

OPINIONS & PERSPECTIVES

On the need for a specialist service within the generic hospital setting for the adult patient with intellectual disability and physical health problems

ROBYN A. WALLACE^{1,2} & HELEN BEANGE³

¹Director of Specialist Healthcare for Adults with Intellectual Disability (SHAID) Clinics, Mater and Princess Alexandra Hospitals, Brisbane, Australia, ²University of Queensland, Brisbane, Australia and ³Public Health Physician, Sydney, Australia

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Introduction

Although the presence of intellectual disability (ID) per se is not usually regarded as a health problem, the biopsychosocial implications of cognitive impairment contribute to the vulnerability of adult patients with ID in any healthcare system. The adult patient with ID differs from a patient in the general population in terms of health determinants, morbidity and mortality profiles, and in the ability to access quality healthcare. These differences represent a risk for adverse health and well-being outcomes in this population, and for increased costs of health services, particularly in the hospital setting. This paper focuses on addressing the issues facing the adult patient with ID, their caregivers, and health professionals, specifically in the setting of secondary and tertiary level healthcare systems.

Health determinants

The majority of adults with ID have a constellation of negative health determinants, including minimal education, low income, unmarried status, unemployment, and often a poorly developed social network (Beange, McElduff, & Baker, 1995; Morgan, Ahmed, & Kerr, 2000; Scheepers et al., 2005).

Most live with their family (in some cases with elderly parents) in the community or in supported accommodation, and a substantial number have previously lived in institutional-style accommodation (Australian Institute of Health and Welfare [AIHW], 2006). These factors in their own right are risks for poorer health outcomes in this group compared to their wealthier, more highly educated and more socially engaged peers (AIHW, 2007; Minkler, Fuller-Thomson, & Guralnik, 2006). Furthermore, the presence of cognitive impairment ensures that individuals with ID have little capacity to overcome the effects of these negative determinants, so an optimal and equitable health service must seek to compensate for these.

Morbidity and mortality

The morbidity and mortality profiles for young to middle-aged adults with ID also differ in a number of ways compared to those of the general population. For example, there are much higher prevalence rates of epilepsy, infectious diseases (such as *H. pylori* and hepatitis), constipation and reflux, sensory impairments, dental disease, congenital heart disease, musculoskeletal disorders, lung disease from aspiration, inactivity, and syndromic conditions involving

Correspondence: Associate Professor Robyn A. Wallace, SHAID Clinics Office, 11 Gordon Road, Bardon, QLD 4065, Australia.
E-mail: robyn.wallace@uq.edu.au

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complex endocrine disorders and organ malformations (Beange et al., 1995; Kapell et al., 1998; Wallace, 2001). At the same time, this group has much lower rates of smoking- and alcohol-related diseases and suicide. Further, there is much evidence to show that among the population with ID, the average number of medical problems per person is about 5, which is many more than the figure for their peers in the general population (Beange et al., 1995; Wallace, 2001). Moreover, more than half of these medical conditions, if present in a patient without ID, would normally require the services of a specialised, hospital-based health professional (Beange et al., 1995; Kapell et al., 1998; Minihan, 1986).

The average life expectancy of an adult with ID is still 10–20 years below that of the general population (Bittles et al., 2002), with lower life expectancy associated with a more severe level of ID and the inability to ambulate or feed oneself (Eyman, Grossman, Chaney, & Call, 1990). There are no data available describing the quality of healthcare provided to these patients with more severe disabilities. However, it can reasonably be speculated that the association between severe disability and premature mortality is not due simply to the disability itself (which may not be progressive), but instead is due to the impact of a lifetime of chronic untreated and unmanaged health conditions, the adoption of a “benign neglect” healthcare approach in place of active standard treatment, and ongoing problems in accessing healthcare for this group.

