Shifting responsibilities: The patterns of formal service use by older people with intellectual disability in Victoria[1]

Christine Bigby

La Trobe University

As adults with intellectual disability age and inevitably lose support provided by parents, many will become more reliant on formal services. Potentially they can utilise both the aged care and the disability service systems, although neither have explicit policies in relation to this group. This qualitative study examined the patterns of service use by 62 older people with intellectual disability from 12 Victorian municipalities. The majority of older people were using aged-care services. As people aged, access to disability services declined and no collaboration between the aged-care and disability systems was evident. Older peoples' informal advocates experienced dissatisfaction with decision-making processes and the withdrawal of disability services. In addition, they were concerned about the appropriateness of aged-care accommodation services. The implicit policy of redirecting older people with intellectual disability towards aged-care services operating at the service level contradicts policy directions of both aged-care and disability services. The importance of explicit policy and program development for this group is discussed within the current Victorian policy context of aged care and disability services.

Australia is experiencing a rapid increase in both the absolute numbers and proportion of older people. The number of people aged 65 years and over doubled between 1974 and 1994 to 2.1 million. By 2021 they will constitute 18% of the population (Australian Bureau of Statistics [ABS], 1993). The 80 plus age group, who have the highest rate of aged related disability, chronic health problems and greatest need for support services, is growing at the fastest rate (Department of Health Housing & Community Services [DHHCS], 1991). The number of older people with intellectual disability is also increasing but from a much smaller base. For example, since 1982 the number of clients, aged over 60 years, registered with the Victorian State Government

intellectual disability services, has increased from 321 (3%) to 1201 (6.35%) in 1997 (Cocks & Ng, 1983; Department of Human Services, [DHS] 1997). An Australian national survey identified 2543 people with intellectual disability aged over 55 years who represented 0.07% of the total population in that age group. The authors estimated that the number would increase by 20% in the next 5-10 years (Ashman, Suttie, & Bramley, 1993). However, predicting the size of this group is difficult as large scale population studies, such as those conducted by the ABS, do not treat people with intellectual disability as a separate group. Although the life span of people with intellectual disability has increased significantly in the past 50 years, they still have higher age-specific mortality rates and shorter life expectancy than the general population (Eyman & Borthwick-Duffy, 1994) which makes extrapolating figures difficult. A further complicating factor is the suggestion that many people remain "hidden" in the community, and are not counted in data held by disability services (Bigby, 1995; Horne, 1989).

Australian studies of older people with intellectual disability reflect trends found overseas. As a group they are dispersed across the community (with some notable concentrations where deinstitutionalisation has occurred), experience lower levels of disability, are more likely to live in supported accommodation and less likely to attend day programs than their younger counterparts (Ashman et al., 1993; Bigby, 1994; Janicki & Seltzer, 1991). In Australia, older people with intellectual disability are predominantly the "younger old"; 50% aged between 55 and 65 years and 90% between 55 and 75 years (Ashman et al., 1993). Growth of the 80 plus age group with intellectual disability is less significant than among older people generally. Only 7.6% of people with intellectual disability over 65 years are aged 80 years or more, a much lower proportion than the estimated figure of 20% for the general community (Ashman et al., 1993; DHHCS, 1991). However, some groups with particular etiologies such as Down syndrome and cerebral palsy may experience premature ageing (Janicki & Seltzer, 1991). Researchers have suggested that older people with intellectual disability have a high need for formal human services - accommodation, day activity, leisure, advocacy, case management and health-related needs (Bigby, 1992; Community Services Victoria, 1988; Gibson, Rabkin, & Munson, 1992; Lakin, Anderson, Hill, Bruininks, & Wright, 1991). Their needs in many respects may be similar to those of other aged people but may occur at an earlier age or for different reasons. For example support with activities of daily living or access to leisure may be required to replace parental care or compensate for poor informal networks rather than because of declining health or loss of function due to the ageing process (Bigby, 1996).

