

Disability and Health Journal 7 (2014) 136-150

Disability and Health Journal

www.disabilityandhealthjnl.com

Review Article

Health outcome disparities among subgroups of people with disabilities: A scoping review

Maya Rowland, M.P.H.^a, Jana Peterson-Besse, M.P.H., Ph.D.^b, Konrad Dobbertin, M.P.H.^a, Emily S. Walsh, M.P.H.^c, and Willi Horner-Johnson, Ph.D.^{a,*}, The Expert Panel on Disability and Health Disparities^d

^aOregon Health & Science University, Portland, OR, USA

^bPacific University, Forest Grove, OR, USA

^cOregon Evidence-based Practice Center, Scientific Resource Center, AHRQ Effective Health Care Program, USA

Abstract

Background: A growing body of research has found that people with disabilities experience lower health status and an excess burden of disease relative to the general US population. However, the population of people with disabilities is quite diverse. Thus, it is important to understand health differences between subgroups of people with disabilities in order to most effectively target interventions to address disparities. An initial step in this process is reviewing and synthesizing available research addressing these subgroup differences.

Objectives: To conduct a scoping review of literature to describe recent research activity that has examined health outcome disparities within populations of people with disabilities.

Methods: We searched for relevant articles in MEDLINE, PsycINFO, and CINAHL databases. Three staff independently reviewed abstracts according to inclusion criteria. Two authors then independently extracted data from each included article.

Results: For many of the health outcomes of interest, there was no published literature in relation to key disparity factors (e.g. race, income) within the population of people with disabilities. The health outcomes most frequently examined were diabetes and heart disease. The most frequently examined disparity factors were the type of disabling condition and gender.

Conclusions: There are significant gaps in available research. Building a body of research that identifies disparities and potentially vulnerable subgroups may improve understanding of the causes of disparities and contribute to efforts to improve quality of life and health outcomes for individuals with disabilities. © 2014 Elsevier Inc. All rights reserved.

Keywords: Review; Systematic; People with disabilities; Health status disparities; United states

Health, as defined by the World Health Organization (WHO), includes physical, mental, and social dimensions, expanding on other definitions of health that are limited to the absence of disease or infirmity. By encouraging health care providers and researchers to think more broadly about

Funding: This work was supported by grant #H133A080031 from National Institute on Disability and Rehabilitation Research/DOE. However, the contents do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government.

Prior presentations: A summary of this work was presented at the 2012 Annual Meeting of the American Public Health Association.

Conflicts of interest: The authors report no conflicts of interest.

health and wellness, this definition has created the potential for all individuals to be regarded as healthy and well in some or all dimensions.

However, health and wellness are not distributed equitably among all individuals or groups. Health disparities are defined by Kilbourne et al² as "clinically and statistically significant differences in health outcomes or health care use between socially distinct vulnerable and less vulnerable populations that are not explained by the effects of selection bias." Differences in health status may be associated with a wide variety of individual, social, and systemic factors. Individual risk markers include characteristics such as disability, gender, and race or ethnicity. Social factors include educational status, occupation, and other indicators of social class. Systemic issues include variables such as access to, type of, and usual source of health care. Receipt of preventive health services, health promotion opportunities, and other resources may be reduced or

^{*} Corresponding author. OHSU Institute on Development & Disability, 707 SW Gaines Street, Portland, OR 97239, USA. Tel.: +1 503 494 9273. E-mail address: hornerjo@ohsu.edu (W. Horner-Johnson).

^d Members of the Expert Panel on Disability and Health Disparities are: Elena Andresen, Ph.D.; Charles Drum, M.P.H., J.D., Ph.D., Glenn Fujiura, Ph.D.; Liza Iezzoni, M.D., M.Sc.; and Gloria Krahn, Ph.D., M.P.H.

strengthened based on these factors, contributing to health disparities.

Study rationale

Approximately 19% of the US population has a disability.³ Prevalence of disability increases with age such that most people will experience some type of disability during their lifetime.^{3,4} A growing body of research has found that people with disabilities experience lower health status and an excess burden of disease relative to the general US population.^{5–7} These studies and others have examined the health disparities experienced by people with disabilities compared to other demographic groups (e.g. people without disabilities, racial and ethnic minorities). However, the full array of human diversity is represented within the population of people with disabilities. Therefore, this group may experience additional health disparities associated with the intersection of their specific disability (or disabilities) and other factors related to disparity.

By selecting and targeting appropriate segments within the population with disabilities, disease prevention and health promotion interventions might be more effective. First, we must understand specifically where disparities lie and determine what factors contribute to them. Prior to initiating original research, however, it is important to have a clear picture of what has been investigated thus far.

At present, the top ten causes of death in the US include both acute and chronic diseases as well as accidents/in-juries. Many of these outcomes represent important public health issues that are driving health care needs and costs in the US. Preventing these outcomes in all populations has the potential to significantly reduce morbidity and mortality in the US. Thus, these key indicators have been examined extensively in the general US population and in some sub-populations of interest. Among people with disabilities, identifying which subgroups are most at risk or carry an excess burden of these top ten conditions is crucial in developing targeted prevention efforts.

Objectives

The purpose of this study was to conduct a scoping review of literature to describe recent research activity that has examined health outcome disparities within populations of people with disabilities. Scoping reviews use broad key questions and aim to describe the extent, range, and nature of research activity in a specific subject area as a means of mapping the landscape of the field. Our review sought to explicate what disability research has occurred and where gaps currently exist. We present extracted data on which population subgroups, health outcomes of interest, and disparity factors of interest have been researched. A secondary objective was to describe which funding institutions have supported the research

in this area, the journals where the work is published and their impact factors.

Methods

Protocol

Scoping reviews use systematic review methods for identifying potentially relevant evidence and assessing it for inclusion. This scoping review used guidelines described by international leaders in systematic review methodology. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement informed the steps and flow of the review. 10 The Cochrane Collaboration Handbook informed the development of key questions and criteria for included studies.¹¹ Reporting of information was informed by the PRISMA Exploration and Explanation Document. 12 The scoping element of our review and subsequent analysis was informed by the Arksey and O'Malley framework. Our key question asked: "what English-language studies, conducted in the US and presenting original analysis of data, have been published in the peer-reviewed literature from 2000 to 2009 that examine disparities in health related to the leading causes of death in the US among subgroups of people with disabilities ages 18-64?" Together with our expert panel, we established a priori definitions for key terms and concepts in the key question including: disability, health disparity, and health status (Table 1). The panel members brought expertise in medicine, public health, epidemiology, and personal experience of living with a disability.

