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**Caring for Persons with Intellectual and
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**Promoting Health and Wellbeing in Persons with
Intellectual and Developmental Disabilities**

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Abstract

Article 25 of the United Nations *Convention of Rights of Persons with Disabilities* indicates that persons with disabilities should have the right to the highest attainable standard of health without discrimination. There is much evidence that this right is not being enjoyed by persons with intellectual and developmental disabilities, not least through the often poor quality of the healthcare they receive. This paper discusses the major health-related issues faced by people with intellectual and developmental disability. It concludes by calling on the health sector and the community to work collaboratively to improve attitudes and awareness of this vulnerable group, and on governments to direct substantial resources to improve the

physical and mental health and wellbeing of children, adolescents and adults with intellectual and developmental disabilities.

Keywords: delivery of healthcare, developmental disabilities, healthcare disparities, intellectual disability, medical ethics

Introduction

Article 25 of the United Nation's *Convention on the Rights of Persons with Disabilities* (CPRD) indicates that ratifying States should "recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability." Evidence, however, strongly suggests that the highest attainable standard of health has not been achieved among people with intellectual and developmental disability (IDD). For example, individuals with severe IDD die on average 20 years younger than the general population, and those with a mild disability die seven years earlier (Bittles et al.; Durvusula, Beange, and Baker; Patja et al.). In addition, adults with IDD experience on average over five medical conditions, with half being unrecognized and/or inadequately managed (Beange, McElduff, and Baker; Lennox et al. 2007; Lennox et al. 2010). Common and overtly obvious conditions such as fractures, hernias, or breast and skin tumors are missed and often many "new" diseases are diagnosed at a late stage, significantly delaying treatment (Webb and Rogers).

The prevalence of mental health disorders has been found to be significantly higher in adults with intellectual disability (Cooper et al.) and children and adolescents (Einfeld, Ellis, and Emerson). The negative impact of poor mental health *per se* on the person's physical health and wellbeing, and vice versa, remains substantial, acting both directly on the individual's experience of wellness and on her or his ability to access services. For example disturbed behavior can make medical and psychiatric assessments difficult and prevent adequate investigation.

This high level of multi-morbidity explains in part the polypharmacy seen in this population. Psychotropic medications have been found to be the most predominant agents prescribed for adults with intellectual disability (Doan et al. 2013) and although their use has been found to be positively associated with having a psychiatric illness and challenging behaviors in adults (Doan et al. 2013) and with behavior problems in adolescents (Doan et al. 2014), there is little evidence regarding the safety concerns of antipsychotic combination therapy (Tranulis et al.).

People with IDD are more commonly extremely underweight or obese compared to the general population, putting them at significant risk of current and future impaired health and wellbeing (Rimmer and Yamaki). Furthermore, exercise levels have been found to be less in people with IDD, with only 8-16% of adults with intellectual disability attaining physical activity levels suggested by guidelines compared to 30-47% of people in the general population (Melville et al.).

Despite the substantial levels of disease and unmet health needs among individuals with IDD, inadequate levels of health promotion and disease prevention have been found across all countries (Aronow et al.; Baxter et al.; Lennox et al. 2007; Lennox et al. 2010). Strategies

to improve health promotion and disease prevention for this population have emerged over the past decade but remain in their infancy with limited evaluation and limited implementation even if good evidence favoring such approaches exists.

People with moderate to profound levels of IDD consume less (or no) alcohol and are much less likely to smoke cigarettes or take recreational drugs than the general population, although this may not be the case for those with a mild or borderline disability (Emerson and Turnbull; Kerr et al.). But for those who experience the criminal justice system, the prevalence of substance use disorders matches the high level of use among inmates without intellectual disability; however, treatment programs are unlikely to target the special needs of this group (Dias et al. 2013a, 2013b).

One of the major determinants of health is socioeconomic position. People with IDD often live in poverty and do not have access to meaningful vocations, or the resources to access recreational activities (UK Department of Health; U.S. Department of Health and Human Services; World Health Organization). They tend to have a limited social range and few friends outside the family or disability community, putting them at further risk of poor health outcomes (Victorian Department of Health; World Health Organization).

