

Ageing and Lifelong Intellectual Disability: Implications for Policy

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This paper reviews gaps between services and needs and describes the parameters of public policy changes required if community agencies and families are to meet the needs of older adults with lifelong intellectual disabilities. A national research project undertaken between 1989 and 1991 provided data on both national and regional demographic, health status and service statistics and was innovative in disseminating this information widely and to a variety of audiences, including through a professional photographic installation. In spite of this effort and the stated intention to provide evidence for action, neither policy nor practice have grown to meet the needs identified. Public policy must value the voices of people with intellectual disabilities and their carers or advocates and actively support partnerships between government sector and community organisations if the needs of communities and families are to be met.

A national research project about older people with lifelong intellectual handicap was undertaken between 1989 and 1991 to determine the size of the population, to assess present health and abilities and to provide reliable information that could be used for providing services and developing public policies (Hand, 1994). It was hoped that the findings of the research would "lead to greater interest in the field by clinicians and researchers and to better understanding by the public of the lives of people with intellectual handicap" (Hand, 1996 p.108). This major project and pilot studies 1986-1988, was followed by focussed investigations of specific issues, most recently a study of the future planning efforts of

families. A current project includes medical examination, information about life expectancy and an update of health and service needs of the original study population.

In 1990 New Zealand had a population of 3.4 million of whom 745 548 were aged 50 or older. The original research identified 1,063 people with lifelong intellectual disabilities living in New Zealand in 1990 aged 50 and older, corresponding to a prevalence of 1.43 per 1000 (Hand, 1994). This was a study of people who had been regarded as mentally retarded since childhood and in 1990 were aged between 50 and 88. Half were aged between 50 and 60 years. There were equal numbers of men and women, and four percent were Maori (Hand, 1994).

Many different and innovative ways of collecting, analysing and disseminating data were undertaken (Hand, 1996; Reid & Hand, 1995). Data produced included national demographic, health status and service statistics, transcripts and audio-tapes of personal interviews with research subjects and some family members, photographs and a number of texts. Products of the investigation were papers in academic journals, reports to health service purchasers, oral presentations to professional conferences, special interest groups, parents and service providers, talks and debates open to the general public and public information sheets. An exhibition of photographs and text was produced in cooperation with a professional photographer (Hand, Reid, & Noble, 1992). A quality photographic installation was created independently by the photographer for display in art galleries and museums (Noble, 1994) and has toured New Zealand for three years.

In spite of these efforts and the research teams' stated intention to provide evidence for action neither

policy nor practice have grown to meet the needs identified. The purpose of this paper is to reconsider the gaps between services and needs, to describe the parameters of the policy changes that we think are needed and to suggest strategies for more effective influence over policy formation.

The Shift to Community

One of the reasons for our original study (Hand & Reid, 1989) was a response to the worries of organisations, like the Society for the Intellectually Handicapped (Inc) (now known as IHC), Presbyterian Support and the Salvation Army about the growing numbers of people with lifelong intellectual disabilities who unexpectedly and urgently needed a home. This need invariably had arisen because of the illness or death of their carer and lack of alternatives among their family, neighbours and community networks. The alarming increase in the number of such situations was a consequence of social and demographic changes limiting the availability of family carers and of public policy changes promoted by the rise of the political and economic new right (Hyman, 1994). This situation was exacerbated by new policies of discharging people from public hospitals to the care of families and community based agencies. This shift of responsibility from hospital to the community has been witnessed in many countries and is not unique to New Zealand.

Changes in the Community

At the same time as responsibility was shifted to community, a fiscally conservative government limited spending, tagged funding for community based agencies and adopted a stance of "less-government-is-good" (Gunn, 1993). Agencies were asked or expected to provide, under contract, essential services formerly provided by government as well as provide new services made necessary by changes in government emphasis. The result for community organisations and workers has been mixed. Most experienced increasing stress due to underfunding, lack of experience of contracting environments, and unmet needs for new and on-going training. Activities were reoriented towards contracted essential services and away from advocacy and other community service activities. While some organisations, notably the churches, have continued to engage in lobbying on a broad range of social issues, many smaller and poorly resourced organisations have been overwhelmed by immediate and contracted tasks and have not been able to advocate effectively on policy issues or to engage in strategic planning. There have been some positive

changes. For example, increased professionalism, indispensability by providing essential services and opportunities for paid work (Gunn, 1993). If the stresses experienced to date are to be productive in the future, community groups must be valued, their co-operation negotiated not presumed, and their sources of funding clarified and adequate.

