

Primary health and disability:

A review of the literature

The NATIONAL CENTRE *of* MENTAL HEALTH RESEARCH,
INFORMATION *and* WORKFORCE DEVELOPMENT

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Te Pou
o Te Whakaaro Nui

Published in September 2013 by Te Pou o Te Whakaaro Nui
The National Centre of Mental Health Research, Information and Workforce Development.
PO Box 108-244, Symonds Street, Auckland, New Zealand.

ISBN 978-1-877537-99-8

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Acknowledgements

This report has been commissioned by Health Workforce New Zealand and the Ministry of Health's Disability Support Services Group to progress the *Disability Support Services Workforce Action Plan*.

This literature review was produced by the Donald Beasley Institute.

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Executive summary

Background

The disability sector has expressed ongoing concern about the health status and access to health care experienced by disabled people. In February 2013 the Donald Beasley Institute was commissioned to conduct a research project on primary health and disability. The project comprised three components: a literature review; survey of disability services; and consultation with disability and primary health professionals. The project was underpinned by the *Disability Support Services Workforce Action Plan* which recognises workforce development as being central to quality disability services and supports. The current report presents the literature component of the project.

The review provides an overview of New Zealand and international research and policy literature related to primary health and disability. Literature relating to physical, intellectual and sensory impairment was explored for the purposes of the review.

To the extent possible, six key issues were considered:

- the health needs of disabled people
- health inequalities of disabled people
- barriers to primary care for disabled people
- potential strategies to increase access to primary care for disabled people
- evaluated strategies for increasing access to primary care for disabled people
- evaluated strategies to address barriers to primary care for other vulnerable groups

Literature review methodology

The review was conducted using integrative literature review methodology. Integrative reviews permit the combination of literature containing different methodologies. An integrative review was deemed appropriate as it provided the opportunity to include a diverse range of empirical, theoretical and policy based material, thus permitting a comprehensive understanding of the issue being studied. Literature was sourced from the Web of Science, Web of Knowledge and Google Scholar literature search engines. The search was conducted for articles predominantly published between 1999 and 2013. A diverse range of key words, phrases and combinations of the two were used to search for relevant literature. As a result, a wide range of journals were accessed that were specific to the key issues that underpinned the review.

Results

This review explored health needs, health inequalities, barriers to primary care, and strategies designed to address these. It also sought to identify issues and strategies with potential to inform current and future workforce development in New Zealand. The greatest volume of literature relating to these topics was found in the field of intellectual disability. While still relatively well researched, there was a smaller volume of literature in the area of primary health and physical and sensory impairment. It is important to note the critical shortage of

available research that explored access to primary health for disabled Māori or for the vulnerable population groups.

Primary health and physically disabled adults

Disabled adults in the general population are most likely to have a physical disability (Statistics New Zealand 2007). Research has found that physically disabled adults experience a higher prevalence of a range of chronic diseases including arthritis, asthma, cardiovascular disease, diabetes, high blood pressure, high cholesterol and stroke. They were also identified as being at higher risk for secondary conditions. Physically disabled women have been reported as being significantly disadvantaged in relation to breast screening and access to breast cancer treatment. Both physically disabled men and women are as likely as the general population to engage in health risk behaviours. The physical environment was identified in the literature as constituting the biggest barrier to primary care for physically disabled people. A lack of knowledge of health care services was also reported as a barrier for physically disabled people. Researchers have contended legislative reform, improvements in the delivery of health promotion, a reduction in environmental barriers, and the prevention of secondary conditions are all critical actions necessary to achieve improved health outcomes. Little is known however about what initiatives have been implemented to improve the health of physically disabled people in New Zealand.

Primary health and people who have an intellectual disability

Empirical evidence in the area of primary health for people who have an intellectual disability is extensive and convincing. Approximately 32,000 people have an intellectual disability in New Zealand (Ministry of Health, 2011). Research has consistently reported that people who have an intellectual disability have high levels of unmet health need, and are impacted by diagnostic overshadowing. Women with intellectual disability, people with high and complex needs, older adults and those who have Down syndrome have been identified as requiring specific attention to ensure their health needs are met. In general terms people who have an intellectual disability are a population group impacted by a range of health determinants that, in turn, contribute to the health inequalities they frequently face. Research has pointed to an absence of targeted and implemented health policy as a systemic barrier to primary care. Operational barriers to primary care are evident at the health service or practice level and are created by a lack of knowledge on the part of health professionals. Two major strategies have been pursued with regard to improving health outcomes for people who have an intellectual disability: the development of health indicators, and comprehensive health assessment (health checks). Health checks in particular have been widely endorsed as having the potential to transform the health status of this group. The extent to which health checks have been implemented in New Zealand is however not known.

Primary health and people who are blind or vision impaired

Over 70,000 people had experienced sight loss in the *2006 Disability Survey*. There is a small but emerging literature in the area of health needs and health inequality experienced by people who are blind or vision impaired. International research has reported that older adults who are blind or vision impaired are likely to be poorer and to have a lower level of educational attainment than their age peers in the general population. These differences in socio-economic status have the potential to lead to health inequalities that can impact on the

quality of life of this group. Similar to other impairment groups who have also been the focus of this review, people who are blind or vision impaired encounter reduced access to primary care in the form of physical barriers and due to the fact that health information is rarely presented in accessible formats. The financial cost of care and attitudinal barriers were also highlighted. There was limited literature about strategies to address access difficulties, however collaboration between vision rehabilitation and primary health services was identified as a potential strategy. Strategies that have been effective in addressing barriers to primary health care for blind or vision impaired people in New Zealand require further investigation.

Primary health and Deaf persons

There are about 9,000 Deaf people in New Zealand.¹ Research has confirmed that Deaf and hard of hearing people have different patterns of service use than other people. Communication difficulties have been identified as the reason for this. Deaf and hard of hearing people have asserted that inappropriate or unresponsive communication exchanges with health professionals result in a reluctance to engage with health services. Those who are Deaf or hard of hearing have been identified as experiencing health inequalities which are caused by a serious lack of health data related to this group, low health literacy, and limited access to health care due to communication barriers. Systemic approaches to improving communication between Deaf and hard of hearing individuals and health professionals have been advocated, including education for health professionals in the area of socio-cultural understandings of Deafness. The critical need for qualified sign language interpreters to support primary health care interactions is widely acknowledged. Strategies used to improve communication and address other barriers to primary health care for Deaf persons in New Zealand require further investigation.

Primary health and other vulnerable groups

There was an acute shortage of literature pertaining to primary health and vulnerable populations. Of most concern was the critical lack of empirical evidence relating to primary health and disabled Māori. Research in the area of kāpo (blind) Māori highlighted that health services typically ignore both culture and disability, a situation that can lead to feelings of marginalisation. People with autism spectrum disorder were found to be disadvantaged in their access due to communication difficulties and anxiety related to the unpredictability of health service environments and health consultations. Disabled migrants were also identified as experiencing difficulty in terms of their access to health care, due in part to a lack of knowledge about services, entitlements and language barriers. Better information about primary health initiatives used to achieve better health outcomes for vulnerable groups in New Zealand is required.

Conclusion

This review has demonstrated that disabled people are compromised in terms of their health status, level of health need and access to health care. Barriers to primary care were multi-faceted and significant. Access to primary care is often difficult for disabled people due to an absence of implemented policy in the area of primary health and disability. A dearth of reliable measures for exploring health status and health need limits the opportunity to gain an accurate picture of the health of disabled people in comparison to their non-disabled

¹ See <http://www.deaf.co.nz/nz-sign-language/about-sign-language/interesting-facts>

peers. For many disabled people, access to primary care is limited at the practice level through inaccessible premises, health information provided in inaccessible formats, and inexperienced health professionals. It has been widely asserted that education and training in the area of disability and primary health should be collaborative and involve health professionals, formal and informal supporters and disabled people themselves in both the delivery and the receipt of such training. It was also seen as particularly important that disabled people receive opportunities to increase their own health knowledge in order to develop the skills that can enable them to manage their own health and health needs. While a range of strategies have been identified that may contribute to improved health outcomes for disabled people, further research is required to develop a better understanding of initiatives that have been implemented and effective within disability services in New Zealand. A survey of disability services and consultation with disability and primary health professionals was subsequently undertaken to examine this.

Background

Focus and structure of the review

The disability sector has expressed ongoing concern about the health status and access to health care experienced by disabled people. In response to this concern, Health Workforce New Zealand and the Ministry of Health commissioned a research project focused on primary health and disabled people. Primary health is understood to mean the first level of contact that individuals have with the health system. Primary health care is community-based, typically delivered by general practitioners (GPs) or practice nurses, and includes a broad range of health related services including health education, counselling, disease prevention and screening (Ministry of Health, 2001b).

The 2006 *Disability Survey* (Statistics New Zealand, 2007) indicates about 17 per cent of all New Zealanders have a disability.² Of the 660,300 people estimated to have a disability in 2006, 90,000 were children (aged <15 years), 350,000 adults (aged 15-64 years), and 220,300 older adults (aged 65+).³ In addition, 14 per cent of disabled children and 16 per cent of disabled adults had high support needs. The Ministry of Health manages supports to 33,000 disabled people (including 4500 Māori) primarily aged under 65 years (Ministry of Health, 2012c).

The primary health and disability project was conducted from February to July 2013, and comprised three components: a literature review, survey of disability services, and consultation with disability and primary health professionals. All components of the project were focused on the health needs and barriers to health care experienced by disabled people, initiatives that have been implemented in New Zealand and overseas to address these health needs, and areas for workforce development in the disability and primary health sector. The project is underpinned by the *Disability Support Services Workforce Action Plan*, which recognises workforce development as being central to quality disability services and supports for disabled people (Ministry of Health, 2013). This report presents the literature review component of the project and is intended to be a companion document to a report titled *Improving Access to Primary Care for Disabled New Zealanders*, which includes findings generated through the survey of disability services, and consultation with disability and health providers.

The review provides an overview of New Zealand and international research and policy literature related to this topic for three important groups: individuals who have physical impairments; individuals who have intellectual impairments; and individuals who have sensory impairments. The review presents research and policy relating to each of these groups of people separately in acknowledgement that disabled people should not be assumed to be homogenous in terms of their health status, health needs or access to health care, or in regard to factors that contribute to these.

² Among New Zealanders with a disability, 82 per cent are adults living in their own home, 5 per cent are adults living in residential facilities, and 14 per cent are children living in households.

³ The most common types of disability among children included special education and chronic conditions and physical and sensory impairments among adults aged 15+.

The review considers six key issues:

- the health needs of disabled people
- health inequalities of disabled people
- barriers to primary care for disabled people
- potential strategies to increase access to primary care for disabled people
- evaluated strategies for increasing access to primary care for disabled people
- evaluated strategies to address barriers to primary care for other vulnerable groups.

Five of these issues are explored with specific reference to people who are physically disabled, individuals who have an intellectual impairment, and people who have a sensory impairment or who are Deaf. The sixth issue, evaluated strategies to address barriers to primary care for other vulnerable groups, is explored in relation to disabled Māori, people with autism spectrum disorder, and disabled migrants. It is important to note that while the review is organised as much as possible to address the six key issues separately, this is a somewhat difficult delineation due to the fact that most of the literature that considers the primary health needs of disabled people tends to encompass some or all of these issues within a single source. As a result, the original specifications for this work included a seventh key issue, outcomes of barriers to primary care. Given that literature on barriers to primary care typically also included comment on the outcomes of such barriers, these two issues have been collapsed into one section.

Terminology

The terminology used in this review has been chosen, as much as possible, to reflect the commonly preferred terminology of the impairment groups who are the focus of this work, therefore different descriptors are used for each group. We acknowledge that People First New Zealand use the term learning disability instead of intellectual disability. We have used the term person who has an intellectual disability as a way of respecting their preference for “person first” language. However due to significant diversity in the terminology that is used to describe learning/intellectual disability internationally (intellectual impairment, intellectual disability, learning disability, mental retardation, developmental disability) we felt it was critical to consistently use one term. To this end, intellectual disability appears currently to be the most widely used and understood term and has therefore been used for the purposes of this review.

A social view of disability places it in context with societal influence, and makes connections between impairment and other social, political and environmental factors. Part of the social model of disability involves valuing lived experience. This is reflected in research that draws on accounts of persons living with disability in order to conceptualise not only their particular needs but also the social construction of impairment and disability more generally. Social model interpretations of impairment and disability have informed the terms used when referring to physically disabled people, and people who have sensory impairments or who are Deaf. Due to the scope of this review, research relating to the health needs of disabled children has not specifically been included and emphasis has been placed on disabled adults.

Methodology

Literature review methodology

This is an integrative literature review. Integrative reviews permit the combination of literature containing different methodologies, for example qualitative and quantitative or experimental and non-experimental research (Whittemore, 2005). Given that the literature relating to primary health and disability is incredibly broad in scope while at the same time showing some critical gaps, the opportunity to include a diverse range of empirical, theoretical and policy based material was important to gaining a comprehensive understanding of the issue under study.

There were a wide range of methodological approaches used in evaluating the health needs and disparities of the research participants and identified groupings. Some were quantitatively researched: cohort studies of individuals with a range of disabilities and impairments (McDermott, Moran, Platt, & Dasari, 2007); randomised trials of participants in health promotion programmes (Horner-Johnson, Drum, & Abdullah, 2011); national surveys of disability health insurance beneficiaries (Iezzoni, Davis, Soukup, & O'Day, 2003). Others used qualitative methods, including in-depth interviewing, focus groups and online interviewing (Williams-Piehot et al., 2010) and literature reviews from which data were extracted and summarised using descriptive statistics (Stuifbergen, Morris, Jung, Pierini, & Morgan, 2010). Other literature reviewed includes policy and legislation, such as that arising from the United Nations *Convention on the Rights of Persons with Disabilities* (UN General Assembly, 2009).

Some gaps were evident in the literature, for example, in the case of quantitative studies, many of the strategies were evaluated in single sites with a small participant demographic. Caution must therefore be taken in terms of drawing more generalised conclusions as to their on-going efficacy for wider populations.

It is also important to note that there was a pronounced difference in the volume of literature relating to each impairment group. By far the most relevant literature to the topic under study was in the field of intellectual disability. Literature relating to physical and sensory impairment was both less abundant, and less obviously related to primary health.

Literature search and article selection strategy

An electronic search of articles from Web of Science, Web of Knowledge and Google Scholar was used to find research in the area of health and the specific disabilities that were relevant to this literature search. This search was conducted for articles predominantly published between January 1999 and June 2013. Key words, phrases and their combinations included in the search were: physical disability; intellectual disability; sensory impairment; learning disability; mental retardation; hearing impairment; deaf; visual impairment; blind; primary care; primary health; public health; barriers to access; health equity; access to health care; health disparities; health care delivery; health promotion; health screening; and visual health.

In addition to the published literature relating to the six issues identified as the focus of this study, government documents and international not-for-profit organisations were also reviewed. The literature search also included the resource library of the Donald Beasley Institute, a library collection which is comprised predominantly of material related to intellectual disability. Finally, resources provided by Te Pou O Te Whakaaro were included in the review.

A wide range of journals were accessed that were specific to the areas of the review. These journals included those focused on both health and disability topics. The article title and abstract was reviewed to ensure that the study was specific to the focus of the review and met the specific criteria of the literature search. Reference lists from each article were scanned for missed articles and useful references were obtained where appropriate.

Primary health and physically disabled adults

Introduction

This section of the review considers the issue of primary health for physically disabled adults. Disabled adults in the general population of New Zealand are most likely to have a physical disability (Statistics New Zealand 2007). The literature has highlighted diverse conceptualisations of the relationship between physical impairment and physical health. In order to examine how physically disabled people conceptualise the health care they received, Bowers et al. (2003) gathered data through in-depth interviews and online interviews with 35 disabled adults and seven parents of disabled children, and analysed this data using grounded dimensional analysis. Results demonstrated that for physically disabled people, the concept of expertise went well beyond the technical competence of health care providers. Further, the interview participants identified three distinct areas of expertise: medical/technical, medical/biographical, and systems, defined as “knowledge and skill related to accessing, using and managing multiple provider and/or service systems” (p. 449). Importantly, it was acknowledged that expertise can be both brought to health care encounters and developed by physically disabled people and health care providers.

Nazli (2012) implemented a social constructionist approach to consider what ‘being healthy’ meant for physically disabled adults and discussed how they defined health within a social framework, and within social environments that impact on this definition of health. Using semi-structured interviews and thematic analysis the research also evaluated the impact of social environments on physically disabled people. Results indicated that physically disabled participants perceived being healthy as equal to not being ill. Furthermore, participants did not see disability as equating to being un-healthy and interpreted their physical adequacy and body image positively. Nazli concluded that despite the medical model’s definition of health, people with physical impairment socially construct their states of being healthy and interpret themselves as “healthy”.

It is important to note, however, that other perspectives question the usefulness of a social model of disability. For example, Shakespeare (2012) posits that despite the usefulness of the social model of disability in terms of promoting the human rights of people with disability, it has also allowed a downplaying of the health aspects of disability. Shakespeare argues that medical, psychological, social and political factors in the lives of disabled people also need to be accounted for. He suggests that because disability is nearly always associated with a health condition, “civil rights law needs to be anchored in a robust definition of the protected class” (p. 129), whereby failure to have health needs met constitutes an important part of the discrimination faced by people with disabilities. Despite this caution, a social model of disability is widely accepted as a more inclusive framework within which to account for the variety of barriers that are faced by people with disabilities when accessing primary care.

