Innovative Methods of Providing Health Services for People with Intellectual Disability

2013

A review of the literature
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Executive summary

Overview

Recent reviews and studies show that people with intellectual disability often have worse health status than the general population. Their life expectancy is lower, and they are 2.5 times more likely to have health problems, including epilepsy, heart conditions, diabetes and morbid obesity.

People with intellectual disability have higher rates of hospitalisation than the general population and similar rates of utilisation of primary care. However, the evidence suggests that they do not receive health services frequently enough, and that the quality of health services they do receive is often inadequate. In New Zealand, people with intellectual disability are four times more likely than people without intellectual disability to enter hospital with an avoidable condition. They also have lower screening rates than people without intellectual disability.

Reasons for inequities

There are many reasons for health status inequities developing for people with intellectual disability, including:

- genetic factors related to the specific syndrome a person has
- greater exposure to the negative determinants of health, such as poor income and social isolation
- poor communication between health care providers and people with intellectual disability and their carers
- differential access to health services, and differing quality of the health services they do receive
- less access to health promotion services and preventive services.

Relations with health care providers

Relations with health care providers are sometimes problematic.

- Carers have a key role in assisting people with intellectual disability to make a timely presentation to health care providers. However, there is evidence that both carers and people with intellectual disability often have low health literacy, and that people with intellectual disability often present late with symptoms.
- Communication between people with intellectual disability and health care providers is often problematic for both parties.
- There is some evidence of diagnostic overshadowing, whereby symptoms are attributed to a person’s disability rather than to a separate condition (particularly for psychiatric conditions).
- Many general practitioners (GPs) and other health practitioners see only a few people with intellectual disabilities, and their training for working with them is often limited.
• Professionals in both primary and secondary care are reported to either not listen to family and/or support workers or to have too many expectations of them (for example, around their caring role), while not consulting the people with intellectual disability themselves.

Innovative initiatives

A number of initiatives have emerged over the last 10 to 15 years to improve the quality of care received by people with intellectual disability. These include increasing the self-management skills of people with intellectual disability, increasing the skill levels and communication skills of health care providers, and introducing more comprehensive assessment processes.

Self-management

An increased emphasis on self-management for people with intellectual disabilities has seen the emergence of a variety of strategies to achieve this. However, many of the published reports focus on trials of innovations, and long-term evidence of the effectiveness of these strategies is lacking.

Reports suggest that the most successful self-management innovations are those where trainers work with people with intellectual disabilities in their homes for an intensive initial period, with periodic follow-ups. Other strategies that have had some success include written material, although this is most successful where it is accompanied by some degree of face-to-face contact and use of the internet.

Increased training for health care professionals

Health care providers, including staff in medical schools, often report that there is inadequate training in medical schools for working with people with intellectual disability. A survey of Australian medical schools found that most courses provided adequate training on knowledge of intellectual disability, but that training on the skills and attitudes required for working with people with intellectual disability was often inadequate. Surveys have found a willingness among GPs to increase their skill levels.

A number of initiatives to increase provider skills, particularly for GPs, have been developed over the last 10 to 15 years. These include the publication of guidelines (often in professional magazines) and providing information at point of delivery, such as material enclosed with annual health check forms (see below). Surveys of health care professionals have shown that short courses and seminars are favoured as training, and there have been a number of reports that suggest they are successful.

Improving communication

In the United Kingdom (UK), the appointment of specialised nursing teams in hospitals with a range of responsibilities for people with intellectual disability has been found to be very successful for training, improving communication between providers and people with intellectual disability, and providing input into policy and practice in hospitals.

A tool called the Health Passport is used in the UK for communication in hospitals, and research has shown this is also popular with people with intellectual disability. The Health Passport is now being rolled out in New Zealand.
There have been some examples of training (particularly in communication) being provided for medical trainees by people with intellectual disability. Studies and reviews have found these to be successful.

There have been a number of other strategies to improve communication skills for health care providers. While research has not yet demonstrated that this leads to improved health status, it is popular with people with intellectual disability, their families and support workers.

**Annual health checks**

A number of initiatives to improve the services that people receive from primary care have been developed. The most significant of these is the annual health check by GPs, which is specifically funded by the government in the UK and Australia. They have also been used in other countries.

The most widely used health checks are the Cardiff Health Assessment and the Comprehensive Health Assessment Program (CHAP). More recently, a similar tool, interRAI (Intellectual Disability Assessment), has been developed. CHAP and an adaptation of the Cardiff Health Assessment are both used in New Zealand.

Research on the effectiveness of the checks usually finds that detection of previously undetected conditions increases. Two randomised controlled trials and a cohort study have demonstrated that the intervention group received more sensory testing, health promotion and disease prevention activities. There have been several studies after 12 months that include reports of improvement in health.
1 Introduction

It has been estimated that 31,847 people (0.7% of the total New Zealand population) have some form of intellectual disability (Ministry of Health 2011). Nineteen thousand of these people receive some form of funding from the Ministry of Health (Ministry of Health 2011). The publicly funded services they receive include subsidies for accommodation, home support and support for independent living, and respite care for family members. Most people with intellectual disability live in the community, while 24% live in residential homes or other subsidised accommodation (Ministry of Health 2011).

International research suggests that the prevalence of intellectual disability is usually between 1 and 3% (Emerson et al 2010). The authors of a New Zealand study (Ministry of Health 2011) estimate the prevalence in New Zealand to be 1.1%.2

In the 1990s and 2000s there was a growing level of concern internationally about the adequacy of health services received by people with intellectual disability (National Health Committee 2003; Mencap 2007; Michael 2008). A number of policies and strategies have been developed to improve the health and related social services available to those with intellectual disability (Office of the Surgeon General 2005; Department of Health [UK] 2009).

Health care services for people with intellectual disability are usually delivered by primary health care providers and, where required, secondary care and other specialists. An increasing focus on self-determination for people with intellectual disability has meant their support workers and families are taking an increased role in health care management (Office of the Surgeon General 2005; Krahn et al 2006; Hale et al 2011).