Despite a high growth rate, it is from a small base and the absolute numbers of older people with intellectual disability in Australia are likely to remain small. They will constitute a small minority group of both aged care and disability service users whose profile differs from that of the general aged population, suggesting that matching policies and services from the aged-care system to their needs may be problematic. Although Ashman and his colleagues recommended that disability services prepare for increased numbers of older people with intellectual disability over the next ten years, they also suggested that people who had remained "hidden" in the community would be likely to approach aged care rather than disability services (1993, p. 86-87).

The major question then, for both the aged care and disability service systems, is what are appropriate policies and models of service provision for older people with intellectual disability?

Three broad service models are suggested in the literature: (a) age-integrated disability services, (b) age specific disability services, and (c) use of mainstream aged-care services. Advantages of each model have been discussed and comparison made between various service experiences (Moss & Hogg, 1989; Seltzer & Krauss, 1987). However, models do not stand alone. Successful access to aged-care services may require varying degrees of negotiation or direct support from a specialist disability service (Bigby, 1992; Lepore & Janicki, 1997). The strategic importance of collaboration and cooperation between the aged care and disability systems to ensure optimum service provision, avoid duplication, utilise available expertise and maximise consumer choice and positive outcomes has been emphasised by Suttie (1996).

In the US, specialist disability programs aim to promote integration into mainstream aged-care services (Moss, 1994). A "surge of activity" has occurred (Hawkins & Eckland, 1990), resulting in policy changes requiring access to aged-care services by older people with intellectual disabilities, and mandating cooperative planning between the two service systems (Janicki, 1994). High levels of integration into aged-care services and shared responsibility for this population between aged care and disability systems have occurred in some States (Seltzer, Krauss, Litchfield, & Modlish, 1989). Moss notes that in the UK, neither promotion of integration into mainstream aged-care services nor development of age-specific disability programs has occurred (1994). He suggests that the flexibility of disability programs, irrespective of client's age, may account for the lack of specialised programs (Moss, 1994).

The Australian national survey found that most older people with intellectual disability relied on age-integrated disability services for residential support, and had limited involvement in community-based social activities. Where day programs were accessed they were provided by disability rather than aged-care services (Ashman et al., 1993). A survey of aged care and disability organisations in Queensland showed similar results. No specialised programs for this group were found, and only a little more than a third of aged-care services had served an older person with intellectual disability in the past year (Buys & Rushworth, 1997).

The present study examined the patterns and experiences of service use in Victoria by people with intellectual disability as they aged. It focused on relationships and collaboration between disability and aged-care services, and between formal and informal sources of support. These various partnerships and experiences were considered from the perspective of informal network members and the older people themselves. The study aimed to contribute to the knowledge about service use, and inform the debate about service models.

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. They were 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. Thirty-three (53%) were known to specialist disability services, although not all were currently using these services. Details of the case-finding process and its results can be found in Bigby (1995). The average age of the sample was 65 years, with a range from 55 - 87 years. On average they had left home 13 years previously at an average age of 52.5 years. Most had a mild or moderate level of disability, and 16 had major health problems that restricted their mobility.

Data were collected using in-depth semi-structured interviews conducted during 1993/4 by the author. The main source of data was one primary informant for each subject who was someone with whom they had a close long term relationship. These were mainly siblings (30) but also included friends (8), nieces (5), cousins (3), an aunt, service providers (13) and parents (2). Additionally, a service provider, in most cases the one who had identified each subject during the case-finding process, was interviewed. The study was not an ethnographic one, as it sought to map a broader terrain than such methods would have allowed. However, with an awareness of the limitations of single interviews, where feasible each person with an intellectual disability was interviewed to ensure they had some voice in the research. Fifty-one of the 63 subjects were interviewed, one person declined and the others were considered by the primary informant to be too cognitively impaired to participate. An interview guide was constructed which sought detailed descriptive data about aspects of the subject's lives and sources of informal and formal supports used since leaving 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 (Richards & Richards, 1994). Some qualitative data such as reasons for residential moves and type of formal services were categorised and quantified. Formal services were classified by their target group and funding source into two groups, "disability specific" and "generic aged care". Disability specific services were those targeted only at people with disabilities, but were not necessarily exclusively for people with intellectual disability. Generic aged-care services were those targeted at older people, irrespective of their health or disability status. Data were not sought in regard to health services. Quantitative data were entered on a relational data base and analysed using descriptive statistics. It is the opinions of the primary informants that are reported in the findings, unless otherwise specifically stated. However, social facts relating to people's life history and service use were often pieced together from information provided by the three sets of informants.