Health needs of physically disabled people

Gaining specific information about the health status and access to primary care for physically disabled adults was difficult due to the fact that much research treated the participant group ‘people with disabilities’ as a

homogenous group. For example, McDermott et al. (2007) claimed the literature on health conditions among adults with disabilities usually reported prevalence based on cross-sectional data. Instead, they calculated the prevalence for a range of medical conditions by disability, from the perspective of gender. That is, they sought to determine if the incidence of specific common health conditions was higher among 770 women with a disability compared with 1097 women without a disability, and 679 men with a disability, all of whom utilised the same primary care medical practices. Results demonstrated a range of disparities between the groups. While rates of a number of health conditions, such as, diabetes, hypertension and obesity were similar for women with disabilities compared with women without, and men with disabilities, women with trauma disability were at greater risk for dementia compared with men with the same disability. They were also at higher risk for depression than women without disability and compared with men with the same disability. The authors concluded that health providers needed to be cognisant of the differences in risk for onset of health conditions between women with or without disabilities, and men and women with the same disabilities.

As previously indicated, it is well documented that physically disabled people have greater health needs than those who are not physically disabled. Indeed, it has been argued that people with physical impairment are less likely to participate in mass screening programmes than those without physical impairment. For example, Park et al. (2009) sought to determine the number of persons with and without physical impairment who participated in the National Health Insurance chronic disease mass-screening programme in South Korea. Their results suggested that although chronic diseases were more prevalent for those with physical impairment, certain types of impairment such as limb, brain, visual and internal organ impairment hindered participation in mass screening programs for chronic diseases. The authors argued the reasons for this disparity should be investigated and health policies altered to ensure that preventative treatments are made more accessible to those with physical impairment.

Health inequalities for physically disabled people

Research has been successful in determining health inequalities for disabled people. Reichard, Stolze, and Fox (2011) compared the health status of individuals with disabilities and individuals without. Using the Medical Expenditures Panel Survey (MEPS) they examined if disabilities were associated with higher rates of common chronic diseases, lower use of preventative care and higher health care expenditures. The authors found individuals who were physically disabled or who had intellectual disability had significantly higher prevalence rates for seven chronic diseases: arthritis; asthma; cardiovascular disease; diabetes; high blood pressure; high cholesterol; and stroke. The same group was also significantly less likely to receive three types of on-time screening and care: no pap test; no mammogram; and no dental visit. These findings suggested a need for public health interventions for physically disabled people.

Disabled women and breast cancer

As previously noted, much literature about disability and health care treats disability as denoting a homogenous group. This was evident, although not exclusively, in quantitative research that focused on the prevalence of health conditions by variables such as gender. In these comparative analyses, disability status is often identified

by entitlement to disability insurance. The literature on women and prevalence of breast cancer is a case in point.

Courtney-Long, Armour, Frammartino and Miller (2011) examined the association between mammography use and having a disability by analysing data from the 2008 Behavioral Risk Factor Surveillance System and controlling for socio-demographic and health variables. Although their risk of breast cancer is similar to that of women without a disability, the authors argued that disabled women “may be less likely to obtain a mammogram within the recommended timeframe” (p. 1279). They found that women with a disability had both a lower rate of self-reported mammography as well as lower odds of mammography use than women without a disability. These results demonstrated that disparities in obtaining a mammogram within recommended timeframes persist. This suggests the need for continued health promotion and prevention aimed at improving its accessibility for physically disabled women.

Little is known about breast cancer treatment for disabled women. McCarthy et al. (2006) compared initial treatment for early-stage breast cancer between women with and without disabilities. In order to examine the association of treatment differences and survival they analysed data from 100,311 women who received a diagnosis of stage I to IIIA breast cancer at 21 to 64 years of age from 1988 to 1999. Within this cohort, women who qualified for Social Security Disability Insurance (SSDI) were considered disabled. The authors examined receipt of radiotherapy and axillary lymph node dissection for those women who received breast-conserving surgery. The research identified that women with SSDI and Medicare coverage had lower rates of breast-conserving surgery and were less likely to receive radiotherapy. Further, women with SSDI and Medicare coverage had lower survival rates than those of other women in all-cause mortality. The authors concluded that disabled women had higher breast cancer mortality rates and were less likely to undergo standard therapy after breast-conserving surgery than other women. The shorter survival was not explained by the difference in treatment.

Secondary conditions

White and colleagues (2011) noted that physically disabled people are at risk of serious outcomes from secondary conditions ranging from pressure sores as a result of immobility, to social isolation as a result of depressive illness. The authors conducted a literature review of health promotion interventions that included physical activity for individuals with physical impairment to determine if they had a positive effect on the reduction of secondary conditions. The results of this investigation were varied: while some studies provided evidence of the reduction of secondary conditions, others showed an increase in the rate of secondary conditions. The authors concluded that research on health promotion interventions containing physical activity lacked description about whether or not such interventions were helpful in reducing or preventing secondary conditions. In addition, they noted that further attention needed to be placed on sustaining health program effects beyond the initial proximal activity gains.

Summary

In the field of physical disability the social model has been dominant. Research in the area of physical disability and health has highlighted that physically disabled people do not see their disability as synonymous with ill-health and interpret themselves as healthy. Despite this, some researchers have argued that social model interpretations of disability have resulted in an under-emphasis on the health aspects of disability. It was difficult to gain specific information about the health status and access to primary health care for physically disabled people as it was common for researchers to use the broad term ‘people with disabilities’ to describe the participant sample. Despite this methodological difficulty, research has reported a higher prevalence rate for chronic diseases, and reduced access to health screening and dental care for this group. Disabled women have been found to be particularly disadvantaged in the area of breast screening, have higher breast cancer mortality rates and reduced access to standard therapy. Physically disabled people have also been identified as being at greater risk for secondary conditions such as pressure sores, or depressive illness.

Barriers to primary care for physically disabled people

It is similarly acknowledged within the disability sector that people with disabilities face a range of barriers to health care, resulting in a range of health disparities when compared with the general population. Indeed, Drum, Krah, Culley and Hammon (2005) argued that people with disabilities may be the “largest underserved subpopulation demonstrating health status disparities that stem from preventable secondary conditions” (p. 29). Bowers et al. (2003) acknowledged that those with disabilities have a more vulnerable health status than persons without, yet this group often receives inadequate primary health care. Further, they face a range of obstacles in receiving this care. The most significant barriers to health for this group have been identified as relating to transportation difficulties, inaccessible offices, insufficient provider knowledge, provider attitudes, and inadequate medical insurance coverage (Gans, Mann, & Becker, 1993). This awareness is evident in the publication of several reports that discuss disability more generally, including the publication *Healthy People 2010*, which is the blueprint for improved health in the US.

One of the barriers identified is how practice factors affect quality and accessibility of primary care for disabled adults. Using a survey of practice characteristics including accessibility, accommodations and payment type, and a retrospective chart audit for quality of care indicators, McColl et al. (2010) demonstrated how they affect quality and accessibility of primary care for physically disabled adults. The authors found that salaried practices scored significantly higher on accessibility and willingness to accommodate patients with physical impairment. They also scored higher in treatment of conditions such as diabetes. Both salaried practices and fee-for-service providers scored more highly than capitation (where physician revenues are computed based on age and gender mix of patients) for preventative care. McColl et al. (2010) suggested that these disparities raise questions in terms of providing those with the greatest need the best possible care.

In the American context, Yee and Breslin (2010) argued that despite the removal of access barriers for disabled people in specific litigation and settlement negotiations, federal laws such as the Americans with Disabilities Act 1990 have not yet resulted in the kind of systemic change needed in the health care delivery system. Drawing on a public health perspective which views changes in public policy and social views of disability as necessary for

achieving long-term success, the authors analysed factors that make it difficult to achieve accessible health care for this population. Yee and Breslin contended that until each part of the health care system (including education, facilities and managed care organisations) acknowledged that it was not providing equality of care, little would change across the sector. The authors concluded that litigation and other policy tools are capable of working in a complementary fashion to improve access for people with disabilities. Further, better disparities research and data will help support individual lawsuits, and encourage complainants to step forward.

Structural barriers

Of central importance to this literature review is an examination of the reasons why barriers to primary care still exist for physically disabled people. In their recent study, Pharr and Chino (2013) explored why that structural barriers still exist for people with physical impairment when accessing health care services, given that 20 years have passed since the Americans with Disabilities Act became law. Structural barriers include: the physical environment of the medical office and medical practice; accessibility of the medical equipment; and transportation to appointments. Physically disabled patients can experience reduced accessibility through: a lack of ramps; narrow doorways; scales that cannot accommodate a wheelchair; and inaccessible restrooms. These barriers compromise patient safety, health care worker safety and the quality of care that is able to be delivered. The purpose of the study was to ascertain if primary care practice administrators' knowledge of the Americans with Disabilities Act was associated with the number of barriers reported in their office. The study identified a relationship between structural barriers and Americans with Disabilities Act knowledge of practice administrators, characteristics of practice administrators and characteristics of the practices. That is, the greater the administrators' knowledge of the Act the more likely they were to be in compliance with its requirements. This suggests that legislation can have an overt influence on the responsiveness of health care services to disabled people.

From another perspective, Nosek et al. (2003) noted that very little research has examined the concept of wellness for people with disabilities. Using qualitative methods, their research explored determinants of, and barriers to, the health of disabled women. In particular, they focused on the concepts and practices used by disabled women to maintain optimal health. These included: a) defining health as a correlate of functional capacity (that is, being healthy means being able to function); b) the importance of a positive attitude in the promotion and maintenance of health and wellness; c) the need for social support; d) the role of health behaviours in health promotion; and e) problems with health providers' lack of knowledge. The study indicated that barriers to health included "certain disability characteristics, stress, inadequate social support, societal attitudes and lack of resources" (p. 6). Unfortunately, it was unclear from this study what particular impairments the disabled women experienced; however, the findings are compatible with those identified earlier for women who have an intellectual disability, and also concur with studies relating to physically disabled women.

More specifically, Becker and Stuifbergen (2003) defined barriers to engaging in health-promoting behaviours as "the subjectively perceived costs inherent in undertaking health behaviors" (p. 75). Their research examined perceptions of barriers to health promotion in three groups of persons with physical impairment: those with multiple sclerosis, those with postpolio syndrome, and polio survivors without postpolio syndrome. All of the groups identified fatigue and their impairment as their most significant barrier, and financial and interpersonal

resources as significant barriers that interfered with their ability to promote their health. For example, many participants stated that inaccessible equipment at exercise facilities and a lack of awareness of fitness professionals and exercise programmes made preventative screenings difficult. Becker and Stuifbergen noted that inaccessible environments affected emotional wellbeing for the participants. The participants also noted that the attitudes of health care workers towards physical disability could sometimes work as a barrier to the effective self-management of good health, as could difficulties with personal finances and insurance. Becker and Stuifbergen concluded that a bolstering of resources, including financial assistance, increased support systems including practical help such as transportation to health care providers, and information targeted to the wellbeing of this particular group was necessary in order to reduce the effects of such barriers on health status.

Other research examined perceptions of health care providers. Bachman, Vedrani, Drainoni, Tobias and Maisels (2006) analysed providers' perceptions of access to health care for people with disabilities. Data were gathered from a mail and telephone survey of providers who contracted with two managed care organisations: the Massachusetts Division of Medical Assistance, and the Assisted Living Association. Results of this comprehensive survey suggested providers were more likely to provide services to patients with chronic illness, mobility, cognitive, or psychiatric impairments than those with communication limitations or visual impairments. Providers also stated individuals with communication limitations were the most difficult to serve. These providers did not consider their facilities inaccessible to people with disabilities, and those who rarely served people with disabilities believed that this was because people with disabilities did not seek their care, rather than because their facilities were inaccessible. Bachman et al. noted that despite changes to the Americans with Disabilities Act of 1990, respondent perceptions indicated that individuals with disabilities continued to face difficulties accessing health care.

Mudrick, Breslin, Yiang and Yee (2012) explored the physical barriers in doctors' offices that affect the quality of health care for people with physical impairment. By rating medical offices using a 55-item instrument to assess criterion for accessible parking spaces, exterior ramps, restrooms and so forth, as well as reviewing various health plans, the authors analysed overall primary care office physical accessibility and identified: a) in which areas offices met access criteria, b) those access criteria which were most commonly not met, and c) if there were urban and non-urban differences. The most important finding of this study was that only eight per cent of provider sites had a height adjustable examination table, and only four per cent of sites had an accessible weight scale. Other findings showed that significant barriers continued to exist inside the health providers' offices: indeed, only 34 per cent of provider offices met all of the interior office access criteria appropriate for their setting. In addition, it was found that non-urban settings showed greater access into the office, a clear space within for turning, and more clear space in the examination room. The authors noted that these findings not only provide a base for quantitative expectations about accessibility nationwide, but showed that physical access is an important factor in affecting quality of care and willingness of patients to engage in preventative care.

Kroll, Jones, Kehn and Neri (2006) argued that although individuals with physical disabilities are less likely to utilise primary preventative health care services than the general population, they are at greater risk of secondary conditions, and as likely to engage in health risk behaviours as the general population. This study investigated barriers to accessing preventive health care services for people with physical impairment, and also identified

strategies to increase access to these services. The authors used a health services framework to identify structural-environmental (inaccessible facilities and examination equipment) and process barriers (lack of disability-related provider knowledge, respect, and skilled assistance during office visits). Focus group participants identified the following strategies to improve access to preventive health care services: disability-specific continuing education for providers; the development of accessible prevention-focused information portals for individuals with physical disabilities; and consumer self-education, and assertiveness in requesting recommended services. The authors recommended a more responsive health care system with the development of consumer- and provider- focused resource and information kits reflective of the strategies identified above.

Summary

People who are physically disabled are less likely to use primary health care, are at greater risk of secondary conditions and are as likely to engage in health risk behaviours as the general population. A range of barriers have been identified as impacting on physically disabled people's access to primary health care. The most significant barriers include transportation difficulties, inaccessible premises, inadequate knowledge of health care providers and, inadequate medical insurance. Research has also determined that the way health practices are funded has an impact on the quality and accessibility of health care. In particular, salaried and fee-for-service health practices have been found to provide more responsive services to disabled people than primary health practices that have been funded using a capitation model.

Potential strategies to increase access to primary care for physically disabled people

A number of potential strategies have been developed aimed at increasing access to primary care for disabled people. Drum et al. (2005) provided a concise set of guidelines to address this disparity in access. Their article aimed to explore the concepts of health and wellness, to summarise recent information documenting disparities in health for disabled people, and to provide a framework for policy recommendations for reducing these disparities. The authors argued that in order to effectively address health disparities for disabled people, it was necessary to make changes in access to medical care, improvements in the delivery of health promotion, increase prevention strategies implemented for secondary conditions, and focus on the removal of environmental barriers. They suggested four categories of policy change: legal and regulator reforms that enforce the Americans with Disabilities Act to address accessibility; health plan benefits that ensure access to needed speciality care; communication enhancement that includes interpreter services; and health promotion programs. Hwang et al. (2009) argued that disabled people often have multiple complex needs, both medical and nonmedical, and are currently at risk of receiving substandard services as a result of facing multiple barriers to health care. As such, a consumer-directed approach to delivering health care to people with disabilities is desirable. The authors suggested that this approach to health care can be “effectual cost-effective and subjectively satisfying” (p. 28), and offered recommendations for future policy interventions. These included: the development of disability-sensitive assessment instruments; refinement of assessment tools; assessment of the long term physical health outcomes of care coordination deficiencies; and the application of the survey to people with disabilities under different health care coverage structures. Other interventions included the

communication of information, such as research, to providers that is related to persons with disabilities, and the development of educational initiatives targeted to consumers.

Summary

In order to effectively address health inequalities for physically disabled people a range of policy and practice level changes are required. Researchers have recommended that improvements in the delivery of health promotion, increased attention paid to the prevention of secondary conditions and the reduction of environmental barriers are critical to achieving improved health for this group. The need for legislative reform has also been highlighted as a way of enforcing health services to be responsive to disabled people.

Evaluated strategies for increasing access to primary care for physically disabled people

More recent publications focusing on public health and disabilities have evaluated strategies addressing disparities in access to primary care for people with physical disabilities. It is worth noting that a number of these studies identified issues and concerns in common, and it is the purpose of the following discussion to present and group these evaluated strategies in an accessible manner.

Rimmer's (2011) research focused on the impact of the Disability Section. The Disability Section is one of the newest sections in the American Public Health Association and is specifically focused on disability. While achieving section status has increased visibility for the disability community, Rimmer argued that in order to build capacity within and across the other sections of the Association it was also necessary to infuse disability content and perspectives on issues that impact disabled people in other areas of public health, for example environmental and gerontological health. In order for this to happen, the Disability Section must be "used as a base for recruiting and deploying health professionals who have an interest in a dyadic area of public health" (p. 6). That is, disability representation must occur across the spectrum of public health in order to ensure greater visibility and action.

Sandel et al. (2010) reviewed the history of the various activities within the Kaiser Permanente (KP) health system from 2001 to 2010. The KP system was set up in response to the enactment of the Americans with Disabilities Act, which followed the settlement of a lawsuit. These activities were enacted to improve access and remove architectural, attitudinal and other barriers for people with disabilities. Sandel et al. noted that one aim of the KP system was to educate and train providers about culturally competent care for people with disabilities and to develop patient-centred best practices for people with disabilities. In this regard, it was noted, the KP health system continued to address attitudinal as well as structural barriers to care for people with disabilities. However, the distribution of these best practices throughout a large and complex health system was identified as an ongoing challenge.

