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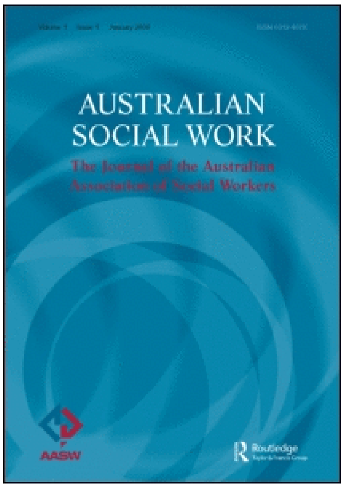

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"I Want to See the Queen": Experiences of Service Use by Ageing People with an Intellectual Disability*

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Abstract

People with intellectual disability are a relatively new but growing minority group within Australia's ageing population. Disability policies point to the equal right of people with disabilities to a quality of life similar to that of other citizens. Disability services are increasingly required to provide individualised and responsive services, irrespective of age, for people with lifelong disabilities. The present study explored the everyday lives of older people with intellectual disability in Victoria and Queensland, examining their experiences of using disability services and the ways in which services responded to their ageing. The aim of the study was to inform practice and service development for older people with intellectual disability. The findings suggest that services facilitate important social relationships with other service users and staff. Most older people had a sense of belonging and led busy but directionless lives in two disconnected worlds. Their lives were subject to significant external present-focused control. Yet, despite this, neither services nor family members took responsibility for ensuring their sense of continuity or supporting the development of plans about their future. The experiences described suggest an urgent need for, but significant challenges in the implementation of, holistic indivdualised planning similar to the UK concept of person-centred planning.

Keywords: Intellectual Disability; Disability Policy; Person-Centred Planning

People with an intellectual disability are a small but growing minority group of Australia's ageing population for whom a marked change in longevity has occurred over the past 50 years. For example, the life expectancy of people with Down

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syndrome almost doubled from 26 years in 1983 to 49 years in 1997 (Carter & Jancar, 1983; Janicki, Dalton, Henderson, & Davidson, 1999; Yang, Rasmussen, & Friedman, 2002). Although those with more severe or multiple impairments or those with specific genetic syndromes continue to have a lowered life expectancy, most people with mild to moderate intellectual disability can now expect to live as long as their non-disabled peers (Janicki et al., 1999). Ageing is a relatively new phenomenon for people with intellectual disability and the first substantially sized cohort is now reaching old age (Bigby, 2004; Gething, 1999).

Contemporary disability policy in Australia and overseas emphasises the equality of people with intellectual disabilities, their rights to be included in the community, and to have a quality of life similar to other citizens (Mansell & Ericsson, 1996; Shakespeare, 2006). For example, the principles of equality, dignity, self-determination, diversity, and nondiscrimination underpin the Victorian State Disability Plan (Department of Human Services, 2002) and the vision of the Queensland Government Disability Services Plan is that of "A society that values people with a disability, upholds their rights and supports their equitable participation in everyday life" (Disability Services Queensland, 2006, p.2). Primary strategies to implement disability policy are (a) specialist disability services; and (b) mechanisms to improve access to services and facilities available to the general population, such as disability action plans (Bigby, 2007). Reflecting the broader policy trends of the past decade, legislation and policy requires disability services to be flexible, responsive to individual needs, and to occur in explicit partnership with informal carers (Baldock & Evers, 2001; Bigby & Ozanne, 2001). For example, Section 25 of the Disability Services Act, 2006, Qld states "services to be tailored to meet individual needs and goals", whereas Section 52 of the Victorian Disability Act, 2006, referring to planning for individuals undertaken by services, states "Planning should—(a) be individualised; (b) be directed by the person with a disability; (c) where relevant, consider and respect the role of family and other persons who are significant in the life of the person with a disability". Similar legislative provisions are found in other Australian states.

