

SUBMITTED FOR PUBLICATION TO DISABILITY AND SOCIETY

January 2008

“I Want to See the Queen” - Hanging on to Future Dreams in a World focussed on the Present - The Experiences of Ageing People with an Intellectual Disability

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Acknowledgements

This research was supported under Australian Research Council's Linkage Projects funding scheme and the support of industry partners, Endeavour, Queensland Office of the Public Advocate, Victorian Office of the Public Advocate, Queensland Department of Housing and Queensland Aged & Disability Advocacy Inc. We would also acknowledge the contribution of other members of the research team at QUT in the study design and data collection.

Key words, ageing, intellectual disability, policy and planning

Total words 6996

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Abstract

Policy debate and research about aging people with intellectual disability segments people's lives by focussing on specific aspects of service delivery, such as day support or accommodation. Their lived experiences are largely absent from research. This study explored the perceptions about their life of 16 older people with intellectual disability from two Australian States, and investigated how those around them responded to their aging. Nolan et al's Senses Framework was used to understand the findings. The study found most older people had a sense of belonging and led busy but directionless lives in two disconnected worlds, of 'services' and 'informal'. Their lives were subject to significant external present-focused control. Despite the older people's firm ideas about their future, nobody in either world took responsibility for ensuring their sense of continuity or supporting their plans. The life circumstances described suggest an urgent need for, but significant challenges in the implementation of person centered planning.

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Increased life expectancy has highlighted the importance of understanding aging for people with intellectual disabilities. At the individual level considerable knowledge has developed about the impact of the aging process on health and care needs (Prasher & Janicki, 2002) and attention is being given to issues associated with future planning for people living with aging parents (Department of Families, Community Services and Indigenous Affairs, 2007; Heller et al., 2007). Research has however, segmented people's lives in much the same way as the service system has done, focusing on day support, accommodation, health or relationships and issues of retirement, aging place, care or family support (Bigby, 2008; Janicki & Ansello, 2000), rather than on people's experiences across the various systems in which they live their lives.

The lived experiences of older people with intellectual disabilities have been largely absent from the research, just as their preferences are often absent from planning about the future (Bigby, 2004; Bowey & McGlaughlin, 2005; Knox & Bigby, 2007). Research that has sought the views of people with intellectual disability suggests their understanding of aging is often based on stereotypical images, and they are concerned about the negative changes such as a lonely life style or loss of job (Lifshitz, 2000; Erikson et al., 1989). It also suggests they have definite views about exercising choice and remaining active as they age (Edgerton & Gaston, 1991; Hand & Reid, 1989; Mahon & Mactavish, 2000).

Research suggests, however, that later life for older people with intellectual disability falls short of their aspirations (Carter & Foret, 1990; Grant et al., 1995; Rogers et al., 1998). For example Grant et al's study found that although people were

resident in the community and used community facilities they lacked direct personal or social connections to their community. Research on accommodation concerns suggests many older people with intellectual disability are misplaced prematurely in residential aged care not due to ill health but simply to the limited existing options (Thompson et al., 2004; Bigby et al, in press).

Debate about policy and program development has concentrated on considering which service system, Aged Care, Disability or Health should be responsible for meeting people's needs. It has been shaped by the interests of different sectors, each of which operates in a context of unmet demand and seeks to safeguard its own resources (Bigby, 2008). In Australia unequivocal policy direction and cross sector collaborative partnerships have proved elusive, other than in short term pilot initiatives (Australian Institute of Health and Welfare (AIHW), 2006; Bigby, 2008).

In the UK, person centred planning and health plans are identified as the primary mechanisms to ensure an effective response (Department of Health (DH), 2001). Similar directions, though not specifically in relation to older people resonate in the disability policies of various Australian states (Disability Services Queensland (DSQ), 2006; Department of Human Services (DHS), 2002). Although significant agreement exists across jurisdictions about the principles that should inform service systems that support people with intellectual disabilities (DHS, 2002; DH, 2001; DSQ, 2006), outcomes sought are often at a high level of abstraction and it not always clear what elements such as participation, inclusion, choice, and independence actually mean in practice (Bigby & Clement, 2007). Bigby (2004) has suggested that Nolan et al's (2001) Senses Framework, which focuses attention on the perceptions of the individual of their "sense of" security, continuity, belonging, purpose,

achievement and significance, may be useful, whereby achieving these 'senses' rather than externally imposed objective criteria is the goal of service provision.

