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Understanding the interaction between support and social participation for people with physical disabilities: a scoping review protocol

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ABSTRACT

Introduction Around the world, the disability rights movements and the social model of disability have placed emphasis on the importance of social participation for people with disability. People with physical disability who have high and complex support needs often need support to access their communities, however, very little is known about the interaction between support and social participation for this population of people. Therefore, the aim of this scoping review is to explore the literature related to the interaction between support and social participation for adults with disability and understand any existing gaps in the literature where further research may be required in order to maximise quality support and social participation.

Methods and analysis This scoping review will be conducted and reported according to scoping review guidelines outlined by Arksey and O'Malley and later modified by Levac *et al*, as well as the Preferred Reporting Items for Systematic Reviews and Meta-Analysis: Extension for Scoping Reviews. Thorough database searches will be conducted across MEDLINE, PsycINFO, CINAHL and Scopus. The search will be limited to papers published in English from 2013 onwards. Citations will be uploaded into Covidence and screened by two independent reviewers. Data extraction will extract data regarding participants, housing, support and study characteristics, as well as qualitative and quantitative data relevant to the research question. A narrative synthesis will be used to summarise findings. A minimum of three consultants with lived experience of disability will be engaged to review and contribute to the final scoping review paper.

Ethics and dissemination It is anticipated that the findings of this scoping review will be made available in peer-reviewed publications and also in plain language formats to ensure accessibility to a wide range of audiences. Ethics will not be required for this scoping review.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This study will be coauthored and coproduced by people with lived experience of disability.
⇒ This study will be the first scoping review to look into the interaction between support and social participation for people with physical disabilities.
⇒ Only papers written in English from the year 2013 onwards will be considered for inclusion.

INTRODUCTION

Around the world, the disability rights movement and the social model of disability have taken prominence in order to promote the full participation of people with physical and other disabilities within society.[1] The disability rights movement asserts that people with disability should live free from discrimination and have equal opportunities and rights, including the right to live and be supported in the community, the right to paid employment and the right to inclusive education.[2] In a similar tone, the social model of disability explains that restrictions to participation do not necessarily come from a person's direct disability impairment, but instead from the environmental barriers around them, such as inaccessible buildings or people's negative attitudes and assumptions.[3] A common example used to describe the social model is that it is not a person's need to use a wheelchair for mobility that prevents someone from entering a building that has stairs, but instead, it is society's failure to instal a ramp or elevator.[4] Many governments in the Global North are beginning to acknowledge these movements by implementing disability funding systems that seek to improve areas of life, such as housing, that have the potential to present participation restrictions to people with disability if not adequately addressed.[5] For example, in Australia, the National Disability Insurance Agency now funds specialist disability accommodation (SDA) for Australians with high support needs.[6] SDA funding assists people with disability to live in homes which are appropriately accessible, meaning more Australians with disability and complex needs are being given access to housing which maximises independence

and facilitates high-quality support.[6] However, the accessibility of housing and its impact on participation is a tangible concept and one that has been widely studied, with a recent study finding that accessible housing leads to improved social participation, quality of life and health and well-being outcomes.[7] Less research has focused on in-depth exploration of other factors which may impact the participation of people with disability and, specifically, people with physical disabilities and high and complex support needs.[1 8]

Outside of appropriate and accessible housing, quality support is considered to be another major contributor to the quality of life of adults with disability.[9 10] Adults with physical disability may receive support from various groups of people, including informal support such as from family members, friends, advocates or peers and formal support from paid disability support workers, support coordinators and health professionals.[11–13] Research suggests that adults with physical disability who receive high-quality support have better health and well-being and are more likely to participate in society.[14 15] It is important to recognise that not all adults with disability have the same support needs.[10] Some may not require any support in their day-to-day lives while others may have very high and complex support needs, and therefore, require support 24 hours a day, 7 days a week.[16 17] The role that supports play in the life of an adult with physical disability can be heavily influenced by this requirement.[18] For adults with disability who have high and complex support needs, their supports may help them with activities such as personal care, household management and social participation.[19]

Social participation often looks similar for people with and without disabilities—whether going out to restaurants and bars, visiting family and friends, going out shopping or engaging in activities such as arts, culture, travelling, education or employment.[20] For people with physical disability, increased social participation can result in benefits such as improved health and well-being, reduced mental illness, increased life satisfaction and increased quality of life.[21 22] However, as discussed by Bigby and Beadle-Brown,[23] many people with disabilities need strong support networks or programmes around them in order to ensure benefits are gained from engaging in any community or social environment. Without adequate and quality support, it can be perceived that social or community participation simply reflects being in a community, rather than of a community—a distinction emphasised by Martin Ginis et al.[24] It is for this reason that this paper uses the term 'social participation', which better reflects this concept as opposed to phrases such as 'community integration' or 'community engagement'.[25]

Despite the established importance of social participation for people with physical disability and the existing evidence that many people with disability require support to participate in the community, it appears that very few studies have sought to thoroughly investigate the interaction between support and social participation for adults with physical disability. Additionally, a recent study

recommended an in-depth exploration of factors that influence social participation.[26] Therefore, the aim of this scoping review is to explore the literature related to the interaction between support and social participation for adults with physical disability and high and complex support needs and understand any existing gaps in the literature where further research may be required in order to maximise quality support and social participation.