Other studies evaluated health communication strategies designed to improve access to primary health care for people with disabilities. Williams-Piehot et al. (2010) conducted an evaluation to assess the relevance and usefulness of health communication materials developed and used by three state disability and health programs

in the US. Data were collected from both health care providers and those with a variety of physical and sensory impairments through key informant interviews, focus groups and a web-based provider survey. The results of this evaluation suggested a need for health communication strategies and messages to be improved across the board. Specific suggestions to achieve improved access and removal of barriers to health care included increasing access to facilities and empowering consumers and educating health care providers about disability. Interestingly, while consumers of these services indicated a need for improvements to the overall content and design of the state-developed health communication materials, health care providers and human service providers were generally satisfied with the materials. Williams-Piehot et al. acknowledged the implications of these findings for public health practice as well as recommendations for improving future health communication materials.

Horner-Johnson et al. (2009) evaluated the Healthy Lifestyles (HL) for People with Disabilities health promotion programme, designed to address an increased risk for preventable health problems for disabled people in the US. The authors analysed the changes in health behaviour for disabled adults who took part in this programme. This HL curriculum incorporated four major principles: an integrated approach defining health as multi-dimensional; self-determination and the right for people with disabilities to practice choice, control and responsibility for their lifestyle choices; salutogenic (health causing) approaches; and the application of Bandura's social-cognitive theory (Bandura, 1986). Study results indicated that a 2.5 day health promotion workshop followed by monthly support groups could be successful in helping adults with disabilities increase healthy behaviours. The authors concluded that a broad implementation of the HL and other similar evidence-based disability-specific programs, health promotion practitioners could be effective in improving the health status of people with disabilities.

Another study by Xenakis and Goldberg (2010) evaluated the Young Women's Program (YWP), a hospital-based centre for disabled women, which is a component of the Initiative for Women with Disabilities. The program offered accessible gynaecology, primary care, physical therapy, nutrition consultations, exercise and fitness classes, and wellness and social work services. Data were obtained via a self-administered program evaluation, and through recruitment and retention statistics to evaluate the extent to which individual health and wellness goals were achieved. Results indicated that the YWP addressed challenges and barriers to health and wellness by exposing the young women to experiences that promoted self-determination and self-competence, including opportunities for socialisation with peers and mentors, the exposure to community resources and the support of self-care skills for independence.

In order to investigate the negative effects of secondary conditions on the health of those with physical disabilities, White et al. (2011) conducted a literature review of health promotion interventions that included physical activity and prevention of secondary conditions among people with physical disabilities. Results of this study were varied, and the authors concluded that the review demonstrated that research on health promotion interventions containing physical activity lacked description about whether such interventions helped reduce or prevent secondary conditions. They argued that further work was needed in terms of sustaining health programmes effects beyond the specific programme context and into the community contexts within which people live.

Stuifbergen et al. (2010) argued that those living with chronic and disabling conditions are often at increased risk of secondary conditions and disabilities, which can result in further decline in health status, independence, functional status, life satisfaction and overall quality of life. The study examined research evidence to identify the benefits of wellness/health promotion interventions for those with chronic and disabling conditions. The authors found that nearly all studies (95 per cent) examined the effects of wellness intervention in a sample diagnosed with a single condition, for example, cancer, stroke and arthritis. Almost all studies (85 per cent) reported positive effects of the wellness intervention, despite variation in delivery and context of interventions as well as the measurements of outcomes. The findings supported an immediate post-intervention positive impact of wellness interventions across persons with chronic and disabling conditions.

Summary

Evaluated strategies for increasing access to primary health care are scarce. One American strategy has been to develop a Disability Section within the American Public Health Association to achieve greater visibility for the disability community and to disseminate disability content and perspectives in the public health arena.

Initiatives designed to address attitudinal and structural barriers have also been trialled, however it has been noted that achieving real change throughout large and complex health systems is difficult. At a practice level, an evaluation of an initiative designed to educate and encourage disabled adults to engage in health promoting behaviours generated evidence that such an approach increased healthy behaviours. Similarly, a programme that offered accessible health care and health promotion to young disabled women was evaluated as being successful in increasing self determination and self care skills.

Primary health and adults who have an intellectual disability

Introduction

Literature in the area of primary health and intellectual disability has been described as converging on the following three key points: people who have an intellectual disability experience poorer health than their non-disabled peers; have a higher level of unmet health need; and are impacted by diagnostic over-shadowing⁴ (Michael & Richardson, 2008).

While an exploration of research and policy in the area of intellectual disability and primary health shows that there has been a relatively long-standing awareness of these key points, concerted efforts to address them have only occurred more recently. Such efforts have been necessitated, in part, by the deinstitutionalisation movement and the fact that far greater numbers of individuals who have an intellectual disability are now reliant on their local, community-based primary health providers (van Loon, Knibbe, & Van Hove, 2005). It is also because more children with significant disabilities are surviving into adulthood, and more adults are surviving into older age (Parrot, Wolstenholme, & Tilley, 2008).

The health needs of adults who have an intellectual disability

Approximately 32,000 people have an intellectual disability in New Zealand (Ministry of Health, 2011). People who have an intellectual disability have the same health needs as their peers in the general population but they have been found to have additional and different health needs to people without intellectual disability (J. Hardy, Woodward, Woolard, & Tait, 2006). Consequently, efforts to ensure that the health needs of this group are met require recognition of both these facts. It has been common for people with intellectual disability to find it difficult to recognise and communicate their health needs, and to experience deficits in service provision (Baxter et al., 2006). These and other issues related to the barriers to health and health care will be explored later in this review.

Research has found that adults who have an intellectual disability have compromised health, are at risk for, or experience a higher prevalence of a broad range of health conditions. One of the most recent and comprehensive briefing papers relating to health inequalities for people who have an intellectual disability has emerged from the UK (Emerson & Baines, 2010). This paper was designed to guide the National Health Service (NHS) Trust to meet their responsibilities to patients with intellectual disability within primary, secondary, acute and specialist health services. Emerson and Baines (2010) identified the key health needs experienced by this vulnerable group at the present time as: mortality; general health status; cancer; coronary heart disease; mental health and challenging behaviour; dementia; epilepsy; sensory impairments; physical impairments; oral health; dysphagia;

⁴ Diagnostic overshadowing refers to the tendency for a person's symptoms to be attributed to their intellectual disability rather than seeking other potentially treatable causes.

diabetes; gastro-oesophageal reflux disease; constipation; osteoporosis; endocrine disorders; injuries; accidents; and falls.

With reference to the New Zealand context, in 2003 the National Health Committee published *To Have an Ordinary Life: Kia Whai Oranga Noa* (National Health Committee, 2003), a document intended to assist the Minister of Health and the Minister for Disability Issues to better understand and meet the needs of New Zealanders with an intellectual disability. *To Have an Ordinary Life* was harsh in its appraisal of the health status of adults with an intellectual disability supported by government funded, residential services. The National Health Committee reported that this group experienced “*inadequate and improper health care provision*” to a level the committee categorised as disturbing. While acknowledging that there are some difficulties with the documented evidence relating to both the location of data collection and way data was collected, the *To Have an Ordinary Life* report identified a range of issues as being strongly supported by the available (predominantly international) evidence, including that:

- people who have an intellectual disability have higher, and different patterns of health need than the general population
- life expectancy for adults with an intellectual disability is increasing, but is still lower than the national average
- the incidence of age-related diseases is increasing among adults with an intellectual disability as a result of increased life expectancy
- there is a high rate of epilepsy among adults with an intellectual disability
- a growing number of syndrome specific conditions are being identified
- many adults with an intellectual disability also have mental health conditions
- there is a high rate of unrecognised health conditions among adults with an intellectual disability
- many adults with an intellectual disability are being prescribed out-dated medications or combinations of pharmaceuticals that are not in line with safe prescribing practices (National Health Committee, 2003).

Obviously, not all these health needs affect all people who have an intellectual disability equally. Disability type, degree of disability, age, sex, living situation and lifestyle are all factors that have an effect on the health status and health needs of this group. It is fair to say, however, that despite the fact that the life expectancy of people who have an intellectual disability is increasing, both men and women can still expect to live a shorter life than their peers. Furthermore, they are also likely to experience a high degree of morbidity during their lives.

A range of studies that evidence some of the health needs referred to above, and how they have been explored, are summarised below.

Epilepsy, skin diseases, visual and hearing impairment, and fractures

Jensen, Krol, Groothoff and Post (2004) reviewed studies conducted between 1995 and 2002 to build a picture of the health problems experienced by people who have an intellectual disability. Recognising that research which compares disabled and non-disabled adults usually does so by drawing on the prevalence rates reported in general health surveys, Jensen et al. limited their review to comparative health research that specifically included a comparison group of people without intellectual disability. While results were limited due to the low number

of studies that met this classification, higher prevalence rates for epilepsy, diseases of the skin, sensory loss and increased rate of fractures were identified for people who had an intellectual disability.

Visual and hearing impairment, dementia and gastrointestinal problems

In an earlier study also based in the Netherlands, van Schrojenstein Lantman-de Valk et al. (1997) conducted a prospective cohort study designed to determine the prevalence and incidence of the most frequent and chronic health problems experienced by people who had an intellectual disability and living in residential services (van Schrojenstein Lantman-de Valk et al., 1997). A high prevalence and incidence of visual and hearing impairment was reported across the study sample and particularly for those with Down syndrome. Also reflecting a known association between Down syndrome and a range of specific health conditions, a higher incidence of dementia was found amongst participants with Down syndrome. Gastrointestinal problems appeared to be experienced by all participants who had an intellectual disability. These results led Van Schrojenstein Lantman-de Valk et al. (1997) to argue that empirical evidence relating to the prevalence and incidence of health problems experienced by this group is critical to the development of more responsive health policy.

Obesity

International studies have consistently reported obesity to be more common amongst people who have an intellectual disability (Bell & Bhate, 1992; Temple, 2013). Recent American research (Rimmer, Yamaki, Davis Lowry, Wang, & Vogel, 2010) explored the prevalence of obesity and obesity related secondary conditions experienced by adolescents (12-18 years) who had intellectual or developmental disabilities. Parents of this group of young people responded to a web-based survey that asked questions about their child's health status, including body weight and existing health conditions. Comparisons with published research relating to young people without intellectual or developmental disability found young people who had autism, Down syndrome, or intellectual disability to be two to three times more likely to be obese, and to have a range of secondary health conditions related to being overweight. Rimmer et al. contended that the prevalence of obesity and obesity-related secondary conditions are strongly linked to the health disparities experienced by people with an intellectual disability in adulthood. Consequently, there is a strong need to create and evaluate the effectiveness of a range of strategies that may help to reduce obesity for this group.

In another American study, Janicki et al (2002) reported that 50 per cent of a sample of over 1,000 adults with intellectual disability living in residential services were obese. Despite this, little attention or action had occurred with regard to the delivery of health care, leading Janicki et al. to suggest that obesity may be seen as the norm for people who have an intellectual disability.

Three recent studies suggest that New Zealand adults who have an intellectual disability are at risk of the poorer health outcomes associated with high levels of obesity. Obesity has been shown to be more prevalent amongst adults with intellectual disability in the New Zealand context. Stedman and Leland (Stedman & Leland, 2010) reported that amongst a study of people with intellectual disability there were significantly higher rates of obesity than reported for the general population in 2005/2006 (intellectual disability 51 per cent; general population 30 per cent). Furthermore, there were a disproportionate number of women with intellectual

disability in Obesity Classes II (Body Mass Index [BMI] 30-34.99) and III (BMI >40). Stedman and Leland advocated for the need to investigate the variables that may be associated with this higher rate of obesity, and to explore strategies that may mitigate the strong tendency to be overweight.

A first attempt to detect possible predictors of obesity in adults with intellectual disability living in a range of different support settings was conducted by Milner, Mirfin-Veitch and Conder (2013). Following an analysis of a range of both direct and indirect measures of the health status and health literacy among 205 people with an intellectual disability who participated in the Special Olympics Healthy Athletes, Health Promotion screen, Milner, Mirfin-Veitch and Conder (2013) reported that approximately 4 out of every 10 women and almost 3 out of every 10 men with an intellectual disability had a BMI in the obese range. Women with an intellectual disability were especially at risk. Despite New Zealand having the third highest obesity rate in the OECD, women who participated in the health screen were significantly more likely to have a BMI in the overweight and obese (73 per cent) and obese ranges (40 per cent) than women in the New Zealand general adult population (60 per cent and 29 per cent respectively) (Ministry of Health, 2012a).

Consistent with other international studies, Milner, Mirfin-Veitch and Conder (2013) found an association between where participants lived and obesity. When other factors were controlled for, participants who lived in more independent support contexts were significantly more likely to have a BMI in the obese range (53 per cent) than those who lived with a family member (22 per cent). Furthermore, odds that a person who lived more independently had a BMI in the obese range were more than four times higher than for participants who lived with a family member. The authors contended that, in addition to reflecting a national trend for material deprivation to be associated with obesity (Ministry of Health, 2011), people with an intellectual disability who currently live more independently may be less likely to develop nutritional literacy or healthy eating habits.

In a third study, the Ministry of Health (2011) in New Zealand found that, after taking into account age, people with an intellectual disability were over four times more likely to receive treatment for morbid obesity than New Zealanders who did not have an intellectual disability in the year ending June 2008.

Health needs for women who have an intellectual disability

Within the population of people who have an intellectual disability, women have been identified as being particularly disadvantaged in terms of their health and access to health care. Despite having well-established, public health initiatives specifically designed to reduce the number of cancer deaths amongst women, it is widely acknowledged that women who have an intellectual disability are significantly less likely to access routine cervical screening and mammograms than their non-disabled peers (Truesdale-Kennedy, Taggart, & McIlfatrick, 2011). Cobigo et al. (2013) explored the equity of cervical and breast screening for Canadian women using health administrative databases and registries to develop two cohorts: all women with developmental and intellectual disabilities; and a random sample of 20 per cent of non-disabled women. Comparison of the two cohorts showed that women with intellectual disability were twice as likely not to have accessed cervical screening, and 1.5 times less likely not to have accessed breast screening than their non-disabled peers (Cobigo et al., 2013).

In New Zealand, the Ministry of Health (2011) recently reported that people with an intellectual disability were 1.5 times more likely to receive cancer care or treatment than people without an intellectual disability. Women who had an intellectual disability were less likely to have participated in either breast or cervical screening than their non-disabled female peers and had an annual cervical screening rate of 34 per cent. This figure stands in marked contrast to a screening rate of 71 per cent for women without disability (Ministry of Health, 2011).

People with high and complex needs

There is only a relatively small body of literature that relates specifically to people who have profound and multiple intellectual disabilities (complex support needs), despite the fact that the primary and secondary health needs of this group are high.

Parrot and colleagues (2008) contributed to the gap in the literature with a study that had the dual aims of providing an analysis of the change in overall number of people with an intellectual disability over a 10-year period, and of exploring the health and support needs of young people with profound and multiple disabilities. The study was conducted in Sheffield, England and data relating to disability, ethnicity and other specific factors were extracted from Sheffield's Learning Disability Case Register for the purposes of the study. The Register facilitates the collation (and provision) of data relating to people with intellectual disability in Sheffield (1980-present) and was developed to enable accurate analysis of disability population trends and changes.

In the period 1998 and 2008 Parrott et al. (2008) reported an overall increase in the number of people who had an intellectual disability, as well as an increase in the degree and complexity of their needs. Results showed a marked increase in the number of young people with profound and multiple disabilities who had significant health issues. Health problems were identified as: breathing and airway problems; eating problems; epilepsy, pressure care; and continence. Parrott et al. concluded that the health and wellbeing of young people with complex needs is compromised by a lack of coordination across primary, secondary and acute services and suggested that a stronger clinical focus on meeting the health needs of this group within the context of community nursing could help resolve this. They also called for capacity building in this area within primary and acute health services.

Ageing

While men and women who have an intellectual disability can still expect to live a shorter life than their peers in the general population, as a population group, they are currently experiencing greater life expectancy than previously. Furthermore, these longer lives are being lived in the community, thus creating the need for primary and secondary health services to be aware and responsive to this specific population group.

Janicki and colleagues (2002) explored the health characteristics and health service utilisation of older adults who had an intellectual disability living in residential services and reported mixed results. Adults aged between 40-79 ($N=1371$) living in New York State were surveyed to determine health status and patterns of disease. Janicki et al. found that most of the adults were in good health but that cardiovascular, sensory, musculoskeletal and respiratory conditions increased with age. By way of contrast, neurological, endocrine and dermatological

conditions did not increase, and psychiatric and behavioural disorders declined with age in this population. In comparison with US national health and nutrition survey results, adults who had an intellectual disability appeared to have a lower overall reported risk of hypertension and hyperlipidaemia, and adult on-set diabetes. However, Janicki et al. questioned these findings as not reflective of other research that has identified this group of adults as experiencing an equal or greater prevalence of cardiovascular and cancer related deaths. Janicki et al. suggested that while these contrasting findings may have been indicative of people with intellectual disability enjoying improved health, they more likely point to a context of under-recognition and/or under treatment of specific risk factors and diseases.

