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# Humanising health and social care support for people with intellectual and developmental disabilities: Protocol for a scoping review

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## Abstract

**Background:** Healthcare is shifting towards a more person-centred model, however, people with intellectual and developmental disabilities can still experience difficulties in accessing equitable healthcare. Given these difficulties, it is important to consider how principles such as empathy and respect can be best incorporated into health and social care practices for people with intellectual and developmental disabilities, to ensure they are receiving humanising and equitable treatment and support.

**Objective:** The purpose of this scoping review is to provide an overview of the current research landscape and knowledge gaps regarding the development and implementation of interventions based on humanising principles that aim to improve health and social care practices for people with intellectual and developmental disabilities.

**Methods:** The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) and Population, Intervention, Comparator, Outcome, and Study (PICOS) frameworks will be used to structure the review. Six databases (PubMed, MEDLINE, Embase, CINAHL, PsycInfo, and Web of Science) will be searched for articles published in English in the previous 10 years that describe or evaluate health and social care practice interventions under-pinned by humanising principles of empathy, compassion, dignity, and respect. Two reviewers will collaboratively screen and select references based on the eligibility criteria and extract the data into a predetermined form. A descriptive analysis will be conducted to summarise the results and provide an overview of interventions in three main care areas: health care, social care, and informal social support.

**Results:** Results will be included in the scoping review, which is expected to begin in October 2022 and be completed and submitted for publication by January 2023.

**Conclusions:** This scoping review will summarise the state of the field of interventions that are using humanising principles to improve health and social care for adults with intellectual and developmental disabilities.

## Keywords

Developmental Disabilities; Intellectual Disability; Delivery of Health Care; Patient Care Management; Social Work; Social Support; Patient-Centered Care; Empathy; Respect

# Introduction

## Background

Although recent efforts are being made to address health inequities, people with intellectual and developmental disabilities (IDD) can experience difficulties in accessing high quality care [1,2]. People with IDD are more likely to have earlier health limitations as well as social determinants that are associated with poor health; healthcare professionals (for this paper, defined as any trained individual providing some type of health or social care support to people with IDD, eg, clinicians, healthcare support workers, allied health professionals, social care workers, etc.) are not necessarily trained and equipped to address their needs in an equitable and empowering way [1,3]. The delivery of healthcare has recently shifted towards a more person-centred, humanising model [4]. Person- or patient-centred models of care empower patients to share responsibility for their health, enhance the personalisation of the care, and enable patients to make informed choices about how to manage their health needs [5]. This shift demonstrates a recognition of the importance of underpinning care practices with humanising principles: empathy and respect for people's dignity, agency, uniqueness, sense of place, personal journey, and holistic well-being [6,7]. Delivering this model of care to a high quality presents a potential challenge in people with IDD, as they can experience barriers to equitable healthcare access such as difficulty communicating, lack of engagement, and fear and embarrassment that are affected and exacerbated by a lack of health education, lack of training for HCPs, negative attitudes of HCPs, short consultation times, and multimorbidities that can increase the complexity of their care needs [8-11]. Clinically, people with IDD have a significantly shorter life expectancy than the general population [12], many due to potentially preventable causes impacted by inequality in access to and provision of care disproportionate to the general population [13]. Given the health inequities faced by people with IDD, there is a clear need for improved means of ensuring that people with IDD are treated with empathy, dignity, and other humanising principles during their interactions with health and social care services.

## Rationale

Although several reviews have been conducted focussing on access and experiences of healthcare for people with IDD [14–17], none of these reviews included an overview of interventions to provide humanising care for people with IDD. Nor did a search of PROSPERO using the terms intellectual disabilit\* OR developmental disabilit\* AND healthcare OR health care OR social care AND humanising OR person centred OR patient centred OR empathy OR dignity OR respect identify any reviews on this topic. Therefore an argument for a comprehensive summary of what interventions are being developed and delivered to improve care for people with IDD in line with humanising principles exists.

