Participatory Action Research for People with IDD: A Research Summary

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Executive Summary

Participatory action research (PAR) is designed to include the people researchers are studying in their projects. This helps researchers and the people researchers want to learn about. For people with intellectual and developmental disabilities (IDD), this means they are involved in the research as active partners. It gives them a voice in the process. It ensures the research includes people with IDD's needs and experiences. It also helps break stereotypes and biases people have about people with IDD.

This paper looks at ways researchers and self-advocates with IDD can work together successfully on research projects. This team of researchers and self-advocates are working together to help more people do PAR. The team wrote this paper to help make sure the work is successful. The team will create training and tools based on this research.

Notes About This Paper

Often when researchers look at disability, they will include people with all types of disabilities, including physical to intellectual. People with these different types of disabilities all have different needs. When researchers combine them, they often miss important individual needs. For this reason, during our research for this project, we did not include research that focused on disability in general. We looked only at research that was about people with IDD.

When writing about people with IDD in this paper, we use the term "self-advocate." In this paper and for this paper's purpose, self-advocates are people with IDD.

Recommendations

This paper looks at ways to help make sure PAR that includes self-advocates is done in the best possible way. The sections are divided into four main categories:

- Benefits
- Effective Practice: Themes
- Effective Practice: Phases of Research Projects
- Barriers

Here is a summary of these four sections.

Benefits

There are many benefits for self-advocates who are partners in PAR. There are also many benefits for the researchers and the research itself. The research is stronger and more reliable because it uses self-advocates' experiences. Self-advocates become empowered. They learn many valuable skills and abilities. Researchers can learn stronger research practices. They can also learn more about the people they are researching.

Effective Practice: Themes

PAR means everyone gets to be part of the research in their own way. Researchers need to consider the different needs and abilities of self-advocates. When self-advocates have choices and control it helps them feel important and included. Trust and respect create a comfortable and safe environment where

everyone can share ideas and work together. When self-advocates are part of the research, they feel connected to the research. Good communication and collaboration lead to better research results.

Effective Practice: Phases of Research Projects

Both self-advocates and researchers need training to effectively work together in PAR. There is much more information about training self-advocates. There is not so much information about training researchers. This is an area that needs to be studied further.

Finding and keeping self-advocates to work on research together is important. Advocacy groups can help find self-advocates. Self-advocates need to be fully included in the research. Their needs must be met. They should also be paid for their participation. Creating a strong team makes the research successful. Researchers can build strong teams by sharing work, seeing each other's skills, and celebrating progress. There are some ways that researchers can collect data while including self-advocates. Two ways are taking pictures to share experiences and using a two-person interview. These both help researchers understand self-advocates better. It's also important to make sure the research is done fairly for all the people participating. At the end of the research, researchers need to include self-advocates in the finished product. They should get credit. They should help share the findings.

Barriers

There are some barriers that can make PAR difficult. Being aware of these barriers can help the research be more successful. Meeting coordination can be difficult, including finding a good time for everyone and staying on schedule. Transportation can also be difficult for some self-advocates and their families. Finding self-advocates who are willing and comfortable to work with researchers can be difficult. Sometimes researchers don't know how to best communicate with self-advocates to make sure they can work well together. Sometimes families and caregivers have concerns that make it difficult for self-advocates to participate.

Conclusion

Participatory action research involving self-advocates helps make research inclusive and meaningful. It gives self-advocates a voice. It makes sure their needs and experiences are considered in the research. This helps challenge stereotypes and biases. These recommendations will help researchers and self-advocates know:

- tools for working together successfully
- effective practices
- benefits of including self-advocates
- importance of choice and respect
- importance of training and team building
- data collection methods
- how to highlight the participation of self-advocates in the whole research process

Even though there are some challenges, knowing about them ahead of time can lead to more successful PAR with self-advocates.

Research Summary

Benefits

PAR benefits self-advocates and researchers alike. It improves knowledge and skills. It changes attitudes and beliefs for the better. It also results in stronger projects and products.