METHOD AND ANALYSIS
The proposed scoping review will be conducted and reported according to scoping review guidelines outlined by Arksey and O'Malley[27] and later modified by Levac et al,[28] as well as the Preferred Reporting Items for Systematic Reviews and Meta-Analysis: Extension for Scoping Reviews (PRISMA-ScR[29]). It is anticipated that this scoping review will begin in the later quarter of 2023.

Identifying research question
The research question central to this scoping review is: What is the interaction between support and social participation for adults with physical disability and high and complex support needs? For the purpose of this research, high and complex support needs are defined as the support requirements of a person with disability which originate from a 'functional impairment which has a substantial impact on the person's independence in one or more activities in the domains of mobility, self-care, domestic life or self-management'—resulting in multiple support needs that are profound, severe, serious or intense.[7] In addition, support is defined as assistance with activities such as personal care, household management and social participation from either informal supports such as family members, friends, advocates or peers, or formal supports such as paid disability support workers, support coordinators and health professionals.[11–13 19]

Identifying relevant studies (developing the search)
The search strategy has been developed in collaboration between the authors and an experienced senior research librarian. An initial search of MEDLINE was undertaken to refine the search terms and search strategy. Three core concepts were extracted from the research question and applied to the search strategy. These were (1) physical disability, (2) social participation and (3) adult. A comprehensive list of search terms was then developed for each of those concepts based on the authors' prior knowledge, keywords contained in the titles and abstracts of relevant articles, and search strategies used in other scoping reviews with similar research questions. Concepts will be combined using the Boolean operator 'AND', with keywords within each concept being combined with the Boolean operator 'OR'. It was consciously decided that the concept of 'support' would not be included in the search strategy due to this term being a broad-ranging concept related to many different forms of support, and

searching for specific supports such as 'family' or 'support workers' may inadvertently exclude relevant articles.

A full search strategy was then developed for MEDLINE (see online supplemental appendix), with search filters of studies only being published in the English language from 2013 onwards being applied. This search strategy will be adapted for all included databases. The databases to be used in this scoping review will include MEDLINE, PsycINFO, CINAHL and Scopus. Both a backward search of the reference list of included studies, as well as a forward search for papers which cite the included studies, will be undertaken to identify any relevant papers which may have been missed in the initial database search.

Study selection
Eligibility criteria

For studies to be eligible for inclusion, they must be peer-reviewed and published in the English language. There will be no study design restrictions due to the anticipated scarcity of research in this area, however, papers will be required to have extractable empirical data. The primary or stated aim of the papers included will be aligned with the scoping review's research question. The paper will also need to have been published no earlier than the year 2013. The last 10 years can be viewed as a point in time when the disability and support landscape changed, with a greater focus on participation and, at least in Australia, legislation to enable people with disability to get support to participate.[30] Specifically, in Australia in 2013, the National Disability Insurance Scheme (NDIS) was legislated, which enables people with disability to get the reasonable and necessary support they need to engage with their communities.[31]

Inclusion criteria

► Clinical population: Included research should focus on adults with physical disability (regardless of origin or co-occurring disabilities) aged 18–65 who are living in the community and have complex or high support needs.
► Support population: In addition to the clinical population described above, research may also include supporters such as close others and support workers as sources of information, contributing to data surrounding the experiences of the clinical population.
► Concept: Studies that report on the interaction between support (informal or formal) and social participation for adults with physical disability living in the community.
► Peer-reviewed articles that are based on research from countries in the Global North (including Australia, Canada, most European countries, New Zealand, the UK and the USA[32]).

Exclusion criteria

► Participants below the age of 18 or aged 65 or above.

The lower age limit of 18 has been selected as in most Global North countries, 18 is considered the age of adulthood and typically the youngest age people would move out of home. The upper age limit of 65 or above is reflective of the upper limit of those accepted onto the NDIS—Australia's primary disability funding scheme.[33]

► Participants who reside in institutions, residential aged care or hospitals.
This has been selected as exclusion criteria as people with disability who do not live in the community often have very little choice and control over their participation in the community (if any at all) and often receive minimal purposive support to do so.[34] This body of literature regarding social participation for people who reside in settings such as institutions, residential aged care or hospitals has already been established[35 36], therefore this piece of research seeks to explore the question in the context of people with disability living in the community.

