PARTNERING FOR RESEARCH AT YOUR CENTER FOR INDEPENDENT LIVING:
TIPS FROM YOUR PEERS

RTC:Rural
Research & Training Center
on Disability in Rural Communities

FACT SHEET

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Krys Standley, Hannah Pepprock, and Rayna Sage

INTRODUCTION

Whether you are just starting to think about doing a research project at your Center for Independent Living (CIL), have been approached by a researcher with an idea for a project, or have just been told by your Executive Director that a research project has been funded at your CIL, we hope you will find the tips in this fact sheet helpful!

The Research and Training Center on Disability in Rural Communities (RTC:Rural) has over 30 years of experience conducting research projects in partnership with CILs. Much of this work has been rooted in the principles of Community-Based Participatory Research (CBPR), an approach that is complementary to Independent Living Philosophy. When practiced well, CBPR projects "cooperatively create co-learning opportunities for researchers and community partners, build capacity within systems and the local community, empower partners and participants to have more control over their lives, and achieve balance between the sometimes competing demands of research and action" (Minkler & Wallerstein, 2008).

As you might imagine, it is difficult to achieve all these goals in every project or even define what these principles look like in practice. This fact sheet is the result of a desire to come up with specific tips for successfully partnering for research that are rooted in the experiences of RTC:Rural researchers and our CIL partners.

INVITING IL PERSPECTIVES

To learn how to better partner with community organizations in our research, RTC:Rural hosted a conference workshop. This workshop built on our evaluation of the Peer Collective, a project designed to evaluate the effectiveness of workshop content created for CIL consumers to help them feel more comfortable with technology, increase peer connections, and reduce social isolation and loneliness. We began the information gathering process by inviting the 11 staff members from the CILs that participated in the 2024 Peer Collective Evaluation to co-present with us at the Annual Conference for the Association of Programs in Rural Independent Living (APRIL), which was held in Chicago, Illinois. Three CIL staff members agreed and collaborated on the presentation content. Two of the three CIL staff members were able to attend the conference and co-presented the workshop alongside three researchers. Workshop participants, who were primarily staff members from rural CIL and State Independent Living Council (SILC) from across the country, were then invited to contribute their ideas about important aspects of CIL-based research projects.

Starting the Conversation. To invite participants to start thinking about these ideas, we asked them to pair up and share their responses to either or both of the following two questions: 1) If you have experience working on research projects at your CIL: What was that like? and 2) What do you think your organization's culture is (or would be) around doing research projects like the one described?

Ranking for Importance. Prior to the conference, the researchers and CIL partners brainstormed nine approaches, activities, or processes that we thought might be helpful in doing CIL-based research.

Nine Helpful Conditions for Partnering for Research

1. Existing relationships with consumers who may be interested in the project

2. Prior experience with the key activities of the research project

3. Having systems for reminding consumers about research projects activities

4. Adequate financial support for CIL staff time

5. Having someone on the research team that I felt comfortable reaching out to

6. Flexibility on the part of CIL staff and researchers when things don't go to plan

7. Being in a group with other CILs and having peer support among CIL staff

8. A clear understanding of the research process

9. Feeling that there is a potential benefit to consumers who participate

Following the conversation about experiences with research, we asked the approximately 20 participants to work in four groups of 4-5 people to review the nine ideas, which were printed on slips of paper, with each item corresponding to a single color. We also provided blank slips of paper for attendees to write down additional ideas.
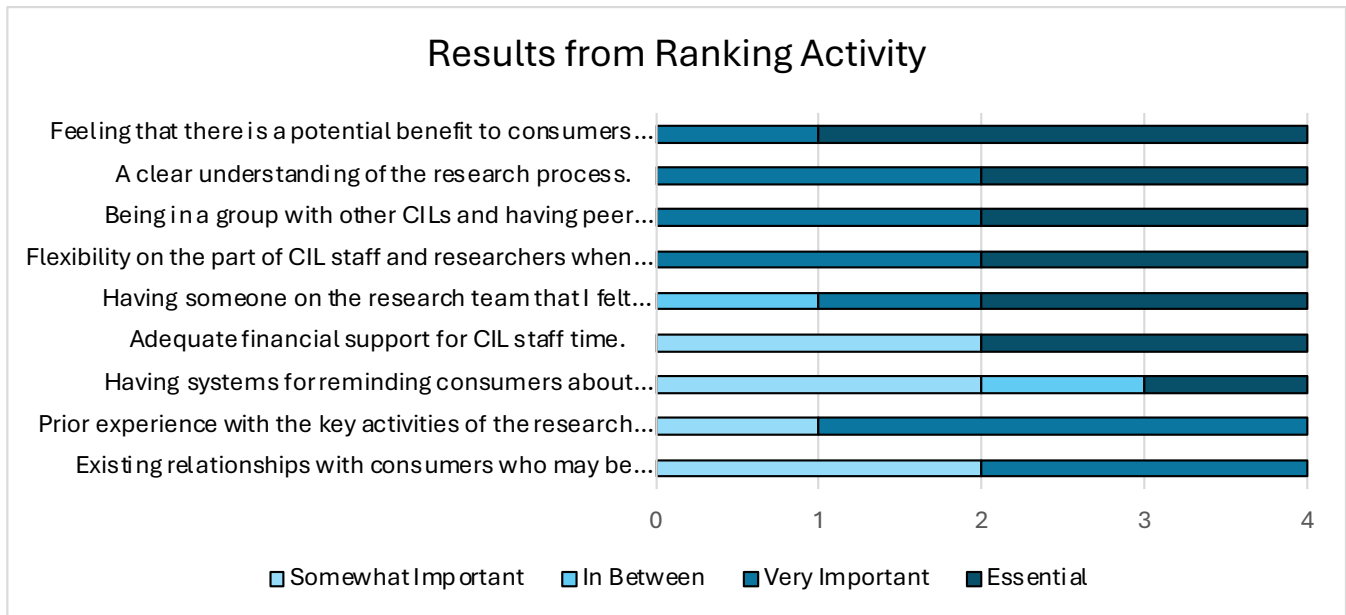
Each group took 20 minutes to sort the ideas into four categories: "Not Important at All," "Somewhat Important," "Very Important," and "Essential." Once each group agreed upon rankings, the sheets of papers were transferred to poster papers with corresponding categories that were posted to the conference room walls. When all groups had posted their rankings, workshop facilitators verbally summarized the results.

