Addressing health inequality and inequity for people with intellectual disabilities: a collective responsibility for all nurses

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Abstract

Purpose – *People with intellectual disabilities are high users of acute hospital care. Given their varied and often complex health-care needs, they often experience health inequalities and inequities, contributing to poorer health outcomes. As nurses are the largest health-care workforce with a patient-facing role, they have an important responsibility in meeting this populations health needs. The purpose of this paper is to explore key issues relating to the role nurses play in providing equitable health care for people with intellectual disabilities.*

Design/methodology/approach – *This service feature draws upon relevant literature to examine key contextual issues highlighting the importance of nurses in providing equitable health care for people with intellectual disabilities.*

Findings – *The findings from this service feature highlight the importance of nurses taking a leadership role in advocating for, and actively supporting the health needs of people with intellectual disabilities. Nurses' leadership role, along with implementing reasonable adjustments, should be underpinned by education and training relating to the bespoke health needs of people with intellectual disabilities. This should help nurses promote the health and well-being of this population.*

Originality/value – *Addressing this populations health needs is a collective responsibility of all nurses. There are many examples of how nurses can be supported through policy, education, training and advocacy and this needs to be considered by key stakeholders and addressed as a matter of priority.*

Keywords *Human rights, Learning disabilities, Intellectual disability, Assessment, Unmet health needs, Adult social care*

Paper type *Viewpoint*

Introduction

Intellectual disabilities are a heterogeneous condition with varying aetiologies which affects approximately 1%–3% of the global population (Maulik *et al.*, 2011). It arises during the period from conception to the beginning of adulthood and includes delays and limitations both in intellectual functioning and adaptive behaviour (Luckasson, 2016). People with intellectual disabilities have poorer physical and mental health than the general population, typically occurring at a younger age and continuing throughout the life course (Liao *et al.*, 2021; McMahon and Hatton, 2021). Poorer health is not only linked to the causation of intellectual disabilities, rather it is potentially explainable in terms of the challenges they experience, such as persistent deprivation, lack of opportunity and barriers accessing health services (Emerson and Hatton, 2014). This service feature discusses the implications for nurses in addressing these issues, highlighting the importance of nurses in providing equitable health care for people with an intellectual disability.

Increased and complex health needs of people with intellectual disabilities lead to frequent use of health-care services (McMahon *et al.*, 2023). Acute health-care settings often present particular challenges (Iacono *et al.*, 2014; Michael and Richardson, 2008; Phillips, 2019), and it is frequently reported that they represent negative experiences and greater risk of poorer outcomes for people with intellectual disabilities (Iacobucci, 2023; Iacono *et al.*, 2014). Reports like 'Death by Indifference' (Mencap, 2012) and subsequent LeDeR reports (2023) highlight these realities, underscoring the critical need for proactive measures to ensure equitable health-care provision (Heslop *et al.*, 2013; Ramsey *et al.*, 2022).

Providing care for this population has important implications for nurses as they are by far the largest provider of health care worldwide. However, some nurses can face challenges navigating systems which are not typically designed to effectively care for people with intellectual disabilities underlining the importance of providing equitable health care for this population. In terms of inequality and inequity, this paper refers to health inequality as differences in health status or outcomes or in the distribution of health determinants across populations representing the concept "sameness", while health inequity relates to those differences that are unjust and avoidable representing the concept "fairness" (Chapman *et al.*, 2024). For example, inequality relates to a descriptive difference such as "access to health care" being unequal for different populations due to factors like availability or socioeconomic status. In contrast, inequity relates to factors that are unfair and unjust that arise from systematic influences when issues such as inadequate policies, reasonable adjustments or discrimination are not addressed.

Access to health care: a human right issue

It is crucial to clarify from the outset that the provision of health care for people with intellectual disabilities is a human rights issue under international frameworks. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) clearly sets out its aim "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities" (United Nations, 2007, p. 4). This includes the full and equal enjoyment of health and equitable access to health care (Article 25) mandating equality, accessibility and respect for dignity in health-care provision. It is clear, therefore, that any inequality in respect to health or health care (including access under Article 9, which mandates the removal of barriers that prohibit access to public services) for individuals with intellectual disabilities represents a violation of their human rights. That such inequity exists is evidenced by the marked differences in health outcomes between people with intellectual disabilities and other matched cohorts in society (Baksh *et al.*, 2021; Mahar *et al.*, 2023). Importantly for nurses, it is worth considering that such outcomes may be grounded in conscious or unconscious bias, whereby some health interventions may not be made available to people with intellectual disabilities. The COVID-19 pandemic underscored significant inequalities and inequities in health-care outcomes for people with intellectual disabilities. In one UK study, Baksh *et al.* (2021) identified that this population had a 56% increased risk of dying from COVID-19 after they were hospitalised even after accounting for confounding factors. Further concerning findings describe where patients with intellectual disabilities were less likely to be treated with tracheal intubation, or be admitted to intensive care settings, despite having more severe symptoms on admission.

