

Health and Support Service Needs of Individuals With Disability From Culturally and Linguistically Diverse Backgrounds: A Scoping Review Protocol

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Protocol

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Abstract

Background: All individuals should have the right to engage meaningfully in occupations that meet their aspirations and life goals as well as promote their health and wellbeing. For individuals with disability, meaningful engagement in occupations is supported by timely, effective and adaptive health and support services. However, research has revealed multiple barriers preventing utilisation of these services by individuals with disability from culturally and linguistically diverse (CALD) backgrounds. This review aims to identify gaps and solutions in health and support services of individuals with disability from CALD backgrounds to meaningfully engage in occupations.

Methods: A scoping review will be conducted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews and follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Scoping Review guidelines. A detailed search strategy will be used to search CINAHL, PubMed, Embase, Scopus, PsychInfo, JBI and Cochrane Library, as well as grey literature in Trove, Mednar and OpenGrey. Studies will be screened for eligibility against specific inclusion and exclusion criteria for relevant studies. Data will be extracted using the JBI data extraction instrument and presented in a diagrammatic or tabular form accompanied with a narrative summary.

Discussion: The scoping review will present the health and support service needs of individuals with disability from CALD backgrounds and will extend the current reviews as it focuses the engagement in meaningful occupation. Findings from this review have the potential to inform local policy discussions and practice-based disability care.

Background

All individuals should have the right to engage meaningfully in occupations that meet their aspirations and life goals as well as promote their health and wellbeing (1, 2). Meaningful engagement in occupation or meaningful occupation are the range of activities or interventions that individuals engage in that are personally or culturally important to, or valued by the individual and provides enjoyment, a sense of self-worth or identity, belonging or fulfilment (1, 3). Research has consistently demonstrated that engagement in meaningful occupations positively impact on health and well-being (3). For example, a systematic review on the wellbeing of elderly individuals showed wellbeing to be dependent on and enhanced by a range of occupations that provide meaning and value to their life (4). Similarly, Eakman *et al* depicted meaningful engagement in occupation to be associated with better psychological well-being and health-related quality of life (5), and a critical review provided moderate to strong evidence that occupation has an important influence on health and well-being (6). A lack of meaningful occupation has negative effects on health and well-being.

However, there are multiple barriers preventing meaningful engagement in occupations for individuals with disability. This includes, policy and practices failing to meet the health and well-being needs of people with disability (7), such as the failure to provide for the inherent ongoing support for individuals in one or more major life activity (8). Specifically, Law *et al* reported that for children with physical disability, restricted physical, social and institutional environments limit a child's engagement in their meaningful occupations (9).

In Australia, it was reported that in 2018, 4.4 million Australians are living with a disability (10), of which approximately 23% are from a culturally and linguistically diverse (CALD) background (11). The National Disability Insurance Scheme (NDIS) is a new scheme implemented in Australia in 2013 (12) with the aim of increasing funding options and access to support through services to individuals living with permanent and significant disability under the age of 65 (13). An objective of this publicly funded insurance scheme is to facilitate the "development of a nationally consistent approach to the access, and the planning and funding of, supports for people with disability" (13), giving individuals more choice and control over their care (12). To reduce some of the barriers preventing meaningful engagement in occupations by individuals with disability in Australia, the NDIS provides individualised support packages that allow participants to choose services and supports that are reasonable and necessary to support their life and pursuit of their goals and/or meaningful occupation (13). However, to be eligible for these packages, the NDIS places the onus of proof on individuals with disability to demonstrate their eligibility, relying on the individuals' underlying health literacy and fluency in English for self-activation (14 2014) and decision making (15 2017). This indirect discrimination against individuals with disability from CALD backgrounds may make them less likely to seek out support services and less successful in effectively advocating for their needs. Despite the CALD communities having the same prevalence of disability compared to the mainstream Australian population (11), the utilisation of support services by individuals with disability from CALD backgrounds is lower (16). Specifically, the participation rate of CALD individuals in the NDIS is currently only 7.2%, as opposed to CALD individuals with disability, making up roughly 23% of the disabled population (11, 17). This is approximately half to one-third the rate of NDIS usage by CALD individuals with disability as compared to participants from non-CALD backgrounds (11). The disparity in support service utilization may be a product of culturally and/or linguistically inappropriate services, failure to accommodate traditional health practices and beliefs, direct discrimination based on race, or indirect discrimination through unconscious biases (11, 18, 19).