► Participants who do not have a physical disability (eg, participants with intellectual disability who do not also have a co-occurring physical disability).
This has been selected as exclusion criteria as people with different types of disabilities (eg, physical, intellectual, sensory or psychosocial) often have very different support needs.[16] Therefore, including all disability types would not provide a fair or accurate comparison when investigating the link between support and social participation.

► Participants who do not have high or complex support needs, and therefore, do not require high levels of support (eg, participants who have a physical disability which may typically be considered 'mild', such as people with single limb amputations or limb difference).
This has been selected as exclusion criteria as people who have high or complex support needs often need hands-on support in order to access the community.[37] This need in itself places different barriers and facilitators on social participation, compared with people with disability who may have lower support needs, and therefore, be able to access their community independently.

Screening

After the conclusion of the literature search, all citations will be uploaded into Covidence and duplicate references will be removed. For title and abstract screening, two independent reviewers from the research team will review the citations against the outlined inclusion and exclusion criteria.

Following the title and abstract screening, any papers that meet the inclusion criteria will have their full text independently reviewed by two reviewers from the research team. For articles that are included after a full-text review, references for those articles will be scanned to identify any other literature relevant to this scoping

review, as well as a forward search for citations of included articles.

Any uncertainties during this screening process, including disagreement on article inclusion, will be discussed between the independent reviewers and an agreement reached. If required, the inclusion/exclusion criteria or search strategy may be modified or a third reviewer from the research team will be consulted if agreement can not be reached.

The results of the literature search as well as the number of articles at each stage will be outlined in a full PRISMA-ScR flow diagram.[38]

Charting the data

The data extraction form will be built iteratively as screening of articles and refinement of inclusion/exclusion criteria occurs to ensure suitability to the research question and eligibility criteria. The development and completion of the data extraction form will be a collaborative process between two reviewers from the research team. The data will then be extracted by the lead author.

It is anticipated that the data extraction form will collect the following pieces of information: (1) participant characteristics (age, gender, type of disability, population type (eg, people with disability, close others, informal or formal supports, professionals)), (2) housing characteristics (living status such as group home, single-residency, living with family, etc), (3) support characteristics (type of support such as paid support workers, family, professionals and quantity of support (eg, paid support hours, level of support (such as 24/7) received/required), (4) study characteristics (author, study year, study design/methodology, sample size, country of completion, measures), (5) qualitative data and quotes relevant to the research question and (6) quantitative data relevant to the research question.

Our intention is to also undertake a quality evaluation of included articles utilising the Critical Appraisal Skills Programme, allowing the methodological rigour of included articles to be reported on.[39]

Collating, summarising and reporting the results

The collating, summarising and reporting of the results will be informed by the PRSIMA-ScR checklist.[27] A descriptive summary of the scoping review will outline the number of citations screened and the number of studies included at each stage. This will be presented in a PRISMA flow diagram.

The key characteristics of the final included articles will be summarised in both table and text formats. Quantitative and qualitative data will be analysed separately, with a narrative synthesis used to summarise the findings of all included articles into themes relevant to the scoping review's research question. This process of a narrative synthesis will allow both quantitative and qualitative data to be discussed in tandem. Additionally, any gaps in the literature identified by the included articles or the authors of this paper will be identified and discussed.

Patient and public involvement

People with lived experience of having a physical disability which results in high or complex needs will be invited to review the first draft of this scoping review and put forward feedback and suggestions. The aim will be to recruit at least three paid consultants with a diversity of experiences via the existing networks of Summer Foundation's and La Trobe University's Living with Disability Research Centre. Lived experience consultants will be sent an electronic copy of the scoping review draft to review at their own pace and to provide feedback in a format that is accessible to them. The objective of this consultation process will be to ensure that the scoping review is informed by the lived experience perspective, assist in identifying any literature gaps that may have been missed and provide advice on dissemination of findings.

Limitations

The primary limitation of this scoping review is that the search strategy is limited to articles in English from the year 2013 onwards. While the year 2013 is deemed an important year for change in the disability landscape, this time limit is deemed an unavoidable limitation which reduces the scope of articles to be reviewed to a quantity which can be reasonably processed by the research team. There is also a risk that very few, if any articles, may be found on the research question of interest. However, although this may prevent the research question from being answered in this particular instance, a lack of articles will also provide justification for further research into this topic of interest.

Ethics and dissemination

Ethics will not be required for this scoping review. The aim of this scoping review is to synthesise the existing literature on the interaction between support and social participation for people with physical disability and high or complex support needs. To the best of our knowledge, this will be the first scoping review in this particular topic area. It is believed that the results of this scoping review will assist in emphasising the importance of quality support in sufficient quantity in order for people with physical disabilities and high or complex support needs to feel that their social participation meets their goals and preferences. Where there is evidence of gaps in the literature, it is hoped that the scoping review will help inform future research in the area. It is anticipated that the findings of this scoping review will be made available in peer-reviewed publications and also in plain language formats to ensure accessibility to a wide range of audiences.

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