ICDR TOOLKIT

Using Participatory Action Research to Center People With Disabilities in Disability and Rehabilitation Research

A Toolkit for Interagency Collaboration

INTERAGENCY COMMITTEE ON
DISABILITY RESEARCH

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Introduction

Reflected in the mantra of the disability rights movement, “Nothing About Us Without Us,” people with disabilities should have the right “to be actively involved as researchers in matters relevant to their own lives” (Ollerton, 2012). Ensuring that the perspectives of people with disabilities are prioritized in disability and rehabilitation research is integral to making the field more equitable. People with disabilities can offer unique insights and perspectives to research questions that those without disabilities cannot offer. Promoting and funding participatory action research is an important way that federal entities can encourage the participation of people with disabilities in the research process and seek to address the historical lack of inclusion for this population in research.

The President’s Executive Order 13985, *Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*, explicitly names people with disabilities as a population underserved by the federal government. This specification is significant as people with disabilities have historically been left out of federal discussions and data collection efforts related to equity. To address this executive order, a current focus area of the Interagency Committee on Disability Research (ICDR) is equity. Increasing the use of participatory action research is an important way that the disability and rehabilitation community can highlight and promote equity for people with disabilities by involving this population as co-researchers throughout all stages of the research process. To move the field of disability and rehabilitation forward, inclusion of people with disabilities across all stages of research is critical. People with disabilities must no longer be seen only as the subjects of research, but also deemed integral research partners that help shape and execute the research agenda.

About the ICDR

The ICDR was authorized by the amended 1973 Rehabilitation Act to coordinate federal research efforts surrounding disability, independent living, and rehabilitation research. The ICDR's vision is to be widely recognized for facilitating and coordinating federal interagency efforts and for promoting collaborative relationships that maximize the use of federal resources for disability, independent living, and rehabilitation research.

Following are the three goals outlined in the **ICDR's 2018–2021 strategic plan**:

> **Goal #1:** Improve interagency coordination and collaboration in four thematic research areas: transition, economics of disability, accessibility, and disparities
>
> **Goal #2:** Develop a government-wide inventory of disability, independent living, and rehabilitation research
>
> **Goal #3:** Promote ongoing stakeholder input on gaps and priorities for disability, independent living, and rehabilitation research

As part of Goal #1, the ICDR seeks to examine disparities for people with disabilities, including those related to opportunities for participatory research. The ICDR also seeks to highlight areas where enhanced training and development are necessary for researchers to ensure people with disabilities are involved throughout all stages of research.

More information about the ICDR's history and significance is available on the ICDR website.

Purpose of the Toolkit

This toolkit provides an overview of participatory action research and the benefits of using this research orientation within the field of disability and rehabilitation research to emphasize the perspectives and priorities of those living with disabilities. The focus of this toolkit is how participatory action research can be used to involve people with disabilities across the entire research process. The toolkit provides an array of federal resources on participatory action research, both specifically with people with disabilities and in general, and highlights several best practices and areas for future research using this research orientation. Lastly, this toolkit provides a variety of resources for disability and rehabilitation researchers and other stakeholders wanting to learn more about participatory action research and how it can be implemented with stakeholder with disabilities.

Background on Participatory Action Research

What Is Participatory Action Research?

Participatory action research (PAR) describes an orientation to research that seeks to understand issues that a marginalized community faces by involving members of that community throughout all phases of the research process (Agarwal et al., 2015). When using a PAR orientation, the trained researcher and the participant both exert control throughout the research process and are essentially co-researchers (Balcazar et al., 1998). The term PAR can be traced back to Kurt Lewin, the founder of action research, in 1944 (MacDonald, 2012), and it also has roots in the consumerism, self-help, and civil rights movements in the United States (Balcazar et al., 1998). Lewin introduced this term to describe "a tactic to studying a social system, while attempting to impart changes at the same time, and emphasizing the importance of client-orientated attempts at solving particular social problems" (MacDonald, 2012).

The aim of PAR is to achieve social change as a result of the research conducted (Argarwal et al., 2015). Participatory-action research (PAR) involves researchers and participants working together to understand a situation and change it for the better from the premise of social change for the good of society (Jacobs, 2018). PAR focuses on social change that promotes democracy and challenges inequality, and often it is targeted on the needs of a particular group. Walmsely (2015) describes inclusive research as occurring on a spectrum, with traditional research, led by academic researchers, on the left end of the spectrum and emancipatory research, with nonacademic community members making the major decisions, on the right end. In between are research with nonacademic people as advisors and research with nonacademic community members working as part of the research team, in partnership. These middle two approaches are the most common ways of practicing participatory action research, especially involving the disability community. There are a wide variety of ways to implement PAR across both qualitative and quantitative research (White et al., 2004). The manner in which PAR is implemented will also vary depending on the subpopulation that is being studied and participating in the research.

There are several other terms in the literature that are used interchangeably, sometimes with conflicting definitions, or that are related to PAR, including **community-based participatory research (CBPR), participatory research, action research, constituency-oriented research and dissemination, emancipatory research, empowerment research, inclusive research, and discovery research** (Nind, 2017; Turnbull et al., 1998). This toolkit uses the term PAR to refer to all types of research that involve collaboration between researchers and stakeholders at all stages of the research process, according to the National Institute on Disability, Independent Living, and Rehabilitation Research's (NIDILRR's) conceptualization of the term (as cited in Turnbull et al., 1998).

While PAR is used across a variety of disciplines, employs a variety of methodological tools, and operates in a variety of contexts, common concepts throughout are engagement and action (Huffman, 2017). In 1997, Selenger identified the seven main components that comprise the PAR process (as cited in MacDonald, 2012):

- The problem being investigated originates in the community itself and is defined, analyzed, and solved by the community.
- The ultimate goal is the radical transformation of social reality and improvements in the lives of the community involved.

What makes PAR unique?

- Focuses on enabling action
- Advocates for power to be shared between the researcher and the researched
- Involves those being researched throughout all stages of the research process

(Baum et al., 2006)

- The community fully and actively participates at all levels of the entire research process.
- Beneficiaries of PAR include people from historically underserved, marginalized communities and minority groups.
- Individuals gain a greater awareness of their own resources and are empowered to mobilize those resources for self-reliant development.
- Community participation in the research process facilitates a more accurate and authentic analysis of social reality.
- The researcher is a committed participant, facilitator, and learner in the research process.

