feeling 'helpless' or 'not in control' of the situation was a source of stress, and more than 30% indicated that their emotional well-being suffered, and the strain put on their family relationships by caring for their adult child was also stressful.
- The physical demands of caring was a common theme evidenced in the majority of participants (53%) experiencing the stress of caring being physically tiring. More than 30% also indicated that their physical health suffered and their sleep was affected (27%) as sources of stress. Other stresses experienced by around 30% of the study participants were restrictions on social activities and outside interests and having little private time for themselves and not being able to take a break or a holiday.

The mean scores for each CADI subscale ranged from 1.45 for 'Financial consequences' to 1.94 for 'Poor professional support'. Comparison of 95% confidence intervals for the mean CADI subscale scores showed that 'Poor professional support' (1.68 – 2.20: 95%CI) was a significantly more common source of stress for participants than both 'Poor family support' (1.28 – 1.56: 95%CI), and the 'Carer-dependent relationship' (1.40 - 1.67: 95%CI). No other significant differences were found. This finding suggests that external stressors were more salient than internal stressors (i.e. from within the family) for most of these parent-carers.

Overall the findings *do not* support the common perception that caring for an adult-son or adult-daughter with intellectual disability is overwhelmingly burdensome. This is not unsurprising given the literature that notes the satisfactions to be gained from caregiving (Grant & Nolan, 1993; Grant et al. 1998). It is important to note that despite the sources of stress noted above with the exception of "It is physically tiring", on all other statements the majority of participants noted that the difficulty specified either *does not apply,* or if it did apply, it was *not stressful*. However the significant stress common to study participants is the physically tiring nature of caring for their adult son or daughter. For a substantial proportion

however there are also other related physical stresses including physical health suffering (31%) and sleep being affected (27%) and emotional stresses including feeling helpless/ not in control of the situation (45%) and emotional well-being suffering (35%).

Research question 2: Do the difficulties perceived by older parent-carers vary with their age, gender, lone-carer status, how much time their adult child spends at home and the level of help their adult child needs with everyday personal care tasks?

The five variables above together explain a significant portion of the variance on four subscales as follows:

- Reactions to Caregiving ($F=8.02$, $p<.001$), explaining 42% of the variance;
- Physical Demands Of Caregiving ($F=16.66$, $p<.001$), explaining 59% of the variance;
- Restricted Social Life ($F=8.4$, $p<.001$), explaining 42% of the variance; and,
- Poor Professional Support ($F=5.0$, $p<.002$), explaining 31% of the variance.

  - On the sub-scale 'Reactions to Caregiving', parent-carer age ($T=-3.38$, $p=.001$) and the amount of help their adult child needs with personal care ($T=2.80$, $p=.007$) were salient predictors of perceived difficulties or stress. Specifically, as age increased, level of stress associated with reactions to caregiving decreased. In contrast, as age decreased, the level of stress associated with help needed by an adult son or daughter increased.
  - On the sub-scale 'Physical Demands Of Caring', the salient predictors were the amount of time their adult child spends at home ($T=2.46$, $p=.017$), and the amount of help their adult child needs with personal care ($T=7.04$, $p=.000$). In other words, the more time the adult child with intellectual disability spends at home and the higher their care needs, the more participants experience this as stressful.
  - On the sub-scale 'Restricted Social Life', the salient predictors were parent-carer age ($T=-2.4$, $p=.019$) and the amount of time the adult child with intellectual disability spends at home ($T=4.20$, $p=.000$). As with reactions to caregiving, as age increased, level of stress associated with restrictions to social life decreased. Further, as the amount of time the adult child spends at home increased, the more participants experienced this as stressful.
  - On the sub-scale of 'Poor Professional Support', only the amount of time their adult child spends at home ($T=2.19$, $p=.033$), and the amount of help their adult child needs with personal care ($T=2.13$, $p=.038$) were statistically significant predictors of perceived difficulty or stress. In other words, poor professional support tended to be more a feature and source of stress in the lives of those participants whose adult child spent more time at home with them and/or whose adult child had higher care needs.

Overall, the findings add weight to the differential effects of age on health status reported earlier. In other words, as age increases study participants were more likely to report better mental health as well as lower levels of stress related to their emotional reactions to caregiving and to the restrictions imposed by caregiving on their social life.

Research question 3: What are the most common and helpful coping strategies employed by older parent-carers of an adult-son or adult-daughter with intellectual disability?

- By far the most common coping strategy employed by parent-carers was 'relying on your own experience and the expertise you have built up', with 97% citing this as *helpfu*l or *very helpful*. This strategy was also efficient with only one user finding this not really helpful.
- In similar vein, 88% of parent-carers identified 'believing in yourself and your ability to handle the situation' as a helpful coping strategy. By contrast, 'getting as much help as you can from professionals…' and 'getting as much practical help as you can from your family' were perceived as helpful by just 58% and 48% of parent-carers respectively.
- Other common and helpful coping strategies, employed by more than 80% of study participants, include 'finding out as much information as you can about the situation'; 'taking life one day at a time'; 'seeing the funny side of the situation'; 'realizing that there is always someone worse off than yourself'; and, 'maintaining interests outside caring'. By contrast, 'ignoring the problem and hoping it will go away' was by far the least common coping strategy – only one participant identified this as helpful. The next least used strategy of 'attending a self-help group' was used by 20% of parent-carers.
- The coping strategies almost always perceived as helpful (that is, the most efficient) were not always those most frequently used. For example, keeping a little free time for yourself was identified as helpful by *all* who employed it (72%) however a substantial 28% of participants did not use this strategy. Similarly the small proportion of participants who used attending a self-help group (20%) and relaxation techniques such as meditation and the like (30%) almost always found these to be helpful.
- Some of the frequently used strategies were also identified by a substantial proportion of users as 'not really helpful'. For example, 'keeping your emotions and feelings tightly under control', was employed by 72% of parent-carers, but over one-third (37%) of users said that this was *not really helpful*. Similarly, 55% of study participants indicated using 'having a good cry', however around one-third of these users said it was *not really helpful*. Similarly for the nearly half (44%) of all participants who used 'letting of steam in some way' almost half said that this strategy was *not really helpful*.

The mean score for each CAMI subscale ranged from 2.4 for Managing/alleviating stress to 2.8 for Managing events/problem solving and Managing meanings. Comparison of 95% confidence intervals for the mean sub-scale scores revealed that coping strategies associated with Managing events/problem solving (2.65-2.90; 95%CI) and Managing meanings (2.65-2.89; 95%CI) were more often used and/or perceived to be helpful than strategies associated with Managing/alleviating stress.