Search strategy

In December of 2010, we searched electronically for articles in the MEDLINE, PsycINFO, and CINAHL databases. We consulted with an expert librarian from our institution to develop search terms that would best fit our definition of disability for the search. The details of this process are described in a separate publication. 15 See Appendix A for a complete search history for the MEDLINE (OVID) database. To test our strategy, the expert panel suggested key articles they would anticipate seeing in our searches. Search strategies that identified these key articles were considered effective. To check for search completeness, we also reviewed all tables of contents of all available issues from 2000 to 2009 of the journals Disability and Health Journal, Journal of Disability Policy Studies, Archives of Physical Medicine and Rehabilitation, American Journal of Preventive Medicine, and The American Journal of Public Health for relevant articles. After articles had been selected for inclusion, their reference lists were reviewed for additional relevant articles not retrieved by electronic database searches.

Eligibility criteria

Inclusion criteria for articles were: published in Englishlanguage peer-reviewed journals during the years

Table 1
Definitions for key concepts

Term	Conceptual definition	Operational definition
Disability	Based on the conceptual domains of the International Classification of Functioning, Disability and Health (ICF). The ICF defines disability as an umbrella term for impairments, activity limitations or participation restrictions. Further, the ICF and contemporary approaches to disability emphasize that environmental factors interact with all of these constructs. ¹	Disability or functional limitation falling into at least one of the following functional categories: physical, sensory, cognitive, mental health, social, or activity limitation.
Health status	As defined by the World Health Organization, health status is a description or measurement of the health of an individual or population at a particular point in time against identifiable standards, usually by reference to health indicators. ¹³	Health status indicators for this review will include measures of morbidity, mortality, and self-reported health of the 10 leading causes of death in the United States (diseases of the heart, cancer, cerebrovascular disease, respiratory disease, accidents/injuries, diabetes mellitus, Alzheimer's disease, influenza/pneumonia, kidney disease, sepsis, or a single outcome variable best represented by multiple from the list).
Health disparity	We modified the health disparities definition by Kilbourne et al ² to apply to differences within subgroups of populations with disabilities. Within the group of people with disabilities, health disparities are observed meaningfully and statistically significant differences in health between population subgroups. 14	Disparity factors of interest are: disabling condition type (mental illness, sensory, physical, cognitive, or combinations thereof), disability severity, number of or severity of secondary conditions, age, gender, marital status, race, ethnicity, language, socioeconomic status, education level, urban/rural status, geographic location (distribution within the US), health insurance payer type (Medicare, Medicaid, private insurance), and provider type.

2000–2009; about adults aged 18–64 who had a disability per our definition and who resided in the US or its territories; inclusion of an analysis of health outcomes associated with the ten leading causes of death in the US, and investigation of health outcomes by at least one disparity factor of interest. Top 10 causes of death were based on the National Vital Statistics Report (2007)¹⁶ and included: heart disease, cancer, cerebrovascular diseases, respiratory disease, accidents and injuries, diabetes mellitus, Alzheimer's disease, influenza/pneumonia, kidney disease, and sepsis. Disparity factors of interest were established by the expert panel and were informed by health disparity research in the general population and priorities of the project funder. Factors included disabling condition category, disability severity, number or severity of secondary conditions, age, gender, marital status, race/ethnicity, language, income or socioeconomic status, education level, urban/rural status, geographic location, health insurance payer type, health care provider type, and usual source of care. We did not limit articles by study design or disability type; however we excluded articles focusing solely on treatments for any conditions. Articles were included only if they presented original analyses of data (e.g., review articles were not included).

Data collection process

Three reader/reviewers independently reviewed article abstracts for inclusion. Abstracts were divided equally between the three reviewers with a 10% overlap to monitor inter-rater reliability and coder drift (changes over time in how items are coded). Exclusion criteria were applied in a hierarchical manner such that abstracts were excluded

based on the first criterion they met and were not reviewed further. Full texts of all articles included at the abstract level were reviewed independently by two reviewers who met to resolve discrepant decisions about inclusion. When reviewers could not reach consensus, an expert reviewer's input was used to resolve discrepancies. The same expert reviewer made tie-breaking decisions for the rare instances in which the two reviewers did not reach agreement. There was 95% agreement between reviewers at the abstract review phase and 94.2% agreement at full text review.

Two of the authors independently extracted data from each included article. Extracted items included: definition of disability used in the article, data sources and collection methods, health outcomes, potential disparity factors, analytic methods, comparisons made, and findings (with significance defined as a p-value of ≤ 0.05 or non-overlapping confidence intervals [CI]). When either author questioned which data to extract, an expert reviewer was consulted for additional guidance. This occurred for nine specific variables within particular studies during the course of data extraction.

Funding sources for included studies were gleaned from article acknowledgment sections. Journal impact factors (JIF), when available, were identified through online searches of each journal's website. When JIFs were not available for the year the study was published, the 2011 JIF was recorded.

Analysis

Univariate analysis assessed how many times each variable (either health outcome or disparity factor of interest) was examined in the included studies. We then created a matrix to review the distribution of research and to cite

which studies examined specific intersections of potential disparity factors and health outcomes.

Results

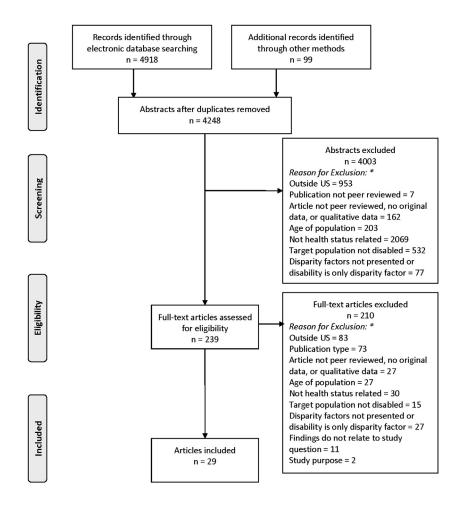
Our search methods retrieved 4248 unique references for review. At the abstract review stage, 239 articles were selected for full-text review. During full text review, we identified 29 articles for inclusion in the present analysis (see Fig. 1).