FINDINGS

Formal service use

All but one person in the study population used formal services, although the significance and degree of support they provided varied enormously. A total of 53 people (85%) used generic aged-care services, only 21 people (34%) used disability services, and 13 people (21%) used both service systems. However, with several

exceptions, such as guardianship or citizen advocacy, both service systems provided similar types of services. Table 1 details the number of older people who used each broad service type, and from which service system it was delivered.

Table 1

Types services used

Service type	Service system Aged care	Disability	Total n=62	
Residential primary care	40	6	46	74%
Supported employment, day or leisure activity	21	13	34	55%
Guardianship	13	NA	13	21%
Domiciliary support	7	0	7	11%
Domiciliary primary care	1	3	4	7%
Case management	2	4	6	10%
Respite care	1	2	3	5%
Citizen advocacy	-	3	3	5%

Note: Some people used several types of service

As Table 1 illustrates, the types of services most commonly used were residential primary care, supported employment, day or leisure activities, case management, domiciliary support, and guardianship, which are discussed in more detail below

Supported employment, day or leisure services

As shown in Table 1, 34 people used supported employment, day or leisure services. Of these, 13 people used a disability service and 21 an aged-care service. Nine people attended an Adult Training and Support Service (ATSS), which was the most common disability day service utilised by a member of the study population. ATSSs provided a range of age-integrated and age-specific programs and often a supportive base from which aged-care services were accessed. ATSSs were much more than just a "day placement". Participants had attended for many years, the centre was the pivot of their social network and, for most, family members provided significant volunteer labour. ATSS staff had strong relationships with participants and their families, and often acted as defacto case managers. Retirement from ATSS is an unresolved issue for both funders and providers of services. It had not been contemplated by the older people themselves, and family members were generally opposed to it. However, 10 people had ceased attending an ATSSs since their transition from parental care.

Sheltered workshops fulfilled a similar function to ATSSs, providing meaningful day activities and opportunities for social interaction. Workshops did not, however, assist their clients to use aged-care services in the community, and families were generally not as involved in these organisations. Three people attended disability-specific social groups, based in organisations such as neighbourhood houses, that provided opportunities for social interaction, recreational and educational activities.

Attendance at such groups was not on a long term basis, occupied much shorter periods, and was less central to the lives of older people than were ATSSs.

Twenty-one people (34%) attended at least one aged-care day service. Those living in aged-care accommodation often went "en masse" with other residents. These programs were usually organised by voluntary organisations such as churches, or by Local Government Aged Services Departments. Daily attendance for lunch at a senior citizens' centre provided the central focus to the lives of two people in the study who both lived at home alone. The older people interviewed spoke enthusiastically about their attendance and relationships with other participants at aged-care day programs.

As well as other types of programs, all the disability day services provided some structured programs aimed at enhancing skills. Such programs were not available at aged-care day services, where the focus was solely the provision of opportunities for leisure activities and social interaction external to a person's place of residence.

Domiciliary support

As shown in Table 1, a disability outreach service provided the primary care for three people. This provided regular reliable assistance, oversight of household management, and a valued safety net for the plethora of non-routine tasks that community living involves. A very similar service was received by one person from a generic domiciliary service funded through the Home and Community Care (HACC) program and run by local government. However, the disability outreach service was supplemented by a weekly home help service, provided by local government. Four other people, all of whom had informal primary carers also received generic domiciliary services funded through the HACC program.