Overall, these findings suggest that **self-reliance, whether by choice or by necessity, is the norm** for study participants. Heavy dependence on coping strategies that involve older parent-carers in relying on their own expertise and trusting their own ability to solve difficulties is evident. Alongside these self-reliant strategies is a heavy reliance on cognitively reframing their life situation to be more 'acceptable' than it otherwise might seem (or appear to outsiders) rather than using strategies associated with managing or alleviating stress.

The relative absence of study participants seeking help from other people adds weight to the strong reliance on self-reported by study participants. For example, around one quarter of study participants do not use 'talking over problems with someone they trust' (25%) nor use 'getting as much help as you can from service providers and other professionals' (28%) while nearly half (48%) do not use 'getting as much practical help as you can from family'. Of those participants who do use these strategies the proportion that think they are helpful varies. Almost all who use 'getting as much help as they can from their family' and 'talking over problems with someone they trust' find these strategies helpful. In stark contrast, almost one-third of older parent-carers who use 'getting as much help as they can from service providers and other professionals' find this is not really helpful.

Research question 4: Do the coping strategies employed and perceived as helpful by older parent-carers vary with their age, gender, lone-carer status, how much time their adult child spends at home and the level of help their adult child needs with everyday personal care tasks?

- These five variables together explained a significant 23% of the observed variance on one sub-scale only - Managing/alleviating stress ($F=3.40$, $p<.01$). No statistically significant association was found between these five variables and the other two CAMI sub-scales. Two variables contributed significantly to the prediction. These were parent-carer age ($T=-2.49$, $p=.016$) and gender ($T=-2.25$, $p=.028$). Specifically, the older participants and the male participants in the study participants tended not to use coping strategies associated with Managing/alleviating stress (e.g. having a good cry), and if these were used, they were perceived as not really helpful.

One possible interpretation of these findings is simply that older-parent-carers and father-carers are more stoic in their response to the demands of caring. To examine this more closely, multiple regression analysis was again employed, but this time looking at selected CAMI items and including only parent-carer age and gender as independent variables. The selected items were 'By having a good cry' and 'Keeping emotions and feelings tightly under control'.

- Parent-carer age and gender together explained a significant 16% of the variance on the item 'Keeping emotions and feelings tightly under control' ($F=5.8$, $p=.005$). However, only parent-carer age contributed significantly to the prediction ($T=3.4$, $p=.001$).
- Parent-carer age and gender together explained a significant 22% of the variance on the item 'By having a good cry' ($F=8.8$, $p=.000$), and both parent-carer age ($T=-2.89$, $p=.005$) and gender ($T=-2.5$, $p=.014$) made significant contributions.

Overall, it appears that the younger mother-carers in the study participants were most likely to openly express their emotions and to employ the coping strategy of having a good cry.

4

Health status, support networks and direct care load[10]

This section reports on the health status of parent-carers, and their use of health care services by comparison with their age-peers.

Research question 1: ***Do older parent-carers experience poorer health than their peers in the Australian population?***

Responses of the older parent-carers in the study participants (n=64) were compared to Australian population norms on the SF12.

- Comparison of the confidence intervals for the mean Physical and Mental health component scores on the SF12 for the study participants and the Australian population show that the study participants reported significantly poorer physical and mental health.
- When the participants was stratified by age and compared with equivalent Australian population norms for the age-groups: 55-64 years, 65-74 years and 75+ years, only one age group indicated significantly worse health than the Australian normative population. The youngest group of participants (those aged 55-64 years) reported significantly worse mental health than the Australian normative population.

Research question 2: ***Does the health status of older parent-carers vary with age, gender and marital status?***

Multiple regression analysis was used to examine the association between the health status of the study participants and their age, gender and marital status.

- Parent-carer age, gender and marital status together explained a significant 23% of the variance on the Physical Health component subscale ($F=5.79$, $p<.005$). However, only marital status contributed significantly to the prediction ($T=-2.5$, $p<.05$). The lone parent-carers were experiencing particularly poor physical health.
- Parent-carer age, gender and marital status together explained a significant 18% of the variance on the Mental Health component subscale ($F=4.12$, $p<.05$). However, only parent-carer age contributed significantly to the prediction ($T=2.14$, $p<.05$). The older, older parent-carers (>70 years of age) reported better mental health.

[10] For details see Llewellyn, Mayes, McConnell, Kendig, Gething & Cant (in preparation). Health of older parent-carers of adults with intellectual disability.

Research question 3: Is there an association between health status, support network type, and direct care load?

In the Network Assessment Instrument (Wenger, 1994) five network types are differentiated: local family dependent, locally integrated, local self-contained, wider community focused, and private restricted.

- Locally integrated networks[11] were by far the most common (n=29) in the study participants.
- Frequency of other network type in descending order is as follows: local family dependent (n=10), local self-contained (n=7) and wider community focused (n=7) and private restricted (2). The networks of nine study participants were either mixed or indistinguishable.

Multiple regression analysis was used to examine the association between parent-carer health status (dependent variable), support network and direct care load (independent variables). Direct care load was measured by two variables: the amount of time the adult child spends at home and the amount of help they need with everyday personal care tasks.

- Support network type and direct care load explained a significant 28% of the variance on the Mental Health component scale ($F=7.29$, $p<.001$). No association was found on the Physical Health component scale. The independent variables that contributed significantly to the prediction: locally integrated network type ($T=2.42$, $p<.05$), amount of time the adult child spends at home ($T=-2.01$, $p<.05$), and amount of help the adult child needs with personal care ($T=3.24$, $p<.005$).

These findings suggest that parent-carers with locally integrated support networks experience better mental health. Parent-carers of adult children with higher care needs and/or who spend more time at home suffer poorer mental health.

Research question 4: Do older parent-carers (65+ years) utilize health care services at the same rate as their peers in the NSW population?

Responses of the older parent-carers in the study participants aged 65 and over (n=41) were compared with those of their age peers on eleven health status and health service use questions from the Older Person's Health Survey with persons over 65 years (NSW Health Department, 2000).

- When rating their health compared with 5 years ago, the majority (n=26, 63%) of the study participants stated their health was worse now compared with 42% of respondents stating worse health in the Older Person's Health Survey (normative data).
- Just over one third (37%) of the study participants stated their health was better now or about the same. This contrasted with just over one half (58%) in the normative participants who reported better or about the same health.
- Approximately one third (23 of 64) of the study participants identified arthritis and/ or 'general problems with bones' as the health problems causing them the most difficulty.

