

# Inclusion

## Advancing and Expecting Inclusive Research

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## **Advancing and Expecting Inclusive Research**

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## **Abstract**

This conceptual methods paper parallels remarks given at the 2022 American Association on Intellectual and Developmental Disabilities conference highlighting the importance of including the voices of people with intellectual disability in research processes. The purpose of this paper was to put forth a call to action to disability researchers to advance, expect, and model inclusive research practices and consider this action as a form of scholarly activism and allyship toward the intellectual and developmental disabilities community. This conceptual paper is organized to engage existing inclusive research literature and offers a method of inclusive research team design with practical suggestions for consideration. Finally, implications for research policy are also presented.

The famed mantra of the disability community, “Nothing About Us, Without Us” (Charlton, 1998) embodies the importance of representation by people with disabilities as full and direct actors in any decisions, policies, or activities that affect that group of people. This conviction came to be because of the long history of nondisabled individuals making decisions on behalf of people with disabilities, as opposed to including them as critical decision makers. Unfortunately, the field of research has also been plagued by this systematic omission and silencing for many decades. In recent years, there has been a reinvigoration and push for extending this notion of “Nothing About Us, Without Us” to include the research enterprise. The research enterprise can be extended by the participation of people with disabilities in all its aspects, from the investigators (the people doing the research) to the peer reviewers to the people deciding who gets funding to the project officers to the people supporting the people applying and doing the research, as well as the research policies, design, and practices that serve as the guardrails for carrying out research projects. This extension to the research enterprise can be summarized as inclusive research.

Inclusive research is not a new term. Originally coined by Walmsley (2001), inclusive research is research in which people with intellectual disability work as researchers. It is meant to embrace both participatory research (in partnership alongside academic researchers) and emancipatory research (having agency to lead, direct, and conduct). Both approaches flip the status quo and center individuals with intellectual disability as active agents and valued contributors to the research and its processes (Strnadová & Walmsley, 2017). In so doing, these approaches align with the disability civil rights movement and amplified calls for better representation of people with disabilities as decision makers on anything that affects them. In relation to research, sentiment was expressed that no longer should research be done to people

with disabilities, but rather they should be part of the doing (Oliver, 1997; Stone & Priestly, 1996; Zarb, 1992). From here, Walmsley and Johnson (2003) offered a framework to make research accessible to people with intellectual disability (Note: In their original work the term ‘learning disabilities’ is used which is the U.K. terminology for ‘intellectual disability’. This has been changed in its presentation below for U.S. audiences.) and called on the field to adopt and embrace these principles in their work. They proposed five characteristics of inclusive research (Walmsley & Johnson, 2003, p. 64):

- The research problem must be one that is owned (not necessarily initiated) by disabled people.
- The research should further the interests of disabled people; nondisabled researchers should be on the side of people with intellectual disability.
- The research should be collaborative: People with intellectual disability should be involved in the process of doing the research.
- People with intellectual disability should be able to exert some control over process and outcomes.
- The research question, process, and reports must be accessible to people with intellectual disability.

Yet, in a recent review of the literature, O’Brien and colleagues (2022) found that the United States is lagging in terms of peer reviewed articles on inclusive research, which presents a unique opportunity for this very work and for the field to critically engage on this topic. Over time, the term “inclusive research” has been expanded and adopted beyond just the intellectual disability community such as for survivors from mental health institutions, indigenous populations, older people, and more (Nind, 2014). There are also similarities and linkages to

other broader research paradigms, methods, and approaches that have sought to engage elements of inclusive research. Nind (2014) describes this umbrella of additional approaches and methods as “participatory, emancipatory, partnership and user-led research—even peer research, community research, activist scholarship, decolonizing or indigenous research.” Yet, not all of these broader paradigms have the same intellectual disability specificity or emphasis in mind. More specifically, some of these methods are used for any population, though often applied for those who are underrepresented in research. However, there are risks of overgeneralizing or missing important nuances by simply applying these approaches and methods to the intellectual disability community. It is imperative to underscore these specific needs so that individuals with intellectual disability are not left out of an approach or method that is designed to be inclusive.