This study adds to the limited knowledge of the lived experiences of aging people with intellectual disability to inform future policy and service development. It explores the perceptions about their life as an older person held 16 people with intellectual disability from two Australian States and investigated how those around them who provided informal and formal sources of support responded to their aging.

Method

Methodological Approach

Social constructionism theory (Crotty, 1998) with its focus on how individuals construct their social worlds provided a lens to guide this study. It enabled multiple perspectives of the same phenomenon (ageing, planning and future aspirations), and the negotiation and construction of these among the varying key players to be explored. Consistent with this approach, qualitative methods of data collection and analysis were used. Approval for the study was granted by the relevant University Ethics Committees.

Participants

Purposive sampling was used to locate individuals labeled by the service system as having intellectual disability, aged 50 years or more and who could communicate verbally. With the assistance of four disability service or advocacy organisations in Victoria and Queensland, information about the study and invitations to participate were given to persons meeting the above criteria using these services. Those interested in participating in the study were asked to contact the researchers directly which allowed the privacy of potential participants to be maintained.

Older people wishing to participate were asked to nominate a family member or someone in a close unpaid relationship, and a direct care worker who might also be interested in participating and give them information about the study, with the assistance of a representative from the organisation if needed. The organisational representative in each case was well known to the person with intellectual disability, but had no involvement in the study. Those nominees interested in participating were asked to contact the researchers directly. In all, sixteen groups of person with intellectual disability, a family member or someone in close unpaid relationship and direct care worker participated in the study.

The sixteen participants with intellectual disability were aged between 52 – 80 years with a mean of 62 years. Six participants were men and ten women. They were equally divided between Victoria and Queensland and within states between major urban, rural and regional locations. Ten participants lived in group homes, three lived alone with drop-in support, and three lived with family members. All had been in supported employment for much of their adult lives. Only five were still employed and the remaining eleven participants attended day programs part time and remained at home with no formal program on the other days. Of the family members or others with a close relationship, eleven were a parent or sibling, two were volunteers who

had become close to the person, one was a former employee who maintained regular contact with the person, and one was a church member. All care provider participants had known the person with intellectual disability for more than a year.

Procedure

In depth interviews, described by Hesse-Biber and Levy (2006) as “a meaning-making endeavour embarked on as a partnership between the interviewer and his or her respondent” (p. 119), were conducted with each older person about their life as an older person and their aspirations. This acknowledged the expertise of the participants on these issues and provided them the opportunity to express their views in their own terms (Minichiello et al., 1995).

The interviews were conducted by a research assistant experienced in working with people with intellectual disability. Interviews lasted between 60-90 minutes. Separate interviews were conducted with the family member or the person with a close unpaid relationship, and with the service provider identified by each person. These latter interviews asked about their perceptions of the person’s aging, the kind of support they provided and their ideas about what the future held. Throughout the interview checks were made with participants to ensure they had the opportunity to discuss relevant issues and to ensure the accuracy of the researcher’s interpretations of their views (Knox et al., 2000).

Data Management & Analysis

With the consent of the participants, each interview was audio taped and transcribed. These transcriptions formed the data, and qualitative data analysis strategies were used as outlined by, amongst others Miles and Huberman (1994). This involved a process of coding, developing categories and constantly comparing and regrouping these categories to elicit the themes and relationships amongst these themes. Analysis

of cases was undertaken separately by each author and then discussed and further refined.

This was an exploratory study with 16 older adults, which focussed on their lived experiences, and from which generalisations cannot be made. The study does however provide an in-depth exploration of their experiences, aspirations about the future and their relationships with formal support services and with other in their lives with whom they have an informal relationship.

