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Later life for adults with intellectual disability: A time of opportunity and vulnerability[1]

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Old age is often regarded as a time of reduced functional capacities, decreasing community participation and narrowing horizons. Such views are sometimes reflected in the nature of programs and services, and the more limited expectations that service providers hold about older people. This paper reports on the findings of a qualitative study of the later life experiences of 62 older people (over 55 years) with intellectual disability. Contrary to the often negative stereotypes, in later life, many of this group experienced considerable personal growth, broadened their horizons and increased their personal autonomy and independence. However, for them, later life was also a time of increased vulnerability to inappropriate residential environments, residential mobility, loss and disruption of social networks and reduced access to specialist disability services. Conclusions are drawn about the ways in which later life opportunities can be safeguarded and vulnerabilities reduced through the development of appropriate policies and services for older people with intellectual disability.

Particularly negative conceptions are held about later life for people with intellectual disability. They are considered to fall into two or more disadvantaged groups and thus be in double or triple jeopardy (Dickerson, 1979, cited in Hogg, Moss, & Cooke, 1988a) or even decajeopardy (McDonald & Tyson, 1988). Policy documents typically characterise older people with intellectual disability as less independent, more frail and less motivated or capable of societal participation or individual achievement (Community Services Victoria, 1992; Health and Community Services, 1993a, 1993b, 1995). These conceptions reflect notions of the classic aging theory of disengagement that portrays old age as a time of decline, stagnation and withdrawal from social life.

People with intellectual disability are often considered to be older at a much earlier age than the rest of the community. In Australian social policy today, 60-65 is regarded as the age at which people are older. However, 55 is commonly the accepted definition

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of an older person with intellectual disability, although some studies use as young as 40 years (Ashman, Suttie, & Bramley, 1993; Bigby, 1995; Seltzer & Krauss, 1987). A younger definition of aging is often justified because people with Down syndrome age prematurely, have a high incidence of Alzheimers' disease and a considerably shortened life expectancy.

Pessimistic conceptions and younger definitions of aging may not however be warranted. Most evidence suggests that people with a mild to moderate intellectual disability without Down syndrome, age in a similar manner to the rest of the population, although diagnosis and treatment of medical conditions may be delayed or ignored. This means, for example, that many will continue to develop right up to their 60s, their cognitive abilities do not begin to decline until the mid 60s and they will not suffer higher rates of disability and chronic illness until into their 70s (Adlin, 1993; Anderson, 1989; Hewitt, Fenner, & Torphy, 1986; Hogg, Moss, & Cooke, 1988b). It should be noted, however, that research findings in this area have been contradictory. Some studies suggest that older people with intellectual disability have a different health status compared with the general community (Ashman, Suttie, & Bramley, 1996) and may be prone to increased rates of aged-related regression in adaptive behaviour (Strauss, Zigman, 1996). Nevertheless, because of the "healthy survivor effect", as a group also older people with intellectual disability have been found fitter and less disabled than their younger peers (Tarjan, Wright, Eyman, & Keeran, 1973). Because of higher age specific mortality rates, the majority of older people with intellectual disability are the "younger old", in their 60s rather than 70s. Approximately half (who are defined as old by researchers) are too young to meet the definition of older that is applied to the rest of the community (Ashman *et al.,* 1993).

A more optimistic view of later life for people with intellectual disability is found in Edgerton's longitudinal research that noted positive changes occurring in old age among a cohort of ex-institutional inmates. They experienced a striking improvement in their life satisfaction, social competence and quality of life as they grew older as a result of increased competencies and the decreased expectations placed by society on older people. Edgerton suggests that, "when they are in their 60s these people are not only more competent in absolute terms than they have ever been before, they are also seen to be relatively more competent than in any prior period of their lives" (1994, p. 60).

Most research on older people with intellectual disability is derived from large scale surveys, and few studies other than Edgerton's have examined the nature of this group's experiences in later life. This study explored the aging experiences of a group of older people with intellectual disability who had spent their earlier adult years at home with parents and left home after the age of 40 years. A subset of research questions was concerned with the changes experienced in the post-parental care phase. Personal development, achievements and changes to autonomy and independence were mapped in addition to changed support and care needs. This paper reports findings concerning the positive aspects of later life changes and changes that make old age a time of particular vulnerability.

