

# Health systems, health policies, and health issues for people with intellectual disabilities in England

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## Abstract

People with intellectual disabilities face health disparities, including in high-income countries such as the United Kingdom, despite publicly funded healthcare. This paper describes the healthcare system in England (a nation of the United Kingdom) for the general population, and more specifically for people with intellectual disabilities. Key legislation that impacts the lives of people with intellectual disabilities, such as the UK Equality Act 2010 (<https://www.legislation.gov.uk/ukpga/2010/15/contents>), the Mental Capacity Act 2005 (<https://www.legislation.gov.uk/ukpga/2005/9/contents>), and the UN Convention on the Rights of Persons with Disabilities, and its implementation in the United Kingdom, is discussed. The role of deinstitutionalization and the shift to living in the community for people with intellectual disabilities is also discussed. Programmes that have been implemented to address the health disparities experienced by people with intellectual disabilities are reviewed. Finally, the recent changes to healthcare organization in the UK, the COVID-19 pandemic, and the implementation of the Valuing People white paper are discussed.

## KEYWORDS

health care, health inequities, health policy, intellectual disabilities, United Kingdom

## INTRODUCTION

The United Kingdom (UK) is a constitutional monarchy that is composed of four devolved nations: England, Wales, and Scotland; and Northern Ireland. (Ministry of Justice, 2022) Each nation has its own healthcare system, thus for this paper, I will focus on the healthcare system in England. The National Health Service (NHS) was established in 1948 and is localized to each nation and provides comprehensive

healthcare to all residents of the UK that is generally free at the point of access (NHS, 2013). People with intellectual disabilities receive much of their care from generalist community-based providers and are less likely to receive healthcare in an institutional setting (Mansell et al., 2007). Despite similar availability of healthcare, adults with intellectual disabilities have a lower life expectancy and may be more likely to die from avoidable and easily treatable causes. Recent programmes in the UK aim to overcome these inequalities (National Institute for Health and Care Excellence, 2021). This article will focus on the health system, both generally and for people with intellectual disabilities, in England, although the health

**Abbreviations:** NHS, National Health Service; ICB, Integrated Care Board; ICP, Integrated Care Partnership; ICS, Integrated Care System; UN, United Nations.

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system in other nations in the UK (i.e. Scotland, Wales, and Northern Ireland) is similar. Legislation discussed frequently applies to all of the UK.

In 2021, the population of England was estimated to be 56 490 048 residents (Office for National Statistics, 2022). In spite of universal health coverage, only 55.7% of the general population was included in recent (2021–2022) health statistics regarding intellectual disabilities prevalence in England. Of those included in these statistics, 0.5% of patients were recorded by their general practitioner as having intellectual disabilities (NHS Digital, 2022). Under the Equality Act, 2010, the public sector has a legal duty to provide services to people with disabilities, including intellectual disabilities, and to make reasonable adjustments (Public Health England, 2020a). Some of these reasonable adjustments may include including clear, simple, and possibly repeated explanations of medical processes and treatments, assistance with attending medical appointments enabling people with intellectual disabilities to access comprehensive publicly-funded healthcare. In accordance with the Mental Capacity Act (2005) there may be a need for people with intellectual disabilities to have accommodation such as having another adult consent on their behalf for medical procedures, if the clinician decides that the person with intellectual disabilities may have difficulties with consent.

## HEALTH SYSTEM IN ENGLAND

The National Health Service was established in 1948 to provide comprehensive, free at the point of use care to UK residents (NHS, 2013). In England, funding for the NHS is voted on by the House of Parliament, and the money goes to the Department of Health and Social Care. The department is overseen by the Secretary of State for Health (Department of Health and Social Care, 2013). The majority of funding goes to NHS England. Prior to July 2022, many (although not all) funds went to Clinical Commissioning Groups which purchased and commissioned care (from both public and private/third party providers) and then the funds were received by NHS trusts and NHS providers (Department of Health and Social Care, 2013). Some, but not all health and social care were, and are still, monitored by the Care Quality Commission, an independent body that ensures national standards of quality and safety are met (Department of Health and Social Care, 2013).