Study samples and methods

Studies were varied in terms of the samples and research methods. Most studies examined disability samples with mental health disorders (10) or using a broad definition of disability that encompassed multiple disability types (9). Others included samples with intellectual/cognitive disabilities (5), physical disabilities (4), or sensory disabilities (1). Subjects were identified as having

a disability in a number of ways including: having a diagnosis indicating disability, reporting a functional limitation, participating in a program serving people with disabilities, or a mixture of these criteria. The majority of studies used secondary data. Nine studies conducted secondary analyses of clinical data^{17–25}; while eleven studies used an extant survey data set such as the National Health Interview Survey (NHIS).^{26–36} Three studies used primary interview or clinical data,^{37–39} most of which was qualitative. Three studies utilized a mix of primary and secondary data^{40–42} and three more used a mix of secondary data sources.^{43–45} See Table 2 for a complete list of articles included in this review, their disability definitions, and data sources.

A review of the purpose statements of included studies revealed that 23 of the 29 articles explicitly stated in their purpose that they were examining disparities among subgroups of people with disabilities. The remaining articles did not report this specific purpose, but presented data that were relevant to our key question.



^{*}Articles were assigned only one exclusion code based on the first exclusion criterion they met in our hierarchy, although they also may have contained additional reasons for exclusion.

Fig. 1. Selection process for the articles included in the final scoping review of literature on disparities in health outcomes among people with disabilities.

Table 2
Description of included articles by disability type and definition, sample size and source

Study	aded articles by disability type and definition, sample size and source Disability ¹	Sample size and data source
Banarjea ¹⁹	Physical; condition specific definition: "Our data include information from the spinal cord disorders registry, which consists of a refined cohort of veterans who use VHA ^a medical care, have an SCI ^b diagnosis, and use SCI specific health care services (SCI inpatient bed section or SCI outpatient clinic stop)."	$N = 8769$, SCI and diabetes $n = 1333$, SCI and no diabetes $n = 7436$. Data source: secondary data — data are from the spinal cord disorders registry of veterans with SCI, that cohort of veterans was merged with the diabetes epidemiology cohort. Micro and macro vascular conditions were identified using ICD_{n}^{OC} codes in subject charts.
Brophy ²⁸	Cross-disability; functional definition: "NHIS — we classified respondents into 3 categories: individuals with no disabilities, with moderate disabilities, and with severe disabilities."	ICD-9° codes in subject charts. N = 133,907, no disability $n = 119,020$, moderate disability $n = 9757$, severe disability $n = 5092$. Data source: extant data set — NHIS data 2004—2005.
Cardenas ³¹	Physical; condition specific definition: "Acute traumatic spinal cord injury (SCI)."	 N = 8668 (all with SCI). Data source: secondary data, extant data set — Model Spinal Cord Injury Systems (MSCIS) centerspersons with SCI from 16 MSCIS centers entered in the National Spinal Cord Injury Statistical Center database between 1995 and 2002.
Carney, 2003 ¹⁷	Mental health; condition specific definition: "Classification of subjects into the mental disorder cohort was based on criteria proposed by Lurie et al for work with administrative databases. In order to assure the best specificity of a mental disorder into a major diagnostic class, such as mood disorders as defined by the DSM-IV ^d , patients must have filed: 1. at least one inpatient psychiatric claim as the primary or secondary diagnoses filed during 1989—1993, or 2. two outpatient mental health claims made by any provider in any position filed during 1989—1993, or 3. any single mental health claim filed by a psychiatrist during 1989—1993ICD-9 codes were mapped to broad diagnostic categories (i.e., psychotic disorders) according to classification by the DSM-IV"	N = 748,466, mental health cohort $n = 74,959$, non-mental health cohort $n = 673,507$. Data source: secondary clinical data — "This study is based on all (100%) Wellmark Blue Cross/Blue Shield of Iowa and South Dakota (Wellmark) inpatient, outpatient, and provider claims data from January 1, 1989 to December 31, 1993. Nearly 93% of the sample was composed of residents of Iowa."
Carney, 2004 ²⁰	Mental health; condition specific definition: "Subjects were assigned to the mental disorder cohort by means of established criteria validated by Lurie et al for use with administrative claims dataSubjects were assigned to diagnostic categories based on the first occurring mental disorder code."	 N = 722,139, mental health cohort n = 72,140, control cohort n = 649,999. Data source: secondary clinical data — Wellmark Blue Cross/Blue Shield of Iowa and South Dakota inpatient and outpatient provider and administrative claims data from January 1, 1989, through December 31, 1993. The data source includes all Common Procedural Terminology codes ICD-9 codes for claims made by all providers.
Chen ³²	Mental health; condition specific definition: "Personality disorders were determined using the NIAAA Alcohol Use Disorders and Associated Disabilities Interview Schedule — DSM-IVDiagnosis of psychiatric disorders was made using the NIAAA Alcohol Use Disorders and Associated Disabilities Interview Schedule-DSM-IV version (AUDADIS-IV). Diagnoses examined in the NESARC included personality disorders, mood disorders, alcohol abuse/dependence, nicotine dependence, and drug abuse/dependence."	N = 43,093, injured persons $n = 6754$, interviewed persons $n = 41,969$. Data source: secondary data, extant data set — "Data were obtained from the National Epidemiologic Survey on Alcohol and Related Conditions (NESARC)a nationally representative face-to-face survey conducted in 2001 and 2002 by the National Institute on Alcohol Abuse and Alcoholism (NIAAA)."
Choi ⁴¹	Sensory; mixed definition: "Three different hearing variables were assessed as potential risk factors for farm work-related injuries. First, hearing loss based on pure tone audiometry threshold average was assessedSecond, hearing asymmetry between the worse and the better ear was evaluated. In this study, we defined hearing asymmetry as the difference of PTA between ears greater than 5 dB (HL).° The 5 dB (HL) cut point was identified as the distributional median of bilateral PTA differenceThird, the self-reported hearing question "Do you have known hearing loss?" was assessed in the occupational history form questionnaire, and was rated at one of "good," "fair," or "poor" levels."	 N = 150 (with and without hearing loss). Data source: primary interview data and primary clinical data — study subjects were 150 farmers who participated in the Iowa Certified Safe Farm study. Information on injury and farm work exposures was collected by computer-aided telephone interviews from September 1999 to October 2002. Health screenings were conducted by a trained nurse at the Spencer Agrisafe clinic.

