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# Planning and Decision Making about the Future Care of Older Group Home Residents and Transition to Residential Aged Care.

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## Abstract

**Background:** Planning for future care after the death of parental caregivers and adapting disability support systems to achieve the best possible quality of life for people with intellectual disability as they age have been important issues for more than two decades. This study examined perceptions held by family members, group home staff and organisational managers about the future of older residents and the decisions made that a move to residential aged care was necessary. **Methods:** Grounded Dimensional Analysis was used to guide data collection and analysis by an interdisciplinary research team. Three sets of interviews over a period of 18 months were conducted with a family member, house supervisor and the program manager for each of seventeen older group home residents in Victoria. For the 8 people for whom it was decided a move was necessary and the 6 who eventually moved focussed questions were asked about the decision making process. **Results:** Whilst plans for lifelong accommodation in a group home proved unfounded, key person succession plans were effective. However, decisions a move to a residential aged care facility was necessary were made in haste and seen as a fait accompli to involved family members. **Conclusions.** Though family members take seriously their mandate to oversee wellbeing of their older relative, they have little knowledge about their rights or avenues to safeguard untimely or inappropriate decisions being made by professionals.

# Planning and Decision Making about the Future Care of Older Group Home Residents and Transition to Residential Aged Care.

A significantly increased life expectancy and the baby boom generation have led to a growing number of ageing people with intellectual disability (Yang *et al.* 2002). Adapting disability support systems and ensuring access to appropriate health and aged care services to ensure the best possible quality of life for people with intellectual disability as they age have been important issues for more than two decades (Cambridge and Carnaby 2005, Sutton 1993, Bigby 2000, Bigby 2004, Hogg *et al.* 2001, Hogg *et al.* 1988, Janicki and Wisniewski 1985). At the broadest level, international covenants and domestic social policies in most developed countries regard people with intellectual disability as citizens with equal rights (Bigby, 2010). By implication, these policies suggest the same support for a healthy and active old age as the general community can expect. These expectations, which are often aspirational and not always fully spelt out in care standard or regulations, include: the ability to age in place and access to care informed by the principles of rights, choice participation and autonomy. The importance of supported decision making to enable people with intellectual disability to achieve these goals has been championed by the United Nations Convention on the Rights of People with Disabilities (Byrnes, et al., 2007) and is now embedded in Canadian legislation and the subject of law reform processes, at the time of writing, in two Australian jurisdictions (Owen and Griffiths 2009).

As people with intellectual disability age, they are more likely to reside in some form of shared supported accommodation rather than in the family home (Emerson *et al.* 2001), suggesting that this system should be a central focus of planning to support older people to age in place. However a recent review of policies for people with intellectual disability in Australia, USA, UK, Canada and Ireland found few examples of specific policies about aging in place for group home residents and that little progress had been made in any of these countries in addressing ageing in supported accommodation (Bigby, 2010). The intra organisational initiatives within existing resources found in some organisations to adapt support to the changing needs of older people compensates in some instances for the lack of broader systems planning (Janicki *et al.* 2002, Wilkinson *et al.* 2004). However, the sustainability of these initiatives as numbers of older people increase significantly is doubtful (Cooke, 2007). Research both in Australia and the UK suggests that despite the best intentions of some provider organisations older people with intellectual disability remain vulnerable to premature and sometimes inappropriate admission to residential aged care facilities (Bigby *et al.* 2008, Thompson *et al.* 2004)