Residential primary care

As Table 1 shows, a total of 46 people received primary care in a residential setting. Six people, including two who had no permanent place and were occupying respite beds, lived in disability accommodation. These services were age-integrated and either community residential units with three or four other residents or larger hostels with at least 20 other residents. All residents in disability accommodation had their own room. They had a long history of contact with disability services and were still attending the ATSS they had attended for many years. In the period since the transition from parental care, most people had experienced residential mobility. Twenty-two people had moved into disability accommodation, but 16 had subsequently moved out again, most to aged-care accommodation. Reasons for leaving disability accommodation included: pressure from the service (11), need for increased support (2), and the fact that the accommodation had been only temporary (2).

Forty people (65%) lived in some form of aged-care accommodation with more than 50 other residents. Twenty-one people lived in aged persons' hostels, 11 people lived in nursing homes and 8 lived in special accommodation houses. These people were clustered together in 23 of the 174 residential services in the two regions in which the study was conducted. For example, eight people lived in the same aged persons'

hostel, four in another and several clusters of two people existed. Most of these aged-care services also had other residents with intellectual disability who were younger or did not meet the criteria for inclusion in the study. However, despite these concentrations, people with intellectual disability always formed a small proportion of the total residents. People living in hostels (except the married couple who shared a room) had their own room while the majority of those in nursing homes or special accommodation houses did not.

Case management

Four of the six people who were in receipt of a case management service had a case manager from a disability services client team of the Department of Human Services. Case managers performed varied functions from service planning to irregular monitoring. No case manager had a long-term relationship with an older person or played a central role in their lives. Twenty-eight (85%) of the 33 people registered with DHS had not been in contact with the Department for over twelve months. However, most informants had been in contact with DHS in relation to a General Service Plan meeting within the last five years. Vagueness characterised the perceptions of family members and service providers regarding the services available from DHS.

In contrast to relationships with disability case managers, two older people had a very warm, long-term relationship with a social worker from an aged-care service who provided a casework/case management service for them. Most of the older people who lived in aged-care accommodation had been assessed by an aged-care assessment team or had short term contact with hospital social workers. The value of these service providers in helping informal key network members to find accommodation was frequently remarked upon by informants. Only one adverse experience was reported with an aged-care assessment team. This involved exclusion of family members from the assessment process, and denial of access to the report.

Guardianship

In Victoria, the Guardianship and Administration Board (GAB) has power to appoint either a guardian or an administrator for persons with a disability who cannot make decisions for themselves and, at the time, require a formally appointed person to make decisions in an area of their life or manage their financial affairs (Carney & Tait, 1993; Victorian Government: Guardianship and Administration Board Act, 1986). The Board operates on the principle of the least restrictive alternative, and will not appoint a guardian unless it is necessary and informal arrangements are not working satisfactorily. Thirteen people had been in touch with the GAB, five of whom had a time-limited guardian appointed for a decision regarding either a medical or an accommodation matter. The majority of requests for guardians had been initiated by formal service providers in the context of the person with the disability having no informal network member to make a decision on their behalf. Guardians, whether formally appointed or informally recognised, can make decisions only within the parameters of available services. One family member who applied for guardianship was refused on

the basis that the dispute was not about the failure to acknowledge his informal decision-making role for his brother, but rather the decision made by the accommodation service that their services were no longer suitable for his brother. Seven people had an administrator, six of whom had family members appointed to this role. Family members were critical of the operations of the GAB, and felt mistrusted and resentful of the detailed annual report required by the Board.

– *Roles of formal service staff*

Staff of formal services were integral members of the support networks of many older people, particularly those who relied on formal services for primary care. Six older people named a formal service provider as a friend, and most of those interviewed living in residential accommodation nominated a staff member as the person they would talk to if they had a problem. Staff of aged-care residential services had organised and encouraged access to external programs, helping the older person to find educational or day activity services.

Accessibility of formal services

The study population depended on informal network members, or other formal services, to locate and arrange access to formal services. Help was primarily sought from aged-care rather than disability services, as informal network members generally had a very poor knowledge of the disability service system and were better informed about aged-care services, often because of their parents' use of these services. Additionally, some of the study population had originally attended aged-care day services with their elderly parents, and continued to attend after the transition from parental care. Access to aged care domiciliary or day services did not seem problematic for these people. However, without consulting service providers and primary carers more involved in negotiating access, no firm conclusions can be drawn. The reluctance of some aged-care residential services to accept people with intellectual disability was raised by some informants. Such reluctance may account for the clustering of people in a few facilities.