Table 2 Continued

Study	Disability ¹	Sample size and data source
Day ³³	Intellectual/cognitive; administrative definition: "persons with developmental disability who received services from the State of California Department of Developmental Services (DDS)a disabling condition found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individualswe excluded individuals unable to walk and climb stairs without support, those who were severely or profoundly mentally retarded, and persons with degenerative conditions."	N = 106,193, history of epilepsy $n = 10,030$, no history of epilepsy $n = 96,163$. Data source: secondary extant data set — subjects were evaluated approximately annually using the Client Development Evaluation Report (CDER). (http://www.dds.ca.gov/FactsStats/CDER.cfm).
Dixon ²⁹	Mental health; condition specific and administrative definition: "The study population consisted of all Medicare enrollees who had at least one service claim during 1991 and who were diagnosed with schizophrenia, which includes the schizoaffective and schizophreniform disorders."	N = 20,967, Medicare $n = 14,182$, Medicaid $n = 6,066$, field study: inpatients $n = 279$, community-based patients $n = 440$. Data source: secondary extant data set — data collected by the Schizophrenia Patient Outcomes Research Team (PORT) to assess the prevalence and demographic and clinical correlates of diabetes within large populations of persons receiving treatment for schizophrenia. The PORT Patient Survey conducted face-to-face interviews with a random sample of persons with a clinical diagnosis of schizophrenia who were currently under usual care in two states, one in the South and the other in the Midwest.
Fitzgerald ³⁷	Physical; functional definition: "The self-selected study population was based upon the eligibility criteria that individuals needed to use a wheelchair as their primary means for mobility."	 N = 596 (all wheelchair users). Data source: primary survey data – telephone survey of wheelchair users – persons indicating an interest in the study were contacted by the investigators by telephone and given a brief telephone survey to verify eligibility and to document their experiences in using motor vehicle transportation.
Folsom ²⁵	Mental health; condition specific definition: "A diagnosis of schizophrenia or schizoaffective disorderPsychiatric diagnoses were based on DSM-IV."	N = 94: 47 matched pairs, schizophrenia $n = 47$, depression $n = 47$. Data source: secondary clinical data — a physician dually trained in psychiatry and family medicine systematically reviewed each patient's chart and recorded demographic characteristics, the number of medical and psychiatric visits in the preceding 12 months, documented medical problemsA physician reviewed the patients' charts to obtain data for a comparison between groups of the number of clinic visits for medical problems, receipt of various components of the physical examination and preventive screening studies, and number of chronic medical disorders.
Goff ³⁰	Mental health; condition specific definition: "Subjects were outpatients with a diagnosis of schizophrenia diagnosed by a research psychiatrist using a modified SCID interview and were between the ages of 18 and 65 years."	N = 1376, CATIE n = 689, NHANES ^f n = 687. Data source: secondary extant data set — data were from the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) schizophrenia trial and control subjects were identified in the NHANES III database and matched on the basis of age, race and gender.
Havercamp ³⁴	Cross-disability; functional and administrative definition: "Disability status is determined by responses to the following four questions: (1) "Are you limited in any way in any activities because of physical, mental, or emotional problems?" (2) "Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?" (3) "A disability can be physical, mental, emotional, or communication related. Do you consider yourself to have a disability?" (4) "Because of any impairment or health problem, do you have any trouble learning, remembering, or concentrating?" For the present study, any respondent who said "yes" to one or more of these questions on the 2001 NC BRFSS was assigned to the Disability group (n 1598)."	 N = 6902, no disability group n = 4,358, disability n = 1598, developmental disability n = 946. Data source: secondary extant data set - data on the health of adults with developmental disabilities living in North Carolina (NC) and NC Behavioral Risk Factor Surveillance System (BRFSS) survey.