For Projects and Products

PAR creates stronger projects and products because it:

- is based on the actual needs and ideas of people with IDD (Cargo & Mercer, 2008)
- is based on the input of all self-advocates—not just some groups (Nind, 2014)
- motivates self-advocates to value and use products created based on their lived experience
- prioritizes the most important needs, which can improve the safety and wellbeing of self-advocates (Cargo & Mercer, 2008)

For Self-Advocates

PAR creates positive changes in self-advocates' attitudes and beliefs by helping them feel:

- part of something important
- valued for their knowledge and experience (Nind, 2014)
- hopeful that the work will change their lives for the better (O'Brien et al., 2014)
- motivated to do more work with and without support (St. John et al., 2018)
- more confident in and proud of their knowledge and skills (St. John et al., 2018; O'Brien et al., 2014, Fullana et al., 2017)
- able to continue working independently
- able to make their own decisions (St. John et al., 2018)

PAR also helps self-advocates develop and improve knowledge of:

- how the world works (Johnson et al., 2014)
- how research works (Fullana et al., 2017, St. John et al., 2018)
- themselves (St. John et al., 2018)
- challenging ideas (Fullana et al., 2017)

It helps self-advocates develop skills including:

- leadership (Strnadova et al., 2014; Nind, 2014)
- teamwork (Johnson et al., 2014)
- how to come up with ideas for research (Johnson et al., 2014; Strnadova et al., 2014)
- how to design resources
- how to interview people
- how to analyze and use data
- how to write and present information (Johnson et al., 2014)

As a result of their work, self-advocates can be mentors for other people with IDD. They can:

- be role models
- ask for better explanations
- share stories of their own lives
- model caring for others
- teach technology (Strnadova et al., 2014)

For Researchers

PAR can improve researchers' processes and products. Self-advocates can help researchers:

- learn insights, challenges, and discover gaps researchers might not see (Nind, 2014; O'Brien et al., 2014; St. John et al., 2018)
- avoid mistakes made by making guesses about people with IDD (Cargo & Mercer, 2008)
- recognize the boundaries and limits (and gifts) of others with IDD (St. John et al., 2018)
- create better, more specific study questions (Cargo & Mercer, 2008; Strnadova et al., 2014)
- produce stronger findings and more meaningful outcomes (Cargo & Mercer, 2008; Nind, 2014)
- reach a wider audience
- teach other researchers to use PAR (Cargo & Mercer, 2008)
- recruit volunteers more easily by creating a trained workforce (O'Brien et al., 2014)

PAR also improves researchers' skills and attitudes. This happens as they watch self-advocates work (St. John et al., 2018). Researchers:

- learn to repeat and revise steps
- learn to work at the pace of those with IDD
- become more flexible and adjust the plan as needed (O'Brien et al., 2014)
- learn to better organize material. They learn to share smaller amounts of information (Strnadova et al., 2014)
- understand more about what they are researching (Cargo & Mercer, 2008)
- look closely at their own biases and the sources of their beliefs (Johnson et al., 2014; Nind, 2014)

Effective Practice: Themes

In good PAR, everyone participates in a way that works for them. Researchers should make sure that it includes considering different needs and abilities. Giving people choices and control helps them feel valued and involved. Trust and respect help people feel comfortable. That makes it easier to share their ideas and work together. Good communication and collaboration are important because they help people share information, work together, and make decisions as a team. This leads to better research results.

Participation Modes and Accessibility

There are many ways self-advocates can take part in PAR. Different types of participation can make it easier for more self-advocates to participate (St. John et al., 2018). Researchers should think about these ideas to make it easier for self-advocates to participate:

- Projects that empower and engage all people in the project are more effective (Cargo & Mercer, 2008).
- Projects should include many ways for self-advocates to participate (Thurm et al., 2021).
- Projects should include self-advocates and their families from the beginning when planning the research project (O'Brien et al., 2014; Phillips et al., 2022).
- Self-advocates should be part of getting funding for the project, including making proposals and bids (Northway et al., 2015; O'Brien et al., 2014).
- Self-advocates should get training on how to work on projects.
- Researchers should get training to work well with self-advocates (Thurm et al., 2021).