The United Nations *Convention on the Rights of Persons with Disabilities* (CRPD), ratified by 181 countries (20), affirms the rights of individuals with a disability to receive equal opportunity and participation in society, and the highest standard of health care without discrimination (21). However, it does not address the direct and indirect cultural and racial discrimination towards CALD groups with disability (21). In Australia, like some of the other member states of the United Nations, there are specific legislations such as the *Disability Discrimination Act 1992* (Cth) and *Racial Discrimination Act 1975* (Cth), which make it unlawful to discriminate on the basis of disability and race. Yet in reality, research has revealed that some individuals with disability from CALD backgrounds continue to experience actual and de facto discrimination in accessing and utilising health and support services (11).

Meaningful engagement in occupations for individuals with disability from CALD backgrounds is largely influenced by both health and support services as they can act as enablers providing care and delivery of resources to improve or maintain function, manage chronic complex conditions, disease or injury (22). It is important that the health and support service needs of individuals with disability from CALD backgrounds are met to facilitate their meaningful engagement in occupations. Individuals with disability are reported to require more health and support services than those without disabilities (23); therefore it is reasonable to anticipate an increase rate of health and support service utilisation for this population (23). However, research has consistently revealed that

CALD groups with disability underutilise these health and support services, and that such underutilisation is dynamic throughout generations (24, 25). For example, in regard to health services, research on refugee children and adolescents in South Australia revealed that only 21% of those who reported clinically relevant depression symptoms had accessed mental health services (26). Of those participants, 90% reported they would not use mental health services due to barriers in lack of culturally appropriate health care (26). The Federation of Ethnic Communities' Councils of Australia's review on older individuals from CALD backgrounds, affirmed that the underutilization of health and support services by older individuals from CALD backgrounds was not due to lesser needs, but is attributed to barriers such as challenges in understanding the Australian systems of care, ability to successfully navigate the healthcare systems, and lack of access to culturally safe and appropriate services (24).

The Australian findings are not unique. Similarly in the USA, a study exploring the perspectives of Asian immigrant parents with children who have special health care needs reported parents experiencing cultural and language barriers in their understanding and navigation of the health-care system (27). *Mirza et al* concluded that existing service systems in the Midwest failed to meet the disability-related needs of refugees, with participants reporting a lack of knowledge related to disability rights and resources and some health care professionals not considering participants cultural traditions (28).

Conversely in New Zealand, *Mortensen et al* found that the use of cultural case workers for children with disability led to benefits for the children's family including improved access, increase knowledge about health and support services and improved relationships with their health services (29).

Due to the heterogeneity of the CALD community and the various types of disability, there does not exist a one size fits all solution. Most of the prominent literature focus on the multicultural issues encountered by recently arrived refugees and asylum seekers, with other CALD groups being underrepresented (30 2010). As countries become more culturally and linguistically diverse, it is imperative that health and support systems are responsive to the health and support service needs of individuals with disability from CALD backgrounds so as to facilitate meaningful engagement in occupations.

The aim of this scoping review is to identify and describe the health and support services needs of individuals with disability from CALD backgrounds to aid meaningful engagement in occupations. A scoping review methodology is chosen for its ability to provide a broad overview of the available evidence and include findings from a broader range of CALD individuals with disability (31).