[11] Locally integrated: Close relationships with local family, friends and neighbours, often characterized by long-term residence and active community participation. Networks are often larger than in the other types.

- There was little different between study participants and the NSW population with regard to their use of health services such as home nursing, physiotherapy and podiatry.

Discussion

Overall the health status of the study participants is poorer than that of the Australian population at large. The significant differences occur for the younger group in the study participants (those aged 55-64 years) and specifically in relation to their poorer mental health. Within the study participants, health status varies on two dimensions. Married/ defacto parent-carers report better physical health and older parent-carers (that is, 69+ years) report better mental health.

Two people in couple families being available to share the physical care load could potentially explain the first finding. This is supported by the qualitative data where mothers noted that having their husband/ partner to share daily care tasks lightened their load and where fathers frequently noted their 'guilt' at realising, since retirement, the care load previously assumed by their wives/ partners.

The finding that older parent-carers (69+ years) report better mental health appears counter intuitive to suggestions that as parents get older there are increased stresses associated with a potentially uncertain future for themselves and their adult child. It could be however that older parent-carers are more accepting of their situation supported by, as Hayden and Heller (1997) found, well-honed coping strategies developed out of necessity raising their child from a time when little community support was available.

The finding that the younger (55-64) participants report significantly poorer mental health is of particular concern given it is likely they will be caring for several more decades. As we note later, restrictions imposed on daily life become more evident at the time when non-disabled children become independent. Parent-carers in this age group experience another sharp realisation of how their lives differ from those of their age peers who are contemplating retirement (or are retired), exploring new interests, and experiencing a new found freedom without the responsibilities of dependent children. Careful attention needs to be given to the mental health needs of this group of younger parent-carers in ways which support their desired parent-caring role at the same time as ensuring their best possible mental health for now and their continuing parent-caring career.

5

Older parent-carers engagement with the service system [12]

Following our development of the typical older parent-carer biography we undertook an in-depth analysis of each older parent-carer's individual biography derived from the interview material. We distinguished four groups of older parent-carers as follows: *go it aloners*, *reluctant users*, *tandem partners*, and *services in charge*. The following provides a brief overview of each group of parents. Demographic characteristics of the four groups of older parent-carers are presented in Table 6.

Table 6: Older parent-carer groups

	Go It Alone (n= 24)	**Reluctant Users (n= 13)**	**Tandem partners (n= 9)**	**Services In Charge (n= 17)**
Parental status	High	Working to maintain	Shared	Low/non-existent
Female/ Male	18/ 6	12/1	9/0	11/6
Marital status:				
Married	18	6	5	10
Widowed	5	2	4	6
Divorced	1	5	0	1
Mean age (range)				
Parents	68.4 (53-89)	64.4 (52-77)	72 (59-90)	70.1 (61-87)
Children	37.6 (21-74)	35.4 (28-49)	42.2 (31-61)	38.9 (30-50)
Adult-child living arrangements:				
At home	18	9	3	0
Away from home	6	4	6	17

[12] For a detailed discussion see Llewellyn, G., Gething, L., Kendig, H., & Cant, R. (submitted). Older parent-carers engagement with the service system. *American Journal on Mental Retardation*.

Go It Alone

'Go it alone' parents identify strongly as responsible for determining their adult child's life situation. They resist the label of carer; they view themselves as parents. They hold a high regard for and are satisfied with their parenting. They are 'in control' of their parenting which is expressed by orchestrating how their son or daughter lives their life. These parents are unlikely to seek help. Their highly perceived parental status obviates the need to seek assistance. They talk openly about their goals for their adult child in terms of "finding solutions" and "making decisions and getting on with it". In essence, the 'go it alone' parents negotiate their involvement with the service system to support a highly developed sense of parental responsibility and desire for significant influence in the adult children's lives. Their service use is typically restricted to day activities, although some have negotiated out-of-home living arrangements for their adult children with agency support. 'Go it alone' parents are generally satisfied with their current situation and, while not ignoring the future, appear certain that they will be able to achieve acceptable arrangements for the care of their adult children.

Reluctant users

On the other hand, 'reluctant user' parents are more intensively involved with the service system, yet dissatisfied with their unwilling dependence on agency support. These parents express ongoing ambivalence about being 'forced' into continuing their parent-caring role. Unable to fulfil their desires for either themselves or their adult children leaves these older parent-carers resigned yet unhappy with their current parental status and their likely future. A cost for 'reluctant user' parents in attempting to retain some control over the services they receive is lack of freedom and sense of control in their own lives. Many seek some spontaneity in their lives, which is often impossible because they are tied to personal care, respite and day program service models, which they regard as inflexible. They see their peers having self-determining lifestyles that they are denied. They also perceive major constraints to achieving their desires for their adult children. Constraints may include accommodation services being either unwilling to take (or are regarded as unsuitable) for their child; no one else to share the caring (as they are widowed or separated); lack of respite which is adequate for their son or daughter's needs; or, no one else in the family appropriate or willing to take on a primary caring role.

'Reluctant user' parents share a strong desire to see their child settled away from home for a number of reasons, including finalizing arrangements before a move is forced upon them by their own ill health or death; wanting to be relieved of the constant care demands and the toll on their health; thinking it would be more appropriate for their adult son or daughter to be living in an environment with others of the same age; and feeling their own lives are much too restricted. A major difficulty however is being assured that the care provided elsewhere will meet their adult children's needs. 'Reluctant user' parents do not have trusting or supportive relationships with service workers. This is most evident in relation to personal care services. Parents are not willing to leave workers alone with their adult children. Staff changeovers are common, requiring new instruction and the need to support their adult child in adjusting to a new worker. The problem is compounded by the fact that frequently, it takes more than one person to carry out caring activities satisfactorily and safely. Many parents reluctantly resign themselves to using personal care services while simultaneously objecting to their invasiveness in their family life and their drain on family time. Parents also resent the fact that

each worker has their own view about how things should be done and are unwilling to listen to parents who feel they have learnt the best way to help their son or daughter through years of experience.

Tandem Partner

'Tandem partner' parents have negotiated satisfying life situations for themselves and their adult children, based on a shared understanding with service agencies and maintained by trusting and confident relationships with service workers. Their parental status is intact primarily because of the 'good fit' between their beliefs and wishes for their adult children and service arrangements. 'Tandem partner' parents also value the flexible service arrangements offered by agencies that suit their family needs. A strong feature of 'tandem partner' parents' satisfaction with their shared parental status with a service agency is their sense of security about the future, accepting that the future life of their adult child is in the hands of (reasonably) competent others. The situation is not perfect, however. With little stability in the service system, their concerns erupt when changes are mooted or take place in government policy, funding directives or service policy, management or service staff. Increasing age and in some instances deteriorating physical and emotional strength also makes parents more aware of their increasing reliance on continuing to work well with service agencies.