Barriers to access to generic health services

Optimal access to healthcare for adults with ID is impeded in a number of ways. The standard triad of history, examination and investigation leading to diagnosis and management is complicated by the fact that the majority of patients with ID do not present with typical signs and symptoms. Moreover, patient history is usually supplied by proxy; examination and investigations may be more difficult due to patient resistance or mobility limitations; and all processes take longer than for the general population. Caregivers who know the patients well can play a vital role in access to healthcare for this group. However in a significant proportion of cases, even caregivers do not recognise symptoms (Beange et al., 1995), while in other cases, health professionals do not recognise the importance of including caregivers in patient assessment and in the formulation of management plans. Both caregivers and health professionals may mistakenly attribute health conditions to the disability per se, instead of seeing them as treatable medical conditions, with the result that patients may

present with advanced or even moribund conditions (Voitk, 1987). Some service providers do not provide adequate funding for the caregiver role in the hospital system, believing that the responsibility of caregivers ceases once the patient enters the hospital setting. In addition, doctors may have had minimal formal training in the health, healthcare, and social implications of treating the adult patient with ID.

Access is also compromised by current hospital practices such as parallel booking of patients (leading to long waiting-times) and short appointment times. The patient with ID may become unsettled during a long wait and may leave before the appointment takes place. Taking a history and performing an examination take a lot longer for adults with disability, so a “rushed job” may be attempted under these conditions.

Access to optimal care is also negatively affected by the well-known conflict between disability and medical services in terms of both philosophy (e.g., the “anti-medical model” vs. the “vegetable” concept) and practice. Doctors may be tempted to provide a lower standard of care or to use a palliative approach in an ordinarily salvageable condition, in the mistaken belief that the patient’s disability automatically means that he or she has a poor quality of life. Similarly, caregivers may resist any perceived “medicalisation” of disability – an attitude that stems from past negative outcomes of the now outdated practice of housing people with intellectual disability in hospitals primarily because of their ID.

Implications of barriers to access

Results from Australian and American research (Durvasula, Beange, & Baker, 2002; Durvasula, Beange, Baker, & Bell, 2004; Kastner, Nathanson, & Friedman, 1993; New South Wales Ombudsman, 2004; O’Hara, 2006; Scheepers et al., 2005; Wallace, 2001) suggest that the failure to address these barriers has contributed to avoidable deaths and missed diagnoses of patients with ID seeking healthcare in generic systems of primary and tertiary care. In Durvasula and colleagues’ (2002) study conducted within generic hospital services, up to 28% of deaths of adults with ID were deemed to be preventable. Audits conducted through two specialist ID centres within generic hospital services (Beange et al., 1995; Wallace, 2001) revealed of the order of 2–3 new diagnoses per person that had previously been missed either by a GP or by generic hospital systems. The New South Wales Ombudsman’s detailed review of deaths of adults with ID in residential care acknowledged that their healthcare is complex, but concluded that there were

deficiencies in their healthcare, and that access to specialist services to address health conditions, as well as to ensure implementation and follow-up of specialist recommendations, was required. An American audit of the cause of death for people with ID identified a number of problem areas in medical management as contributing factors, including: (a) a lack of previous medical history; (b) the lack of availability of previous medical records for patients with known chronic illness; (c) delays in diagnosis or missed diagnosis; (d) non-compliance with previous or new recommendations; (e) limited parental/guardian choice regarding medical management, follow-up and/or hospitalisation; (f) parental/guardian dilemma between the convenience of local medical care and the need for specialised care; (g) patient behavioural problems complicating diagnostic procedures and management; (h) delay in the management of acute conditions (i.e., less aggressive management compared to patients without disability); (i) unsatisfactory communication between medical staff, patients, families, agencies, group homes and others regarding education about patients' conditions; and (j) inadequate planning of care, follow-up, and coordination of services (Kastner et al., 1993).

An important observation to reiterate from these reviews is that the sources of healthcare failure relate to system error in both the hospital and disability sectors: shabby logistics of healthcare management at home; various patient characteristics not acknowledged in the health system; a failure of the health system to accommodate differences in presentation and health profile; disability and healthcare professionals not working as a team; and disparities in quality of care provided by hospital staff and systems. It is evident that minimising these sorts of access barriers requires concessions equally by healthcare systems and professionals and by the disability sector.