This document looks at some of the ways in which new forms of health service delivery for people with intellectual disability have developed over the last 10 to 15 years. It covers:

• the health status of people with intellectual disability
• disparities in health status and the reasons for these
• access to health care services
• improvements in health services, including:
  – the development of self-management for people with intellectual disability and their family and carers
  – improving the education available for health care providers
  – ways of improving communication between people with intellectual disability and health care providers
  – new ways of delivering services by health care providers.

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1 This does not include funding from other agencies such as the Ministry of Social Development.
2 This figure is lower than the 1.3% in the New Zealand Disability Survey, which may be in part because of different definitions that may identify more people with mild disability.
2 Health status, disparities and service utilisation

2.1 Reasons for disparities

The health status of people with intellectual disabilities, particularly those with moderate or severe intellectual disability, is often poorer than that of people without intellectual disabilities (Kerr 2004; Krahn et al 2006; Department of Health [Victoria] 2009; Emerson 2010).

The health status of people with intellectual disability is affected by a number of factors, including:

- genetic factors specific to the syndrome (eg, congenital heart disease for people with Down syndrome and Williams’s syndrome, and hypothalamic disorders in people with Prader-Willi syndrome), the impact of which can often be reduced with appropriate, timely treatment
- greater exposure to the negative determinants of health, such as poverty, low income and social isolation (Scheepers et al 2005; Emerson et al 2010)
- the level of communication between providers and people with intellectual disability and their family, which is sometimes inadequate (Ianoco 2004; van Schrojenstein Lantman-de Valk et al 2008)
- the differential outcomes for similar conditions, which suggests that the access to, and quality of, the health and social services people with intellectual disabilities receive are variable
- access to health promotion services and preventive services, which is often less comprehensive than for people who do not have intellectual disabilities (Scheepers et al 2005; Robertson et al 2010; Ministry of Health 2011).

People with intellectual disabilities have lower life expectancy than people without, which is a key indicator of health status. In New Zealand, men with intellectual disability live 18 years less than the average life expectancy and women almost 23 years less (Ministry of Health 2011).

International evidence shows that people with intellectual disabilities are more likely to have some health conditions not directly related to their condition. These include coronary heart disease, morbid obesity, poorer dental health, epilepsy and respiratory conditions. Coronary heart disease and respiratory disease are leading causes of death for people with intellectual disabilities (Emerson 2010).

People with intellectual disability also have poorer mental health status than the general population. They have higher rates of many psychiatric disorders, are more likely to demonstrate challenging behaviour and are more likely to be depressed. The prevalence of dementia is also higher.

Research indicates that health service utilisation by people with intellectual disability in New Zealand is similar to or higher than that of the general population for many conditions (Ministry of Health 2011). However, indicators such as life expectancy, avoidable hospitalisation (Balogh et al 2010), frequency of consultation (Felce et al 2008) and uptake of preventive health measures (Lennox et al 2001; Ministry of Health 2011) suggest that this level of treatment may be inadequate for the level of needs (see section 3).
2.2 Secondary care

In the UK an estimated 26% of people with intellectual disability are admitted to hospital each year, compared to 14% of the general population (Backer et al 2009). In New Zealand, people with intellectual disability are over twice as likely as people without intellectual disability to be discharged for either an unscheduled medical or a surgical hospitalisation (Ministry of Health 2011).

In the year to June 2008 people with an intellectual disability were nearly three times as likely to be discharged from an acute admission (Ministry of Health 2011). They were 2.5 times as likely to go to an emergency department in a public hospital and twice as likely to be hospitalised for elective or arranged treatment (Ministry of Health 2011).

People with intellectual disability are considerably more likely to receive hospital treatment for many conditions, including epilepsy (30 times), dental treatment (15 times) and obesity (four times) (Ministry of Health 2011). They are over twice as likely to be treated for heart disease, injuries, diabetes and renal replacement, and 1.5 times as likely to be treated for cancer and breathing disorders (Ministry of Health 2011).

2.3 Mental health care

The New Zealand report (Ministry of Health 2011) calculated the prevalence of mental health disorders from hospital discharges and pharmaceutical prescriptions. In the year to 30 June 2008, 9.7% of people with intellectual disability were treated for mood disorders, particularly depression, and 3.7% were treated for a psychotic disorder. Dementia is 10 times more common, and in the case of people with Down syndrome onset is often at an earlier age (Ministry of Health 2011).

People with intellectual disability are three times more likely than the general population to receive care or treatment for any type of mental disorder (Ministry of Health 2011). They are twice as likely to receive care for depression or other mood disorders and 17 times as likely to receive care or treatment for a psychotic mental disorder (Ministry of Health 2011).

Cooper et al (2007) determined the prevalence of mental health disorders in a sample of people with intellectual disability, 93.7% of whom lived in the community with or without a support worker. The study showed that 40.6% had a mental disorder of some kind. People with mild intellectual disability (34.4%) were less likely to have a mental disorder than those with a moderate or profound disability (45%) (Cooper et al 2007). The most common diagnoses were personality disorders (22.5%), behavioural disorders (7.5%), affective disorders (6.6%) and psychotic disorders (4.4%) (Cooper et al 2007).

2.4 General practice

In New Zealand, in the three months to 30 June 2008, 63.9% of people with an intellectual disability consulted a GP at least once (Ministry of Health 2011). This is 1.5 times more often than people without an intellectual disability.
Most people with intellectual disability were enrolled in a primary health organisation (95.2% compared with 91.8% of people without an intellectual disability) (Ministry of Health 2011). Nearly 6% were enrolled for Care Plus\(^3\) primary health services (Ministry of Health 2011).

Currently there is little detailed New Zealand information on the reasons that people with intellectual disability consult GPs. A Dutch study (Van Schrojenstein Lantman-de Valk et al 2000) analysed the data records of 318 Dutch people with intellectual disability registered with general practices and compared this with a control population of people without intellectual disability. Their analysis suggested that people with intellectual disability have 2.5 times more health problems.