Table 2 Continued

Study	Disability ¹	Sample size and data source
Hinkle ⁴²	Cross-disability; functional definition: "The disability was self-reported, but, in general, participants considered themselves disabled if they were not gainfully employed or needed assistance with activities of daily living due to their condition."	N = 146 (all with disabilities). Data source: primary interview and clinical data — the research team set up tables at various health promotion, awareness, or educational events targeted to people with disabilitiesthose who agreed completed the Stroke Risk Screening Tool and a short consent with a section to indicate whether they had a disability and to identify the nature of the disabilityEach participant's BP was measured and pulse counted.
Hsieh ⁴³	Cross-disability; functional definition: "Developmental disability."	 N = 268 (all with developmental disabilities). Data source: secondary clinical data and other (interviews with staff and observations) — authors conducted baseline assessments of 331 residents with developmental disabilities ≥30 years of age living in the 18 nursing homes in the Chicago, IL, USA, area serving this population. Data were collected through interviews with house staff or unit supervisors, reviews of client records, and observations of the residents and facilities.
Kilbourne ⁴⁴	Mental health; condition specific definition: "In this study, patients with mental disorders were identified based on ICD-9 diagnoses of schizophrenia, bipolar disorder, other psychotic disorders, major depressive disorder, or other depressive disorder. Based on previously established definitions from NARDEP, other depressive disorders included the following ICD-9 code diagnoses: depressive disorder not otherwise specified, dysthymia, adjustment disorder with depressed mood, mood disorder due to medical condition, mood depressive personality disorder, of which the majority were diagnosed with depressive disorder not otherwise specified or dysthymia."	N = 147,193, diagnosed with schizophrenia, n = 22,817, bipolar disorder n = 15,203, other psychosis n = 7336, major depressive disorder n = 34,952, or other depressive disorder diagnoses n = 50,813, without mental disorder diagnoses n = 16,07. Data source: extant data set and secondary clinical data — data from the LHSV (Large Health Survey of Veteran Enrollees), the VA's National Psychosis Registry (NPR), the National Registry of Depression (NARDEP) and a random sample cohort of veterans without mental disorders. LHSV data on patient, clinical, and behavioral factors were linked to mortality data from the Centers for Disease Control and Prevention (CDC)'s National Death Index (NDI) Plus database. Additional data, including age were from VA electronic medical record data.
Kinne ²⁶	Cross disability; functional definition: Endorsing of disability questions on BRFSS survey.	N = The text indicates 1140 study participants with serious mental illness, and the tables indicate 1132. There is no information about the missing participants. Data source: extant data set — "data from the 2001 and 2003 Washington State Behavioral Risk Factor Surveillance Survey Disability Supplement (BRFSS-DS)"
Lamberti ²¹	Mental health; condition specific definition: "Presence of a clinical diagnosis of a psychotic disorder or major mood disorder."	 N = 436 (all with mental disorders). Data source: secondary clinical data — retrospective chart and medical record review.
McDermott 2007 ²²	Cross disability; condition specific definition: "Our definition of disability was impairment based, thus, patients with a disability were identified by the electronic medical records using a search process that included ICD-9 codes"	N=3533 patients without a disability $n=2084$, all patients with a disability $n=1449$, sensory $n=117$, blind $n=81$, deaf $n=36$, developmental $n=692$, autism $n=51$, cerebral palsy and MR $n=154$, cerebral palsy without MR $n=23$, psychiatric and MR $n=156$, mental retardation $n=308$, trauma $n=155$, spinal cord injury $n=35$, traumatic brain injury $n=120$, psychiatric $n=485$, schizophrenia $n=343$, affective psychosis $n=142$.
McDermott 2005 ⁴⁰	Mental health; condition specific definition: "The case definition for the 357 patients with schizophrenia and the 146 patients with affective psychosis was the diagnosis in physician progress notes and/or problem lists, and the ICD-9 codes of schizophrenic disorders and affective psychoses listed in the record."	Data source: secondary clinical data — medical records. N = 2586, with schizophrenia n = 357, with affective psychosis n = 146, comparison group n = 2083. Data source: primary interview data and secondary clinical data — the record review relied on both computerized medical records and the companion paper records archived from earlier medical care. A sample of patients participated in an interview.

Table 2 Continued

Study	Disability ¹	Sample size and data source
Miller ⁴⁵	Mental health; mixed definition:	N = 608 (all with serious mental illness).
	"This study defined patients with serious mental illness as individuals requiring at least one inpatient psychiatric hospitalization within Ohio's public mental health system."	Data source: extant data set and secondary clinical data — ODMH ^g Patient Care System (PCS) database and death records from the Ohio Department of Health (ODH). Patients from ODMH and ODH files were matchedThe US general population from 1998 to 2002 was used as the standard
Pandiani ¹⁸	Mental health; administrative definition: "Extracts from the database of Vermont's Division of Mental Health provided information about all individuals served by community programs for adults with serious mental illness."	reference population in this study." N = 456,823, general population n = 453,506, adults with serious mental illness n = 3317. Data source: secondary clinical data — the Vermont Cancer Registry provided information about all adults with a cancer diagnosis and the database of Vermont's Division of Mental Health provided information about all individuals served by community programs for adults with serious mental illness.
Rasch ³⁵	Cross disability; functional definition: Respondents were classified into 3 groups: those with mobility limitations, nonmobility limitations, and no limitations. Using MEPS and NHIS.	 N = 13,897. Data source: extant data set — Medical Expenditure Panel Survey (MEPS) and the 1995 National Health Interview Survey (NHIS) Disability Supplement (NHIS-D).
Rasch ³⁶	Cross disability; functional definition: "Respondents were classified into 3 groups for analysis: those with mobility limitations, nonmobility limitations, and no limitations. Adults reporting difficulty climbing stairs, walking, standing, or bending/stooping, or who reported use of mobility devices were classified with mobility limitation. Adults without mobility limitations who reported any other types of limitations (nonmobility) or who reported use of assistive technology other than mobility devices were classified as having other limitations. All other adults were classified as having no limitations. Methods for limitation group classification have been described in more detail elsewhere."	N = 12,302. Data source: extant data set — MEPS and the NHIS-D.
Shavelle ²³	Intellectual/cognitive; administrative definition: "Traumatic brain injury: subjects were selected from a computerized database of 186, 461 persons who received any services from the California Department of Developmental ServicesTo be eligible, individuals are mentally retarded or havea disabling condition found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, but shall not include other handicapping conditions that are solely physical in nature."	 N = 2320 (all with TBI). Data source: secondary clinical data — a computerized database of persons who received any services from the California Department of Developmental Services. All subjects were evaluated approximately annually, using the Client Development Evaluation Report (CDER). Mortality information was obtained from annual computer tapes from the State of California."
Sohler ²⁴	Physical; functional definition: "Data were obtained from a community-based specialty medical practice for people with intellectual disabilities in New York City. Subjects were included in this analysis if they had an intellectual disabilityData obtained from the DDP-2 include socioeconomic information and ID diagnoses."	N = 291 (all with intellectual disability). Data source: secondary clinical data — from a community-based specialty medical practice for people with intellectual disabilities in New York City. Data include information from administrative service utilization records, medical chart reviews, and the Developmental Disabilities Profile (DDP)-2. Administrative data were used to define the study sample.
Vladutiu ²⁷	Cross disability; functional definition: "We measured disability consistent with recommendations from the NCHS) ^h and WHO-ICFDH ⁱ . Disability types were classified as: use of assistive technology, cognition limitations, hearing limitations, motor functional limitations, serious psychological distress, and vision limitations."	N = 86,180, total non injured $n = 81,919$, injury in the home $n = 2189$, injury outside the home $n = 2072$. Data source: extant data set — NHIS.
Vogel ³⁹	Physical; condition specific definition: "Spinal cord injury — impairment was measured using the neurologic level, the American Spinal Cord Injury Association (ASIA) Motor Score, and the ASIA Impairment Scale as described in the International Standards for Neurological Classification of Spinal Cord Injury."	N = 216 (all with SCI). Data source: primary survey or interview data — a structured questionnaire designed for this study was used. Information was obtained by interviewing subjects about their experiences during the past 3 years.

