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National Residential Intellectual Disability Providers

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SERVICES FOR OLDER PEOPLE WITH INTELLECTUAL DISABILITY – PAPER FOR THE MINISTRY OF HEALTH

Executive Summary

The National Residential Intellectual Disability Providers Group (NRID) is becoming increasingly concerned about funding for care of people with intellectual disability who are aged 65 years or older. NRID has surveyed it member organisations, which includes over 50 providers of services to people with intellectual disability. It is evident from the survey that providers are endeavouring to meet the needs of older people with intellectual disability through their own resources, and by means of private [charitable] funding. NRID therefore recommends that the Ministry of Health review current funding arrangements for this demographic group.

1. Introduction

In November 2007, NRID members discussed issues that have been arising in relation to the day payment for people aged 65 years and over. NRID providers have expressed concern that people with intellectual disability who are 65 years or older, do not have their care funded by either the Ministry of Health or the Ministry of Social Development.

In 2008, NRID members were surveyed to establish the extent of these issues. The purpose of this paper therefore is to provide to the Ministry of Health an outline of issues identified in relation to the funding of care for people with intellectual disability and aged related conditions, to link this to international evidence and to recommend solutions to address issues raised.

2. Survey results

The survey was carried out by means of an email sent to all NRID members requesting the following information:

- How many people aged 65 years and over does the provider support?
- What funding and from what source does the provider receive to support this group?
- What are the costs to the organization of supporting this client group?

- Are there any other issues relating to the provision of services to this group which should be highlighted?

It is evident from the results of the survey that providers are endeavouring to meet the needs of older people with intellectual disability through their own resources, and by means of private [charitable] funding. This parallels the evolutionary coping strategies seen in providers overseas – as volumes increase this approach becomes less sustainable. One provider had to develop their own programme as there was nothing suitable in the local community. Comments from providers emphasized that fact that older people with intellectual disability may have higher needs that other older people, and may therefore require more support. Moreover their needs change quickly when age-related health factors compound their support needs.

3. The needs of older people with intellectual disability

Our population in New Zealand and in other similar countries (e.g. Australia, United Kingdom) is an aging population. By 2051 approximately 26% of our population will be 65 years or over[1]. Improvements in health care mean that we are likely to live longer, and social changes mean that we expect to receive a level of care that enables us to be as independent as possible, for as long as possible.

These expectations are no less valid for people with intellectual disability, most of whom (89%) live in households, with the remaining 11 % (3,500) in residential care[2]. However, current funding for disability support services and the lack of appropriate support for older people with intellectual disability, severely limits the extent to which these expectations can be met. This means that once people with intellectual disability reach the age of 65, they are often no longer able to participate in programmes that enhance their quality of life and maintain their independence.

The World Health Organization defines active aging as 'the process of optimising opportunities for health, participation and security in order to embrace quality of life as people age. It applies to both individuals and population groups[3]'. The vision of the Ministry of Health's Health of Older People Strategy is that 'older people participate to their fullest ability in decisions about their health and wellbeing and in family, whanau and community life. They are supported in this by co-ordinated and responsive health and disability support programmes[4]'.

New Zealand therefore has an obligation to ensure that older people, including people with disabilities have the opportunity to live independent, full and active lives. At present, this obligation cannot be met if people with intellectual disability are denied the funding (and therefore the opportunity) to participate in their communities.

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[1] *Health of Older People in New Zealand: A Statistical Reference: Ministry of Health*
[2] *New Zealand Disability Survey Snapshot 8 (2001).*
[3] *World Health Organisation: What is 'active ageing'? www.who.int/ageing*
[4] *Health of Older People Strategy: Ministry of Health, April 2002*

4. Key issues

New Zealand's population is aging, and the number of people with intellectual disability in that population is increasing, largely due to the fact that people with intellectual disability are living longer and healthier lives. Although older people with intellectual disability should expect to receive the same level of services as their peers without disability, there are some issues that specifically affect older people in this group. Those issues are summarized below.

4.1 Mental health

Historically it was commonly believed that people with intellectual disability could not develop any form of mental illness because it was thought that they could not develop the psychological processes leading to the development of mental illness (Schnieder 1959, Gardner 1967, Winokur 1974).

It is now accepted that people with intellectual disability are more vulnerable to the risk of mental illness than the general population (Fraser and Nolan 1995, Menolascino et al 1986, Shakau et al 1988). However, it is not well-diagnosed or may be assumed to be present, without accurate assessment. The presentation of mental illness in people who have intellectual disability is often very different from the general population, particularly in severe forms because of communication and language difficulties. This can mean that frustration, confusion and fear – all of which are normal among older people, and more so when communication or understanding are limited – are considered to be signs of dementia and are not addressed appropriately.

This may also mean that people with intellectual disability are placed in inpatient mental health services, where they would function better in supported care in the community.

It appears as though people with intellectual disability are more likely to develop dementia at a younger age than their peers. This is a verified fact for people with Downs Syndrome. At least one response to the survey noted difficulties in accessing suitable services for a client who had developed dementia but who was not over 65 years. Existing dementia care services do not adequately meet the needs of this group. There are issues of access and issues of appropriate diagnosis and rehabilitation.