Another, more recent, Dutch study (Straetmans et al 2007) showed that the top five diagnoses for people with intellectual disability per 1000 people in primary care were epilepsy (178.2, compared with 3.2 in the control group); dermatomycosis (123.2 versus 55.5); diabetes mellitus (117.7 versus 61.5); acute infection of the upper respiratory tract (109.4 versus 62.4); and excess cerumen (95.6 versus 29.5) (Straetmans et al 2007). Mental health concerns were less frequent causes of consultation in general practices.

### 2.5 Pharmaceuticals

Straetmans et al (2007) found that people in primary care received an average of 4.3 prescriptions, compared with 3.1 prescriptions for people without intellectual disability during consultations. The most frequently prescribed medications were psycholeptics (63%), antibacterials (36.8%), anticonvulsants (26.7%), anti-inflammatory and antirheumatic products (26.7%), and sex hormones and modulators of the genital system (25.8%). People without intellectual disability were considerably less likely to receive any of these medications.

People with intellectual disability received an average of 5.4 repeat prescriptions, usually for the same types of medication, compared with an average of 1.6 repeat prescriptions for people without intellectual disability (Straetmans et al 2007).

In the year to 30 June 2008 people with intellectual disability in New Zealand were dispensed an average of 5.8 different medications from community pharmacies (Ministry of Health 2011). This was nearly twice as many as for people without intellectual disability. The number dispensed increased with age, as it does for people without intellectual disability. There were only small differences between sexes and different ethnic sub-groups.

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\(^3\) Care Plus is an integrated service for people with high levels of service use and/or high health needs because of chronic conditions or terminal illness.
3 Access to primary and secondary care services

Although people with intellectual disability consult with GPs and are seen at hospitals more often than those without, it is difficult to be sure whether this level of consultation is appropriate for people with their conditions or whether they receive equal quality of care. Some research suggests that the recognition and management of many conditions may not always be as timely as desired, and that the use of preventive methods may not always be as effective as it could be (Krahn et al 2006; Emerson et al 2010).

3.1 Avoidable hospitalisations

Overseas research shows a high rate of hospitalisation for potentially avoidable conditions among people with intellectual disability. These conditions include infections, respiratory conditions, dental treatment and mental health (Emerson 2010).

One of the common ways to determine the quality of primary care is via the rate of ambulatory sensitive admissions, assessed as avoidable admissions. In Canada, Balogh et al (2010) found that people with intellectual disabilities were 54 times more likely to be hospitalised for epilepsy and 15 times more likely for schizophrenia. They were also seven times more likely to be admitted for constipation and four times more likely to be admitted for diabetes. The rate ratios were highest for people aged 30 to 39 and those living in urban areas.

In New Zealand, in the year to 30 June 2008, an average of 14.6 people with intellectual disabilities per 100 were discharged from hospital after admission for an avoidable condition (Ministry of Health 2011). This was four times the rate for people without intellectual disability. The rate was highest among children and older people.

3.2 Preventive health services

The prevalence of screening can also be a marker of the effectiveness of primary and other health services. Over two years, women with intellectual disability aged 45 to 69 (39.9%) were less likely than women without intellectual disabilities (48.7%) of the same age to receive breast screening (Ministry of Health 2011). Older women (over the age of 50) with intellectual disability were also less likely to be screened. Over three years, 33.3% of women with an intellectual disability aged 20 to 69 received a cervical screen, compared with 70.6% of women without intellectual disability of the same age.

There is no New Zealand data on other forms of screening for people with intellectual disability. However, overseas evidence suggests that other forms of screening are also inequitably delivered. Emerson et al (2010) reported low rates of assessment for vision and hearing impairment, yet both conditions are disproportionately distributed among people with intellectual disability. They are also less likely to obtain routine dental care.
3.3 Barriers to care

Various studies and reviews have suggested a number of reasons why people with intellectual disability may receive inadequate health care. Although most studies focus on GPs, similar issues arise for practitioners in secondary care (Alborz et al 2005; Krahn et al 2006; Backer et al 2009).

**Poor health literacy among support workers, family and people with intellectual disability**

Support workers have a key role in bringing people with intellectual disabilities who are unwell to the attention of the appropriate health care professionals. This requires some awareness of the health problems that may affect people with intellectual disabilities. Without this knowledge, people with intellectual disabilities may present late. Where this happens, the problem may often be due to limited health literacy among people with intellectual disabilities and their carers (Krahn et al 2006).

**Inadequate training for health care providers**

Both practitioners and medical school teachers report limited or inadequate training for professionals who may be working with people with intellectual disabilities during their training (Lennox et al 1999; Krahn et al 2006). Primary care providers are likely to report they have received little information on treating people with intellectual disability while they were in training. One study found that only 8% of practice nurses in the UK had received any training on working with people with intellectual disability (Melville et al 2005).

**Infrequency of contact between providers and people with intellectual disability**

Practitioners often see a very small number of people with intellectual disability, and those they do see may have different syndromes and related health risks. Research indicates that the average number of people with an intellectual disability of any type or degree that a GP will see annually is five to eight (Lennox 1997; Dovey et al 2001; van Schrojenstein Lantman-de Valk et al 2008). There is no data on the number of people with intellectual disability that different secondary care practitioners would see on average.

Practitioners may also have difficulties accessing specialised information and advice for their patients (Lennox et al 2007a). While this is a particular problem for primary care, secondary care providers have also reported that they have poor access to specialised advice (MacArthur et al 2010).