Newcomers to specialist services in later life were rare; people using the disability service system had generally done so for many years. Since the transition from parental care, only four people had begun using disability services, and the total using them declined from 36 to 21. Evidence suggested that disability services were inaccessible to older people who were first time users. For example, in four instances, informal network members or generic service providers who approached DHS were given the impression that either no services could be offered to an older person, or that the person would not be eligible, thus, pursuing the inquiry was not worthwhile. Aged-care service providers had not made referrals to disability services, or provided information about them to informants. The reasons for this could not be fully investigated as only a few aged-care providers whose functions included referral were informants. However, it is possible that aged-care providers lacked knowledge of the disability system or that they considered it was inaccessible and had nothing to offer

older people with intellectual disability. This latter view was expressed with considerable frustration by one aged-care assessment team geriatrician, who said he never referred anyone to DHS as there was a two year waiting list. Disability services did not maintain ongoing relationships with older people after they had left particular services such as day centres, accommodation, or outreach programs. This trend, together with the shift towards aged-care residential services, explains why so few older people used services from both the aged care and disability systems.

Experiences of using formal service

Concerns expressed about disability services differed from those expressed about aged-care services. Informants were critical of the quality and appropriateness of aged-care residential services and, in contrast, were critical of decisions, administrative processes and the availability of disability services. Informants' experiences of the receipt of disability case management services spanned the last seven years, yet their views were remarkably similar. Typically, these services were considered overstretched and ineffective. For example one older person's brother said:

> Their (DHS) General Service Plans and their Individual Program Plans are just paper work. Nothing has been actioned from any of my sister's plans. When you question them (DHS) or ask for support it's always in the too hard basket ... The caseload was too big. The waiting list was too long.

Informants considered that disability case managers based their action plans on a superficial understanding of the older person and failed to listen to family members or utilise their knowledge. Some family members had felt unsupported and left to manage difficult transitions alone. Paradoxically, one older person had a case manager during his transition from parental care but, his sister-in-law had described the need for a competent case manager when asked what would have made the process of transition easier.

With the exception of disability case management services, current users and their informal network members were very positive about disability services. General anxiety was expressed, however, about future policy changes and budget cutbacks. In contrast, ten informants connected with ex-disability service users were not so positive. Hostels, outreach services and, to a lesser extent, ATSSs were criticised primarily for their withdrawal of services to older people and lack of flexibility. The core of these concerns was the merit of decisions taken by service providers that their particular service was no longer appropriate for an older person. Informants considered that decisions about the continuing appropriateness of services were based on system requirements, such as budget constraints or ideological commitments, which had precluded full consideration of the optimum outcome for the older person. For example, when one older man had begun to show symptoms of dementia, he had been asked to leave by the management of the group home where he lived. This man's sister said, "The hostel wanted him out. They had reduced their staff and increased their numbers". The supervisor of the group home was very explicit about the reason the

service was no longer considered appropriate for this man and why he had to leave. She said: "It was costing an absolute fortune [for him to continue to live here] with extra hours for staff to assist him".

It is difficult to judge the merits of decisions made by service providers about the appropriateness of services in retrospect and with limited information. The subjective views of those involved, who were the informants, provide only part of the picture. However, what is important is that questions regarding the merits of decisions to withdraw specialist services were quite common. The merits of decisions were questioned by informants in respect of nine people (15%) across several different services. The withdrawal of disability services resulted in residential moves for all of the older people, and for seven, a move to a more restrictive living situation in an aged care rather than disability service.

