
Title registration for a systematic review: Multifaceted interventions for supporting community participation among adults with disabilities

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Multifaceted interventions for supporting community participation among adults with disabilities: a systematic review

Background

The University of Kansas, in partnership with the University of Montana, operates a Rehabilitation Research and Training Center on Promoting Interventions for Community Living (RRTC/PICL). The purpose of the Center is to examine the effectiveness of interventions to support greater community participation for individuals with physical and co-occurring multiple disabilities and to promote the dissemination and utilization of effective interventions. Currently, in its first year of operation, the RRTC/PICL is charged with developing and promoting interventions that support individuals with disabilities and positively impact community participation outcomes for such individuals. One of the goals of RRTC/PICL is to identify key components of effective evidence-based, multifaceted interventions that support individuals with disabilities in the community through a systematic review of the literature.

Numerous US laws have been passed to increase protections and opportunities for people with disabilities to live more independently in the community. Section 504 of the Rehabilitation Act of 1973 was created to increase opportunity for physical and programmatic access in institutions (e.g., universities) that received federal monies. Title VII of the Rehabilitation Act established Centers for Independent Living (CILs) and mandated four core services: information and referral, advocacy, peer counselling, and independent living skills training; a fifth core service, transition, was added in the latest version of the Workforce Innovation and Opportunity Act of 2014. The Fair Housing Amendments Act of 1988 allowed tenants to make reasonable modifications to their apartments at their own expense; the Americans with Disabilities Act of 1990 was designed to protect the civil rights of citizens with disabilities; the *Olmstead v. L.C.* Supreme Court decision (1999) allowed people to live in least restrictive environments; and the currently proposed Disability Integration Act (DIA), S. 2427 would create a civil right to home and community-based services and supports as an alternative to institutions. Despite these enacted laws, many people with disabilities lack personal knowledge, skills, resources and/or enabling environments that would allow them to take advantage of these rights and resources and live more independently in the community.

Multi-faceted interventions that measure outcomes relevant to community participation will be examined in this systematic literature review. A *community participation intervention* is defined as something that is done to, with, or for the person with a disability or the environment in which they interact or want to interact with to achieve community participation outcomes. We define *community participation outcomes* as outcomes that are chosen by/desired by the individual with a disability, occur in the community (i.e., integrated with people without disabilities), and are reflective of (a) direct access to or participation in the community or (b) dimensions of community participation (i.e.,

outcomes for which there is a research base linking them to community participation). See the outcomes section for examples of direct access to or dimensions of community participation.

For this and our other grant activities, we rely heavily on research conducted by our research team member Bryce Ward, Ph.D., the Associate Director at the Bureau of Business and Economic Research and Director of the Bureau's Health Care Research Program at the University of Montana. Dr. Ward has published work on community participation of disabled persons in peer-reviewed journals. This systematic review is proposed for multifaceted interventions that promote community living among people with disabilities. Studies of the impact of single-faceted interventions on community participation of adults with disabilities are numerous. An example of a systematic review of a single intervention is a study of the efficacy of using service dogs for people with physical disabilities (Winkle, Crowe, & Hendrix, 2012). Other reports examining the impact of a single intervention on community participation for adults with disabilities include a study of transportation vouchers (Samuel, Lacey, Giertz, Hobden, & LeRoy, 2013), an exercise intervention (Dean et al., 2012), and a cognitive intervention to reduce fear of falling and associated avoidance of activity among older adults with disabilities (Haastregt et al., 2007). However, our review is focused on the effectiveness of multifaceted interventions, which are defined as interventions that address two or more personal characteristics or environmental barriers to change (Eldh & Wallin, 2015). The hypothesis is that multifaceted interventions will be more effective, especially when confronted with multiple, complex, and interacting factors affecting outcomes of such a complex phenomenon such as community participation by people with a wide range of disabilities.