METHOD

The sample comprised 62 adults with intellectual disability aged 55 years and over who had left parental care after the age of 40 years. The sample was recruited by means of an intensive case finding strategy in 12 municipalities of Melbourne to ensure people "hidden" in the community and unknown to disability services were included. Details of the case finding process and its results can be found in Bigby (1995). The average age of the sample was 65 years and the average age of leaving parental care was 52.5 years. The majority, 40, lived in generic aged supported accommodation, 6 lived in disability accommodation and 16 lived in a private home supported informally or by domiciliary services.

Data were collected using in-depth semi-structured interviews conducted during 1993/4 by the author. The main source of data was a primary informant for each participant. This was someone with whom the person had a close, long-term relationship. They were mainly siblings but also included friends, nieces, cousins, an aunt, service providers, and parents. Additionally, the service provider who identified each participant during the case finding process and 51 of the 62 participants were interviewed. Interviews sought detailed descriptive data about all aspects of the person's life since they had left parental care. The qualitative data were analysed for common themes using the constant comparative method (Huberman & Miles, 1994) and with the aid of a "search and retrieve" computer program, the Ethnograph. Some qualitative data, such as type of informal support and residential movement, were categorised and quantified. Factors such as later life personal development which are relative to each individual's previous life experiences are not easily quantified and evidence of these was gained from informants' impressions rather than systematic measurement and comparison pre and post parental transition.

FINDINGS

Personal development in later life

Half the study population experienced considerable personal development following their transition from parental care. Quite spontaneously, informants drew attention to increased personal autonomy and independence, expansion of social and domestic activities and the development of new skills and personal relationships experienced by sample members.

Bronwyn's case is illustrative of later life development. She talked at length about her life since her mother had died. One of the most memorable things she said was "I didn't get out then [when mother was alive] like I do now to different places. I couldn't go and leave her."

> Bronwyn is 63 years old and had lived at home on her own with her cats since her mother went into a nursing home a year ago. In her "old age" she was going out and participating in a much greater range of activities than she had ever done before and had made a lot of new social acquaintances. She went to several older persons clubs organised by the local council, she was learning to read at a

> specialist literacy class held at TAFE college and regularly called in on several women who lived in the neighbourhood. She was cooking for herself and managing her household with domiciliary support from the local council. She contrasted her life now with that she had lived with her mother and said, "she [mother] wouldn't let me go out. She didn't think I was as old as I am. She wouldn't let me be friends with anybody. She wouldn't even let me talk to anybody."

A defining feature of many later life developments was the unplanned and unexpected nature of them. For example, Vera was quite frail at the time of the study and following a long period of hospitalisation had moved to an aged persons' hostel. Her nieces said:

> "Vera has become more independent. Now she copes really well. She just does things that she would never have dreamt of doing once upon a time."

Rod and Isobel are also good examples of people whose life developed in a totally unexpected way following transition from parental care:

> Rod and Isobel married when they were in their 50s, several years after their respective parents had died. They lived together independently in the community for about 24 years, supported informally by members of their church community. The family friend who managed Rod's affairs since his parents died said, "of course they [his parents] never expected Rod to marry. That's the last thing in the world they ever imagined."

In the post parental care phase, some subjects exercised greater control over their everyday lives than they had ever done before. Three people married. Sixteen lived for a period, either with a friend or alone in a private home in the community albeit with varying levels of domiciliary support. Remarkably, increased autonomy was experienced both by those who moved into supported accommodation as well as those who remained in the community. According to his sister-in-law, Walter, who had chosen to live in the same aged persons' hostel as one of his friends, developed into his own person after he left parental care. She said:

> "the biggest change has been now (moving into an aged persons' hostel). Because now, he's totally a person. Now he can just please himself."

Following transition, some people began to participate in a range of new activities, develop new skills and move around the community to a much greater extent than they had done previously. Lucus's mother contrasted the expectations that staff at the community residential unit had of him compared with when he had lived at home. She said:

> "he never went out on his own (at home), but he does now. They send him to the bank on his own".

Amy moved to a specialist intellectual disability hostel after living with her sister for some time. Her niece described her as really blossoming since the move. She said,

> "her life has changed dramatically for the better because she was doing things that she had never done in her life before and social occasions (sic). I can remember mum [Amy's sister] being floored the first time Amy came home and said she needed bathers because they were going swimming. I don't think Amy had ever had a pair of bathers in her life. And going to the football and going for counter meals, outings and to the pictures and shopping and things like that. Her life is just wonderful now. She is as happy as Larry."

Godfrey is another example of someone who experienced more independence in later life. One of his brothers said:

> "Godfrey can go anywhere: travels on his own to work. Mother let him out very seldom. She let him go down to the shops in Bromely. Now he gets all round Melbourne."