Accessibility is important for PAR. It makes sure everyone can be involved. Researchers get better information. The research is stronger and done fairly for everyone. To make research accessible for self-advocates, researchers should:

- write using plain language (INVOLVE, 2012; Phillips et al., 2022; The All of Us Research Program Investigators, 2019)
- use materials that are made especially for self-advocates (Phillips et al., 2022)
- ask self-advocates what changes they personally need to make something accessible (Fullana et al., 2017)
- look for barriers that would make it difficult for self-advocates to participate and be included (Northway et al., 2015)
- create a vocabulary for the research (INVOLVE, 2012)
- give questions and other tools before self-advocates are supposed to talk about them (Phillips et al., 2022)
- give time for scheduled discussions (Fullana et al., 2017)
- give time for follow-up questions (O'Brien et al., 2014)
- make sure resources are available to everyone, such as giving access to technology or Wi-Fi (INVOLVE, 2012)

Here are some ways to help self-advocates participate in research:

- Self-advocates can use apps and websites (The All of Us Research Program Investigators, 2019).
- Researchers can give self-advocates surveys, including in more than one language (The All of Us Research Program Investigators, 2019).
- Researchers and self-advocates can use pictures and videos (Frankena et al., 2019; Fullana et al., 2017).
- Researchers can include explanations for the pictures they use (Fullana et al., 2017).
- Researchers can use self-advocates to run focus groups to get information for the research. Two self-advocates can run the groups. Or a self-advocate and a co-researcher can share running the groups. Or a co-researcher can coach a self-advocate (O'Brien et al., 2014).

Choice and Control

All self-advocates need to have a choice in how they participate. It's also important for them to have control of how they participate. Equal participation and power for researchers and self-advocates can be hard. To make it easier, researchers should:

- find out how much everyone wants to participate (Cargo & Mercer, 2008)
- find out what parts of the research they want to participate in. It's okay if they don't want to participate in all of it. They should know they can stop at any time (Cargo & Mercer, 2008; INVOLVE, 2012)
- give self-advocates a voice in how the research will work
- ask them to participate in the beginning when deciding how they will do the research
- ask them to participate at the end when deciding how they will use findings (Cargo & Mercer, 2008)

Trust and Respect

Trust and respect create a safe and welcoming place to work together. Everyone will feel empowered and feel like they own the work. These are some ways to build trust and respect:

- Researchers should understand the culture and safety of self-advocates.
- Researchers should think about what all people can do for the project.
- They should respect each other's time (Cargo & Mercer, 2008).
- They should start team building from the beginning of the project (Strnadova et al., 2014).
- Everyone should talk about issues honestly and respectfully (Cargo & Mercer, 2008).
- Some people will need time to become comfortable sharing their opinions (O'Brien et al., 2014).
- The research must be truthful, and researchers must treat self-advocates with respect (St. John et al., 2018).

Ownership

It's important that people care about the outcome of their work. They are more likely to work hard. They are more likely to stay involved long-term. For example:

- The research should have a goal that is important to self-advocates (Thurm et al., 2021).
- Self-advocates want to shape research that affects them.
- They are concerned about their rights. Researchers must recognize these rights to help the partnership grow.
- Partnerships that increase understanding and learning help empower people and communities (Cargo & Mercer, 2008).

Communication and Collaboration

PAR cannot happen without good communication and collaboration. They are not easy to separate. Both must work well. The following sections look at ways researchers and self-advocates can communicate and collaborate.

- Collaboration is successful if it:
  - answers important questions
  - reaches people it would not otherwise
  - uses and thinks about self-advocate knowledge
  - is valued by self-advocates
  - makes a positive impact (Nind, 2014)

- Self-advocates must feel comfortable working and communicating with researchers. For example:
  - Self-advocates are more comfortable answering questions from other self-advocates. They get longer answers from other self-advocates (St. John et al., 2018).
  - Self-advocates are more honest when other self-advocates ask them questions. This can create more accurate results (O'Brien et al., 2014).
  - Some research might make self-advocates uncomfortable. There should be a plan about how to get support if they want to talk about their feelings (INVOLVE, 2012).
- When creating a team, researchers should:
  - think about the right size for the team. If the group gets too large, it can be hard to form relationships. If this happens, create smaller groups that report back to the larger group (Ouellette-Kuntz et al., 2013)
  - let people know what they are supposed to do. Create job descriptions (INVOLVE, 2012)
  - treat self-advocates as equal team members. Give them credit on final publications (Phillips et al., 2022)
  - work in pairs. It allows the partners to learn from each other
  - be available to offer support and answer questions (St. John et al., 2018)
- There are tools researchers and self-advocates can use to strengthen communication and collaboration. These include:
  - writing in diaries. This is helpful for self-reflection. This information can help guide the research (Strnadova et al., 2014)
  - having self-advocates test any tools that will be used for self-advocates
  - using self-advocates' feedback (Northway et al., 2015)

Effective Practice: Phases of Research Projects

Self-Advocate Training

Training is very important for self-advocates. Self-advocates learn how to communicate well and do research. It is important to keep self-advocates safe during research.

