People with an intellectual disability in the discourse of chronic and complex conditions: an invisible group?

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Abstract

People with an intellectual disability and their families experience poorer health care compared with the general population. Living with an intellectual disability is often challenged by coexisting complex and chronic conditions, such as gastro-intestinal and respiratory conditions. A literature review was undertaken to document the needs of this vulnerable population, and consultation was undertaken with mothers of children with disabilities and with professionals working within disability services for people with an intellectual disability and their families. Based on this review, there is a need to increase the profile of people with an intellectual disability in the discourse surrounding chronic and complex conditions. Strategies such as guideline and competency development may better prepare health professions to care for people with disabilities and chronic and complex care needs and their families.

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What is known about the topic?

People with an intellectual disability have diverse health care needs, including chronic conditions and a high rate of morbidity. Long-term illness and intellectual disability have adverse socioeconomic consequences for individuals and their families, and people with intellectual disability are often disadvantaged because of a lack of representation in policy and planning.

What does this paper add?

This paper describes the burden of complex and chronic disease in people with an intellectual disability and identifies the limited capacity of the Australian health system to meet the needs of people with an intellectual disability.

What are the implications for practitioners?

The authors argue for a greater emphasis on chronic and complex needs and intellectual disability in policy, planning and research on the basis of equity and justice principles.

THE NOMENCLATURE SURROUNDING disability can be ambiguous and misleading. A range of terms have been used to describe people with intellectual disabilities over the last thirty years. Mental deficiency, mental retardation, mental handicap,

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developmental disability and learning disability are examples. In May 2001, the World Health Assembly endorsed the use of its framework for health and disability, the International Classification of Functioning, Disability and Health (ICF)[1] to conceptualise and classify disability.[2] According to the ICF; disability is a term that describes a range of components including impairment, activity limitation and participation restriction that is influenced by environmental factors. Impairments are "problems in body function or structure such as significant deviation or loss". Activity limitations are "difficulties an individual may have in executing activities". Participation restrictions are "problems an individual may experience in involvement in life situations". Environmental factors "make up the physical, social and attitudinal environment in which people live and conduct their lives".[2] (pp. 16–17) As health care systems face the burden of chronic and often complex conditions it is important that we consider the

unique needs of all individuals in order to develop effective, equitable and just models of care, particularly in Australia where there is a system of universal health care coverage.

This paper documents the history of health services for people with an intellectual disability in Australia and their health care needs, and identifies implications for practice, policy and research, particularly in relation to complex and chronic conditions. A comprehensive literature review was undertaken using integrative methods. The Medline, CINAHL and Psychlit databases were searched using key words such as "disability", "mental deficiency", "mental retardation", "intellectual disability", "developmental disability", "learning disability", "chronic disease", "chronic conditions" and "chronic illness". Searching of the worldwide web was also undertaken using the Google search engine (Google Inc., Mountain View, Calif, USA). Reference lists of retrieved articles, policy documents and government reports were examined and relevant material sourced.

Definition of disability in Australia

In Australia, the term intellectual disability is commonly used, viewing the individual's disability experience as a dynamic interaction between the person and their environment. This is considered a more favorable approach compared with the biomedical model of the past, which perceived the disability to be a characteristic of the person linked to pathological symptoms.[1] Australia recognises four disability groups: intellectual (3%); psychiatric (5.2%); sensory (7.6%); physical (17%) and head injury/brain damage (2.2%).[3] Intellectual disability is further categorised into intellectual disability/learning disability; developmental delay; intellectual; specific learning, attention deficit disorder; and autism. The term intellectual disability is applied to conditions that appear in the developmental period between 0 and 18 years and is associated with impairment in mental functioning, difficulties in learning, challenges in performing activities of daily living, and a limiting of adaptive skills in community environments compared with others of the same age. It is associated with a range of conditions including Down syndrome, fragile X syndrome, tuberous sclerosis and cri-du-chat syndrome.[1]

Profile of people with intellectual disability in Australia

The 2003 Survey of Disability, Ageing and Carers[4] found that 3 946 400 Australians (20%) identified themselves as having a disability. This survey identified people reporting at least one of a list of limitations, health conditions or impairments that lasted or was likely to last at least 6 months and which restricted their involvement in everyday activities. Among this population, 1 238 600 (6.3%) experienced severe or profound core activity restriction, meaning they sometimes or always needed personal assistance or supervision with self-care, mobility, communication and schooling or employment restrictions.