In the United States, community research is a term that has been used to describe research that actively engages communities and policy makers in conducting research, including all of its steps (Fawcett, 2021). The underlying premise of community research is that research should be generated not only by traditional academic researchers; rather, it should be a partnership approach that equitably involves community members, organizational representatives, researchers, and others in all aspects of the research process, with all partners in the process contributing expertise and sharing in the decision-making and ownership. This approach also includes coproducing research deliverables (Baker et al., 1999; Brown et al., 2020).

These terms of community or collaborative research have roots in the fields of both action research and participatory research. Kurt Lewin describes action research as a process of action–reflection–action to engage teams of multiple stakeholders in research (Lewin & Gold, 1999; Wallerstein, 2020). Participatory research emerged from activist scholars in the 1970s, drawing from Paulo Freire (1970) to join forces with social movements and challenge societal

inequities. Another related term, participatory-action research, 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). Participatory-action research focuses on social change that promotes democracy and challenges inequality and often targets the needs of a particular group. Specific to intellectual disability, Bigby and colleagues (2014) describe three main ways of doing inclusive research: (i) Where people with an intellectual disability give advice to traditional academically trained researchers about what to do; (ii) Where people with an intellectual disability lead and control research (considered emancipatory research) (iii) Where people with and without intellectual disability work together as a group with different jobs based on their different interests and skills. Most commonly, individuals with intellectual disability are thought of as non-academically trained in terms of formal credentials. However, one could and should argue that training as part of being on a research team and fully participating member of the group is a form of academic training, even without degree credentials. Traditional research processes do require an individual with some formal academic training to oversee the study design, ethics issues and other key elements that the institutional review board provides oversight on, but this does not preclude individuals with intellectual disability from conducting research and contributing to all stages of a research project.

This foundational framing about inclusive research and related terms will guide the remainder of this paper. It is also important to understand the author's positionality and perspective on disability and research which is provided in Table 1.

[INSERT TABLE 1 ABOUT HERE]

### **Benefits of Inclusive Research**

This shift toward inclusive research design requires intentional foresight, commitment, communication, engagement, and openness to change practices and procedures. The value of inclusive research cannot be underestimated. Inclusive research allows for traditionally silenced voices to be raised and to help shape the research being conducted. Further, inviting and encouraging these voices throughout the processes adds depth, relevancy, and nuances that could be missed otherwise. Those with the lived experience of disability navigate the world uniquely and often encounter ableism. These experiences can be valuable to better understand the overarching context, barriers, and challenges and to design and conduct research with intentionality to avoid perpetuating ableism or silencing certain voices. Involving people with disabilities in research as coinvestigators and co-designers has the potential to shed light on nuances and experiences of ableism of which nondisabled researchers may not otherwise be aware. Isaacson (2021) further emphasizes the importance of including people with disabilities in research by stating that “we cannot expect people to design solutions for situations they have never seen before. When we do not see the problem, we can be part of the problem.” (Isaacson, 2021, p. 537). With these benefits in mind, the next section focuses in on the specifics of inclusive research methods followed by inclusive research team design.

### **Inclusive Research Methods**

There is no singular inclusive research method. In fact, inclusive research encompasses a range of approaches and methods and is sometimes under the umbrella of, or connected to, other larger paradigms, such as community-based participatory research or participatory action research (PAR). Other times, inclusive research is included or described among approaches such as participatory, emancipatory, partnership, user-led, community, decolonizing, or indigenous research (Nind, 2014). This section takes a meta approach of inclusive research team design and



is focused more on the approach and method of designing inclusive research teams, as opposed to a methodology that is adopted to carry out the proposed research project itself, because specific research questions lend themselves to specific study design and research methodology. For any research team, care should be taken to assess all members' specific areas of interest, strengths and support needs and wherever possible consider these elements as the work is carried out. The fundamental starting point for inclusive research team design includes key tenets of PAR and universal design.

From the field of PAR, researchers and participants work together to understand a problematic situation and change it for the better (McTaggart, 1991; Martin et al., 2019). There are many definitions of the approach, which share some common elements. At its core, PAR is a collaborative process of research, education, and action (Hall, 1981) with an orientation towards social change (McTaggart, 1997). The approach emphasizes participation and action by members of communities affected by that research, they are seen as co-researchers, and it seeks to ask questions about the world by trying to change it collaboratively and embraces principles of reflection throughout and among the team. This reflective element is strongly associated with Paulo Freire (1970), who argued that liberation for those who experience oppression can be achieved only by means of reflection coupled with action. The premise here is that intentional reflection and subsequent action can bring about change and transformation.