Implementing PAR in the Context of Disability and Rehabilitation Research

PAR has been adopted across a variety of research fields and is increasingly beingimplemented across disability and rehabilitation research. Balcazar et al. (1998) defined four major principles of PAR with people with disabilities:

- Individuals with disabilities themselves articulate the problem and participate directly in the process of defining, analyzing, and solving it.
- Direct involvement of people with disabilities in the research process facilitates a more accurate and authentic analysis of their social reality.
- The process of participatory research can increase awareness among individuals with disabilities about their own resources and strengths.
- The ultimate goal of the research endeavor is to improve the quality of life for individuals with disabilities.

> **"The concept of inclusive research epitomizes the transformation away from research on people, to research *with* them."**
>
> *—Melanie Nind (2017)*

Why Is Participatory Action Research Important?

Historically, people with disabilities have been viewed as "passive objects of study" rather than active participants in the research process (Balcazar et al., 1998). Furthermore, people with certain types of disabilities—particularly those with disabilities affecting communication, those with intellectual and developmental disabilities (IDD), and those with multiple disabilities—have had even less access to involvement in research activities (de Haas et al., 2022). PAR attempts to address this lack of inclusion by making sure the voices of people with disabilities are heard and prioritized and by including research participants as important members of the research team throughout all stages of the research process.

Furthermore, research processes have traditionally focused on theoretical interests, with less focus on action (Balcazar et al., 1998). PAR attempts to address this condition by ensuring that the results of the research have direct links to action to improve the quality of life for the subpopulation being studied.

> “If the research community heard more from people with profound intellectual disabilities and their families, the benefits could be transformative. We might think differently about the costs in money, time, space, and effort of including them and appreciate the value of their lives.”
>
> —de Haas et al. (2022)

PAR is important for federal agencies to consider funding as it offers several major benefits for disability and rehabilitation researchers. A study by Nind and Vinha (2012) found through a series of focus groups with people with intellectual disability (UK term is learning disabilities) that inclusive research can **create knowledge (the research goal); give voice and build self-advocacy (the political goal); bring funding to organizations (the practical, sustainability goal); and provide training, skills, jobs, networks, and friendships (the wider agenda)**. By using inclusive research orientations such as PAR, researchers can “tap into the meaning contained within and around people’s lives while striving to realize their contributions, recognizing that all people hold valuable knowledge” (de Haas et al., 2022).

Benefits and Challenges of Conducting Participatory Action Research

When implementing PAR, it is important to consider the breadth of both the benefits and challenges associated with this orientation to research. The table below describes several potential benefits and challenges to this research orientation as discussed in the literature.

Potential Benefits and Challenges of Using a PAR Orientation

BENEFITS	CHALLENGES
Builds trust with those participating in research	Potentially more time consuming for participants and researchers
Provides valuable research skills to those participating in research	Ethical issues (confidentiality, guardianship, institutional review board concerns, etc.)
Fosters self-advocacy	Fluctuating participation
Identifies actionable changes to address the needs of the population being studied	Need for increased resources for recruitment efforts
Prioritizes the voices of people with disabilities, leading to unique insights from personal experiences	Funding entities' requirements and/or lack of specific funding for co-researchers with disabilities
Allows people with disabilities to help shape the research agenda	Transportation for co-researchers with disabilities
Produces more authentic knowledge, as it is more grounded in the experiences of people with disabilities	Impact of PAR on research outcomes is not well understood

(Balcazar et al., 1998; Danley & Ellison, 1999; MacDonald, 2012; Nind, 2014; O'Brien et al., 2022; St. John et al., 2018)

Research Methodologies That Align With Participatory Action Research

PAR is a research orientation that can be applied to a variety of methodological contexts. The following methodological approaches are identified as aligning with the core values of PAR across the literature:

Autoethnography	Method that values researchers' own experience as meaningful data
Community Mapping/ Transect Walks	A mapping technique where community members and people with the skills to identify and propose solutions to issues walk through the community and record their observations
Community Meetings	A large group meeting to promote dialogue, problem-solving, and collaboration
Concept Mapping	A mixed-methods research approach that utilizes both qualitative and quantitative data collection methods, including brainstorming, card sorting, and ratings with the multivariate statistical techniques of multidimensional scaling and cluster analysis to create a data-driven visual representation of thoughts or ideas of a group
Creative methods (film/video, photography, drama/ theater, storytelling, use of media, etc.)	Methods that use art to create data and provide an opportunity for creative participation beyond words
Focus Groups	A form of group interview that capitalizes on communication between the research participants in order to generate data

Interviews	Face-to face verbal interactions in which the researcher attempts to elicit information from the respondent, usually through direct questioning, with both the researcher and the participant sharing and learning in a reciprocal manner
Participatory observation	Method where the researcher is acting or participating in the lives of those they are trying to understand
PhotoVoice	A visual method that focuses on participant-led photography
Resource Mapping	A method of generating spatially explicit information for multiple decision-making purposes
Timeline analysis	A visual representation that the participant develops with an interviewer that can help the participant focus on key elements and can create new meanings and understandings—especially helpful with sensitive or complex topics
Vignettes	A method of nonparticipatory observation that develops vivid portraits of events in everyday life and provides rich and thick descriptions of the subject and their interactions with others

(Berger & Lorenz, 2015; Boxall & Ralph, 2009 & 2011; Cluley, 2016; Duea, et al., 2022; Gjermestad et al., 2022; Haines, 2017; MacDonald, 2012; Marshall, 2019; Mietola et al., 2017; Simmons & Watson, 2015; Ward et al., 2016; Warwick, 2015)

Federal Resources and Research on PAR Conducted With People With Disabilities

This section highlights existing federal projects and resources focused on PAR by government agency. The resources included focus both on the use of PAR generally for research as well as the use of PAR for research with people with disabilities.

National Science Foundation

PAR-oriented research proposals could be submitted to the National Science Foundation under a number of different programs. Several programs in the STEM Education Directorate (EDU) could accept research and development proposals with a PAR orientation intended to focus on individuals with disabilities. They include EDU Core Research (ECR/Core), Discovery Research PreK-12 (DRK-12), Advancing Informal STEM Learning (AISL), Improving Undergraduate STEM Education: Directorate for STEM Education (IUSE: EDU), and Faculty Early Career Development Program (CAREER). Interested applicants are encouraged to read the full program solicitations and reach out to the program contacts with specific questions about their proposal ideas. Consult the program pages for more details and submission instructions.

In addition, NSF recently established a program focused on workplace equity for individuals with disabilities, Workplace Equity for Persons with Disabilities in STEM and STEM Education. This program supports fundamental, applied, and translational research that advances knowledge and practice about diverse, equitable, inclusive, and accessible STEM and STEM education workplaces and postsecondary training environments for persons with disabilities. By its nature, this program is interested in PAR oriented proposals. Consult the program page for more details and submission instructions.