Use of public transport was a skill that many of the study population developed in later life which facilitated their movement around the community. Other skills developed were banking, shopping, literacy, housekeeping, cooking and use of the phone. For example, since her mother died, Gina has lived on her own with support from the local church community. Her church elder said:

> "she certainly has become far more independent and able to undertake more things for herself now than she was able to do in the past. I got a feeling of real growth and development. We are quite proud of her and think she has come along remarkably."

Participation in new social activities often coincided with more opportunities to make friends and acquaintances that, in turn, fostered the development of social skills and competence. Barbara developed a network of friends at the day centre she began attending after she left parental care. Her social development was actively encouraged by her sisters, one of whom said,

> "When she was living with mum and dad she [Barbara] just stayed in the home. I wish they could see what she's been doing. You know, she's marvellous at pottery. She'd never done anything like that before. She should have done [things like this] before. That's what my sister and I decided: to get her involved with other people".

Several people formed a close relationship with a non-family member for the first time in their lives, which gave them great pleasure. The marriage between Isobel and Rod mentioned above is one illustration. Another is that of Nadia who lived alone after her mother died and formed a close relationship with a widower who lived in a nearby flat.

> Nadia's sister thought that he was probably the first real friend she had ever had. When Nadia showed me a picture of her friend she said, "this is my boy. I'm very proud of him".

Explanations of later life development

Explanations of later life developments may be found in the parental attitudes that had restricted earlier developmental and social opportunities for the person with intellectual disability. It was only in later life, when the transition was made from parental care, that they were treated as adults rather than children. Informants frequently contrasted the current situation with previous lifestyles. Nigel's sister-in-law, talking about his earlier life at home, said:

> "he didn't have a life of his own. He was always a child to mum and dad, and told what to do."

References to these protective parental attitudes were not judgemental or blaming and often drew attention to the historical context and attitudes held about people with intellectual disability and informants noted the dramatic changes to services and attitudes:

The opportunities presented by new residential environments and the attitudes of new primary carers or those who took responsibility for their well-being contributed to later life developments. For example, talking about Humphrey's move to a retirement village, his brother, who also lives there, said:

> "Humphrey's had more opportunities to travel here. Normally we do two or three trips a year away from the village. Had dad been still alive he [Humphrey] probably wouldn't have had the opportunity to do that."

People who replaced parents as primary carers or took responsibility for oversight of well-being often had a different perspective from that of parents. Some of them, like Barbara's sisters, took definite steps to encourage skill development, seek out opportunities for social contact and broaden the horizons of the person with intellectual disability. The case of Bruce illustrates someone whose primary carer fostered social development. His sister said:

> "I used to let him go to the village one day a week for just social events, interacting with other people. This was after mum went. Mum would never let him out of her sight. Mum wouldn't let him go anywhere. I've always felt it was better for him to mix because he was very good with people."

Another factor that may be associated with this later life development is the cessation of caring responsibilities and an interdependent relationship with aged parents. The transition from parental care freed adults with intellectual disability from obligations to parents and restricted opportunities that may have resulted from living with them. Middle-aged adults with intellectual disability had often shared the aged life style of their parents well before their health warranted such restrictions. George pointed out how being at home with his elderly mother had restricted his freedom to pursue his own interests. At the time of the study, he was living in a specialist intellectual disability hostel and said:

> "if mum and I had stayed in the house together, I would have been housebound. I wouldn't have been able to do the things that I am able to do now. I couldn't. If I went to the Melbourne Cricket Ground all day Saturday I'd come home and find mum on the floor. I just couldn't go away and leave her on her own."

Later life losses and vulnerabilities

As this group of people with intellectual disability aged, they experienced considerable residential mobility. Twenty-eight people (45%) did not move house when their parent relinquished care but by the time of the study, an average of 13 years later, only nine people had still not moved. Eighty-six percent had moved home at least once and half had moved more than once (17 twice, 8 three times, 2 four times, 3 five times, one 6 times). Length of time away from parental care was associated with residential mobility. Those who had been away for more than 10 years were more likely to have moved twice or more than those who had been away for less time ($\chi^2=9.44$, $df=1$, $p<.01$). Residential moves were more frequently the result of contextual factors such as changes experienced by carers, problems with the quality or the inflexibility of services or changed policies rather than the alteration of personal characteristics or greater care needs of the older person.

The residential mobility of older people with intellectual disability meant they not only had to leave their family home but most also moved from the locality in which they had lived with their parents. This meant that social contact with neighbours and the local community was lost. Whereas the 16 people who stayed on in their family home or moved within the local area had retained local friendships and acquaintances after the death of their parents. They all had one or more neighbours who were an important source of support and whom they regarded as friends. A high proportion of older people with intellectual disability moved to supported accommodation where, although they had contact with co-residents, they were no longer part of a neighbourhood.