Such imperatives are very similar to the person-centred planning (PCP) approach found in the UK policy for people with intellectual disability *Valuing People* (Department of Health, 2001). PCP places the aspirations and views of the person with the intellectual disability in the centre of a web of formal and informal sources of support, very clearly acknowledging their complimentarity and the need for partnership (O'Brien & O'Brien, 2000). Although the UK policy mandates PCP across all age groups, PCP together with health plans are identified as primary mechanisms to ensure an effective response to each individual's needs as they age. In addition to the development of PCP, disability service systems in both the UK and Australia are reorientating and shifting from the block funding of services to individualised funding mechanisms that aim to increase the control, choice, and flexibility of people with a disability over the support they receive (Davey et al., 2007; Stainton & Boyce, 2004). However, many such programs remain in the pilot/demonstration phase and include relatively small numbers of people with intellectual disability (Stainton, in press).

Australian policies about disability service provision have no age qualifiers for people with lifelong disability and there are no specific policies to guide the provision of services to this group by either the disability or age care sectors. It was clear from a 2007 National Enquiry into the Commonwealth State and Territory Disability Services Agreement that disability service organisations are grappling with the implications of their clients' ageing and to respond to issues such as retirement and ageing-in-place within their existing program structures (Bigby, 2008; Senate Community Affairs Reference Committee, 2007). It is also clear from a Victorian survey that residential aged care facilities struggle to accommodate the needs of older people with intellectual disabilities (Bigby, Webber, McKenzie-Green, & Bowers, 2008).

Research suggests that people with intellectual disabilities who are ageing face particular challenges due to characteristics and life experiences associated with their lifelong disability, such as limited informal social networks, poor health status, premature ageing, and high incidence of early onset dementia (Bigby, 2000; Cooper, 1997; Torr & Chiu, 2002), and as a result of structural aspects of society, such as discrimination and low expectations of staff (Bigby, Fyffe, Balandin, Gordon, & McCubbery, 2001; Moss & Hogg, 1989; Walker & Walker, 1998). Studies that have sought the perspectives of people with intellectual disability suggest that these people have definite views about exercising choice and remaining active as they age (Edgerton & Gaston, 1991; Hand & Reid, 1989; Mahon & Mactavish, 2000). In a similar vein, studies have found that people with intellectual disabilities are reluctant to retire from paid work or formal day activities and want to remain engaged in a range of social and leisure activities (Ashman, Suttie, & Bramley, 1995; Bigby 1992, 1997a). It is suggested that the understanding of ageing of people with intellectual disabilities is often based on stereotypical images and that they are concerned about negative changes, such as a lonely lifestyle or loss of job (Erickson, Krauss, & Seltzer, 1989; Lifshitz, 2000). Studies point to the validity of such concerns and that despite their aspirations, older people with intellectual disabilities experience few opportunities to participate in meaningful activities of their choice (Bigby 1992, 1997a; Grant, McGrath, & Ramcharan, 1995; Rogers, Hawkins, & Eklund, 1998) and that as they age their access to specialist disability services is likely to be reduced and restricted (Bigby, 2000; Thompson, Ryrie, & Wright, 2004).

Although the characteristics of people ageing with an intellectual disability are increasingly well mapped and some insight has been gained into their views about ageing, limited knowledge exists about their experiences of service use, which could inform service development. Conceptualisation of service needs has relied on frameworks derived from earlier parts of the lifecourse, in particular quality of life (Brown & Brown, 2003; Felce & Perry, 1995). Eight key domains are commonly identified as contributing to a person's overall wellbeing: physical, emotional: mental health, interpersonal relations, material, personal development, self determination, social inclusion, and rights (Schalock & Alonso, 2002). However, quality of life is still a contested concept surrounded by considerable critique and debate in relation to its conceptualisation and measurement (Hatton, 1998). Bigby (2004) suggested that

Nolan, Davies, and Grant's (2001) "Senses Framework", which aims to provide directions for care staff and guide service development across a range of settings for older people, may be useful in informing the development of quality services for older people with intellectual disability. This approach positions outcomes against the subjective views and perceptions of the older person him- or herself rather than externally imposed subjective criteria, and sensitises professionals to key dimensions of importance in older person's lives, which are suggested as achieving a "sense of" security, continuity, belonging, purpose, achievement, and significance.

The present study explored the everyday lives of older people with intellectual disability in Victoria and Queensland and their experiences of using disability services as they aged. It used Nolan et al.'s (2001) "Senses" as a conceptual framework to understand the experiences of this group of service users with the aim of informing practice and service development for older people with intellectual disability.