**Inadequate communication**

Communication between a practitioner and a person with intellectual disability and/or their carer is often a problem, both for providers (Iacono et al 2004; Lennox et al 2007a; van Schrojenstein Lantman-de Valk 2008) and for people with intellectual disability. Most of the material located related to GPs, but there is some evidence that similar problems arise in secondary care (Brown et al 2011).
Wullink et al (2009) reported on a focus group discussion with a group of people with mild to moderate intellectual disability living in the community. They were unhappy with the level of communication they had with their GPs. Particular issues raised included: GPs would not discuss issues directly with them (rather than with their carers); they were not allowed to discuss their conditions; and they were not questioned well, listened to or taken seriously. Some were concerned that they had insufficient time, that the doctor did not explain what was going to happen in advance, or that the doctor did not ask them for permission to discuss things with their support workers. The authors noted that most of these issues were seen as core to effective communication for GPs with any patient.

Establishing and maintaining the level of communication necessary for maintaining case notes, diagnosis and assessment, especially where the person does not communicate orally, is not easy. Providers often report having inadequate knowledge of the medical history of the person with intellectual disability (Lennox et al 2007a). Support workers often have a key role in providing this knowledge about the health status of those they care for, but research has shown that support workers and family are sometimes unaware of health problems (Krahn et al 2006).

There is also some evidence for diagnostic overshadowing, whereby the person’s health condition is inaccurately attributed to their intellectual disability instead of the condition. This is particularly – although not exclusively – the case with psychiatric conditions (Krahn et al 2006).

**Barriers in secondary care**

Most of the studies of barriers to health care have focused on primary care, the most likely provider of services, rather than secondary care. Backer et al (2009) reviewed research into access to secondary care over 18 years (1990 to 2008). These studies identified several levels of barriers to appropriate care in hospitals, including:

- for the individual with intellectual disability, their fears about hospital, their lack of choice (eg, whether the carer remains at the consultation or which waiting room to use), and inattention to feeding and continence needs
- a lack of recognition of the role of carers and/or over-reliance by health professionals on them rather than the person with intellectual disability, an expectation that carers would provide basic nursing care, and poor provision of advice to carers
- the knowledge and communication styles of hospital staff, and their uncertainty in dealing with people with intellectual disability (eg, they communicate with the support worker rather than the person or ignore the person, lack appropriate skills, and treat people in a way that does not make allowance for their disability, such as rushing them through the emergency department)
- the physical environment of the hospital, such as access, poor signage and poor layout.
4 Improving quality of care

A variety of responses to address health status disparities have been developed. While many reports on these focus on primary care, in particular annual health checks, the issues raised often apply to both primary and secondary services. More recently there has been increasing emphasis on developing the role of the person with intellectual disability and their carer in maintaining their own health (Scheepers et al 2005; Krahn et al 2006; Lennox et al 2010).

Krahn et al (2006) have identified four major over-arching strategies, drawn from a number of international strategies and recommendations, to improve the health status of people with disability. These were to:

- promote the principles of early identification of intellectual disability and the right to inclusion and self-determination for people with intellectual disability
- reduce the occurrence and impact of associated comorbidities and secondary conditions among people with intellectual disability
- empower family members and support workers to meet the health needs of people with intellectual disability
- promote healthy behaviours among people with intellectual disability.

These strategies are consistent with current thinking on quality of care for people with intellectual disability, and they also address the reduction of barriers to health. Achieving these aims would involve a mixture of increasing health literacy, regular health monitoring, providing quality care, providing assistance and support for support workers and family, and including people with intellectual disability in health promotion and preventive health measures across their life span.

4.1 Provision of education and support for people with intellectual disability and their families/carers to manage their own health (self-care)

There is a large literature on individual programmes to increase the ability of people with intellectual disability to manage their own health care. However, the samples in these studies are often small, reducing their generalisability. With some exceptions, most of this material is descriptive rather than analytical.

The material discussed below is selective and representative of a wider range, but some clear themes emerge.
Increased focus on self-determination

One of the results of a greater focus on self-determination for people with intellectual disability and their carers has been an increased focus on the development of education programmes for people with intellectual disability and their carers to take responsibility for their own health. A recent New Zealand qualitative study demonstrated that people with mild to moderate intellectual disability were able to develop knowledge about diabetes and different levels of understanding of diabetes (Hale et al 2011).

The participants were asked about the strategies that enabled them to self-manage their diabetes. These included having a nominated buddy to encourage their exercise, and having someone – not necessarily a formal support worker – to provide advice and reminders. The authors noted that it was important that ongoing advice and support were provided.

Although small, this study suggests that where good support is provided, people with mild to moderate intellectual disability can develop sufficient knowledge and understanding to play a key role in their own health self-management. Programmes and resources are a key way to provide support for this process. These programmes are often designed by professionals and taught by carers.

Family and support workers

There is some evidence to indicate that further training for support workers could be valuable. Krahn et al (2006) noted that support workers were often unaware of the health conditions of those they were looking after. Melville et al (2009) reported on a survey of 63 support workers’ knowledge and perceptions of healthy lifestyles of adults with intellectual disability. They found a low level of knowledge of health recommendations on diet and physical activity, and found they placed a greater emphasis on diet than physical activity. They tended to believe that poor diet and lack of exercise were more the choice of the person with intellectual disability than communication or physical barriers.

Lennox et al (2010) reported that support workers found the resource they were provided with on diabetes useful, and also helpful in interactions with health care providers. Some studies on obesity programmes found that parents could be over-protective, which reduced participation in exercise (Jinks et al 2010). They noted that it was important to involve family and support workers in the programmes.

Face-to-face interventions

There is some evidence to support the use of health promotion classes for adults with intellectual disability living in the community (Alborz et al 2005). Bazzano et al (2009) reported on a seven-month, twice-weekly education and exercise programme for adults who were overweight/obese, and with another factor such as diabetes. In the post-programme assessment they found that two-thirds of participants had maintained or lost weight, with a mean weight loss of 1.2 kilograms (with a range from 0.9 to 10.9 kilograms). The average body mass index (BMI) had declined, and girth had declined in 74% of participants. The mean exercise participation had increased from 133 minutes to 206 minutes per week. Over half the participants reported increased life satisfaction.
Instruction given by health providers, either in home visits or in residential facilities, can often be effective. Llewellyn et al (2003) evaluated a home-based intervention targeted at parents with intellectual disability to increase their awareness of child health and home safety in the preschool years. Webb et al (2008) described a 12-session health awareness programme, including sessions on interacting with health providers, which the participants reported increased their confidence and their understanding of different types of illness and healthy eating.