Hospital care of the adult patient with intellectual disability

A hospital-based specialised unit would need to consider all the above barriers to access, and to then broker the unique biopsychosocial needs of the individual with ID, their disability service provider, and the requirements of the hospital, to work out practical plans for hospital ambulatory and inpatient care. Such a service would have responsibility for the logistical planning of outpatient healthcare services, such as transition care from paediatric developmental services, general adult clinics, appropriate timing of appointments, physical access, ensuring that equipment such as hoists and appropriate weighing

machines are available, and assisting in clarifying home responsibilities in healthcare and follow-up. It would also have responsibility for inpatient issues such as clarifying and optimising the role of the patient's caregiver. A specialist unit would also provide back-up and support to mainstream clinical staff and services, but not necessarily take over care. The unit would have responsibility for ensuring that patients with ID are offered the same standards of healthcare that apply for the general population. Health professionals working in the specialist unit would need to develop knowledge of the biopsychosocial profile of adults with ID, gain experience with this population, be able to work with caregivers, demonstrate an ability to advocate for their patients with ID, and promote disability philosophies among their health colleagues as required.

Lack of availability of specialist hospital services for adults with ID

In Australia, only a few such formal hospital services exist (e.g., St Vincent's Transition Clinic, Melbourne; SHAID Clinics, Mater Hospital, Brisbane). A recent unpublished survey (Wallace, 2004) revealed that the majority of children with ID are managed in well-established specialist paediatric developmental disability centres in hospitals, but that once they reach adulthood, they generally lose access to these paediatric services and their healthcare passes into the hands of their GP. Thus we have a situation where the patient with ID who is aged over 18, who up to this point has required specialist paediatric services, and who now requires adult specialist services, is instead being managed by a GP. Appropriate adult hospital services are simply not available. In specialist paediatric units, the unique needs of children with disability and their families are accommodated, usually via a multidisciplinary approach. These are units in which staff with expertise in the care of children with disability perform reviews and follow up to make medical diagnoses and formulate management plans which are made available to the patient's GP and other health professionals. They also facilitate referral to other sub-specialist paediatricians within the same generic hospital. In addition, wards are designed so that parents can stay with their child if necessary; thus there is an acknowledgement and an accommodation of the involvement of the child's home supports in their healthcare. There appears to be no community disagreement about the validity of the need for this type of service. However, the needs of these children do not disappear once they reach adulthood.

We would argue that a specialist hospital service for adults with ID urgently needs to be established in major public hospitals along the lines of this paediatric model.

Hospital utilisation and costs

About 2% of the population has some level of ID, so one might expect that at a bare minimum, a similar percentage of hospital admissions would involve patients with ID. However this figure is likely to be an underestimate, given the high number of co-morbidities per individual in this population that would normally require specialist services. In Australia, the total number of patients with ID presenting to adult hospital services and their total healthcare costs are unknown, partly because medical charts are not necessarily coded for the presence of ID, and partly also because referral patterns to hospitals are unknown, and may differ from the adult general population. Having said this, there are some Australian and international data to suggest that current usage by the adult population with ID is higher, more expensive, and less effective than for the general population.

Beange and colleagues' (1995) Australian population study found that adults with ID presented to hospital twice as frequently as patients from the general population. Their additional finding from a specialist ID service that about half the medical problems of patients with ID had not previously been diagnosed by generic (mainly GP) systems suggests that healthcare by both GPs and generic hospital services was incomplete. In a later survey on mortality among the same population group (Durvasula et al., 2002), the overall standard mortality ratio was found to be 4.9; moreover in a follow-up study (Durvasula et al., 2004), the number of hospital admissions among those whose death was deemed to have been avoidable was greater than among a control group with ID who did not die.

In the UK, a study by Morgan and colleagues (2000) found that adults with ID had an increased uptake of medical and dental services, but a reduced uptake of surgical specialties, and that overall access to hospital services was not greater than that of the general population. In the Netherlands, the cost of caring for patients with ID across all age groups and all living situations using generic hospital resources accounted for the highest proportion of the country's total healthcare costs (10–16%) (Meerding, Bonneux, Polder, Koopmanschap, & van der Maas, 1998).

In the US, adult patients with ID were found to have a higher number of emergency department

admissions, a longer length of stay, and different morbidity profiles compared to patients from the general population (Hsieh, 2005). In a survey by Janicki and colleagues (2002), a significant percentage of nearly 1,500 adults of all ages with ID living in the community were found to have accessed hospital services over a 12-month period (16% had been hospitalised and 30% had presented to an emergency department).