In the 2003 ABS Survey of Disability, Ageing and Carers 317 900 children (8.3%) were identified as having a disability.[3] The four disability groups included the following statistics for children up to 14 years: intellectual (166 700); psychiatric (81 000); sensory/speech (129 700); physical/diverse (162 800, which included the 22 800 children with an acquired brain injury).[3] The main disabling conditions for children under 15 years of age included: cerebral palsy, attention deficit disorder or attention deficit hyperactivity disorder (ADHD), intellectual disability, autism and related disorders and other developmental disorders.[1] One in four children who are less than 15 years with severe or profound restriction required help in three core areas; most of this help came from family and friends.

The number of children identified with severe or profound restriction increased from 6.4% to 7.7% from 1993 to 1998.[5] This occurred when the screening question within the Australian Bureau of Statistics surveys was altered from "slow at learning" to "difficulty learning or understanding" in 1998,[5] and results were maintained in 2003.[4] There was a sharper increase in the number of boys with developmental disability

(9.8%) compared with girls (5.5%).[3,5] This is partly related to the identification of intellectual disability through early intervention services and the education system. However, there have also been increases in the numbers of children diagnosed with ADHD and autism, due to increased knowledge of the disorders within the community and changes in diagnostic approaches.[1,3]

Changes in the care of people with disabilities

For the major part of the last century, institutions were seen to be an appropriate model of care for people with a range of disabilities. People with intellectual disabilities were perceived to have unique needs and were generally moved from their families and communities to large institutions usually segregated from society, thus decreasing their visibility. They were often mixed with people who had mental health problems,[6] were over medicated and living in overcrowded facilities with limited numbers of staff. Over time, they were moved to separate wards and cared for by psychiatrists and registered nurses, who were often trained in the area of intellectual disabilities that was still under the jurisdiction of the health department.[7] In the 1970s there was a worldwide trend to deinstitutionalise people with disabilities.[8,9] Group homes were opened within the community, and unregistered (non-health professional) personnel were employed to provide care. In 1981, the "Year of the Disabled" further promoted this move from institutional to community living with the use of generic services and the goals of promoting attitude change, enhanced awareness of disability issues and increased mainstream integration. The *Disability Services Act 1986* (Cwlth) promoted the rights of people with disabilities, equating these to the rights of all people in society and containing a framework for service delivery.[10] Positive outcomes included an improvement in adaptive behaviour, an increase in community participation and greater contact with family and friends.[9] The long-term goal was greater use of generic services and therefore a reduction in the number of special services.[11]

The deinstitutionalisation movement resulted in 99% of families caring for their child with an intellectual disability in the family home. The majority of carers were mothers (85%); 10% were fathers, and the remainder family or friends, and often women.[5] Parents were encouraged to be involved with their child's programs, thereby reducing family stress, improving developmental outcomes for the child and increasing confidence levels in the parents.[12] In spite of these favourable trends, there are some adverse aspects of deinstitutionalisation. Notably, people with intellectual disabilities continued to experience high mortality rates, preventable deaths, and limited attention to regular physical or mental health assessment or health promotion.[13] The second issue concerns the health of the family, particularly the mother, who in meeting the needs of her child may lose sight of her own needs, ignoring changes in her health status or the presence of symptoms.[14] Notably, 30% of children with a disability live within a single parent family compared with 18% of children without disabilities, reflecting the stress on relationships.[5]

Physical health of people with intellectual disabilities

The World Health Organization emphasises that health and wellbeing are a fundamental right.[15] Australia's population is ageing and an increasing number of people are living with chronic illness, including 20% of the population with a disability.[1] People with intellectual disabilities are following the trends of the general population and are living longer. In spite of this, their life expectancy remains lower than the general population. Today, children born with a range of physical, genetic and chromosomal conditions are surviving to adulthood with quite complex and continuing health needs, in part due to technological advances.[16] A range of health targets have been identified for people with intellectual disabilities that have been selected because the conditions were "highly prevalent, easily detected and respond to treatments that are readily available".[13] (p. 285) These goals have been devised to:

(1) reduce avoidable premature death; (2) prevent avoidable morbidity; (3) reduce loss of skills due to ill health and hospitalisation; (4) achieve measurable improvements in health status; and (5) support developments that maintain the health of carers.[13] Targets for health interventions address: dental health, as many people with intellectual disabilities lack understanding of treatment regimes;[17] sensory impairments requiring regular monitoring as early as possible;[18] nutrition, which is often linked to swallowing difficulties, subsequent weight loss or obesity.[19] Constipation is a sadly neglected issue, with overuse of aperients and a lack of awareness of bowel movements;[20] epilepsy has been found to occur in 20% of people with an intellectual disability;[21] and there is a higher risk of hypothyroidism in people who have Down syndrome,[22] and osteoporosis due vitamin D deficiency.[23] Further targets are associated with: gastro-oesophageal reflux disease and *Helicobacter pylori* infection;[24] regular medication and immunisation status reviews;[13] physical activity and exercise;[25] comprehensive physical assessments;[26] regular reviews by a clinical geneticist;[27] and women's health.[28] Mental health problems occur in up to 40% of this population,[29] and it is considered one of the most neglected areas of service delivery both in Australia and internationally[6] (p. 9). The risk factors for a mental illness in a person with an intellectual disability are similar to all people, however, the presence of genetic disorders with behavioural phenotypes, epilepsy, or taking a range of medications can further increase the risk. When people with intellectual disabilities are able to access mental health services they are highly vulnerable, at risk of assault, have to travel long distances to find a psychiatrist with an understanding of intellectual disability and may not receive regular medication reviews.[30]

Mortality rates in people with disability

Higher mortality rates have been found in people with intellectual disabilities compared with the general population. One of the few studies in Australia by Durvasula et al[31] looked at 693 people with intellectual disability in the lower North Shore of Sydney from 1989 to 1999 identifying the causes and risk factors for death and avoidable conditions. Their study found that 44.7 percent of the people who died had severe to profound intellectual disabilities, were more inclined to have severe and complex medical disorders and required a great deal of support with core areas such as eating, mobility and incontinence. A Victorian study[32] of children and adults with cerebral palsy, found an increased risk of death due to respiratory disease, particularly in children with severe spastic quadriplegia, epilepsy and intellectual disability. Chaney and Eyman[33] found similar results in a longitudinal study in the United States identifying those most at risk as young, with feeding difficulties, and severe to profound intellectual disability. Alternatively, people with mild intellectual disabilities were more likely to experience the same life expectancy as other members of society without disabilities, with respiratory disease as the main cause of death. Durvasula et al[31] recognised the need for closer supervision or earlier medical attention to prevent adverse outcomes. Risk factors for premature death include immobility, tube feeding, incontinence and epilepsy.

Hospitalisation in people with an intellectual disability

When a physical or mental health crisis occurs for the person with an intellectual disability and chronic health needs, there may be challenges in the acute care setting, with health professionals experiencing uncertainly regarding the person's complex clinical presentation.[33] Brittle[34] suggests that in the past the right of access to acute care settings was denied to this population even though their health care needs were more complicated than others in society.[16] Australian health service delivery systems tend to promote a simple acute care model, with clinicians focusing on the presenting problem rather than the person's overall health.[35,36] This model of care usually involves the patient initiating the consultation, with short-

term treatment. However most people with chronic conditions will live with rather than die from their condition and therefore require a holistic long-term approach.[37] The general population with chronic health care needs is expected to coordinate their own care across a range of services and individual health professionals who may not communicate with each other regarding the person's condition.[35] The area of chronic illness has been described as "a need in search of a system"[35] (p. 10), yet for those with intellectual disabilities and their families that situation is much more complex.

People with intellectual disability experience difficulties accessing the acute health care system, and in identifying and meeting their health care needs.[37] The difficulties include: lack of understanding; difficulties with communication and behaviour; over-reliance on parents or formal carers; negative attitudes and a lack of confidence in the hospital staff.[35,36] Buzio et al,[38] in an Australian study, found that when people with cerebral palsy entered the acute setting, staff lacked knowledge and skills to plan for their needs in hospital or upon discharge. The families of children with intellectual disabilities and complex health care needs are under pressure to manage the disability and a range of health care issues. When further symptoms arise in the child or the parent, the situation can be fraught with difficulties with potential for a crisis that may necessitate intervention.[39]

The health of families caring for a child with an intellectual disability

There is growing evidence that caring for a family member with an intellectual disability is linked to an increase in mental and physical health problems for the caregiver. Caregivers of people with severe disability are at extreme risk of being highly stressed and clinically depressed.[40] Barr[41] describes chronic sorrow and levels of depression, social isolation, and the risk of physical and mental health problems due to the responsibility of caring for a child with a long-term intellectual disability. Certain events may trigger periods of sadness, such as anniversary dates for the birth or

diagnosis, missed milestones, or the inability of the child to gain a career or to get married and have children.[42] Emerson[43] found that families with children with an intellectual disability were economically disadvantaged compared with other families. The Australian Institute of Health and Welfare[3] report on children with disabilities in Australia found that 34% of families felt the need for financial assistance, possibly linked to the 62% of mothers not employed in the labour market. The mother of a child with a disability is an individual who will, over time, experience physical, emotional, mental, social and spiritual alterations to their own health status. Mackey and Goddard[44] found in a 2004 study that the pressing health care needs of a child with disabilities led to the mother putting her own needs into the background, not thinking about them or picking up the symptoms of ill health. The physical and emotional hard work of mothering resulted in tiredness and coping alone, ever vigilant to the health needs of their child. Even though there was a greater incidence of physical and mental health issues, the women did not have the time to notice or address these.