With the completion of the preliminary search, no studies were found which discussed the influence of health and support services on meaningful engagement in occupation or what makes occupations meaningful, specific to individuals with disability from CALD backgrounds. However, studies referring to other population groups were found. For example, a review on the meaningful occupations by individuals with dementia living in residential aged care (32), and engagement in health programs by disadvantage populations (33).

Review questions

The specific review questions that will be guiding this study are:

1. What are the health and support service needs of individuals with disability from CALD backgrounds to meaningfully engage in occupation?
2. What are the gaps in existing health and support services of individuals with disability from CALD backgrounds?

Methods

Study design

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews (34), to assess and synthesize the evidence in published and unpublished literature on individuals with disability from CALD backgrounds. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA-P) checklist (see Additional file 1) has been followed to confirm the content of this protocol [35]. The review will follow the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist to ensure transparency and completeness of the review (35).

Eligibility criteria

Participants

This scoping review will consider all published and unpublished studies relevant to individuals with disability from CALD backgrounds and their health and support services needs. Individuals from CALD backgrounds are defined mainly by their "country of birth, language spoken at home (36)" or characteristics including year of arrival in the adopted country and parents' country of birth (36).

Studies involving individuals with disability from CALD backgrounds will be considered. Disability is defined as the interaction between an individual's impairment in their body structure or function and their personal and environmental factors (37). It leads to activity limitations and participation restrictions, which may prevent meaningful engagement in occupations (37).

Concept

The review will consider all studies that describe the health service and health service needs related to individuals with disability from CALD backgrounds. These services are practices that assess, document, maintain or improve an individual's health, treat and diagnose illness or disability, or prescribe medication (38).

Studies that describe support service and support service needs related to disability will be considered. These services are government services that provide income support to individuals with disability, provision of services and provision of funds to organizations to carry out services (39).

Studies that describe meaningful engagement in occupations at a healthcare level will be considered. Meaningful engagement in occupations is the degree to which an individual finds their occupations to be worthwhile, important, and in line with their values and sense of self (1). Occupation refers to a wide range of activities that individuals “need to, want to, are expected to do” (1), that are worthwhile, important and compatible with their values and sense of self, ultimately bringing meaning to their life (1).

Context

Research conducted in primary and secondary health and support care setting will be considered. Primary care is usually the first contact an individual has with the health system and covers majority of an individual’s health needs, and delivering community-based care by various health professionals (16). Secondary care requires more specific knowledge, skills and equipment and is provided by a specialist or hospital upon referral by a primary care professional (16).

Information sources

This scoping review will consider experimental and quasi-experimental studies, analytical observational studies, descriptive observational studies, qualitative studies, systematic reviews, text and opinion papers that meet the inclusion criteria. Studies published in English language will be included. Studies published since 1974 will be included in order to be comprehensive and attempt to ‘cover the field’.

Search strategy

A three-step search strategy will be undertaken (34). An initial search strategy was devised in consultation with a librarian (KC) and employed on CINAHL (EBSCOhost) to identify relevant articles, the text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles to develop a full search strategy (see Additional file 2). Initial keywords include disability, culturally and linguistically diverse, multicultural, culturally diverse, linguistically diverse, ethnic minority, minority group, immigrant, migrant, health service, support service, and disability service. A second search will be undertaken including all identified keywords and index terms, which will be adapted for each database. The databases to be searched include PubMed, Embase (Ovid), Scopus, PsychInfo (EBSCOhost) and Cochrane Library, as well as searching for grey literature in Trove, Mednar, OpenGrey and Google Scholar. As the scoping review aims to search for a diverse range of literature in a topic area [41], meaningful engagement in occupations and meaningful occupations was not applied to the search strategy. Boolean operators and wildcards were applied to search terms to ensure a comprehensive search. Thirdly, the reference list of identified reports and articles will be searched for additional sources.

