

“What do you expect? She is mentally retarded!”: On Meeting the Health Challenges of Individuals with Intellectual Disability

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Abstract

On balance, the life expectancy of people with intellectual disability is significantly less than it is for the general population. For the most part, individuals with intellectual disability die from the same diseases as “the rest of us”: heart disease, stroke and cancer. But for the most part, they die earlier from those same diseases, not because of the special nature of intellectual disability, but because they are less likely to be diagnosed and treated in time, and because they are less likely to be exposed to health promotion and disease prevention information, services and supports. The literature on the subject is clear: overall, the health needs of people with intellectual disability are not being effectively met. In this article, the author discusses the reasons for this state of affairs and suggests ways to correct the condition.

INTRODUCTION: LEARNING LESSONS THE HARD WAY

A woman with severe intellectual disability and no comprehensible verbal communication was taken to a community health clinic. Support staff were concerned about her disruptive behaviour. They didn’t know how to deal with the behaviour and were worried that it might be an indication of more serious problems. On cursory examination, the attending physician was quick to attribute the behaviour to the nature of the woman’s disability. With some impatience he declared: “What do you expect? She’s mentally retarded!” Unsatisfied with the explanation, support staff insisted that the woman was usually mild mannered and that the disruptive behaviour was out of character. Subsequent investigation found that the woman had a massive gallstone¹.

In this case, a fundamental failure was to only see the patient’s behaviour as representative of a population for whom the physician maintained certain preconceptions. This limited perspective prevented the physician from viewing the patient’s behaviour as descriptive and symptomatic communication. The patient’s behaviour was dismissed as largely inconsequential, and it was only by fortuitous circumstance (determined support staff) that the young woman’s condition was eventually uncovered. Until prodded, the physician was prepared to bypass thorough examination and substitute presumption for diagnosis.

THE HEALTH CARE DISPARITY

Though the lifespan of individuals with intellectual disability has been steadily increasing, life expectancy is still about 10 years less than for the general population. While aetiology or syndrome-specific factors account for a small portion of the difference, evidence shows that on balance, people with intellectual disability have a high level of undiagnosed and unmanaged health problems². Heart disease, hypothyroidism and osteoporosis are conspicuous amongst those problems³. What’s more, the research indicates that individuals with intellectual disability are four times more likely than other members of the general population to die prematurely from preventable causes⁴. This suggests that although effective health promotion, illness mitigation, and disease prevention strategies exist, not everyone benefits equally from these interventions, and that individuals with intellectual disability are especially vulnerable⁵. Inasmuch as intellectual disability is a clear, measurable determinant that places individuals in a position of health care disadvantage, the World Health Organization has charged that people with intellectual disability have been, and continue to be, a devalued and often neglected population⁶.

REASONS FOR THE DISPARITY

Most health care practitioners will, from time to time, work with patients who have an intellectual disability. It has been

estimated that a General Practitioner with 1,500 patients, for instance, will have 20-30 patients with mild intellectual disability, and 4-6 patients with severe intellectual disability⁷. In many cases, though, General Practitioners and other health care professionals are poorly prepared to meet the often complicated health needs of their patients with intellectual disability. In one study, eighty-one percent of medical school students said that they did not receive any clinical experience with individuals with intellectual disability, while sixty-six percent stated that they did not receive sufficient classroom instruction⁸. In a survey of 500 nurses in New Jersey, most nurses indicated that they received little or no information about intellectual disability and other developmental disabilities during their nursing education⁹. In a study of Canadian-educated psychiatrists, respondents reported receiving only minimal education about intellectual disability, and many admitted that they had little or no interest in working with patients who have an intellectual disability (work in the field of intellectual disability has been referred to as the “Cinderella of psychiatry”)¹⁰. Similar results were found in a survey of Australian psychiatrists¹¹.

When they do work with patients with intellectual disability, absence of adequate instruction and supervised clinical experience during pre-registration education has led many health care practitioners to feel uncomfortable and ineffectual. In some instances, the gap in education has permitted maintenance of misconceptions and prejudicial attitudes that have contributed to substandard health care. The tendency toward diagnostic overshadowing, for example, or the practice of attributing all behaviours and symptoms only to intellectual disability, i.e. “This is a ‘mental retardation’ problem”, or, “That’s just the way they are”, has meant that serious conditions have been ignored and untreated. As evidence, Reiss and colleagues found that clinicians in their study were more likely to assign a diagnosis of mental health disorder to a symptomatic individual without intellectual disability, than to an individual with intellectual disability who presented with the same description of symptoms¹².