The degree of the child's disability has an impact on the caregiver; those with high support needs, including epilepsy, feeding difficulties or behavioural problems have the potential to increase the mother's stress levels, reducing sleep, and causing an inability to leave the child with anyone else for fear of a medical emergency.[45] Further variables found to increase potential for health problems included: the amount of assistance with, and cumulative effects of, physical care and behaviours; hands on care over a long duration; and the number of adjustments to daily life to accommodate the child.[46] Sleep disturbance in the child was a major problem in a study by Didden et al,[47] with only 19% of parents receiving appropriate treatment. Parents reported a number of issues including: lack of sleep (20%), fatigue (47%), irritability (28%) and failure to cope (9%). Shu et al[48] identified the need for adequate training and education of health professionals and untrained carers, continuity of care and adequate resources to support mothers with mental health problems.

The burden of chronic and complex health issues

Children with intellectual disabilities often experience long-term chronic conditions which, combined with the disability, require ongoing daily management, time and resources. Cerebral palsy can vary in severity, and can include epilepsy and movement difficulties and increase the family's stress levels.[49] When exploring chronic conditions in children with disabilities there were a number of difficulties, not least of all the interpretation of health issues; a child could have a severe disability but still be perceived as healthy. Long-term chronic conditions are found in 44% of children up to the age of 14 years, 25% had two long-term conditions and 18% had three or more conditions.[49] These conditions included asthma, hay fever and allergies. The family can experience social and financial disadvantage associated with the strain of caring, and the mother or carer may not be able to return to her previous employment, creating further hardship and increasing a sense of loss.

It is important to note that care-giving is not necessarily seen as a "burden" by the care-giver — alternatively, they may derive pleasure and fulfillment in the role. However it is different to paid employment, in that the carer is working 24 hours a day, 7 days a week and can continue for lengthy periods of time without a break.[50] Further, this role often isolates the carer from broader societal interaction. It is difficult to predict when a crisis may occur given the sleepless nights, the potential health crisis, or the impact on family relationships.

Issues in accessing health care services

People with intellectual disabilities and chronic conditions face challenges in accessing services in a health care system primarily configured for acute care conditions. The complexity of the Australian health care system in relation to federal and state government funding can also confound the funding of appropriate services. Challenges in chronic care are heightened in people with an intellectual disability. People who are marginalised experience discrimination, inadequate access to health care, and are often exposed to environmental dangers that increase the potential for health problems.[51] Today, people with disabilities are clearly saying that they want to take their place in the world, to be part of society rather than marginalised.[52] Crisp[53] identified that people with disabilities developed different responses to health professionals depending on their sense of wellbeing. People who struggled to cope had a low sense of wellbeing, tending to feel dissatisfied with health professionals, and expressing fear and anger at being disadvantaged by stigma. Those with a high sense of wellbeing felt confident, they did not emphasise their disability, experienced satisfying relationships with health professionals and presented as assertive, competent individuals with personal control over their situations. These observations have particular implications for health care interventions that promote self-management and coordination of care. Factors associated with having an intellectual disability include prejudice, stereotyping, marginalisation, socioeconomic deprivation and a lack of advocacy.[54]

Significantly, issues of health literacy and perception impede engagement in main stream health services. Vezeau[55] states that without literacy, health care interactions fail to meet the intended goals, with illiteracy creating health risks and exacerbating health conditions. People with disabilities require health professionals to collaborate within an alliances framework rather than a paternalistic, purely biomedical model. People with a disability may have fulfilled the dependency role for many years, demonstrating learned helplessness which has been reinforced by caregivers and professionals further disempowering the individual.[56] Like all people with a chronic illness, people with a disability require engagement and promotion of self-management skills. Within this framework clinical assessment should not focus on barriers such as functional limitations, but also on the positive attributes to promote health.[57] It is likely that stigma and misconceptions influence care planning in this group.[58]