Stigma across the lifespan for people with intellectual disabilities is well documented, and this brings associated negative health outcomes (Hotez *et al.*, 2023). Research has shown that attitudes of health-care professionals can contribute to pervasive stigma (Hotez *et al.*, 2023) where nursing staff in acute care settings were found to have more negative emotions and fewer positive emotions while caring for a person with intellectual disabilities compared to a person with a physical disabilities (Lewis and Stenfert-Kroese, 2010). While negative attitudes do not infer negative behaviour, some research conducted with those supporting people living with dementia found that negative attitudes and individual staff characteristics

appeared to be associated with a negative impact on the quality of person-centred care delivered (Boumans *et al.*, 2021; Gerritsen *et al.*, 2019). Taken together, these issues raise some key questions for nurses who care for people with intellectual disabilities from the perspectives of advocacy, care delivery and treatment decisions.

Equitable health = care provision and meeting of health outcomes for people with intellectual disabilities must be premised on ensuring that the current service paradigms are grounded in human rights. This, however, requires the collective efforts of nurses, health-care workers, people with intellectual disabilities and formal/informal carers. A crucial step in addressing health inequalities and inequities faced by this population is supporting primary care services to provide accessible quality care. Suggested strategies to achieving this may include the following:

- the use of regular health checks to identify risks and increase empowerment for people with intellectual disabilities and their carers;
- education of health professionals in the use of communication enhancement tools (e.g. health passports) to support better communication;
- revision of primary care system structures to ensure they address the needs of people with intellectual disabilities (Lennox *et al.*, 2015); and
- implementation of anti-stigma interventions to positively impact the knowledge and attitudes of health-care professionals, and the care they deliver (Sreeram *et al.*, 2022).

Such strategies and perspectives will promote the provision of equitable health care by nurses to people with intellectual disabilities.

Nursing principles

Nursing principles are grounded in human rights and demand that care be person-centred and delivered with dignity and respect. At the core of this is the recognition that all persons, irrespective of levels of ability, have the same rights as other members of society (Health Service Executive, 2018). Cognisant of the fact that modern nursing practice is often delivered in a variety of settings, interdependent of disability service provision, nurses need to ensure that each person is offered equal health-care access (Mafuba, 2023). Nursing principles can be further supported by the FREDA Principles (Fairness, Respect, Equality, Dignity and Autonomy) (Curtice and Exworthy, 2010), which provide a framework for all nurses for ensuring that all individuals with intellectual disabilities receive care that upholds their human rights.

Evidence based, person-centred care is fundamental when supporting the health of people with intellectual disabilities, and is associated with improved health outcomes (Doody *et al.*, 2023). It is important for nurses to recognise the link between person-centred care and human rights, and to ensure that this is communicated to the wide range of people who support the person's health, including health and social care professionals, voluntary providers and caregivers, to ensure that decision making is, as much as possible, guided by the person's choices and desires.

Although it is accepted that person-centeredness underpins all nursing practice, those nurses who do not regularly support people with intellectual disabilities should be aware that it pervades their care and support throughout all aspect of their lives, not only in relation to health. It facilitates informed decision making, promotes autonomy and self-determination, while safeguarding those who may be unable to make their own decisions. At its core is the provision of compassionate, dignified care, recognising the uniqueness of each person, their ways of communicating, the complexity of their health-care conditions and multi-dimensional nature of their care needs. The relationships between nurses, people with intellectual disabilities and their caregivers are driven by human rights, inclusion, self-advocacy, protection and support for independent living. It is critically important, therefore,

that these principles continue to guide the delivery of care to this population in health-care settings (Doyle *et al.*, 2016).