Over half of those who had attended a specialist day centre when they were living with their parents had left by the time of the study. These people had attended the centres for many years and they had been an integral part of their life: their friends were there and their parents had established the voluntary organisations that founded and ran these services. Most who had "retired" from day centres had done so at the instigation of staff rather than choice, and on no occasion was attendance at a centre replaced by an alternative day program.

A characteristic of the study population's social networks was the context specific nature of friendships. People did not have contact with friends outside the specific context in which they were made, usually a day or residential service (Bigby, 1996).

Thus their vulnerability to residential mobility, cessation of specialist day programs and the nature of their social networks also made them vulnerable to loss of friendships. Norman, who had not seen any of his friends since he moved to a nursing home, was typical of people who had ceased attending a specialist day centre or moved from specialist disability accommodation. His sister, Wendy, said:

> "I think it was a real shock going from the hostel to the nursing home. All his friends were in the hostel. I thought that they [staff from the hostel] would have gone to see him and take his friends. Perhaps that was my fault".

As people aged they were also likely to lose their key person and source of advocacy from their informal network. This was someone who oversaw their wellbeing, negotiated with formal services and monitored the quality of care. For the majority, a close relative, usually a sibling or family friend, had taken over this parental role. But as sample members aged, so too did their advocates, some of whom died and were not replaced. By the time of the study 16 people did not have an informal advocate compared with only three at time of transition from parental care.

As people aged, they were more likely to live in larger congregate style accommodation than in private households or small scale specialist accommodation, such as community residential units. They were also more likely to live in generic aged than specialist disability accommodation. Table 1 demonstrates this trend by contrasting the types of accommodation, directly after people left parental care with that at the time of the study. When movements into and out of accommodation during this period were tracked (which is not evident from the table) a trend of moving into but then out of specialist disability accommodation was found. For example, 22 people had moved into specialist accommodation and 16 of these subsequently moved out again. The movement from specialist supported accommodation was often a contentious decision, disputed as inappropriate by informal carers.

People with intellectual disability were vulnerable to the loss of specialist disability support services as they aged. At the time of the study, only 21 were using such services compared with 36 straight after transition from parental care. Once people had moved to generic aged accommodation, contact was rarely maintained by specialist disability services. Generic service providers received no support or consultation from specialist staff regarding the provision of appropriate care or programs for their clients with intellectual disability, and most of those in such accommodation did not participate in specialist day programs or receive case management. Being older appeared to act as an obstacle to obtaining help for the first time from specialist services. The carers of four older people who had never used specialist services, when they enquired about services, were advised by officers of the State Department of Health and Community Services that they had little to offer older people, and were discouraged from submitting formal requests for assessment and services.

Table 1

Type of accommodation straight after transition from parental care and at the time of the study

Living Situation	Straight after transition		At time of the study	
	n	%	*n*	%
Private home alone	10	16%	7	11%
Private home with sibling	23	37%	5	8%
Private home with other relative	3	5%	2	3%
Private home with co-resident	2	3%	-	-
Private home with friend	-	-	2	3%
(Total private home)	(38)	(61%)	(16)	(25%)
Aged persons' hostel	9	15%	21	34%
Special accommodation house	3	5%	8	13%
Nursing Home	1	1%	11	18%
(Total generic aged supported accommodation)	(13)	(21%)	(40)	(65%)
Intellectual disability hostel	7	12%	4	6%
Community residential unit	3	5%	1	1%
Specialist respite care	1	1%	1	1%
(Total specialist intellectual disability accommodation)	(11)	(18%)	(6)	(8%)
Total	62	100%	(62)	98%

Note: Due to rounding, some figures do not add up to 100

People also appeared to be vulnerable, as they aged, to living in environments considered by their close associates as inappropriate. No informants raised concerns about the quality of specialist supported accommodation but concerns were voiced about all three types of generic aged accommodation. Such residential environments were criticised for fostering dependence rather than independence, providing insufficient stimulation, comprising people much older than the people with intellectual disability and having staff who were not attuned to their needs. Critical comments about the environment of generic aged residential services far outweighed positive ones.

As the study population aged, they experienced the physiological processes of ageing which, for some, began to mean some deterioration of their health and loss of physical and adaptive functions. These losses were particularly marked for four of six people with Down Syndrome, who experienced the early onset of Alzheimer's disease and those in the over 65 age group. Since they left parental care 15 people (26%) had developed major health problems, limited mobility or had become very frail.