Previous reviews have examined the experiences of, challenges to, and barriers for people with IDD in accessing health care services [14–18]. Key barriers identified included difficulties communicating between patients and healthcare professionals; poor quality or lack of services, often due to deficits in healthcare professionals understanding, training, and skills; and other organisational barriers relating to procedures or facilities [14–18]. Although the databases and years searched were comprehensive, the reviews focused on particular services (mental health [17], physical healthcare services [18], or acute care settings [14,15]) or populations (people with autism [18]). One was published in 2005, and therefore does not reflect any recent changes in healthcare delivery [16]. Although the reviews focused on the

experiences of the people with IDD, they did not provide an overview of any efforts being made to address and mitigate the barriers identified, and they did not specifically address humanising principles. A review by Busch et al (2019) focussed on humanisation of care - it highlighted the importance of empathy and respect in patient-provider interactions and the availability of sufficient time and resources to support this - but it was not specific to people with IDD [6]. None of the reviews identified focused on informal social support for adults with IDD. The search of PROSPERO only identified two planned or ongoing reviews that were relevant (a review of accessibility to public health services for people with IDD and a review about improving social care outcomes). However, neither focused on humanising principles or provided a broad overview of interventions and one was removed for no longer being within the scope of PROSPERO.

Given the barriers and health inequities that people with IDD experience when accessing health and social care services, an overview of the potential solutions being explored, developed, and implemented is needed. A scoping review will provide a summary of the state of the field, the inclusion of humanising principles in these interventions, and the strengths and weaknesses of the interventions. This will help to inform directions for future research and development and provide an initial assessment of the potential of these interventions.

## Aim and Research Question

The aim of this review is to identify and provide an overview of interventions that promote health and social care practices for people with IDD based on humanising principles. To do this, the scoping review will focus on the following research question: *What professional interventions are being developed and delivered to promote empathy, dignity, kindness and recognition in health and social care encounters with people with IDD?*

## Methods

The review and search strategy were structured using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR; Appendix A) [19] and the Population, Intervention, Comparator, Outcome, and Studies (PICOS) frameworks (see Table 1).

Table 1. PICOS framework

Population	Adults (>18 years old) with IDD
Intervention	Formal and informal health and social care interventions and practices under-pinned by humanising principles of empathy, compassion, dignity, kindness and recognition (e.g. referrals, assessments, clinical judgements, treatments, service management and commissioning, multi-agency team working, clinical and social training, informal community and peer support systems).
Comparator	How defined interventional types compare to the general adult population (outside of review population scope); however, no comparator is required for inclusion.
Outcome	The primary outcome will be the inclusion of humanising principles in professional interventions for health and social care encounters with people with IDD. Secondary outcomes will include the type and characteristics of

	the interventions, study type, perspectives of people with IDD about the interventions, and strengths and limitations of the interventions.
Study types	All study types that describe or evaluate a relevant intervention will be eligible for inclusion. Reviews, meta-analyses, and conference abstracts or posters where no full text is available will be excluded.

## Search strategy

This review will search 6 databases to identify potentially relevant references: PubMed, MEDLINE, Embase, CINAHL, PsycInfo, and Web of Science. Relevant MeSH terms and keywords were identified for the search based on a preliminary examination of the literature and previous reviews conducted on related topics. These terms were grouped into three themes and were searched using the following search string structure: IDD (MeSH OR Keywords) AND health and social care services (MeSH OR Keywords) AND humanising principles (MeSH OR Keywords) (Table 2).

Table 2. Search string

Category	MeSH	Keywords (in title or abstract)
IDD	Developmental Disabilities OR Intellectual Disability OR Learning Disabilities OR Autistic Disorder	“Developmental disabilit*” OR “learning disabilit*” OR “intellectual disabilit*” OR “learning disorder*” OR “developmental disorder*” OR “special need*” OR “mental retardation” OR “mental inadequac*” OR “mental handicap” OR autis* OR “Down syndrome” OR “Down’s syndrome” OR “fetal alcohol” OR “learning difficult*” OR “congenital cognitive impairment” OR “mental impairment*” OR “pervasive development” OR “ADHD” OR neurodivers* OR “neurodevelopmental disorder*”
Health and social care services	Delivery of Health Care OR Community Health Services OR Social Work OR Social Support OR Patient Care Management OR Patient Care Team OR Quality of Health Care OR Caregivers	Healthcare OR “health care” OR “health and social care” OR “primary care” OR “secondary care” OR “specialist care” OR “palliative care” OR “end of life care” OR “care service*” OR “healthcare service*” OR “health care commissioning” OR “health commissioning” OR referral* OR assessment* OR diagnos* OR “clinical judgement*” OR “clinical judgment*” OR formulation OR investigation* OR treatment* OR “service management” OR “multi-agency team” OR “multi-disciplinary team*” OR “clinical training” OR “social training” OR “professional development” OR “social care” OR “social work” OR