Adults who have Down syndrome

It is important to make specific mention of the health of individuals who have Down syndrome. A range of health conditions are associated with Down syndrome including: congenital heart disease; mitral valve prolapse; leukaemia; thyroid disease; sleep apnoea; respiratory infections; epilepsy; orthopaedic conditions; vision and hearing conditions; and obesity (Vander Ploeg Booth, 2011). The fact people with Down syndrome are often subsumed into the wider population of people who have intellectual disability has been recognised as having the potential to skew research results relating to the health status and prevalence of certain health conditions. Consequently, researchers have highlighted the need for disability sensitive analyses of health related data.

Vander Ploeg Booth (2011) advocated for greater understanding of the specific genetic etiologies of health conditions experienced by individuals who have Down syndrome as a way of ascertaining the true genetic contribution to health disparities. Vander Ploeg Booth notes the need to explore other important health determinants; social circumstances, environmental determinants, individual behaviours and health care access in order to gain a comprehensive understanding of the health status and health needs of this group.

The particular health needs of children, young people and adults with Down syndrome have been recognised in New Zealand through the development of a document containing information about recommended clinical practice for this group (Ministry of Health, 2001a). The document stressed the need for increased consistency with regard to the medical management of people who have Down syndrome, and regular multidisciplinary input and review in order that optimal health and wellbeing is able to be achieved.

Summary

Researchers agree that people who have an intellectual disability experience poorer health, have a higher level of unmet health need, and are negatively affected by diagnostic overshadowing. Due to deinstitutionalisation, and because adults who have an intellectual disability are living longer it is becoming more critical primary health programmes and primary health providers deliver appropriate and effective services. Research has consistently shown people who have an intellectual disability are at increased risk for a range of health conditions. Further to this, the health of some individuals is even more greatly impacted due to the known association between a range of specific syndromes and certain health conditions. While not all individuals who have an intellectual disability have the same health needs, both men and women who have an intellectual disability can expect to live shorter lives than their peers. Research has identified that women who have an intellectual disability, people with high

and complex needs, older adults, and those who have Down syndrome may require specific attention in order to ensure their health needs are met, and access to health services assured.

Health inequalities experienced by adults who have intellectual disability

Determinants of health, for all people, are influenced by an individual's genetic makeup, lifestyle, and the social context in which they live. That is, determinants of health include socio-economic, cultural and environmental conditions and some individual or population groups may be vulnerable to one or all of these determinants. In the case of people who have an intellectual disability, additional attention and support may need to be provided in order that they are not automatically disadvantaged in terms of health status and access to health care (Brehmer-Rinderer, Zigrovic, Naue, & Weber, 2013).

While there are many different meanings attached to the terms health disparity, inequality and inequity, it is generally agreed that these terms are used to describe differences in health that are *avoidable* and *unfair* (Vander Ploeg Booth, 2011; Whitehead, 1985). In a document developed for the World Health Organisation, Whitehead (1985) considered the meaning of equity in health and stated:

The term inequity has a moral and ethical dimension. It refers to differences which are unnecessary and avoidable but, in addition, are also considered unfair and unjust. So in order to describe a certain situation as inequitable, the cause has to be examined and judged to be unfair in the context of what is going on in the rest of society. (p. 5)

In the case of people who have an intellectual disability there is agreement, at least amongst the disability sector, that the disadvantages that this group experience are both avoidable and unfair in many cases.

Emerson and Baines (2010) described five categories of determinants of health inequalities experienced by people with learning disabilities and these are summarised below.

Social determinants of health: Social determinants of health refer to social issues such as poverty, poor housing, unemployment, social disconnection and discrimination. People who have an intellectual disability are significantly affected by all these issues, thus at increased risk of experiencing health inequalities known to result from them.

Health needs and their relationship with genetic and biological causes of intellectual disability: Genetic and biological factors have a role in the increased morbidity and mortality rates experienced by some people who have an intellectual disability, particularly those with specific syndromes, for example Down syndrome (congenital heart disease and early onset dementia), Prader-Willi syndrome (hypothalamic disorders obesity) and Rhetts syndrome (mental health problems and challenging behaviour).

Communication difficulties and reduced health literacy: Communication and health literacy relates to the ability people who have an intellectual disability have to recognise or convey their health needs to those in a position to

respond. Furthermore, it is not uncommon for this group to lack knowledge about health-promoting behaviours that could enhance their health and wellbeing.

Personal health risks and behaviours: Personal health risks and behaviour refer to aspects of health such as diet, exercise, obesity and underweight, substance use and sexual health. The ability to engage in health promoting rather than risky behaviours in these areas is often reduced for people who have an intellectual disability to a lack of access to health education and health promotion.

Deficiencies in access to and the quality of health provision: Access to and the quality of health care is often compromised for people who have intellectual disability due to a range of organisational barriers including: too few services; physical access issues; inappropriate/inaccessible strategies for communicating health information; lack of interpreters; diagnostic overshadowing; and discriminatory attitudes.

Specific detailed examples of research that has identified health inequalities experienced by people who have an intellectual disability are presented in the remainder of this section, commencing with research that has expressly sought the perspectives of adults who have an intellectual disability themselves.

The health experiences of people who have an intellectual disability

Similar to the wider literature relating to intellectual disability, it is still relatively uncommon for research to seek the views of people who have an intellectual disability themselves with regard to their experiences of, and views about, health status, health promotion and health care services. This has been identified as a serious omission due to the fact that effective health promotion and health policy requires a well-developed understanding of patient perspectives (Parish, Moss, & Richman, 2008).

In a study designed specifically to redress this gap, Parish et al. conducted seven focus groups with adults who the authors described as having developmental disabilities. All but three of the 30 participants were diagnosed as having an intellectual impairment. The focus groups explored seven key topics: overall health status; specific health conditions; health promotion behaviours; risk and health promoting factors; access to medical care; access to dental care; and access to mental health care.

Parish and colleague's study showed marked contrasts and inconsistencies. While a significant majority of participants reported good or excellent health (86 per cent), 29 out of 30 people reported having a secondary health condition, most commonly a mental illness or emotional or behavioural difficulty. Medication rates were high. One-third of participants were taking at least one psychotropic medication while only a quarter reported that they were not prescribed any medication. Most participants reported that they had a primary care physician and yearly check ups. However there appeared to be an absence of mammograms for women and of PSA tests for men. Inadequate access to dental care was common for this group of participants. It is interesting to note that the participants in this North American study had a good knowledge of the importance of healthy lifestyles and their risk behaviours such as smoking and drinking were low.

The importance of health care advocacy was strongly highlighted by Parish and colleague's study. Participants identified that informal support providers (commonly family or friends) played a critical role in helping them to maintain good health by: promoting positive health habits; being aware when health care was needed; providing information to adults with an intellectual disability about health providers in their local communities; assisting people to make appointments; advocating during services; and following up after appointments. Parish et al. (2008) identified the following strategies as having the potential to lead to improved policy and practice in the area of primary health among people who have an intellectual disability: paying specific attention to increasing access to dental care; formally recognising the role informal carers play with regard to health advocacy by offering education and training in this area; increasing education in the area of intellectual disability for health professionals (including dentists); and providing education to people who have an intellectual disability themselves so they can be more equal partners in their own health care.

In another study that sought the views of adults who have an intellectual disability (Ward, Nichols, & Freedman, 2010) four themes were identified as important within the participants' narratives: access, knowledge, communication, and quality. Access issues included both an experienced difficulty in locating appropriate health providers, of feeling forced to remain with a paediatrician in the absence of coordinated health care for adults, and excessive wait times for health care professionals (and especially those knowledgeable about intellectual disability). The theme of knowledge and communication related to a perception that health care professionals frequently had not had any personal experience with people who had intellectual disability, and/or were not sufficiently trained in this area. As a consequence, health care professionals were often viewed as insensitive to the particular needs of this group. People who had an intellectual disability felt a lack of direct communication with health care professionals and poor quality was identified as lengthy waits followed by a sense of being rushed through the consultation. Similar to other researchers, Ward et al. (2010) contended that health care inequalities could be addressed by improved training of health care professionals, including contact with individuals who have an intellectual disability, knowledge of the environments in which they live, the supports they receive and their communication strategies. They also suggested that individuals with intellectual disabilities, families and community support staff require education to become informed health care consumers.

In the Australasian context Ziviani, Lennox, Allison, Lyons and Del Mar (2004) conducted a qualitative study designed to better understand factors impacting on communication exchanges between GPs and their patients who have an intellectual disability. GPs, adults who have an intellectual disability, support workers and advocates were interviewed for the study. Analysis of interview data derived from participants who had an intellectual disability resulted in the identification of three important themes. First, participants reported that communication with their GP was made more difficult when they felt they were being rushed. While the involvement of support workers had some benefits, it often eliminated the opportunity for them to talk alone with their GP about their personal health issues. Second, participants who had an intellectual disability wanted to feel as though their GP recognised them as a person, was interested in them, and treated them in an age-appropriate way. Third, participants were negatively affected by encounters with their GP during which the GP made communication difficult with them, either by inappropriate body language or through communicating health information about them to their support person.

Conder, Mirfin-Veitch and Bray (2007) presented findings related to the health experiences of New Zealand adults with an intellectual disability in order to demonstrate their relevance for health professionals, particularly nurses, working in the primary health environment. In this study, adults who had an intellectual disability frequently said they found nurses more supportive than doctors, feeling that they were able to take more time with them than their GP. It was also common for the participants to have a poor knowledge and/or recall of their own health history. While this deficit was more pronounced for those who had experienced institutionalisation, those who lived more independently or at home with their families also had difficulty recalling important health information. Further to this, participants were frequently unable to identify their medications or why they took them, with some appearing to have been deliberately misinformed about the purpose of medications they were taking. Low self esteem and a lack of independence meant that many participants felt unable to take responsibility for their own health, including arranging necessary appointments or to describe symptoms to a health professional.

Conder et al. (2007) asserted that health outcomes for people who had an intellectual disability could be improved by the adoption of several simple strategies within primary care settings. First, in order for adults with intellectual disability to take responsibility for their own health, it is important that children and young people are included in discussions relating to their health and health needs from an early age. Further to this, young people with an intellectual disability must receive (accessible) health education to ensure they are not disadvantaged by a lack of their health knowledge in adulthood. Conder et al. also suggested that investigation of the role practice nurses could play in delivering health checks or other health assessments would be beneficial to the overall goal of ensuring primary health needs are met for people with intellectual disability in New Zealand.

Research data collected from adults who have an intellectual disability about their health and their health care experiences clearly points to significant health inequalities, particularly in the areas of communication, reduced health literacy and access to and quality of health care provision.

Other examples of research on health inequalities

In the New Zealand context, the Ministry of Health recently compared a selection of health status and health care utilisation indicators for New Zealanders with and without an intellectual disability (Ministry of Health, 2011). People with an intellectual disability were found to be 1.5 times more likely to have consulted with a GP in a three-month period, and were over four times more likely to have avoidable hospitalisations. Furthermore, in comparison to people without an intellectual disability, people who had an intellectual disability were 1.5 times more likely to receive care or treatment for cancer, coronary heart disease, diabetes, kidney disease, cancer and morbid obesity. This combination of poor health status and high health service utilisation has contributed to a situation whereby people with an intellectual disability receive on average three times the amount of government funded primary and secondary funded health care than that received by the general population. The health indicator report findings suggest that despite the high level of resourcing adults receive in primary and secondary health, this group of vulnerable New Zealanders are not experiencing the health outcomes that might be anticipated from this level of investment.

In 2006, Krahn, Hammond and Turner (2006) discussed what they referred to as “a cascade of disparities” (p. 91) for people who had an intellectual disability. These authors provided a representation of determinants of health and health status that depicted the disparities experienced by this group as being related to: genetics; social circumstances; environmental conditions; health promotion; and medical care access. Krahn et al. (2006) particularly highlighted that disparities are created through a lack of: attention to individual care needs, including where a person lives; preventative care and health promotion; and access to health care.

The over-prescription of psychotropic medication has been identified as constituting a health inequality for adults who have an intellectual disability, as such medications are frequently prescribed on the basis of challenging behaviour rather than on evidence of symptoms of mental ill-health. Doan, Lennox and Taylor-Gomez (2013) recently reported on the results of an Australian cross-sectional study conducted between 2000 and 2002 which explored the Comprehensive Health Needs Assessment Programme (CHAP), a health screening tool designed specifically for use with people who have an intellectual disability (Lennox et al., 2007). Medication data were separated from the wider body of data collected through the administration of the health-screening tool. Additional demographic and medical information relevant to participants’ medication use were sought from care providers and health professionals. Doan et al.’s research confirmed a relatively high use of psychotropic medications among the population of people who have an intellectual disability. Of the total sample of 117 participants, 35 per cent were prescribed psychotropic medications and 26 per cent were prescribed anticonvulsants. While the use of psychotropic medications was found to be significantly associated with having a psychiatric illness and challenging behaviours, it is important to note that 30 per cent of participants who were receiving these medications were not diagnosed as having a mental illness or challenging behaviour. Doan et al. suggested the study results may indicate that prescribing rates of psychotropic medication to people with an intellectual disability may be as high in the community as they were in institutional contexts, and may be highly inappropriate and possibly detrimental to their general health.

As previously mentioned, strong concern has also been expressed about prescribing practices in the New Zealand context (National Health Committee, 2003) and recent national research has again indicated that adults who have an intellectual disability may be being disadvantaged in this area. Through a study of the health status, health knowledge and health literacy of people who had an intellectual disability and who completed the Special Olympics HAS Health Promotion screen, Milner, Mirfin-Veitch and Conder (2013) were able to analyse medication use. Results showed 7 out of every 10 participants were taking prescribed medication, and where people lived was the strongest predictor of medication use. Nine out of every 10 individuals who lived in a staffed community group home were reported as taking medication. With specific regard to psychoactive medication, approximately one out of every three participants for whom data was available were taking one or more psychoactive medications. Further to this, more than half of the participants who lived in a staffed community home were reportedly regularly taking psychoactive medications, whereas less than one in every five participants who lived at home did the same. These findings point to the need for further research designed to comprehensively explore the factors that may contribute to these differences in prescribing rates and practices.

Summary

People who have an intellectual disability may require additional and focused attention to ensure they are not automatically disadvantaged in terms of their health status and access to health care. The differences in health that this group experience in comparison to the general population are classed as health inequalities due to the fact that they are often avoidable and unfair. Researchers generally agree on five determinants of health as contributing to the health inequalities experienced by people who have an intellectual disability: social determinants of health; health needs and their relationship with genetic and biological causes of intellectual disability; communication difficulties and reduced health literacy; personal health risks and behaviours; and deficiencies in access to, and the quality of health provision. The over-prescription of psychotropic medication has also been identified as constituting a health inequality for adults as such medications are frequently prescribed on the basis of challenging behaviour rather than on evidence of symptoms of mental health. Both these issues have been found to impact on adults who have an intellectual disability in New Zealand. While only a small body of literature has sought information directly from adults who have an intellectual disability, that which has, has highlighted the need for improved communication with primary health professionals to ensure that health information is conveyed in a way that is accessible. Research involving adults has also identified the need for family or formal support workers to take on an advocacy role within some primary health contexts.

Barriers to primary care for people who have an intellectual disability

Barriers to primary care have been comprehensively explored for adults who have an intellectual disability. Ruddick (2005) conducted a review of the research literature in order to gain a comprehensive understanding of the barriers to accessing health services for people who have an intellectual disability. Her review highlighted a wide range of factors that have the potential to impact on the extent to which this vulnerable group is able to access health services that are critical to maintaining good health. Barriers identified by Ruddick included: the absence of a shared understanding of who holds responsibility for ensuring that health policies are implemented; insufficient emphasis on health as a key quality of life domain during the evaluation of disability services; a paucity of reliable measures that can be used to explore health with people who have an intellectual disability (and that enable comparison with the general population); and communication difficulties that impede the diagnosis and treatment of health conditions.

As previously noted, adults who have an intellectual disability are particularly sensitised to factors that reduce their access to health professionals and health services. Researchers have pointed out that access is a term that is frequently used by those commenting on health issues and policy. While in a general sense access is understood as referring to waiting times, capacity issues, and geographical positioning of health services. This more narrow definition does not reflect the additional and different access issues experienced by people with disabilities. Barriers to health services (that is, reduced access) are also created by the service's physical context, the attitudes of health professionals, knowledge of the specific impairments and the health conditions that are associated with them, and systemic factors such as funding or eligibility (McColl, Jarzynowska, & Shortt, 2010).

Access

In recognition of the fact that people who have an intellectual disability frequently have their access to health care mediated by other people, Hames and Carlson (2006) examined whether primary health care team members were aware of the services and support offered by their local learning disability team. Learning disability teams are a UK-based initiative that are multidisciplinary in nature and focus on health promotion and health facilitation for people who have an intellectual disability. Community nurses experienced in intellectual disability often take a central role in such teams. Despite a relatively low response rate to their survey-based study (29 per cent), Hames and Carlson established that only 36 per cent of survey respondents (including GPs, practice nurses, health visitors, physiotherapists, dieticians, and counsellors) had had contact with their local learning disability team. In conjunction with this, survey respondents expressed a lack of knowledge about the role of the learning disability team, and particularly the functions related to health facilitation and health promotion frequently being undertaken by community nurses. These findings highlight the challenges inherent in achieving a high level of interaction between intellectual disability and primary health services.

Preventative care pertains to pre-symptomatic health services to delay, defer or avoid developing disease or illness. While preventative care is regarded as the most efficient way to deliver health care and promote wellness, this can present a challenge for adults who have an intellectual disability who find it hard to access health promotion. Responding to the low rate of participation in breast and cervical screening by women who have an intellectual disability, Cobigo et al. (2013) suggested that disparities in the area of preventative health screening could be reduced by: ensuring screening services specifically consider vulnerable populations during planning; educating women with intellectual disabilities themselves about the importance of screening; educating health professionals about the importance of screening for women who have an intellectual disability; and developing clinical guidelines relating to the primary care needs of this group.