Educational and training needs

Furthermore, it is crucial that education is provided to health professionals if quality, equitable health care is to be achieved (Watkins and Colgate, 2016). Such education and training input can be viewed as It has been noted, however, that such education is often lacking in respect of the needs of people with intellectual disabilities, and this has been identified as one of the most significant barriers to making health care accessible for these people (Lalive d'Epinay Raemy and Paignon, 2019; Trollor *et al.*, 2016a; Trollor *et al.*, 2016b; World Health Organization, 2022). From a nursing perspective, it is noteworthy that Ireland and the UK are the only jurisdictions to offer direct entry to pre-registration intellectual (learning) disability undergraduate nurse education (Gates *et al.*, 2020; Mafuba, 2023). In some parts of The Netherlands, nursing students can specialise in intellectual disabilities in the final year of their generic nursing programme; however, in other countries that offer generic undergraduate nurse education programmes, there is minimal input in the curricula on the knowledge and skills required to deliver quality care and support the person with intellectual disabilities (Appelgren *et al.*, 2018; Robinson & Trollor *et al.*, 2016a). Keenan and Doody (2023) have recommended curricular changes to address these deficits.

Health-care providers have identified the need for education and training in how to support people with intellectual disabilities (Doherty *et al.*, 2020; Hemm *et al.*, 2015; Lewis *et al.*, 2017). Furthermore, health-care professionals have reported feeling unprepared, fearful, and lacking in knowledge regarding intellectual disabilities and the challenges with communication (Noronha and Pawlyn, 2019). Deficits in care across acute settings could be ameliorated if health-care professionals had a greater understanding of legislation, policies and best practice guidelines which safeguard people with intellectual disabilities from discriminatory and inequitable treatment in health care (Appelgren *et al.*, 2018; Iacono *et al.*, 2014; McCormick *et al.*, 2021). Critical issues typically relate to compassion and respect, communication and information sharing. Including intellectual disabilities related content in nursing and interdisciplinary curricula will be crucial in equipping health-care professionals with the knowledge, skills and competencies required to support the person with intellectual disabilities at all stages of their health-care journey. Increased and appropriate use of communication, application of reasonable adjustments and access to appropriate resources will positively impact that journey as will the introduction of liaison intellectual disabilities nurses (McCormick *et al.*, 2021).

Alongside curricular change, the provision of training interventions may also help redress health inequalities and inequities experienced by this population. Studies conducted to explore the outcomes of such training have reported positive impact for those involved (Hemm *et al.*, 2015; Ryan and Scior, 2016; Soni *et al.*, 2014). It is suggested that the inclusion of individuals with intellectual disabilities in such training programmes may help to conceptualise learning (Hemm *et al.*, 2015). This exposure is also associated with more positive attitudes toward individuals with intellectual disabilities (Brown and Kalaitzidis, 2013). Such contact and training in this area could also be advantageous in promoting interest in seeking opportunities to specialise in this field (Ryan and Scior, 2016; Soni *et al.*, 2014).

The use of simulation may also offer a promising avenue for preparing nurses to support people with intellectual disabilities and ameliorating ethical issues regarding capacity and consent. Simulation is increasingly being used in training delivery for health-care professionals and several studies report positive findings in its use for intellectual disabilities training, with greater understanding of reasonable adjustments, improvement in communication skills and interactions with individuals, a positive shift in attitudes and enhanced understanding, confidence and knowledge demonstrated (Billon *et al.*, 2016;

Iannelli *et al.*, 2020; Watkins and Colgate, 2016). However, it is acknowledged that simulation training is more expensive than traditional didactic and e-learning approaches but the sustainable impact on participants, health-care environments and the improvement of the experience of individuals with intellectual disabilities could be more cost effective in the long term (Iannelli *et al.*, 2020).

Intellectual disabilities clinical nurse specialists and liaison nurses have been identified as being particularly useful in the delivery of training (Hemm *et al.*, 2015; Tuffrey-Wijne *et al.*, 2014; Walsh *et al.*, 2014). Indeed, a component of the intellectual disabilities clinical nurse specialist role involves supporting staff with education, training and advice (Doody *et al.*, 2017). The introduction of liaison intellectual disabilities nurses has been recognised as a positive support and having a significant impact in hospitals in the UK and Ireland (Brown *et al.*, 2016; Ní Riain and Wickham, 2023; Walsh *et al.*, 2014). One example in a National Health Service (NHS) hospital illustrated how partnership working was essential in the success of a screening programme for people with intellectual disabilities. The registered nurse in learning disabilities played a key role in providing training for screening programme staff and assisted them in understanding and establishing a reasonably accommodated care pathway. The development of training focused on specific needs of the group was a key component in the success of this initiative (Heslop *et al.*, 2019). However, while positive outcomes from such positions are reported, not all health-care settings have such posts in place. For example, in Ireland, this is now only an emerging role (Ní Riain and Wickham, 2023; Sheehan *et al.*, 2016). From an acute nursing perspective, these roles should be embraced and used as a supportive mechanism towards providing equitable health care for people with intellectual disabilities. Additionally, from the perspective of service delivery there is a need for ongoing commitment to develop training and support such specialist posts so as to ensure a sustained improvement in health outcomes for people with intellectual disabilities. Overall, to address the education and training needs of nurses, health-care providers should adopt ongoing mandatory training programmes integrating simulated experiences that reflect real life scenarios. These, supported by liaison nurses and curriculum changes are actional areas where improvements can be made.