Some – though not all – of these interventions were relatively short term. Chapman et al (2011) describe an intervention to reduce obesity and BMI for a group of 38 people, with a control group of 50. The intervention group and their carers received a number of visits in the first year from a trained health care coordinator, with annual follow-ups. BMI in the intervention group reduced over six years: they showed more improvement in their obesity level and lost more weight than the control group. However, the differences did not reach statistical significance, which the authors attributed to small sample size and the impact of other interventions for both groups.

**Written material**

Some programmes encouraged the participants to undertake ‘homework’ between face-to-face sessions. Lunsky et al (2003) found significant increases in women’s understanding of health issues using this strategy.

A number of strategies rely on the preparation and distribution of written material alone. Studies of their effectiveness do not always include a comparison with more interventionist strategies, such as home visits (Aronow et al 2005; Lennox et al 2010). Usually these written-material-only strategies are less effective than home visits and other face-to-face interventions.

One study compared the use of written information only with information plus home visits in training for parents with intellectual disability. Llewellyn et al (2003) found that the combination resulted in greater recognition of home risks, and increased knowledge of when to consult and how to use medicines, although they were unable to determine the effectiveness of each component. All gains were maintained at three months post-intervention. The intervention was effective regardless of parental health, literacy and IQ.

Other studies also indicate there is some value in written material, although it appears to be less effective than face-to-face intervention, with or without written material. Aman et al (2007) found that a series of eight booklets on anti-epileptic and most psychotropic medicine with basic information on a range of issues was well received by adults with intellectual disability.

Lennox et al (2010) combined written information with a website. The feedback from the small implementation study indicated that the written information was more effective than the website, although a larger sample would have been necessary to determine the effect of each.

**Obesity programmes**

Jinks et al (2010) reviewed 12 papers on obesity control for people with intellectual disabilities. All but one adopted a clinical trial approach, although many of the samples were small and the authors noted a lack of qualitative studies.
A wide variety of professionals, including learning disability nurses, advanced practice nurses, dieticians and health educators, presented the courses. Approaches based on a series of presentations were the most likely to show some improvement. Overall the authors found the review promising, although they noted that the methodological limitations of many of the studies weakened any assessment or generalisability of the reports.

People with intellectual disability as trainers

Although the value of a role for people with intellectual disabilities as co-trainers is recognised in training with health care professionals (see section 4.2), little literature was found on a similar role for health promotion. One exception was Krahn et al (2006), who described the development of the Healthy Lifestyles curriculum, which involved people with intellectual disabilities as co-trainers. Their research showed that this relatively brief intervention was able to support people with mild intellectual disabilities to change their health behaviours. It seemed probable that this strategy is more common than the literature might suggest.

4.2 Increasing the education of health care providers

GPs recognise they have a significant role in providing health care for people with intellectual disabilities. Dovey et al (2001) surveyed a sample of New Zealand GPs, and most felt they had a key role in treating people with intellectual disability, although most saw only a few patients. The authors noted that health promotion and screening were conducted less frequently than with the general population. Only 25% agreed that regular hearing and vision assessment was the responsibility of the GP, and only 24% agreed that an annual health check was their responsibility (Dovey et al 2001). A lack of training for GPs was often mentioned.

Adequacy of training of health care providers

Phillips et al (2004) surveyed a large sample of practising GPs in Victoria, Australia, on the adequacy of their prior training and their interest in further training in nine health care areas. They achieved a sample of 24% of practising GPs.

With regard to treating people with intellectual disability, the GPs reported they had received inadequate training in behavioural or psychiatric issues, human relations and sexuality issues, complex medical problems, and preventive and primary care. Ninety-four percent were interested in further training in at least one area, with the most frequently mentioned being behavioural or psychiatric problems, syndrome-specific medical problems, sexuality and relationship issues, and collaborating with government agencies.

Lennox (2007a) found in a survey of GPs in Australia that 93% said they were prepared to receive further education on working with people with intellectual disability. A large number also reported that they would have liked more information on working with people with intellectual disability during their training. They reported that their preferred options for acquiring this information were meetings and/or seminars, a local resource, journal articles, and synopses of current literature.

Another option that GPs suggested was for them to have access to specialists on intellectual disability, either by phone or by email. This strategy is sometimes used with psychiatric disorders, but no relevant research on intellectual disability was located.
Verger et al (2005) reported that GPs who relied on their own experience rather than the literature on whether to refer a woman for breast cancer screening were less likely to make a referral. The authors believed GPs without a grounding in the literature may make inaccurate assumptions, such as that women with intellectual disability are much more likely to decline to be screened if asked.

Studies on hospital services have also shown the need for education, guidance and training for staff to improve attitudes and the quality of care (Backer et al 2009). There have been fewer studies on education for secondary specialists working with people with intellectual disability. Burge et al (2002) surveyed people in a psychiatric resident training course in Canada. Half the sample reported that they had received some undergraduate training, but 85% of these believed this was inadequate. The other half reported that they had received no training at all. Almost all believed they should have received training.

**Medical school training on intellectual disability**

Lennox et al (1999) designed an ideal curriculum for education on intellectual disability in Australia using input from experts. This covered three main areas:

- **knowledge**, including common health problems for people with intellectual disability, understanding of the impact of intellectual disability on the individual and his/her family, and the availability of community resources
- **skills**, including communication methods, examining people with intellectual disability, referral patterns, and obtaining information for people and their support workers or family
- **attitudes**, including treating people with intellectual disability with respect, seeing the person not the disability, and showing respect for carers’ knowledge and opinions.

