

Chaotic and Poorly Informed: Decisions about the Transition from Group Homes to Residential Aged Care for Older People with Intellectual Disability

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Background

Increased life expectancy and numbers of people aging with intellectual disability

Parental anxiety 'What happens when I die'

Policy response support for older carers, continue caring and plan for the future

Focus on transition from parental care not later life (middle age)

- Accommodation
- Finance

Importance of key person succession planning— caring about not for, flexible respond to change over time

Idea of continuous planning down the generations parents –siblings – nephews/nieces (Bigby, 1997, 2000)

Broad policy aims for older people with ID derive from aged care policy and disability policy

- Ageing in place, world class care, rights, autonomy and independence

Indicators susceptible to mobility as age (Bigby, 2000, Thompson, 2004)

Little organisational or individual planning within services (Bigby, Knox, 2009)

Misplaced in residential aged care (Janicki & Dalton, 2000; Wilkinson et al., 2004, Bigby et al., 2008)

Staff think move inevitable (Bland, Hutchinson, Oakes, & Yates, 2003; Fyffe, Bigby, & McCubbery, 2007; Hatzidimitriadou & Milne, 2005)

Pathways to Residential Aged Care

ARC Linkage study

Transitions in later life people with intellectual disability and health problems

Specific questions

- Planning for older age – perceptions and planning by families, staff and organisations about the future
- How are decisions about made to move from ‘post parental’ home

Methodology

Longitudinal study of 17 older people identified as having health problems living in group homes in Victoria

7 different organisations – govt and non govt

17 clusters – person, family member, staff

Plus 5 aged care assessment team staff

62 people interviewed over 18 months– most 3 times

Initial interview face-to-face – then by phone

To date 122 separate interviews conducted

Grounded theory – theory-generating using grounded dimensional analysis for data collection and analysis

People with intellectual disability

6 females & 11 males

age (46-81 yrs, median 58 yrs) at year 1

3 died during study

12 had been hospitalized during study

1 hospitalized just prior to study

6 people moved to residential aged care

16 had involved family members

- 12 siblings, 1 niece, 1 cousin, 2 mothers

1 person no family no advocate (ex institutional resident)

Roles and Relationships of Family Members

Strong long term emotional bonds

Siblings/cousin/niece replaced 'caring about' role of parents as foreseen

, but 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 and there's the story. (cousin 11F)

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 4F)

Often supported by other siblings, spouses and children

- Protector- advocate-' just keeping an eye on things'
 - Regular visits or contact weekly- monthly
 - Managed finances – as formal administrators
 - Regular contact with staff
 - Point of call re major issues
 - Some more involved in day to day care, medical appointments discussion
- my brother and I are his guardians but my brother looks after his, my son looks after his finances because he has some money left to him. *Sort of like a financial power of attorney. ...Advocate, Richard does that.* (10F)

• EG xxx

, I've taken the role of Mum I suppose, he'd want me and my sister wouldn't go. She'd say I can't do that, I ask her to go to hospital to see him and she's too busy, that's okay I've gotten over that, but my husband is really good too, if he had to go because I was a while getting somewhere he'd always go. (4F 3)

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 her, herself as her, her niece, as Susan's niece, and so yes she's definitely family but I'm still very aware that this is that added layer of sort of added legal responsibility and I suppose that's how I look at it being legally (paid?), but it's legal responsibility, you know, fighting for her human and legal rights as, as well as to being my sister, it's, it's a different sort of a role to a normal sister role I think, yes. (13F)

Yeah look 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 they, 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.....(1 F)

Revisiting previous plans

Parents had foreseen issues of aging

Invested time, energy, funds and faith in ngo's

And in bricks and mortar

And they set great store by what the role the Brother's play... god forbid my mother is alive and found out what did happen up there, but she sort of took that as insurance, but was always fearful that Robert wouldn't be looked after. 3 F1

Well, the reason we'd started the farm was that as the people aged they would be there for life.6 F 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 usLook 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. 18 F (mother)

Next generation avoided the issue

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. Bad enough for anyone 8 F 1

Well I think that's something that Sib and I have never discussed (9F)

I'm not one of these people who looks ahead in the future (4F)

Expect a move to RAC to be inevitable

Fearful, disappointed, let down by government and ngos

‘Fully expect the day will come’ ‘When the time comes’

Now, when we had to abandon that idea, we were then told by the Bethel organization that yes, they would be cared for within that organization for life, but now I believe that they are going to nursing homes. I think Bethel had to have actual nursing home type houses but can't get the funding. The Government says, if you do that you have to take in other people and that's not the point so we try very much to save all the money we have for him in case of a nursing home being needed. **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.** 6 F 1

A line that will be crossed

'when needs can't be met' within capacity of group home

Lack of specificity –

- need a more appropriate place
- remaining would jeopardize health
- one to one care not possible
- staff availability
- group home only funded for certain number of carers
- can't manage health any more
- resident no longer the type of person for whom group home set up

if she has to leave there because she's getting older, and they can't manage her, health any more 13 F

and again 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. 15 F

Staff perceptions clear – non negotiable line

‘I wouldn’t wish that for anybody’

But

- Not set up to deal with changed condition
- Somewhere else can do it better
- An assessment has been made we can’t do it
- Not a choice

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, we have to, yeah, 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.**unfortunately they can resist all they like, if we don’t have the...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.** 1HM 1

Not an ideal solution - but better health care

and I reckon it happened four, five times and the last time he stayed in hospital for longer and his health was deteriorating. **He was past the stage of being able to stay at home, like he'd stopped walking, eating, no he was eating a small amount but wouldn't feed himself so he was getting quite agitated if anyone tried to shower or bath him, even a sponge bath.** 7 HM 2