Devaluing of the specialty of intellectual disability

Over the last decades, people with a disability have slipped from public focus and become less visible for a range of reasons. A key reason is the deinstitutionalisation movement, which is a two edged sword with both enabling and disabling features. Another key factor has been the transition in paid-care giving, away from primarily specialist nurses to often non-registered disability care workers, or family or friends.[59] Until the late 1980s, care for people with intellectual disabilities was provided by registered nurses who specialised in the area, although at the time were termed Mental Retardation nurses in New South Wales, Victoria and Tasmania, and Mental Deficiency Nurses in South Australia.[7] No such discipline existed in Queensland, the Northern Territory or Western Australia. The nurses in this area were described by Nehring[60] as caring for the people with whom they worked with great passion. Care of clients included a holistic approach to health care, the provision of basic nursing care, medication and health promotion, however, it also involved coordination and collaboration in accessing educational, employment, financial, housing, recreational, and social services systems. "It is a nursing specialty that has been stigmatized, just as the population it serves has been".[60] (p. 2)

In 1984, the Commonwealth Government announced that it supported the transfer of nurse education from the hospital to the higher education sector. Before and up until 1995 there were six separate undergraduate nursing curricula covering general, psychiatric, intellectual disability, geriatric, midwifery and mothercraft nursing in NSW.[61] The new tertiary curriculum was deemed to be a comprehensive program covering the six areas of nursing mentioned above. This was indeed an extremely important move when considering the professionalism of nursing. The new curriculum was to offer knowledge and skills to undergraduate nurses to enable them to register as nurses and gain employment across all care groups and clinical areas. The end result, however, was quite different: for example, in Victoria

the needs of this and other vulnerable groups were not being met as the theme of intellectual disabilities became invisible and was gradually eliminated from the program.[61] Stevens and Dulhunty[62] found that final year nursing students in four NSW universities mainly considered the area of medical surgical nursing to be the prime focus of their nursing programs. This was reinforced by Happell.[63,64] Her Victorian study explored student nurse preferences before and after the inclusion of psychiatric nursing into their curriculum. There is little research into the integration of the intellectual disability theme in nursing curricula in Australia. A consequence of the changes in the education of student nurses has resulted in a workforce that has had very little experience with people with disabilities.[59]

In the 2001 Census, 2510 Registered Intellectual Disability Nurses were employed by the large institutions or in positions within specialised community services.[65] This fall in number of a key group of professionals with background knowledge, commitment and clinical experience has significant implications for the ongoing health care of people with a disability. Hartley[66] refers to the National Patient Safety Agency which identifies that while nurses and other health professionals lack the skills and knowledge, people with disabilities are at risk of physical and emotional harm. These nurses need to develop a visible professional identify to take their place as key resources to health services, where their expertise is known and valued.[52] Of significance has been the paucity of studies to look at the management of chronic and complex conditions in people with intellectual disabilities.

Increasing the visibility of intellectual disability and complex health care needs

As outlined above, people with intellectual disability not only experience disadvantage relating to their condition, but this is compounded across the life trajectory by chronic illnesses related to ageing and the impacts of socioeconomic disadvantage. It is evident from the data described above that there

is a need to investigate strategies to improve the care of this vulnerable population and their carers. A range of potential solutions are evident on the basis of this review. Firstly, a positive policy platform is required to support disability services; secondly, developing interventions and strategies to increase the knowledge of health care workers, particularly nurses, caring for people with intellectual disabilities will likely improve the health care needs of this population and their families; thirdly, a range of governance and monitoring mechanisms to ensure the wellbeing of people with a disability, particularly within a deinstitutionalised framework, is needed; fourthly, there is a need to support the carers of children with a disability, who are primarily women; and finally, there is an important need to include intellectual disability issues in the chronic care research agenda to develop appropriate strategies to decrease individual and societal burden.

Conclusions

Although a substantive body of literature exists in relation to chronic illness, particularly cardiovascular, respiratory conditions and mental health, there is little discussion on the impact of an intellectual disability on this burden of chronic disease. It is well recognised that chronic disease management places significant emphasis on self-management. Yet there is little theoretical development of the implications of self-management within the context of the person with an intellectual disability and their family who are also at increased risk of chronic and complex health conditions. As the burden of chronic disease increases in people with an intellectual disability there is an urgent need to consider these issues and increase their visibility in the debate and discussion of the management of chronic conditions. This should be a particular consideration within Australia where equity within a context of universal health care coverage is promoted.

Competing interests

The authors declare that they have no competing interests.

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