The authors then surveyed experts in 10 medical schools to determine how these issues were covered in the current curriculum. Five schools covered all the skills and only four covered all the attitudes thought necessary for working with people with intellectual disabilities. Much of the training was for general expertise, and often the requirements for intellectual disability were expected to be generalised from more general training. Overall the authors considered that students were relatively well taught about the factual knowledge they would require but that skills and attitudes were not always well covered.

**Providing training for GPs and other doctors**

There has been a growth in the production of concise guidelines in medical journals in the 2000s for GPs and their co-workers. In the UK some of this training is provided by the members of the Hospital Liaison Nursing Service (see below) or specialist nurses.

Lennox (2001) found that GPs reported that the most effective way of learning about their patient (from several options) was a synopsis of literature provided by the researchers. Other research has found a preference for continuing medical education courses for GPs on working with people with intellectual disability (Iacono et al 2004; Lennox et al 2000).

The average GP may not often see some of the rarer syndromes or be familiar with the likely health treatment. The Comprehensive Health Assessment Program (CHAP) health check form includes a detailed section outlining the conditions that people with intellectual disability are likely to have. The designers of CHAP see this material as a useful point-of-care type of education for GPs, particularly for the rarer conditions they may seldom or never have seen before.4

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4 Personal communication, Professor Nick Lennox, Director of the Queensland Centre for Intellectual and Developmental Disability, 10 June 2012.
Short training sessions for practice nurses

Short training sessions are a preferred option for many medical and health professionals for most training, and there is a growing body of literature on the effectiveness of this approach in many areas. There is, however, limited published analysis of the effect of such training for intellectual disability.

Melville et al (2006) compared the effectiveness of various training formats with three groups. One group received a three-hour training session and a 45-page training pack, another only received the training pack, while the third received no educational input at all. The combined intervention included receiving information on the health needs of people with intellectual disability, health promotion and screening, communication and care, and the support of people with intellectual disabilities.

Those who received either intervention were very positive about it. Most (81%) of the nurses reported that they felt better able to meet the needs of their clients and 66.6% reported that they had changed their practice as a result. Those who had received both components were significantly more likely to report change in knowledge and self-efficacy than those who had received only the pack.

Hospital Liaison Nursing Service

In the 2000s a Hospital Liaison Nursing Service was established in many UK hospitals. This is a team of hospital-based specialist nurses who work with staff, carers and people with disability. The service was endorsed in a major review of services for people with intellectual disability (Michael 2008).

One of the major purposes of the team is to provide hospital staff with information on working with people with intellectual disability. An evaluation in Scotland found that providing education and advice on practice development was one of the major tasks of the service (Brown et al 2011). Information was shared, both informally and formally, through induction courses, updates, continuing professional development programmes, and generally educating professional groups. Hospital staff reported that it raised their confidence in working with people with intellectual disability.

People with intellectual disability as co-trainers

There have been some examples of training sessions presented by people with disability. In the United States the Healthy Lifestyles curriculum was co-presented by people with intellectual disability (Krahn et al 2006). Biswas et al (2009) endorsed the involvement of people with intellectual disability and their support workers in all levels of training for medical and psychiatric professionals. They noted that the involvement of service users has been demonstrated to be a successful method for effective training.

In the UK’s Buckinghamshire Hospitals National Health Service Trust a two-hour session is provided to assist hospital staff to improve the patient experience of those with intellectual disability (Audit Commission 2009); two people with intellectual disabilities are co-trainers with the disability team. The report noted that staff found the presentations powerful and informative. Key achievements noted included:

- staff became more aware of the Trust’s policies for people with intellectual disability
- there was a greater awareness of the Health Passport (see below); one attendee was so impressed that they organised a subsequent session, which 51 people attended
- staff became aware of where they could obtain further information.
Increasing medical trainees’ familiarity with people with intellectual disability

Some research has indicated that many health providers have a negative attitude towards people with disability. One response to this has been to increase their contact with people with intellectual disability while in training.

A recent qualitative study by Iacono et al (2011) explored the impact that viewing stories of people with intellectual disabilities on a DVD had in professional education. Survey data was collected and focus groups were conducted with first-year health care students. The survey did not find a significant change in responses pre- and post-DVD viewing. However, the focus groups found that the DVD had caused changes in assumptions, perceptions and understanding of the impairments depicted. The authors concluded that DVD scenarios of real people with intellectual disabilities in real settings offer a means of providing training opportunities.

4.3 Improving communication between people with intellectual disabilities and their health care providers

Wullink et al (2009) noted that GPs could potentially play an important role in sharing knowledge about self-management with individuals with intellectual disability and their support workers. This process would require effective communication. However, their research found this was frequently lacking in the experience of people with intellectual disability.

As noted above, Verger et al (2005) found that women with mental and physical disability who had problems with communication were less likely to be screened. The authors were concerned that GPs who did not recommend breast cancer screening were making implicit judgements on the woman’s quality of life and life expectancy.

Health Passports

One strategy developed in the 2000s in the United Kingdom has been the Health Passport. This is a document held by the person with a disability or their carer, which they give to providers when they enter hospital (whether outpatient or inpatient services). This has a record of their health condition and issues such as the medications they receive and previous consultations. The records of each consultation are added.

No academic evaluations of this innovation have been completed, but one primary care trust in the UK surveyed people with intellectual disability, their support workers and family to determine the success of the passport and how it might be improved (Ridgeway Learning Disability NHS Partnership 2008). Although the response rate was low (12.6%), and not everyone answered all the questions, the survey provided a picture of the way the passport had been used. It was generally thought to be a good idea and made information easy to understand. The respondents also found it to be a useful communication tool with professionals.

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5 A range of information on the UK Health Passport can be found at www.healthpassport.co.uk
A Health Passport is being rolled out in New Zealand by the Health and Disability Commission. Following a successful pilot at Capital & Coast and Hutt Valley District Health Boards (DHBs) in 2011, the Health Passport has now also been established at Waitemata and Waikato DHBs. The Health and Disability Commission is now working with other interested DHBs to implement the initiative.