Informants raised issues about the process as well as the substance of decisions in respect of 10 people, representing (50%) of disability service users. They felt that service providers did not pay regard to their concerns and implemented service delivery decisions despite their opposition. Some service decisions were taken in a climate of conflict and left informal network member members feeling powerless and frustrated in their quest to ensure the wellbeing of the older person. Such experiences were more than a few isolated incidents, which suggest that it is a systemic issue which cannot be put down to the failings of individual workers. Informal network members were more likely to have experienced conflict with disability than aged-care service providers. Conflict that had occurred with aged-care services had been about quality of residential services, rather than the merits or process of staff decisions.

No consistent issues were raised about the quality of aged-care domiciliary, day or case management services. However, concerns were consistently expressed about the quality and appropriateness of aged-care accommodation. Informants criticised environments for fostering dependence rather than independence, providing insufficient stimulation, comprising people much older than the person with intellectual disability, and having staff not attuned to the needs of people with intellectual disability. The comments of one man's sister encapsulated these concerns, she said "ince he's been there (nursing home) the deterioration has been so great. There's no stimulation. They are just left to sit, left to rot. One of the things was there are no activities for him. They weren't really listening to him." Critical comments about the environment of aged-care residential services were more frequent than positive ones.

Perceptions of unmet service needs

Although informants were critical of various aspects of formal services, most found it very difficult to pinpoint what type of support it would have been useful to have had in the past. The need for knowledge and information about services was highlighted. For instance, one man's sister, who had provided primary care for both him and his mother, said: "people sitting would have been a good service. They probably thought I knew. You know people think that you know about these things. They take it for granted that you know." Primary care options were perceived as too limited. Informants considered that older adults with intellectual disability fell into a service gap between disability

and aged-care services - too old for the disability system but too young for aged-care services. This view is summed up by one woman's brother who said, "She doesn't fit into intellectual disability services. They said they didn't have much to offer and she's too young for aged-care services". Despite an inability to express what services would have been useful, informants who were informal network members, consistently felt that they had been let down by formal services, particularly disability ones. When they had sought help, little had been forthcoming or there had been conflict and dissatisfaction with services.

DISCUSSION

The pattern of service use found in this study differed from that reported by the national survey, where a much higher proportion of older people used disability services (Ashman et al., 1993). The differing samples used by the two studies may explain this. The national survey's sample was drawn primarily from existing disability services users, whilst the study reported here actively sought to include people who were not in touch with disability services. The finding that first time access to disability services is difficult in later life helps to explain the lower use of disability services amongst the sample in this study, which comprised people who have remained out of the residential service till the age of 40.

Neither the Federal or the Victorian State Governments have any specific policies in respect of older people with intellectual disability (Bigby, 1996). However, the findings of the present study suggest that an implicit policy of redirecting them toward the aged-care service system and withdrawing disability services is operating at the level of service provision in Victoria. This was evident from the high reliance on aged-care services and trends of declining use and inaccessibility of disability services as people aged. It was also demonstrated by the deflection of new requests for services, the redirection of existing disability service users towards the aged-care system and complaints about the unwillingness of disability services to adapt to the needs of older users. Support for the premise of an implicit policy are found in reports of Victorian advocacy groups that document examples of older persons being moved precipitously and inappropriately from disability to aged-care services (Office of Public Advocate, 1993; Westernport Speaking Out, 1996). The lack of collaboration between the aged-care and disability service systems found in the present study suggests that the push towards the use of aged-care services is not supported on an individual or systemic level by the disability service system.

The implicit policy and consequent model of generic aged-care service provision was not reported as problematic in relation to domiciliary care and day activity services except by informants who felt older people had been forced to leave ATSSs. Informants and subjects were generally satisfied with the quality and their participation in aged-care day services. However, further research is needed before it can be concluded that such a service model is optimal. It was not clear from this study that older people had exercised any choice in the selection of and attendance at aged-care day services, or that services had been matched to their interests and skills. Further, the lack of skill development or maintenance programs offered by aged-care services and

the "en masse" attendance at day programs by residents in aged-care accommodation suggests that neither opportunities nor choice had been maximised. An earlier study by the author suggested that aged-care accommodation proprietors do not have sufficient resources or understanding of the needs of older people with intellectual disability to match aged-care day services optimally to an individual, and that for this to occur, consultation or brokerage from a disability service would be necessary (Bigby, 1992).