In the particular instance we studied, birth families (if known) were asked to volunteer, and agencies were contracted to provide homes in the community for people who had been living in public hospitals. Over 500 of our study group now live in community settings but generally, agencies and families have not been able to meet the needs of people with lifelong intellectual disabilities. The survey of health and support service utilisation and demand showed that 7-10% urgently required services like dental care, speech therapy and nutritional advice. The unmet demand for social and family support like transport (15%), budgeting and leisure education (22%), and citizens advocacy (12%) was even larger (Hand, 1994). As these are the kind of services that enable community participation and individual independence demand is likely to increase.

Demand for direct support of carers is also likely to rise as the inadequacy of present provision is demonstrated. For example, publicly funded respite care is available but must be sourced by carers. The limited informal networks of carers restrict their knowledge of quality respite options and translate to compromised respite choices. In one instance, respite in an unknown family with small children was identified for a man with constant support needs. It was essential for his usual carer, a parent, to have a break, but the worry of the adequacy of respite care severely compromised her respite.

Demographic and social changes have limited the number of potential family carers able and willing to provide informal support either in the long or short term, particularly when a relative with lifelong intellectual disability requires the presence of another person in the household at all times. The willingness of the new generation of carers to sacrifice income, recreation and freedom will be tested by the limitations of direct support.

Trends among families

A combination of several trends rather than a single trend impacts on the abilities of families to provide support or to continue to look after a family member with a lifelong intellectual disability. One trend in recent decades is towards smaller household groupings (Royal Commission on Social Policy, 1986; Statistics

New Zealand, 1997). Single-person households are the fastest growing category of household type, increasing from one in eight in 1971 to one in five in 1991 (Statistics New Zealand, 1994). This trend is reported for people at all ages and "...reflects changes in the attitudes and choices of New Zealanders..." (Statistics New Zealand, 1997, p128). People are increasingly choosing to live by themselves and not with other people.

The general fertility pattern over many decades shows a continued decrease in the numbers of live births per woman. It is now at a point where the average family size is 2.04 which is just below the level required for the population to replace itself in the long run without migration (Statistics New Zealand 1994). In turn, this means smaller families and therefore fewer potential family carers are available to provide ongoing care. For example, one family in our study had included a woman and a man with Down syndrome. The woman was the only possible future family carer and inevitably assumed responsibilities of 24 hour day care when the parents died.

Between 1981 and 1991, women's participation in the employed labour force rose from 38% to 43%, although women (31%) are much more likely than men (8%) to have paid part time work (Statistics New Zealand, 1994). This effect of increasing participation in the paid workforce and an overall economic necessity to work, even part-time, means that women are less likely to be in a position to assume daily caring responsibilities for relatives.

In addition, New Zealanders are a mobile people, both within and between regions (Statistics New Zealand, 1996). A drift north has occurred over many decades meaning that families are more likely to be located in different parts of the country. Family networks therefore are not likely to include opportunities for sharing daily or regular caring responsibilities.

Policy and change

The findings of the series of studies undertaken since 1986 demonstrate the mismatch among demographic and social trends, family and community changes, and government policies (Hand & Reid, 1989; Hand 1994; Hand et al, 1994; Hand & Reid, 1996). It was apparent, for example, in early reports that people with intellectual disabilities were in danger of social exclusion (Hand & Reid, 1989) and that family carers, usually women, often living in one person households, were undertaking lifelong and 24 hour caring responsibilities, as proxy for "the community".

The costs to individuals and organisations were hidden in rhetoric about community caring. For example, respite care was available (where it could be accessed) but day-care that would permit a carer to engage in paid work, volunteer work or in recreation was not. One woman, caring for her brother with Down syndrome, explained that she would like to be able to play outdoor bowls. However, day-care respite at a local rest-home (her only option, since there were no other relatives in that town) had to be booked well in advance. The unpredictability of weather on bowling days meant that by committing herself to the bookings system required by the rest-home, she ran the risk of having to spend scarce money to pay for something she no longer needed if the bowling were cancelled. Other women had to run the risk of leaving a person alone while they did the shopping. There is a need for regular all day care and for short term occasional day respite. Given the trends outlined above, this is likely to be a formal publicly funded service. Such a service would enable carers to be in paid employment, to maintain their own health, join in retirement and recreational activities, or even to shop without anxiety. To date services to meet the needs of the unpaid sole carer at home, ways of reimbursing for special costs or to compensate for lost employment opportunities have not been developed.