Services in charge

Older parent-carers in this group have the lowest parental status. In contrast to the 'go it alone' parents who are intimately involved in determining the course of their adult children's lives, these parents are 'divorced' from, and outside any sphere of influence over their children's life situation. They have no say in, or control over, what happens in the lives of their adult children, all of whom live away from their parents either in residential hostels, group homes or semi-independently with agency support. Parental status may have been lost many years ago or more recently. Agencies and the service system are in charge and regarded as the decision-makers.

When parents relinquished control early in the child's life, parents talk about placing their child in care. This was viewed as their only option: either because they could not manage their child's behaviours, they were very concerned for their other children, or their living conditions, housing and resources could not support their child's needs. Other children left their homes around the ages of twelve or thirteen. Holding fears for the physical safety and emotional wellbeing of their other children or unmanageable behaviour usually drove this decision. Great effort and time was taken in trying to find a school with residential facilities or a residential care placement with education provided. Parents regarded these places positively and talked about this as if they had sent their child to boarding school. Parent health also acted as a catalyst placing younger children with disabilities in residential care. A final trigger in the move away from home is the death of a parent. Left alone by their husband's deaths, several widows sought alternative accommodation for their adult children although it might take many years to realize their wishes.

‘Services in charge’ parents are not satisfied with the services that their adult children receive. They express a great deal of concern about poor staffing levels, as well as the quality of the staff – noting that often the staff employed are young and inexperienced. They talk about declining quality of staff, and have concerns about the philosophy and ideals of service agencies. One overriding concern is the lack of respect paid by staff to parents’ knowledge, ideas and wishes for their adult children. They are also concerned about lack of attention to their adult child’s medical needs and physical health. These parents are most concerned about the unanticipated and increasingly more frequent changes in government policy that require agencies to reconfigure the services they offer. Parents live with the fear that the agency may ‘reject’ their child, either because of their behaviours or because policy directives change. Fear of the future looms very large in their lives. The greatest concern for these parents is having no idea what to do if their adult children no longer have a place to live away from home. Controlled by and dependent on stability in the service system and agency goodwill, ‘services in charge’ parents are extremely vulnerable to any systemic changes.

Discussion

The generational cohort effects such as a ‘culture’ of personal responsibility noted earlier go some way to help explaining differences between generations, however these fail to take into account the different expectations and solutions achieved by parent-carers within a generational cohort. Our analysis of older parent-carer narratives briefly described above uncovers differential engagement with, and experience of, the service system.

These differing expressions of relationships between older parent-carers and the service system raise a number of issues for consideration. The first is the critical importance of including sound strategies and rigorous methods in service practices that are able to uncover older parent-carers’ beliefs and values and their expectations of desired life situations for themselves and their adult children. Without service policies which explicitly acknowledge older parent-carers' narratives, we run the risk of continuing to impose ‘standard’ solutions that deny individual differences and distance those we aim to assist. Second, the findings from this study refute services fashioning their practices according to whether adult children remain at home with their parents. We found that place of residence of adult children was not a determining factor in older parent-carers’ satisfaction (or lack of) with services. Third, older parent-carers’ use of and satisfaction with the services offered, the fit between services and parent values and adult children’s needs, and the extent to which older parent-carers are confident with and trusting of service workers, are intimately related to the influence they are able to exert over their adult children’s (and by default) their own lives.

This is not so surprising given the experiences common to the paths taken by older parent-carers over their lifetimes that we presented in the previous section. In brief, older parent-carers come to understand that their disabled child is perceived as being less able and consequently less worthy by others. This evokes a strong protective response that ‘sets the scene’ for parents to follow their parenting ‘instincts’ in family care decision-making over their lifetimes. Added to this is a sense of ongoing hurt and deep frustration when, in spite of their developing expertise, parents remain outside those admitted to the inner circle of experts – the professionals. Together, these experiences heighten their strong perceptions of themselves as ‘those who know best’ for their child, irrespective of their child’s age. Set against the background of a swinging pendulum of acceptable practices from segregation to

inclusion, older parent-carers have come to understand themselves and their values as the only stable and responsible constant in their children's lives.

The challenge for the service system is to respect this strongly held parental expectation and belief about constancy at the same time as supporting other parental and family values including achieving adult status for their disabled children (the 'go it aloners'); flexibility and individualized services to promote parent independence ('reluctant users'); a stable and secure future free from funding and policy constraints ('tandem partners'); and, accepting diminished or relinquished parental status for those who desire this without taking away all vestiges of parental control ('services in charge').

Within the cross-sectional study design it was not possible to determine all the factors that influence fluctuating involvement with the service system. For example, declining health or death of a partner or loss of independence can 'force' re-evaluation of the extent to which one can maintain an intensive parent-caring role. External changes such as new and more flexible service options may also attract the attention of older parent-carers increasing their level of engagement with the service system. Although the findings from this study are supported by studies in the generic caregiving literature about why carers do or do not use services (such as inappropriateness of service offered or concerns about security and safety) further work is needed to provide a comprehensive inventory of older parent-carers' concerns implicit in these general statements. Similarly further work is needed to expand indicators of older parent-carers' positive service use. A standout suggestion here is the urgent need to fully explore the service philosophies, policies and practices in services used by 'tandem partner' parents and their relationships with their service workers. Knowing what works and why for these older parent-carers and their adult sons and daughters with intellectual disability would go some way to providing sound data upon which service models acceptable to older parent-carers could be developed.

6

Service providers' perspectives

Our intention was to hold four focus groups, two in the Central Coast area and two in the area bounded by North Sydney- Berowra-Ryde- and the Peninsula. Invitations were sent to the 13 agencies that had referred older parent-carers to the project. In total three focus groups were held, with 17 workers participating. One focus group included workers from the same disability service and who had originally referred participants to the study. In another group most but not all were original referrers, the other participants being colleagues working with older parent-carers. Both these groups were keen to engage with the issue of older parents caring for adult sons and daughters with intellectual disability. In the third group, the opposite occurred: few still worked in the positions held at the time of referral and there was a reluctance to engage with issues raised. In the final group, which did not proceed, all referring workers had moved departments, taken maternity leave or resigned. This not only made them difficult to contact, it required a measure of explanation about the research project to an appropriate 'alternative' person (who was also often very difficult to locate) before an invitation to participate in a focus group could be sent out. This group was arranged on two separate occasions. On both occasions workers failed to turn up, despite reminder phone calls and agreement to participate.

