

Factors Leading to the Success of Social Participation Promotion Programs for People with Intellectual Disability: A Protocol for A Systematic Review

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Protocol

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Abstract

Background People with intellectual disabilities have been historically excluded from decision-making processes. Previous literature indicates that social participation may be an effective tool to increase social inclusion, but no systematic review of interventions focused on social participation of people with intellectual disabilities have been conducted. This study aims to identify and organize the factors associated with social participation interventions having a positive impact on social inclusion of people with intellectual disabilities; and to provide a set of best of practices for future interventions.

Methods/design This systematic review of the literature will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) recommendations. The databases Web of Science, EBSCO, Scopus, LILACS and PubMed will be searched for articles between January 1 st , 2004 and December 31 st , 2019; a grey literature search will also be conducted. Randomized control trials, nonrandomized control trials, and controlled before and after studies will be included. If necessary, noncontrolled before and after studies will also be included. Observational or qualitative studies will be excluded. The primary outcome is success of intervention. Secondary outcomes include measures of social participation. Two reviewers will independently screen articles, extract relevant data and assess the quality of the studies.

Discussion This systematic review will add to our understanding of successful social participation interventions for people with intellectual disability. It will allow us to identify and organize which factors lead to an increase in social participation and help us define a set of best practices to be followed by future interventions.

Systematic review registration This protocol is submitted to the PROSPERO registry of the University of York (reference number: 189093).

Background

People with disabilities (PWD) have been historically excluded from decision-making processes and they have been pushed to the role of subjects of care instead of full citizens with rights, with freedom for choosing when and how to participate in society. This situation has been slowly improving since the United Nations (UN) published the Convention on the Rights of Persons with Disabilities (CRPD) in 2006. The Convention has been signed by 163 countries and ratified by 181. These countries have been trying to implement rights-based intervention programs aiming to facilitate the participation of PWD with varying degrees of success. We are interested in the particular case of people with intellectual disability (ID) as they tend to face stronger barriers against participation than other PWD (1).

ID is a neurodevelopmental condition characterized by alterations in cognitive development and adaptive behavior, as determined by standardized assessment procedures (2,3). People with ID tend to be ignored and relegated from participation and advocacy groups as they face stigma related to alterations in verbal communication, learning difficulties and cognitive alterations, along with the kind of supports they require (4). Adults with ID want to be heard, to participate in their life choices, to be treated as adults and accepted as individuals (1). It has been shown that people with ID need tools to empower them and spaces where they can learn about their rights and opportunities, because their exclusion causes them to assume they do not have the abilities to change their situation (5).

Social participation is a tool of change and social justice that facilitates taking into account the needs of stakeholders in a given situation and increases social inclusion. Previous studies have confirmed that there is a direct relationship between participation, quality-of-life, and well-being at personal, familiar and social levels, and that social inclusion improves self-esteem, trust, happiness, mental health and elevates the effective contribution of people with ID to society (6,7). Furthermore, social inclusion enhances the ability to make decisions, and decreases negative attitudes, discrimination and stigma towards people with ID (8,9). Social inclusion also decrease loneliness and exclusion (10).

Given the relevance of social participation for people with ID, we are interested in identifying interventions that focus on it as a tool for increasing social inclusion. It is important to understand how these interventions work and which factors lead to their

success. This review is an attempt to identify those factors and deliver the foundation for a set of best practices in social participation programs.

As the concept of social participation has been used in different ways in recent years, we will adopt the following definition to guide the search: social participation is the realization of actions by an individual, that contribute to themselves and others, and that occur in both personal and societal levels (11). In the case of social inclusion, we will use the model of two overlapping, mutually supporting domains: interpersonal relationships and community participation (12). These domains interact and reinforce each other: better interpersonal relationships may lead to more participation in the community and vice versa; in turn, this leads to an increase in social inclusion. The issue for many people with ID is that this reinforcement cycle never occurs and social inclusion is nonexistent (13). Simplican's model (12) offers an ecological approach to the model, capturing how variables from each domain interact between them and offer pathways to and from social inclusion. This approach nests variables in five levels: individual, interpersonal, organizational, community and socio-political. Interventions at one level, may affect other levels and jumpstart the reinforcement cycle required for social inclusion. These models of social participation and inclusion will guide our search and provide a framework for categorizing interventions.