THE RESULTS

The approaches, activities, and processes ranked highest by workshop attendees included three items generated during the workshop and four pre-printed items. The three new items were: 1) "CIL consumers providing inspiration for, or input into, the topics researched," 2) "Providing accommodations," and 3) "Clear delineation of responsibilities among CIL staff and researchers." Because of their overlap with pre-printed ideas, we incorporated them into the summary and tips below.

The top four pre-printed items (which were developed in collaboration by researchers and CIL staff ahead of the workshop) were: 1) Feeling that there is a potential benefit to consumers who participate, 2) Flexibility on the part of CIL staff and researchers when things don't go to plan, 3) Being in a group with other CILs and having peer support among CIL staff, and 4) A clear understanding of the research procedures.

Results from Ranking Activity

Statement	Value
Feeling that there is a potential benefit to consumers…	
A clear understanding of the research process.	
Being in a group with other CILs and having peer…	
Flexibility on the part of CIL staff and researchers when…	
Having someone on the research team that I felt…	
Adequate financial support for CIL staff time.	
Having systems for reminding consumers about…	
Prior experience with the key activities of the research…	
Existing relationships with consumers who may be…	

Legend: □ Somewhat Important ■ In Between ■ Very Important ■ Essential

The above table illustrates how each of the statements was ranked across the four groups. For example, two groups ranked the statement "Adequate financial support for CIL staff time" as "Somewhat Important" while two groups ranked the statement as "Essential."

The approaches, activities, and processes ranked lowest included: 1) Having someone on the research team that I felt comfortable reaching out to, 2) Existing relationships with consumers who may be interested in the project, 3) Prior experience with the key activities of the research project, 4) Adequate financial support for CIL staff time, and 5) Having systems for reminding consumers about research project activities. However, none of the groups ranked any items as "Not Important at All." In other words, all the approaches, activities, and processes were deemed to be at least "Somewhat Important" to CIL-based research collaborations.

CONCLUSION

When thinking about partnering with researchers to do a CIL-based research project, you may want to consider the following:

- Will consumers, CIL staff, and other disability community members be involved in making decisions about research design, activities, and project implementation?
- Will consumers benefit from their participation in the research project?
- Is there a clear research process or a system in place to make sure all partners and participants understand the expectations and roles?
- Are other CILs participating, and will there be opportunities for peer support between CIL staff?
- Is there flexibility within the research design to make changes when things do not go as planned or is the research design more rigid?
- Does the research team have a member you would feel comfortable reaching out to when you have questions or concerns?

In CBPR, these and other questions about partnering for research at your CIL can be explored cooperatively between researchers, CIL leadership, and CIL staff. These conversations can happen at many stages, including the idea development phase of the project before the project is funded. Some other questions to ask might include:

- Do researchers describe the opportunity as a chance for both parties to learn and grow together?
- Will the project result in increased capacity for my CIL, the CIL network, and/or the disability community?
- Will the project empower CIL staff and consumers to have more control over their lives?
- Does the project lead to action that will improve disability justice?

We have found that collaborative and participatory research projects are a good fit for CILs because of the strong commitment to elevating the input and expertise of those who would be impacted by the research outcomes. CBPR principles are well-aligned with the tenets of Independent Living Philosophy, where "Nothing about us without us" rings throughout the research process.

CITATION

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https://scholarworks.umt.edu/ruralinst_independent_living_community_participation/104/

FOR ADDITIONAL INFORMATION

Research and Training Center on Disability in Rural Communities

The University of Montana Rural Institute for Inclusive Communities
Rm 253 Corbin Hall, Missoula, MT 59812-7056
(800) 732-0323
rtcrural@mso.umt.edu
www.umt.edu/rural-disability-research/

RTC:Rural
Research & Training Center
on Disability in Rural Communities

Rural Institute
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