The Disability and Rehabilitation Engineering (DARE) program supports **fundamental engineering research** that will improve the quality of life of persons with disabilities through the development of new technologies, devices, or software combined with advancement of knowledge regarding healthy or pathological human motion or advancement in understanding of injury mechanisms. Research may be supported that is directed toward the characterization, restoration, rehabilitation, and/or substitution of human functional ability or cognition, or to the interaction between persons with disabilities and their environment.

Research activities that involve individuals with disabilities across all phases of the research are encouraged at the NSF. Such research seeks to understand issues that the disability community faces by more actively involving members of that community throughout the research process.

U.S. Department of Health and Human Services

ADMINISTRATION FOR CHILDREN AND FAMILIES

The Office of Planning, Research, and Evaluation in the Administration for Children and Families within the U.S. Department of Health and Human Services (HHS) hosted a meeting in 2021 entitled Enhancing Rigor, Relevance, and Equity in Research and Evaluation through Community Engagement. This meeting discussed community-engaged research, including how to conduct this type of research, community members' experiences with this type of research, ways funders can support this type of research, and tools and resources to promote community engagement research and evaluation. While this meeting did not specifically address community-engaged research with people with disabilities, it provided helpful information regarding community-engagement research currently being conducted at the federal level and ways to continue to promote similar research across the federal government.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

In 2004, RTI International prepared the report, ***Community-Based Participatory Research: A Summary of the Evidence***, for the Agency for Healthcare Research and Quality (AHRQ). This report describes the definition of CBPR, ways it has been implemented to date, evidence of CBPR resulting in intended outcomes, and criteria and processes to use when reviewing CBPR grant proposals.

The AHRQ website hosts a web page that discusses benefits and challenges of using CBPR as well as AHRQ-funded grants that used CBPR.

CENTERS FOR DISEASE CONTROL AND PREVENTION

In 1984, Congress authorized the Prevention Research Centers (PRC) Program at the Centers for Disease Control and Prevention (CDC) to conduct applied public health research (Faridi et al., 2007). An Institute of Medicine review of the PRC Program in 1997 suggested that the PRCs could “involve research and dissemination projects that are jointly planned and produced with community partners who have joint ownership of programs” (Faridi et al., 2007). While some PRCs partnered with the community prior to 1997, after this review the PRC Program formally integrated CBPR into its research framework.

ADMINISTRATION FOR COMMUNITY LIVING

Administration on Disabilities

National Gateway to Self-Determination

In 2011, the National Gateway to Self-Determination, a consortium of University Centers for Excellence in Developmental Disabilities in partnership with the National Self-Determination Alliance, released *Getting Involved in Research and Training: A Guide for Persons with Intellectual Disabilities*. This guide, funded by a grant from the Administration on Disabilities, is designed to inform people with intellectual disabilities about what to expect when getting involved in research and training. It uses plain language and discusses how to get involved in research and why being involved in research is important, and it provides plenty of information to help people with intellectual disabilities prepare to be involved in research and receive any support they may need to do so.

National Institute on Disability, Independent Living, and Rehabilitation Research

As part of the Rehabilitation Act Amendments of 1992, the National Institute on Disability and Rehabilitation Research—now known as NIDILRR—was encouraged to promote PAR and establish a policy to promote consumer involvement in research (Balcazar et al., 1998). Responding to this call, NIDILRR promotes PAR through a variety of its grants. The following are several NIDILRR grants that incorporate PAR.

Americans with Disabilities Act Participation Action Research Consortium

The NIDILRR-funded ADA Participation Action Research Consortium (ADA-PARC) builds on a long history of PAR and collaborates with all 10 ADA Regional Centers, the ADA Knowledge Translation Center, and a national network of disability organizations and communities to look at social and economic factors that influence the societal participation of people with disabilities at both the community and regional levels. ADA-PARC is a program of the Independent Living Research Utilization at TIRR Memorial Hermann in Houston, Texas. Its work focuses on disparities across three main target areas: community living, community participation, and employment/economic equity. The ADA-PARC website hosts its findings in multiple, accessible formats for stakeholders to use in a variety of settings. In 2020, ADA-PARC released a publication on a study that used PAR to understand participation in the community for people with disabilities after institutionalization. This research article offers an example of how the PAR orientation can be implemented with people with disabilities.

Culturally Appropriate Research in American Indian Employment Programs

Culturally Appropriate Research in American Indian Employment Programs (CARE), an NIDILRR-funded project at Northern Arizona University, is using CBPR to determine the characteristics of practices and policies used by the American Indian Vocational Rehabilitation Services (AIVRS) programs and their effectiveness in assisting American Indians/Alaskan Natives who have disabilities to obtain and maintain quality integrated employment and improving employment outcomes. This project uses CBPR methods to partner with AIVRS program directors, counselors, and consumers, with support from an American Indian/Alaskan Native-led advisory council. The aim of this project is to develop descriptions of policies and practices used by AIVRS programs, publications of research findings, and practice briefs.

Impacts of Internalized, Interpersonal, and Systemic Ableism in Healthcare Services and Systems: A Field-Initiated Project

An NIDILRR-funded project at Children's University Medical Center uses CBPR to conduct exploratory and descriptive research to examine three levels of ableism (internalized, interpersonal, and systemic) and identify how to dismantle and disrupt these types of ableism to address health disparities. This project is disability led and disability centered and uses a panel of experts who have lived experiences with disability to guide decision-making, and it builds on the successes of a pilot project that established a Center for Dignity in Healthcare for People with

Disabilities. Outcomes of this project will include research-informed resources regarding various types of ableism in healthcare services and best practices for medical professional, payers, and hospital systems to dismantle ableism. Additionally, this project will produce and disseminate scales/measures, manuscripts for academic publication, webinars and conference presentations, and plain-language summaries.

Rehabilitation ERC on Technologies to Support Aging-in-Place for People with Long-Term Disabilities

The NIDILRR-funded Rehabilitation ERC on Technologies to Support Aging-in-Place for People with Long-Term Disabilities (TechSAge RERC II) at Georgia Tech and the University of Illinois at Urbana Champaign aims to "advance knowledge and accelerate the development, modification, and testing of technology-based interventions and strategies for use in the home and community to promote aging-in-place and reduce secondary conditions among people with long-term disabilities." In 2021, TechSAge RERC II developed a tool that provides information on how to incorporate persons aging with disabilities into research studies. Emphasizing the importance of including people with disabilities in research, it provides recommendations for incorporating people with disabilities at the various research stages, highlights examples of studies that include people aging with disabilities from TechSAge, and provides resources on learning more about working with individuals aging with disabilities in research projects.