Method

Methodological Approach

Social constructionism theory (Crotty, 1998), with its focus on how individuals construct their social worlds, provided a lens to guide the present 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 labelled 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 people meeting the above criteria who were using the 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 wanting to participate were asked to nominate a family member or someone in a close unpaid relationship and a direct care worker who may also be interested in participating and to give them information about the study, with the assistance of a representative from the organisation if needed. In all, 16 triads, comprising a person with intellectual disability, a family member or someone in a close unpaid relationship, and a direct care worker, participated in the study.

The 16 participants with intellectual disability were aged between 52 and 80 years, with a mean age of 62 years. Their characteristics are set out in Table 1. Participants

Table 1 Participant Characteristics

Person	Gender	Age (years)	Occupation	Accommodation
Rachel	Female	62	Involuntarily retired	Family home with parents
Rod	Male	62	Works in sheltered workshop	Family home with sister
Angie	Female	55	Works in sheltered workshop	Private rental with husband
John	Male	56	Works in sheltered workshop	Own house with drop-in support
Janine	Female	58	Has never worked	Own unit in retirement village
Amy	Female	80	Retired	Group home
Judy	Female	64	Has never worked	Group home
Malcolm	Male	62	Works in sheltered workshop	Group home
Ivor	Male	57	Has never worked	Group home
Laura	Female	63	Involuntarily retired; currently doing voluntary work	Group home
Trevor	Male	52	Voluntary work	Alone in rented flat
Caroline	Female	60	Voluntary work in the past	Group home
Jed	Male	71	Voluntary work in the past; now retired	Group home
Janie	Female	53	Used to work in sheltered workshop; now retired	Group home
Freda	Female	68	Works in sheltered workshop	Group home
Wally	Male	69	Worked in sheltered workshop in the past; now retired	Group home

were divided equally between Victoria and Queensland and, within the states, between major urban, rural, and regional locations. All had been in supported employment for much of their adult lives. Only 5 were still employed and the remaining 11 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, 11 were a parent or sibling, 2 were volunteers who had become close to the person, 1 was a former employee who maintained regular contact with the person, and 1 was a church member. All care provider participants had known the person with intellectual disability for more than 1 year.

Procedure

Indepth interviews, described by Hesse-Biber and Leavy (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 regarding their life as an older person and their aspirations. This acknowledged the expertise of the participants on these issues and provided them with the opportunity to express their views in their own terms (Minichiello, Aroni, Timewell, & Alexander, 1995).

The interviews were conducted by a research assistant experienced in working with people with intellectual disability. Interviews lasted between 60 and 90 minutes. Separate interviews were conducted with the family member or the person with a close unpaid relationship, as well as with the service provider identified by each person. These latter interviews asked about these people's perceptions of the person's ageing, 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, Mok, & Parmenter, 2000).

Data Management and Analysis

Each interview was audiotaped and transcribed. These transcriptions formed the data and qualitative data analysis strategies were used as outlined by, among others, Miles and Huberman (1994). These strategies involved a process of coding, developing categories, and constantly comparing and regrouping these categories to elicit the themes and relationships among these themes. Analysis of cases was undertaken separately by each author and then discussed and further refined.

The present study was an exploratory study with 16 older adults that focused on their lived experiences and from which generalisations cannot be made. Qualitative research of this kind should be evaluated on the basis of trustworthiness, which includes credibility, transferability, and confirmabilty (Cresswell, 1998; Lincoln & Guba, 1995). Transferability has been addressed by the rich, thick description of the participants' situation derived from interview transcripts. A process of peer debriefing occurred on a frequent and regular basis within the research team. Direct member checking occurred as interviews were conducted to ensure accurate understanding of what had been said.

Results

Being Connected and Valued

For all except one person, services were an important catalyst for an identifiable set of positive social relationships with staff and other service users that gave older people a sense of belonging, being valued, and recognised as an individual.

Malcolm (a service user) 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 in which Wally was held, despite his idiosyncratic crankiness: "everybody loves him, he's a grumpy old bugger he is, but he's everybody's favourite". Rod [service user] 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 ... one boy down there in the book section, Doug".