The failure of policy as created by the governmental sector to support family caregivers, and to take into account changes in the household/ family sector reflects unexamined assumptions about the community and family. In reality, home and care has been the territory of families and home and care tasks have been borne mostly by women. One of the reasons why policy has not effectively or efficiently achieved community integration for people with lifelong intellectual disability is that this real meaning of community has not been acknowledged. Consequently, trends in the size and composition of households and in female participation in the paid workforce have not been taken into account. Contemporary social and demographic trends and changes in the roles of women affecting households' ability to care must be considered if people with lifelong intellectual disabilities are to reside outside state funded households or institutions.

Costs to family and agency caregivers have been underestimated and unacknowledged. The assumption that resources of the community are available for care is doubtful, or at least not strategically established. The effects of social and demographic trends, as well as a decade of governmental restructuring and policy change on community organisations, are difficult to estimate. The effects on individual and family caregivers have been largely negative as evidenced

by the four carers who had to give up paid work (Reid & Hand, 1997) and the two carers already mentioned who were unable to access respite appropriate to their needs. The issue here is not whether there is mutual caring and help. Many families demonstrate these values (Noble, 1994). The issue is that unremitting demands and lack of support result in progressively negative effects and inability to sustain caring roles.

Unmet Needs

The national survey (1989-1991) identified the following major service needs:

- membership in clubs, day programmes
- recreational and retirement services
- support and respite for families
- review of medication, and regular health checks and treatment
- vision and hearing services
- education and learning of self care and social skills
- transport (to increase independent mobility, to enable participation)
- more choice in place of residence

Nearly 10 years later, the person with a disability, whether living with their natural family or in a agency group home, is not yet participating in community leisure and recreational services (Reid & Hitchcock, 1996) or in voluntary or paid work. The major activity available to those aged 50+ remains the segregated workshop or activity centre. Most of the voluntary and recreational groups in which people in their later life participate require a level of skill and life experience that has not been shared by older people with intellectual disabilities, particularly those who have lived hospitalised lives. Yet solutions are relatively simple and quite cheap. For example, access to Senior Centers and other generic activities of the retirement age group are limited by personal skill factors and by lack of transport. In most cases a taxi and a companion to ease the introduction would enable participation and at the same time give the 24-hour carer some hours respite.

Education and learning of skills that promote or maintain independence were also identified as an urgent need (Hand & Reid, 1989). However, bureaucratic stereotyping and policy emphasis on vocational skills and training for work have excluded much of this population. People with intellectual disabilities are highly likely to be officially classified as not actively seeking work and are therefore

presumed to be unavailable for paid work. But it has been demonstrated that some such people have the motivation and ability to work (Reid & Bray, 1997). This evidence warrants a new look at such discriminatory classification as well as encouragement of community agencies as brokers and advocates with the private sector. Workers with intellectual disabilities valued the paid employment opportunities very highly and reported that assistance to find and keep paid work was important (Reid & Bray, 1996). Public policy must revisit categories of "unemployable" and definitions of vocational training and adult education needs if rights of participation and potential for community contributions are to be realised.

It is curious that policies whose stated goal is to reduce dependency may conflict with policy that demands individuals and families "go it alone". Some policies cancel out or obstruct each other. For example, policies to reduce the number of people receiving state-provided income support by encouraging participation in paid work turns out to be incompatible with the lack of day-care services for adults. The lack of daycare services reflects the policy demand that all adults be independent. Yet such services are essential to enable individuals or families who care for a person with chronic disability to participate in work and social activities. The scarcity of daycare suggests that the opportunity costs to carers, and the increase in dependency resulting from their inability to engage in paid work have not been considered. It also suggests a belief that such services are of low priority because of the general availability of unpaid community based carers. This belief, as noted earlier, is erroneous. The lack of adequate policy for family and other household caring has resulted in a poorer quality of life for all involved and ultimately in unnecessary and premature residential placement outside the household for the older group and for those who are now children and young adults. There are recent accounts of the exclusion "...through prejudice, indifference and failure to provide adequate resources..." (Wills, 1996) of children with disabilities and their families from participation in society, demonstrating that this problem is not confined to one age group or one type of disability.

Health Care and Health Promotion

Survey data showed that about half of the older population had major physical problems (Hand & Reid, 1996) and that most families had experienced difficulty in obtaining information about diagnosis, prognosis and support services and continued to have difficulty in accessing ongoing care. Care for treatable

conditions, like problems with vision and hearing, was not easily available even for people living in institutions. Medication review was inadequate and there was a lack of specialist care (Hand & Trewby, 1996). These findings are supported by a recent study which concluded that people of all ages with an intellectual disability are not receiving appropriate health care (Webb, 1996).

