The health care of people with intellectual disabilities

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"People with intellectual disability experience inequalities in health outcomes, and inequity of health care access. Compared to the general population, this group experiences lower life expectancy and greater prevalence of health problems. However not infrequently these health conditions are either under recognised or inadequately managed. It has also been established that people with intellectual disability do not access preventive health care and health promotion programmes to the same extent as others in the community."

Durvasula and Beange, 2001[1]

There are a variety of reasons why the health care of people with intellectual disabilities is challenging, and why, with undiagnosed and untreated conditions, the health status of people with intellectual disabilities is much lower than that of the general population.

Until very recent years, the health of people with intellectual disabilities, and issues that impinge on it, have largely been ignored in New Zealand.

Barriers to health care of people with intellectual disabilities have been succinctly summarised by Lennox, Diggens and Ugoni[2] who especially note:

- communication difficulties that affect the doctor's ability to obtain information, and the patient's ability to understand the doctor;
- difficulties obtaining accurate histories from both the patient and support staff. This is especially the case where the patient has spent years in an institutional setting, and has been resettled in community settings with little or no historical information on file and available;
- poor compliance with the doctor's instructions;
- a common lack of knowledge on the part of the doctor about intellectual disability and associated health issues.

In addition to these factors there are other issues:

- variable attitudes on the part of general practitioners towards people with intellectual disabilities and how they should be medically supported;[3]
- people with intellectual disabilities are typically disadvantaged socioeconomically. This is particularly apparent for those people in residential care services such as group homes, whose only discretionary income is a small personal allowance.[4]
- Health promotion occurs on a much lower scale for people with intellectual disabilities. Efforts to reduce obesity and smoking and to encourage healthy nutrition, exercise and healthy lifestyles are less than for the general population and there is very little health promotion material available in formats that are accessible to people with intellectual disability.[5]
- Many people with intellectual disability depend on their family or caregivers to initiate and facilitate access to all health care, making them one of very few groups in society to be so dependent.[4]
- Primary care is typically dependent on patients who are able to 'complain' and to tell their health workers what is wrong and what

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IHC'S HEALTH PROMOTION TEAM*'s service inititatives within IHC include the introduction of annual health screening, more in depth health screening of people with high health needs, the introduction of systems for the monitoring and review of medication, and a variety of initiatives to provide ongoing education and support to general practitioners working with people who have intellectual disabilities.*

they think they require from them. Many people with intellectual disabilities either cannot or do not do this.

In the face of this information about barriers to health care, evidence of the deficits in the provision of health care to people with intellectual disabilities are summarised (Table 1).

Within New Zealand, a number of initiatives have sought to reduce the impact of some of the barriers to health care, and to develop ways to assist primary health care providers especially discover health needs that might otherwise not be obvious.

In essence, these strategies involve a combination of health screening and planned health care. Some of these are noteworthy:

General health screening

It is fortunate that New Zealand is a country which has embraced health screening for many groups within its population. National screening and monitoring programmes aim to identify early signs of cancers, sensory deficits and developmental problems and to facilitate early therapeutic interventions where indicated (e.g. cervical screening programme, mammography screening programme, WellChild screening programme; Plunket Society support and monitoring of babies and children, and others).

For people with intellectual disabilities, Jones and Kerr[12] demonstrated that 'prompts' to GPs made a dramatic and positive effect on consultation patterns. They concluded that *'health screening specifically targeted at remediable health problems would clearly benefit the population with intellectual disability.'* They suggest that *'considering their current pressures of work, GPs are unlikely to provide the necessary screening on a purely opportunistic basis'*. They also note that *'responsibility must rest with intellectual disability services to forge strong links with them in order to ensure that the health needs of people with intellectual disability are met.'*

Martin, Roy and Wells[13] further demonstrated that health screening strategies produced significant gains in identifying physical disorders, although mental health problems continued to be under-reported.