Findings and Discussion

Although each older person had their own unique combination of social relationships, interests, activities and life circumstances, common overarching characteristics were reflected in their lives; valued social relationships, ideas about their future, activity and routine, external control, un-actioned plans, and service centred and present focussed decisions. Each person inhabited two separate but parallel worlds, that of the service system, populated by formal programs, large organisations, paid workers, and other service users, and the non service or informal world, populated by family members, volunteers and acquaintances unconnected to formal services.

Being Connected and Valued

Although the frequency of contact, nature and strength differed, all except one person had an identifiable set of positive social relationships which connected them to one or more social grouping, and gave them a sense of belonging, being valued and recognised as an individual. For example, Malcolm spoke of his role in the business service, “I’m the second one up in command. I’m the supervisor ... He [staff member] said I was perfect ...He leaves me in charge”. A staff member spoke of the affection with which Wally was held despite his idiosyncratic crankiness, “Julie

[service user] idolises him, everybody loves him, he's a grumpy old bugger he is, but he's everybody's favourite".

Most had close and long-term friendships with other service users, which had originated in the disability programs they attended or lived in. For example, Josh plays bowls at the weekends in a bowling team with other service users. They have travelled widely to participate in competitions. He said, "when we don't bowl in the afternoons, we just go to Sizzlers or something. Gary and Trish and all the others from bowls...". Rod talked about his friends at work, who included staff as well as other service users. "I got friends... Mandy [program manager], is my friend, also Peter [staff member] when he comes down... and Ted and Mike our supervisor and Andrea our new boss.... only one boy down there in the book section, Doug".

Friendships with other service users were maintained through shared activities, either in the service setting or community venues after hours. Such activities did not involve 'outsiders' and did not broaden their social relationships beyond service users. Friendships seldom crossed the boundary of their 'service world'. For example, Angie and Paddy, married for 10 years, met in a supported accommodation service and both now worked together at a supported employment service. They bowled every week with their friends from work. Paul, a staff member talked about the contained nature of service user's world when he noted, "pretty much all of them go to bowls ... they all associate on the weekends at bowling".

The significance of intimate relationships for several older people was evident. For example, Malcolm describes his relationship with Lesley. "She works here. She cheers me up all the time... We've been sitting over there together for a couple of weeks holding hands... Oh happy, happy!" Ray points to the importance of his relationship with Meg, but also to the restrictions imposed on it.

That's my girlfriend. I see Meg every day, Meg used to be down at the day program with me and I used to see her every day and then I was shifted and Meg went up to Harvey street. I still see her Monday's and Wednesday s but not Fridays.

Most older people had enduring relationships with family members, who consistently gave them a sense of their own value and an identity beyond that of service user. As Amy's sister said, "she's just Amy to us". Kathy said, "I was a bridesmaid at my brother's wedding. He was real proud of me. I did a good job". Jo said, "I'm an aunty too ... my nieces love me; they really do"

For most, a family member played a key instrumental or supportive role, such as managing finances, overseeing affairs or for some providing support with activities of daily living. For example, Jed's service provider said, "Jess [sister] plays a big part in his life - she's always been there". Angie spoke of the practical support given by her in-laws, "Paddy's dad and Alison [mother in law] pay all our bills and get the money for us; they do all the banking for us too".

Relationships with family generally involved shared social activities such as outings or visiting. Rachel for example, described the pleasure gained from shared activities with her family. She said, "I go out and have lunch with my sisters. I like shopping with them too". After Josh's parents died he stayed in the family home, and his brother stays with him when he travels down from the country for his work.

For some, their family relationships provided an avenue to a wider group of acquaintances or involvement in a local church or community group. Rod described this saying:

On the weekends I help George ... and when he's not around I go shopping with Gloria (sister) and Sunday we go to church at Chersey. .. Last Sunday we

went over to Redland and I met my great nephew. and Gloria and I and a couple of friends of ours went out with the church group.

Older people alluded to the changes occurring to their family relationships as parents died, when as other studies have shown (Bigby, 2000) other family members, usually siblings or nieces and nephews had taken over some of the roles previously fulfilled by parents. Josh's worker explains,

He's got a niece ...his mother and father are both long dead. I think Josh's very fortunate is niece is willing to be there for him, which a lot of people don't have.