Education and training of health professionals

The fact that there is comparatively little emphasis on intellectual disability within medical training, and small numbers of patients so labelled within individual practices, means that it is difficult for GPs to build expertise in supporting the health needs of this group. Recognition of the critical role that GPs play in ensuring primary health access for people who have an intellectual disability is widespread. Lin and colleagues (Lin et al., 2008; Lin et al., 2009) explored the role of GPs in the health care of people who have an intellectual disability in Taiwan using a cross sectional survey design. Mirroring other studies that have sought to gain substantial input from GPs, the response rate was relatively low (16 per cent) with only 331 surveys returned despite the fact that 2286 questionnaires were mailed out to all GP members of the Taiwan Medical Association. GP respondents were found to have little experience or knowledge of intellectual disability, leading to an expressed need for more training in the field. Further to this, despite the fact that GPs typically agreed that theirs was an important role with regard to health care provision for people who have an intellectual disability, they reported that they were often not satisfied with what they had achieved for this group of patients. Lin et al.'s study highlighted an inconsistency in the level of training in comparison to the perceived level of skill and experience required to work effectively with this group of people.

Obtaining good quality health information

The difficulty in obtaining accurate and complete health information has been well recognised as a barrier to good health for people with an intellectual disability, with some researchers considering there is an over-reliance on self report data as a result of this difficulty (Swaine, Parish, Ghosh, Luken, & Wright, 2013). In an attempt to move some way toward redressing this imbalance, Swaine et al. piloted a procedure for gathering retrospective medical record data in order to be able to measure the rate of participation in cervical and breast screening for a group of 199 women who were involved in a community-based, randomised controlled trial of a health education initiative between 2006 and 2009. Despite using a relatively simple tool for recording medical information, the research highlighted the difficulties associated with obtaining retrospective medical record data from primary health practices. While most practices agreed to requests to provide medical information, response and completion rates were highest for the most recent medical data with retrospective data largely incomplete. As a result of this exploratory study, Swaine et al. warned that while obtaining retrospective medical data is possible, it is often a lengthy process that requires extensive input and follow-up, and that older records are frequently incomplete, thus impacting on the quality of data and subsequent analysis.

Summary

A wide range of factors have been identified as having the potential to negatively impact on whether people who have an intellectual disability are able to freely access health services. Barriers occur at both a systemic and at an operational level. Systemic barriers include an absence of a shared understanding of who holds the responsibility for implementing health policies and a lack of reliable measures for exploring health for people who have an intellectual disability. Operational barriers are those that occur at a practice or service level and work to limit access. With regard to access, people who have an intellectual disability are impacted not only by the physical context of the service, but also the attitudes and knowledge of health professionals.

Potential strategies to increase access to primary care for people who have an intellectual disability

While evidence to support the claim that people with an intellectual disability experience poorer health is readily available (Emerson & Baines, 2010), there is no universally agreed way to address this issue. In an attempt to move the research agenda towards developing practical strategies to help this group access health care, Moss, Fraser and Pathman (2008) developed a model for this purpose. The model was designed specifically for adults with severe communication difficulties unable to advocate for their own health needs. The model, which was not fully implemented or evaluated, was titled the North Carolina Primary Health care for Adults with Developmental Disabilities (NC PHAADD) model and was based on four central tenets identified through the literature as being critical to accessible primary health care for those with complex disability and health needs. These tenets were: that health care professionals are often inexperienced in intellectual disability and particularly those with complex needs; that some of the activities related to accessing health care could be performed by people other than health professionals (family, support workers, and advocates); checklists and other accessible information or guidelines could assist people with an intellectual disability and their supporters know when

medical attention is required; and a complete medical record or history could help health professionals be more responsive to the health of individuals with complex needs.

Moss et al's (2008) NC PHAADD model included a health care tool kit, which contained both a person's health history and other information about common health risks and conditions. It also recommended the introduction of health advocates who could be trained to make appointments, assist during clinical meetings, monitor health status outside of the primary health setting and to assist with communication between health care professionals, and their patients, families or support workers. A coordination role whereby a care manager arranges interactions between patients and physicians, liaises with health services and in some cases, provides education and training was suggested, as was the need for systemic change through increased information-sharing and coordination between disability and health services.

Canadian health professionals concerned with addressing the health needs of people who have an intellectual disability developed a guideline for primary health providers (Sullivan et al., 2006). Recognising that responsive and appropriate primary care is critical to improving the health status of this group, Sullivan et al. drew on research evidence and consultation with clinical experts to develop a preventative care checklist that highlighted general issues in primary care (including ethical issues) for adults who had an intellectual disability. This was accompanied by recommendations for responding to the identified issues. It is important to note that the guidelines were more strongly informed by the practical knowledge health professionals experienced in intellectual disability than evidence-based research. This situation reflects the fact that while a great deal of research has explored and reported on health disparities and the reasons for these, there is a paucity of research that has rigorously examined potential responses to such disparities.

Pointu (2005) developed an education care programme for social care staff that had the aim of improving health for people who had an intellectual disability and epilepsy (Pointu, 2005). The epilepsy programme was initiated in response to expressed concern from disability support staff, organisations, professionals and families and was led by a London-based learning disability team. The training encompassed both epilepsy awareness and appropriate administration of rectal diazepam, and concluded with both written and practical assessments of participant learning. Over 1500 support staff participated in the training and in the author's view, improved their ability to appropriately respond to the epilepsy related health needs of people with an intellectual disability. In recognition of the fact the health of citizens with intellectual disability lagged behind that of the general population, the US developed *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation* (US Department of Health, 2002). The report detailed six specific goals (outlined below) with related action steps intended to decrease the gap between health needs and health services for people with intellectual disabilities.

- Goal 1: Integrate health promotion into community environments of people with intellectual disability.
- Goal 2: Increase knowledge and understanding of health and intellectual disability ensuring that knowledge is made practical and easy to use.
- Goal 3: Improve the quality of health care for people with intellectual disability.
- Goal 4: Train health care providers in the care of adults and children with intellectual disability.

- Goal 5: Ensure that health care financing produces good health outcomes for adults and children with intellectual disability.
- Goal 6: Increase sources of health care services for adults, adolescents and children with mental retardation, ensuring that health care is easily accessible for them.

In the UK, the *Independent Inquiry into Health care for People with Learning Disabilities* led by Michael (2008) concluded that people with an intellectual disability experience an avoidable level of suffering due to untreated ill-health. In a subsequent article Michael and Richardson (2008) made a number of recommendations for change to the health system as a way of addressing this issue. The recommendations were linked to three overarching areas related to planning and service delivery: leadership and direction setting; visibility; and assurance. In the area of leadership and direction a critical need for effective leadership was noted, particularly with regard to general health services, in order to achieve positive change in attitudes and behaviour towards patients who have an intellectual disability. Specific to the UK context, the recommendation was made to amend the Core Standards for Better Health (the framework for audit and regulation within the NHS so it is a requirement that services make “reasonable adjustments” for people with an intellectual disability. It was also recommended that the UK government should direct health care commissioners to ensure these reasonably adjusted services were implemented, for example, health checks and support to access the NHS. The value of leadership and direction setting was recognised as being critical at all levels, including having people with an intellectual disability themselves, and their support people involved in planning, delivery and assessment of services. Recommendations related to the theme of visibility reflected the fact that people with an intellectual disability were found to be invisible, or not easily identifiable at all levels of the NHS. As a consequence, the quality of the care this group receives is extremely difficult to assess and little is known about their trajectories through health services. To improve data and information at all levels it was recommended that a National Confidential Inquiry and intellectual disability observatory partnership be established to facilitate information sharing between clinicians and managers about data, clinical risks, assessment and management. Recommendations relating to assurance centred on responsibility and accountability, advocating for effective, safe and personalised services at all levels of the health care system. Deficiencies in knowledge, education and training in the area of intellectual disability were noted at all levels of the health care system and led to the recommendation that education and training should be compulsory, and the delivery of education should involve people with an intellectual disability and those who support them.

In response to specific concerns relating to obesity, recent New Zealand research (Kayes et al., 2011) sought to identify how barriers to healthy eating and exercise might be reduced or removed for children and adults with intellectual, physical or sensory impairments. Initiated through a collaboration between the Ministry of Health and Health Research Council of New Zealand, the study included extensive contributions from disabled people, family/whānau, advocates and service providers. Analysis of these contributions led Kayes et al. to recommend the implementation of six guiding principles to facilitate access to *living well* for disabled adults and children (including those with intellectual disability). The recommendations were wide ranging and included: prioritising living well; making living well a possibility; creating living well opportunities; accounting for individual needs and values of living well; working together; and equipping people with the skills to live well.

Summary

While researchers concur that people who have an intellectual disability have greater health needs than their peers in the general population, as yet there is no agreed or comprehensive strategy for addressing this situation. One-off initiatives and more systemic approaches have both been reported in the literature. Key components of single site or single context initiatives have been related to increased education and training for health professionals and support workers. At a systemic level change has been recommended in the areas of planning and service delivery. Leadership and direction of health services have been identified as critical to achieving a positive change in attitude and behaviour toward health service users who have an intellectual disability. Increasing data and information relating to people who have an intellectual disability so that this group of health service users becomes more visible was also seen as important. Deficiencies at all levels of the health care system have been noted leading to the recommendation that education and training in the area of intellectual disability should be compulsory.

Evaluated strategies for increasing access to primary care for people who have an intellectual disability

As already noted, it is difficult to locate *evaluated* strategies specifically designed to increase access to primary care for people with an intellectual disability. In the case of the Health Matters Program (Marks, Sisirak, & Chang, 2013) the intention was to educate disability support staff working in community-based services to be able to deliver effective health promotion for this group. The initiative was based on the premise that while health promotion has been effective for people who have an intellectual disability, such education has generally occurred in controlled settings. The Health Matters Program was designed for delivery in the settings within which people who had an intellectual disability lived and worked. Thirty-four disability support staff participated in an eight-hour training that would equip them to deliver a 12-week health education programme that involved both physical activity and health education to people with an intellectual disability. A range of measures administered at the conclusion of the programme showed a marked improvement in the health status, knowledge, self-efficacy and fitness of participants with an intellectual disability. Marks et al. contended that these results confirmed that, with appropriate training, intellectual disability support workers could successfully undertake health promotion activities with the people they support.

In Scotland, Campbell (2007) reported on the quality of health services for people with complex health needs. Using a set of evidence-based quality indicators, the performance of 15 NHS boards were assessed with particular reference to the quality of services for people with complex health needs. The quality indicators were used to assess performance quality with reference to four key areas: involvement of children and adults with intellectual disabilities and carers in service planning; meeting complex health needs; inpatient/hospital services; and planning services and partnership working. While this evaluation was broader than primary health service provision, it is interesting to note that open communication at all levels was identified as a critical element to quality health services for people with disability and complex health needs. Furthermore, Campbell suggested that where health services demonstrated a high level of commitment to meeting the needs of vulnerable population groups in general, they were typically more successful in delivering health services responsive to the needs of people with intellectual disability and complex health needs.

Also in Scotland, Curtice and Long (2002) reported on the development of a health monitoring tool, the health log, which was designed as a confidential, hand-held record of the health and health needs of people with complex communication difficulty. Following a 3-year pilot process the tool comprised 10 sections: client profile; diagnoses; history of hospitalisation; consultation checklist; report on consultation; current medications; past medication; immunisations; overview by manager; and other health related resources. Curtice and Long concluded that use of the log resulted in a more coordinated focus on a person's health assisting in both the residential and primary health environment.

Health indicators

It is commonly agreed that health disparities between those with and without intellectual disability have been firmly established through empirical research. However, there is a concern, that no evidence-based assessment tool has been developed which has the potential to: gather important health data; illustrate health inequity; and generate models that explain the cause of such inequities (Perry et al., 2010).

Health indicators are tools for gathering reliable, valid and comparable health data. Health indicators have been recognised as having the ability to contribute to an improved health status for people with an intellectual disability as they enable comparisons between populations or parts of the population (Noonan-Walsh, 2008). Despite their potential for measuring disparities few studies have explored health indicators in depth. Ouelette-Kuntze (2005) contended that health disparities for adults with an intellectual disability should be addressed through the development of explanatory models for health inequities. In recognition of the fact that these explanatory models or causal pathways will vary in relation to specific health outcomes, Ouelette-Kuntze advocated for an approach that would encompass particular health indicators, as well as consideration of modifiable variables such as lifestyle factors, behaviours, social networks and living conditions.

The Pomona Project (Noonan-Walsh, Hall, Ryan, & Pomona Partnership, 2008) involved European Union (EU) researchers who shared a commitment to addressing the paucity of empirical evidence in the area of health indicators and intellectual disabilities. This group had the aim of developing a *systemic research framework* that could facilitate greater understanding of the determinants of health for people with an intellectual disability in Europe. This was in recognition of the fact that previous research in the area of health and intellectual disability had not always been well planned and tended to report on studies that included only small numbers of adults with an intellectual disability who used formal services. Furthermore, studies that included a comparative sample of people from the general population were rare, limiting the potential for understanding the extent to which people who have an intellectual disability are disadvantaged in terms of their health status (Noonan-Walsh et al., 2008).

Supported by the European Commission, the Pomona Project (Noonan-Walsh et al., 2008) aimed to develop a set of health indicators for Europeans with an intellectual disability (Pomona I) and then to implement these indicators (Pomona II). The Pomona Health Indicator Set was designed to mirror health indicators that had previously been developed for the general EU population. The indicators were arranged under four categories: demographic characteristics; health status; health determinants; and health systems, and were typically included in general population health surveys.

The Pomona II Project was required to trial the efficacy of administering the Pomona Health Indicator Set and as a result was focused on the issues faced by partner countries that were involved. The P15 is the assessment tool trialled within the Pomona II Project (Perry et al., 2010) and is able to be administered directly with the person with an intellectual disability, or with someone who knows the individual well. The developers acknowledged the P15 is not a validated assessment instrument but is an *assessment battery which complements an indicator set* (Perry et al., 2010). The Pomona Project facilitated the development and trial of health indicators for people with intellectual disability and advocated for these to be included in national health interview surveys.

From a workforce development perspective, the Pomona Project had a focus on identifying all relevant training and education being conducted in partner countries. It was concluded that a national register of health and intellectual disability related training and education should be compiled, and that this should be open to all EU members. It was also recommended that a PhD programme in the area of intellectual disability and health should be developed as a strategy for developing capacity and expertise in this area.

Health checks for adults who have an intellectual disability

Although the efficacy of regular health checks for the general population has been challenged (Laine, 2002; Prochazka, 2005), the introduction of annual health checks has repeatedly been recognised by researchers and disability advocates as having the potential to transform the health status of people who have an intellectual disability (Kerr, Felce, & Felce, 2005; National Health Committee, 2003; Robertson, Roberts, Emerson, Turner, & Greig, 2011). A range of health assessment tools (health checks) have been developed for people who have an intellectual disability. The most commonly used of these tools include the Cardiff Health Check, (Baxter et al., 2006) the OK Health Check (Matthews & Hegarty, 1997) and the Comprehensive Health Assessment Programme (Lennox et al., 2007; Lennox, Green, Diggins, & Ugoni, 2001).

While individual health checks can be organised in different ways, the critical components of a comprehensive health check have been identified as including: family history and risk factors; immunisation record; health screening and health promotion; vision and hearing; chronic illnesses including epilepsy; physical examination including fitness, mobility and posture; review of mental health and emotional needs; syndrome specific check medication review; oral health; sexual health; drug and alcohol use; continence; behavioural disturbance; carer details and constraints; referrals made; and subsequent follow-up identified areas of risk and actions taken (Baxter et al., 2006; Lennox et al., 2007; Matthews & Hegarty, 1997).

The Comprehensive Health Assessment Programme (CHAP) appears to be one of the only intellectual disability health assessment tools that has been subject to controlled evaluation (Lennox et al., 2007). Lennox et al. conducted a cluster randomised controlled trial with matched pairs of adults who had intellectual disabilities. One member of the matched pair underwent a health check and was followed up one year later. The second member of the matched pair was subject to usual care only. This research confirmed the efficacy of the CHAP as contributing to increased health promotion and the detection of new disease. The CHAP includes the collection of historical medical data (which can be captured by a family member or support worker) before the second component of the tool is completed by a GP. The GP is expected to review the medical history before

conducting a targeted examination, and developing a health action plan. To assist GPs and other health professionals during the administration of the CHAP, information relating to health conditions known to affect people who have an intellectual disability along with a chart of co-morbidities that are syndrome specific are included in the programme. The randomised controlled trial confirmed that administration of the CHAP resulted in increased health promotion, disease prevention and the detection of new disease. For example, increases in immunisations, women's health screening, and the detection of vision impairment were all reported. Lennox et al. concluded that the CHAP instigated a significant lift in the level of attention that GPs paid to their patients with an intellectual disability.

Attention has been paid to how to implement health checks into health policy. More progress toward this goal has been made in the UK than in New Zealand. Wales now funds annual health checks for adults with an intellectual disability as part of a Direct Enhanced Service (DES) within primary health care services. England has also increased access to annual health checks also using a DES model within Primary Care Trusts and Strategic Health Authorities (Robertson et al., 2011).