NATIONAL INSTITUTES OF HEALTH

INIH has funded a number of CBPR projects and programs related to disabilities over the past several years. Following is a list of projects and programs of note. All numbers referenced are NIH grants linked to online descriptions in *NIH RePORTER* unless otherwise noted.

AASPIRE

The Academic Autistic Spectrum Partnership in Research and Education (AASPIRE) is a long-term CBPR partnership that was founded in 2006. AASPIRE brings together the academic community and the autistic community to conduct research projects relevant to the needs of adults on the autism spectrum. Autistic people take part in the research in many ways, including as scientists, community partners, and study participants. The partnership adheres to the principles of CBPR, whereby academics and community members serve as equal partners throughout the research process. AASPIRE has conducted research on a range of topics related to the experiences of adults on the autism spectrum, including healthcare, health outcomes, employment, mental health, and reproductive health (**R01MH121407** and **K23MH123934**, 2020–present).

Autism Centers of Excellence (ACE) Program

The Autism Centers of Excellence (ACE) program is an NIH-wide initiative created in 2007 that supports large-scale multidisciplinary studies on autism spectrum disorder (ASD). The program includes ACE research centers, which foster collaboration between teams of specialists who share the same facility to address a particular research problem in depth, and ACE research networks, which consist of researchers at many facilities throughout the country, all of whom work together on a single research question. Each ACE has a specific Plan for Enhancing Diverse Perspectives (PEDP) as part of its proposed research project. The PEDP outlines strategies to increase participation of women and individuals from traditionally underrepresented groups in the ACE biomedical, behavioral, and clinical workforce. Additionally, the PEDP is intended to increase the participation of underrepresented and underserved populations in research. In addition to the PEDP, each ACE has an external advisory board that includes individuals with ASD and/or parents of individuals with ASD as members. ACE investigators also engage with the ASD community to learn about their needs and research concerns and to inform them about research findings and plans for future studies (**P50HD109879**, **P50HD109861**,

R01HD055741, P50HD111142, P50HD093074, R01MH132218, P50MH130957, R01MH100028, R01ES034554, 2022–present).

BRIDGE Collaborative

A research-community collaborative group called the Southern California BRIDGE Collaborative was developed based on CBPR principles to improve community-based care for infants and toddlers at risk for autism through the implementation of evidence-based practices. The collaborative included a transdisciplinary team of practitioners, funding agency representatives, researchers, and families of children with autism. The specific aims of the project were to develop a coalition for community and research collaboration; identify and adapt an effective, sustainable intervention model for infants and toddlers at-risk for ASD and their families; and conduct feasibility testing of the adapted intervention (pilot study; K23MH077584, 2007–2013; R21MH083893, 2009–2012; Brookman-Frazee et al., 2012)

Center for American Indian Resilience and the Southwest Health Equity Research Collaborative

The NIH-funded Center for American Indian Resilience and the Southwest Health Equity Research Collaborative supported a project on “Community Inclusion, Personal Development, and Health Equity among Youth with Intellectual and/or Developmental Disabilities,” that resulted in a community-engaged photo story telling project with Native American youth with intellectual and developmental disabilities (IDD) focused on health and wellness. Through the project and discussions with the coalition, the partners identified that there are limited opportunities for youth with IDD to self-select meaningful participation in the community to explore their life goals and career interests. Service learning opportunities provide volunteer experiences to promote community engagement of youth with IDD and can assist the youth with IDD in self-determining their future career and educational pursuits. (P20MD006872, 2012-2017; U54MD012388, 2017-present; U54CA143925, 2009-present; Tuefel-Shone et al., 2018).

Children's Environmental Health and Disease Prevention Research

The National Institute of Environmental Health Sciences (NIEHS) and U.S. Environmental Protection Agency (EPA) jointly funded the Children's Environmental Health and Disease Prevention Research Centers (Children's Centers) to explore ways to reduce children's health risks from environmental factors. Centers included the Center for Children's Environmental Factors in the Etiology of Autism at the University of California, Davis, and the New Jersey Center for Childhood Neurotoxicology and Exposure Assessment at the University of Medicine and Dentistry. Children's Centers were required to include a CBPR project, and the centers have mobilized community members to participate in planning, implementing, and evaluating the effectiveness of interventions and public health strategies for healthier children, families, and future generations. For example, the New Jersey center worked with community partners during the research design, recruitment, outreach, and communications processes, and community partners served on the external advisory board of the center (Requests for Applications, 2004–2022, described at RFA-ES-03-004, RFA-ES-05-004, RFA-ES-08-002, RFA-ES-12-001, and RFA-ES-14-002; Israel et al., 2005).

Clinical and Translational Science Awards (CTSA)

The National Center on Advancing Translational Sciences (NCATS) Clinical and Translational Science Awards (CTSA) Program supports a national network of medical research institutions (called hubs) that work together to improve the translational research process to get more treatments to more patients more quickly. This program has supported research on disabilities, such as a project that created a community partnership between clinician researchers and autistic/neurodiverse and gender-diverse community collaborators to study the lived experience autistic/neurodiverse and gender-diverse (A/ND-GD) people, identify barriers they face, and priorities for this subset of the community. Multiple facets of the A/ND-GD lived experience are examined, including through narratives provided by A/ND-GD community partners (KL2TR001877, 2016–2021; Strang et al., 2019).

Investigation of Co-occurring conditions across the Lifespan to Understand Down syndromE (INCLUDE) Project

The INCLUDE (Investigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) Project is a trans-NIH research initiative focused on critical health and quality of life for individuals with Down syndrome. A Notice of Special Interest (NOSI) announced NIH's support for exploratory/developmental grant applications that are focused on CBPR in Down syndrome to address health disparities and that meet programmatic objectives for the INCLUDE project (NOT-OD-22-142, 2022–present). The goal of the NOSI is to encourage CBPR where researchers fully engage with community members to understand culturally appropriate issues, evaluate systemic and structural barriers, determine appropriate research methods, engage the community in the data collection and analysis process, plan effective interventions, share knowledge and skills, implement interventions with input from community members, strengthen community partnerships, and educate and return research findings to the community with the ultimate goal of reducing health disparities.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

In 2018, the Substance Abuse and Mental Health Services Administration held a webinar on PAR as a methodology to engage marginalized groups as co-researchers. This interactive webinar covered the definition of PAR, highlighted its differences from other research approaches, and introduced considerations when implementing a PAR study. This webinar also described pros and cons of PAR and provided examples of implementing PAR in the behavioral health setting.