Two participants, notably both with no contact with family members had a friendly relationship with volunteers. Ivor, first met his volunteer friend Jamie through an initiative between the church and the day program whereby dances were held at the church. Jamie described their relationship as, "blossoming into a friendship' and it has opened up for Ivor a new circle of social acquaintances beyond the service world. Jamie said,

I pick Ivor up and bring him to church, and often on a Sunday afternoon go for a drive with him, my friends ask when are you bringing Ivor? So we go and take Ivor out and we return him by tea time. ...I call him my son occasionally in fun. He calls me dad..... I just felt that he's got nobody and he's virtually become a very close friend.... He goes to all activities at church. Anything we were putting on... I will go and pick him up.

Ivor in a similar vein said, “Jamie, he’s my friend, he’s the only contact now I get. Yeah, he’s mine and he takes me out for morning tea, afternoon tea and everything.”

Janine’s situation was exceptional. She had moved to a retirement village following the death of her parents and did not mention relationships with other service users. Unlike the other older people she was the client of a case management service and did not spend a significant portion of her time in a segregated service only attending a day program 2 days a week. She had antagonistic relationships with some of those who lived nearby. She said, “I’ve got this snake of a neighbour ... she’s an evil snake ... she abuses me, she insults me. Nobody talks to me”. Her case manager said of Janine,

No part at all of a social group, she doesn’t go into the restaurant, they’ve got a restaurant and they have a bus that they go out so she doesn’t participate in any of those things. She has no social network. ..the day centre she attends from 9 to 3 isn’t really working out very well at the moment but she doesn’t have any formal supports, doesn’t have any friends, doesn’t go out at night or any of that.

Her sister commented,

I think that losing her mother and then losing her dad, she really had no one. I am the only one that she keeps in touch with. My brothers, they all care for her but they all work and they can’t just run up there. Before I used to go up and down, now I can’t do that. And the lady next door to her, Josephine says that she put everyone against here, in the 6 units and nobody talks to her and at the back, they’ve got a tiny bit of grass and some flowers, and this lady she’s got a

gate. And what she does, she goes and makes noises at night at Janine's house.

You know she moves chairs and knocks on windows.

Though Janine largely inhabited a non service world, living in an 'inclusive' retirement village, she lacked social relationships with family, friends or acquaintances to offset the absence of relationships with other service users.

A Life Focused on Being Active

Joanne, a service provider suggested a key function of services was, "keeping them occupied, that's the best". Most of the older people routinely participated in a range of activities. Ken intimated busyness describing his routine as,

"Monday, Tuesday, go to the movies – but stopped now for Christmas, and Tom's cabin for Christmas party. Dancing too and to the day centre, Wednesday we stay home and have aged care".

Trevor also indicated a busy routine at the day centre,

"Ooh yeah, I love it, then Wednesday's I go bowling again, twice bowling. ..and Thursday's we go shopping. .. last week we went in the country. ..and we go different places. ..Friday's we go to the country for a drive. .. sometimes we go for a barbeque

Similarly participants' activities and relationships with family members were characterized by routines and key social occasions such as Christmas and birthdays. For example, Malcolm talked about his brother who lives Melbourne. He said, "I spend seven nights down there. They give me a room every Christmas. Jean [sister in law] comes up every year to see me now". Nina spoke fondly of her family's holiday house where for many years she had stayed here with her extended family several times a year.

Purposeful Ideas About the Future

Only Caroline connected future plans to the process of aging, she said,

I'd like to put my name down for a nursing home later on, down the track because now I'm getting on. I like to go to Good Samaritan but I don't know how to go about it. How to go to the doctors and ask for a form or go to the Good Samaritan and ask for a form, I don't know?