## LEGISLATION REGARDING THE HEALTH SYSTEM IN ENGLAND

Under the Health and Social Care Act, 2022, Clinical Commissioning Groups were replaced by Integrated Care

Systems (ICs), composed of an Integrated Care Board (ICB) and an Integrated Care Partnership (ICP). ICBs are responsible for commissioning care and are accountable to NHS England, while ICPs have some membership from ICBs and integrate NHS and local authorities (who may provide social care and public health) to provide care (King's Fund, 2022). These new functions were established with the aim of better integrating health and social care locally. Such meetings allow providers to provide more joined-up care planning and delivery across sectors. As of July 1, 2022, there were 42 Integrated Care Systems (ICs) in England, highlighting some of the complexities of delivering care at the local level (NHS England, 2022). The aim of establishing ICBs and ICPs was to deliver more integrated care to patients and service users, allowing for more communication and collaboration between hospitals and health organizations, social care providers, and the community and voluntary sector. Especially since adults with intellectual disabilities may receive care from numerous providers, having structures that allow for greater communication and collaboration across organizations and providers may allow for more joined-up care, and ultimately better health outcomes (King's Fund, 2022).

At the local level, Integrated Care Systems (ICs) in conjunction with their constituents, commission primary and specialist healthcare. Primary care is mainly delivered by general practitioners (non-specialist physicians) and associated staff such as nurses, nursing assistants, and community pharmacies (Thorlby, 2020). General practitioners may refer patients to specialized care, which may be ambulatory or in-patient, and is delivered at public hospitals with different levels of specialization and different catchment areas. Most care delivered by the NHS is free at the point of contact, with the exception of some services (i.e. co-payments for prescription medications, fees for dispensing optometry products).

## Legislation regarding people with intellectual disabilities

The United Nations (UN) Convention on the Rights of Persons with Disabilities was adopted by the UN General Assembly on December 13, 2006, and its entry into force was May 3, 2008 (United Nations, 2007). The UK signed the convention on March 30, 2007, and the UK ratified the convention on June 8, 2009. In 2011, the Office for Disability Issues (HM Government, 2011) issued a report on how the UK government was meeting the UN Convention, especially in light of the Equality Act, 2010. The UN Committee on the Rights of Persons with Disabilities held an inquiry as to whether the UK was fulfilling its requirements under the Act in 2016, and the

UK issued a follow-up report with its progress meeting each article of the Convention in 2021 (Department for Work and Pensions, Disability Unit, 2021).

Much of the legislation in the UK relevant to people with intellectual disabilities comes from the Equality Act, 2010, which outlines the protected characteristics of people that cannot be discriminated against. These characteristics include age, gender reassignment, disabilities, marriage and civil partnership, race, religion or belief, sex, and sexual orientation. This legislation specifically addresses reasonable accommodations in housing, employment, provision of health and government services, education, and transport, and defines the forms of discrimination that are not allowed. The Equality Act, 2010 defines disabilities as: a person is disabled if he or she has a physical or mental impairment resulting in substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. 'Long-term' means that the effect of the impairment has lasted or is likely to last at least 12 months. This definition applies when determining whether someone is disabled for the purposes of this Act.

There are other pieces of legislation in the UK that apply to individuals with intellectual disabilities, and provision of health and social care. The Mental Capacity Act, 2005 covers processes for obtaining consent if the person is unable to provide consent, such as intellectual disabilities. Another key piece of legislation with regards to provision of healthcare is the Health and Social Care Act, 2012, which made major structural changes to the NHS. Further changes to healthcare provision were made by the Health and Social Care Act, 2022.

## THE ORGANIZATION OF HEALTH AND SOCIAL CARE FOR ADULTS WITH INTELLECTUAL DISABILITIES IN ENGLAND

Historically, much, but not all, of the healthcare for adults with intellectual disabilities was delivered as part of publicly funded institutions. However, beginning in the mid-twentieth century, there was a shift to delivering healthcare to adults with intellectual disabilities within the community, resulting in better health outcomes (Emerson & Hatton, 1996).