Universal design is design that is usable by all people, to the greatest extent possible, without the need for adaptation or specialization (Mace, 1985). From their conception, universally designed products accommodate individual preferences and abilities; communicate necessary information effectively; and can be approached, reached, manipulated, and used with ease regardless of one's potential disability. Application of universal design principles minimizes

the need for assistive technology, results in products compatible with assistive technology, and makes products more usable by everyone—not just people with disabilities. These principles, however, go beyond product development and push for the adoption of universal design thinking, or proactive consideration of disability and inclusivity. Universal design is about incorporating elements of accessibility from the very beginning, which helps lessen the need for retrofitting or remediation to make something accessible after the fact. Importantly, Hamraie (2017) reminds the field that universal design is a relatively recent discourse and is not only principles, or a way of approaching new products or spaces, but also a disability activist driven movement that seeks to challenge dominant understandings and structures of disability. For a comprehensive historical overview and understanding of the theoretical underpinnings of universal design, refer to *Building Access: Universal Design and the Politics of Disability* (Hamraie, 2017). That said, the premise of universal design-based thinking is the element that is critical for building inclusive research teams, which will be discussed next.

### **Inclusive Research Team Design**

By adopting and embodying these core foundational principles of both PAR and universal design, inclusive thinking guides every decision and process of the research group and building of the research team. The following are recommended methods or approaches to build an inclusive research team design which are also summarized in Table 2.

First, intentional recruitment of individuals with intellectual disability and other disabilities to be coinvestigators and members of the research team or group must occur. Researchers should consider leveraging connections from University Centers for Excellence on Developmental Disabilities, state Developmental Disabilities Councils, university programs for

students with intellectual disability (such as those offered by Think College), as well as community-based disability organizations, such as Centers for Independent Living and others.

Next, set the tone and expectation that all members of the team are equal. This step is important to ensure the dismantling of disability hierarchy (Chan et al., 2009) and to signal to all members of the team that they are valued contributors. It means that all members adhere to the agreed upon expectations, such as regular participation in meetings. It will be important to explain what equal membership means for your research team. For example, it is common practice that not everyone who is in a research group or performing paid work on a specific project will necessarily be involved in the writing of deliverables. But that does not mean that certain individuals should always be excluded from writing assignments or kept from authorship opportunities; rather, it means that these elements should be discussed on a project-by-project basis with transparency and agreement among the team.

It is essential to assess strengths, skills, goals, and accommodation needs of the members of the research team. Each researcher on the team brings their own specific interests and abilities to the team, and whenever possible, matching those interests and abilities when forming teams to carry out specific projects or project tasks will be beneficial. Regardless of disability, every individual has unique strengths and skills they automatically bring to the table but may also have a goal to develop a specific skill or to learn a certain task. Further, every individual on the research team may have unique support needs. There should be a direct conversation about accommodation needs to best understand how to ensure success for every project team member. Importantly, this conversation about accommodations is never a one-time conversation; in an inclusive culture, it should be expected to occur on a regular ongoing basis, especially as tasks evolve and to assess whether a specific accommodation works well or needs adjusting. This

conversation where the agency and self-determination of the research team members with disabilities are centered, allowing them to lead the way in sharing what works well for them. That said, it is also important to recognize that because many research activities and tasks are different from academic or on-the-job accommodations, the individual may not know what will work best for them.

There may be need to break down what steps are involved in a task and to develop a shared plan for each step. For example, if the task is to interview research participants about a specific topic, it will be important to break that down into the pre-interview activities of obtaining consent, the logistics of getting to the interview if in person or the technological steps of getting to the virtual interview, the interview itself, as well as what questions are to be asked, if the order matters, who else will be asking questions, what to say or not say in response, how to ask for clarification, who will ensure the interview is being recorded, and what to do when the interview finishes. If an individual has a specific strength, it may be helpful to match that strength with having them ask those questions from the protocol.