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. HM 12

the person has actually been assessed as needing nursing home care, we can't provide that care...HM 2 & 9. 3

Making a decision the line had been crossed

Decision re need to move decision made for 8 people

6 people moved - 2 averted

Two stage process

- making the decision
 - Mostly in chaotic situations but can also be measured foresight
 - Mostly compliance but challenge pays off
- making the move
 - hurried – slow considered – postponed - averted

No simple algorithm of circumstances

Combination of factors with a trigger

Interaction of context and resident characteristics

Resident Characteristics

- **pre change status-** health and functional capacity, likeability
- **changing needs** – complexity of and co occurrence of health needs, challenges of behaviour, acuteness, chronicity,
- **social network** – strength and availability of advocacy

Context

- **pre change status** - physical fabric and accessibility of the house, staffing model, resident mix, staffing skills, philosophy of house
- **flexibility available** - resources available, able to be negotiated, ease of interaction ease with other support egs hospitals/ in home nursing etc,
- **impact of change and additional changes** - disruptions experienced by other resident, changing needs of other residents, staff stress and tolerance of situation, expectations of what it could be like elsewhere.

Degree of change – rather than health or support needs per se need

Trigger – hospitalisation, acute health, episode, stress

Professional decisions

Made by—organisational managers or health professionals

‘we felt that we needed to find an alternative’ 12 AM

‘it was getting difficult, for staff, I mean I suppose I initiated it in a lot of ways’ 10 HM

At times without consultation with group home staff

In midst of chaos in caring and acute health issues

In conjunction it was myself, our PASA our Program and Services Advisor, and we had Emily placed on the disability services register for alternative accommodation. HM 12

a lady came from some other department and asked a few questions and then she arranged for Adele from ACAT to come and assess him and she assessed him and said he needs high level care and she gave me the form and she said I want you to go now and look at nursing homes 18 F

They were, the people from Monash anyway, 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. 11 F1

He got an infection, he got worse, and basically they did the assessment we never got the results of any of the assessments but I don't think they knew what to do with him then they said that he had to go to a, he wouldn't be able to, he wasn't fit enough to come back here, they'd have to look for a nursing type facility. Which they did, he was sent there 1 HM 3

Fait Accompli for individuals and families No sense of rights or processes

so that was that' 'I was told he had to move'

Uncertain who has the power to plan or decide

"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? 10F 3

One grey area we have still is that I understand it, I don't know enough about the regulations and provisions and that... that once Robert becomes of pensioner age, you know of old age, it is really a grey area, he is just another aged pensioner person, and the system doesn't adequately cater for someone who is intellectually handicapped, as I understand it. Now I may be wrong 3F 1.

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. 14F 2

Expectation that families would implement and search for alternatives

So he, Paul told me to more or less start to look for alternative accommodation because they couldn't manage in the house, you know? 15 F 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 10 F 1

Sense of coercion/exercise power if necessary

'when you've got the ACAS assessment you know you've always got that to fall back on'. (staff)

Potential for families to challenge and postpone

Delayed 18 months

after a while I got cross, and I rang them and I said: “I think you are trying to push him out”,I said: “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”, I said: “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 because you know, we had managed to delay it for over a, more than a year, 18 months, I, we were doing our best to pretend that it wasn’t going to happen, and then when this other lady came, and my brother came too, and we were all there, and she said more or less: “Well oh we’ll look at three months”, 10 F2

Averted

- . they told me to more or less start to look for alternative accommodation because they couldn’t manage in the house, you know .. anyway, I had an appointment with Jenny Tor and I told her a few of these things (15 F)

Demonstrate potential to adapt

Avoided irreversible decisions made at time of acute health needs

Planned collaboration and consensus

Not always chaotic or reflecting multiple health needs

2 year planned process

Well Cheryl 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 called Tender Living Care who do source retirement placements and I think it took two years to actually settle on a place that we were all happy with, there were fairly difficult criteria I guess, it needed to be a place where Tony would be able to engage in activities and be stimulated mentally because of his mental state and yet it needed also to be a place where he could be accommodated and looked after because of his physical problems so it was a long drawn out thing to try and find a place that we were both happy with and suited those criteria and ultimately Blue Waters in Camberwell seemed to fit as best possible and we settled on that. 16 F

One resident planned respite in residential aged care

Aware of the issues but system/organisational planning just starting

' we just don't have the right mob'... 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 (HM 12)

"Well can we get these active nights?" and it was a flat "No", because DHS, it's all up to DHS, they provide the fundingwe're not 24 hours, we don't get paid for it and we're lowly paid as it is, and I mean you know they expect everything from us, we're meant to be mothers, fathers, doctors, lawyers, and everything like that... (HM 10 3)

The group home is not really set up for wheelchair access 16 F

think it's the partnership with the Aged Care and we're very much talking about that with DHS, ...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 (AM 2)

obviously we do have policies for withdraw of service if we, you know, depending on behaviour problems with clients as well. (9HM)

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 (12 13)

Long way from principles of choice, autonomy and independence

No objective line – that person in that context –

Combination - pre-existing situation, degree and impact of change, flexibility of resources

Professional decision making –trad professional paradigm -

Chaotic crisis situations -absence process or independent advocacy

Uncertain family rights – where does the person themselves fit into this?

Importance of family advocacy – delay - avert

Advocacy can force adaptation potential

Provide space for reflection

Avoid decisions at time of acute health issues

Potential inequities

- similar objective needs different contexts
- capacity to challenge, delay or avert
- variable access to flexible resources

Demonstrated potential for more thoughtful collaborative processes

Outcomes - another story –