Although they did not conceptualise the future in terms of ageing, older people had very clear ideas about what they enjoyed and the directions it should take. Malcolm for example, who lived in a rural accommodation services said, "I'd like to live with my girlfriend - that's what I've got in the back of my mind. I'd like to have my own house with her. I've worked out how I can move .. but it's not happening". Janine did not want to stay in the retirement village, because of the social ostracism she experienced, she said, "I'd like to live near Alison's house. Because about 8 years ago I was renting there in the same street. I was happy there. Rachel who lived with her elderly parents had a vision of what she wanted for her future.

I'd like to move somewhere where there's no stairs and somewhere where there lots of shops and trains ... I've had too much of here ... Forty years nearly forty-one. I'd like to live near my sister – that would make it home.

Janie had a life long interest in the royal family and wanted to visit the Queen. She said.

I want to go to England.. to see the Royal Family, I love the Royal Family... I could tell you about the children, the dates of their birthdays, anything like that.

Controlled Lives and Un-actioned Plans

Many aspects of the older people's lives, including, where to live, who to live with, where to work and activities they could participate in, were controlled by others, staff in the 'service world' and family in the 'informal world'. Janine described the decision-making process around which day program she would participate in,

“Adriana [case manager] doesn't want me to go there and Matthew my guardian doesn't want me to go there. So... my guardian and Adriana they asked Betty the boss could she take me.

She went on to talk about the difficulties she encountered in trying to move, “I want to but the state trustee, they won't do nothing about it. They took me to court and they said you live in this house”. Joanne expressed her opposition to the decision made by others about her retirement.

All of a sudden they told me they didn't want me anymore. [they said] you can ring up and go to the Willows and have a coffee and a chat, and I said “what's the point in doing that? Catching a bus all the way out to Willow's just for a coffee and a chat”.

Rachel vividly describes the control exercised over the activities in her day program, “they always say you have to do what everybody else does. ... well say when everyone else is dancing they say “you've got to dance” ... And you do it ... Yes”.

Kerry, Malcolm's support worker, illustrated the impact of the control exercised by the service organisations over people's living companions when she describes Malcolm's separation his friend Joe, “someone decided Joe wasn't suitable – so they moved him away from here. So Malcolm doesn't see him much now”.

Family members also exerted considerable control over aspects of people's lives. For example, when Janie described her desire to go to England to visit the royal family she commented,

My sister-in-law's got different plans for me. ..When I get old, really old and Donna [service provider] told me this too I have to go to a nursing home because they can't take care of you.

Caroline talked about her sister's attitude to her trying to get a driving license, saying, "I rang my sister up and she said, "don't you dare get your license. You won't be able to afford the cost of the car anyway". Rachel's comment summed up the feelings expressed by many service users, "I just keep on my own way ... always doing things the way other people want me to do"

Service Centered Present Focused Decisions

Operational service requirements took precedence over the needs or interests of older people, making decisions more likely to service than person centered. For example, Caroline said,

Donna used to take us shopping on a Wednesdays but now she can't do it for some reason. When I first came over here we used to have Aged Care at our place every day. They closed down that service because they can't afford to send anybody else.

Both staff and the older people were frustrated by the absence of an orientation to the future. Hilda, a service provider talked about the management of her organisation, "they don't think about, when people get older, where are they going to put them you know, they could put them anywhere you know". Judy, said "see I've got no idea ... Why isn't there something like this for people like that? There must be places... something that should be looked into". Jules, another service provider, felt powerless

to challenge what she saw as the only alternative for older people provided by her organization, “ And then what? They put her into a nursing home like they did with Tracy ... She won't cope with that”. Julie, one of the older people, expressed this well when she spoke about her own future, “not sure what will happen probably I'll just stay here...depends on where else to go”.

Some families had thought about the future. For example Rod, said, my brother George, comes around a lot.. Gloria said if she passed away I've got to go to George's home”. However, other families, particularly those where parents still played a major role, were reluctant to think explicitly about the future or discuss it with service providers. For example, referring to future planning Julie a service provider said. “We've never had that discussion [with families]. I don't think any of them would think of the future, they just go along with the flow you know” Rachel's mother unlike Rachel had no clear ideas about the future, saying,

I just take each day as it comes. I know the girls [her other daughters] will do the right thing ... Yes, I don't like to think about it. What's going to happen to her? It's a terrible feeling... I'm quite happy with her here ...She loves all her things around her

For several older people, the potential for decisions made by others to jeopardise their future quality of life was clearly illustrated. For example, Rachel described her views on having to move from her long term workshop to a day program.