Robertson and colleagues recently conducted a systematic review of evidence relating to health checks for people who have an intellectual disability (Robertson et al., 2011). In this review Robertson et al. identified only three studies which had implemented a randomised controlled trial design, and that the majority of studies reported on results generated through a single administration of a health check.

While support for health checks is strong, it is recognised that they represent only the first step in identifying and meeting the health needs of adults who have an intellectual disability. Researchers have highlighted a number of priorities that will ensure the potential benefit of annual health checks are realised (Cobb, Giraud-Saunders, & Kerr, 2008). At an individual level, health issues identified through annual checks need to be acted on, and an appropriate plan for follow-up needs to be agreed. At a collective level, health check data should be used to inform the development and delivery of primary health care services. Critical to this second point is the need to specifically identify people who have an intellectual disability within the population of people who use primary health services. This has not been common practice and has resulted in people with an intellectual disability being a hidden population within primary health services (Cobb et al., 2008). New Zealand research has been compromised by this same issue.

As previously mentioned, the majority of research about the implementation and impact of health checks has been conducted in the UK. Annual health checks have been part of national health policy in Wales since 2006 (Cobb et al., 2008) and an evaluation of the implementation programme has occurred. Baxter et al. (2006), for example sought to explore the impact of the Cardiff Health Check within primary care in the UK, and were specifically concerned with identifying: the disability characteristics of the people with an intellectual disability using primary care; the nature of newly discovered disease; and the extent to which newly discovered disease is actively responded to (Baxter et al., 2006). Complete health checks were conducted with 181 adults who had an intellectual disability. Of this group of study participants, 51 per cent had new health needs recognised. Furthermore, 17 per cent of those with newly identified health needs were diagnosed with conditions that were classified as serious (for example, breast cancer, suspected dementia, asthma, post-menstrual bleeding, diabetes,

hypothyroidism, high blood pressure, and haematuria). While efforts related to condition management had been instigated for 90 per cent of the identified new health needs and concluded for 61 per cent of health needs, this process was ongoing for 39 per cent of participants. While a small number of patients or their carers had refused treatment, it was most common for treatment delays to have occurred due to scheduling difficulties or other factors. Baxter et al. (2006) also commented on the fact 49 per cent of sampled individuals had new health needs that were less serious in nature (for example, vision and hearing difficulties) but still had the potential to impact significantly on people who may have already experienced social and communicative difficulties.

In order to address the question about the benefit of repeated health checks, and optimal spacing of health checks, Felce et al. conducted a study whereby adults who had participated in an initial health check had a repeat check at differing intervals. Thirty-nine individuals had a repeat check an average of 28 months later, 36 individuals had a repeat check an average of 44 months later, and 33 individuals received no further health check. Most of the participants resided in staffed community-based group homes rather than their family home or independent living. The repeat health checks resulted in at least one new need per person being identified, a figure that matched that of the initial administration of the health check. Felce et al. (2008) contended the results of this research provided justification for the Welsh Assembly Government's 2006 decision to fund annual health checks for adults with intellectual disability.

Further investigation relating to the impact of health checks has been undertaken by Felce and colleagues (2008). In order to ascertain whether health checking led to increased interaction with GPs or other primary health professionals, and/or an increase in health promotion related activities, medical records relating to 77 adults with an intellectual disability were analysed for eight six-month periods before and seven six-month periods following their health check. Analysis showed no significant differences in the number of primary care or specialist interactions a person had following their health check. In contrast, health promotion related activity was found to have increased following their health check. Felce and colleagues considered that results indicated a need for future research to further explore the extent to which increased health promotion activity amongst adults with an intellectual disability impacts on health.

Health checks in the New Zealand context

While the sector as a whole has promoted the need for a policy of offering annual health checks for adults who have an intellectual disability, little progress has been made toward this goal in New Zealand. A number of intellectual disability service providers have implemented health checks, although predominantly with residential service users using a variety of assessment tools. There is only one New Zealand study that has explored the use of health checks. The Cardiff Health Check was implemented by IHC New Zealand in the late 1990s. Webb and Rogers (1999) analysed data relating to 1311 adults with an intellectual disability and found that 73 per cent of those screened required some form of follow-up health action.

The structured nature of, and educational components inherent to, formal health checks have the potential to ensure the health needs of people with an intellectual disability are recognised and responded to within primary health contexts (Baxter et al., 2006). Canadian researcher Ouellette-Kuntz (2005), while positive about the potential benefits of widespread uptake of health checks, cautioned that further research is required to fully

realise such potential. In particular, research that is focused on identifying the reasons that impede or enhance the likelihood that primary care physicians (GPs) would utilise a formal health check tool with patients who have an intellectual disability is required. In the absence of such research Ouellette-Kuntz speculated that GPs may be impacted by a range of issues including: lack of time; inadequate reimbursement; inadequate training; discomfort raising sensitive issues; or poor communication skills when considering whether to use a formal health check with patients who have an intellectual disability.

The United Nations Convention on the Rights of Person's with Disabilities

Article 25 of the United Nations *Convention on the Rights of Person's with Disabilities* acknowledges that people with disabilities have the right to the “*highest attainable standard of health*” and that health services are accessible, responsive to issues of gender, community based and free (UN General Assembly, 2009).

The Convention has been used as a framework for promoting the health of disabled people. A recent article by Brehmer-Rinderer et al. (2013) considered the extent of progress and achievement made by Spain and Hungary⁵ related to the implementation of the Convention with specific reference to the health of people with intellectual disabilities. After analysing the reports of both countries Brehmer-Rinderer et al. contended the information contained in the formal state reports did not adhere to the reporting requirements contained within the Convention. Of particular concern was the fact that many important health related issues were ignored, for example, the fact that access to health does not simply refer to physical access and availability of services, but also to the expectations and needs of disabled people, and the proficiency of health professionals to work with them. Brehmer- Rinderer et al. concluded that for the Convention to achieve its intended impact, involved governments need to ensure disability policies and politics are in alignment with the document and to develop targeted action plans related to specific Convention articles.

New Zealand became a signatory to the United Nations Convention in 2007. New Zealand's involvement was ratified in 2008. As a state party, and in accordance with Article 35 of the Convention, New Zealand is required to report on actions taken to meet its obligations under the Convention.

In keeping with the requirements of being a state party to the United Nations *Convention on the Rights of Person's with Disabilities*, the New Zealand Government has funded the Convention Coalition Monitoring Group⁶ to undertake regular monitoring in order to generate information that can be used to develop disability policy that is informed by persons with disabilities themselves. The monitoring report, *Disability Rights in Aotearoa New Zealand 2012: A Report on the Human Rights of Disabled People in Aotearoa New Zealand*, contained a focus on health as one of the six key areas chosen for monitoring and consultation in 2012. The Convention Coalition Monitoring Group commented on the extent to which New Zealand had met its obligations to the Convention with particular reference to Article 25. Perhaps most importantly the monitoring

⁵ Spain and Hungary were the first European Union countries to submit a United Nations Convention report.

⁶ The Convention Coalition Monitoring Group is a national group made up of eight individual Disabled People's Organisations. The Convention Coalition used the Disability Rights Promotion International guidelines as a framework for the monitoring process. The New Zealand Convention Coalition also chose to undertake some additional consultation-based activities in order to gain feedback from disabled people. These activities included fora, fono and hui in five different locations, an open submission process, and an online survey.

group reported unequivocally that at the present time New Zealand law and policy does *not* ensure that persons with disabilities experience a very high standard of health, and are not discriminated upon with regard to this access on the basis of disability. The report also noted a great deal of inconsistency in how individual District Health Boards respond to disability issues within their specific jurisdictions.

The monitoring process highlighted that disabled people in New Zealand experience differences in the *range, quality and standard of free or affordable health care* according to where they live. This contravenes Article 25. Furthermore the 2012 Budget included increases in prescription charges and the removal of access to specific pharmaceutical and alternative treatment options utilised by some disabled people. The monitoring report also acknowledged the lack of progress toward addressing the poor health status of people with an intellectual disability identified through the National Health Committee's work on *To Have an Ordinary Life*. This lack of progress was despite the fact that a range of strategies have been recommended as having the potential to create significant positive change for this group of disabled New Zealanders. One of the key recommendations was the need for the introduction of a government funded health assessment programme for people with an intellectual disability. The monitoring report, which was prepared nine years following *To Have an Ordinary Life*, specifically noted that this had yet to occur. However, disability services themselves had implemented such programmes for their service users at considerable cost. Finally, the monitoring report also drew on the findings contained within the *Health Indicators for New Zealanders with an Intellectual Disability* report published by the Ministry of Health to evidence that people with an intellectual disability continue to experience poorer health status than their non-disabled peers. Specific recommendations related to Article 25 contained within this report were:

That the Ministry of Health, in partnership with the Association of Blind Citizens of New Zealand, investigate the production of all health related brochures and medication labels using the European Blind Unions standards for accessibility. Further, that People First be consulted for advice and information about how to produce these in Easy Read formats.

That the Ministry of Health convenes an Intellectual Disability Health Care Task Force, to prepare a national plan of action to implement the recommendations of the "To Have an Ordinary Life" and "Health Indicators for People with Intellectual Disabilities" reports. Any plan to be backed up by a set of national best practice guidelines. These plans are to be developed in full partnership with people with learning/intellectual impairments.

That the Minister of Health direct District Health Boards, under the Public Health and Disability Act, to prepare and implement annual... [United Nations *Convention on the Rights of Person's with Disabilities*] plans, working in collaboration with Disabled Peoples Organisations. The Ministry of Health (in partnership with Disabled Peoples' Organisations) to monitor these plans to ensure consistency in the way that disability issues and disabled people themselves are treated by District Health Boards and all publically funded and/or contracted health services around the country.

That both the... [Convention] and Intellectual Disability Health Plans incorporate achievable targets for improving physical and other service access, collation of appropriate health and disability statistics/data and enhanced training of ALL medical and other allied health service staff throughout the country in disability awareness.

That the New Zealand Government remove all cost barriers to disabled and other low income people accessing prescription medications. (Convention Coalition Monitoring Group, 2012, p. 83-84)

Strategies to increase the capacity and responsiveness of the health and disability workforce

A significant proportion of primary health and disability research highlights the education and training needs of health professionals. Many of the potential strategies for reducing health inequalities outlined earlier in this report made repeated and strong mention of this fact. A smaller literature has detailed specific strategies to increase the capacity and responsiveness of the health and disability workforce and these are summarised here.

Krahn, Hammond and Turner (2006) developed a comprehensive list of recommendations for future actions that have the potential to decrease the level of disparity experienced by people who have an intellectual disability. The four key recommendations were to: promote principles of early identification, inclusion and self-determination for people who have an intellectual disability in quality health care; reduce the occurrence and impact of associated, comorbid, and secondary conditions amongst people in this group; empower caregivers and family members to meet the health needs of people in their care; and promote healthy behaviours.

As mentioned earlier in this review, Australian researchers Ziviani et al. (2004) proposed a framework for guiding primary health encounters which they titled *Model of Cooperation – Meeting in the Middle*. Consistent with other work that has considered this topic, Ziviani et al. highlighted the need for collaboration between GPs and their patients (and their supporters) and considered that: awareness and training; improving access to health services; preparation for consultation; appropriate sharing of information during consultation, treatment and follow up were the key components of successful primary health consultations.

It has been common for the primary health literature to identify the important role that both informal (Parish et al., 2008) and formal carers (Conder et al., 2007) can play in ensuring that adults who have an intellectual disability have their primary health needs met. In a Scottish study, Melville et al. (2009) explored carer knowledge and perceptions of healthy lifestyles relating to adults who have an intellectual disability in order to more clearly determine the training needs of carers. As one component of a wider study on diet and exercise for people with an intellectual disability, Melville et al. sought to explore (paid) carer knowledge and beliefs on this topic, and specifically to ascertain whether carers are: aware of existing public health recommendations relating to diet and activity in general; recognise the benefits of a healthy diet and physical activity for people who have an intellectual disability; and can identify the barriers for this group in relation to achieving a healthy diet and regular exercise. Sixty-three paid carers completed a questionnaire based on those used in large national studies such as the NHS Health Scotland Survey (Melville et al., 2009; NHS Health Scotland, 2004).

In relation to carer knowledge of dietary recommendations Melville et al. (2009) assessed paid carers as having a poor level of knowledge about diet, apart from the recommendation of five servings of fruit or vegetables per day. Similarly, carers also showed a lack of knowledge about the recommended frequency, duration and intensity of physical activity. With regard to understanding the health benefits associated with healthy eating and regular exercise, paid carers were found to perceive a healthy diet as having a greater importance on a person's health than physical activity. Furthermore, paid carers did not appear to attribute much importance to improved self image as a potential benefit of healthy eating and exercise. Paid carer perceptions of barriers to achieving a healthy lifestyle were also interesting as they were found to focus on intrapersonal factors such as motivation, knowledge and skills rather than external barriers like finance or transport. Melville et al. concluded that tailored training for paid carers should be pursued. Such training would enable carers to be fully briefed on: public health recommendations in the area of healthy eating and exercise; the benefits of healthy lifestyles (including improvements in quality of life and self-image); and identifying and overcoming barriers to changing lifestyle and health behaviours. In acknowledgement of the fact that the intellectual disability workforce can have high turnover, Melville and colleagues suggested that this training should be provided during the induction of new support staff.

Summary

It was difficult to locate evaluated strategies for increasing access to primary care. One factor that contributes to this situation is the absence of an evidence-based assessment tool for gathering health data, illustrating health inequality, and generating models that may explain the cause of such inequalities. Health indicators have been identified as having the potential to play an important role in efforts to improve the health status of people who have an intellectual disability as they facilitate the comparison between populations or parts of populations. Annual health checks have been widely promoted within the field of intellectual disability as having the potential to transform the health status of this vulnerable population. Research that has focused on the efficacy of the health checks has confirmed that health checks can result in increased health promotion, the detection of new disease, and an increase in the level of attention GPs pay to their patients who have an intellectual disability. The United Nations *Convention on the Rights of Person's with Disabilities* has also been used as a framework for promoting the health of disabled people. Article 25 of the Convention states that people with disabilities have the right to the "highest attainable standard of health." Countries who are signatories to the Convention have an obligation to ensure this right is upheld by aligning disability policies and developing targeted action plans. Monitoring of Article 25 in the New Zealand context resulted in a range of specific recommendations that are viewed as having the potential to transform the health of disabled people. The literature relating to primary health and intellectual disability has also highlighted the need for greater education and training for both those in the primary health and disability sectors. Increased education and awareness can serve to reduce the health inequalities faced by people who have an intellectual disability. It has been recognised that primary health professionals are often inexperienced and ill-informed about disability and require education that promotes the principles and importance of inclusion and self-determination for people who have an intellectual disability in achieving quality health care. The important role that families and formal support workers frequently play in linking the people they support with primary health services and professionals has also been recognised, leading to the assertion that opportunities for them to increase their health related knowledge is also an important component of improved primary care.

Primary health and sensory impairment

This section of the review considers primary health in relation to adults who are blind or vision impaired, and Deaf persons. Estimates indicate there are over 70,000 people in New Zealand who experience sight loss (Statistics New Zealand, 2007), and about 9,000 Deaf people.⁷

Primary health and adults who are blind or vision impaired

There is a scarcity of literature addressing the barriers faced by people with blindness and vision impairment in accessing primary health care. However, there appears to be an interest in addressing, amongst other issues, disparities in health for people with blindness and low vision. The following studies are representative of the scope and variety of research being conducted in this area of the disability sector, most of which have originated from the US.

The National Centre for Chronic Disease (CDC) Prevention and Health Promotion released a report entitled *The State of Vision, Aging and Public Health in America* (2011). Data were collected during 2006-8 across 19 states that used the Vision Impairment and Access to Eye Care Module of CDC's Behavioral Risk Factor Surveillance System. This report outlined the prevalence of vision loss and eye diseases reported by people over the age of 65, and discussed these people's access to eye care, their health status, and co-morbid conditions. Key findings of the study included differences in the prevalence of moderate or extreme vision according to factors such as physical location, ethnicity, education level, health status and medical conditions.

Barriers to primary care for people who are blind or vision impaired

Using data from the Medical Expenditure Panel Survey (2002-4) Spencer, Frick, Gower, Kempen and Wolff (2009) examined the relationship between blindness and vision impairment in relation to accessing medical care. The authors argued that those with blindness and vision impairment have more access problems relating to a range of factors. These factors included the cost of care, availability of insurance coverage, transportation issues, and, in some cases, refusal of services by health providers. Interestingly, the same individuals did not report lower rates of health care in comparison to those without vision impairment. The authors concluded that access to health care for these individuals was problematic; however, these issues were also amenable to policy interventions.

In response to findings such as those above, recent research has sought to develop health risk profiles as a means of predicting health outcomes as a result of identified barriers to primary care for people with blindness. For example, Jones, Crews, and Danielson (2010) used the International Classification of Functioning, Disability and Health Framework as a conceptual framework to develop a health risk profile for adults aged 65 years or older with blindness. Results of their research showed that older adults with blindness were more likely to be poorer

⁷ See <http://www.deaf.co.nz/nz-sign-language/about-sign-language/interesting-facts>

and less educated than older adults without vision loss. This put them at greater risk for socially determined health inequalities that had the potential to reduce their quality of life. The authors concluded that disability-sensitive interventions were needed in order to address serious psychological distress and physical inactivity for those affected by such barriers to their primary health care.