   Topics. Training self-advocates has many important parts. Training comes from many sources. It can be other team members. Mentors can train self-advocates (INVOLVE, 2012). Topics for training include communication and research skills. Communication skills include how to:

- share comfortably
- listen carefully before answering
- handle when someone takes over the conversation
- get consent
- understand the role of interpreters (O'Brien et al., 2014)
- ask questions using prompts (O'Brien et al., 2014; Strnadova et al., 2014)
- lead interviews
- role-play interviews
- understand body language (Strnadova et al., 2014)

Research skills that may require training include how to:

- do research ethically (O'Brien et al., 2014; Strnadova et al., 2014)
- identify the problem
- recognize how the problem affects a group
- identify how the problem relates to themselves
- prepare a research plan
- create a realistic schedule
- use technology
- take notes
- conduct interviews
- share results (Strnadova et al., 2014)

Format/Modes. A training manual for self-advocates should include the following:

- plain language
- pictures
- project goals
- description of roles
- interview skills
- confidentiality rules
- consent
- practice interviews (St. John et al., 2018)

Researcher Training

Researcher training is equally important to self-advocate training. Researcher training focuses on the creation of non-leading questions. It is also valuable to teach how to give positive and helpful feedback (O'Brien et al., 2014).

Design

It is important to carefully plan a project. There are many important factors to consider.

Long Term vs. Short Term. Many research projects are short term. That means they meet for a shorter time. They may only meet for one or two years. Some research projects are long term. That means they meet for several years. There are many benefits of meeting over several years. They include:

- finding time to try different methods
- growing more comfortable with each other
- developing friendships
- learning more skills (Frankena et al., 2019)

Ethics Considerations. Before doing research, it is important to plan to protect everyone. An ethics committee will protect people in the study. Researchers carefully think about ways to avoid hurting people.

Researchers complete these tasks. They should:

- learn about the ways they could accidentally harm self-advocates

- ask for information from people who are at risk of abuse
- include people who are at risk rather than exclude them by trying to protect them
- include self-advocates in the process of meeting with an ethics committee
- adapt documents to plain language (Northway et al., 2015)

An ethical study means that self-advocates should understand certain things about the research. They should know that:

- they do not have to do anything they do not want to
- they can stop doing the research at any time
- researchers will not use their names in any reports
- anything they say is private unless someone is getting hurt
- support is available if they get upset about anything in the project (Northway et al., 2015)

Recruitment and Retention

It is very important to get the right people on a project. It is also important to plan ways to keep the participants on the project.

    Recruitment. Good research has a balanced mix of researchers and self-advocates (Cargo & Mercer, 2008). There are many good questions to ask during recruitment. Ask the questions again at the end of the research. Some great questions to ask include:

- Who will benefit from the research?
- How does their participation make the research better?
- What subjects or areas of study should be part of the research?
- Who should be involved to make sure everyone's values are respected?
- Who should be included to ensure that the research findings are used effectively?
- Who should be involved in maintaining a balance of scientific importance?
- Who should be involved to make sure the research is socially important?
- Who should be involved to make sure the research considers cultural importance?
- Who should be included to gather information from those who will benefit from the research?
- Who should be involved to keep the research going smoothly?
- Who else could help the partnership achieve its goals (Cargo & Mercer, 2008)?

Advocacy groups and organizations that support self-advocates are helpful when looking for people to join a research study (O'Brien et al., 2014; Phillips et al., 2022). The members of these groups are often good at speaking up for themselves (O'Brien et al., 2014). Here are some ways to recruit people from these groups:

- Invite people individually and talk to them in person.
- Have self-advocates invite other self-advocates (O'Brien et al., 2014; Ouellette-Kuntz et al., 2013).
- Recruit people quickly after they show interest, so they are still available.
- Include different kinds of people with IDD.
- Pay people to participate.
- Show pictures of the researchers and explain the research clearly.