For ease the discussion from the focus groups is presented under three headings. Under the first two, issues raised and possible solutions respectively, summary comments are noted as dot points. The third heading summarises the similarities and differences found between workers' and older parent-carers' perspectives on difficulties of caring and managing strategies.

Issues raised

Declining health and energy levels compounding difficulties

Workers reported declining health and energy levels that raised anxiety in older parent-carers. This could be exacerbated by age-related additional impairments for their son or daughter and oftentimes also for their spouse. There is also the loss of social support associated with their networks dissipating with age. These situations compound parents' fears and anxieties about the future with parents universally expressing their wishes that their child would die first – leaving some parents to consider suicide for themselves and their adult child

Parent values, beliefs and past experiences, a barrier to accessing services

Values were seen to be generational as well as reflecting individual families beliefs and ideas. Specific values thought by workers to be held by older parent-carers were: asking for assistance was unacceptable as this constituted an admission of failure and/or dependency; dignity and pride and a belief in coping independently; reluctance to draw attention to themselves and a fear of losing what little they have if seen as a "troublemaker"; guilt and sadness of possibly having to pass the parent-carer baton on to another son or daughter, a situation they wished to avoid at all costs; and, unwillingness to reconsider services given their disastrous experiences in the past.

Parent-carers economic and household situations help determine responses

Many older parent-carers particularly after a lifetime of caring for and supporting their now adult child are socio-economically disadvantaged. Some households rely on the disability support benefit as a major source of income. Single parent households are common with household activity organised around the adult child.

Change in and 'distancing' of services

Many older parent-carers previously involved with whole of life non government services are now required to negotiate a complex and challenging service system primarily designed to suit the needs of younger carers. With loss of institutionalisation and parent-initiated organizations, older parent-carers are likely to be increasingly isolated from the support provided by other parents and a 'caring' organization.

Betrayal by the 'system'

Older parent-carers having spent a lifetime initiating services for their children feel betrayed that the services they now need are not available. Indeed, funding priority has gone to families who previously institutionalised their sons or daughters as children. Anger and frustration at missing out despite their lifetime of caring (away from the public purse) not surprisingly causes older parent-carers in this situation to be unlikely to respond positively. They are left with strong feelings of promises broken, rules being changed, feeling cheated, being abandoned and having no choice but to deal with stressful, sad and challenging situations such as searching for a nursing home for their adult son or daughter (often in a crisis situation) after years of keeping their child out of institutional care. They may also be left with feelings of despair and grief for the life they were unable to lead – as they devoted themselves in the absence of few supports to the care of their now adult child with a disability.

Complex, fragmented and alienating system resulting in late, delayed point of contact

Workers reported many challenges facing older parent-carers when they do try to access the service system. Often they do not know what is available. Typically older parent-carers make contact when it is too late and in a crisis situation. Even so there are major challenges. For

example, parents have to argue the case for needing services –this adds insult to injury for those who have cared for their child independently for a lifetime and more so as they now have less energy to argue their case.

Different responses from older and younger parent-carers

Older parent-carers may also regard the variety of services being accessed by younger parent-carers with suspicion and a degree of sadness. According to service providers' older carers have mixed attitudes about services younger families receive. They may be:

- Scornful that a younger parent is not 'doing their job' by having services to assist with the parenting role
- Jealous or resentful that they did not have the same opportunity for services when their children were younger
- Remorseful if they find a service that meets their needs, as this can lead parents to think "Have I wasted my time for 40 years? I could have had this sooner."
- Grief at the 'what ifs': "if I had had those services now available, I could have had a very different life"
- Mourning at lost opportunities for themselves by fighting to keep their child at home
- But also sad for families who do not keep their child at home for their loss of a closer relationship with their child.

Furthermore, services are typically focused on the needs of younger carers: early intervention, transition services, respite and leisure activities, post-school options and so on.

Professionals not understanding older parent-carers' issues and concerns

Given changes in policy and service provision over their lifetimes, service providers (often generations younger) are unable to appreciate older parent-carers' lifetime of caring and the situation in which this took place. Many have never seen institutional care – nor experienced society's rejection and exclusion of children who now attend school, community activities, get help to prepare for employment, live in the community, and in many instances, also become parents themselves. For older parent-carers they may see these younger professionals as lacking knowledge or arrogant; it may simply be the case that the professional has no idea about and even less understanding of previous service contexts.

Possible solutions from service providers' perspectives

- Provide better, more accessible and simpler information about entitlements and ensure this is available at community contact points such as general practitioners
- Reduce duplication with one central point of access for older parent-carers across all systems: health, ageing, and disability
- Provide high quality support for future planning: legal, financial, accommodation and emotional and social support

- Provide planning for the future which takes into account the desires of parents, the individual with a disability and other family members and which focuses on providing ongoing supportive and knowledgeable care for the individual taking into account their routines, preferences and needs
- Provide support and assistance to the family – not just the one identified parent-carer and the adult with a disability but to both parents and their relationship and others in the immediate family particularly given some of the potentially difficult issues around siblings taking on ongoing care
- Provide a greater and more flexible range of daily living services (meals on wheels, laundry services, personal assistance) to reduce the physical load of caring
- Provide accommodation options including village style accommodation, which is (anecdotally) much desired by older parent-carers.

Perspectives on older parent-carers' difficulties and managing strategies

During the focus groups workers were asked to rate the most to least stressful issue for older parent-carers on the CADI, and the most to least useful management strategy used by older parent-carers on the CAMI. There was reasonable consensus on management strategies (CAMI) with little agreement on older parent-carer difficulties (CADI). This was in direct contrast to the older parent-carer participants' responses. Older parent-carers used (and found helpful) diverse management strategies but were more likely to agree on the difficulties of caring.

The three CADI items identified by the greatest number of workers as causing the most difficulty were 'I feel guilty about the situation', 'Professional workers don't seem to appreciate the problems carers face', and 'I can't devote enough time to other family members'. In contrast 86% of the older parent-carer participants reported that feeling guilty about the situation did not apply to them or was not stressful. When the items were ranked according to older parent-carers' perceptions of most to least stressful difficulties, feeling guilty about the situation was almost the last to be considered stressful (28th out of 30) with not being able to devote enough time to family members also being ranked low at 20th out of 30. Where there was agreement between older parent-carers and workers was in reporting that 'professional workers don't seem to appreciate the problems carers face'. Forty-one percent of older parent-carers identified this item as stressful (the third highest item); on average, this item was identified second by workers as causing most difficulty for older parent-carers.