Potential strategies to increase access to primary care for people who are blind or vision impaired

Potential strategies to increase access to primary health care for individuals with blindness have focused on increasing awareness of and knowledge about the barriers faced by people who are blind or visually impaired. Crews, Kirchner and Lollar (2006) introduced a Special Supplement of the *Journal of Visual Impairment & Blindness*, a publication which attempted to bridge the fields of vision rehabilitation and public health. Its aim was twofold: to encourage those in the vision rehabilitation field to collaborate with those in public health to improve health care for those with vision impairment, and to persuade those in public health to be more inclusive of disabilities in their programmes and services. The articles in this Special Supplement promoted the intersection of public health and rehabilitation to improve the lives of people with vision loss.

In a similar vein, and with a related focus on educating health professionals, McKenzie and Henzi (2010) conducted a pilot study to investigate medical students' knowledge of visual impairments, including their overall comfort with, and knowledge of, examining the eye and understanding of ocular conditions, their ability to work with those with visual impairments, and knowledge of educational and rehabilitation services for people with visual impairments. The results of this study indicated a need to increase the time spent learning about eye pathology, and understanding of individuals with visual impairments and the educational and rehabilitation services to which they could be referred. The authors also identified a need for greatly increased collaboration with medical schools regarding information about visual impairment.

Summary

There is increasing research interest in health inequalities for people who are blind or visually impaired. Similar to physically disabled people, those who are blind or visually impaired have been reported as experiencing reduced access to primary health care for reasons related to the cost of care, and to physical and attitudinal barriers that operate at the practice level. It has also been highlighted that older adults who are blind or visually impaired are likely to be poorer and less educated than their peers without vision loss, and more likely to experience health inequalities that have the potential to impact their quality of life. It has been suggested that there is a need for the fields of vision rehabilitation and primary health to collaborate to achieve more inclusive services, and for medical training to include a stronger focus on visual impairment.

Primary health and Deaf persons

Few studies over the past decade have examined the health needs and expectations of Deaf persons who use sign language. Of the work that has been done in this area, Steinberg, Barnett, Meador, Wiggins and Zazove (2005) argued that Deaf people use health care services differently to other people, and little research has explored the

reasons why. By conducting focus groups and applying qualitative analysis, the authors sought to better understand the health care experiences of Deaf people who use American Sign Language (ASL). They found that communication difficulties for Deaf people were pervasive, with resultant feelings of fear, mistrust and frustration. Positive responses were attributed to practitioners with medical experience and certified interpreters, health care practitioners with sign language skills, and practitioners who made an effort to improve communication. Many of the study's participants were fully aware of their legal rights, and some believed that health care practitioners should learn about the socio-cultural aspects of Deafness. The authors concluded that further research was needed to explore the perspective of clinicians working with Deaf people, and ways in which communication may be improved, and to measure the impact of programs that aim to educate Deaf people about self-advocacy skills and their legal rights.

In a similar vein, Jones, Renger and Firestone (2005) argued that Deaf persons' access to health-related information is limited by barriers to spoken and written language. Despite this, no published reports of community analysis focusing on health education priorities for Deaf communities exist. In response to concerns about vulnerability to cardiovascular disease, the authors conducted a seven-step community analysis to learn the health education priorities in Arizona Deaf communities and to inform the development of culturally relevant health education interventions in Deaf communities. Following the community analysis, a heart-health education intervention, the Deaf Heart Health Intervention (DHHI) was developed.

Another area in which more research needs to be conducted is related to the quality of life of Deaf persons. In their article, Fellingner et al. (2005) suggested that it is difficult to structurally assess the quality of life and mental distress in Deaf people. They described the development and reliability of an interactive computer-based assessment package for measuring quality of life and psychological distress in the Deaf population. Tested on 236 Deaf persons, the article concluded that for those who are sign language users, quality of life and mental distress can be effectively and reliably assessed with the use of translated and adapted common instruments.

A more recent report by Nilsson, Turner, Sheikh and Dean (2013) outlined a EU project focused on enhancing the language skills of Deaf people, interpreters and health care professionals. The report authors reviewed current knowledge of policy and practice, and embedded their resulting analysis into programmes for reflection, knowledge and skills development. The findings were reported as follows: 1) sign languages are now widely recognised; 2) sign language interpreters should mediate between hearing and Deaf people; 3) communication is best facilitated with recognition of the interpreter as a linguistic partner and active participant in the joint creation of meaning; 4) there exists a wide variation in partner countries in terms of their recognition of health care interpreting for Deaf people; 5) there is non-existent or insufficient training and associated resources for interpreters, health care staff and Deaf people; and 6) it was recommended that members of all key groups become familiar with a common set of assumptions and practices so as to operate to maximise positive outcomes.

Health inequalities experienced by Deaf persons

There is a small body of literature (Barnett, Klein, et al., 2011; Barnett, McKee, Smith, & Pearson, 2011) that has focused on the health inequalities of Deaf persons who use ASL. Barnett et al. (Barnett, Klein, et al., 2011) argued that users of ASL are medically underserved and often excluded from health research. Using a community participatory approach to develop and administer an ASL-accessible health survey, the authors identified Deaf community strengths, such as low prevalence of smoking, and three health inequalities: obesity, partner violence and suicide. This work represents the first time a Deaf community has utilised its own data to identify priorities in health.

A larger and more inclusive review by Barnett et al. (2011) acknowledged that at the time of writing, 20 years had passed since the Americans with Disabilities Act of 1990, and there were ongoing health care inequalities still unaddressed. In addition, the full effect of these inequities remained largely un-researched. This article described four issues that underlie health inequities experienced by Deaf sign language users: data on the health of Deaf persons was lacking; many had low health literacy; barriers existed that limited health care for Deaf sign language users, and Deaf persons may have a biologic basis for some health differences. The authors proposed six public health approaches to address these health care inequities. These included: public health entities needing to work together with Deaf sign language users to address inequities in health information access; Deaf persons being included in health research; surveys collecting Deaf-related information; Deaf sign language users should be supported to participate in public health; Deaf sign language users being encouraged to pursue careers in public health, health research and health care; and advocacy for funding to support communication access costs for public health programs and research.

Summary

It has been argued that Deaf people use health care services differently to other people, and that it is important to understand why. Research that has explored this issue has exposed the impact of communication difficulties experienced by Deaf people, asserting that inappropriate or unresponsive communication exchanges lead to feelings of fear, mistrust and frustration. Within the health care context, Deaf people have identified that positive communication with health professionals is dependent on certified interpreters being available and health professionals themselves being familiar with sign language. It has also been recognised that there is significant value in health professionals receiving education about the socio-cultural aspects of Deafness. Research that has specifically explored health inequalities experienced by Deaf persons has identified several factors as contributing to such inequalities: a lack of data relating to the health of this group; low health literacy; and limited access to health care as a result of communication barriers.

Barriers to primary care for Deaf persons

Iezzoni, O'Day, Killeen and Harker (2004) argued that effective communication between physician and patients is necessary in order to achieve patient-centred care, and that those who are Deaf or hard of hearing face considerable barriers to this communication. The authors aimed to understand perceptions of health care experiences and suggestions for improving care among Deaf and hard of hearing individuals. They collected data from group interviews conducted in ASL and Communication Access Realtime Translation, and identified

the following as broad themes: conflicting views between physicians and patients about being Deaf or hard of hearing; different perceptions about what constitutes effective communication; medication safety and other risks posed by inadequate communication; communication problems during physical examinations and procedures; difficulties interacting with office staff; and problems with telephone communication. Patients' suggestions included clinicians asking patients about their preferred communication approach and having patients repeat critical health information so as to identify potentially dangerous miscommunication. The study concluded that as the population ages, physicians will encounter many more people with hearing difficulties and while physicians were not subsidised in America for providing language interpreters, ensuring effective communication was essential to safe patient-centred care.

Meador and Zazove (2005) also argued that those who are Deaf or hard of hearing have altered health care utilization patterns and significant communication difficulties with physicians, often resulting in misunderstandings about their disease or treatment recommendations. It was suggested that physicians be aware that Deaf persons probably have low reading levels and their writing is usually non-standard English. The authors discussed five particular barriers common to the Deaf and hard of hearing communities: linguistic accommodations; lack of trust of the 'hearing world'; the need for confidentiality; respect for intelligence; and dissemination of information. They concluded that physicians have a moral and ethical obligation to conduct further research on how best to improve communication between physicians and patients.

Woodcock and Pole (2007) profiled the health of Deaf and hard of hearing Canadians. Using a cross-sectional survey conducted by Statistics Canada, the study examined health care utilisation, several commonly accepted health outcomes, engagement in health promotion activities, and perceptions of overall health. The authors concluded that Deafness – both the disability and the culture – creates barriers to health communication. They argued that health practitioners needed to consider the communication needs of Deaf and hard of hearing individuals.

Scheier (2009) outlined a (largely American) literature exploring the barriers Deaf people face when trying to access health care. Communication was identified as a major barrier to health care for individuals with hearing loss. This was compounded by the fact that although they were legally bound to, health care providers did not always use interpreters. Further, interpreters may not have been certified. Other barriers included health care workers' lack of sensitivity toward people with hearing loss because of preconceived notions and marginalisation of the Deaf. Scheier also noted that health care professionals were not cognisant of Deaf culture and values and therefore did not understand Deaf behaviours. In addition, health care workers may discount or be unaware of the extreme impact of hearing loss on a Deaf person's ability to communicate, learn and care for one-self. Scheier also noted a dearth of English language proficiency among Deaf, and the presence of animosity between hard of hearing and Deaf people.

Scheier discussed reasons why these barriers were encountered and the difficulties that were met as a result of these barriers. This included a lack of understanding amongst Deaf persons of their diagnosis and medication directions, and a general distrust of the health care system. Scheier noted that many Deaf people have not had access to safe sex education, and as a result, had higher rates of Human Immunodeficiency Virus (HIV), sexually

transmitted infections, and alcohol and substance abuse. An inability to communicate in a hearing world can also lead to higher rates of mental illness, low self-esteem, and health care knowledge gaps. In addition, it can be very difficult for Deaf people to read English.

Scheier addressed a misunderstanding between Deaf people and their hearing health professionals, as well as issues relating to medical interpreters, and the ways that those working with Deaf people might overcome these barriers. For example, there exists the potential for miscommunication because ASL word order is not the same as English word order. Another potential for miscommunication may occur in terms of facial expression: for example, Deaf people consider it rude to drop eye contact with a Deaf person.

Scheier's research aimed to increase health professionals' awareness of the needs of Deaf people and the cultural differences that must be taken into account when working with them. For example, many Deaf people may not want family members to interpret when discussing personal information. In addition, health care professionals need to be aware of lip-reading needs: for example, moustaches, accents and surgical masks make lip reading difficult/impossible in a clinical setting.

Scheier described other special considerations that should be taken into account by health care professionals. For example, it should not be assumed that a patient understands medical terms. Furthermore, fear that they may not be understood is a significant emotion for many Deaf people and one that impacts on their willingness to visit a physician. Despite these known barriers, many health care providers are unaware of ways to improve communication. Economic issues also play a part. It costs more to spend time to treat and teach Deaf patients and to hire qualified interpreters to assist with these tasks.

Scheier suggested a range of strategies for improving communication. These included: the introduction of new technology (telemedicine, pagers or vibrating devices); modifications (for example, access to communication devices, qualified interpreters, and increased privacy); and more research to find ways to educate the pre-lingually Deaf and give them better access to better health education. The authors also called for research into methods of educating health care providers in the needs and legal rights of Deaf patients (that is, they are legally obligated to provide interpreters). This may involve knowledge of appropriate protocol for Deaf persons such as *not* putting intravenous lines into hands. Glickman and Gulati (2003) recommended a culturally affirmative approach to mental health care for Deaf people, for example, avoiding the use of idioms that have no exact translation in ASL, and hiring Deaf staff members.

Pereira and Fortes (2010) analysed the perceptions of 25 sign language-using patients to recent changes in Brazilian private and public health systems to make special services available to Deaf patients. The authors reported communication difficulties between these patients and health services staff, as well as an inability among the service providers to distinguish among the roles of companions, caretakers and professional translator/interpreters. This resulted in prejudice during treatment and information exchange, damage to autonomy, limits on access to health care service, and reduced efficacy of therapy. Pereira and Fortes were of the view that these barriers need to be addressed in order for health inequalities for Deaf sign language user patients to be reduced.

Kritzinger (2011) identified the following as barriers to health care services and information in South Africa: limited access to English communication; misunderstanding of medical terminology; irregular contact with health care professionals of the same language and cultural background; and the need to overcome challenges experienced by using others as interpreters in a health care setting. Deaf people cannot overhear conversations, have limited access to mass media and present with low literacy rates. Kritzinger explored barriers and facilitators to accessing health care services and health care information for Deaf people. Participants reported communication and socio-economic factors as barriers to accessing health care services. The main barrier to accessing health care information was considered to be the inaccessibility of the mass media.

Drawing from a case study of a 28-year old Deaf woman in Cape Town, Haricharan, Heap, Coomans and London (2013) explored what the 'right to health' means for signing Deaf South Africans who are unable to communicate with health care professionals in a language they understand. The authors identified the following barriers to equitable and effective health care for this population: misdiagnosis, incorrect/delayed treatment, lack of proper treatment, and not being given standard care. A number of rights may be violated as a result of these barriers including the right to health; information; to participate in decisions; to give informed consent; confidentiality; and to be treated with dignity and respect. The authors recommended that sign language via professional interpreter services is essential to their South African constitutional right of access to health care.

Summary

Research has identified a number of barriers affecting those who are Deaf or hard of hearing in accessing primary care. The most prevalent concern is that of compromised communication between Deaf persons and health care professionals, which has manifested in several ways that significantly impact on the quality of primary care experienced by Deaf and hard of hearing communities. These difficulties in communication between health care professionals and Deaf and hard of hearing include: conflicting views about being Deaf or hard of hearing; attitudes towards Deaf persons by health care professionals and an unmet need for confidentiality and respect for intelligence for Deaf and hard of hearing persons; a lack of trust in the 'hearing world' on the part of some Deaf persons; a lack of interpreting services available; and a lack of knowledge on the part of health care professionals on the communication needs and protocols of Deaf persons and those who are hard of hearing.

Other significant barriers to more accessible health care for Deaf persons and those who are hard of hearing have been identified as socio-economic factors; the inaccessibility of the mass media to access information about health promotion and education; low literacy rates; and the resultant potential for misdiagnosis and reduced efficacy of therapy. To an extent, these barriers are experienced more generally for people with disabilities who are marginalised from mainstream culture and therefore have limited access to information promoting health and wellbeing.

Potential strategies to increase access to primary care for Deaf persons

There is a dearth of literature that focuses on evaluating potential strategies to increase Deaf persons' access to primary care. In one of the few studies sourced for this literature review, Folkins et al. (2005) argued that in order to address the barriers to health care access that Deaf community members face, educational programs must be designed in the appropriate format and language to meet their needs. These authors surveyed Deaf men before and after viewing a cancer video in ASL with open text captioning and voice overlay. These participants showed significant increases in cancer understanding, and the effects remained significant at a follow up two months later. It was discovered, however, that for maximum effect, only one topic rather than two or more should be covered in future educational videos.

Evaluated strategies for increasing access to primary care for Deaf persons

A number of strategies have been developed to address the health disparities and barriers to primary care for Deaf persons. Margello-Anast et al.'s (2005) study identified limited information on how communication barriers impact on the health status of Deaf persons. The authors described the development of a standardised interview tool to collect health-related information from Deaf adults via face-to-face interviews in ASL. This proved to be an effective and well-accepted means of collecting health related information from a diverse sample of Deaf individuals. The authors argued that the use of interviewers who were native signers and members of the local Deaf community, as well as the rapport that each health care system had with its Deaf patients, likely contributed to the survey's success.

The aim of Jones et al.'s (2007) study was to test the effectiveness of the Deaf Heart Health Intervention (DHHI) in increasing self-efficacy for health-related behaviours among culturally Deaf adults – in this case, identifying risk factors for cardiovascular disease. The authors tested 84 participants using the sign language version of the Self-Rated Abilities Scale for Health Practices, and the results supported the development of interventions tailored for Deaf adults so as to increase their self-efficacy for health behaviours.

In one of the few studies in this area of research that focuses specifically on issues particular to women's health, Choe et al. (2009) identified barriers that Deaf women face when accessing information about cancer. The authors conducted a blind, randomised trial to evaluate the knowledge gain and retention of Deaf women who viewed a graphically enriched, ASL cervical cancer education video. The results of their trial showed that after only one viewing, the experimental group gained and retained significantly more cancer knowledge than the control group. The article concluded that showing Deaf women the ASL cancer education video⁸ significantly increased their knowledge of cervical cancer.

⁸ See <http://cancer.ucsd.edu/deafinfo>

Iezzoni et al. (2003) argued that people with physical and sensory disabilities face particular challenges in accessing high-quality health care. However, they noted that little systematic information exists that documents how people with specific disabilities perceive their care. The authors identified persons with disabling conditions by using a 1996 nationally representative survey of 16403 community-dwelling elderly and disabled Medicare beneficiaries. They found that most people were satisfied with their care and were equally as likely as those without disabilities to perceive their physicians as competent and well-trained. However, those with disabilities were significantly more likely to report other problems, commenting that physicians were hurried, had incomplete understandings of medical histories, a lack of thoroughness and inadequate levels of communication. The authors contended that thoughtful systematic approaches are necessary to improve accommodations for communicating with blind and Deaf persons, and to reduce the time demands and physical efforts of people with impaired mobility.