**Communication with GPs**

There is a growing body of research and guidelines on effective communication between GPs and people with intellectual disability. Lennox et al (2004) developed the *ask* diary, an intervention to facilitate better communication between people with intellectual disabilities, their support workers and advocates and GPs. This has similarities to the Health Passport, and comprises a 39-page document (*All about Me*), which records details about the patients such as their place of residence and other health care providers; a section on advocacy, including information on how to prepare for the visit to the doctor; a section for the clinician on how to work with people with intellectual disability; and a medical records section, including vaccinations, medical history, etc.

Lennox et al (2007b) compared the effectiveness of the *ask* diary and the CHAP one-off health check over 12 months. They did not find any strong changes in the measured outcomes for health promotion, disease prevention or individual conditions in the *ask* diary group. The authors noted, however, that although the *ask* diary did not have similar results to the CHAP test, it was strongly supported by people with intellectual disability and their families and support workers.

The CHAP also encourages communication between GPs and people with intellectual disability, their families and support workers, although on a one-off basis. Lennox et al (2007b) noted the GPs kept better notes in the CHAP and believed this would lead to better communication.

**General strategies to improve communication by GPs and other health providers**

Lennox et al (2000) reported that doctors in training in medical schools rarely learnt communication skills for dealing with people with intellectual disability. Much of the advice that GPs receive on increasing their communication skills with people with intellectual disability comes through short articles in medical journals.

Harper et al (1992) describe a programme designed for health care workers, including a self-study text and a 20-minute video on methods of communication. An evaluation of a small sample demonstrated that this was effective with resident physicians, medical students, nurses and nurse assistants. It improved their knowledge and communication skills, and led them to be more proactive in health care interviews.

**The communication role of Learning Disability Liaison Nursing Service**

The UK Liaison Service often plays a significant role in facilitating communication between people with intellectual disabilities and service providers. A recent evaluation (Brown et al 2011) found that among the key elements of their role were advocating for the person with intellectual disability, ensuring access to care through organising admissions, care coordination and discharge planning, and being seen as an appropriate person to advise, for example, on alternative treatments by others in the hospital. Many of the stakeholders interviewed saw facilitating communication as an important part of their role to enhance the patient’s experience.
4.4 Annual health checks

Many conditions that people with intellectual disabilities are likely to develop can be effectively responded to by their GP. The GP is the practitioner that people with intellectual disability are most likely to consult, and most GPs see themselves as the appropriate health care provider for most issues for people with intellectual disability (Lennox et al 2000; Dovey et al 2001).

Situations where primary care provision does not always meet ideal standards have been identified. Some of the difficulties that arise in the communication and service requirements between primary health care services and people with intellectual disability have been discussed above. These include communication issues and how to address these, and the level of training that both primary and secondary care providers receive.

One strategy that has received a considerable amount of attention and research attention in recent years is a yearly, or otherwise regular, health check for people with intellectual disability. Kerr (2004) noted that common features in the results of health checks, where these were conducted, were the identification of:

- untreated yet treatable medical conditions
- untreated specific health issues related to the individual’s disability
- a lack of uptake of generic health promotion, such as blood pressure screening.

The Australian government introduced specific funding for annual health checks for people with intellectual disabilities in 2004. Michael (2008) endorsed the use of annual checks in his review of the UK’s National Health Service (NHS) provision of services for intellectual disabilities, and these checks were subsequently funded through the NHS in England and Wales.

Types of assessment

There are a number of health checks available, including the Cardiff Health Check (Baxter et al 2006), CHAP (Lennox et al 2007a) and interRAI-Intellectual Disability (Hirdes et al 2006; Martin 2007). In New Zealand, IHC has used an adaptation of the Cardiff Health Check since 1998 (Webb et al 1999). Spectrum Care has recently completed a small trial of the CHAP test. The results have not been published at this stage.

These assessments are usually administered by GPs, although there are some reported examples of them being conducted by specialist teams or nurses in association with GPs. In Scotland and Northern Ireland a more comprehensive test is administered by a specialised learning disability nurse (for example Martin et al 2004).

While there are differences between these types of assessment, they usually include developing a medical history (often provided with assistance from the person’s support worker or family member), a checklist for a variety of preventive and diagnostic checks to be checked and (if necessary) provided by the GP, and a health management plan. The CHAP test also includes syndrome-specific information for GPs. Support workers and/or families are usually involved in the assessment.

More recently, an assessment tool for people with intellectual disability has been piloted to add to the interRAI suite of evaluation tools. This evaluates the needs, strengths and preferences of people (Hirdes et al 2006; Martin et al 2007) to support a personalised care plan. There are trigger responses that identify people who should be referred to other clinicians, and also outcome scales that help to prioritise need and measure changes over time.
The assessment covers similar areas to the other two tests. An advantage not shared by the others, apart from in trials, is that the use of this test automatically develops a database on people with intellectual disability over time. A range of people (who could include practice nurses) can be trained to use it.

**Systematic review of research**

The key points from a comprehensive systematic review of studies of health checks between 1989 and 2010 (Robertson et al 2010) were as follows.

- The majority of reports were based on a single health check, and only four studies reported on the outcome of multiple assessments.
- There is good evidence that the health check picks up a wide variety of previously undetected health conditions in the recipients.
- Carers were frequently involved either in completing the history and/or attending the check interview.
- New health problems were located in between 40 and 90% of the health checks with between one and five or more conditions identified.
- Previously unidentified conditions often found included ear wax, cardiovascular problems, problems associated with epilepsy and hypothyroidism, heart conditions, obesity, mental health problems, and dental health problems.
- One study noted that in many of the cases where new problems were found, the person with intellectual disability or their support worker reported there were no problems.
- People were often referred to further follow-ups for reasons including screening, vaccination or immunisation, earwax syringing or (less often) minor surgical work.
- Three studies reported on outcomes after 12 months. One audit study (Lennox et al 2001) reported that outcomes included reduction of frequency of seizures, better weight management, improved hearing, and reduction in urinary tract infections.
- A small number of studies explored the acceptability of the health check to the person with intellectual disability (Lennox et al 2009). Most reported that the patient had liked seeing the doctor, although they were often concerned about things like blood tests.
- Many professionals reported that their knowledge of the health needs of people with intellectual disability had increased.