In the Asia-Pacific region, 10–15% of a sample of Taiwanese adults with ID living in institutions or in the community accessed the hospital system over a 4-year period, or an average of 1.56 hospital visits per individual per year (Loh et al., 2007). This was higher than for the overall population with disabilities in Taiwan, for whom the inpatient rate was approximately 9% per year.

Given the high number of known co-morbidities of adults with ID, many of which are present during childhood and require specialist paediatric services, these figures suggesting a higher use of hospital services than for the general population are not surprising. The findings of higher costs could point to inefficiency in the system, or alternatively they could mean that true costs are higher for this population.

Evidence that specialist units for adult patients with ID work

Because so few adult ID services exist, there is limited published evidence to show that improved healthcare delivery from hospital-based services for patients with ID directly improves their health and well-being. However there is some supportive evidence. For example, in paediatric health services, at one time children with Down syndrome and congenital heart disease were not offered corrective surgery, even though the technology was available. As a result, fewer than 50% of these children survived until the age of 30 years, compared to 80% of those without heart disease (Baird & Sadovnick, 1987). Some time later, children with Down syndrome and congenital heart disease began being offered corrective heart surgery. Subsequent mortality studies confirmed a positive impact of this care on life expectancy for this group: those offered surgical correction were found to have a similar life expectancy to those without congenital heart disease (Mathew et al., 1990). Along a similar line, but among adult patients, a 20-year longitudinal survey of a cohort of adults with cerebral palsy found that those who received specialised attention to their physical health problems in hospital had a good prospect of reaching pensionable age (Jancar, Sabogal, & Wiley, 1996).

More national data are required on the health outcomes and morbidity and mortality rates for adult patients with ID in the hospital setting. It has been recommended that health providers should maintain a mortality and adverse events register for adult patients with ID, and that this register should be analysed using standard risk management programs (Scheepers et al., 2005).

Philosophy of care

Conflict between disability and health sectors

Over the years, there has been some antagonism between disability and health professionals about service provision, which has arguably contributed to the record of poor health outcomes for the population of adults with ID. In the extreme, disability proponents have refused to accept any relevance of the medical profession to the care of their client with disability. They have, for example, given patients with cognitive impairments choices on medical matters – choices for which they do not have sufficient cognition to make, resulting in preventable pathology. On the other hand, health professionals have often been overwhelmed by the patient's disabilities, and in the belief that the person has no quality of life, have often inappropriately adopted a palliative approach in situations where active treatment would normally be offered to a person without disability. Moreover, an “unfriendly” adult hospital healthcare system with pressures of limited time and space and a reliance on patient independence for medical assessment are features that are incompatible with the needs of the majority of adults with ID.

Philosophies that should be included in the model of care

A tertiary model of healthcare should respect the disability principles of normalisation (Nirje, 1970; Wolfensberger, 1972) and least restriction (Turnbull, 1981). It should also adhere to the United Nations General Assembly's recent (2006) Adoption of the UN Convention on the Rights of Persons with Disabilities, which states that parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of their disability.

Similarly, disability service providers and caregivers need to realise that doctors use a formal and thorough process of health evaluation which requires accurate information (in most cases provided by a caregiver), and should accept the responsibility of an actively collaborative role in patient healthcare.

There has also been controversy among health professionals over the years about the value of a “one-stop shop” model of healthcare, whereby adult patients with ID can access all their health needs in the one location, rather than using the generic healthcare system. Although this idea has theoretical appeal in terms of time efficiency, current philosophy favours a less institutionalised approach. The Physical Health Special Interest Research Group within a major international disability body – the International Association for the Scientific Study of Intellectual Disabilities (IASSID) – has adopted the recommendations of the European Manifesto (Meijer, Carpenter, & Scholte, 2004) on healthcare for people with ID. This statement favours a specialist unit within generic services: “Health professionals who are specialised in the specific health needs of individuals with intellectual disabilities are available as a backup to mainstream health services. These professionals can advise, treat specific medical problems, or take over [a part of] the medical care for people with intellectual disabilities” (Meijer et al., 2004). Such a unit would be run by health professionals who are not only familiar with the biopsychosocial concerns of the adult patient with ID, but are also specialists in their own field of medicine or surgery, and are competent in managing the complex patient with or without ID.