- Use the internet and online platforms (Ouellette-Kuntz et al., 2013).
- Use surveys to find interested participants (The All of Us Research Program Investigators, 2019).

It is valuable to include self-advocates early in the research process. Everyone can feel like they are working together and have a common goal (INVOLVE, 2012). When doing research with self-advocates, it is also important to think about their special needs and ideas. Communicate clearly and include everyone in the research journey (INVOLVE, 2012).

Informed Consent. Informed consent is very important. It ensures that everyone understands what will happen (The Open University, 2023). Effective informed consent should include the following:

- Tell what the study involves.
- Provide contact information for all participants.
- Sign a consent form.
- Keep copies of the form.
- Tell about the process in case self-advocates want to stop being in the study (The Open University, 2023).

The Kennedy Krieger Institute has an example informed consent form. The example form created by Kalb (2018) shares the details of the study. It makes sure that everyone understands what is going to be researched. https://jhmi.co1.qualtrics.com/jfe/form/SV_0qVkNRkjhfK6hJb

This is a guide for obtaining informed consent created by The Open University (2023). https://www.open.ac.uk/research/sites/www.open.ac.uk.research/files/files/Documents/hrec-information-and-consent-guidance.pdf

Burrow and Miller (2021) developed a resource that includes information about how to obtain informed consent when doing work related to trauma-sensitive topics such as sexual assault. https://selfadvocatecentral.org/wp-content/uploads/2021/11/SAPR_ListeningSessionProtocol.pdf

Retention. To retain a strong research group, use these important strategies.

- Have the same people in the group.
- Make sure they attend as many meetings as possible (O'Brien et al.,2014).
- Be clear about how long the research will take so everyone can plan their time.
- Think about each person's needs and make sure they can easily take part.
- Use interpreters or visual aids.
- Have a leader who can answer questions and help everyone (INVOLVE, 2012).
- Pay everyone to show they are important (INVOLVE, 2012; O'Brien et al., 2014).
- Focus on finding solutions to problems instead of just talking about them (Northway et al., 2015).

Teamwork

The ability to work as a strong team is very valuable. Having shared goals helps build a strong team.

Teambuilding. The goal is to build a strong team that will work well together and achieve success in the research.

To create a strong team, researchers can use these helpful strategies:

- Make team building an official goal (Fullana et al., 2017).
- Work in small groups to build the team.
- Celebrate the team's progress to feel good about the work (O'Brien et al., 2014).
- Spend time together doing work and having fun.
- Understand what each person likes and recognize everyone's skills.
- Give credit to all team members as writers of the research (Strnadova et al., 2014).
- Self-advocates and researchers can spend time together. They can go to classes, community events, and book clubs.
- Self-advocates can learn together. They can share research, use online learning, and recommend books (University of Cumbria, n.d.).
- Plan in case someone on the team gets sick (INVOLVE, 2012).

Meeting Format. The organization of meetings is very important in PAR. Some successful strategies are:

- Keep the sessions shorter to stay focused and engaged.
- Create a safe space where everyone feels comfortable talking.
- Encourage respectful debates in a safe area (Fullana et al., 2017).
- Talk in small groups before making decisions as a big group.
- Plan time for coming up with ideas.
- Make sure there is time for asking questions.
- Give extra time for solving problems.
- Use the same format to start and end the meetings.
- Use strategies to stick to the schedule and manage time well (O'Brien et al., 2014).

Data Collection

Data collection is an important part of a study. It is valuable to include many ways to meet the needs of self-advocates. It is valuable to use different ways to get data for the research.

Photovoice. Photovoice is a way for people to participate in community research. It is often used to help people who get left out of research to participate. People take pictures to show their experience. Then self-advocates talk with the other researchers about the pictures. Chinn and Balota (2023) tell about ways photovoice can be used successfully with self-advocates.

Benefits of Photovoice. Photovoice is an accessible way for self-advocates to show their lives. Researchers can see what the self-advocates see.

Photovoice lets self-advocates choose what their lives look like. Self-advocates can choose how meaning and new knowledge is created. They can make changes in their communities.