Summary

Research aimed at evaluating strategies to increase access to primary care for Deaf and hard of hearing persons has focused on improving communication between Deaf and hard of hearing persons and health care professionals. Communication tools that have been evaluated include a standardised interview tool to gather information from Deaf persons who use ASL sign language and a graphically enriched ASL health education video about cervical cancer. This research demonstrated that tools developed to more effectively gather health-related information from Deaf and hard of hearing persons are well accepted and result in better uptake of health information. Other research included testing the efficacy of a Deaf Heart Health Intervention, the results of which supported the use of interventions tailored specifically for Deaf adults. Findings from a range of research suggested that systematic approaches to improving communication between physicals and people who have sensory impairments are necessary in order to provide more effective primary care.

Primary health and vulnerable populations

Disabled Māori

Research relating to disabled Māori and primary health is extremely limited. Higgins, Phillips, Cowan, Wakefield and Tikao (2010) explored how the impairment of blindness affects Māori and how health and education services impact on their identity cultural well-being and health. Drawing from a number of case studies and interview data the authors argued that kāpo Māori are ‘othered’ when there is “little account taken of their culture or impairment when encountering health and education services” (p. 246). That is, insufficient acknowledgement of the influences of culture or impairment leads to marginalisation of disabled Māori.

The report noted that across the health sector Māori health outcomes have historically been poor. Research to date has indicated that Māori are less likely to access health services and when they do, their outcomes are more likely to be poorer than for Pākehā (Ellison-Loschmann & Pearce, 2006). It also confirmed previous findings that fewer kāpo Māori access services, were less likely to have a diagnosis or be assessed for vision loss, and have treatment for their condition. Furthermore, there was a lack of services that were culturally relevant and appropriate for Māori. The report made the following recommendations: that health and education services become more culturally consonant; that vision health and education services be available; that Māori health and education professionals be supported and encouraged to enter the field of disability; and that non-Māori professionals be committed to supporting the principles of the Treaty, to become more culturally aware. More generally, services that meet whānau needs should be readily available.

According to the Ministry of Health’s 2012 *Whāia Te Ao Mārama: The Māori Disability Action Plan* (Ministry of Health, 2012b), one in five Māori live with a disability. Developed by Māori disabled people, their whānau, and disability support workers, the aim of this plan was to establish priority areas of high-level action and to reduce barriers that may impede Māori disabled people and their whānau from gaining better outcomes. The plan identified four core elements as necessary for supports to be effective for Māori: te ao Māori (a person’s ability to participate in their own whānau, hapu and iwi); te ao hurihuri (services and the political, economic, social and environmental trends that support influence and affect disabled Māori); te rangatira (Māori disabled as individuals living life and having the whakamana to take up their various roles); and tuhonohono (the personal milestones and relationships that Māori disabled have with their whānau, hapu, iwi and caregivers, who are in turn supported through disability support services or other agencies). The four priorities were as follows: improved outcomes for Māori disabled; better support for whānau; good partnerships with Māori; and responsive disability services for Māori.

Autism spectrum disorder

In outlining the needs of people with autism spectrum disorder, Hardy & Holt (2007) presented a number of ideas to support people in primary care. These suggestions included: finding out the person’s communication abilities before meeting; providing information about the service in order to alleviate anxiety; booking early appointments so as to avoid anxiety and crowded waiting rooms; booking double appointments to allow

adequate time for communicating information; supporting abstract information with visuals; avoiding the use of negative words; using active language; avoiding open-ended questioning; minimising sensory stimuli; monitoring medication; and an emphasis on accessible health promotion.

Disabled migrants

A 2012 report prepared by ChangeMakers Refugee Forum (Bloom, 2012) addressed the difficulties people from refugee backgrounds with disability needs can face in navigating disability services in Aotearoa New Zealand. Despite a refugee quota which includes specific provisions to resettle refugees with disability needs, such challenges remain. The report focused on the absence of a disability strategy that included people from refugee backgrounds. This was compounded by a lack of coordination across refugee support agencies and primary health care and disability service providers, resulting in people from refugee backgrounds not realising their rights to live independently or access clear information about their disability. These issues were based on interviews conducted with 10 people from refugee backgrounds living in Wellington, some with a disability and some who were caring for a person with a disability. Staff from Wellington-based disability, health and refugee service delivery organisations were also consulted.

A lack of service provision and support was identified in the report as the greatest barrier to participation in society for people from refugee backgrounds with disability needs. The report also identified: a lack of interagency coordination and provision across agencies; a dearth of information available to people from refugee backgrounds about disability services and entitlements; the ad hoc provision of disability services to this population; the reliance of family in the absence of disability service provision and a related lack of support for these families; and the issue of protracted isolation and limited independence for those research participants.

Recommendations included the addition of refugee-background communities as a target population by local District Health Boards and mainstream primary health care providers. It also suggested that members of the health, disability and refugee sectors address these gaps in service delivery through a cross-agency strategy for service coordination and support of people from refugee backgrounds with disability needs. It was recommended that this report be disseminated to various government agencies, that they be referenced in *Wellington's Refugee Health and Wellbeing Action Plan*, and that disability support strategies address the needs of people with disabilities who arrive in New Zealand as quota refugees, Refugee Family Support Category arrivals and successful asylum seekers, as well as those already living in New Zealand.

Evaluated strategies for increasing access to primary care for other vulnerable groups

There exists a marked scarcity of literature and research addressing the health care needs of other vulnerable groups. The following study is an important and seminal example of an evaluated strategy for increasing access to primary care for other vulnerable groups.

The *New Zealand Autism Spectrum Disorder Guideline* (Ministries of Health and Education, 2008) is a summary of recommendations for providing support for individuals, families and carers of individuals with autism spectrum disorder and specifically addresses the issue of health and access to health care for this group. Recommendations for people with autism spectrum disorder include: providing individualised support to manage their health care; providing comprehensive medical assessments; the development of a health-assessment profile; regular check-ups; health care practitioners being aware of the symptomatology of autism spectrum disorder; an investigation into their dental needs; an assessment of the quality and quantity of their sleep; further research into health care needs; for health care professionals to seek appropriate information about autism spectrum disorder in the absence of evidence for effective interventions to address specific health problems; for all children with autism spectrum disorder to be fully immunised; to investigate the effectiveness of health-promotion campaigns; for health care recommendations to be implemented in relation to people with autism spectrum disorder who also have a disability; for sensory issues to be identified and addressed; and for research to examine the effectiveness of methods and treatments used to address sensory issues.

Summary

There is an acute lack of empirical evidence that considers the primary health needs of disabled Māori. A study in the area of kāpo Māori highlighted that Māori are marginalised or “othered” when culture and impairment are ignored in health contexts. People with autism spectrum disorder and disabled migrants have been considered within the context of access to primary health care. Similarly to all other disability populations included in this review, accommodations at the primary health practice environment, particularly in the area of appropriate communication, have been highlighted as critical to the achievement of improved health status and access to health care for this group.

Discussion

This review has considered the relationship between primary health and disability. The review specifically focused on literature that explored health need, health inequalities, barriers to primary care and initiatives designed to address these. It also sought to identify issues and strategies with the potential to inform current and future workforce development in New Zealand.

As mentioned earlier in this review, there was a large body of empirical evidence relating to primary health for people who have an intellectual disability. While still relatively well researched, there was a smaller volume of literature that had considered primary health for physically disabled people or people with sensory impairment. It is important to note that there was a critical shortage of available research that explored access to primary health for disabled Māori. Similarly, there was little evidence relevant to primary health and other vulnerable population groups.

The review responded to six key issues.

- the health needs of disabled people
- health inequalities of disabled people
- barriers to primary care for disabled people
- potential strategies for increasing access to primary care for disabled people
- evaluated strategies for increasing access to primary care for disabled people
- evaluated strategies for increasing access to primary care for other vulnerable groups.

This discussion has been structured, to the extent possible, to consider each of the key issues for each disability group. It also highlights the similarities and differences between these groups with regard to health need and access to health care.

Primary health and physically disabled adults

Adults with a disability in New Zealand are most likely to have a physical disability (Statistics New Zealand, 2007). Social model conceptualisations of disability have been dominant within the field of physical disability. Consistent with such thinking, physically disabled people usually do not perceive their disability as synonymous with ill health. In contrast to this view, some disability theorists have suggested that there has been an under-emphasis on the role and impact of health in the lives of physically disabled people. Despite this concern, research clearly indicated a higher prevalence for chronic diseases including arthritis, asthma, cardiovascular disease, diabetes, high blood pressure, high cholesterol and stroke. Physically disabled people were also identified as being at higher risk for secondary conditions. In the case of physically disabled women health inequality was observed through the significant disadvantage experienced by these women with regard to breast screening and access to breast cancer treatment. Physically disabled men and women were identified as being as likely as the general population to engage on health risk behaviours, thus increasing the need for primary health information and promotion.

Unsurprisingly, the physical environment was identified as having the biggest impact on whether or not physically disabled people were able to access health care easily. The most widely felt barriers included transportation difficulties, inaccessible premises, and inadequate financial resources. A lack of knowledge of health care services was also reported as a barrier for physically disabled people.

As a consequence of physically disabled people being identified as experiencing high health need, health inequalities, and difficulty accessing primary health services, a number of suggested strategies for rectifying this situation have been made. Researchers have contended legislative reform, improvements in the delivery of health promotion, a reduction in environmental barriers, and the prevention of secondary conditions are all critical to improved health outcomes.

It was difficult to find *evaluated* strategies designed to increase access to primary health care for all of the disability groups considered as part of this review. In the case of physically disabled people, initiatives that have sought to raise the visibility of the disability community within public health, encourage health-promoting behaviours, and to offer accessible health care and health promotion have been evaluated as achieving successful outcomes. Further research is required to develop a better understanding of primary health care initiatives that have been implemented in New Zealand to improve the health outcomes of physically disabled people and the efficacy of these.

Primary health and people who have an intellectual disability

The empirical evidence in the area of primary health and intellectual disability is extensive and convincing. There are about 32,000 people who have an intellectual disability in New Zealand (Ministry of Health, 2011). Research has consistently reported that people who have an intellectual disability experience high levels of unmet health need, and are impacted by diagnostic overshadowing due to assumptive attitudes about intellectual impairment. Deinstitutionalisation, and the fact that people are living longer than ever before, means that adults who have an intellectual disability are often reliant on primary health professionals who are not always knowledgeable about intellectual disability. Women with intellectual disability, people with high and complex needs, older adults and those who have Down syndrome have been identified as requiring specific attention to ensure their health needs are met.

Researchers also agree that people who have an intellectual disability frequently require focused attention to ensure they are not critically disadvantaged in terms of their health status and access to health care. People who have an intellectual disability are often impacted by a range of health determinants that contribute to the inequalities they face with regard to their health. These include social determinants; health needs and their relationship with genetic and biological causes of intellectual disability; communication difficulties and low health literacy; personal health risks and behaviours; and deficiencies in access to and quality of health services. Inappropriate prescribing practices have also been identified as constituting a health inequality for this group.

Barriers to primary care for adults who have an intellectual disability occur at both the systemic and operational levels. Systemic barriers have been identified as being created by an absence of agreed health policies and the lack of a shared understanding about who is responsible for their implementation. Operational barriers encountered by people who have an intellectual disability are a result of inaccessible physical environments, but are also created by the attitudes and knowledge of health professionals. Specifically, health professionals continue to exhibit deficits with regard to the level of knowledge and expertise about the health needs of people who have an intellectual disability. Finally, the ability to improve health outcomes for this group is compromised by the lack of reliable health measures.

While there is strong agreement that people who have an intellectual disability have greater health needs than their peers in the general population, it appears there has been no comprehensive strategy for addressing this issue. Both one-off and more systemic approaches have been cited in the literature. One-off initiatives have tended to occur within a single site or single service context and have usually focused on the provision of education and training for support workers and health professionals. At a broader level, strategies have been recommended in the areas of planning and service delivery. In particular, leadership and direction within health services has been seen as critical to creating positive attitudinal change toward people who have intellectual disability within primary health contexts.

Two major approaches have been pursued with regard to improving health outcomes for people who have an intellectual disability. First, there have been attempts to develop health indicators that allow comparison between the health and health status of people with and without intellectual disability. Second, comprehensive health assessments (health checks) have been widely endorsed as having the potential to transform the health status of this population group. New Zealand and international research has supported the efficacy of this strategy and annual health checks have been government funded in several countries. As an overarching framework, the United Nations *Convention on the Rights of Persons with Disabilities* has recently been explored as a potential strategy for monitoring access to health services for people with intellectual and other disabilities. To support better health outcomes for people who have an intellectual disability, more needs to be known about strategies used within disability services in New Zealand, including their use of health indicators and health checks.

Primary health and people who are blind or vision impaired

There is a small but emerging literature in the area of health needs and health inequalities experienced by people who are blind or vision impaired. The 2006 *Disability Survey* indicates over 70,000 people in New Zealand experience sight loss. International research has reported that older adults who are blind or vision impaired are likely to be poorer and have a lower level of educational attainment than their peers in the general population. This can lead to health inequalities that have the potential to impact on their quality of life. Similar to physically disabled individuals, people who are blind or vision impaired encounter reduced access to primary care in the form of physical barriers, but also experience significant difficulties in receiving health information in accessible formats. The financial cost of primary care and attitudinal barriers were also highlighted. There was a limited literature available relating to strategies that could serve to address access difficulties, including those used in

disability services in New Zealand. However, the need to achieve greater collaboration between vision rehabilitation and primary health services was identified as a potential strategy.

Primary health and Deaf persons

There are about 9,000 Deaf people in New Zealand.⁹ Research has reported that Deaf or hard-of-hearing people utilise health services differently to other people. Research involving members of these communities has consistently exposed communication difficulties as being at the centre of this issue. Deaf people have asserted that inappropriate or unresponsive communication exchanges exacerbate feelings of fear, mistrust and frustration within primary care context. Similar to other disability groups, Deaf and hard of hearing persons have been identified as experiencing health inequalities. Such inequalities are thought to have been caused by a serious lack of health data relating to this group, low health literacy and limited access to health care due to communication barriers.

Research in the area of evaluated strategies to increase access to primary care has tended to focus on improving communication between Deaf and hard of hearing persons and primary health professionals. Graphically enriched health education videos have also been found to be successful in increasing health awareness and knowledge. Systemic approaches to improving communication between Deaf or hard of hearing individuals and health professionals have been advocated, including the need to educate health professionals about socio-cultural understandings of Deafness. Within primary health services, positive communication is dependent on the availability of qualified sign language interpreters, and ideally, health professionals themselves should be familiar with sign language. Whether such strategies are being used within primary health care services in New Zealand requires further investigation.

Primary health and other vulnerable groups

There was an acute shortage of literature specifically focused on primary health for other vulnerable population groups. Of most concern was the dearth of empirical evidence relating to disabled Māori. The research that was available explored kāpo (blind) Māori who identified that health services rarely considered either culture or impairment. New Zealand now has an action plan focused on disabled Māori and this document provides a framework to inform the development of culturally responsive health and disability services.

People with autism spectrum disorder were also found to be disadvantaged in their access due to communication difficulties and anxiety related to unpredictable health service environments and consultations. A range of strategies designed to reduce the level of unpredictability within primary health contexts have been suggested, with most priority placed on developing autism spectrum disorder awareness and responsiveness in health exchanges. Finally, disabled migrants also experience major barriers to primary health and are particularly impacted by their own lack of knowledge about services and entitlements, as well as by language barriers. The strategies used within disability services to improve the health outcomes of vulnerable population groups requires further investigation.

⁹ See <http://www.deaf.co.nz/nz-sign-language/about-sign-language/interesting-facts>

Conclusion

This review has demonstrated that disabled people are compromised in terms of their health status, level of health need and access to health care. Barriers to primary care were found to be multi-faceted and significant. Despite the obvious differences between individuals with different types of impairments, there was a high level of consistency in the literature about the barriers to primary health care. Access to primary care is often difficult for disabled people due to systemic barriers such as inadequate disability content within health care policy, or the failure to develop rigorous implementation processes. An absence of reliable measures for exploring health status and health need limit the opportunity to develop an accurate picture of the health of disabled people or to make comparisons to their peers without disability.

Operational barriers, often at the practice level impact, on the extent to which disabled people are able to access primary health care. For many, access is limited by inappropriate physical environments, or because they lack knowledge about the primary care services available to them. Access issues are further exacerbated when primary health professionals hold attitudes about disability that do not acknowledge current disability theory and politics. Moreover, if health professionals are deficit in their understanding of the health status, unmet health needs, and specific health conditions that can accompany certain disabilities, opportunities for effective health consultations may be lost.

Research reviewed for the purposes of this review repeatedly highlighted that access to primary health care for all disabled people is centred on effective communication. While the literature related to each disability group emphasised that different communication techniques were required for different disability groups, all saw communication as perhaps the most critical factor in achieving improved health outcomes for disabled people. It was also repeatedly stated that education and training related to primary health should be collaborative, with health professionals and formal and informal supporters having the opportunity to learn about strategies for effective communication from disabled people themselves. Furthermore, it was asserted that education relating to primary health and disability should be offered to disabled individuals as a way of increasing the opportunity for individuals to develop the skills to manage their own health needs.

This review has identified a range of primary health strategies that may contribute to improved health outcomes for disabled people in New Zealand. Nevertheless, little is known about the initiatives that have been used in New Zealand within disability services or about their efficacy. A survey of disability services and consultation with disability and primary health professionals was subsequently undertaken to examine this.

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