Position statement

The population of adults with ID has a physical health profile that differs markedly from that of the general population. This group has a high number and diverse range of co-morbidities many of which require specialist services, has a greater number of negative health determinants than the general population, and presents difficulties in the application of the usual method of medical assessment. Inadequate acknowledgement and accommodation of these issues by both disability providers and generic health service providers and systems has contributed to poorer health outcomes in this group, as evidenced by the high numbers of missed diagnoses and untreated health conditions, and the lower life expectancy for these individuals.

Children with disabilities have access to a well-developed hospital care system, however there is no adult equivalent in place. Much of the specialised care for adults with ID is currently transferred to GPs who are not equipped with the appropriate knowledge or organisation. A specialised tertiary level healthcare service for adults with intellectual and motor disabilities therefore needs to be developed. From practical, economic and disability

Table 1. Logistics of service development for a specialised healthcare unit for adult patients with ID

Goal	Logistic
Announcement of new service	Funding approval; formal announcement to hospital and community of new service for adults with ID who have physical health problems and need care within the hospital facility
Naming of the service	E.g., SHAID (Specialist Healthcare for Adults with Intellectual Disabilities); notification on website and on main hospital intranet menu
Staff appointment	Medical team within Internal Medicine or Rehabilitation Medicine departments: Physician, Registrar, nurse, administrative support
Staff hours	Allocation of Physician positions to allow for 4–5 sessions per week of direct patient care (inpatients and outpatients) and 2 days for non-clinical work; ideally a nurse to be present on the clinical days
Access within hospital	Large consulting-rooms to accommodate wheelchairs and many caregivers and families; hoists; booked times for appointments; duration of 1 hour for appointments; toilets located close by
Access from outside hospital	Phone numbers or contacts for staff by appropriate means by caregivers, other health professionals, other members of the public
Outpatient organisation	Referral needed; pre-appointment questionnaire including some basic information; map for clinic location; what is needed for the appointment (e.g., well-known caregiver; series of appointments for baseline assessment; appointments of 1-hour duration; system of follow-up in place; copy of letters to GP, patient and caregivers; for large hospitals, of the order of 4–5 sessions per week needed so that health professionals have practice
Approach in outpatients	Full biopsychosocial review, including review of aetiology*; proactive looking for known morbidities; consider syndrome-specific clinics; consider model of baseline review*; anticipation if patient has high likelihood of hospital admission and pre-planning for this*
Inpatient organisation	Clarification of reason for inpatient care; determination of patient's non-medical inpatient needs; clarification that nursing staff are unable to provide 24-hour care; organise for caregivers to be present to support patient if required; liaison with inpatient unit Charge Nurse regarding needs of the patient and caregiver; organisation of pre-treatment documentation about the disability for treating health professionals*
Facilitation of care by other sub-specialty departments	Determine each department's needs in terms of review (e.g., background full review, specific questions for their consideration, statutory health attorney details, ensuring caregivers are organised and aware of the reason for consultation); particular care to determine the needs of the Emergency Department
Time allocated to develop relationships between individual caregivers and health professional, and also between disability service providers and the hospital	To discuss and determine the mechanics of outpatient preparation; to discuss and determine caregiver input to any inpatient care; to include caregivers in loop of communication on health matters so that their role is understood and management is tailored to the capabilities of the service provider; to work with disability service providers to clarify their role in tertiary healthcare of their clients, to inform them of hospital needs, and to devise various adaptations to suit both the disability and health sectors
Monitoring service	Development of register using existing hospital databases; quality assurance processes; establish an adverse events and mortality register and undertake analysis
Outlining what is not within scope of service	For example, providing respite care or providing care for people with primary behaviour problems; does not provide primary care
Education	On a formal basis, medical students to be allocated terms; medical and rehabilitation registrars to be allocated terms; participation in departmental professional development, for example by including disability-relevant cases or literature
Representation in hospital policy development	Health professionals in the specialist ID unit to contribute to generic hospital policy and programs; also considered to be a representative of patients with ID
Links with disability sector	To formalise links with government and non-government disability sector and interest groups; to invite collaboration and develop collegiality between disability and health sectors through this service. Consider formalising a position for hospital such as a disability project officer whose job would be to promote disability awareness, troubleshoot, raise awareness of disability, and inform health service of disability issues.