In New Zealand, the tool that had been developed in Cardiff by Jones and Kerr for annual healthscreening was introduced for use with IHC service users in 1997. In line with the experience in the United Kingdom, in New Zealand, out of 1 311 IHC service users who received their first general health screen, 72.6% required follow-up interventions.[14]

- 18.6% required health protection actions (vaccinations, smoking cessation assistance, further checks for existing conditions);

Table 1.

PERCENTAGE OF UNMANAGED HEALTH PROBLEMS FOUND IN SIX SURVEYS OF ADULTS WITH INTELLECTUAL DISABILITY

MEDICAL DISORDERS	Howells 1986[6] %	Beange 1986[7] %	Thomas et al 1988[8]	Wilson et al 1990[9] %	Beange et al 1995[11]	Beange et al 1990[10]	Average %
Obesity	20	46	23	29	22	57	32%
Vision	25	44	31	64.5	38	68	45%
Hearing	24.5	25	11	41.5	20	25	25%
Dental	***	27	***	***	29	86	47%
CNS Disorder (including epilepsy)	17.8	17.5	30	13.8	35	53	28%
Cardiovascular	10.5	11	18	15.3	19	24	16%
Skin	13.2	11.5	34	16.9	25	96	33%
Endocrine	2.6	***	***	***	9.5	29	13%
Behaviour	***	25	35	***	24	26	27%
Skeletal	3.3	13	***	***	28	***	15%
Gastrointestinal	4.6	***	***	1.5	9	17	8%
Genitourinary	3.3	***	56*	9.2	16	***	8%
Respiratory	13.9	***	***	***	5	10	10%
Psychiatric/Emotional (including psychosis)	***	7	***	***	4	9	7%
	n=151	n=165	n=104	n=65	n=251	n=202	

* includes incontinence
*** no figures available

Table compiled by Sam Shepard, unpublished work, 1997

Appendix 1. Syndrome specific checklist (of recognised *potential* medical complications)

	Down's Syndrome	Prader Willi	Fragile X
Audiovisual	Visual impairment (Multifactorial) (Annual ophthalmic assessment recommended) Hearing impairment (multifactorial) (Annual audiological assessment recommended)		Visual impairment (Multifactorial) Hearing impairment
Endocrine	Thyroid disorder (Annual TFT recommended)	Non insulin dependent Diabetes Mellitus (secondary to obesity)	
Psychiatric/Psychological	Alzheimer's type dementia (clinical onset uncommon before 40 years)	Hyperphagia Impulse control difficulties Self injury	Attention deficit hyperactivity Disabilities in social functioning
C.N.S.	Epilepsy		Epilepsy
Cardiovascular	Congenital heart disease Mitral valve prolapse		Aortic dilation Mitral valve prolapse (related to connective tissue dysplasia)
Muscular/Skeletal	Atlanto occipital Atlanto axial instability	Hypotonia	Connective tissue dysplasia Scoliosis
Other	Blood dyscrasias Skin disorders Obesity Sleep apnoea (Hypoplastic Pharynx) Increased susceptibility to infections	Severe obesity Undescended testes	Herniae (CT related) Abnormalities of speech and language
Inheritance	Most cases are sporadic 2% due to translocation involving chromosome 21 or rarely parental mosaicism	Atypical most sporadic	Atypical X linked

- 11.6% required interventions relating to their sight (vision tests, treatment for glaucoma, cataracts);
- 10.8% required haematology (blood counts, checks on medication levels, LFTs, cholesterol levels, blood sugars and hepatitis B tests);
- 10.3% required ENT follow-up (hearing tests, wax removal, speaking and swallowing aids);
- 9.6% required gynaecological follow-up (cervical smears, mammography, breast lumps, menstruation interventions, uterine tumours);
- 9.4% required dental interventions;
- 9.3% were either obese or underweight;
- 7.7% required gastro-intestinal follow-up.

Up to 7.5% required specialist medication reviews, had dermatological problems that required follow-up, had either diabetic or thyroid function problems, had genito-urinary problems (including prostate and testicular problems), or had cardiovascular problems;

A further 16.5% required follow-up in psychological, neurological (mainly epilepsy), podiatry and orthotics, respiratory, mobility, communication or counselling areas.