Clearly, then, although people with IDD have a right to the *highest attainable standard of health*, this is not being achieved. Using further declarations from the CRPD as headings, and examples from our clinical experience and the literature, we will in the remainder of this paper discuss the barriers to good health experienced by this population.

Provide Persons with Disabilities with the Same Range, Quality, and Standard of Free or Affordable Health Care and Programs as Provided to Other Persons

Given the elevated health care needs experienced by people with intellectual and developmental disability, as outlined above, they have a greater corresponding need for equitable access to high quality health care. However, such access remains a significant challenge for people with IDD and their families, further compounding their health problems. Areas characterized by low socioeconomic status often have fewer general practitioners/family physicians per head of population. When afforded opportunities to consult their practitioners, this population, which has greater unmet health needs than wealthier populations, receives shorter consultations (Boulton et al.; Wilson).

People with IDD are more likely to attend or be admitted to an acute general hospital. A UK study estimated 26% of people with IDD were admitted per year compared to 14% of the general population (Band). A Canadian study found that people with intellectual disability were approximately six times more likely to be admitted for an ambulatory care sensitive condition and suggested the large discrepancy in rates of hospitalization is an indicator of inadequate primary care for this vulnerable population (Balogh et al. 2010). However, they also experience many barriers to hospital care including systemic processes such as waiting times, staff attitudes, knowledge and communication, and the physical environment (Backer, Chapman, and Mitchell).

Beyond these factors are challenges associated with access to healthy lifestyles, such as the lack of support for healthy diets (Rimmer and Yamaki), exercise or resources to accessible equipment, or inclusion in sporting activities (Bodde and Seo). In addition,

mainstream health promotion and disease prevention messages are often inaccessible and inappropriate to many people with IDD, especially where the information requires health or general literacy or a conceptual understanding of the long-term health consequences of such behavior.

Provide Health Services Needed by Persons with Disabilities Specifically Because of Their Disabilities

For some with a disability, such as individuals with Autism Spectrum Disorder, waiting for a consultation can cause extreme distress and may result in unpredictable behavior as they express their concerns and potentially disturb other patients or staff. Some health services have strategies to address this issue; however, the uncertainty about whether these strategies will be in place prior to attending appointments, renders many patients, their parents, and paid caregivers hesitant to seek care. It may lead to support staff avoiding or not prioritizing difficult visits to health services. In addition, where people with IDD have experienced painful events during previous visits, such as injections, their anxiety can be overwhelming. General anesthesia is commonly required to facilitate medical and dental investigations or procedures but may not be readily available.

Even the seemingly simple issue of physical access for those with mobility difficulties can be a barrier to access, as many medical and other health care clinics do not have wheelchair access or consulting rooms with height adjustable examination beds or hoists to allow safe transfer of the patient. In Australia, only in the past year have height adjustable examination couches been recommended for primary healthcare providers (Royal Australian College of General Practitioners).

Beyond access barriers to healthcare are the fundamental needs for the clinician to gather a clear and accurate health story from the individual. For many people with IDD, recall, communication, and speaking up for themselves about their mental or physical sensations or feelings is difficult, and for some it is impossible. Evidence suggests people with IDD do not present with health concerns as often as the general population and when they do come to the attention of healthcare practitioners, the process of assessment makes accurate diagnosis less likely as practitioners struggle to comprehend the validity and meaning of the presenting signs and symptoms (Whitfield, Langan, and Russell). The challenge of arriving at an accurate diagnosis and the development of a comprehensive management plan can be substantial (as the case involving Jenny aptly illustrates; see Box 1). This challenge can be exacerbated by the extra time needed in this situation as a result of under-resourcing and the fragmentation of social and healthcare services (UK Department of Health; U.S. Department of Health and Human Services).

Despite early mortality, high levels of unmet health needs and a clear failure of the health promotion and healthcare systems to address deficits in the health and healthcare of people with IDD, few resources are directed to this population. In most countries, health care providers are poorly trained to address these needs and whatever expertise is available is located in small, poorly funded centers or services that continually face the threat of defunding. Only two countries have medical specialists specifically trained in the area (the Netherlands and the UK) and only the former trains nursing specialists. Elsewhere, the

training of general health professionals in pertinent issues remains *ad hoc*, unsubstantial, and inadequate, providing little basis for confidence of patients with IDD and their families in the knowledge, skills, and attitudes of the health practitioners (Lennox and Diggins; Torr et al.).