There were all stapling down there and I used to go along counting all the papers and count up to 40 and when I got up to 40 ...stapled them down by a stapler ... I were at the workshop for over 25 years. From there I went right upstairs to the day program and I went onto paper work and I made coffee and teas and all those sorts of things ... I'd rather be doing stapling. I know that I

want to do stapling again ... I've told the supervisor so many times ... I don't like it here and I've got no friends here and I'd like to get paid again

Her connectedness and sense of personal worth had been fractured and in her 'new' day program.

The Impact of Living in Separate Worlds

As suggested the lives of these older people fell into two distinct and quite separate spheres - the service world and the informal world. For those with social relationships in both worlds each seemed equally important but little knowledge or communication passed across the boundaries. Family members had only a fleeting involvement with service organisations or the staff who worked in them and knew little of the older person's life in the service world. Comments such as that made by Claude (family member) were common. "We're continually forming relationships with different staff", as were those made by Gillian's mother who said about the day service, "We don't know that much that goes on there" Another family member said,

there's not much communication between the centre, you might go down there once a year to speak with staff ... I don't take too much notice actually. I feel better if I don't, I don't know how long they'd keep her there.

Communication was often limited to everyday matters rather than more considered discussion about the future. For example, Janie's sister said, "I usually just pop in to say I'm taking Janie home or whatever".

The disconnection between worlds meant that no one was aware of the complete picture of each older person's life. Paid staff consistently reflected that they knew little of the person's history or their life beyond the service confines. For example, comments by a staff member about Wally's annual visitors suggested a lack of knowledge about his family as well as perhaps enormous lost opportunities.

He only sees them once a year they pick him up and he goes out to have dinner with them ever year. Family? I don't know who they are. ... They were friends of his family or something like that. ... they've been doing it for years. Indeed there was a sense that no one from either of their two worlds had a mandate to know the whole person or the right to do so. For example, Jamie, Ivor's volunteer friend indicated, 'I wouldn't have a clue of what he's got in money and I'm not interested in that money, that's got nothing whatsoever to do with me.' Margaret expressed this point cogently when she noted the limitations of her staff role,

My role is limited in a certain way ... Laura's been in Algester about 30 years I think ... see I'm not too sure of her history. I think she was 18 when she went to Algester, I think. I'm not too sure.

The lack of communication limited shared problem-solving as those in each world made assumptions about each other, and were unsure of their mandate to cross boundaries. For example, Amy's service provider said about the future, "I think the family have got that sorted out. Least I think so" Another said, "we're aware of boundaries with family, and we can't do it we can only suggest it"

As the foregoing has shown, at times the control exercised by others and the present focused nature of decisions made for them, not only reduced the older people's autonomy but risked the continuation of activities and relationships they enjoyed. The tight boundaries that limited the focus of those in each of their worlds and the disconnection between these worlds left these older people without support to pursue their interests or to work on their own plans and ideas for the future.

A typical example is Janie who, as she points out, needs support to pursue her goal of going to see the Queen, "but I can't do that on my own ... I'm not allowed I'm

not allowed to travel.” Despite her dream being acknowledged by both the service world and the informal world, “she wants to go to England” (family member), “she wants to visit the Queen and that’s part of her goals, her long term goals” (service provider), and having sufficient personal funds for herself and a carer to travel to England, it is not addressed. Like the realisation of most goals for people with intellectual disability of all ages, Janie’s required skilled effort, collaboration and advocacy. But for her like the other people in this study, there is no collaboration between her separate worlds, and advocacy does not figure strongly in either.