Intensive screening of people with high health needs

The results of health screening for IHC service users was followed up in 2001, with a more intensive screen of people who were considered to have especially high health needs. It was felt that the general screen was not sufficiently detailed to prompt primary health care workers to assess the higher levels of needs that exist in some people. These are peo-

	Sturge Weber	(Classical) Phenylketonuria	Neurofibro - matosis	Tuberous Sclerosis
Audiovisual	Glaucoma		Hearing impairment (Glioma affecting auditory nerve)	Retinal tumours
Endocrine				
Psychiatric/Psychological	Variable intellectual capacity	Variable intellectual capacity Disabilities in social functioning	Variable intellectual capacity	Variable intellectual capacity
C.N.S.	Epilepsy Variable clinical phenomena depending on the site of angioma	Epilepsy Hyperactivity	Variable clinical phenomena depending on the site of the tumours	Cerebral astrocytomas Epilepsy
Cardiovascular		Poor peripheral circulation		Cardiac Rhabdomydomas
Muscular/Skeletal		Hypotonia	Skeletal abnormalities especially Kyphoscoliosis	
Other	Haemangioma (mainly skin and meninges)	Eczema	Variable clinical phenomena depending on the location of the neurofibroma Tumours are susceptible to malignant change Other varieties of tumours may be associated	Kidney and lung Haemotomas Polycystic kidneys
Inheritance		Autosomal recessive	Autosomal dominant	Autosomal dominant

ple who might be considered to be inherently 'medically fragile', or to be elderly and so encountering the health issues that accompany other people when they age.

It is worth noting that people who have intellectual disabilities have, historically, not lived long. This is no longer true. Whilst people with intellectual disabilities still live shorter lives than do the general population, their average age of mortality has been steadily increasing over the last 50 years. Now over half of IHC's service users in the Central Region of the country are over the age of 55 years. The health concomitants of aging that are found in the general population are, therefore, also found in this group, especially in those who have Down's syndrome for whom there is a link with Alzheimer's disease.

Whilst this project has continued in IHC services throughout the country, figures are available for the work completed in the South Island.[15] Of the 420 residents, 140 (30%) of residents were considered to have unusually high health needs. Their ages varied from 18–82 years (mean age 47 years, s.d. 15 years). The identified categories of needs and the percentages of the high health needs group requiring targeted support were:

Of the 140 screened residents, between 30 and 60% required assistance with feeding, bathing, toileting, continence management, and skin cares. Over half were visually impaired, and nearly half had difficulties expressing themselves. A third had mobility problems and/or used wheel chairs.

Half wanted to be independent but were considered 'unsafe' by support staff, especially in hazardous situations. Thirty-three per cent had minimal or no family contact.

It is noteworthy that only seven people (5%) did not have a daily community-based activity programme.

Medication usage was high, averaging 3.3 medications each (mostly laxatives, inhalers, shampoos/creams, anticonvulsants, multivites, and benzodiazepines).

Medications

Whilst the number and nature of medications per person identified in the survey of people with high health needs seemed high (controlled comparisons were not available), the broader issue of the use of medications with people with intellectual disabilities is, internationally, of concern. This especially applies to the use of neuroleptic medications:

- Suggested estimates of prevalences of mental illness range from 20–30% and even higher.[16] However, uses of neuroleptic medications in New Zealand are much higher than this. Webb[17] found that 54% of IHC residents were taking neuroleptic medication and that polypharmacology was common. Sixty per cent were taking two or more, 27% taking three or more, and 10% were taking four or more concurrent neuroleptic medications.
- More recent reports from pharmacological audits indicate that the situation is unchanged.[18]
- Ahmed et al[19] have suggested that a substantial proportion of people with a learning disability prescribed antipsychotic medications for behavioural purposes rather than for treating psychotic illnesses can have their drugs reduced or withdrawn.