Study selection

A range of data will be considered in this scoping review, including peer-reviewed journal articles, publications, practice guidelines, policy, reports and statements. This review will include studies relevant to individuals with disability from CALD backgrounds and their health and support service needs. Following the search, all identified citations will be collated and uploaded into Endnote X9 (Clarivate Analytics, PA, USA) and duplicates will be removed. Titles and abstracts will be screened for eligibility against the inclusion criteria. The full text of selected citations will be assessed in detail against the inclusion criteria. Reasons for exclusion of full text studies that do not meet the inclusion criteria will be recorded and reported in the scoping review. The results of the search will be reported in full in the final report and presented in a PRISMA flow diagram [42] (see Additional file 3).

Data extraction

Data will be extracted from papers included in the scoping review using a modified JBI data extraction instrument (40) (see Additional file 4) by author (JP) as supervised by co-authors. The data extracted will include citation and study information (author, year of publication, aim, study population, study design, setting and methodology), as well as results relevant to the scoping review (type of CALD groups, type of disability, micro-meso-macro system factors and relevant key findings and themes). Where required, authors of papers will be contacted to request missing or additional data.

Risk of bias assessment or quality appraisal

As the scoping review aims to identify gaps in existing evidence and map all available evidence, a risk of bias assessment will not be undertaken. Quality appraisal will be undertaken independently by two reviewers for all included studies using the JBI appraisal tools (41) to assess the methodological quality of the studies as well as to determine the extent to which the articles had addressed the possibility of biases. Following an independent review, any discrepancy in interpretation of the data will be discussed between authors to obtain consensus. A kappa coefficient will be obtained.

Data presentation and synthesis of results

As the studies considered will include a mix of qualitative, quantitative and mixed research methodologies, meta-aggregation will be used for the synthesis of qualitative results. Meta-aggregation is a process that summarises common findings that are then synthesized and may be from different methodologies (42). They produce generalisations that lead to recommendations for action, hence statements can be useful for evidence-based practice (43). Individual studies will be summarised, then categorized into common themes among all qualitative studies before synthesis. The extracted data will be presented in a tabular form in a manner that aligns with the objective of this scoping review. A narrative summary will accompany the tabulated results and will describe how the results relate to the review objective and questions.

Discussion

Since our preliminary literature search identified a paucity of publications pertaining to individuals with disability from CALD backgrounds, a scoping review was chosen for its utility in mapping major concepts across a diversity of literature to provide a descriptive overview of the degree, scope and nature of

research activities in a broad topic area (44) and identify gaps in evidence (34). It is expected that the findings of this review will provide clear evidence of the health and support service needs of individuals with disability from CALD backgrounds. Furthermore, gaps in existing health and support services of individuals with disability from CALD backgrounds will be described. The review will extend the current reviews as it focuses on all CALD communities and the engagement in meaningful occupation. There will be no patient or public involvement in the research. This protocol is co-designed with CALD stakeholders: VI, DL and JP. Studies that undergo quality appraisal will remain included as the function of the quality appraisal is not selective but rather descriptive. The review poses negligible risk and will only use existing collections of data or records already in the public domain. Results of the review will be disseminated through a peer-reviewed publication published in the public domain and has the potential to inform local policy discussions and practice-based disability care.

Abbreviations

CALD: culturally and linguistically diverse

JBI: Joanna Briggs Institute

NDIS: National Disability Insurance Scheme

CRPD: Convention on the Rights of Persons with Disabilities

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-analyses

PRISMA-P: Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols

PRISMA-ScR: The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews

Declarations

Ethics approval

Ethics exemption was granted by Western Sydney University Human Research Ethics Committee (EX2020-02).

Consent to participate

Not applicable

Availability of data and materials

All data and materials generated or analysed are included in this article.

Competing interests

This scoping review is JP's Honours project.

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Authors' contributions

DL and JP devised the project concept. DL, JP, AI, SH, CE and VI reviewed and edited the protocol. KC assisted in devising the initial search strategy. All authors approved the final manuscript.

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