In contrast to service and system level planning for older age, the likelihood that parents will outlive their adult son or daughter, and anxiety about 'what will happen when I die' has been a catalyst for identification of 'older carers' and programs to support both their continued caring and planning for the future care of their offspring (Bigby and Ozanne 2004, Freedman *et al.* 1997, Bowey and McGlaughlin 2005, Bowey and McGlaughlin 2007, Heller and Caldwell 2006, Heller and Kramer 2009). The emphasis of this type of more individualised planning has been on the transition from parental care which occurs in mid life for the person with intellectual disability and old age for their parents. The focus has been on accommodation, financial and guardianship issues. Continued informal support or advocacy provided by siblings, other relatives or family friends has also been flagged as important given the difficulty of parents making formal plans for the next 40 or 50 years of their middle aged child's life. (Krauss *et al.* 1996, Seltzer and Seltzer 1985, Bigby 1996). Bigby's (2000) Australian study that looked retrospectively at the implementation of plans for older adults who had spent the first four decades of their life in the family home, demonstrated the effectiveness of informal, 'key person succession plans'. Such plans were characterised by the 'planned transfer of responsibility for overseeing the well-being of the person with intellectual disability to a nominated person' thus replacing some but not all aspects of the parental role (Bigby, 1997, p.300). They ensured someone committed to the adult with intellectual disability was available to oversee their well being, act as an advocate especially in respect of formal services, and respond flexibly to the contingencies likely to arise in the post parental care phase of the life course. This study highlighted the continuing nature of planning, or the importance of building into plans mechanisms to take account of changed circumstances. Since that time, ideas about building committed networks or circles of informal supporters around a person with intellectual disability have gained widespread recognition through policies of person centred planning and social inclusion (Mansell and Beadle-Brown 2005, Cambridge and Carnaby 2005, O'Brien and O'Brien 2000). Parent led initiatives such as Plan in Canada (Etmanski 2000)and PIN in Australia (www.**pin**.org.au) provide good examples of individual network building to replace roles of parents into the future.  The limited research on later life informal networks indicates siblings, other family members or in some instances others such as church ministers replace some parental roles when parents die, particularly when there has a been a long history of residing in the family home, and that these ‘key person successors’ can play a critical role in their family member’s life (Bigby 1997, Knox and Bigby 2007, Gordon *et al.* 1997, Greenberg 1999, Bigby and Knox 2009).

The study reported here brings together these two bodies of thought about planning for the future and ensuring a good quality of life for people with intellectual disability as they age by examining care transitions for older adults with intellectual disability. Its focus is not transition from parental care that tends to occur in middle age, but later transitions as a person experiences age associated changes to health and functional capacity. The paper examines the interface in the case of group homes residents between the plans made by parents for post parental care and service system responses to their age associated changes. It reports on a subset of data from a larger study that examined pathways into residential aged care for ageing people with an intellectual disability (Webber *et al*. 2006). It considers the planning done by families, staff and organisations about the future care of ageing residents of group homes, their perceptions of the future and how decisions are made about a move from a group home to residential aged care. Its focus is not the often sustained attempts to support ageing in place but the point at which decisions are made that a person can no longer be supported, and how and by whom such decisions are made.

## Methodology

Consistent with its exploratory purpose a qualitative theory generating methodology, Grounded Dimensional Analysis (Bowers & Schatzman, 2009) was used to guide data collection and analysis by an interdisciplinary research team. This is a ‘second generation’ Grounded Theory methodology (Morse et al, 2009). Based on the same theoretical foundations (symbolic interaction) as other Grounded Theory methodologies, and following the same general procedures, Dimensional Analysis is distinguished by the timing and sequencing of theoretical sampling and by the absence of focus on basic social processes (Glaser, 1967)

### Location and sample

The study took place in Victoria, Australia in 13 group homes, each with between 4-6 residents, which were managed by seven government or non-government disability organisations. The group home program aims to support residents to learn new skills, make choices about their life and be active in their community. Rostered staff support residents with household management, self care, personal hygiene and community participation

(Department of Human Service, 2009). Most homes have sleepover staff who are available for emergencies but not generally expected to be awake during night time hours. Group home staff are not trained to care for people with serious or chronic health conditions, but have basic first aid training. Victoria has no mid level policies or systematic strategy in place (apart from individual funding arrangements negotiated one by one with providers) to adapt the level of support that is provided in group homes, for people whose needs change as a result of aging, that would enable residents to age in place. Rather a reading of the legislation that deals with rights of residents in group homes suggests that they cannot regard the group home as their permanent home and may be expected to move if their needs change. For example, one the reasons under section 76 (1) of the Victorian Disability Act (2006) that a disability service provider may give a resident notice to vacate a group home is due to a change in the resident's support needs and the type of support provided is no longer appropriate to meet the resident's needs (Department of Human Services, 2007)