Disease specific screening

A number of identified syndromes that are associated with intellectual disability also have identified comorbidities. The health screening tool developed by Jones and Kerr[11] adopted by IHC New Zealand, incorporates a very brief 'Syndrome Specific Checklist' to further prompt general practitioners who are carrying out screening exercises (Appendix 1).

In addition to these, there is robust evidence that suggests that some syndromes and the lifestyles of many people with intellectual disabilities incur health risks of their own. For example, gastro-intestinal disorders present particular problems:[20]

- People with cerebral palsy who are prone to unusually high levels of reflux are more likely to suffer oesophageal inflammations and to aspirate reflux material into the lung.
- People who live or who have lived in institutional or group home settings are likely to have helico-bacter pylori infections.

Of particular note, epilepsy is a major issue for people who have intellectual disabilities. Approximately one fifth of people with intellectual disability also have epilepsy: this increases to about one third of people who have Autistic Spectrum Disorder, and reaches as high as 50% for people who have additional neurological disorders such as cerebral palsy.[21]

Barriers to the health care of this patient group have been identified; all are surmountable with consideration and planning

Kerr et al[22] have published a review of the available evidence for antiepileptic interventions. Webb and McKirdy[23] have prepared service guidelines for support agencies who are supporting people with intellectual disabilities and epilepsy. (This will be available on the Epilepsy New Zealand and IHC New Zealand websites.)

A randomised controlled study by Webb et al[24] demonstrated significant improvement in the quality of life and adaptive abilities of people with intellectual disabilities and epilepsy following a single consultation with a specialist neurologist for the purposes of reviewing their antiepileptic medications.

Support for general practitioners

The speed with which people with intellectual disabilities are taking their place amongst us, living in ordinary homes, working for real wages, paying taxes, and having expectations for lifestyles and qualities of life that are similar to the general population, is setting increasing demands on the workforce that supports them.

In response to this, health professionals are expected to be as conversant with the needs of people with intellectual disabilities as they are for children, people who are elderly, and other groups that make up the general population. As for other groups, the first port for the health call is to the primary health care professional.

In the face of growing evidence of syndrome-specific and intellectual disability lifestyle-related health risk factors, and in recognition of the needs of primary health care workers for more information to assist them with their work, a growing amount of advice is becoming available to them:

A number of agencies are seeking to become more involved in the undergraduate and postgraduate education of health-care workers, and specialist postgraduate courses now exist to train professionals about Autistic Spectrum Disorder and Specialist Needs Assessment. More courses are planned.

The New Zealand Ministry of Health[25] has provided a reference text to assist health providers provide appropriate health care for people with Down's syndrome throughout their lifetime.

A practical reference for general practitioners and other primary health care workers has been provided by Lennox and Diggens.[26]

Conclusions

People with intellectual disabilities are presenting huge challenges to medical practitioners, and especially to general practitioners to whom

they present as one more group within the general population who come to them first for health care.

Barriers to the health care of this patient group have been identified; all are surmountable with consideration and planning.

Health screening, at various levels of specialisation, is likely to make an important impact on the health status of people with intellectual disabilities.

There remains, however, syndrome-specific and lifestyle-related health-risk factors that need to be understood.

The benefits in terms of quality of life and adaptive skills of regular neurological reviews for people with intellectual disability who have epilepsy must be appreciated.

The under-diagnosis of psychiatric disorders and the need to target appropriate pharmacological interventions in keeping with the evidence bases must be recognised.

At the same time, the overuse of medications for behavioural management is a specific area that needs to be addressed. The options for behavioural instead of pharmaceutical interventions need to be understood and accessed via the disability service agencies.

A number of individuals and organisations are providing courses and reference material for primary health care professionals and these are likely to be useful as the numbers of people with intellectual disabilities in our communities increase, and their expectations for lifestyles and health care that are similar to the general population persist.