Accommodations will vary greatly depending on the individual need. Some accommodations provided also help to make the research itself better and stronger. For example, if a research team member uses a screen reader, it can help to ensure that all research materials are accessible via screen reader—especially helpful if planning to have research participants who may use screen readers! On inclusive research teams, sometimes accommodations are recording and transcribing internal meetings to create a document that individuals unable to take notes in real time can refer to later. Another accommodation may be completing a specific task in pairs or in smaller teams in order to chunk the task into meaningful pieces and get input from all individuals. Yet another type of accommodation is setting up documents in a specific way to

allow for greater individualized accessibility, readability, and understanding. For example, instead of using words to qualitatively code, a team might use emoticons and define what those emoticons mean for that project to allow for greater ease in what could be a text-heavy task. Some accommodations mean trying out a plan, debriefing as a team on whether that worked well or was too hard or frustrating, and then making a shared decision on how to adjust or change the plan moving forward. This approach means that instead of assigning and delegating tasks with or without accommodations and then regrouping too far out, there are regular opportunities to check in and ensure the processes and accommodations are working as intended.

As much as possible, it is recommended that individuals be matched to projects based on that assessment of strengths and goals, and in some cases accommodations. For example, as a wheelchair user, I might ask for assistance with manual labor tasks that would be difficult for me to complete, such as loading and unloading the car with research materials needed for the school-based data collection day. This matching process, while not an exact science, helps members of the inclusive research team to see that their goals will be met and that their strengths are valued by the team.

With intentionality, it is recommended that a mentoring structure with mini-teams be developed if size allows. This structure helps to balance out strengths of team members and provides an opportunity for team members to develop their own mentoring and teaching skills too. For example, on an inclusive research team, for larger tasks, such as transcription, a task leader can be identified. Then, there may be multiple people working on that task, but there is an identified person to go to with questions or concerns or challenges that might come up outside of scheduled meeting times. Some inclusive research team members benefit from having an assigned mentor they can consult. In some cases, this mentoring relationship and the structure of

how often they meet individually can be part of an accommodation for a specific need, but having an overall mentoring and mini-team structure also helps everyone, not just those with specific disability needs.

As has been described throughout, it is essential for inclusive research teams to build in reflection time to be able to correct course or make process notes about what is working or not working or things to try differently in the future. Reflection should be not only about accommodations, but rather about team functioning and processes in general. This is a direct application of Freire's point of the importance of using reflection as a tool to transform, in this case using reflection as a key tool of inclusive research team design.

Lastly, where possible, based on the shared vision and needs of the inclusive research team, all products generated by the research team are created with this inclusivity built right in. It may be necessary to adapt corresponding research protocols with these modifications or accommodations in place and may require submitting amendments or updated protocols to the institutional review board of record. However, this step also means that there is more inclusive research being generated, expected, and developed that is responsive to researchers with disabilities needs and therefore may be more accessible up front for potential participants with disabilities too.

[INSERT TABLE 2 ABOUT HERE]

### **Research Policy Implications**

In the U.S. federal government, some research policies are legislative, based on statute, whereas others are based on regulations. A regulation is a rule spelling out how a law will be implemented. When Congress passes a law, it often leaves details up to an administrative agency

because certain decisions require expertise that may exist in the administrative agency.

Regulatory policy provides the frameworks used by agencies when developing rulemaking. It sets forth the guidelines for developing, promulgating, implementing, and enforcing this complex system of public protections. Regulatory policy guides agencies' rulemaking agendas.

Additionally, there may be specific grant mechanisms or programs or structures imposed within research institutes to address gaps—such as intentional grants or procedures to better support investigators from underserved backgrounds, including disability. It is imperative to have strategic thinkers coming from this perspective of inclusive research who are working to implement and expand or create new research policies as well as engage in these conversations with other research institutes and leaders across the federal government who are also in the research grant making space.

More specifically, President's Biden executive orders related to equity (Exec. Order No. 13985, 2021; Exec. Order No. 14035, 2021) are helpful examples. Executive orders state mandatory requirements for the executive branch and have the effect of law. They are examples of legislative documents that do not directly concern research policy but have the potential to help us to push for more inclusive research policy.