Table 2 Continued

Study	Disability ¹	Sample size and data source
Xiang ³⁸	Cross disability; functional definition: "In our study, respondents who responded "yes" to at least one of the following four questions were classified as having activity/participation limitations: (A1) "Are you limited in the kind or amount of work you can do because of any impairment or health problem?" (A2) "Because of any impairment or health problem, do you have any trouble learning, remembering, or concentrating?" (A3) "Do you use special equipment or help from others to get around?" (A4) "Are you limited in any way in any activities because of any impairment or health problem?"	N = 2602, no limitations $n = 2023$, moderate limitations $n = 435$, severe limitations $n = 144$. Data source: primary survey or interview data — Colorado Disability Survey using the Behavioral Risk Factor Surveillance System.

- ^a Veterans Health Administration (VHA).
- ^b Spinal Cord Injury (SCI).
- ^c International Classification of Diseases, Ninth Revision (ICD-9).
- ^d Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).
- ^e Five decibels (dB) of hearing loss (HL).
- ^f National Health and Nutrition Examination Survey (NHANES).
- ^g Ohio Department of Mental Health (ODMH).
- h National Center for Health Statistics (NCHS).
- World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF).

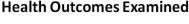
Definitions of disability

Definitions of disability varied widely between studies and were quite different even within sub-populations of people with the same disability type. For example, in the four articles that used samples with mobility limitations, mobility limitations were defined in three different ways: using a wheelchair; level of difficulty standing, walking, or using the stairs; or having medical record codes that indicated a mobility limitation. Similar heterogeneity existed for other sub-populations as well, particularly among articles describing populations with mental health disorders and those using functional definitions of disability (Table 2).

Concentration and gap analysis

Univariate analyses showed that nearly all our health outcomes and disparity factors of interest were examined at least once. Health outcomes observed most frequently were diabetes mellitus, heart disease, cancers, and accidents/injuries. Sepsis and kidney diseases were not represented at all. Disparity factors examined most frequently were disabling condition type, gender, age, and disability severity. Disparity factors that were absent from included studies were: language spoken, health care provider type, and usual source of care. Many of the studies looked at more than one health outcome and/or disparity factor. Frequencies of health outcomes and disparity factors in included studies are presented in Figs. 2 and 3.

Our bivariate gap analysis matrix indicated that most intersections of health outcomes with disparity factors of interest have not been addressed in published literature pertaining to people with disabilities (Table 3). However, there were several bivariate combinations observed multiple times. Type of disability was considered for disparities in a number of outcomes: diabetes mellitus (10 studies),



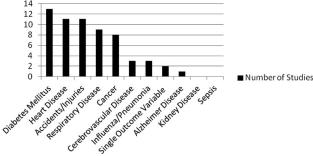


Fig. 2. Study frequency by health outcome.

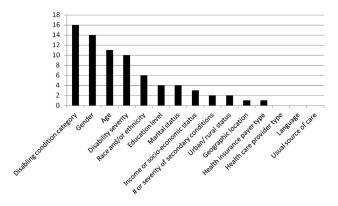


Fig. 3. Study frequency by disparity factor of interest.

Table 3
Concentration and gap analysis matrix
Health outcome variable

	Health outcome va	riable									
Disparity factor	Heart disease	Cancer	Cerebrovascular disease	Respiratory disease	Accidents/injuries	Diabetes mellitus	Alzheimer's disease	Influenza/ pneumonia	Kidney disease Sepsis	Single outcome variable	# of studies
Disabling condition category	Day '05 Havercamp '04 Kilbourne '09 McDermott '07 McDermott '05 Rasch '08a Rasch '08b	Carney '03 Carney '04 Day '05 McDermott '07 Rasch '08a Rasch '08b	Kilbourne '09 McDermott '07	Day '05 Rasch '08a Rasch '08b Folsom '02	Fitzgerald '07 Chen '08 Day '05 Hsieh '01 Rasch '08a Rasch '08b Vladutiu '08	Banarjea '08 Day '05 Havercamp '04 Kilbourne '09 Lamberti '04 McDermott '07 McDermott '05 Rasch '08a Sohler '09 Folsom '02	Day '05	Day '05 Rasch '08b		Banarjea '08	16
Disability severity	Shavelle '01			Shavelle '01 Vogel '02 Cardenas '04	Xiang '05 Brophy '08 Chen '08 Choi '05 Hsieh '01	Banarjea '08 Sohler '09				Banarjea '08 Vogel '02	10
# or severity of secondary conditions						Banarjea '08 Dixon '00				Banarjea '08	2
Age	Goff '05	Pandiani '06		Kinne '08 Vogel '02	Fitzgerald '07 Kinne '08 Brophy '08 Hsieh '01 Xiang '05	Banarjea '08 Lamberti '04 Sohler '09 Dixon '00 Goff '05				Banarjea '08 Vogel '02	12
Gender	Hinkle '06 McDermott '07 Miller '06 Goff '05	Pandiani '06 McDermott '07 Miller '06	Miller '06	Kinne '08 McDermott '07 Miller '06 Vogel '02	Fitzgerald '07 Kinne '08 Xiang '05 Brophy '08 Hsieh '01 Miller '06	Hinkle '06 Lamberti '04 Miller '06 Sohler '09 Dixon '00 Goff '05 McDermott '07		Miller '06		Vogel '02	14
Marital status					Xiang '05 Brophy '08	Banarjea '08 Dixon '00				Banarjea '08	4
Race and/or ethnicity				Kinne '08	Kinne '08 Brophy '08 Xiang '05	Banarjea '08 Lamberti '04 Sohler '09 Dixon '00				Banarjea '08	7
Language											0
Income or socioeconomic status				Kinne '08	Kinne '08 Xiang '05 Brophy '08						3

(Continued)