Participants were recruited through an advertisement distributed to the families of residents and staff within organisations providing group home programs in Victoria. Families and staff associated with an ageing person with intellectual disability who was identified by staff as having recently moved to a residential aged care facility or likely to move in the near future were invited to participate. Seventeen clusters of participants were recruited, each of which centred on an older resident (age range at first interview from 49 to 81 with an average age of 60 years). Each cluster included at least one family member, the house supervisor/manager and accommodation/agency manager. One cluster did not include a family member as no family or other unpaid network members could be identified for this resident. For the other 16 residents, family members included two mothers, 12 siblings, one niece and one cousin. Consent was sought from next of kin or formal guardians, and the study was approved by the Human Research Ethics committees of the relevant Universities.

### Data collection

Cluster members were interviewed at the start of the study and then twice more, over the next 12 months, or more often if a serious health issue or care transition occurred. Although several residents were present during interviews with family members, the resource constraints of the project, and communication difficulties, poor health and the severity of intellectual disability precluded their involvement as direct informants. Initial interviews were conducted face to face; for staff this was at the service site and for family members at a place of their choice which was usually their own home. Subsequent interviews were conducted by phone. They lasted from between 2 hours for some of the first round interviews to 15 minutes if no changes had occurred in the previous six months. Following the Grounded Theory Methodology, early interviews were very non directive, asking participants to talk about ageing in a group home, family relationships, contact with group home staff, ideas about future care and how respondents felt about the current support and care provided for the person with an intellectual disability. For those residents who moved to residential aged care, interviews were also conducted with staff and managers of residential aged care, at the time of move and again after about six months. For these residents, the initial interviews with cluster members about planning and expectations for future care were followed by detailed questioning about the process used for decision making. In total 120 separate interviews were conducted with 59 individuals by the three authors and a senior research associate. Interviews were transcribed and distributed to the team for analysis. Analysis was conducted on each interview prior to conducting follow up interviews. Follow up interviews were not always conducted by the same researcher. However, as the entire research team was involved in analysis of each interview, interviewers always had knowledge of past interviews.

## Analysis

Analysis was done collaboratively by the research team using Grounded Dimensional Analysis which though similar in many respects to Grounded Theory differs in the balance between open and axial coding by continuing open coding much longer and does not adhere to the coding families identified by Glaser (Caron & Bowers, 2000; Bowers & Schatzman, 2009; Glaser, 1967; Strauss, 1987). In keeping with the theory-generating approach, early interviews were open and exploratory, evolving over time to become more focused, facilitating axial and selective coding. Open coding of initial interviews revealed a significant number of comments about health issues, responses to developing health conditions, the relevance of the conditions for continued residence in the group home, and expectations about future care. In particular spontaneous references to continued residence versus a move to aged care were common in these descriptions. Several directions were pursued during axial coding, including the process of making decisions about staying or leaving and the response and actions that such decisions triggered. Respondents were asked to talk about what decisions had been made, how, at what point and by whom they were made, and what had followed such decisions. As the sample was fixed, and follow up interviews were conducted with all participants, theoretical sampling was achieved through evolution of interview questions rather than through selection of participants. Emerging themes were discussed regularly at face to face meetings and teleconferences. Initial analysis was shared with a steering group for the project drawn from recognised experienced advocates and practitioners from the aged care and disability fields.

## Findings and Discussion

### Family roles and relationships: Overseeing Wellbeing

For all but one of the older people whose parents had died, another family member had replaced at least some of the roles previously played by parents. Similar to Bigby's findings in 1997 this had been foreshadowed informally before the death of parents.

> another cousin and I had always said we would look out for Adam in the event of his parents passing and his mother passed away six years ago, next month actually, and, so Brian and I stepped in ([1]cousin, 11, 1)

> I did it because I knew Mum was getting elderly and I'd always promised that I would be there to look after him (sister, 4, 1)

For the two people whose parent was still alive some of the parents' role was being taken over by other relatives. Family members demonstrated a strong sense of 'caring about' the older person with intellectual disability, which was characterised by looking out for them or overseeing the care they received and their wellbeing. They talked about this role as being an 'advocate' 'protector' or 'keeping an eye out'.