		“social service*” OR “care support” OR caregiver* OR “social care commissioning” OR “social support” OR “peer support” OR “informal care” OR “information social care” OR “unpaid care” OR carer* OR “informal carer*” OR “informal social support” OR “community care” OR “care networks”
Humanising principles	Patient-Centered Care OR Empathy OR Respect	Empathy OR compassion OR dignity OR kindness OR recognition OR respect OR humanis* OR humaniz* OR humanity OR “patient-centred care” OR “patient-centered care” OR “person-focused care” OR holistic OR relationship OR equity OR equality OR fair

### Inclusion criteria

The review will include studies that describe or evaluate any type of health and social care intervention for people with IDD (e.g. training, digital support, organisational or physical changes) that are based on humanising principles including empathy, dignity, and respect. Studies will be included where they describe the development of such an intervention or evaluate its implementation (at any stage). Therefore, all study types that describe or evaluate an intervention will be eligible for inclusion. Studies concerning people with any type of IDD will be eligible for inclusion.

### Exclusion criteria

As the aim is to provide a broad overview of interventions and humanising healthcare practices for people with IDD, there are few exclusion criteria. The focus of the review is on adults, however, so studies concerning humanising healthcare interventions for children with IDD (under 18 years old) will be excluded. Likewise, studies exploring humanising healthcare interventions for the general population will also be excluded. Studies that do not describe the development of or evaluate a specific humanising intervention (or set of interventions) for adults with IDD will be excluded (e.g. reviews, meta-analyses, conference abstracts or posters with no full text versions). To ensure that the review examines recent interventions and practices, the search will be limited to the previous 10 years; articles published before 2011 will be excluded. Studies published in languages other than English will be excluded, as the review team has limited ability to effectively undertake their analysis.

### Screening and Article Selection

References will be stored, and any duplicates automatically removed, using the citation management software EndNote X9. The first screening will be done by inputting keywords relating to the inclusion and exclusion criteria into EndNote X9’s search function. Two independent reviewers will screen the remaining titles and abstracts and the full-texts and exclude articles with reasons will be screened by two independent reviewers (with articles excluded with reasons). Any disagreements on eligibility at either stage will be discussed by the two reviewers and a third reviewer will be consulted if agreement cannot be reached. A

PRISMA flow diagram will be used to record the details of the screening and selection process (and reasons for exclusion) to ensure reproducibility and transparency.

## Data Extraction

The two reviewers will extract predetermined outcomes from the full texts (see Table 3). As with the article selection, any disagreements between the reviewers will be discussed and resolved by a third reviewer if necessary.

Table 3. Article information and data extraction

Article information	Data to be extracted
General study information	
	Year of publication
	Sample size (if applicable)
	Study type
	Target population (e.g. those with a specific developmental disability)
Health and social care practices / interventions	
	Category of intervention (healthcare, formal social care, or informal social care)
	Type of intervention
	Aim of intervention
	Humanising principle(s) based on
	Brief description of intervention (features / components)
Evaluation of intervention	
	Strengths of the intervention
	Limitations of / barriers to the intervention
	Perspectives of people with IDD (if reported)

## Data Analysis and Synthesis

A large variety of study types, measures, and outcomes is expected, so a descriptive analysis will be used to provide an overview of the different types of health and social care interventions using a three-pronged approach. The interventions will be categorised depending on their main area of focus: healthcare, formal social care, or informal social care. Within these categories, a thematic analysis of the evaluations of the interventions will be



conducted to summarise common strengths, weaknesses, and perceptions of the interventions. Common themes will also be explored across the three categories, to determine similarities, differences, and gaps in the inclusion of humanising principles in interventions across different care contexts. Any qualitative data relating to perspectives of people with IDD that is included in the studies reviewed will also be summarised using thematic analysis.