### Deinstitutionalization and its impact on the lives of adults with intellectual disabilities

In recent decades, there has been a shift from institutionalization of people with intellectual disabilities to community living in many European countries, including the

UK (Mansell et al., 2007). In the UK, including England, in recent years healthcare for adults with intellectual disabilities has been delivered through a mix of state (National Health Service or NHS) funding and private and benefits funding.

In 1948 with the founding of the NHS, much of the responsibility for caring for people with intellectual disabilities was transferred to NHS-run hospitals (Mansell et al., 2007), although some people with intellectual disabilities lived in the community. By the 1960s, there was growing public recognition regarding some of the problems of institutional care, and in 1971 there was an increasing focus to increase outpatient and community-supported care for adults with intellectual disabilities (Mansell et al., 2007). In the 1960s and 1970s when NHS Mental Handicap hospitals were decommissioned, initially, people with intellectual disabilities with less support needs were transferred to existing community supports like hostels and supported group housing or living with family or independently (Emerson & Hatton, 1996). The focus at the time was on residential support for people with more severe or complex needs (Emerson & Hatton, 1996), however since the 1990s advocates for community inclusion demonstrated in during this time that people with intellectual disabilities, even with complex needs, can live in the community with appropriate supports (Mansell et al., 2007). By the 1980s and 1990s, the community inclusion model, led by advocates with physical and sensory disabilities, was more widely adopted, and resulted in a greater focus on community inclusion (Mansell et al., 2007).

The shift away from institutional care has had positive impacts on the lives of adults with intellectual disabilities. In the 1990s, Emerson and Hatton (1996) found in their review that there was more engagement in activities, including social activities, and greater contact with staff in supported housing than institutional care, more social contact including with family members, and greater life satisfaction. Similarly, Hamlin and Oakes (2008) found that community based residential care led to greater social contact, while provision of care was still similar. By 2004, fewer individuals with intellectual or developmental disabilities received non-profit or for-profit institutional care (28% and 29%), and only 12% of individuals with intellectual disabilities were residing in NHS-funded hospitals (Emerson, 2004).

Although people with learning disabilities are increasingly living in the community, they receive a hybrid model of generalist and specialist support. Much primary care is delivered by community-based general practitioners and other providers at general practitioner surgeries and community pharmacies, with more specialized medical care delivered at hospitals. Community-based learning disabilities nurses, a profession that is unique to the UK and the Republic of Ireland, also provide and coordinate much

community-based care for adults who are registered with their general practitioner as having an intellectual disability (Breau et al., unpublished data). The aim of this unique health professional role is to provide preventive care and coordinate healthcare for this group.

Despite the growing push for adults with intellectual disabilities receiving care and support in the community, some adults with intellectual disabilities are still hospitalized long-term, for multiple reasons. After the Winterbourne View Hospital scandal in 2011, when it became public that some residents were abused at this private hospital and staff were prosecuted, the government introduced a plan to encourage health and social care to work more closely together, and for the CQC to more closely and thoroughly investigate facilities providing care (Department of Health, 2012). In 2015, the Building the Right Support policy paper was issued, to further push for more joined-up services for adults with intellectual disabilities (Local Government Association, ADASS, & NHS England, 2015). Given the recent legislation (Health and Social Care Act, 2022) calling for greater integration of health and social care, these developments may result in more integrated care and ultimately better health outcomes for people with intellectual disabilities.

## Health care provision for adults with intellectual disabilities

The NHS provides general and specialist care for adults with intellectual disabilities similar to the general population. However, in recent years, there have been programmes that have been commissioned in collaboration with the NHS with the aim of reducing health inequities. These programmes include the Learning Disabilities Mortality Review Programme and the Oliver McGowan Mandatory Training programme to ensure adults with intellectual disabilities are prescribed medication appropriately, and additional training for healthcare providers. It is important to note that frequently the term for intellectual disabilities used by the UK government and NHS is “learning disabilities”, which includes individuals with intellectual disabilities.