A systematic review is appropriate in this case because we have clear questions and definitions to guide the search for relevant studies. Specifically, the research questions for this systematic review are:

1. What are the reported community participation outcomes of multifaceted interventions targeted on adults with disabilities?
2. What are the identified components of effective multifaceted interventions?
3. How do the identified multifaceted interventions conform to standards of HCBS quality?

Objectives

The purpose of this systematic literature review is to synthesize the research on the effects of multifaceted interventions provided in community settings for the purpose of promoting community participation outcomes of adults (18+ years old, no longer receiving secondary education services) with disabilities in studies using quantitative – randomized-controlled trials, quasi-experimental, and qualitative research design methods.

We seek to identify components of multifaceted interventions that are effective in facilitating community participation for adults with disabilities, particularly those with severe limitations (e.g., cognition, mobility) that impede their participation in the community. The results of the literature review will inform policy makers in their practical decisions about social and behavioural interventions and public policy regarding funding and services to provide such interventions. In addition, the literature review results have the potential to help health and social work practitioners in

the field who work directly with people with disabilities to understand and apply the information regarding multi-faceted interventions in their daily work.

The findings will also inform modifications of our planned interventions to be addressed in the subsequent years of the Center and will be the basis for at least one peer-reviewed publication. In addition to filling a critical gap in the research literature, we expect the results of the systematic literature review to provide us with information to modify and finalize our multifaceted intervention research.

Existing reviews

Studies of the impact of single-faceted interventions on community participation of adults with disabilities are numerous. There are very few systematic reviews of multifaceted interventions related to disability issues. Most reviews on the topic of disability and community relate to descriptive factors serving as barriers or facilitators to participation (e.g., White et al., 2011). In searching The Cochrane Collaborative, The Campbell Collaboration, and NARIC databases, we found no systematic reviews related to multifaceted interventions to enhance community participation by adults with disabilities of any type. There were a few systematic reviews of multifaceted interventions focused on other topics. For example, Williams et al. (2007) conducted a systematic review of multifaceted interventions to improve depression care and found strong evidence for the effectiveness of care management for depression.

Intervention

The interventions in the studies must meet the following criteria:

- Intervention measures one or more community participation outcomes targeted for change
- Intervention targets persons with a disability/ies for at least a portion of the sample – with an identifiable impact on the disability sample
- Intervention seeks to change/impact two or more personal characteristics or environmental factors that are in different domains (e.g., transportation skills and employability skills)

Population

The intervention must target persons with a disability/ies for at least a portion of the target sample – with outcomes identified for the disability sample.

Samples in selected articles will include adults:

- Who are 18+ years old
- Whom have left the secondary education/high school setting
- Whom have one or more disabilities

Study samples will **not** include individuals under 18 years old or whom are still participating in a transition program (18-22 years) in secondary special education

Outcomes

Community participation outcomes are defined as being chosen by/desired by the individual with a disability, occur in the community (i.e., integrated with people without disabilities), and are reflective of (a) direct access to or participation in the community or (b) dimensions of community participation (i.e., outcomes for which there is a research base linking them to community participation).

These are to include the following outcomes and examples below:

Direct access to or participation in the community

- Integrated competitive employment
- Continued learning
 - Education
 - Training
- Housing
 - Place
 - Housemates
 - Usability
- Civic involvement
 - Voting
 - Advocacy
 - Committees/leadership
 - Volunteer work
- Recreation
 - Sports
 - Arts
 - Music
 - Community events (e.g., art in the park, parades, block parties)
- Navigating the community/accessing community

Dimension of community participation

- Increased self-determination
 - Autonomy
 - Self-advocacy
- Improved health
 - Physical
 - Mental
- Improved quality of life
- Increased family support/activities in the home
 - Caregiving
 - Supporting children/parenting
 - Household chores/care
- Social networking
 - Friendships
 - Relationships (e.g., boy/girlfriend, spouse)
 - Church/religious activities

Descriptive studies that do not include outcome measures will be excluded.