> My attempt is to every couple of weeks to get out there and see him. ....simply to keep a tap on exactly how he is because I tend to feel myself that it's best just to keep an eye on him otherwise in the end you're just leaving it up to them and I've said to them continually, it doesn't matter what time, day or night that you ring, you ring if there's any major problem of any sort so. (brother, 1, 1)

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[1] [1] The source of quotes is identified by relationships of informant to the person with intellectual disability, number of the cluster to which they belong and the number of the interview, i.e. cousin, cluster 11, interview 1 as cousin, 11,1,

> Oh, well I suppose I'd see myself as being a bit of a protector because of her rights, and because she doesn't speak, and so she can't look after herself, and but I also see myself as her sister, so, and my daughter sees herself as her niece. (sister, 13, 1)

The 'caring about' tasks family members undertook varied but included: regular visiting or phone contact with both the older person and group home staff; providing companionship through visits and outings; managing financial affairs; being a point of contact for the house about health or other issues that required decisions to be made.

In several instances family members were also more directly involved in the day to day organisation of health care and took responsibility for making and attending appointments with GPs and specialists. However, their role did not extend trying to 'caring for' or tending tasks (Dalley, 1988). Although one relative usually took the lead, they often shared tasks or were supported by their siblings, spouse or adult children.

> my brother and I are his guardians, my son looks after his finances because he has some money left to him, sort of like a financial power of attorney. ..Advocate? Richard, my brother does that. (sister, 10, 1)

> I've taken the role of Mum I suppose, …my husband is really good too (sister, 3, 3)

### Family perceptions of the future: An unanticipated but inevitable line between group homes and aged care that will be crossed

Many family members had assumed the person with intellectual disability would have lifelong care in the group home once they left the institution or the family home, or at least continuing care within the organization. For example, the two mothers referred to the time, energy and funds they had invested in non government organisations with the hope these would provide lifelong care for their adult son or daughter. This had been in the form of bricks and mortar such as the establishment of farms, housing and workshops. Both these two mothers and some siblings reflected their disappointment that staff and policy changes had undermined such plans or in failing to consider old age plans had not gone far enough.

> Well, the reason we'd started the farm was that as the people aged they would be there for life. (sister, 6, 1)

> We raised the money and we built the workshop and we built the residential….Our idea then was the original place would be there for our people when they got old but

> that didn't happen, we got a new administrator in and she changed things which upset a lot of us ….they did the right thing by building these three houses but they should have thought of something for later on when those people get older and need more help. (mother, 18, 1)

Although siblings paid less attention to the future than parents had many had also assumed or hoped that their relative had a lifelong place in the group home. For example, in reply to a researcher's question about what might happen in the future one sister said, 'you must think I'm awful for not thinking about it'. Another two said;

> they said we'll keep them all their life and there was an old people's home around further and I thought well that's what they'll do, they'll all go on to the next stage. (sister, 10, 1)

> Well I think that's something that my sister and I have never discussed, (sister, 9, 1)

However, discussion with house staff who raised questions about future accommodation or conversations with the researchers acted a catalyst for some siblings to consider the future more deeply and change their views. Despite some having been more hopeful earlier, by the end of the study siblings held the view of 'fully expecting the day will come' when a move to residential aged care would be inevitable.

> Basically the answer is, no I haven't thought about it. There's been no plan, no thinking, and no discussion at all. ...And somehow in my mind I thought there was some magic place within Bethel they moved them on, but I'm realizing that there isn't and he will become part of the aged care federal government system which is absolutely terrifying (sister, 8, 1)

> Now I suppose the subject does come up, but nobody addresses it or goes further… and we have always been of the opinion that the time will come, possibly Robert would have to retire, not just from work, but also from this facility and alternative accommodation would have to be found. (brother, 3, 1)

> I fully expect that one day he will be in a nursing home because the staff won't be able to manage five elderly men who will be in all form of dementia. (sister, 6, 1)

Whether it had been thrust upon them by group home staff, arrived at in a collaborative fashion or the realisation had came more slowly, family members envisaged that one day their relative would cross a line that meant their ‘needs can’t be met’ within the capacity of the group home and they would have to move. Views about what that line constituted lacked specificity and varied considerably from: needing a more appropriate place; remaining would jeopardize their health; requiring one to one care provision which was not possible; funding for the group home was restricted to a certain number of carers or their relative no longer the type of person for whom group homes were set up.