In 2013, the Department of Health established the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities to investigate the premature deaths of people with intellectual disabilities especially in southwest England (Kennedy et al., 2021). Consequently, in 2017, the Learning Disabilities Mortality Review Programme was commissioned by Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England, with the aim of investigating the deaths of people with intellectual disabilities and/or autism, and the health and social care they

received (NHS, n.d.). This programme aims to improve care, reduce health inequalities, and prevent early deaths in people with intellectual disabilities and autism, and has carried out over 9000 reviews to date. A 2018 report found many of these deaths were attributed to preventable and treatable conditions: sepsis (11% of deaths), constipation, dysphagia and associated aspiration pneumonia (16%), and cancer (14%), including cancers for which population-based exist (NHS England, NHS Improvement, 2019).

Other recent initiatives to enhance the health care provided include the Learning Disabilities Core Skills Education and Training Framework (Skills for Health, Health Education England and Skills for Care, 2016) that was established to provide training to staff providing care to people with intellectual learning disabilities. It draws from existing legislation, and provides knowledge and skills to staff who have contact with people with intellectual disabilities. This framework was updated in 2019, and consists of three levels of training: training for health and social care staff and family members who may make decisions about care for people with intellectual disabilities, health and social care staff who may not be in a decision-making role but provide care to adults with intellectual disabilities, and staff who need a general awareness about intellectual disabilities. (Skills for Health, Health Education England and NHS England, 2019). While this training is not legally binding by legislation, it is highly recommended and promoted to health and social care staff by the NHS and affiliated organizations.

Despite this initiative, prescribing of certain medications, such as antipsychotic medications, is greater in people with intellectual disabilities: 14.5% of people with intellectual disabilities were prescribed this medication in 2021–2022, compared to approximately 0.9% of the general population (NHS Digital, 2022). In response to the 2016 death of a teenager, Oliver McGowan, who had autism and had antipsychotic medication administered improperly, and the resulting campaign led by his mother, the Oliver McGowan Mandatory Training programme was implemented and a report was commissioned by NHS Health Education England (2023). This programme aimed to train healthcare professionals on proper psychotropic medication prescribing for people with intellectual disabilities and/or autism (National Development Team for Inclusion, 2022).

In 2001, the Valuing People White Paper was released, outlining several key policies and programmes for individuals with intellectual disabilities (Department of Health, 2001), including the development of Partnership Boards. This report was followed up in 2010 with the publication of the Valuing People Now Report (Department of Health, 2010), although there has been little policy action on this topic since then. However, given the recent stories in the media regarding people

TABLE 1 Key recent studies regarding the healthcare system for adults with intellectual and disabilities.

Author and year	Title of publication	Type of publication	Aim	Reference
Bur et al. (2021)	The impact of intellectual disability nurse specialists in the United Kingdom and Eire Ireland: An integrative review	Integrative review	The objective of this review was to systematically identify, appraise and synthesize the best available evidence for the impact of intellectual Disability Nurse Specialists in comparison with an alternative or no intervention	Bur, J., Missen, K., & Cooper, S. (2021). The impact of intellectual disability nurse specialists in the United Kingdom and Eire Ireland: An integrative review. <i>Nursing Open</i> , 8: 2018–2024
Cooper et al. (2018)	Management and prevalence of long-term conditions in primary health care for adults with intellectual disabilities compared with the general population: A population-based cohort study	Cross-sectional observational study (in Scotland)	The aim of this study was to measure the management of long-term conditions within primary health care for adults with intellectual disabilities, and to compare this with the general population, using indicators of best practice from the Quality and Outcomes Framework	Cooper, SA, Hughes-McCormack, L., Greenlaw, M., McConnachie, A., Allan, L., Baltzer, M., McArthur, M., Henderson, A., Melville, C., McSkimming, P., & Morrison, J. (2018). Management and prevalence of long-term conditions in primary health care for adults with intellectual disabilities compared with the general population: A population-based cohort study. <i>Journal of Applied Research in Intellectual Disabilities</i> . 31(S1): 68–81
Glover et al. (2017)	Mortality in people with intellectual disabilities in England	Data linkage study (in England)	The authors identified the rates and patterns of mortality of people living in England and identified by their GP as having intellectual disabilities, in relation to age, sex and causes of death	Glover, G., Williams, R., Heslop, P., Oyinlola, J., Gray, J. (2017). Mortality in people with intellectual disabilities in England. <i>Journal of Intellectual Disability Research</i> . 61(1): 62–74
Heslop et al. (2014)	The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study	Quantitative	Aim of Confidential Inquiry to establish how similar or different circumstances of death in people with intellectual disabilities were to people without intellectual disabilities	Heslop, P, Blair, P, Fleming, P, Hoghton, M., Marriott, A., & Russ, L. (2014). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study <i>Lancet</i> . 383: 889–895
Paton et al. (2016)	Quality of prescribing of antipsychotic medication for people with intellectual disability under the care	Quantitative	To determine the prevalence and quality of antipsychotic prescribing for people	Paton, C., Bhatti, S., Pirandare, K., Roy, A., Barnes, T. (2016). Quality of prescribing of antipsychotic medication