Despite abundant evidence of substantial health needs that exceed those of the general population, it is clear that impediments to appropriate health care continue to confront individuals with intellectual disability¹³. Educational deficiencies and unsupported prejudices are prominent in maintaining those impediments. To illustrate further, parents

have reported that it has not been unusual for their sons or daughters to be disallowed recipient status for organ transplant surgery, with disability given as the reason for exclusion:

- “I was told by her cardiologist that she is not eligible for a transplant because of her Down syndrome.”
- “We were told that if he was ‘normal’ like us he would be a great candidate for a corneal transplant.”
- “The first doctor we saw told us that no transplant could be done because our son was ‘retarded’”.
- “I was told that at the university hospital they will transplant a kidney but not even consider a heart transplant for someone with Down syndrome”¹⁴.

While people with intellectual disability are no longer universally excluded from transplant surgery (when organ transplantation was first introduced, intellectual disability was grounds for automatic exclusion), many people with intellectual disability still do encounter discrimination when it comes to referral, evaluation, and actually receiving a donor organ¹⁵. In one case, a doctor who was compelled by U.S. antidiscrimination legislation to evaluate a woman with Down syndrome concluded that her explanation--- that she “wanted to live”--- was not sufficient reason to qualify her for transplantation¹⁶. In another case, a woman with intellectual disability was denied life-saving transplant surgery by two California transplant centers. The decisions were not the results of careful examination and medical judgment (one of the centers had never met with nor examined the woman), but reflected a categorical view that people with Down syndrome were not appropriate candidates for heart/lung transplants. In Canada, a 17-year old boy with Down syndrome had his application for a lung transplant turned down because he did not meet the hospital’s written criterion of “satisfactory intelligence”. It wasn’t until his parents “went public” that the hospital revised its policy and placed the boy on the transplant waiting list (this, incidentally, caused a flood of telephone calls with callers accusing the hospital of “wasting organs” on the intellectually disabled)¹⁷.

A number of reasons are characteristically cited for reluctance or refusal to include individuals with intellectual

disability on transplantation lists. Prominent amongst these is the belief that post-operative self-care requirements are compromised by intellectual disability, and that transplantation success is rendered less likely. A review of the worldwide literature on kidney transplants shows that this is not the case. At one-year post transplant, the survival rate for recipients with intellectual disability was 100 percent, while the three-year survival rate was 90 percent. These rates are comparable to survival rates for the overall population of transplant recipients (individuals with intellectual disability and significant dependency needs commonly have formal support providers to assist with post operative care regimens)¹⁸.

Evidence of exclusionary practice can be found across all health care domains. When all things are equal, aside from presence or absence of intellectual disability, the research shows that life-saving surgery in its various forms is less frequently recommended for ill children with intellectual disability than for ill children without intellectual disability¹⁹. It has also been found that health care professionals, with exceptions, assume that the most interventional treatments: intensive care, surgery and resuscitation should not be extended to people with intellectual disability²⁰. The controlling factor may be the view that the severity of an individual's disability, or in some cases, simply the presence of intellectual disability, mitigates the need for surgery and other life-saving actions. Often genuinely expressed as a caring or humane, “in the best interests of the patient” viewpoint, this presumes a negative conclusion about the quality of an individual's life that is generally unsupported by the views of individuals with intellectual disability themselves (health care professionals do not have an enviable track record when it comes to judging the quality of life of patients with intellectual disability).

The mental health care field has had noticeable equality of access challenges. For example, though children and adolescents with comparatively mild intellectual disability experience suicidal thinking and associated behaviours at rates similar to those of other children and adolescents, they are less likely than others to receive proper mental health services²¹. Similarly, children with intellectual disability and a coexisting major psychiatric disorder are significantly less likely to receive expert help than are their age group peers without intellectual disability²². In a study of adults with moderate to profound intellectual disability and psychiatric illness, 75% did not receive treatment for their psychiatric

illness. On the whole, referrals to psychiatric services tend to decrease as severity of intellectual disability increases. Symptoms are commonly conceptualized as “behaviour problems”^{23, 24}.