> if she has to leave there because she’s getting older, and they can’t manage her health any more. (sister, 13, 1)

> if they had of got the right funding but in reality this is not a group home that can cater for someone not going to work, it’s not staffed like that because the people who live in group homes are supposed to be competent. (sister, 15, 1)

## Staff and organisational perspectives: ‘We are not set up for that type of care’

### *Staff perspectives*

Staff were much clearer than family members and without having to rethink prior assumptions, they thought the time would come when a line would be crossed and older residents would have move to residential aged care. Many expressed a similar sentiment however, that they ‘wouldn’t wish that on anyone’. Staff members varied in their views about what constituted the line but were more definite and specific than family members, often unquestionably accepting the right of others to make an assessment. The line would be either crossed when: they assumed that better care could be provided somewhere else; an assessment had been made that the group home could not provide the necessary care or when a person’s condition had changed and they considered the group home was not set up to provide that type of care.

> she will perhaps never have the care she’s getting here like the one on one but she’ll have specialized trained people in aged care, she’ll have the nutritional diet already made there and hopefully the doctors that can see her regularly if she needs regular enemas which is the other thing we’re looking at is if she, she could possibly have regular enemas. (house supervisor, 12, 1)

> the person has actually been assessed as needing nursing home care, we can’t provide that care… (house supervisor 2 & 9, 1)

Some staff suggested there would be no choice in the matter, that it was driven by the duty of care they owed to their clients. For example one house supervisor said:

> …….unfortunately they [families] can resist all they like, if we cannot provide the care, our duty of care is to the client we cannot provide that care we can no longer have them here. (house supervisor, 1, 1)

Where staff drew the line however was not referenced to objective indicators, rather it was relative to the customary care provided in each particular group home and the pre existing staffing, design or resident characteristics. It was therefore highly variable.  For example, where a house did not have active night staff it was suggested the line may be crossed when an older resident required this, whereas other houses already had active night staff as a matter of course. Examples of discrepancies about where staff thought the line should be drawn were also found in relation to medical procedures, mobility issues and personal care tasks.

> Unless it becomes really a proper nursing thing that they need injections or they need really complex dressing and things like that, wound care and things like that because we just don't have that care.  But if it's short term that's not a problem, we're talking about long term (house supervisor, 1, 1)

> ... in my opinion, whether that person needed to have PRN [administer as needed] for behaviours, I think that would be the tipping point for this type of accommodation...PRN, if their behaviour was such that they needed to be medicated like on call sort of thing, that would be a turning point in whether you can manage that here. (house supervisor 15 & 18, 2)

> We are not the medical model we can't provide her with the specialist medical care that she needs (agency manager, 12, 1)

> The group home is not really set up for wheelchair access (brother, 16, 1)

*Organisational perspectives*

More senior organizational staff were very aware of the looming issues associated with increasing number of older residents, but organizational responses were in the early stages of development

> ...think it’s the partnership with the Aged Care and we’re very much talking about that with Department of Human Services, ...we’re actually going to start setting up meetings between the eastern Aged Care area and our organisation and start to do something, because we see it as the biggest 5,6,7, 8 (agency manager, 2, 1)

> Ageing is a big issue within this organisation as I believe it is in the whole sector in regard to the people we support are accessing mainstream aged care services. (house supervisor, 12 & 13, 1)

Despite an awareness of the issues managers were unable to point to proactive planning strategies around individual residents or organisational systems planning that went beyond cross training staff or supporting one off staff development as specific issues arose. Some did speak of the supportive partnerships with staff in the government departmental funding divisions in working through issues for individual residents. At this stage of development most organisations dealt with ageing issues on a one by one rather than more systematic basis. It seemed that no one, families, staff or the Department that funded disability services were prepared for the health changes likely to be associated with ageing of residents in group homes.