(Continues)

TABLE 1 (Continued)

Author and year	Title of publication	Type of publication	Aim	Reference
	of UK mental health services: a cross-sectional audit of clinical practice		with intellectual disability	for people with intellectual disability under the care of UK mental health services: a cross-sectional audit of clinical practice. <i>BMJ Open</i> , 6: e013116

with intellectual disabilities being placed long-term in in-patient situations, NHS England, as part of its Long-Term Plan, unveiled the Mental Health, Learning Disability and Autism Inpatient Quality Transformation Programme in 2022 to help address these issues. (NHS England, [n.d.](#)). It remains to be seen if some of these policy actions will be translated into actions addressing the health inequalities experienced by people with intellectual disabilities.

## KEY RECENT STUDIES REGARDING THE HEALTH AND SOCIAL CARE SYSTEM FOR ADULTS WITH INTELLECTUAL DISABILITIES

In Table 1, five articles that address the health of people with intellectual disabilities, are summarized to provide greater information about key issues affecting healthcare provision in adults with intellectual disabilities in England. These articles provide information regarding some of the contemporary health issues raised in this manuscript, including the role of the learning disability nurse in the UK, greater information and data on mortality patterns for adults with intellectual disabilities in England, and data on adults with intellectual disabilities' experiences accessing health care, including accessing primary care and overprescription of anti-psychotic drugs (Bur et al., [2021](#); Cooper et al., [2018](#); Glover et al., [2017](#); Heslop et al., [2014](#); Paton et al., [2016](#)).

## CONCLUSIONS AND FUTURE DIRECTIONS

Healthcare in England is often provided free at the point of access, and there are generally, with the exception of Learning Disabilities Nurses, limited specialist health services for adults with intellectual disabilities. Recent legislation introduced in the United Kingdom, the Health and Social Care Act, [2022](#), may have an impact both on how health care is organized and commissioned and will,

through ICBs and ICPs, lead to more collaborative planning between the health and social care sectors. Other initiatives in England, such, Oliver McGowan Mandatory Training programme to monitor medication prescribing to people with intellectual disabilities, and training for health and social care staff may have an even greater impact in the coming years.

The COVID-19 pandemic has also had a major impact on the health of adults with intellectual disabilities. Due at least in part to this health challenge, Public Health England was disbanded in 2021 and replaced with the UK Health Security Agency and the Office for Health Improvement and Disparities (Public Health England, [n.d.](#)). While the latter aims to improve health and reduce health disparities, it remains to be seen if this agency facilitates reducing the health disparities faced by adults with intellectual disabilities (Office for Health Improvement and Disparities, [n.d.](#)). In addition, the death rate from February 2020–June 2020 for COVID-19 for adults who were identified as having intellectual disabilities was 240 per 100 000, a rate 2.3 times higher than the general population (Public Health England, [2020b](#)). Given some of the other challenges people with intellectual disabilities faced with accessing health and educational support (e.g. Jeste et al., [2020](#)) and the impact of COVID-19 on the health of people with intellectual disabilities more generally (Totsika et al., [2021](#)), it remains to be seen the long-term impact of the COVID-19 on healthcare provision for adults with intellectual disabilities. Additionally, given the increasing focus of the NHS on providing preventive care and chronic disease management, and moving away from acute care, the health disparities faced by this group may be reduced.

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## CONFLICT OF INTEREST STATEMENT

The author declares no conflicts of interest.

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