Table 3

	Health outcome variable	variable									
Disparity factor Heart disease	Heart disease	Cancer	Cerebrovascular Respiratory disease disease	Respiratory disease	Accidents/injuries	Alzheim Accidents/injuries Diabetes mellitus disease	Alzheimer's disease	Alzheimer's Influenza/ disease pneumonia	Kidney disease Sep	Single Kidney outcome disease Sepsis variable	# of studies
Education level				Kinne '08	Kinne '08	Dixon '00					4
					Xiang '05 Brophy '08						
Urban/rural status					Xiang '05	Banarjea '08				Banarjea '08	2
Geographic						Banarjea '08				Banarjea '08	1
location											
Health insurance						Banarjea '08				Banarjea '08	1
payer type Health care											0
provider type Usual source of											0
care											
# of studies	11	~	3	10	12	14	1	3	0 0	2	

heart disease (7), accidents/injuries (7), cancer (6), and respiratory disease (4). Investigations of disability severity focused on outcomes in respiratory disease (3) and accidents/injuries (5). There were studies that examined agerelated disparities in: accidents/injuries (5) and diabetes mellitus (5). Gender disparities were analyzed for: heart disease (4), cancer (3), respiratory disease (4), accidents/injuries (6), and diabetes mellitus (7). Studies of potential racial and/or ethnic disparities included: accidents/injuries (3) and diabetes mellitus (4). For the factors of income/ socioeconomic status and education, there were three studies each on accidents/injuries.

Publication and funding

Twenty-one of the 29 studies were funded by grants from one or more of the following federal agencies: the Centers for Disease Control and Prevention (CDC: 10 studies), the National Institute of Mental Health (NIMH: 5 studies), the National Institute on Disability and Rehabilitation Research (NIDRR: 3 studies), the Department of Veterans Affairs (VA: 3 studies), and the Substance Abuse and Mental Health Services Administration (SAMHSA: 1 study). Various other organizations contributed to or were sole supporters of individual studies (see Table 4). Five studies did not indicate a funding source. Articles were published in 20 different journals. The most common journals were Archives of Physical Medicine and Rehabilitation (4), and Psychiatric Services (3). Journal Impact Factors ranged from 0.48 (Social Work in Health Care) to 6.08 (Schizophrenia Bulletin) with a mean JIF of 2.36 (Table 4).

Discussion

Summary of the literature landscape

While most variables we assessed have not been well studied, our review reveals concentrations of research on some health outcomes (diabetes, heart disease, cancer, respiratory disease, and accidents/injuries) and disparity factors of interest (disability type, disability severity, age, gender, race, income, and education). In other words, studies are clustered in a few areas, leaving a significant lack of research in other areas. With regard to intersections of variables, a few emerging areas were observed: disparities by gender, age, disability type, and disability severity in injuries/accidents; disparities in diabetes among several subgroups of people with disabilities; and disparities by disability type or disability severity in heart disease, cancer, and diabetes. These emerging areas of research on health outcome disparities among sub-populations of people with disabilities are characterized by data that is too heterogeneous for synthesis. Thus, there is still considerable research needed to build an evidence base regarding disparity patterns.

Table 4

Journals, JIFs, and funding sources for included articles

Journals, JIFs, and funding sources for included articles			
American Journal of Industrial Medicine	1.307	Choi, '05	NR ^a
American Journal of Physical Medicine and	1.006	Shavelle, '01	NR
Rehabilitation			
Archives of Physical and Medical Rehabilitation	1.656	Cardenas, '04	NIDRR ^b
Archives of Physical and Medical Rehabilitation	2.159	Banarjea, '08	VA ^c
Archives of Physical and Medical Rehabilitation	2.159	Rasch A, '08	CDC^d
Archives of Physical and Medical Rehabilitation	2.159	Rasch B, '08	CDC
Assistive Technology	0.66*	Fitzgerald, '07	NIDRR
Community Mental Health Journal	1.23*	McDermott, '05	CDC
Disability and Health	0.904*	Kinne, '08	CDC
Epidemiology	5.406	Brophy, '08	Alpha Omega Alpha Carolyn L. Kickein Student
			Research Fellowship and & CDC
General Hospital Psychiatry	2.699	Kilborne, '09	VA
Injury Prevention	1.536	Xiang, '05	CDC
Injury Prevention	1.837	Chen, '08	CDC
Injury Prevention	1.837	Vladutiu, '08	CDC
Journal of Clinical Psychiatry	4.806	Lamberti, '04	Committee to Aid Research to End Schizophrenia
Journal of Intellectual Disability Research	1.596*	Hsieh, '01	NIDRR
Journal of Women's Health	1.522	McDermott, '07	CDC
Neurology	4.947	Day, '05	NR
Psychiatric Services	1.885	Folsom, '02	NIMH ^e and VA
Psychiatric Services	2.81*	Miller, 2006	NR
Psychiatric Services	2.81*	Pandiani, '06	SAMHSA ^f
Psychosomatic Medicine	3.429	Carney, '03	NIMH
Psychosomatic Medicine	3.687	Carney, '04	American Cancer Society and NIMH
Public Health Reports	1.61	Havercamp, '04	CDC
Rehabilitation Nursing	0.67*	Hinkle, '06	Bristol-Myers Squibb
Schizophrenia Bulletin	6.085	Dixon, '00	Schizophrenia PORT ^g and NIMH
Schizophrenia Research	4.231	Goff, '05	NIMH
Social Work in Health Care	0.48*	Sohler, '09	NR
The Journal of Spinal Cord Medicine	1.4*	Vogel, '02	Shriners Hospitals for Children

^{* 2011} impact factor.

We expected to see, but did not find, research on several traditional disparity factors in this review. Language, geographic location, health insurance payer type, health care provider type, and usual source of care are all disparity factors of interest that were examined only once or not at all. Given the ongoing national dialog about health insurance, availability of quality care, and culturally appropriate services, we were surprised that even these traditional disparity factors had been infrequently examined among people with disabilities. *Healthy People 2020* identifies culturally sensitive healthcare providers (language is an aspect of cultural sensitivity), health insurance, and geographic location as disparity factors that influence health status. Ae Research that explores intersections of disability with these more traditional health disparity factors is needed.