The close and long-term friendships, and sometimes intimate relationships, with other service users originated in disability programs and were maintained through shared activities, either in the service setting or in community venues after hours. Such activities did not involve “outsiders” or broaden social relationships beyond service users. Friendships seldom crossed the boundary of their “service world”.

For example, Angie has been married to Paddy for 10 years, who is also a service user. They met in a supported accommodation service and both now work together at a supported employment service. They bowl 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”.

Malcolm, a service user, pointed to the importance of his relationship with Meg, another service user, 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 Mondays and Wednesdays but not Fridays.

Most older people also 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”. 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 [service user] 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. Older people and service providers alluded to the changes occurring to family relationships as parents died and other family members, usually siblings or nieces and nephews, took over some of the roles previously fulfilled by parents. Two participants, notably both with no family contact, had a friendly relationship with volunteers that had been facilitated by their day service. Ivor [service user], 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. Ivor 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, had antagonistic relationships with some of the other residents, and did not participate in the activities organised in the village. 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.

Janine did not mention relationships with other service users and, unlike the other older people, she did not spend a significant portion of her time in a segregated disability service, only attending a day program 2 days a week. Although she largely inhabited a nonservice 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.

Keeping Active and Being Controlled

Most of the older people routinely participated in a range of activities. Joanne, a service provider, suggested a key function of services was "keeping them occupied, that's the best". Trevor, a service user, indicated a busy routine at his day centre:

> Ooh yeah, I love it, then Wednesdays I go bowling again, twice bowling ... and Thursdays we go shopping ... last week we went in the country ... and we go different places ... Fridays we go to the country for a drive ... sometimes we go for a barbeque.

Both large and small decisions were made for these older people by staff and family. Janine [service user] talked 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". Judy [service user] 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 [service user] 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 ... I just keep on my own way ... always doing things the way other people want me to do.

Janie [service user] 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".

Service-Centred Present-Focused Decisions

The decisions that others took for the older people appeared to be service rather than person centred, with operational service requirements taking precedence over the person's needs or interests. For several older people, the potential for decisions made by others to jeopardise their future quality of life was clearly illustrated. Caroline [service user] said:

> Donna [staff member] 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.

Rachel [service user] described her views on having to move from her long-term workshop to a day program:

> They 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.

Both staff and the older people were frustrated by the absence of an orientation to the future by senior management or in organisational policies and operating procedures. All older people had firm ideas about the future, but received little support to follow these through. 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". Malcolm (a service user), who lived in a rural accommodation service 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". Rachel, a service user 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.

Freda, a service user, 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?

Some families had thought about the future, but others, particularly those where parents still played a major role, were reluctant to think explicitly about it or discuss it with service providers. Rod, a service user, said, “my brother George comes around a lot. My sister said if she passed away I’ve got to go to George’s home”. Rachel’s mother, unlike Rachel (a service user), 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.

The Impact of Living in Separate Worlds

The lives of these older people fell into two distinct and quite separate spheres: the service world and the nonservice 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. Claude, a family member, said, “We’re continually forming relationships with different staff”, whereas Malcolm’s mother 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 and services did not appear to take a lead in raising questions about the future with families. 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”.

The disconnection between family members and the service world 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. I don’t know who they are. They’ve been doing it for years”.

Indeed, there was a sense that no one from either of the two worlds had a mandate to know the whole person or the right to do so. 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 because 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 has got that sorted out. Least I think so". Another staff member said, "we're aware of boundaries with family, and we can't do it, we can only suggest it".

The control exercised by others and the present-focused nature of decisions they made for the older people not only reduced the autonomy of the people with intellectual disabilities, but risked the continuation of activities that were important to them and a fracturing of their relationships with other service users. The rigid boundaries that limited the focus of families and service providers alike and the disconnection from each other left 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 pointed 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 her service and nonservice 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 was not addressed. Like the realisation of most goals for people with intellectual disability of all ages, Janie's required skilled effort, collaboration, and advocacy. However, for her, like the other people in the present study, there was no collaboration between her separate worlds and an absence of advocacy to force any issues on her behalf.

Although the relationships and support provided by services and families were central to older people's wellbeing, the focus of support was active current lifestyle. No one knew these older people well enough or had a sufficient sense of responsibility towards them to plan with them, as a whole person, collaboratively across both the boundaries of family and service worlds. As a result, despite their ideas about the future, older people like Janie led busy but directionless lives; 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.