Photovoice is helpful because it gives people who communicate without words a way to share their stories. It makes it easy for all self-advocates to share ideas, feelings, and issues. It helps people remember ideas and makes group discussions easier. And it includes and empowers people who have been left out of research because of their level of disability.

When people see photos from self-advocates, it raises awareness of social barriers and helps change stereotypes. It shows the abilities and accomplishments of self-advocates.

Self-advocates who do photovoice:

- feel pride and success
- learn about themselves
- have fun
- get confidence
- learn about what they are studying
- learn about advocacy
- get leadership skills and can support others
- make new friends

Using Photovoice Effectively. Here are some ways to use photovoice so it works well for everyone:

- Family members and friends can help researchers know the background of the self-advocate's life. It is important to help family and friends keep their views separate from the self-advocate's views.
- Sometimes the researchers might have more power in the relationship. Some researchers keep research journals to help them see when they have wrong beliefs about self-advocates.
- Researchers give instructions about how to take pictures and use cameras. They can use plain language forms and slide shows.
- Researchers should teach self-advocates about asking permission before taking pictures of other people.
- Researchers do not give many instructions about what to take photos of so self-advocates can make decisions about what is important. Some researchers can give self-advocates more specific topics but also include many different choices on that topic.

When using photovoice, there are options for how self-advocates can participate:

- Some researchers let self-advocates use their own smart phones to take pictures. Some researchers give simple digital cameras to self-advocates.
- Some researchers train self-advocates in groups. Some researchers train with just one person.
- Self-advocates can take photos on their own or in groups.
- Researchers talk about the photos with the one person who took the photo. They also talk about the photos in groups. Talking about the photos with self-advocates can help researchers understand what the photos mean.
- In one project, self-advocates took photos to show how public transportation was not accessible.

When self-advocates communicate without speech, researchers use other ways to learn about the photos. These ways are:

- meeting the self-advocate many times to get to know them
- researchers making notes while the self-advocate takes the photos

- asking friends, family, or caregivers about why the self-advocate might have taken the photo while looking at the photo with the self-advocate

Self-advocates who communicate without speech may depend on family or caregivers to help talk about their photos. Sometimes family or caregivers might include their own views rather than the self-advocate's views. It is important to be aware of this problem.

Two-Person Interview Technique. This is a way to interview self-advocates that uses a support person to help self-advocate voices to be better understood. Head et al. (2021) share one successful way to do these interviews with self-advocates.

The interview is a series of three different interviews that include the self-advocate and an important support person for the self-advocate. This way of interviewing helps keep the self-advocate's voice the most important one.

This is the interview technique:

- First, interview the self-advocate alone.
- Then, interview the support person with the self-advocate present (about one week later).
- Finally, interview the self-advocate alone again.

There are some important parts of doing the interview. They include the following:

- Ask the support person to imagine that they are the self-advocate. When they give their answers, they must act like they are answering for the self-advocate.
- During the interview with the support person, the interviewer should stop and ask the self-advocate if the support person is answering correctly. The self-advocates are told they could interrupt during the support person's interview if the support person was not getting it right.
- After the support person answers questions, the self-advocate is asked if the support person answered as they would have.

This interview technique helps in two ways:

- For self-advocates who communicate with words, the support person can add a new way for researchers to think about what the self-advocates have already said.
- For self-advocates who communicate with fewer or no words, the support person can help add information that the self-advocate might not have words to explain.

The support person must understand that answering for the self-advocate from their perspective can be emotional. They should agree to do this and know they can feel many unexpected emotions. Both the self-advocate and support person should have informed consent.

Equity Thermometer. Panagaki (2022) describes an equity thermometer. It is a tool that will help tell if a project is fair. The goal is to be at the top of the thermometer. The top of the thermometer represents where different people are in the study. The bottom of the thermometer represents where the research is not fair. The bottom of the thermometer has unclear goals.

Here are two versions of Panagaki's equity thermometer. This one can be printed.

https://forequity.uk/app/uploads/2023/04/Blank-Thermometer-V002.pdf

This one can be used online.

https://thermometer.forequity.uk/

Findings and Conclusions

After finishing a research study, it is important to follow up in several areas. Here are some things researchers can do to prepare for the end of the project:

- Have a plan for the end of the research (INVOLVE, 2012).
- Ask questions about what worked well and what did not (St. John et al., 2018).