References

1. Durvasula, S, and Beange, H. Health inequalities in people with intellectual disability: strategies for improvement. The Health Promotion Journal of Australia 2001; 11:3.
2. Lennox N, Diggens J and Ugoni AM. The general practice care of people with intellectual disability: barriers and solutions. Journal of Intellectual Disability Research 1997; 41:380–90.
3. Webb OJ. A survey of attitudes of general practitioners towards people who have intellectual disabilities. Journal of International Disability Research 2000; 44:553–61.
4. Roberts S. Paper for NZ National Health Committee, in progress. 2002.
5. Beange H and Bauman A. Caring for the developmentally disabled in the community. Australian Family Physician 1990; 19:1555–1563.
6. Howells G. Are the medical needs of mentally handicapped adults being met? Journal of the Royal College of General Practitioners 1986; 36:449–453.
7. Beange HP. Caring for a vulnerable population. Medical Journal of Australia 1986; 164:159-160.
8. Thomas AP, Bax MCO and Smyth, DPL. The provisions of support services for young adults with physical and mental handicaps. Mental Handicap 1988; 16: 92–96.
9. Wilson DN and Haire A. Health care screening for people with mental handicap living in the community. British Medical Journal 1990; 301:1379–1381.
10. Beange H, and Bauman A. Health care for the developmentally disabled. Is it really necessary? In Fraser, WI, (ed) Key Issues in Mental Retardation Research, Routledge. London. 1990.
11. Beange H, McElduff A and Baker W. Medical disorders of adults with mental retardation. American Journal of Mental Retardation 1995; 99:595–604.
12. Jones RG and Kerr MP. A randomised control trial of an opportunistic health screening tool in primary care for people with intellectual disabilities. Journal of Intellectual Disability Research 1997; 41:409–415.
13. Martin DM, Roy A, Wells MB. Health gain through health checks: improving access to primary health care for people with intellectual disability. Journal of Intellectual Disability Research 1997; 41:401–408.
14. Webb OJ and Rogers L. Health screening for people with intellectual disability: the New Zealand experience. Journal of Intellectual Disability Research 1999; 43:497–503.
15. Rogers L and Webb OJ. Paper presented to 36th Annual Conference of Australian Society for the Study of Intellectual Disability, Melbourne, November 2001.
16. Borthwick-Duffy SA and Eyman RK. Who are the dually diagnosed? American Journal of Mental Retardation 1990; 94:586–595.
17. Webb OJ. Patterns of medication use in IHC community homes. New Zealand Family Physician 1996; 23: No. 4, August.
18. Kentra Pharmaceuticals. An overview of the medication usage in 10 IHC areas. Work in progress 2002.
19. Ahmed Z, Fraser W, Kerr MP et al. Reducing antipsychotic medication in people with a learning disability. British Journal of Psychiatry 2000; 176:42–46.
20. Del Giudice E, Staiano A, Capano G et al. Gastrointestinal manifestations in children with cerebral palsy. Brain Dev 1999; 21:307–11.
21. Coulter DL. Epilepsy and mental retardation: an overview. American Journal of Mental Retardation 1993; 98: Supplement, 1–11.
22. Kerr MP and a working group of the IASSID. Clinical guidelines for the management of epilepsy in adults with intellectual disability. Seizure 2001; 10:401–409.
23. Webb OJ. Guidelines for the delivery of service to people who have intellectual disability and epilepsy: a review of the literature. Paper presented to IASSID congress, Seattle, 2000.
24. Webb OJ, Dovey S, Rogers L et al. Effects of reviewing antiepileptic medication in people with intellectual disability and epilepsy: a randomised controlled trial. Paper presented to IASSID International Congress, Seattle, 2000.
25. NZ Ministry of Health. The clinical assessment and management of children, young people and adults with Down's syndrome, recommended clinical practice. Ministry of Health, Wellington; 2001.
26. Lennox N and Diggens J, Eds. Management guidelines: people with developmental and intellectual disabilities. Therapeutic Guidelines Ltd. Melbourne, 1999.