### Deciding the line had been crossed: ‘So that was that’

Prior to or during the 18 months period of this study a decision that it was necessary to move to a residential aged care facility was made in respect of 8 of the 17 residents. Only 6 residents moved however, suggesting the potential for an initial decision to be delayed or overturned. The circumstances that led up to each decision were different and, as the discussion of staff perceptions about crossing the line has foreshadowed, no simple algorithm of circumstances provided the underpinning rationale. However, the common dimensions in all decisions were: the degree of change that occurred in an older person’s health and support needs; the impact of such changes on staff and other residents; the coexisting other issues affecting the operation of the house such as staffing or changed needs of other residents; and the degree of flexibility in the use of resources or success in garnering additional ones. These two descriptions from house supervisors illustrate these underlying factors that led up to the decisions that Emily and Walter had to move.

> I have to co-ordinate with the hospital this week because I’ve been thinking I need to go back to a gastroenterologist and get an urgent appointment with him. I need to get

> an appointment with the psychiatrist, hopefully the last one or a referral to [specialist psychiatrist] which would be great. So you’ve got all of these ageing issues, the other issue I have is you don’t have the trained staff, I have some knowledge about aged care, even that’s not enough for me ..it’s the impact on the other ladies as well, it’s a hot day…. Emily can be pacing, like this is wonderful now, the Valium is helping the pain in her arm and the pain in the tummy plus she had an enema not this weekend, last weekend. …..Whereas if you’re in facilities that have nurses who could do that [its easier]. See it’s a drama for poor Emily to get in the car, go into hospital, ....we’re just dragging her, like there are days where you’re physically [pushing], she would not get in the car, she’d scream and go to the door and absolutely go berserk, we couldn’t take her to a doctor. (house supervisor, 12, 1)

> You know, it was killing all the staff, and it was only a matter of time before he either injured himself, injured them, because in the end, the last three months, he would fall on the floor, and you’d say: “Come on Walter, help yourself up”, put a chair there, and you know like: “Roll round on your stomach, get up on your knees”, he couldn’t do that, he’d just lie on his back with his legs up in the air, and he couldn’t process the information and he’d be there for ages …….but the way, you’re not allowed to, with manual handling you can’t lift people, …a worker bends over to pick them up and they injure their back, they’ve had it, you know?... “Well can we get these active nights?” and it was a flat “No”, ....but yes he was a danger to himself…and basically my position is to protect my clients, and my staff, and I could see them getting injured, damaged…. We’ve just gone too far, we’ve taken this too far”… we just don’t have the right mob….It was really getting to the point where it was just becoming ridiculous it disrupted my health, staff were taking holiday it was getting to all of us starting to have tension between staff. (house supervisor, 10 & 3, 1)

An acute health episode and or a sense of intense stress for house staff was often the trigger for a move when the combination of others factors existed. Decisions a move was necessary fell into two distinct groups, those that were made in haste in the midst of an acute health or staff crisis, and those that were more measured taken in collaboration with family members with time for consideration.

### *Hastily made decisions*

Hasty decisions were presented as a ‘fait accompli’ to family members, and made by staff either in the organisation that managed the group home or associated with hospitals. Family members were expected to implement this type of decision but their comments suggested they did not feel involved in the process or adequately consulted.

> They all stepped in from there. So when I arrived I was basically bombarded with four people, one a social worker and these other people and you know and had papers put in front of me really, you know, and he hadn’t at that time been assessed. That was on a Monday and they were hoping to get him assessed on the Tuesday but it didn’t happen until the Friday. (cousin, 11, 1)

> So he, [HM] told me to more or less start to look for alternative accommodation because they couldn’t manage in the house, you know? (sister, 15, 2)

> … one day one woman rang me up, not from the house, to say you’ll have to find a home for Walter, you’ll have to put him in an aged care, we can’t keep him any longer…And I got such a shock. .. ….didn’t give much airspace to the main carer and he’d been in hospital for two weeks (sister, 10, 1)

Family members who were handed such decisions were very uncertain about what if any standing they could have in the decision making process or whether they had the power to challenge it. This lack of knowledge, together with the assumed power by formal services left most family members feeling bewildered which for several acted as a catalyst for resistance.