U.S. Department of Veterans Affairs

The U.S. Department of Veterans Affairs (VA) developed the Strengthening Excellence in Research through Veteran Engagement (SERVE) Toolkit 2.0, which provides best practices for engaging veterans and other stakeholders in research. This toolkit was developed through a collaboration between seven VA hospitals that prioritize veteran engagement in research. The toolkit describes best practices that have been used across the VA and provides a variety of web-based resources useful for engaging stakeholders in research efforts.

Best Practices for Using PAR in a Disability Context

While research on using PAR with people with disabilities is still limited, this section provides an overview from disability and rehabilitation researchers of several best practices in the field on how to implement PAR with this population. The best practices cover a variety of topics, including the virtual use of PAR, use of PAR to partner with disability organizations, practical strategies and promising practices, ways federal funders can support this type of research orientation, and reflection questions for researchers interested in this research orientation.

Lessons Learned From Federal Community-Engaged Research and Ways Federal Funders Can Support Community-Engaged Research

In 2021, the Administration for Children and Families, Office of Planning, Research, and Evaluation in HHS held a methods meeting entitled Enhancing Rigor, Relevance, and Equity in Research and Evaluation Through Community Engagement. During one session of this meeting, presenters discussed several lessons learned from federal community-engaged research that was conducted with the Tribal Early Childhood Research Center. Lessons learned may prove applicable for federal funders in the disability and rehabilitation field as well. Among those lessons:

- Ensure projects have the necessary time and funding commitments before conducting community-engaged research.
- Consider relationships and relationship building as essential elements.

- Consider research approaches beyond traditional research paradigms.
- Tailor research dissemination strategies to the unique needs and priorities of each audience.

During this same meeting, presenters discussed several ways funders can support community-engaged research and recommended that funding entities focus on the following three areas:

- **Value** – All possible benefits associated with a proposed project should be considered.
- **Access** – Funders should consider which applicants may not have the same opportunity or access as others.
- **Accountability** – Funders should take into account how connected applicants are to the communities being studied.

Federal funders discussed the many barriers that currently exist in relation to using project funds to compensate researchers and explained that the structure of federal research and evaluation contracts can create obstacles to supporting community-engaged research. The speaker who presented on the project team's research with the Tribal Early Childhood Research Center said that the project team addressed these challenges by adjusting the project and funding structures to promote community engagement. They shifted resources to develop "practice-based research networks" that supported the process of community members and researchers sharing power throughout the research project. Other important suggestions for federal funders hoping to support community-engaged research include examining biases, approaching community-engaged research with humility, and acknowledging the important of small changes achieved through research.

Practical Strategies for Promoting Full Inclusion of Individuals With Disabilities in Community-Based Participatory Intervention Research

In a study funded by NIDILRR and the National Institute of Mental Health, Hassouneh et al. (2011) identified several **inclusion strategies that can be used as a checklist when planning community-based participatory research with a disability community.** These strategies include the following:

- Recruit and hire team members from the selected community.
- Analyze work patterns. Adjust workload to meet the individual needs of team members who work at a slower pace than others, whose work pace is variable, or who can only work limited hours per week.
- Create redundant systems based on work pattern analysis.
- Discuss team member accountability and the importance of communicating what work is and is not being done. Design systems to evaluate performance.
- Ensure that training sessions are not overlong and include frequent breaks (i.e., are "disability friendly"). Cover basic concepts and be prepared to repeat content periodically throughout the study.
- Make sure training materials are accessible to everyone.
- Be prepared to provide extensive training to community members assuming critical roles.
- Assess and plan for multiple and changing accommodation needs throughout the project.
- Estimate costs for accommodations and discuss the challenges and rewards of "accommodating each other."

- Try to match skills with abilities, and be open to changing essential job functions for team members if needed throughout the duration of the project.
- Discuss accommodation as a community value and ways the team will address this issue proactively. Develop protocols that are congruent with community values.
- Review pros and cons of available partners (for partnership expansion) with regard to financial status, community services, and community reputation in collaboration with the rest of the team.
- Factor in additional time for follow-up and referral of study participants when community resources have been eliminated or depleted.

The authors of this study also provided two strategies specific to university investigators:

- Work with benefits counselors and university grants and contacts staff to establish multiple payment systems for team members receiving Supplemental Security Income/Social Security Disability Insurance.
- Have regular meetings with research grants and contracts staff to discuss methods for supporting financial inclusion. Serve as a bridge between community partners and university grants and contracts departments.

Promising Practices From the University of Washington’s Center for Neurotechnology for Engaging People With Disabilities in Research

In 2019, the Center for Neurotechnology at the University of Washington shared several promising practices that they use for inclusion of people with disabilities in all aspects of the research center (Burgstahler & Bellman, 2019). These strategies are broken down by category and include the following:

RECRUITMENT AND ENGAGEMENT

- Develop strategic partnerships, including those with disability and veteran service units, and employ joint recruitment strategies.
- Recruit people with disabilities, including veterans, onto advisory boards and leadership teams.
- Develop outreach activities and programs especially for students with disabilities, including veterans, and also recruit individuals with disabilities into programs for all students.

COMMUNICATION

- Promote disability awareness.
- Highlight the achievements of people with disabilities.
- Include images of people with disabilities and information on how to request accommodations in promotional materials.
- Encourage faculty, staff, and student leaders to engage in disability-related conferences and training opportunities.
- Share disability-related practices at conferences.

ACCESSIBILITY OF FACILITIES, INFORMATION RESOURCES, PRODUCTS, AND ACTIVITIES

- Apply universal design and provide reasonable accommodations.
- Consult with individuals with disabilities in lab/facility design.
- Conduct website, document, and video accessibility reviews and remediate.

AN INCLUSIVE CLIMATE

- Consider disability as a diversity issue.
- Provide mentoring opportunities for individuals with disabilities.
- Address disability-related issues in grant proposals to enhance and expand ERC initiatives.

DATA COLLECTION AND EVALUATION

- Collect disability status along with other demographic information in application and evaluation forms.
- Analyze data to determine the effectiveness of activities for people with disabilities.