While both the relationships and support provided by the service and the informal worlds are central to older people’s well-being, the focus of support is active *current* lifestyle. No one in either world knew the older people well enough or had a sufficient sense of responsibility towards them to plan with them as a whole person collaboratively across both their worlds. As a result, despite their ideas about the future, older people like Janie led busy but directionless lives, drifting between two worlds. Janie had seemingly resigned herself to this, while still keeping hold of her dream. At the moment, she takes the next best option in pursuing her dream by looking at books of the Royal family borrowed from the library.

Conclusions

All of this small group of older people are in receipt of one or more specialist disability support services. Yet this study has shown that the support they receive and the characteristics of their lives fall far short of the principles and rhetorical goals found in current disability policy. We use Nolan et al’s (2001) Sense Framework to help bring into focus where change is required to reduce the gap between the policy rhetoric and reality of older people’s lives.

With one exception, all the older people had a social network of meaningful relationships which gave them a sense of belonging to various ‘communities’ and a sense of significance. However, like many other people with intellectual disability, they lived in a ‘distinct social space’ (Todd et al., 1990) comprised of family, paid staff and others with intellectual disability. Largely absent were relationships with unpaid people without disabilities. For this group of older people too their distinct social space was divided into two disconnected spheres. The friendships of two older men with volunteers demonstrate however possibilities for boundary crossing, for initiatives taken in the service world to provide the opportunity for older people not only to develop relationships in the informal sphere, but ones that form a bridge into participation in community groups and further friends or acquaintances without disabilities. Older people with intellectual disabilities can have a sense of belonging and be part of the envisioned ‘inclusive community’ (DHS, 2002), as well as family and service communities, but this requires effort and vision by the service world to develop initiatives to provide the opportunities. This study suggests such initiatives are particularly important for older people, such as those in this study, whose informal world is vulnerable to shrinkage as family member’s age, and as relationships with other service users are threatened by the decisions made by others about where and with whom they will live or spend their time.

The evidence about the busy lives led by the older people in this study, their enjoyment of the activities in which they participated, and their clearly articulated ideas about the future, suggests it is safe to conclude they had a sense of purpose. However, the connection between their activities and their own interests or goals for the future was not always evident. They received little or no support to pursue their own goals, which were left in abeyance as operational service needs or the wishes of

others took precedence, and thus created a substantial obstacle to their gaining a sense of achievement by realising their goals.

Detailed data about health and other forms of daily care received by this group of older people is not reported here, so there is insufficient evidence to draw conclusions about their receipt of sensitive and competent care and thus their sense of security. However, their own uncertainty about their future care and that of their care workers and family members alike is not indicative of a sense of security.

The final 'sense' that of continuity is defined by Nolan et al., (2006) as recognition of biography, using the past to make sense of the present, and help to plan the future; working within a consistent team using an agreed philosophy of care" (p 9). Many of the characteristics identified in the lives of these older people contributed to a fractured sense of continuity; the division of their lives between parallel unconnected worlds fragmented their biographies and the support they received, and meant no one had the role of boundary crossing or challenging the piecemeal present focussed decisions or took responsibility for supporting them to refine and implement their plans.

This study has shown that policies of person centred planning have not touched the lives of this group of older people, and at a systemic level detailed policy and program development and implementation about support for older people with intellectual disability is yet to occur in Australia. Policy and program development must consider questions of how to achieve more successfully a sense of continuity, purpose, achievement, security, belonging and significance for older people with intellectual disability. It suggests too that significant work will be required to implement person centred planning, with the challenge of knitting together the different fragments of people's lives to develop future orientated plans informed by

the person and those with whom they have significant relationships from both the service and non service world, and to find or build sources of formal or informal support to enable plan implementation and person centred action to occur (Mansell & Beadle Brown, 2006). To be successful, implementation strategies will need to consider some of the some of the questions raised by this study; why are people's worlds so separate, what are the obstacles to greater collaboration, why do service not support the implementation of people's own ideas about the future, what stops services from listening and taking notice of what older people are saying and what stops both services and families letting go of some of the control over people's lives. In particular it must be considered who, within what part of the disability system, should be responsible for person centred planning and taking the lead in turning drifting between two worlds into more purposeful lives for older people reflecting their own biography, and the skills required to do this.

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