> “Do you think we should ask a solicitor?” but I don’t want to fight anybody, I just want to know what the rights are as far as the bureaucracy is concerned…I mean they can’t just say: “Look, he has to go this afternoon”, can they? (sister, 10, 3)

> whoever is involved in the Gracefield Drive situation because it’s up to them, I, I have assumed that’s for them to decide whether they can manage Helen. (niece, 14, 2)

Several family members managed to delay implementing the decision to move by challenging it and two averted a move altogether by seeking out alternative or specialist medical opinions and treatment.

> After a while I got cross, and I rang them and I said: “I think you are trying to push him out. Well, I don’t like any of the places that the broker has sent us to, and other places, and I don’t, and he’s lived there for 35 years…This is, it’s his home, you

> know, it’s like his family too up there”, and the head at that stage said to me: “Well look, fair enough, we will not insist on Walter going, until you’re satisfied you’ve found somewhere there that’s very nice..And we had managed to delay it for more than a year, 18 months, we were doing our best to pretend that it wasn’t going to happen (sister, 10, 2)

That delay of a decision about moving, until a health crisis has passed, may be sufficient to avert the need to move was also evident in some of the follow up interviews. Several respondents indicated that the health of a person who had moved to residential aged care had stabilised to such an extent that questions had been raised retrospectively about whether the move had really been necessary.

*Collaborative measured decisions*

Not all decisions were hastily made or in a context characterised by staff stress or a health crisis. In Tony’s case a more forward looking planned and collaborative approach had been adopted. Tony had moved to a residential aged care facility approximately a year before the study commenced, and a two year period had elapsed between the decision being made that he should move to the actual move occurring, during which his family and the service organisation had searched for an appropriate facility. The house supervisor suggested that a primary driver for the decision to move was Tony’s steadily decreasing mobility in a group home that was not designed to be wheelchair accessible, and in which despite some modifications being made, the narrow internal corridors made access difficult. The option of relocating Tony to a more accessible group home had been considered and discarded as it was felt by staff and his family that Tony’s declining health meant he would inevitably require the high level of care offered by residential aged care.

> Well, in this particular house, it was mooted that maybe we might move, specially Tony who was becoming wheelchair bound to another newer place that has great wide corridors and all the rest of it but we talked with family and that and we felt that that may have been more stressful for him. That we knew that the move to a nursing home was going to be inevitable and another move in between would probably be too much. (house supervisor, 16, 1)

> Well the house supervisor contacted me reluctantly because obviously it’s not something that they want to do …but it was coming to a time where he had to be

> relocated into a more appropriate place and we engaged jointly a company who source retirement placements and I think it took two years to actually settle on a place that we were all happy with (brother, 16, 1)

Another significant factor in the decision was Tony’s close long term relationship with another resident Jo, for whom staff felt a diagnosis of dementia also made a move to residential aged care inevitable. Once the initial decision had been made it was followed by a long but collaborative search by Tony’s family and staff to locate an appropriate facility, to which Tony and Jo could move together, although Jo could possibly have remained in the group home a little longer.

> And with Jo, the dementia was trigger too because he would want to get out, his time completely shifted, day/night completely changed, he became incontinent, there were fairly major issues., We knew that we could have kept him here for perhaps another six months but we knew that the move was inevitable and the fact that we managed to get the two of them (Jo and Tony) [a place] and they moved together I think was good so Jo perhaps out of all of them, has moved a little bit earlier than perhaps I would have liked but again, still with the GP, she knew him very well and felt that just as I said, we knew it was inevitable (House supervisor, 16, 1).

This more considered collaborative approach to decision making that takes a longer term view was exemplified in respect of another resident from this organisation’s service who was spending regular ‘holiday’ periods of respite in residential aged care facilities; although a decision has not yet been made that a move is necessary.

## Conclusions

The data presented in this paper are insufficient to reach any judgement about the merits of the decision that a group home resident should move to residential aged care, or the potential advantages or disadvantages of such a move. The cases where decisions were challenged, delayed or averted, demonstrated however that crises do pass, group homes do have a capacity to adapt to the residents needs at least in the short term and other avenues can be followed to resolve difficulties. This should be an alert to avoid major and irreversible decisions being made in a situation of acute health crisis or staff stress both of which are likely to pass.