When the study is complete, here are some things researchers can do. They can:

- share the results widely to ensure that the research impacts various groups of people
- present the findings at conferences and special events
- share the results with different types of people, including:
    - other self-advocates
    - policymakers
    - care providers
    - police
    - family members (Northway et al., 2015)
- help self-advocates find other research opportunities (INVOLVE, 2012)

Reflection

It is very helpful to think about the research process when it is over. Self-advocates can reflect on what they learned with:

- attending online meet-ups
- sharing polls
- completing surveys
- talking to other activists
- writing to policymakers
- signing petitions (University of Cumbria, n.d.)

Barriers

Many barriers make PAR difficult. However, it is important to overcome these barriers. It makes the research project successful when they do. It includes self-advocates and respects their needs and experiences.

Meeting Logistics

There are barriers to having effective meetings. Some meeting barriers are:

- not planning to involve everyone
- not following the plan (Cargo & Mercer, 2008)

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- lack of time (O'Brien et al., 2014)
- managing everyone's schedules
- in-person meetings that may require more support staff (Ouellette-Kuntz et al., 2013)

Another barrier to meeting together is that researchers need money to recruit self-advocates and to create tools like consent forms. Often, ethics committees want to know about the research before they will approve payment for these projects (Northway et al., 2015).

Transportation

Transportation coordination can be a big problem (Fullana et al., 2017; O'Brien et al., 2014; St. John et al., 2018). The schedule can be challenging. It can be hard to find a time that works for both self-advocates and those who provide their transportation (St. John et al., 2018).

Recruitment

Recruitment for PAR can be a challenge. Some problems recruiting self-advocates include logistical issues like:

- Recruiting friends to join a research study can make a group biased and less diverse (O'Brien et al., 2014).
- In-person meetings can make it hard for some people to take part, which means fewer people can participate (Ouellette-Kuntz et al., 2013).
- It can be very expensive to recruit in multiple places.
- Some workplaces have too much noise or stimulation (Phillips et al., 2022).
- Finding the right people for the research can take a long time (St. John et al., 2018).

Other recruiting difficulties are more about the people involved. These are some barriers:

- It can be hard to include self-advocates and their families if they must speak English, meet special requirements, or if the researchers don't understand their culture.
- Sometimes self-advocates may not trust the researchers.
- Self-advocates may not have enough time.
- Self-advocates may not understand the project.
- Researchers may have trouble understanding self-advocates' needs (Phillips et al., 2022).
- Information sessions explain the study to interested people, but only some people will want to continue (St. John et al., 2018).
- Sometimes self-advocates are taught that they must do what other people tell them. This can make it hard to recruit them for research (Strnadova et al., 2014).
- Some self-advocates may choose not to participate because they are afraid of being bullied for being different.
- Some self-advocates may feel like they are less important than the researchers (Thurm et al., 2021).

Communication

There are many communication barriers in PAR. Some barriers include:

- Researchers oversimplify the information. It feels like the resources are written for children (Fullana et al., 2017).
- Explaining procedures can be challenging for researchers.
- Family, friends, or caregivers can sometimes speak for the person they are helping, which stops self-advocates from sharing their own opinions (O'Brien et al., 2014).
- There can be a distrust for police and care providers. This can make self-advocates afraid to be honest. They worry about getting in trouble (Ouellette-Kuntz et al., 2013).
- Not everyone's communication needs are the same.
- Not all self-advocates have access to email or a phone (St. John et al., 2018).
- Sometimes self-advocates are taught that they must do what other people tell them. This can make it hard for them to trust their own opinions and share their own ideas (Strnadova et al., 2014).

Family and Caregivers

Families' support can affect the participation of self-advocates involved in a project. It is important to understand and address these family concerns. Some concerns families have include:

- confidentiality (St. John et al., 2018)
- self-advocates having the right skills or having problems participating
- managing schedules and time commitments (St. John et al., 2018; Thurm et al., 2021)
- knowing how the study might complicate their everyday life (Thurm et al., 2021)

Additionally, families may not be interested in participating. This can make it hard for self-advocates to attend all the meetings (O'Brien et al., 2014).

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