Study designs

Types of intervention studies that will be reviewed include:

- quantitative – randomized-controlled trials
- quasi-experimental
- mixed methods (quantitative component will be included when it meets quality expectations for the methodology)

The team will ensure that the research of selected studies is high-quality using adapted versions of the National Technical Assistance Center on Transition (NTACT) Quality Indicator Checklists for Group Experimental studies and Qualitative studies (see <http://www.transitionta.org/effectivepractices>).

Types of intervention studies that will not be included in the review:

- case studies
- single subject research design
- single group – pre/post

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- Workforce Innovation and Opportunity Act Public Law 113-128 (2014).

Review authors

Lead review author: The lead author is the person who develops and co-ordinates the review team, discusses and assigns roles for individual members of the review team, liaises with the editorial base and takes responsibility for the on-going updates of the review.

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Roles and responsibilities

Please give a brief description of content and methodological expertise within the review team. It is recommended to have at least one person on the review team who has content expertise, at least one person who has methodological expertise and at least one person who has statistical expertise. It is also recommended to have one person with information retrieval expertise. Please note that this is the *recommended optimal* review team composition.

- Content:
 - Judith Gross – Judith has worked in the field of special education for over 25 years. She has experience and education that is cross disability and lifespan. She has 12 years of experience conducting training, technical assistance, and research in areas related to adults with disabilities and community participation, especially with regard to integrated and competitive employment.
 - A Scientist-Consumer Advisory Panel (SCAP) has been established for our broad research which includes the systematic literature review. The role of the Systematic Review SCAP subcommittee is to offer guidance on selection of keywords, inclusion / exclusion criteria, and quality standards and to advise staff on specific issues that arise in conducting the literature review. At the conclusion of the systematic literature review on multifaceted interventions related to community participation, we will convene a meeting of all SCAP members, including the co-director from the HCBS RRTC on Outcome Measurement, to discuss the implications of our findings.
- Systematic review methods: Judith Gross, Chad Nye, and Debbie Davidson-Gibbs
 - Judith Gross – Judith conducted a qualitative systematic literature review for her dissertation related to participant direction of supports and services.
 - Chad Nye – conducted systematic reviews published in Campbell, Cochrane, and refereed publication.
 - Debbie Davidson-Gibbs – A Researcher with American Institutes for Research (AIR), worked with a team to conduct a systematic literature review for The College Board. In 2016, she participated in an 8-hour workshop sponsored by AIR on conducting Systematic Literature Reviews. In 2017, Debbie participated in a webinar sponsored by QSR International titled: *Accelerating Your Literature Review with NVivo 11 for Windows*.
 - Amalia Monroe-Gulick - University of Kansas Associate Faculty Librarian with experience conducting systematic and scoping reviews (Peterson-Besse et al., 2014; White et al., 2013). She has extensive training in: database searching and retrieval, online database interfaces, quantitative and qualitative research methods, and systematic reviews.
- Statistical analysis: Chad Nye – experience using CMA
- Information retrieval: Amalia Monroe-Gulick is an Associate Librarian at KU who has previously worked with the RRTC/Community Living on two different systematic reviews. MLS, Indiana University; MS, Political Science, Illinois State University; BS, Political Science, Illinois State University

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In addition, AIR provided staffing support (research assistant and consultant) and technical assistance in the completion of the review to meet Campbell standards.

Potential conflicts of interest

There are currently no known conflicts of interest. However, it is possible that articles by White, Ravesloot, Summers, or Nary (RTC PICL staff) may be selected in the article search process if they meet the inclusionary criteria.

Preliminary timeframe

Note, if the protocol or review is not submitted within six months and 18 months of title registration, respectively, the review area is opened up for other authors.

- Date you plan to submit a draft protocol: 6/15/17
- Date you plan to submit a draft review: 10/31/17