The implementation of the implicit policy was clearly problematic in regard to residential services, and accounts for some of the tension between informal and formal sources of support for this group of older people. At an administrative level, the lack of explicit policy meant that service decisions were not underpinned by policy guide-lines, and were difficult to challenge. At a substantive level, service decisions based on this implicit policy had outcomes contrary to current directions of aged care and disability policy. Policy goals of ageing in place and community care, that aim to assist elderly and disabled people to remain in their own homes as long as possible, were not implemented (DHHCS, 1991). For example, disability services became home for some people after their transition from parental care. Yet, few attempts were made to adapt such services to peoples' changing needs as they aged. Neither was the broad array of flexible in-home supports developed to assist older people to remain at home drawn on by disability services.

In the eyes of many informants, the drive towards use of aged-care accommodation led to inappropriate and unnecessarily restrictive options being offered. Concerns expressed regarding the inability of the aged-care system to provide appropriate services may have been exacerbated by the lack of collaboration between the aged care and disability service systems. Collaboration is suggested as essential to ensure that generic services provide effective, appropriate services and achieve quality outcomes for people with intellectual disability. It includes taking pro-active steps to facilitate access, coordinate services, support individuals in integrated settings and provide complementary services, consultation and training for generic service staff by the specialist service system (Janicki, 1991, 1992; LePore & Janicki, 1997; Van Dam & Cameron-McGill, 1995).

The service model operating in Victoria characterised by integration and the use of mainstream services, is consistent with the principles in both State and Federal legislation (Disability Services Act, 1986; Intellectually Disabled Persons' Services Act, 1986). However, rigid adherence to general principles such as these, particularly without collaboration with disability services, neglects other important principles - choice, continuity of care, ageing in place, and the least restrictive alternative.

The economic and funding environment of the Victorian disability system provides another explanation of the implicit policy. Victoria has an enormous unmet demand for disability services, for which no entitlement exists, and services operate on very tight budgets (DHS, 1995). In such an environment, little incentive exists to adapt to the changing needs of older residents which involve increased costs. Federal policies that restrict the provision of HACC services, except at full cost, to people living in state-funded disability services, despite it being their home, increase the costs of adapting to changing needs. The costs of subsidising aged-care accommodation (nursing homes and hostels) is borne by the Federal government, whereas the bulk of the disability

accommodation costs are borne by the State Government. This arrangement is a disincentive to adapt State-funded services to meet changing needs and provides a strong incentive for disability service to direct new requests for service towards the aged care rather than the disability system. The operation of this implicit policy could be construed as cost-shifting, and one way of dealing with budget restrictions and waiting lists for State-funded disability services.

CONCLUSIONS

Differential expectations, the context of an overstretched service system, and a lack of formal policy may account for the disillusionment and conflict experienced by informal network members in their relationships with formal service providers, particularly those from disability services. A contributory factor may be the relative inexperience of case managers and residential care workers, within the disability system, in dealing with issues confronting older people and members of their informal support network. Such networks are likely to differ from those of their younger peers, as key network members are less likely to be parents and more likely to be siblings, more distant relatives and friends (Bigby, 1997). Informal support is a vital complement to formal services and the findings of this study strongly suggest the need for staff in disability services to develop expertise in issues both of ageing, and of supporting and negotiating with informal support network members.

The outcomes of the implicit policy of diverting older people with intellectual disability towards aged-care services without complementary disability services or collaboration can be contradictory to established policies and detrimental to the quality of services available to this group. Disability services in Victoria, particularly accommodation, do not appear able to respond with any degree of flexibility to the changing needs of people as they age. Also, the use of mainstream aged-care services alone, does not seems to ensure optimal service provision. Joint Federal/State policy and initiatives are required to counter the current climate, which is more conducive to cost shifting than cooperation and collaboration, especially since responsibility for the provision of services does not fall clearly under the responsibility of either the aged care or disability systems. However, each system will have to actively contribute its services and expertise in order to ensure optimal services for older people with intellectual disability.

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