The top five management items identified by workers show a reasonable degree of consensus with those strategies identified by older parent-carers. These are included in Table 7 with the commonly identified strategies noted in italics.

Table 7: Top five management strategies identified by workers and older parent-carers

Worker Identified Management Strategies	Older Parent-Carer Identified Management Strategies
1. Realizing there's always someone worse off than me	1. Relying on my own experience and the expertise I have built up
2. Taking life one day at a time	2. Seeing the funny side of the situation
3. Remembering all the good times I used to have with the person I cared for	*3. Realizing there's always someone worse off than me*
4. Realizing that the person I care for is not to blame	4. Maintaining interests outside caring
5. Talking over my problems with someone I trust	*5. Realizing the person I care for is not to blame*

7

Lessons learnt: Invisible carers facing an uncertain future

In this section we present our analysis and synthesis of the findings of this study in light of previous reports and the national and international research literature. We have chosen to present this synthesis under six headings based on the themes evident in our research and the research of others. From this we draw out the implications for policy and practice and summarise these in four key recommendations in the final section of the report.

Advancing age

Becoming older after an adult lifetime of caring brings physical and emotional tiredness and concern for the future. Faced with the non-normative expectation that, as older parents, they will most likely die before their cared-for adult son or daughter heightens the anxiety already felt about the likelihood of deteriorating health and being unable to continue primary carer responsibilities. While many authors have commented on how few older parent-carers plan for the inevitable future it would be most unwise to conclude that the future is not an immediate concern in every older parent-carers' mind. Although expressed in different ways by parents in each of our four groups all confirmed that their fears for the future are firmly embedded in their everyday lives. The following quote from a mother in a study by Richardson and Ritchie (1986) summarises this succinctly:

> "…it (the future) starts off as an occasional niggle at the back of your mind when your child is young and builds up, year by unrelenting year, to a constant crescendo of concern".

Duration of care

An adult lifetime of care by parents – for the entire life of their adult son or daughter, 20 or 30 or 40 or 50 years – creates an emotional, physical and (in many cases) financial inter-dependence between parent and adult child with a disability not typically encountered between parents and their adult children. Despite family-centred approaches becoming the new mantra in disability services, most service delivery systems continue to identify the individual with the disability as the primary 'client'. For older parent-carers this flies in the face of their family reality where their lives and that of their adult son or daughter with a disability are inextricably linked over a lifetime together.

Lone carers

Older parent-carers are more likely to be caring alone either through death of their partner (most usually a husband) or breakdown of their marriage frequently reported to be due to the atypical demands placed on family relationships by childhood (and later, adult) disability. Likelihood of caring alone increases with age as our findings demonstrate: 35% of our participants under 69 years of age were lone carers with this figure increasing to 57% for older parent-carers over 70 years of age. Additionally, as parent-carers grow older they face loss of support (through death or declining health) from key family members – their own parents and siblings – and from friends and extended family.

Distancing from professionals and the service system

As the typical caring biography derived from our participants' narratives demonstrates, older parent-carers experienced early rejection and exclusion from professional services and an institutional service system. As Walker and Walker (1998) aptly summarise " Parents of a learning disabled (intellectually disabled) child were often faced with the stark choice between institutional care and unsupported care at home" (p. 10). Few service providers, policy personnel, professionals or politicians, being considerably younger, have direct experience of the limited options available to older parent-carers in the 1950's –1970's. Their professional experience of a considerably different service system (1980's to present) that promotes early intervention, family support, and independence for children and adults leaves them *ill-prepared to appreciate* older parent-carers' caution, suspicion, and downright cynicism of the service systems' ability to support or assist their family.

Strong self-reliance and reluctance to seek help

Several authors have noted the seeming reluctance of older parent-carers to seek assistance even when their situation appears to warrant help from the paid service system. Walker and Walker (1998, p. 11) summarise the reasons suggested across a number of studies as follows: a reaction to their struggle to get help in the past; rejection of assistance in the past; dissatisfaction with current or past provision; a very deep sense of personal responsibility; the belief that requesting help is a sign on failure on their part; the fear that drawing attention to their own difficulties could result in a withdrawal of services or lose control over the care of their adult son or daughter.

We would add to this our strong conclusion that how parent-carers engage (or otherwise) with the service system is firmly driven by their experience of the past. Three findings are pertinent. The first is our finding of strong protective parental responses and the consequent heightened sense of parental responsibility developed early in their parenting-caring careers which remains aided and abetted by professional denial of their expertise, thus delegating older parent-carers to remaining outside the 'circle of experts'. This results in older parent-carers turning first to "falling back on their own devices".

The second is the well-honed coping strategies reported by our study participants in particular 'relying on your own experience and expertise that you have built up' (used and found helpful by 98% and 97% respectively of our study participants) and 'believing in yourself and your ability to handle the situation' (used and found helpful by 94% and 88% respectively).

The third is a not unexpected cautious reaction to seeking assistance in a constantly changing climate of policy and practice with little, if any, sense of security about the "next moves" by government, funding agencies and the service system in relation to ongoing support to adults with an intellectual disability. This is particularly worrisome when older parent-carers have experienced (or heard by report) unsatisfactory or downright abusive service practices. As we argue in full elsewhere[13]:

"Over time parent-carers face remarkably different options and pressures resulting from changes in policy and practice direction. More deeply felt however is the impact these changes have on parental identity and satisfaction. Here we return to our example of where disabled children 'should' live. Older parent-carers participating in this study considered that, in keeping their child at home in the early years, they had rejected public opinion and overcome the objections raised by others. They felt they had done a good job, a not always easy and sometimes quite difficult job. Not surprisingly, they felt an important and deep sense of satisfaction in doing so, and in so doing, becoming a competent parent of a disabled child. This sense of parental competence was reinforced by others changing opinions – parents came to be seen as those solely responsible for their child and as their child's protector ready and willing to provide whole of life care.