**Randomised controlled trials**

One of the earlier trials of an opportunistic health check (Jones et al 1997, cited in Robertson et al 2010) found little difference between the intervention group and the control group. The authors attributed this result to poor uptake among the GPs and felt that opportunistic tests would be ineffective.

Lennox has conducted two cluster randomised trials using the CHAP test. In the first (Lennox et al 2007b) the researchers compared CHAP with treatment as usual. They found that compared to the control group there was a 30-fold increase in hearing testing, a 6.6-fold increase in detection of vision impairment, an increase in immunisation (a nine-fold increase in tetanus/diphtheria), and improvements in women’s health screening (smears were eight times more common). The detection of new diseases increased by 1.6 times.
Lennox et al (2010) conducted a more complex analysis with a follow-up at 12 months with four groups: treatment as usual, CHAP alone, the ask diary, and CHAP and the ask diary. The CHAP test had a positive impact on pneumococcus vaccination, hearing testing, Hepatitis A vaccination, vision testing and weight measurement.

These studies have strengthened the evidence that the health checks detect otherwise undetected health conditions. At present, however, there are no long-term trials that could demonstrate whether the health checks lead to health gains.

Recently, Lennox et al (2010) conducted a pooled analysis of their two earlier studies (2007b, 2010) and the Cooper et al study (2006), which contained 795 participants (407 were screened and 388 were not) using the CHAP and Cardiff Health Check test, respectively. In all studies data was also collected 12 months post-intervention. The pooled intervention group received more sensory testing and more health promotion and/or disease prevention activities, although the confidence levels varied. The authors recognised these were intermediate outcomes but thought that the screens were likely to provide real long-term benefits.

**Cost studies**

There have been few studies of the costs of health checks or their cost effectiveness. In part this is because most of the studies reported rely heavily on intermediate outcomes and rarely have control groups. Robertson et al (2010) found only one study that explored the service use patterns and costs for 50 people who had the Cardiff Health Check, matched with 50 people who received only standard care. The Cardiff Health Check was conducted by a primary care nurse who referred to a GP and advised the patient’s own GP. The total cost of the check was £4,080 (£82 per person). The authors argued that this was a low cost compared to the cost of paid and unpaid carer time. They noted that many of the costs for the test were fixed, and the overall costs of the test would therefore decline with time.
Appendix: Methods

Overview

This report focuses on innovative rather than routine health services for people with intellectual disability. It includes information on the role of people with intellectual disability themselves, their family, support workers and health care professionals in maintaining and improving the health status of people with intellectual disability.

The study is not a systematic review but it draws on the range of evidence available. This selection has been informed by larger reviews such as those by Alborz et al (2005) and Krahn et al (2006). Although the generalisability of many studies is limited, some clear patterns emerge.

Aim

Following initial reading (e.g., Alborz et al 2005 and Krahn et al 2006), four main strategies were identified for analysis. These were strategies to:

1. provide education and support for people with intellectual disability and their families and support workers to enable them to manage their own health
2. increase the level of expertise of health care providers to provide care for people with intellectual disability
3. reduce communication barriers between people with intellectual disability and their health care providers
4. increase the quality of care provided and reduce comorbidities.

There is only a small literature on the delivery of health care services for people with intellectual disability in New Zealand. In part because of the small sample size there is limited analysis by different population sub-groups such as Māori or older people.

Search strategy

A broad strategy was designed to find articles in peer-reviewed journals since 1990. Boolean logic was used to search Medline, Cochrane Library, PsycInfo, Mosby’s Index, and ERIC databases. Where relevant, appropriate subject headings (e.g., MeSH—Medical Subject Headings) were applied to the searches. In addition, government and non-governmental organisation websites across New Zealand and Australia were searched for relevant grey literature. Where appropriate, further library and/or Google Scholar searches on specific topics for each strategy were conducted.

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6 ‘Grey literature’ is a term often used for reports and data that are not released in peer-reviewed journals. This can be by non-government organisations, government departments and other groups.
The review focused on the following types of reports:

- those with an emphasis on higher-grade research, such as randomised controlled trials, where this was available.
- material published in peer-reviewed journals, although some specific material does not meet this criterion
- systematic reviews, such as Cochrane reports, health technology reports and journal articles
- articles that draw out the lessons from these studies, where they are based solidly on the evidence
- programme evaluations.

Although publications were not excluded because of the date they appeared, there is a focus on the last 12 years (after 2000) rather than on earlier material.

**Developing the report**

The report draws on a range of, mainly academic, literature. However, while there is a large body of evidence on health services for people with intellectual disabilities, the strength of much of this evidence is not always high. There are a number of reasons for this, including the following.

- The population with intellectual disability is heterogeneous, with intellectual disabilities resulting from a variety of conditions and aetiologies (where known).
- There are sometimes communication problems between people with intellectual disabilities and researchers. Support workers and families who often report on their behalf have been known to under-report conditions (Krahn et al 2006).
- Sample sizes are often small and the capacity for meta-analysis is limited.
- Few studies have a control group.
- Few studies were underway long enough to show that health status has changed. Often they rely on intermediate outcomes (eg, the number of previously undetected conditions detected during a health check).
- It is often difficult to determine a causal relationship between an intervention (eg, training practice nurses) and any health status outcomes.
- Some studies are specific to syndromes, and their generalisability may be limited.
- Different health and social support systems affect the types of services offered, and this can limit the generalisability of specific services to New Zealand.

Preference has been given to systematic and other reviews of the evidence, along with randomised control trials, but the number of high-quality studies is limited.
References


Innovative Methods of Providing Health Services for People with Intellectual Disability