Implementing reasonable adjustments

It is important that nurses consider that reasonable adjustments in health care are fundamental to reducing inequities experienced by people with intellectual disabilities. Communication barriers have wide-ranging negative consequences. For people with intellectual disabilities who typically have receptive and expressive communication difficulties, it is imperative that nurses make reasonable adjustments to support these individuals. An example of this is using a person's health passport which lets health-care staff know all about their abilities and needs as well as augmentative communication tools such as picture boards or simplified language and easy read material. Such adjustments can empower individuals with intellectual disabilities to actively engage in key decision-making (Burke *et al.*, 2023; Fleming *et al.*, 2023). While these may seem small or "non-high tech" interventions, they can ensure that a person's voice is heard and respected within the health-care process. The failure to make reasonable adjustments to the rights to assessable services under the UNCRPD is not just a practical barrier, but a breach of their fundamental rights.

Moreover, adopting alternative assessments in terms of health-care assessment is also important. For example, the use of quantitative heel ultrasound for evaluating bone health instead of the conventional DXA (dual-energy X-ray absorptiometry) acknowledges the need for adapted health-care practices (Burke *et al.*, 2019). Such adjustments facilitate a more inclusive and accessible approach towards assessment, removing barriers that individuals with intellectual disabilities might face in traditional assessment methods.

Adjustments, therefore, should be considered by nurses who are at the forefront of care delivery as they can be important advocates for people with intellectual disabilities.

Additionally, aforementioned intellectual disabilities liaison nurses can play an important role in supporting other nurses to develop reasonable adjustments within the health-care setting and thus facilitate the participation of individuals with intellectual disabilities (McCarron *et al.*, 2018; Phillips, 2019) ensuring that services are tailored to the specific needs of this demographic (Bur *et al.*, 2021). Liaison nurses can work alongside other nurses to undertake capacity assessments, develop individualised communication strategies and help bridge the gap between health-care providers, individuals with intellectual disabilities and their caregivers (Bur *et al.*, 2021). Through collaboration and effective communication, they can facilitate a health-care journey that is holistic, addressing both the medical needs and the unique requirements of these individuals (Doody *et al.*, 2023). In essence, integrating practical applications of reasonable adjustments into health-care practices is crucial for the health and wellbeing of individuals with intellectual disabilities. It is imperative to create an environment where health care is truly inclusive, fostering active participation and ensuring that no one is left behind. Using hospital passports, alternative and individual communication strategies, alternative assessments like the quantitative heel ultrasound with liaison nursing input are all examples that can help to ensure people with intellectual disability can attain equal and fair health-care congruent with the UNCRPD framework.

Conclusion

Addressing health inequalities and inequities that people with intellectual disabilities experience is critically important. As nurses are the largest health profession, nurses must take a leadership role and advocate for policy change, training improvements and systems design to accommodate the needs of people with intellectual disabilities to ensure they receive equitable health care. This service feature has attempted to contextualise some key issues that are central to reducing inequality and inequity. The obvious systemic challenges health-care services face may augment the poorer outcomes that people with intellectual disabilities are experiencing. The mainstream nature of health-care structures inevitably leads to challenges in respect of inclusivity, accessibility and sensitivity to the heterogeneous needs of groups such as those with intellectual disabilities. This creates genuine challenges for nurses who must try to balance the needs of this population on one level, while also working in an environment which hinders their ability to adapt and provide holistic person-centered care. The UNCRPD advocates that people with disabilities should receive the same care as everybody else and adaptations such as reasonable adjustments are necessary to achieve this. Along with education and training, nurses play a leading role in promoting the health and well-being of people with intellectual disabilities. By following the FREDA principles nurses can ensure that their practice is aligned with standards that promote the human rights of people with intellectual disabilities. However, nurses need support from, education and advocacy stakeholders to help address health inequalities to ensure equitable care for people with intellectual disabilities.

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