DISCUSSION

These findings demonstrate that for some people with intellectual disability later life could be a time of broadened horizons and personal growth. Such development often relies on the expectations of those in their support networks, both formal and informal, and opportunities provided in their environments. This suggests that notions of the "third age", as time when people are "old" but still healthy and productive and able to pursue new roles and experiences, may be applicable to older people with intellectual disability (Laslett, 1989). Therefore, if their potential is to be realised, the disability service system must revise its pessimistic preconceptions of older people. If a more positive, optimistic stance towards later life were adopted a climate could be fostered that would ensure that the full range of primary care and day activity and leisure options is considered for adults in later life.

Retirement from specialist day centres in Victoria, is an unresolved issue for both voluntary associations and the Department of Human Services, and no upper age limit exists for the receipt of specialist service. Rather than focusing on retirement, the focus must shift to how existing or alternative new services can provide optimal living environments, skill maintenance and development, stimulating leisure, recreational and social opportunities appropriate to each individual's rate of aging. Such services are likely to utilise and support access to generic aged programs some of which however may be inappropriate for the "younger young old" people with intellectual disability.

Some losses associated with aging were unavoidable but many resulted from external factors and are open to manipulation. Few people had the opportunity to "age in place", a central plank of aged care policy. Denial of this opportunity, residential mobility and concerns about precipitous and inappropriate moves from specialist to generic aged services are also reported by Victorian advocacy groups (Office of the Public Advocate, 1993; Westernport Speaking Out, 1996). Younger older people with intellectual disability may be falling between the two service systems, perceived as "old" by the disability system but quite young by the aged care system geared more to the needs of the frail elderly. Various strategies to address this could be adopted.

Strengthening the flexibility of specialist services and their ability to let residents age in place is one way to address this service gap and the vulnerability to inappropriate residential environments that stems from it. Use of the expertise of professionals from both residential and domiciliary generic aged services would facilitate this process.

Nursing homes and hostels may be liable to provide insufficiently stimulating environments for some older people with intellectual disability because they are there for different reasons and are much younger (in this study average 65 years) than other residents (average 80-81 years) (Australian Institute of Health and Welfare, 1993). Apart from the small group with Down syndrome who experienced early onset of Alzheimers' disease and substantial functional decline, the primary reason most other people with intellectual disability were resident in generic aged accommodation was the loss of their primary carer. Their needs for assistance with activities of daily living stemmed from their pre-existing disability rather than age-related decline, which was the case for other residents.

However, an inappropriate milieu is a possibility, not an inevitability, and can be mediated by the quality of services. High quality services will have individualised programs and skilled staff, who are aware of working with residents who have diverse needs. Strategies can also be implemented to optimise generic residential environments for people with intellectual disability. Consultation and training can equip generic staff to recognise their particular needs and to provide services that challenge and stimulate as well as provide care. Clustering a small group of people with similar specialist needs within generic aged services is a strategy adopted in relation to people from non English-speaking background (Department of Community Services and Health, 1995). This approach could be replicated for people with intellectual disability and would ensure special attention was paid to their needs within a generic service.

Another way of addressing these issues is to place more emphasis on alternatives to supported accommodation, particularly for those people who have access to a private home and frequent contact with a key network member who can oversee provision and monitor domiciliary care. Increasingly, both aged care and disability services are developing models that separate accommodation from support and aim to maintain people in the community (Challis & Davies, 1986; Parmenter, 1994). Several members of the study population used such models receiving regular specialist outreach or generic domiciliary services. However, there is an over-demand for such services in the disability field, and access to generic programs is often quite variable.

If residential or other changes are inevitable, greater account should be taken of their effect on informal networks. Plans should be formulated to minimise disruption of networks and facilitate the continuation of relationships. The increasing number of older people without a key informal network member to act as their advocate are particularly vulnerable to poor quality, or inappropriate, services. This suggests the importance of ensuring informal advocates are replaced by, for example, encouraging those who are elderly to plan and negotiate a continuing commitment from potential successors. Consideration should also be given to the way formal services can foster the development of informal relationships to fulfill this informal advocacy role.

Policy and service development for older people with intellectual disability must aim to optimise and safeguard opportunities for personal development and broadened horizons and reduce vulnerability to loss, mobility and inappropriate environments. All the strategies suggested here, however, rely on ideas from the disability services system and a pro-active policy towards the provision of specialist and generic services for older people with intellectual disability.

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