Methods/design

Objectives

The goal of this systematic review is to identify personal, social, and methodological factors that improve the effectiveness of social participation promotion programs for people with intellectual disability. Our secondary goal is to delineate a set of best practices for social participation promotion programs based on the evidence collected. To this end, this proposed review will attempt to answer the following questions:

1. Do social participation promotion programs have an effect on subsequent social participation of people with ID?
2. For question 1, which kind of programs appear to increase social participation?
3. For question 2, are there personal factors shared by participants in those programs?
4. For question 2, are there social factors shared by participants in those programs?
5. For question 2, are there methodological factors shared by those programs?
6. For questions 3 to 5 above, is there a common set of personal, social and methodological factors shared by successful programs?

Eligibility criteria

Studies will be selected according to the criteria outlined below.

Study designs

We will include randomized control trials, nonrandomized control trials, and controlled before and after studies that compare an intervention designed to improve social participation of people with ID. If not enough controlled studies are found, we will also include uncontrolled before and after studies. We will exclude observational or qualitative studies.

Participants

We will include studies about promotion programs involving people with ID as part of the participants. We will include studies about programs where at least 50% of the participants are people with ID. We will include studies about promotion programs referring to other disabilities if a) there are participants with ID in those programs, or b) the studies report results separately for

people with ID. We will include studies that recruited people regardless of gender, ethnic group, medical diagnosis or multiple diagnoses, as long as they have been identified as people with ID.

Interventions

We are interested in social participation promotion programs involving people with ID, taking a broad perspective. Besides programs that focus on people with ID, we will also consider programs that address social participation of people with disability in general but include people with ID in the participant groups. We will consider both offline and online programs. We will include studies reporting either successful or unsuccessful impact on social participation.

We broadly define social participation promotion programs as interventions targeting one or more of the ecological pathways of the social inclusion model with the explicit goal of facilitating people with ID to participate, that is, to perform actions contributing to themselves and others, in the Community and Socio-political domains of the model. We will exclude studies reporting programs that do not fit the previous definition.

Outcomes

The primary outcome is intervention success, a dichotomous outcome that indicates whether the social participation program was considered successful or not. Secondary outcomes will include any measures of social participation reported by the studies: well-being, stigma, employment rate, weekly hours of community work, membership in advocacy networks, etc. Secondary outcomes will also include measures of knowledge about rights and advocacy processes if they are available. Outcomes will be collected as reported. We will consider creating an aggregate index of success if the collected studies warrant it.

Timing

Studies will be selected for inclusion regardless of the duration of the intervention. Outcomes will be grouped into three categories to represent short-term (less than 6 months), medium-term (between 6 and 12 months) and long-term outcomes (more than 12 months).

Setting

There will be no restrictions by type of setting.

Language

We will include articles reported in Spanish, Portuguese and English.

1st, 2004 and December 31st, 2019) in the following databases: Web of Science, EBSCO, Scopus, LILACS and PubMed. We will also conduct a grey literature search.

Search strategy

We will seek peer-reviewed articles about quantitative studies. No study design, date, or language limits will be imposed on the search, although only articles in Spanish, Portuguese and English will be included. We will search the databases Web of Science, EBSCO, Scopus, LILACS and PubMed for articles between January 1st, 2004 and December 31st, 2019. The search strategy for Web of Science can be found in Additional file 1. The strategy will be adapted to the specific syntax of each

database. We will also conduct a grey literature search. This protocol conforms to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols (PRISMA-P, 14) guidelines, found in Additional file 2.