With little consultation or regard for their views, the tide of professional sentiment turned and parents became the guilty party if their adult child remained in the family home. Phrases such as 'over-protective parents' entered professional discourse and writers began urging parents to 'let go' of their adult disabled children. Comparisons were drawn between the expected ages of leaving home and independence for non-disabled adults and the so-called extended dependence of disabled adults upon their parents. Institutionalization was now regarded as very bad – and indeed in many situations no longer available – while living away from home was considered the preferred option. In an ironic twist, parents' behaviours now became framed as obstructionist and particularly so with regard to the rights of their adult disabled children. In earlier days they had kept their young children at home (then not advised, and now recommended). Now they were willing to continue their parental responsibilities and have their adult children remain at home with them – their desire to do so now criticized as interfering with their adult son or daughter's right to be independent. Against these deeply conflicting views experienced within one parent-caring lifetime career how certain can an uncertain future become for older parent-carers of adult sons and daughters with intellectual disability?"

Decision-making for the future

There is an inescapable logic in the desire of service providers to have older parent-carers make concrete and detailed plans in the face of an inevitable future. Key concerns include overwhelming demand for supported accommodation, often in crisis situations, which challenge orderly service planning. Currently, unpaid carers through family and other arrangements at little or no cost to governments provide the majority of accommodation support for people with disability. It appears that a key concern for policy makers is a fear that within a short period of time a substantial number of the estimated 3,000 parent-carers aged

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[13] Llewellyn, G. (in press). Family decision-making in later life. In Nolan, M., Lundh, U., Grant, G., & Keady, J. (Eds.). *Partnerships in Family Care: Understanding the caregiving career*. Open University Press.

over 65 in NSW of people with severe and profound handicap will seek accommodation support for their adult sons and daughters[14]. Fear of this (unlikely) 'onslaught' has unsettled a service system driven primarily to supporting people with a disability living away from family.

According to *A Matter of Priority*, *Report on Disability Services*, Second Report, Standing Committee on Social Issues, December 2000, priority in funding has been given to those already living within the residential care system with less attention being paid to families caring for their adult disabled son or daughter at home. The interests of policy makers and service providers could be seen to reside primarily in considering *who will pay for the care* of the adult with intellectual disability once their parents are no longer able to do so rather than the health and welfare of their older parent-carer and their adult disabled child.

The interests of older parent-carers in the uncertain future are rooted in their strong parental identities established in response to earlier rejections of their children, their traditions of independence and personal responsibility and their experiences having their parental expertise overlooked or denied. The key factors, which distinguish this group of older parent-carers, challenge simplistic solutions to engaging these parent-carers in future planning (or at least in ways thought desirable by service agencies). Simply put, for older parent-carers the question is *who* will look after my child and *in the way* that I have done? The following policy and practice implications are offered in the hope of forging a more positive and trusting environment to develop more certain futures for older parent-carers and their adult sons and daughters with intellectual disability.

[14] *A Matter of Priority. Report on Disability Services.* Second Report. Standing Committee on Social Issues, Legislative Council NSW Parliament, December, 2000

8

Implications for policy and practice

We draw this report to a close by summarising the findings from each part of the study into a series of recommendations. Each recommendation has been carefully considered in the light of the findings and relevant literature. We are aware of the emphasis that has been placed in previous reports on older parent-carers in crisis situations (see for example, *A Matter of Priority*, *Report on Disability Services*, Second Report, Standing Committee on Social Issues, December, 2000). While not in anyway suggesting that this emphasis is misplaced we err here on the side of recommendations more directly targeted to the larger group of older parent-carers continuing to care for their adult sons and daughters in the community. These older parent-carers are vulnerable and at-risk, if not in or approaching crisis situations. It is incumbent on government to ensure that they do not join the ranks of those older parent-carers already in crisis.

Recommendation 1

That the NSW government through the Chief Executive Officers of Human Services require:

- All government and government funded services to incorporate a personal futures planning program for older parent-carers, their adult sons and daughters with a disability and other family members in their service offerings and,
- Evaluate these personal futures planning programs against agreed best practice standards.

Rationale

Throughout this study and embedded within the literature is a central theme of older parent-carer reluctance to engage in futures planning. While it can easily be appreciated why this is so, it is incumbent on parent-carers particularly when there is unlikely to be assistance from within the family or their social network, to consider the ongoing everyday living and care needs of their adult son or daughter. There are many instances in NSW where innovative programs have been introduced (albeit initially with some resistance) by non-government organizations to deal with the inevitable future. These programs include a number of components including one-to-one work with older parent-carers, group programs and multi-service initiatives to engage older parent-carers in the planning process (see, for example, Tunnicliff, 2000). Currently other services are only now beginning to become aware of the need to engage older parent-carers in this futures planning process.

There is a good case to be made for gathering examples of best practice in futures planning, preparing resource materials and funding workshops and consultations so that all government and non-government services can benefit from the experience of those already engaged in this process and develop programs and strategies to enhance their own services. Given the importance of this issue of older parent-carers in the context of an ageing population and the interest which this research study addressing this topic has generated it is our considered opinion that such an endeavour by the Department of Ageing, Disability and Home Care would be meet with enthusiasm by the sector and not be overly expensive to implement.

We would see this initiative as being quite practical in nature with experienced service providers offering their wisdom in conducting such programs and contributing to the production of a resource package which details strategies for engaging older parent-carers as well as topics to cover and methods to implement planning in a detailed resource format (possibly including video, on-line resources, training materials and so on) ready for use by service organizations. The essential criteria upon which personal futures planning programs could be evaluated would be drawn from the fundamental question exercising the minds of all our participants (and frequently reported in other studies), that is, *who* will look after my child and *in the way* that I have done? As noted earlier confronting the immediate presence of an uncertain future needs to be a central component of service agencies case management policies and practices. The challenge for policy and practice is to initiate (and then evaluate) family care partnerships that create a more certain future acceptable to both older parent-carers and their adult sons and daughters with intellectual disability. This recommendation provides the foundation for this process to begin.

Recommendation 2

That the NSW government through the Chief Executive Officers of Human Services urgently address:

- In the first instance the need for careful and empirically based planning to develop, in a timely fashion, the services required to support older parent-carers and,
- Secondly the funding required to ensure a more certain future (accommodation, day services, health and personal care and someone to ‘look out’ for them) for the adult sons and daughters of older parent-carers currently living in the community.

Rationale

Throughout this study and in the literature attention has been drawn to the ongoing, debilitating and anxiety provoking concerns of older parent-carers about their adult son or daughter’s future (see, for example, Heller and Factor, 1993 and Delaney, 1994 for the NSW situation). A standout finding in this study was the significance of “I can feel helpless/ not in control of the situation” as a source of stress for older parent-carers. In the absence of any certainty about policy and practice directions older parent-carers are not surprisingly sceptical about bureaucratic ‘solutions’ to their difficulties, which they see as poorly understood. The findings of this study suggest there is an urgent need for innovative policy and alternative accommodation options to be considered in the face of restricted opportunities in government and non-government services for group living arrangements. There appears to be a growing chorus of concern not only about the paucity of available places but also the limited types of

accommodation available. There is also increasing resentment on the part of older parent-carers about this narrow range particularly when there are broader ranges of congregate accommodation options open to other older people in the community, for example, hostel and retirement village living.