Discussion and Conclusion

All of the present small group of older people were in receipt of one or more specialist disability support services. They are not part of the estimated 27,800 and 3,700 Australians with a disability who, respectively, have an unmet need for accommodation or respite care and community access services (Australian Institute of Health and Welfare, 2007). Yet, the present 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. Nolan et al.'s (2001) Sense Framework helps 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 that gave them a sense of belonging to various "communities" and a sense of significance. Many of these relationships were fostered by attendance at disability services and, similar to other research (Bigby, 1997a), the present study suggests that relationships with other services users are vulnerable to fracture by decisions made by others about retirement. The present study, like other research (Bigby, 1997b, 2000), demonstrates the partial replacement of parental roles by siblings and more distant relatives, suggesting that initiatives to build and nurture relationships are particularly important for older people whose social networks are vulnerable to shrinkage as family members age and relationships with other service users are threatened. Like many other people with intellectual disability, this group of older people lived in a "distinct social space" (Todd, Evans, & Beyer, 1990) comprised of family, paid staff, and others with intellectual disability. Largely absent were relationships with unpaid people without disabilities. For most, their distinct social space was divided into two disconnected spheres: family and services. The friendships of two older men, who both attended the same service, with volunteers demonstrate possibilities for boundary crossing. In their case, initiatives taken in the service world provided the opportunity for them not only to develop relationships in the informal sphere, but also formed a bridge into participation in community groups, friends, or acquaintances without disabilities. Older people with intellectual disabilities can have a sense of belonging and be part of the envisioned "inclusive community" (Department of Human Services, 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. The importance of building informal networks or circles of support around people with intellectual disabilities to support PCP, community inclusion, and a form of protection when parents die is well recognised in the literature (Etmanski, 2000; O'Brien & O'Brien, 2000). However, it is not clear where in the Australian service system responsibility lies for building informal relationships of older people with intellectual disability. Such boundary spanning is the raison d'être of case managers (Moxley, 1989) and social workers (Payne, 1995); however, with one exception, such roles, or staff with a mandate for this task, did not figure in the types of services delivered to the older people in the present study.

The evidence about the busy lives led by the older people in the present study, their enjoyment of the activities in which they participated, and their clearly articulated ideas about the future suggest it is safe to conclude they had a sense of purpose. However, a connection between their activities and 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 because operational service needs or the wishes of others took precedence. Thus, a substantial obstacle to gaining a sense of achievement by realising their goals was created for this group of older people.

Detailed data about health and other forms of daily care received are not reported here, so there is insufficient evidence to draw conclusions about the receipt of sensitive and competent care by the older people surveyed, and thus their sense of security. However, their own uncertainty about their future care, as well as that of staff in the services they attended and family members alike, is not indicative of a sense of security.

The final "sense" is that of continuity, which is defined by Nolan, Davies, and Brown (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-focused decisions, or took responsibility for supporting them to refine and implement their plans.

The present study has shown that policies of individualised services and planning that reflect the individual's needs and goals have not touched the lives of this group of older people and suggests that, at a systemic level, policy and program development to support older people with intellectual disability is yet to occur in Australia. Such development must consider questions of how to achieve a sense of continuity, purpose, achievement, security, belonging, and significance for older people with intellectual disability more successfully. Direct funding or individual budget mechanisms are a potential force to drive more individualised support for older people with intellectual disability. However, many in this group, like those in the present study, are long-time users of traditional block-funded day support, employment, or accommodation support services and are unlikely to be first in line for the new funding, which is more likely to be tied to innovative delivery mechanisms. The study also suggests that significant work will be required to implement individualised planning with this group. The challenge will be to knit 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 nonservice 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 successfully implement contemporary disability policy and notions of PCP strategies will need to consider some of the some of the questions raised by the present study, such as why are people's worlds so separate? What are the obstacles to greater collaboration? Why do services 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? What stops both services and families letting go of some of the control over people's lives? In particular, consideration must be given to the skills required and who, within what part of the service system, should be responsible for individual planning and taking the lead in turning drifting between two worlds into more purposeful lives for older people that reflect their own biography.

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