## Results

The full scoping review has not yet begun. It will be started in October 2022 and is expected to be completed and submitted for publication by January 2023.

## Discussion

### Comparison to Prior Work

Recent reviews relating to the access of health care services by people with IDD have identified a variety of barriers [15,17,18], but no reviews were identified that examined efforts to address these barriers using humanising principles. This scoping review will add to the state of the field by providing a summary of the current state of the field of research regarding the interventions that aid the humanising of health and social care for adults with IDD.

### Limitations

One limitation of the scoping review is that a risk of bias assessment will not be performed on the studies. Risk of bias assessments are not a standard requirement for scoping reviews [19], but it limits the ability to examine research gaps related to research quality, which could provide further insight on areas for improvement in the design, development, and evaluation of humanising interventions for health and social care for people with IDD. Another limitation is that scoping review methodology does not search for grey literature. Grey literature was excluded to keep the broad scope of the review manageable and to focus on evaluations that have been peer-reviewed, since an independent quality assessment is not being conducted. However, this means there is the potential to overlook some promising interventions that have been developed but not formally evaluated.

## Conclusions

By providing a clear overview of what is currently being explored, the strengths and weaknesses of those interventions, and the gaps in the field, this scoping review will help to inform the design and development of interventions and health and social care practices that are based on humanising principles to ensure people with IDD are treated with dignity, empathy, and respect. The health inequities people with IDD face, their higher likelihood of needing care, and the shift towards more person-centred healthcare make this issue particularly important to address. A clear understanding of what efforts are being made in this area will help to identify good practice and areas for improvement that will enable future interventions to facilitate more humanising care and treatment. Using established and developing networks and publication to broadcast an enhanced understanding are just two, not an exhaustive list, of possible avenues to influence practitioners' practice. Once current strategies and interventions have been identified and examined, future work will have a solid

base upon which to design improved interventions and implemented learnings from the review into clinical and social care practice. Conclusions will be drawn that reflect the data, acknowledging the limitations of the scoping review and identifying key areas for future research, and will be disseminated via journal publication. Findings will also be summarised in plain English for distribution to any relevant clinical or governmental stakeholders identified during the review.

## Author Contributions

RS and DG conceived of the concept for the protocol and developed the research question and PICOS. MMI drafted the protocol, which was reviewed by KL, RS, DG, RL, and EM. TH and MMI revised the paper in response to peer review and editorial feedback.

## Conflicts of Interest

EM is the Editor-in-Chief of *JMIRx Med*. All other authors declare no conflicts of interest.