Executive Order 13985: Advancing Racial Equity and Support for Underserved Communities Through the Federal Government directs federal agencies to evaluate whether their policies produce racially inequitable results when implemented and to make the necessary changes to ensure underserved communities are properly supported. Executive Order 14035: Diversity, Equity, Inclusion, and Accessibility in the Federal Workforce seeks to create a government-wide initiative to promote diversity, equity, inclusion, and accessibility. Both executive orders define equity as the consistent and systematic fair, just, and impartial treatment

of all individuals, including individuals who belong to underserved communities that have been denied such treatment, such as Black, Latino, Indigenous and Native American, and Asian American and Pacific Islander persons, and other persons of color; members of religious minorities; lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons; *persons with disabilities*; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality.

Both executive orders name disability as an essential part of equity, diversity, inclusion, and accessibility work. The field of disability has known this for a long time; however, having it specifically included in this way in these executive orders amplifies its importance and helps policy makers and research institutes to have this support when promoting inclusive research policies. It enables us to weave in these elements of equity throughout the entire grant making process and related policies—such as throughout notices of funding opportunities (NOFOs) and throughout the peer review process.

For example, within NOFOs, using elements from these executive orders has been helpful to begin to address systemic inequities in federal funding programs, processes, and policies that may serve as barriers to equal opportunity. Advancing equity in NOFOs with intentionality has the potential to create opportunities for the improvement of communities that have been historically underserved, which benefits everyone. This work does not happen overnight; there are a lot of resisters even within the disability community. Disability hierarchy—or privileging certain disabled voices over others—is also real, stratifying stigma from least—people with physical disabilities—to most— people with psychiatric disabilities, developmental disabilities and/or intellectual disability (Chan et al., 2009; Andrews & Forber-Pratt, 2021). Thus, it is imperative to be intentional with inclusion of individuals with the highest



support needs and individuals who are multiply marginalized and therefore often underrepresented or absent. In the context of research grants, if there is a requirement for intentional inclusivity in a NOFO, it should also be connected to an evaluation criterion, demonstrating that scoring of that criterion is a priority in determining grant awards. For example, NOFOs may require that proposed projects have diverse racial representation of a disability population or require that the applicant describe how input of individuals with disabilities and other key stakeholders was used to shape the proposed research activities.

The ideals of inclusive research team design can be supported, recommended, or required through research policy. For example, in NOFOs, the executive orders on equity opened the door to ask more intentionally about the equity experience of the project team to encourage the sharing of lived experience and expertise in this section of the grant. Some NOFOs ask applicants to describe the experience of the project team and encourage the applicant to describe the equity experience of the project team, which may include, but is not limited to, project team's individual identities.

At NIDILRR, we went through the regulatory rulemaking process to amend our peer review criteria that can be found at 45 CFR 1330.24. Specifically, we sought to amend the criteria under the project staff criterion. The final rule advances equity in the project staff peer review criteria that NIDILRR uses to evaluate disability research applications across all its research programs. This change will allow NIDILRR to better evaluate the extent to which grant applicants conduct outreach to people with disabilities and people from other groups that traditionally have been underserved and underrepresented. This change disaggregates disability from other underserved populations in the project staff peer review criterion so we can more directly evaluate and score the extent to which applicants describe their outreach practices and

encourage applications for employment from people with disabilities and from other underrepresented groups separately and distinctly. This change aligns with our goal of ensuring people with disabilities are involved throughout the entire research process across NIDILRR-funded projects. The revised criterion (45 CFR 1330.24(n)) now reads:

*In determining the quality of the project staff, the Director considers one or more of the following factors:*

- *The extent to which the applicant encourages applications for employment from people with disabilities, who may include but are not limited to people with disabilities who have the greatest support needs.*
- *The extent to which the applicant encourages applications for employment from people who are members of other groups that have traditionally been underrepresented in research professions based on race, ethnicity, national origin, sex (including sexual orientation and gender identity), or age.*

The regulatory rulemaking process is largely unfamiliar to the general public, but it is the mechanism to propose and carry out changes such as the one described, which directly affects and changes research policy. It is important for researchers to be aware of this process (Office of the Federal Register, 2011) to know how and where they are to engage with the public.