The study raises concern about the way decisions about a major life transition are made for some older group home residents. In most instances the traditional professional paradigm (Tarulli and Sales 2009) clearly dominated the process, not only excluding involved family members but also failing to canvas ways of eliciting the preferences of the person with intellectual disability. Such approaches are a long way from Australia's international obligation to ensure that people with impaired decision-making capacity have their preferences taken into account, rather than simply having their decisions made by, informal or formally appointed substitute decision-makers. For example, Article 12 of the United Nations Convention on the Rights of Persons with Disability enshrines the principle of equal recognition before the law and sets an expectation that governments will ensure that the preferences of people with impaired decision-making capacity are ascertained, their views heard, and their decisions reported and respected (Byrnes *et al.*, 2007). Neither do the approaches found in this study reflect the current intent of disability policy in Australia, in terms of supported decision making and person centred planning or even involving those who know a person well in decisions about their lives (Cramp and Duffy 2006, Disability Services Act, 2006). The findings of this study flag an important class of decision, the move to residential aged care, that will require particular attention and scrutiny as policies about supported decision making are further developed in Australia. The findings also highlight that instead of respecting the rights of the person with a disability and viewing their needs and preferences as paramount, resource and organisational issues that stem from an ill prepared disability system shaped many of the decisions about a move to residential aged care. This situation was fuelled by the absence of policies that affirm the right, and funding mechanisms that support, aging in place for group home residents.

This study highlights the difficulties faced by parents in attempting to plan for future accommodation support and seek firm undertakings from non government organisations about the care of their son or daughter with intellectual disability that may extend many years into the future. It confirms the efficacy of parental planning that nominates an informal key person thereby ensuring someone outside the formal service system is committed to overseeing and monitoring the wellbeing of their sons and daughters as they age (Bigby, 1997). The significance of informal key people in the lives of older people with intellectual disability was evidenced not only in the different types of support they provided but also in their willingness to challenge hastily made major life decisions instigated by others and successfully delay or avert what in their view would have been a disadvantageous move from a group home to residential aged care. In some cases their intervention created a circuit breaker to a chaotic stressful situation for group home staff and forced slower and more considered thinking to occur about a move, which had the potential to avert it.

Of concern however was the absence of independent advocacy for the resident who had no informal key person, or indeed the involvement in decisions about her life of anyone not directly involved in the direct provision of her daily care. A further concern was the uncertainty of key people about their standing in decision making and their lack of knowledge about formal avenues for advice about their status as a substitute decision maker, despite their close involvement in the older person's life. Of greater import perhaps was the failure of group home staff and organisations to alert family members to information sources about these things. This suggests an urgent need for outreach and public education by the statutory bodies responsible for administering formal schemes such as Guardianship, which in the case of Victoria is the Office of the Public Advocate or the Guardianship List of the Victorian Civil and Administrative Tribunal. If parental key person succession plans are to be effective those who replace the parental role of overseeing well being need knowledge and advice to equip them to play expected roles as key people in the lives of older people with intellectual disability. Although several initiative, led by the Rehabilitation Research and Training Center on Aging with Developmental Disabilities (Heller *et al.* 2008) have occurred in the United States to provide resources for siblings in their current or future roles in relation to their brother or sister with intellectual disability in Australia resources about future planning have been targeted at older carers rather than siblings or other family members.

This study confirms a previously identified trend that a proportion of older residents of group homes will move from group homes to residential aged care (Bigby et al. 2008, Heller et al. 2008, Thompson 2003). It points to a sense of inevitability about such moves by both family members and staff, and the likelihood of inequity for residents in where the line is fixed by organisations that manage group homes. The line to be crossed is determined by the degree of change in a person's characteristics and its impact on others which is referenced to pre existing care structures rather than objective health or support needs. These findings affirm the already identified need for government and organisation policies on ageing in place in group homes to avoid inappropriate transition to residential aged care and draws attention to the iniquitous situations that may trigger such a move. Suggested too is the need to formalise a decision making process for this class of decision, to ensure this type of major life decision does not occur at time of crisis, is not driven by organisational needs, that alternatives are fully explored and both the person with the disability and key people in their lives are involved so processes reflect current policy intent rather than an earlier now superseded professional led paternalistic paradigm.

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