Note. *As used in SHAID Clinics (available on request from the corresponding author).

philosophy perspectives, such specialised health services should be designed and implemented through public generic services. In order to optimise accessibility, availability and quality of health services within the hospital setting, a specialist unit should comprise health professionals who have competencies in the unique health issues facing adults with ID.

The roles of a specialised healthcare unit for adult patients with ID should include:

- direct provision of secondary and tertiary level outpatient services for comprehensive diagnoses and formulation of management plans for patients referred by GPs or other specialists
- facilitation of consultations with other hospital-based healthcare providers as required
- provision of backup to mainstream clinical services involving other health colleagues in the hospital setting
- an advocacy role in providing healthcare in line with best-practice standards and disability philosophy
- development of recommendations for adaptations to the standard organisation of healthcare provision, to ensure optimal access without compromising quality
- provision of consultations for inpatients with ID admitted under the care of other colleagues
- participation in the logistics of inpatient healthcare planning with disability service providers and caregivers with respect to their support of the patient
- participation in the logistics of outpatient healthcare planning with disability service providers and caregivers with respect to their support in organising follow-up and monitoring of healthcare plans
- teaching of medical students, junior and senior colleagues, and participation in hospital education programs
- providing an information resource for all on matters relating to the physical health of adult patients with syndromes associated with ID
- participation in quality assurance programs in ID health within the facility
- development of accreditation standards at a College level for such services
- establishment of a hospital mortality and adverse events register and responsibility for its analysis
- development of a risk management process
- practice of evidence-based guidelines for healthcare

- contribution to community-based services for health promotion
- a consultation service for community-based health bodies

The logistics of organising such a specialised healthcare unit for adult patients with ID are outlined in Table 1.

Conclusion

This document opened with a description of the basic biopsychosocial profile of the adult with ID. The evident vulnerability of this population in terms of healthcare compared to their general population peers was demonstrated by their increased levels of morbidity and mortality, a whole host of access barriers, and some evidence of increased costs in generic hospital settings. The roles of health professionals, caregivers, and healthcare and disability service systems were acknowledged as important in addressing this disparity, although currently there is no existing body in Australian hospital services to organise such a system. The model of existing paediatric developmental disability units within hospitals is an example of a successful specialised system of care within a generic system. This paper proposes that a similarly designed system of specialised care for the adult patient with ID also be introduced into the generic adult hospital system.

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References

- Australian Institute of Health and Welfare (AIHW). (2006). *Disability support services 2004–05: National data on services provided under the Commonwealth State/Territory Disability Agreement*. AIHW Cat. No. DIS 46. Disability Series. Canberra: AIHW.
- Australian Institute of Health and Welfare (AIHW). (2007). *Chronic Disease Indicators Database*. Canberra: AIHW. Available at: http://www.aihw.gov.au/cdi/cdi_njs/index.cfm?DisplCommand=DataAvailableList.
- Baird, P. A., & Sadovnick, A. D. (1987). Life expectancy in Down syndrome. *Journal of Pediatrics*, 110(6), 849–854.