### **Call to Action**

In order to grow the field of inclusive research, it is on all of us—but especially on those of us who are already engaged in conceptualizing, conducting, and disseminating disability-related research—to be intentionally inclusive in our own practices. Further, it is on those of who help to construct and implement research policy to adopt this inclusive mindset and lens to that

work too, at all levels— in and outside of the government, within universities, and within our own research groups or teams or projects. These inclusive actions and approaches can serve as a model to others who may not think of themselves as doing or engaging in inclusive research. All research—regardless of whether the topic relates to disability—benefits from inclusive research team design, and investigators from other disciplines can learn from us championing the way. “Nothing About Us, Without Us” *must* include the research enterprise, but in order to do so it will take us all to make this intentional commitment and to learn from each other along the way.

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Table 1. Positionality Statement

Positionality Statement
<p>“I am a brown, disabled woman researcher who is a manual wheelchair user. I serve as the Director of the National Institute of Disability, Independent Living, and Rehabilitation Research (NIDILRR) within the Administration for Community Living. While this is a solo-authored piece based on remarks given at the 2022 American Association on Intellectual and Developmental Disabilities, it is imperative that future inclusive methods pieces be coauthored with individuals with intellectual disability too. This special issue contains a mix of pieces written by researchers with intellectual disability, sharing their experiences with inclusive research to empower others to advance opportunities for inclusive research and methods pieces, focused how research policy and practice can advance inclusive research opportunities. The ideas, methods, and approaches described come from years of experience working alongside and with multiply disabled colleagues, students, mentees, research group members, coworkers, and team members, in addition to the research policy lens learned from my current role. While my current role makes coauthoring challenging, I invite commentary from coinvestigators with intellectual disability to respond to this article and share how their experience with research and being on research teams aligns or does not align with the approaches discussed.</p> <p>I acquired my disability due to transverse myelitis when I was 4½ months old. As a young child, I initially struggled until I found the disability community and saw that people like me could grow up and go to college, have a job, start a family, live on their own. I distinctly remember seeing people in racing wheelchairs competing in the Boston Marathon, and it was a light bulb moment, seeing that they were successful adults with disabilities. This power of representation as a young girl was monumental. As Jean Driscoll went on to become an eight-time winner of the Boston Marathon, her photo and news stories were all over the television and newspaper—and she was disabled, like me! It was the first time I had seen a person with a disability on the front page of the main newspaper, and I latched onto the role models from that moment. I did eventually make my way to the Paralympic stage and had an incredible athletic career, but it was not without challenges, including taking on my high school district in federal court due to discrimination on the basis of disability. The barriers and ableist encounters were numerous, but this experience also taught me the value of activism and the way to be that representation for others.</p> <p>Then, as I entered the academy and the world of research, I once again found the lack of disability representation to be dismal. I began to see many similar attitudinal barriers and intersections with ableism that I had experienced in high school and that likely point to why the numbers of disabled researchers are so low. It was also challenging to even find statistics about disabled researchers. The National Center for College Students With Disabilities estimates that 4% of all faculty members have disabilities (Grigely, 2017), and the University of California at Berkeley reports that only 1.5% of full-time faculty members are disabled (Grigely, 2017). For various reasons, disability is not tracked as a marker of diversity at many institutions of higher education. Also, it goes without saying that there can be and are disabled researchers who are not affiliated with universities, such as those in the community or with disability organizations or foundations engaged in disability work. So, even statistics from our institutions of higher education for these data likely underestimate the true number of researchers with a disability who exist. Also, the self-report nature of these data must be considered as many who may have a disability choose not to disclose it in this type of reporting for various reasons, sometimes for fear of retaliation or stigmatization. One of my main priority areas for the national scope of the disability research field is working intentionally to increase the representation of investigators with disabilities and greater disability representation as a whole, across all aspects of the research enterprise.”</p>



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Table 2. Summary Recommendations for Inclusive Research Team Design

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Summary Recommendations for Inclusive Research Team Design
<ul style="list-style-type: none"><li>• Intentional recruitment of individuals with intellectual disability and other disabilities to be coinvestigators and members of the research team or group.</li><li>• Set the tone and expectation that all members of the team are equal.</li><li>• Assess strengths, skills, goals, and accommodation needs of the members of the research team.</li><li>• Consider adopting a mentoring structure with mini-teams be developed (if size allows).</li><li>• Build in reflection time for the research group or team.</li><li>• Ensure all products generated by the research team are created with inclusivity and accessibility built in.</li></ul>

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