While it is clear that diagnosis of individuals with severe disability can be very challenging, absence of sufficient education and experience, and submission to faulty belief systems are acknowledged factors that predispose those who are involved in forming a diagnosis and related treatment plan.

Even though it is evident that the vast majority of health care providers are caring and committed practitioners, and that substandard health care is largely unintentional, it is also evident that individuals with intellectual disability are too frequently exposed to substandard care. Britain's Secretary of State for Health and the United States Surgeon General, amongst others, have recognized this as an inequity that needs correction. Both have urged health care professionals to examine their own educational needs and prejudices where they exist, so that they are better able to provide health services that are equal to those received by the general population^{25, 26}.

CORRECTING THE HEALTH CARE DISPARITY

Correction of the health care disparity begins with the acknowledgement that, on the whole, people with intellectual disability have poorer health than the larger population, and that there is an overall difference in health care provision and accessibility that contributes to this situation. The view that people with intellectual disability are equally valuable members of society, and that they have the same entitlements to accessible and appropriate health care as everyone else is another fundamental precursor to needed change. To reinforce these fundamental entitlements, many countries have enshrined “equality rights” in legislation. For example: The Equality Rights section [15] of the Canadian Charter of Rights and Freedoms²⁷ prohibits discrimination based on disability, while the Americans with Disabilities Act [ADA]²⁸ in the USA does the same. Britain's Disability Discrimination Act²⁹ requires organizations to make “reasonable adjustments” to ensure that people with disability are not excluded from services and do not get worse service than people without disability. The intended outcome of these acknowledgements, declarations and laws is that health care is given on the basis of clinical need (equal treatment for equal need), and that it is not obviated by personal biases and subjective value judgments.

Education about intellectual disability and health matters that have an impact on people with intellectual disability, and education about strategies to better accommodate patients with intellectual disability, are other primary strategies for correcting the health care imbalance. In addition to providing health care practitioners with information and tools to better understand and assist patients with intellectual disability, education has had the effect of changing attitudes about patients with intellectual disability, when those attitudes have been negative or exclusionary. The related research shows that health care providers who complete structured courses on the health of individuals with intellectual disability express greater willingness to work with patients with intellectual disability³⁰.

To help correct the health and health care imbalance, the World Health Organization has said that people with intellectual disability, and their support providers, require appropriate and ongoing instruction about healthy living practices³¹. To a large extent, information about healthy living practices has been inaccessible to many people with intellectual disability because of their dependency on others, and because of limited ability to understand, integrate and independently act on lifestyle information to which they may have been exposed.

In this context, gaining the attention of people with intellectual disability and their support providers is vital if effective health promotion is to occur. According to the U.S. Surgeon General, this means that healthy lifestyle information needs to be accessed, discussed, practiced and reinforced in the places where people with intellectual disability live, work, learn and socialize³². Toward that end, health promotion planning requires the conscious, deliberate inclusion or targeting of people with intellectual disability and the development of strategies that better promote understanding and intended action by people with intellectual disability and their supporter providers.

CONCLUSIONS

Intellectual disability is characterized by a longer learning (or understanding) acquisition period and a lower learning/understanding ceiling: the time it takes to learn or understand is typically longer, and the level of complex learning is more limited than for people without intellectual disability. The extent to which the individual acquires intended learning or understanding, however, depends on more than innate ability, but also on the quality of learning experiences to which the individual is exposed. This

suggests that for individuals with intellectual disability, learning or understanding involves a complex interaction of factors that includes the individuals who are attempting to bring about learning or understanding (health care professionals for example). These factors must all be considered when evaluating why an individual with intellectual disability may be having difficulty learning a concept or task or simply understanding information or instructions. In this sense, the essential questions for health care professionals are: “How am I, or how are we, contributing to or inhibiting successful learning or information acquisition?” and “How are the current environment and the accompanying circumstances affecting successful learning or information acquisition?” The willingness to engage in this kind of self-examination and environmental assessment is an important attribute for any health care professional or to possess. However, it is particularly important when working with people with intellectual disability because they have been a population whose individual members have often been viewed as owning their own “problems” or illnesses, without benefit of others assuming some level of contributory responsibility ... “What do you expect, she’s mentally retarded!”

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