- Beange, H., McElduff, A., & Baker, W. (1995). Medical disorders of adults with mental retardation: A population study. *American Journal on Mental Retardation*, 99, 595–604.
- Bittles, A., Petterson, B., Sullivan, S., Hussain, R., Glasson, E., & Montgomery, P. (2002). The influence of intellectual disability on life expectancy. *Journal of Gerontology (Series A: Biology Sciences and Medical Sciences)*, 57, M470–M472.
- Durvasula, S., Beange, H., & Baker, W. (2002). Mortality of people with intellectual disability in northern Sydney. *Journal of Intellectual & Developmental Disability*, 27(4), 255–264.
- Durvasula, S., Beange, H., Baker, W., & Bell, D. (2004). Mortality of people with intellectual disability in northern Sydney: Associated factors [Abstract]. *Journal of Intellectual Disability Research*, 48(4–5), 432.
- Eyman, R. K., Grossman, H. J., Chaney, R. H., & Call, T. L. (1990). The life expectancy of profoundly handicapped people with mental retardation. *New England Journal of Medicine*, 323(9), 584–589.
- Hsieh, K.-F. (2005). Analysis of hospital utilization among adults with intellectual disabilities in one American State [Abstract]. *Journal of Policy and Practice in Intellectual Disabilities*, 2(3/4), 199.
- Jancar, J., Sabogal, N. M., & Wiley, Y. V. (1996). Life expectancy of mentally retarded hemiplegics. *Journal of Intellectual Disability Research*, 40(2), 180–182.
- Janicki, M. P., Davidson, P. W., Henderson, C. M., McCallion, P., Taets, J. D., Force, L. T., et al. (2002). Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *Journal of Intellectual Disability Research*, 46(4), 287–298.
- Kapell, D., Nightingdale, B., Rodriguez, A., Lee, J. H., Zigman, W. B., & Schupf, N. (1998). Prevalence of chronic medical conditions in adults with mental retardation: Comparison with the general population. *Mental Retardation*, 36(4), 269–279.
- Kastner, T., Nathanson, R., & Friedman, D. L. (1993). Mortality among individuals with mental retardation living in the community. *American Journal on Mental Retardation*, 98, 285–292.
- Loh, C.-H., Lin, J.-D., Choi, I.-C., Yen, C.-F., Hsu, S.-W., Wu, J.-L., & Tang, C. C. (2007). Longitudinal analysis of inpatient utilization among people with intellectual disabilities: 1999–2002. *Journal of Intellectual Disability Research*, 51(2), 101–108.
- Mathew, P., Moodie, D., Sterba, R., Murphy, D., Rosenkranz, E., & Homa, A. (1990). Long-term follow-up of children with Down syndrome with cardiac lesions. *Clinical Paediatrics*, 29(10), 569–574.
- Meerding, W. J., Bonneux, L., Polder, J. J., Koopmanschap, M. A., & van der Maas, P. J. (1998). Demographic and epidemiological determinants of healthcare costs in Netherlands: Cost of illness study. *British Medical Journal*, 317(7151), 111–115.
- Meijer, M. M., Carpenter, S., & Scholte, F. A. (2004). European Manifesto on basic standards of health care for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1(1), 10–15.
- Minihan, P. M. (1986). Planning for community physician services prior to deinstitutionalization of mentally retarded persons. *American Journal of Public Health*, 76, 1202–1206.
- Minkler, M., Fuller-Thomson, E., & Guralnik, J. M. (2006). Gradient of disability across the socioeconomic spectrum in the United States. *New England Journal of Medicine*, 355, 695–703.
- Morgan, C. L., Ahmed, Z., & Kerr, M. P. (2000). Health care provision for people with a learning disability. Record-linkage study of epidemiology and factors contributing to hospital care uptake. *British Journal of Psychiatry*, 176, 37–41.
- Nirje, B. (1970). The normalisation principle: Implications and comments. *British Journal of Mental Subnormality*, 16, 62–70.
- New South Wales Ombudsman. (2004). *Reviewable Deaths Annual Report 2003–2004*. Sydney: NSW Ombudsman.
- O'Hara, D. (2006, January). The unwell patient with intellectual disability presenting to hospital risks their life due to the process and not the illness. *Newsletter of the IASSID Physical Health Special Interest Research Group*.
- Scheepers, M., Kerr, M., O'Hara, D., Bainbridge, D., Cooper, S.-A., Davis, R., et al. (2005). Reducing health disparity in people with intellectual disabilities: A report from the Health Issues Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities (IASSID). *Journal of Policy and Practice in Intellectual Disabilities*, 2(3–4), 249–255.
- Turnbull, H. R. (Ed.). (1981). *The least restrictive alternative: Principles and practices*. Washington: American Association on Mental Retardation.
- United Nations General Assembly. (2006). Adoption of the UN Convention on the Rights of Persons with Disabilities. Available at: <http://www.un.org/esa/socdev/enable/rights/adhoccom.htm>.
- Voitk, A. (1987). Acute abdomen in severely mentally retarded patients. *Canadian Journal of Surgery*, 30, 195–196.
- Wallace, R. A. (2001). Biopsychosocial profile of adults with intellectual disability. *The Medical Journal of Australia*, 174, 200–201.
- Wallace, R. A. (2004). *Results of census of Australian doctors working with patients with intellectual disability*. Brisbane: Association of Australian Doctors in Developmental Disability Medicine. [Unpublished survey].
- Wolfensberger, W. (1972). *The principle of normalisation in human services in Toronto*. Toronto: National Institute of Mental Retardation.