Selection process

We will follow a two-stage screening process. First, review authors will independently screen the titles and abstracts yielded by the initial search against the inclusion criteria. Two senior reviewers will check a report about all titles appearing to meet the inclusion criteria, and those where there is uncertainty. Second, full texts of all retained articles will be procured and assessed independently by two reviewers. Any disagreement will be solved through a discussion between the two reviewers and, if necessary, the involvement of a third reviewer. In case it is needed, we will seek additional information from study authors to determine eligibility. We will record the reasons for excluding studies. No review authors will be blind to the journal titles, the study authors or institutions.

Data extraction and management

The team will design and pilot standardized forms for data extraction. The information to be extracted includes: study methodology, study setting, study population, participant demographics, baseline characteristics, intervention details, outcome measurements and timing, and information for the assessment of risk of bias. Due to the broad perspective for programs, the forms may require constant refinement during the data extraction process to include previously unidentified outcome measures. Four reviewers will participate in the data extraction process. To ensure consistency, we will conduct calibration exercises before starting the review. For each study, data will be extracted independently by two reviewers. Reviewer's disagreement will be resolved by discussion, and one of two arbitrators (MT or PA) will adjudicate unresolved disagreements. We will contact corresponding authors if necessary, to seek out further information.

We will use Mendeley to manage the references. We will use Covidence to carry out the review.

Risk of bias in individual studies

The methodological quality of each of included study will be assessed independently by two reviewers. As we will be including both randomized and nonrandomized study designs, we will use Cochrane's respective risk of bias tools: RoB for randomized designs and ROBINS-I for nonrandomized designs. For each study, all risk of bias domain will be rated and categorized as low, high or uncertain. If there is disagreement between reviewers, it will be solved by discussion and one of two arbitrators (MT or PA) will adjudicate unresolved disagreements.

Measures of effect

Whenever possible, we will calculate measures of effect. For studies with a separate control group, we will express the intervention effect as either a risk ratio (for dichotomous variables) or standardized mean differences (for continuous variables) with corresponding 95% confidence intervals. For studies without a separate control group and at least three measures before and three measures after the intervention, we will express the effect as standardized level and slope differences of before and after regression lines (15). For studies without a separate control group and less than three measures before and after the intervention, we will use the standardized mean difference between the latest measure before intervention and the earliest measure after intervention.

Evidence synthesis

We will provide a systematic narrative synthesis of the results extracted from the full-text articles. We will include a summary of studies including information about authors, study design, participants and their characteristics, success of the intervention as the primary outcome, any secondary outcomes, and limitations of the studies. Given our interest in identifying the characteristics of successful intervention programs, we will emphasize identifying and classifying which program characteristics may be factors for success. We will weigh the relative strength of each factor taking into account how many studies provide evidence for it and the qualities of those studies. A summary of these findings will be provided as an attempt to characterize a set of best practices for social participation programs for people with ID.

Discussion

The barriers against the participation of people with ID tend to be higher than for other PWD and, because of this, they are at risk of being excluded from decision-making processes involving their well-being, and from society at large. Increasing social inclusion of people with ID depends on facilitating their participation at individual, interpersonal, organizational, community and socio-political levels. Determining which factors lead to the success of intervention programs aiming to increase social inclusion through social participation is important to guide the design, development and implementation of better interventions and public policy. By identifying and categorizing these factors, this systematic review will help create a set of best practices for future interventions and public policy and, hopefully, improve the social inclusion of people with ID.

List Of Abbreviations

PWD: People with disabilities; UN: United Nations; CRPD: Convention on the Rights of Persons with Disabilities; ID: Intellectual disability; RoB: Cochrane's Risk of Bias Tool for Randomized Trials; ROBINS-I: Cochrane's Risk of Bias In Non-Randomized Studies or Interventions.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Availability of data and materials

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

MT is the guarantor. AA and RE drafted the manuscript. All authors contributed to the development of selection criteria, the risk of bias assessment strategy and data extraction criteria. AA developed the search strategy. MT and PA provided expertise on intellectual disability. All authors read, provided feedback and approved the final manuscript.

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Not applicable

Amendments

None. This is the first protocol.

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