Adults with mental retardation can also be considered a population at risk for premature onset of cardiovascular disease (Pitetti & Campbell, 1991). This risk can be attributed to a sedentary lifestyle and overeating. It may be addressed by providing health education about the importance of activity and healthy food choices. People in positions to make or influence these choices should facilitate participation in active work, arts and sporting activities or by providing programmes directed at fitness. For example, an intensive weight training program for a group of adults was enjoyed and was successful in increasing body strength and improving general fitness (Rimmer et al, 1996).

Most older adults in this population have never experienced choice of where to live and how to live. One way to reduce the related stress and thereby promote health is to support self-advocacy (A Group of Women with Disabilities, 1996) and so facilitate their participation in decisions that affect them. The older people with intellectual handicap we interviewed were a group of diverse personalities. They spoke about their own needs and desires. Many had worked and wanted to work again. They wanted to be involved in plans affecting them (Hand & Reid, 1989).

Recommendations for policy

In this paper, we propose the policy changes we think are needed in order to reflect the needs of a particular population. To clarify whether or not the community is able to absorb increased responsibilities of caring for citizens with lifelong intellectual disabilities, we suggest that the term community be operationalised as two components:

1. households, composed of family and non-family households;
2. organisations, trusts and agencies.

The characteristics of these community units have changed over the past few decades. The definition of what constitutes family continues to be re-visited according to cultural and social trends. Officially, the definition of family relies on two kinds of relationships; a couple (from a legal or de facto marriage) with or without children; or a parent/child relationship. Other

living arrangements, such as several siblings, are described as non-family households (Statistics New Zealand, 1994). It is important also to acknowledge that carers are likely to depend on support from family members outside of the 24 hour care situation (Reid & Hand, 1997).

Organisations over the last decade have also experienced changed conditions in which they operate, including competing against each other for funds, an increasingly professionalised environment, and an increase in the volume of work and range and numbers of organisations (Gunn 1995). In one area, the number of organisations increased by 40% over the years 1982-1994 (Gunn 1995). Many funding agencies only partly fund applications, thereby forcing organisations to make multiple applications and to experience reduced certainty of being able to continue their service.

We recommend explicit state policy:

1. *to expand employment and recreational opportunities for people with lifelong intellectual disabilities*

The provision of recreational and social activities, vocational training, and paid work meets the needs of people with intellectual disabilities and is an integral component of living in and contributing to their community. The promise of community inclusion and increased independence can be fulfilled in this way.

2. *to resource community services and household carers adequately and flexibly*

The responsibilities of caregivers must be shared. As people with lifelong intellectual disabilities expand their social contacts, receive opportunities to contribute to the community and to reduce their loneliness, the task of full time supervision is shared among the community and commercial sector, rather than laid solely on family caregivers. In turn, carers such as the woman mentioned earlier are freed to participate in paid work, voluntary and community activities and personal friendship and recreational networks.

3. *to provide specialist health care and health promotion services*

Lifestyle related illness and disease can be reduced by providing more opportunities for active pursuits and by strengthening the ability to make healthy choices. Improved health care, particularly specialist care and medication review is an important foundation for living. This requires an expansion both of services and of expertise and so rests on both health

and educational policy. The lead agencies in these initiatives potentially are the Ministries of Health and Education, the University Schools of Medicine and Health Sciences and the Health Funding Authority.

4. to value the voices of people with disabilities

Finally, we recommend that the voices of the people with lifelong intellectual disabilities and of family carers be heard loud and clear and be valued. Policy shifts like those listed above supported by funding depend on better understanding and active advocacy by the public, by professionals and by people with lifelong intellectual disabilities themselves. We can reasonably expect that funding at an adequate level for such brokerage and for provision of services is unlikely without advocacy. We also anticipate a spiral of deprivation. The most needy are the least likely to have sufficient resources. Advocacy by professionals and the publication of credible research data have not achieved sufficient change. The most important advocates, the people themselves, lack the skills and the credibility to advocate on their own behalf or to influence policy that affects their opportunities. Formal comment by such groups should be valued by the government ministries that call for consumer and citizen input.

State policy to lead and support other public policies is essential under current political structures. At the same time improved cooperation between the governmental sector and community organisations will establish effective policy and efficient use of resources. The challenge for policy and practice is to admit the needs of people with lifelong intellectual disabilities and to be frank about the cost entailed. Dependency is not confined to this population or age group. No one really "goes it alone". All need support from friends, neighbours, relatives, and from politicians and leaders. When we interviewed families they were clear about the costs entailed. State policy should follow their lead.

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