Box 1

Jenny communicates using gestures that can only be interpreted by a few people who know her well. She requires support for eating, transport, and personal care. She has started moaning continuously and “hitting out” for the past three months. Only after multiple visits and investigations by health practitioners were the two painful dental abscesses found and treated. After recovering from the procedure, Jenny stopped moaning and hitting out.

One targeted health initiative has a gold standard evidence of effectiveness: the primary care based health assessment. A health check (or assessment) has been shown to substantially increase health promotion and disease prevention activities compared with usual care (Lennox et al. 2011). Embedded in this tool is a systematic health history collection and a series of prompts to ensure unmet health needs are considered.

There is a dearth of studies that rigorously evaluate the organization of health care services for persons with IDD (Balogh et al. 2008). Funding for healthcare evaluation research remains limited and this population is often excluded from generic research or is not identified within general population data sets (Lin et al.). People with IDD are commonly excluded, either actively or passively, from significant generic health research as they provide an additional burden to the researcher to gain informed consent for the research or to gather information by written questionnaires or interviews. The lack of consistent and rigorous medical research is a major structural barrier to effectively addressing the overlapping healthcare needs of this population.

Prevent Discriminatory Denial of Health Care or Health Care Services on the Basis of Disability

The discrimination of people with intellectual and developmental disability starts from pre-conception and carries through beyond their death. The entry and exit from life bookend an existence where the intrinsic dignity of life constantly remains under threat. When parents consider their future child, their expectations are to have a “normal and healthy baby.” When parents first become aware that their newborn has a disability, they may experience grief and loss. Over time, many express shame for that immediate response (Bingham, Correa, and Huber).

In resource rich countries, such as Australia, pregnant women are offered screening tests to determine if their child is at risk of an abnormality. If an abnormality is detected, parents commonly terminate the pregnancy. In about 90% of cases where a baby is detected to have Down syndrome, the parents chose to terminate (Choi, Van Riper, and Thoyre; Collins et al. 2008a, 2008b). Questions raised by terminations of these pregnancies include, but are not limited to: Did the future parents really understand the decision they were

making when they chose termination of pregnancy? Did the information provided to them convey a true reflection of what the future held for this child, the parents, and other family members? Is such an understanding even possible, given that parents of children born with a disability typically describe a journey of new understanding and changing perceptions of their child?

Box 2

Lenny was born with Down syndrome and left to die by the medical staff. However, a nurse on duty at the time told Lenny's mother her baby was still alive. Lenny's mother fled the hospital with him. Over the next 35 years Lenny's mother refused treatment for Lenny's heart condition despite many visits to the emergency department. When Lenny's mother died his sister sought treatment; however, it was too late and Lenny died from his cardiac condition.

The discrimination of people with IDD also emerges during times of major life threatening illness and death. Families and paid support staff report that clinicians frequently assume the patient is not a candidate for resuscitation, or treatment is withheld as the clinician assumes the person has no quality of life (Wiese et al.). The case of Lenny (see Box 2) describes an extreme version of such medical neglect. Clinicians may advocate palliative care when curative interventions are very likely to be effective, beneficial, and hence indicated. More subtle, but no less potentially damaging, is clear evidence of inadequate diagnostic examinations of people with IDD (see Box 3), described by clinicians and documented in the literature (Heslop et al.). The discrimination of this population has profound negative effects on their lives generally and is demonstrated within the context of healthcare provision with potentially lethal consequences.

Box 3

Thirty-four year old Patrick has spastic quadriplegia and has a voice distorted by his severe muscle spasms. He takes a long time to convey his story and relies heavily on others. He is at risk of reflux of acid and cancer of his esophagus. The first referral to a gastroenterologist did not result in the key investigation being performed. Only after repeat referrals accompanied by journal articles linking this man's clinical presentation and increased risk of pre-carcinoma and cancer of the esophagus was the procedure performed; fortunately only treatable, pre-cancerous changes were found, which could be managed and monitored.