4.2 Physical health

The physical needs of people with intellectual disability may be different to other older people. The same age-related conditions emerge (degenerative arthritis, heart disease, deteriorating sight and hearing) but some conditions are more prevalent among older people with intellectual disability. For example, people with Down Syndrome are particularly prone to congenital heart problems.

Health needs that have not been identified or addressed throughout a person's lifetime are more likely to have a negative impact on health in old age. These can include poor oral health (resultant difficulties in eating), lack of exercise and poor diet (obesity) and lack of engagement in primary health screening programmes.

People with intellectual disability also have a higher rate of certain conditions than the general population, particularly as they age. Such conditions include:

- Coronary heart disease
- Respiratory disease
- Epilepsy
- Sensory impairments
- Dementia
- Osteoporosis
- Oral health.

Evidence from the UK indicates, for example, that general practitioners are not pro-active in offering regular health checks to people with intellectual disability, despite this group being less likely to participate in programmes such as cervical screening or breast cancer screening programmes.

4.3 Expectations of independence

People with intellectual disability who are now moving into older age (that is, 65 years or older) have different expectations of independence than their peers. Most people in this group have spent at least part of their lives in residential care.

Like other older people, people with intellectual disability should continue to be supported in their own homes wherever possible. This is emphasized in the report Pathways to Inclusion, in which it states that 'people with age-related issues should be given the opportunity to remain in their own homes with supports such as personal cares and day programmes'[5].

Some older people with intellectual disability do not wish to retire when they turn 65, and would enjoy and benefit from continued participation in vocational programmes. However, current funding arrangements preclude this, effectively reinstating 'compulsory retirement' at age 65.

4.4 Provision of care

Like other older people, those with intellectual disability who have lived in their own home often have a very reasonable expectation that they will be able to remain in that environment. Since aged care was devolved to DHBs there has been little communication with the providers of services to people with intellectual disability. As a result, it has become increasingly difficult for older people with intellectual disability to remain in their own homes.

Older people with intellectual disability may face significant changes in their care network, the most common of these being the death of parents or other caregivers. This may mean that they are faced with a significant change in residence despite still being relatively independent. This can be compounded by loss and grief, and the confusion that arises from being placed in an unsuitable residence (such as a rest home or mental health service).

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[5] *Pathways to Inclusion: Improving Vocational Services for People with Disabilities: Office for Disability Issues, Department of Labour, 2001.*

There is emerging evidence that aged residential care services are poorly prepared to provide appropriate care to people with life-long disabilities such as intellectual disability.

4.5 Training for health professionals

Assessment of elderly people with intellectual disability requires different skills to those used to assess other elderly people. However, it appears as though there is little or no such training available at this time.

> *There is a lack of understanding by health professionals around ID. A comment made to myself recently by a Medical Social Worker was that an elderly client (83) who had sustained a broken hip, had dementia – because she was unable to tell him where she lived. In the last 83 years and certainly the 20 years I have known her, she has never been able to explain where she lives. .*

For example, training for comprehensive nurses includes approximately six weeks' of training about intellectual disability, but does not include the care of older people with intellectual disability. The care of the elderly training offered by polytechnics and schools of nursing does not include the care of older people with intellectual disability.

There are particular issues in relation to dementia in older people with intellectual disability. Part of routine testing for Alzheimer's disease or other dementia includes a series of questions (the 'mini mental state exam'), which may be unsuitable for people in this group. For example, some people with intellectual disability may not know their address or date of birth, and would be unlikely to know the name of the current Prime Minister. This can lead to a [false] diagnosis of dementia.

NIRD providers consider there is an urgent need to enhance the training for health professionals and others involved in the care of older people with intellectual disability.

4.6 Collaborative working

It is obvious that District Health Boards, Needs Assessment and Coordination Services (NASC) and the Ministry of Health need to work together to fund aged care for people with intellectual disability. This practice is effective for people with mental illness.

NASC Services will "roll over" funding for people over 65 years of age who are already in residential support. However, this arrangement fails to meet the needs of people who are living with families, who are unsuitable or unacceptable for rest home care, as well as those people who are in need of mental health services. Older people with intellectual disability should be able to [continue to] access funding for day services, with a view to remaining independent in their own homes for as long as possible. This may necessitate contracts between DHB's and ID providers which are currently not in place.

5. Conclusion

It is evident that older people with intellectual disability are not well-provided for under current funding arrangements through DHBs, the Ministry of Health and the Ministry of Social Development. This means that people with intellectual disability who are aged 65

or over, are often unable to access vocational and social support programmes. In addition, this client group is often poorly-supported in their own homes, and may not receive appropriate diagnoses or care for age-related conditions.

6. Recommendations

NRID therefore recommends that:

1. the Ministry of Health be asked to review current funding arrangements for people with intellectual disability who are over 65;

2. the Ministry bring this paper to the attention of, and discuss with, the Health Professionals Regulatory Board as there is a need for practitioners to have training in competence working with people who have intellectual disability and age related conditions.

3. the Ministry note the offer of NRID providers to be involved in the development and delivery of training for health professionals, about older people with intellectual disability.