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## Abbreviations

IDD: Intellectual and Developmental Disabilities

PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews

PICOS: Population, Intervention, Comparator, Outcome, and Studies

MeSH: Medical Subject Headings

## References

1. Anderson LL, Humphries K, McDermott S, Marks B, Sisarak J, Larson S. The State of the Science of Health and Wellness for Adults With Intellectual and Developmental Disabilities. *Intellect Dev Disabil* NIH Public Access; 2013 Oct;51(5):385. PMID:24303825
2. Disability and health [Internet]. World Health Organisation. 2020 [cited 2021 Jun 11]. Available from: <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>
3. Anne-Dörte Latteck DB. Inclusion of People with Intellectual Disabilities in Health Literacy: Lessons Learned from Three Participative Projects for Future Initiatives. *Int J Environ Res Public Health* [Internet] Multidisciplinary Digital Publishing Institute (MDPI); 2020 Apr [cited 2021 Jun 11];17(7). PMID:32260257
4. Phelan A, Trinity College Dublin, Ireland, McCormack B, Dewing J, Brown D, Cardiff S, Cook N, Dickson C, Kmete S, Lorber M, Magowan R, McCance T, Skovdahl K, Štiglic G, van Lieshout F, Queen Margaret University, Edinburgh, Queen Margaret University, Edinburgh, Ulster University, Northern Ireland, Fontys University of Applied Sciences, Eindhoven, The Netherlands, Ulster University, Northern Ireland, Queen Margaret University, Edinburgh, University of Maribor, Slovenia, University of Maribor, Slovenia, Queen Margaret University, Edinburgh, Ulster University, Northern Ireland, University of South-Eastern Norway, Norway, University of Maribor, Slovenia, Fontys University of Applied Sciences, Eindhoven, The Netherlands. Review of developments in person-centred healthcare. *Int Pr Dev J Foundation of Nursing Studies*; 2020 Sep 30;10(Suppl2):1–29.
5. Coulter A, Oldham J. Person-centred care: what is it and how do we get there? *Future Hospital Journal Royal College of Physicians*; 2016 Jun;3(2):114. PMID:31098200
6. Busch IM, Moretti F, Travaini G, Wu AW, Rimondini M. Humanization of Care: Key Elements Identified by Patients, Caregivers, and Healthcare Providers. A Systematic Review. *Patient* 2019 Oct;12(5):461–474. PMID:31203515
7. Todres L, Galvin KT, Holloway I. The humanization of healthcare: A value framework for qualitative research. *International Journal of Qualitative Studies on Health and Well-being* [Internet] 2009;4(2). [doi: 10.3402/qhw.v4i2.5003]
8. Brown M, Chouliara Z, MacArthur J, McKechnie A, Mack S, Hayes M, Fletcher J. The perspectives of stakeholders of intellectual disability liaison nurses: a model of compassionate, person-centred care. *Journal of Clinical Nursing* 2016;25(7-8):972–982.
9. Ali A, Scior K, Ratti V, Strydom A, King M, Hassiotis A. Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PLoS One* 2013 Aug 12;8(8):e70855. PMID:23951026
10. Doherty AJ, Atherton H, Boland P, Hastings R, Hives L, Hood K, James-Jenkinson L, Leavey R, Randell E, Reed J, Taggart L, Wilson N, Chauhan U. Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review. *BJGP Open* [Internet] 2020 Aug;4(3). PMID:32605913
11. Stringer K, Terry AL, Ryan BL, Pike A. Patient-centred primary care of adults with severe and profound intellectual and developmental disabilities: Patient-caregiver-physician relationship. *Can Fam Physician College of Family Physicians of Canada*; 2018 Apr;64(Suppl 2):S63. PMID:29650747
12. Health and Care of People with Learning Disabilities , Experimental Statistics: 2017 to 2018 [PAS] [Internet]. NHS Digital; 2019 Jan. Available from: <https://digital.nhs.uk/data-and->

information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018

13. Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet* 2014;383(9920):889–895.
14. Bradbury-Jones C, Rattray J, Jones M, Macgillivray S. Promoting the health, safety and welfare of adults with learning disabilities in acute care settings: a structured literature review. *J Clin Nurs* 2013 Jun;22(11-12):1497–1509. PMID:23445535
15. McCormick F, Marsh L, Taggart L, Brown M. Experiences of adults with intellectual disabilities accessing acute hospital services: A systematic review of the international evidence. *Health & Social Care in the Community* [Internet] 2020; [doi: 10.1111/hsc.13253]
16. Alborz A, McNally R, Glendinning C. Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. *J Health Serv Res Policy* 2005 Jul;10(3):173–182. PMID:16053595
17. Whittle EL, Fisher KR, Reppermund S, Lenroot R, Trollor J. Barriers and Enablers to Accessing Mental Health Services for People With Intellectual Disability: A Scoping Review. *Journal of Mental Health Research in Intellectual Disabilities* 2018;11(1):69–102.
18. Mason D, Ingham B, Urbanowicz A, Michael C, Birtles H, Woodbury-Smith M, Brown T, James I, Scarlett C, Nicolaidis C, Parr JR. A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. *J Autism Dev Disord* 2019 Aug;49(8):3387–3400. PMID:31124030
19. Tricco AC, Lillie E, Zarin W, O’Brien KK, Colquhoun H, Levac D, Moher D, Peters MDJ, Horsley T, Weeks L, Hempel S, Akl EA, Chang C, McGowan J, Stewart L, Hartling L, Aldcroft A, Wilson MG, Garritty C, Lewin S, Godfrey CM, Macdonald MT, Langlois EV, Soares-Weiser K, Moriarty J, Clifford T, Tunçalp Ö, Straus SE. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med* 2018 Oct 2;169(7):467–473. PMID:30178033