The Importance for Persons with Disabilities to Recognize Their Individual Autonomy and Independence, Including the Freedom to Make Their Own Choice

In many situations, the fundamental right for self-determination and inclusive decision making is violated for people with intellectual and developmental disability. These situations include the choice of co-inhabitant within their own home or their involvement in occupational, vocational, and leisure activities, as well as the choice of what, when, and how much to eat, smoke, or imbibe. It is not uncommon for the best interests of the system of

care or those who employ support staff to be considered first, rather than the individuals with IDD. Depending on their decision making capacity, individuals with IDD may be left with varying degrees of independence in relation to decisions that affect their lives (as the case of Mary illustrates; see Box 4). However, systems of support for people with IDD often fall short if they are unable to carefully assess the level of competence of the person with IDD or are unwilling to carefully balance the interests of all involved and implement a response that is considered, individualized, respectful, and inclusive.

Box 4

Mary came to her health practitioner deeply distressed, as her adult son lives in supported accommodation where the service provider believes in her son's right to choose what to eat and drink, despite his morbid obesity and the dire medical consequences of his decisions, which he had no capacity to understand or anticipate. Mary wants limits placed on his access to food items; however the service provider refuses to implement "restrictive practices" and her son becomes more obese.

Further, people with IDD are often restricted in their expression of sexuality and close human relationships although they have the same needs as the rest of the population (Noonan and Taylor Gomez; Taylor Gomez). Systems of support surrounding people with IDD largely remain focused on harm minimization and risk management (Pownall, Jahoda, and Hastings; Taylor Gomez). Fear of the consequences of sexual expression has led to mass sterilization of people with intellectual disabilities; the procedure is often performed even today in some countries without the consent of the person being sterilized (Roy, Roy, and Roy). The very real risk of abuse and sexual exploitation are ever present for all vulnerable groups; however, too often the response is overly blunt and merely denies the person's need for sexual expression. In Queensland, Australia it is illegal to have a sexual relationship with a person with IDD (Roy, Roy, and Roy).

Communicating with a person with IDD about death and dying holds many challenges such as how, when, and who is best to deliver the news of their impending death. Given the right support, people with intellectual disability will understand dying (McEvoy, MacHale, and Tierney). Although many paid staff are very committed to providing support and inclusion of the person in the decision making process, their ethical positions on these issues may not be shared by the person's parents or health practitioners and other staff members (Wiese et al.). Differences and conflicts regarding how, what and when information is provided can arise. Negotiating this process requires a high level of skill and commitment of time that the paid support staff, family, or health practitioners may not possess (Wiese et al.). Only recently have training and resources been developed to assist in the process, to train staff and others to negotiate end of life care (National Health Service).

Conclusion

People with intellectual and developmental disability experience unacceptable health inequities that are exacerbated and, at times, even caused by poor system responses to their health needs. Too often, the health sector falls short of meeting the requirements of

international declarations, such as the CRPD, requiring the acceptable, accessible, and appropriate delivery of health and support services to persons with disability. Further, as a community, our approaches to people with IDD are overly homogenous and fail to consider the capabilities and contributions that individuals among this diverse population can make towards their own health and well-being.

In this paper, we have briefly touched on some of the key issues we experience as practitioners and researchers who are attempting to make contributions to the improved health and wellbeing of people with IDD. Through this discussion, we have highlighted that we have far to go before we achieve the highest attainable standard of health as required by the CRPD. In particular, we must continue our efforts to build multidisciplinary bridges and work collaboratively to improve attitudes and awareness among the community, professionals and key decision-makers. We must aim for the complementary goals of inclusion and reduced health inequities among one of the most vulnerable and marginalized groups. Together, we must insist that governments direct substantial resources to improve the physical and mental health and wellbeing of children, adolescents, and adults with intellectual and developmental disability. We must work together to ensure the aspirations described in Article 25 of the United Nations *Convention on the Rights of Persons with Disabilities* (United Nations) are actively pursued and achieved.

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