Reflection Questions for Researchers Wanting to Engage in Inclusive Research

In 2017, Melanie Nind published a journal article that discusses the concept of inclusive research with people with intellectual disabilities (called learning disabilities in the UK), including several challenges that inclusive researchers in the United Kingdom have faced and ways collaboration has addressed some of those issues. While the questions for reflection that she poses are focused on a specific subpopulation of people with with intellectual disabilities, these questions may be able to be applied to research with other types of disability subpopulations. Nind provides the following reflection questions for researchers wanting to engage in inclusive research to consider:

- Is the topic relevant to the lives of people with intellectual disabilities and interesting to them? Could it become relevant?
- Does the research involve people with intellectual disabilities in a meaningful and active way?
- Are the participants in the research treated with respect?
- Is the research communicated in a way people with intellectual disabilities can understand and respond to?
- Is there honesty and transparency about everyone’s role and contribution?
- Were the ways of working carefully thought through and adapted in response to needs?
- Does the research create worthwhile knowledge?
- Are there likely long-term wider benefits for the people involved, e.g., new networks, skills, funds, roles, social inclusion?
- Are the research questions the kind that inclusive research can best answer?

- Does the research reach participants, communities, and knowledge that other research could not reach?
- Does the research use, and reflect on, the insider cultural knowledge of people with intellectual disabilities?
- Is the research genuine and meaningful?
- Will the research make impact that people with intellectual disabilities value?

Strategies to Promote Inclusive Virtual Engagement in PAR

In a journal article, Ahlers et al. (2020) describe several **practical strategies for virtually engaging individuals with intellectual and developmental disabilities (IDD) in participatory action research** in the context of the COVID-19 pandemic. While these tips are focused on the researchers' work with the IDD community, they may have relevance for conducting PAR virtually with other groups of individuals with disabilities. Ahlers et. al (2020) offer the following best practices for engaging in PAR virtually:

- Provide multiple methods for team members to contribute to the conversation.
- Ask about communication preferences up front.
- Provide multiple opportunities for input.
- Create space for small group discussion.

More in-depth information on each of these tips and how they specifically apply to engaging people with IDD virtually is available in the journal article.

Tips and Best Practices From the PAR Partnership Between the Beach Center on Disability and the Grassroots Consortium on Disabilities

As a result of a PAR partnership between the Beach Center on Disability at the University of Kansas and the Grassroots Consortium on Disabilities, the Beach Center on Disability developed a research highlights document containing several tips, key highlights, and lessons learned and best practices for conducting PAR (Beach Center on Disability, 2001).

The following **tips for engaging in PAR** are recommended by the Center:

- Forge new alliances by initiating and sustaining joint partnership activities that are meaningful for everyone with an active role in the PAR process.
- Seek to build mutual trust, understanding, and respect among the PAR partners since they may have little prior shared history and experience with one another.
- Be sensitive to time factors. Allow time to get acquainted; time for different, culturally dictated concepts of pace; time to accommodate competing demands of the PAR partners; and time for mutual education.
- Be sensitive to financial factors. Support fiscally disadvantaged partners and participants by compensating them directly for their time and/or offering support for their programs (e.g., grant writing, use of staff/resources).
- Design research to be relevant, beneficial, and fundable, using methodologies that are both scientifically sound and comfortable for families.
- Provide opportunities for mutual learning, honest dialogue, and ongoing partnership activities.
- Recognize the strengths each of the parties brings to the collaborative effort.

As a result of its research, the Center provided the following **lessons learned and best practices to consider when engaging in PAR:**

- Getting to know one another, following up, and planning shared activities help to establish and sustain viable and sustainable partnerships.
- Seek an open dialogue about the PAR process, thereby helping to establish predictability, trust, and mutually realistic expectations.
- Acknowledge that not all activities benefit partners equally all the time.
- Recognize the strengths, perspectives, and diverse contributions of each PAR member.
- Recognize that the PAR partnership may slow the research process but give partners the time needed to fully involve their members in the discussions.
- Understand the contexts and realities of all PAR partners and how they impact the participation of community groups.
- Make leadership teams on both sides responsible for organization-wide communication and follow-up activities.
- Identify and correct mistakes born of inexperience or misperceptions.

Areas for Future Research and Development in PAR With People With Disabilities

To facilitate the increased use of PAR across disability and rehabilitation research, more research is needed. After examining the literature on participatory action research for people with disabilities, the following three areas warrant additional research and development:

- **More resources are needed for researchers who want to apply PAR to the disability context.**
  While many resources exist for the general population, there are few specific disability-focused resources. This toolkit compiles the disability-specific resources that do exist, but ICDR stakeholders should consider developing additional resources to guide disability and rehabilitation researchers on how to best conduct research that involves people with disabilities in research projects from beginning to end.

- **Federal agencies should consider funding research that encourages grantees to include people with disabilities as co-researchers throughout the research process.**
  NIDILRR has encouraged its grantees to incorporate a PAR orientation in their research for decades (as cited in Turnbull, Friesen, and Ramirez, 1998), and NIDILRR currently requires all grantees to address how people with disabilities will be included in research projects as part of the application process. Additionally, NCMRR at NIH requires the inclusion of people with lived experience in applications submitted to select notice of funding opportunities. In a similar manner, other federal agencies should consider requesting this information in

grant applications focused on disability as well to ensure adequate inclusion of people with disabilities throughout the research process.

- **Researchers should consider investigating the use of PAR with youth with disabilities and other disability subpopulations.**
  While PAR is beginning to be applied in the disability context, little information is currently known about the use of PAR with youth with disabilities (McDonald et al., 2021). Additionally, while PAR has been implemented with people with learning disabilities and IDD, more research is needed on the use of this orientation with other specific disability types where best practices may differ. Research with these specific subpopulations would be helpful to guide best practices for researchers wanting to implement this research orientation in their own work.

Resources

The following are both federal and nonfederal resources related to conducting PAR as well as several specific to conducting PAR with people with disabilities. The goals of gathering these resources are to encourage collaboration among federal entities on PAR and to increase the engagement of people with disabilities in being part of the research process from start to finish. The resources are organized by type and include handbooks and books, journal articles, research and practice guidelines, toolkits, and websites.