Studies included in this review were published in a variety of journals with a broad spectrum of JIFs (0.48–6.08). Many of the journals were targeted at direct service health care professionals (e.g. *The American Journal of Physical Medicine and Rehabilitation; Psychiatric Services*). Fewer

than half of the articles were published in journals specifically related to the field of disability and health, preventive medicine, disparity reduction, or a specific disability, which indicates that these findings are reaching an audience outside of the disability field. Through publication in direct service-oriented journals, the findings of these studies have the potential to inform the practices of health care professionals in their work with people with disabilities. In the future, expanding the scope of publication to journals with a disease prevention focus may help to increase the visibility of these issues and prompt further investigation.

Nine of the included studies were funded by federal sources that specifically address disability or a specific type of disability (such as mental health). It is encouraging that these national bodies recognize the importance of funding this research. Continued funding for similar research is critical for reducing health disparities among people with disabilities in the US. Future research to identify and compare health outcomes between sub-populations with disabilities should use consistent and clear definitions of disability

^a Not reported.

^b National Institute on Disability and Rehabilitation Research.

^c Department of Veterans Affairs.

^d Center for Disease Control and Prevention.

^e National Institute for Mental Health.

^f Substance Abuse and Mental Health Services Administration.

^g Schizophrenia Patient Outcomes Research Team.

and employ rigorous methodologies in data collection, analysis, and reporting of findings.

Study limitations

Using our search criteria, disability is a broad term used to capture a diverse range of intellectual, mental, physical, and other conditions. Consequently, we were limited in our ability to make generalizations or definitive statements about specific patterns of disparities. There were methodological limitations of the review process. Since this was a scoping review with a broad research question, electronic database searches resulted in a very large number of results. We needed to balance the comprehensiveness of sources searched with the feasibility of reviewing an unmanageably large number of results. Therefore, the search was limited to the published literature, which excluded reports and other so-called gray literature. In addition, we limited our electronic search of the published literature to MEDLINE, PscyINFO, and CINAHL databases. These databases were recommended to us by a librarian with expertise in systematic reviews who suggested that they would be most relevant to our search topic. Publications that are not listed in these databases may not have been uncovered by our search. To decrease the chances of missing studies, we included hand searches of several relevant journals, reviewed reference lists of included articles for applicable titles, and invited the expert panel to nominate articles for review.

Conclusions

There are many significant gaps in research on health disparities among people with disabilities. Most of the disparity factors and health outcome intersections examined in this scoping review are typified by little to no data. More research is needed to understand which groups are most at risk and what factors are associated with health disparities between subgroups of people with disabilities. Future research should use rigorous methods and clear and consistent definitions of terms. Building this body of research is a vital first step to identifying causes of disparities and improving quality of life and health outcomes for individuals with disabilities, particularly those in especially vulnerable subgroups.

Acknowledgments

We thank Dolores Judkins of OHSU libraries for her guidance and consultation on our electronic search strategies. We also thank Colleen Kidney and Erin Stack for their assistance in reviewing abstracts and articles for inclusion.

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Appendix A

Medline search strategy

- Disabled persons/or amputees/or hearing impaired persons/or mentally ill persons/or visually impaired persons/or mentally disabled persons
- 2. (disabled person\$ or disab\$ or disabled people).mp
- 3. amputee\$.mp
- 4. (hearing impaired person\$ or hearing impaired people).mp
- 5. (mentally disabled person\$ or mentally disabled people).mp
- 6. (mentally ill person\$ or mentally ill people).mp
- 7. (visually impaired person\$ or visually impaired people).mp
- 8. Activities of daily living
- 9. activit\$ of daily living.mp
- 10. Developmental disabilities/or developmental disability\$.mp
- 11. Mental retardation/or mental\$ retard\$.mp
- 12. Mobility limitation/or mobility limitation\$.mp
- 13. Dependent ambulation/or dependent ambulation.mp
- 14. Paraplegia/or paraplegia.mp
- 15. Quadriplegia/or quadriplegia.mp
- 16. Hearing loss/or hearing loss.mp
- 17. Blindness/or blindness.mp
- 18. Vision disorders/or vision disorder\$.mp
- 19. exp self-help devices/or assistive technology.mp
- 20. Mental disorders/or mental disorder\$.mp
- 21. psychiatric disabilit\$.mp
- 22. (mental health disabilit\$ or mental health impairment\$).mp
- 23. functional limitation\$.mp
- 24. activity limitation\$.mp
- 25. mobility impairment\$.mp
- 26. vision impairment\$.mp
- 27. hearing impairment\$.mp
- 28. cognitive impairment\$.mp
- 29. intellectual disabilit\$.mp
- 30. participation limitation\$.mp

- 31. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30
- 32. exp heart diseases/ep, mo
- 33. exp neoplasms/ep, mo
- 34. exp cerebrovascular disorders/ep, mo
- 35. exp respiratory tract diseases/ep, mo
- 36. exp accidents/mo, sn
- 37. exp "wounds and injuries"/ep, mo
- 38. exp diabetes mellitus/ep, mo
- 39. exp Alzheimer disease/ep, mo
- 40. exp influenza, human/ep, mo
- 41. exp pneumonia/ep, mo
- 42. exp nephritis/ep, mo
- 43. exp nephrosis/ep, mo
- 44. exp sepsis/ep, mo
- 45. 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44
- 46. 31 and 45
- 47. health status indicators/
- 48. floating sub ep or mo
- 49. 31 and 47
- 50. floating sub search combined with 49
- 51. "31 and 45" or "31 and 47" or 48 or 49 or 50
- 52. Limit 51 to English language, humans and years
- 53. Limit 52 to publication years "2000-2009"
- 54. Limit 53 to "adult (19–44 years)" or "middle age (45–64 years)"
- 55. Limit 54 by publication types: clinical trial, all or clinical trial, phase i or clinical trial, phase ii or clinical trial, phase iii or clinical trial, phase iii or clinical trial or comparative study or controlled clinical trial or "corrected and republished article" or evaluation studies or government publications or journal article or meta analysis or multicenter study or randomized controlled trial or "research support, American recovery and reinvestment act" or research support, nih, extramural or research support, nih, intramural or research support, non us gov't or research support, us gov't, non phs or research support, us gov't, phs or "review" or technical report or twin study or validation studies.