While it is not the place here to list all the areas of everyday life about which older parent-carers hold concerns for the future, the issue of adequate health and personal care services which provide a safe environment to ensure their son or daughter's well-being is paramount. Some families in this study – those in tandem with services – have been able to achieve a satisfactory relationship with service providers to allay – for the most part - their fears and concerns about a safe, healthy future. Many older parent-carers have not been able to achieve this and many urgently desire to do so. Years of experience, intimate knowledge of their own child, superior knowledge of the service system and the changes therein, and a heightened motivation to ensure safeguards are in place before it is too late, make this group of older parent-carers an ideal one for government to enlist to assist in working out acceptable and appropriate solutions.

Many older parent-carers, after years of thought, have developed innovative strategies that deserve the undivided attention of politicians, government bureaucrats and service providers alike. We ignore these at our peril faced with a steadily increasing and growing number of older, older parent-carers and older, older adults with intellectual disability.

An often-neglected consideration is who will 'look out' for the adult with intellectual disability once the older parent-carer is no longer able to do so. In the absence of family or friends to take on this role, many older parent-carers are looking for acceptable alternatives. Again, many have developed potential solutions that require careful consideration. The Standing Committee on Social Issues of the NSW Parliament have recently clarified the commitment to government responsibility to people with a disability along with a 'market' for community and welfare services. One innovative solution to ensure someone to 'look out' for an adult son or daughter no longer able to rely on their parents could be a government conducted Support Advocacy Program responsible for the ongoing health, safety and wellbeing of the individual concerned, not as a service provider per se, but as a critical friend, to ensure their emotional and social wellbeing over time.

Recommendation 3

That the future planning needs of older parent-carers and their families are given higher priority:

- In the first instance by the Department of Ageing, Disability and Home Care giving equal policy, funding and service attention to older parent-carers currently caring for their adult son or daughter with a disability at home and,
- Secondly by establishing a consultative process with older parent-carers and organizations which represent their needs to address the consensus finding in this study that *professional workers do not seem to appreciate the problems parents face* and develop information, training and resource strategies to overcome this.

Rationale

The findings of this study support those of other authors who have noted the discrepancy in views held by older parent-carers and their workers (e.g., Grant, McGrath & Ramcharan, 1994). In this study both older parent-carers and professional workers rated "professional workers do not seem to appreciate the problems parents face" as one of the most significant stresses for parents. While some of this can be attributed to older parent-carers and workers coming from different generations and contradictory service contexts (previous institutionalisation policies versus current community care) it would be extremely remiss if this explanation provided support for ongoing and clearly dysfunctional service practices. With an ageing population of parent-carers and their adult children also ageing, it is incumbent upon government and community services to confront and address the specific needs of this group of older parent-carers. Not only have this group lessened a significant community services debt by caring almost single-handedly; they have done so at some cost to themselves (and their health), their families and their adult sons and daughters. In a climate of government rhetoric about prevention and early intervention policies and practices, for example, through the Families First initiative, here is one group of families – well defined as vulnerable and at risk - immediately excluded from family support programs.

The study findings support anecdotal data and that gathered in consultations (see for example, *A Matter of Priority, Report on Disability Services,* Second Report, 2000) that by far the most common strategy older parent-carers use in managing their everyday lives is "relying on your own experience and the expertise you have built up". Given this experience and expertise developed in some cases in excess of three decades of parent-caring a logical and common-sense solution would be to engage older parent-carers in sharing their knowledge and expertise with professional workers. We identified a seeming reluctance on the part of professionals to value parent-carers knowledge – indeed as our participants put it – to deny older parent-carers experiential knowledge and rely on professional technocratic knowledge. One part of that is to deny the self-reliance developed because older parent-carers had little choice and to appreciate now that with increasing age self-reliance may not be such a useful strategy for older parent-carers.

The opportunity now exists to capitalise on older parent-carers' experience and expertise as the foundation for a 'grass roots' information, training and resource package to educate and inform professionals about the real life circumstances, challenges, and the strategies used to manage these developed by experienced older parent-carers over time. And further, to inform, educate and support older parent-carers in later life when uncertainty increases, as their formerly useful self-reliant strategies are no longer as effective in the face of impending health decline, energy depletion and mortality.

Recommendation 4

That the health needs of older parent-carers be accorded higher priority:

- By identifying these needs in general medical practice and,
- By ensuring the necessary community based interventions and supports are in place to reduce unnecessary stress on physical and mental health status.

Rationale

A notable finding in the current study is that the older participants reported their health to be worse than five years ago and the mental health status of the younger parents was significantly worse than that of their age peers and of the older participants. Not surprisingly perhaps, the most frequently cited stressful difficulty was that caring is physically tiring.

The health assessment statutory requirements under the Enhanced Primary Care initiative (Department of Health and Aged Care, 1999, 2000) require among other items that general practitioners ascertain "the patient's social function, including availability and adequacy of paid and unpaid help and whether the patient is responsible for caring for another person" (p. 30, *Enhanced Primary Care*, Royal College of General Practitioners, 2000). This provides an excellent opportunity for general practitioners to find out about the older-parent carer's responsibilities in line with a primary health care assessment (see, for example, Sims et al., 2000 on the role of the general practitioners in Australia in promoting healthy ageing).

Currently the Enhanced Primary Care health assessment requirements are applicable only to those aged 75 and over or in the case of Aboriginal and Torres Strait Islanders to those aged 55 years and over. Given the findings in this study of poorer than population mental health in younger older parent-carers there is a strong case to be made for reducing the age for an annual Enhanced Primary Care health assessment for all parent –carers to at least 60 years of age.

However given the sense of individual parental responsibility demonstrated by older parent-carers and identified by themselves and workers in this study it is highly probable that some may not readily self-identify as carers. There is an urgent need therefore for information to be made available to general practitioners about the at-risk health status of this group of older parent-carers (some of whom between the ages of 60 to 75 years may not currently be considered as older). Further information and training sessions for general practitioners are urgently needed to enable them to appropriately investigate a patient's carer status and subsequently put in place the recommended case planning and case conferencing guidelines to coordinate and supervise appropriate health and community services supports for the older parent-carer and their family.

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