Handbooks and Books

Disability and Qualitative Inquiry: Methods for Rethinking an Ableist World
This book discusses a wide range of issues related to conducting qualitative research on disabilities and covers a variety of methods, including participant observation, interviewing and interview coding, focus groups, autoethnography, life history, narrative analysis, content analysis, and participatory visual methods. The authors frame how these methods align with emancipatory research, where research is viewed as a collaborative effort with the research subjects who should ultimately benefit from the research being conducted.
https://books.google.com/books?hl=en&lr=&id=ZbW1CwAAQBAJ&oi=fnd&pg=PP1&dq=participatory+action+research+AND+disability&ots=m306BLiFD3&sig=784mlOzY3Ieyk5iv3npWkMuQ_dc#v=onepage&q=participatory%20action%20research%20AND%20disability&f=false

Handbook for Participatory Action Research, Planning and Evaluation
Through several grants from Canada's International Development Research Centre,

organizations across five continents collaborated for the Social Analysis Systems2 (SAS2) Initiative that developed this handbook. The handbook is divided into six modules, covering topics such as the theoretical foundation of PAR, guidelines and tips for implementing PAR, participatory tools to gather information, stakeholder analysis, risk assessment, etc. While this toolkit is focused on the context of PAR in international development, it offers a variety of tips and tools that can be generalized for use of PAR with people with disabilities as well.
https://www.participatoryactionresearch.net/tools

A Handbook for Participatory Action Researchers

This handbook released by the Center for Psychiatric Rehabilitation at Boston University provides a guide for conducting PAR based on a model with people who have psychiatric disabilities. It consists of principles and strategies to use when conducting PAR that can be applied to various purposes and contexts. Though examples included in the toolkit are from a PAR project conducted with people with psychiatric disabilities, the authors state that these guidelines may be generalizable to other populations as well.
https://repository.escholarship.umassmed.edu/handle/20.500.14038/45353

Principles of Community Engagement (Second Edition)

In 2011, the National Institutes of Health's (NIH's) Clinical and Translational Science Awards Consortium's Community Engagement Key Function Committee formed a task force to update the 1997 publication, Principles of Community Engagement, published by the CDC and the Agency for Toxic Substances and Disease Registry. The second edition of Principles of Community Engagement was compiled through the collaboration of the Clinical and Translational Science Awards Community Engagement Key Function Committee, which included representatives across NIH and CDC. Principles of Community Engagement (Second Edition) provides a guide for understanding community engagement for researchers or community leaders. It offers a variety of practical tools and information on how to mobilize community

members to partner in health-related research initiatives.
https://www.atsdr.cdc.gov/communityengagement/index.html

The SAGE Handbook of Action Research
This updated handbook provides an overview of the latest qualitative and quantitative approaches in the field of action research. Topics covered include areas such as what the benefits of action research are, how to integrate knowledge with action, and how to collaborate with co-researchers.
https://methods.sagepub.com/book/the-sage-handbook-of-action-research-3e

Journal Articles

"Advancing inclusive research with people with profound and multiple learning disabilities through a sensory-dialogical approach" (2023)
This article provides a comprehensive review on inclusive research for people with profound and multiple learning disabilities. The authors discuss how a sensory-dialogical approach can be used as a way to rethink inclusive research.
https://journals.sagepub.com/doi/full/10.1177/17446295211062390?rfr_dat=cr_pub++0pubmed&url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org

"Applying participatory action research in traumatic brain injury studies to prevent post-traumatic epilepsy" (2019)
This journal article discusses the integration of PAR into large-scale multicenter studies, and the authors provide an overview of their experience with PAR principles in a study focused on post-traumatic epilepsy prevention. Recommendations are provided for how multicenter studies can integrate PAR and achieve the corresponding benefits to consumers.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6338533/

“Building a culture of engagement at a research centre for childhood disability” (2021)
This journal article discusses how families of children with disabilities have been engaged in research studies at the CanChild Centre for Childhood Disability Research in Ontario, Canada. The article discusses stories from CanChild researchers, staff, students, and parents about their experiences and provides information on what made this type of co-research successful as well as suggested improvements to make moving forward.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8572501/pdf/40900_2021_Article_319.pdf

“A community-based participatory research approach to the development of a peer navigator health promotion intervention for people with spinal cord injury” (2014)
This study uses a CBPR framework to examine an intervention using community-based peer navigators with spinal cord injury to provide health education to individuals with spinal cord injury. This article discusses challenges associated with the CBPR framework and factors that helped to sustain the CBPR partnership between the academic researchers and the community-based team of individuals who have spinal cord injury or provide services to this population.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4166442/

“Co-research with adults with intellectual disability: A systematic review” (2018)
This journal article is a systemic review that synthesizes the literature on aspects of co-research, including challenges, facilitators, benefits, and best practices. The authors discuss how these techniques can apply to co-research with people with intellectual disability.
https://onlinelibrary.wiley.com/doi/10.1111/jar.12435

“Conceptualizing inclusive research with people with intellectual disability” (2014)
The authors of this article discuss three different approaches to conducting inclusive research with people with intellectual disability and provide a framework for conducting inclusive research with this population. The article provides a literature review as well as examples from the authors’ experiences.
https://onlinelibrary.wiley.com/doi/10.1111/jar.12083

“Developing, testing, and sustaining rehabilitation interventions via participatory action research” (2013)
This journal article discusses the use of PAR in rehabilitation intervention research by reviewing the literature and providing examples from a randomized control trial in this field that integrated PAR. The authors provide five recommendations on how to integrate PAR into rehabilitation intervention research.
https://pubmed.ncbi.nlm.nih.gov/23260776/

“Participatory research, people with intellectual disabilities and ethical approval: Making reasonable adjustments to enable participation” (2014)
This journal article discusses participatory research with people with intellectual disabilities and addresses how to balance ensuring ethical approvals are met while promoting meaningful participation. Specifically, the article discusses several reasonable adjustments that can be made to ensure inclusion.
https://onlinelibrary.wiley.com/doi/10.1111/jocn.12702

“Reflections from co-researchers with intellectual disability: Benefits to inclusion in a research study team” (2018)
This study discusses the impact of PAR research on people with intellectual disabilities. The authors look at the perspectives of co-researchers with intellectual disability and discuss several themes that emerged from three interviews with co-researchers with intellectual disability.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6348152/pdf/nihms-1007290.pdf

“A scoping review of end user involvement in disability research” (2016)
This scoping review examines end user involvement in disability research across 27 different studies. The authors discuss the unique benefits of end user experience at different stages of the project as co-researchers.
https://pubmed.ncbi.nlm.nih.gov/26596694/

“You say you want a revolution: An empirical study of community-based participatory research with people with developmental disabilities” (2016)
This article discusses how CPBR is aligned with disability rights principles and how it is increasingly being used with people with disabilities. The authors discuss a multiyear CBPR project with people with developmental disabilities and describe successes and challenges related to this study.
https://www.sciencedirect.com/science/article/abs/pii/S1936657415002113?via%3Dihub

Research and Practice Guidelines

AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants
These guidelines were developed from an institutional ethnography of the following three research partnerships using participatory methods with autistic adults from 2006 to 2018: the Academic Autism Spectrum Partnership in Research and Education, Partnering to Address Violence Against People with Developmental Disabilities, and Pregnancy Decision-Making and Supports for Women with Developmental Disabilities. The research team used discussions with community and academic partners as well as artifact review to develop these guidelines. The guidelines are designed to “promote the inclusion of autistic adults as

co-researchers" and span the topics of developing partnership goals, discussing roles and choosing partners, creating effective communication processes, power-sharing, developing trust, compensating partners, etc.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6776684/pdf/nihms-1519429.pdf

Community-Based Participatory Research: A Guide to Ethical Principles and Practice
This guide was developed under a research project funded by the Arts and Humanities Research Council in the United Kingdom. The guide describes a variety of lessons learned regarding ethical issues and dilemmas commonly faced in CBPR.
https://www.durham.ac.uk/media/durham-university/departments-/sociology/Community-Based-Participatory-Research-A-Guide-to-Ethical-Principles,-2nd-edition-(2022)-.pdf

Doing Research Inclusively: Guidelines for Co-Producing Research with People with Disability
These guidelines, developed by the Disability Innovation Institute in Australia, describe the benefits, principles, and strategies that the Institute uses to co-produce research with people with disabilities. The content of the guidelines was drawn from a comprehensive literature review, the experience of leading inclusive researchers at University of New South Wales, and community organizations of people with disabilities. In 2022, the Institute also released an update, called Doing Research Inclusively: Co-Production in Action, that provides additional information and practical strategies for each step of the process of co-designing research studies with people with disabilities.
https://www.disabilityinnovation.unsw.edu.au/inclusive-research/guidelines

Equity and Inclusion Guiding Engagement Principles
This document from the Patient Centered Outcomes Research Institute (PCORI) provides a set of guiding engagement principles for placing diversity, equity, and inclusion at the center of health research partnerships. Developed by PCORI's

Advisory Panel on Patient Engagement, the four principles—Inclusion, Equitable Partnerships, Trust/Trustworthiness, and Accountability/Actionability—are offered to ensure that diversity, equity, and inclusion are an explicit goal of partnerships from the start. This document is intended for any person or organization involved in the research community, including leaders and members of multi-stakeholder research teams, leaders and staff of health research organizations, health systems, patient and other stakeholder organizations, and training institutions. The document includes self-assessment questions and practical suggestions for teams to incorporate into activities.
https://www.pcori.org/engagement/engagement-resources/equity-and-inclusion-guiding-engagement-principles#:~:text=Developed%20by%20PCORI%E2%80%99s%20Advisory%20Panel%20on%20Patient%20Engagement%2C,an%20explicit%20goal%20of%20partnerships%20from%20the%20start

Measuring What Matters for Advancing the Science and Practice of Engagement
This article from Patient Centered Outcomes Research Institute (PCORI) provides identification and summary of aspects of engagement in health research that need to be measured to generate evidence fort hose who practice and study engagement. PCORI identified 28 concepts about engagement in research, organized into five main domains. The goal of this article is to contribute to a discussion about an emerging framework to inform measurement tool development and guide and study engagement in health research.
https://www.pcori.org/resources/measuring-what-matters-advancing-science-and-practice-engagement

Participatory Research with People with Developmental Disabilities
This document from the Nisonger Center at the Ohio State University contains a list of journal articles and corresponding resources on best practices for engaging in participatory action research with people with developmental disabilities.

Resources include information on ethical challenges, examples of roles and responsibilities, visual communication examples, and accessibility guidelines. https://nisonger.osu.edu/wp-content/uploads/2019/05/McDonald_participatory_research_resources_5_7_2019.pdf

Toolkits

Participatory Action Research (PAR) Toolkit
This toolkit developed by NIH and Care Research's School for Public Health Research examines whether PAR can be used when looking at student mental health in schools. While this toolkit is not focused on disability, it provides a helpful overview of PAR and the PAR process, benefits of PAR, and tips and tools for PAR success. https://sphr.nihr.ac.uk/research/school-culture-and-student-mental-health-a-participatory-action-research-study/

Toolkit for Remote Inclusive Research
The Research, Engagement and Advocacy for Community Participation and Health (REACH) Lab at Temple University and the Youth and Young Adult Empowerment, Leadership, & Learning (YELL) Lab at University of Florida released this toolkit focused on remote inclusive research for people with IDD. It is designed for research team leaders who want to understand strategies for including research team members who have IDD. The toolkit covers accommodations, adaptations to use strategies during remote collaboration, accessible resources, free and low-cost technologies for remote collaboration, and examples of research projects that have used these strategies. A video and fact sheet are also available, highlighting important information included in the toolkit.
https://sites.temple.edu/reachlabtemple/toolkit-for-remote-inclusive-research/

Websites

Academic Autism Spectrum Partnership in Research and Education (AASPIRE)
Founded in 2006, AASPIRE conducts action research focused on improving the lives of autistic adults through a CBPR approach where autistic and non-autistic scientists and community members work together in all phases of the research process. AASPIRE's website hosts an Inclusion Toolkit, a Q&A video series on practical aspects of participatory research, journal articles on inclusion and collaboration, and a variety of other resources.
https://aaspire.org/

Berkeley Youth Participatory Action Research (YPAR) Hub
This site from the University of California Berkeley is a hub for curriculum and resources to help enrich YPAR projects. Resources include information for getting started with YPAR, investigating a problem, strategizing for action, and a variety of articles and videos of case studies using YPAR across the world.
https://yparhub.berkeley.edu/home

Carlton College Participatory Action Research
This website created by a university-affiliated PAR team in collaboration with community partners provides a variety of resources for those interested in PAR, including general information, history, and examples of PAR. The target audience includes youth, teachers, university faculty, communities and community organizations, and organizers.
https://participatoryactionresearch.sites.carleton.edu/about-this-site/

Community Tool Box – Community-based Participatory Research
This section of the University of Kansas's Community Tool Box specifically focuses on CBPR. It provides information on what CBPR is, why it can be effective, who

might use it, and how to set up CPBR and conduct it. Additionally, the Community Tool Box provides a checklist, examples of CBPR in action, and a variety of links to other online resources.
https://ctb.ku.edu/en/table-of-contents/evaluate/evaluation/intervention-research/main

Engage2020 Action Catalogue
The Engage2020 Action Catalogue is an online tool funded by the European Commission that helps researchers, policymakers, and others engaging in inclusive research to determine what method of research best suits their project's goal and specific needs. The website also has a tutorial on how to use this tool.
http://actioncatalogue.eu/

Organizing Engagement—Participatory Action Research and Evaluation Models
Organizing Engagement, an online publication focused on "advancing knowledge, understanding, and practice at the intersection of education organizing, engagement, and equity," hosts a webpage that provides an overview of PAR, including information on the definition, methods, strategies, case examples, and evaluation challenges.
https://organizingengagement.org/models/participatory-action-research-and-evaluation/

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