



# **Participatory Action Research for People with IDD: A Research Summary**

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## Plain-Language Summary

This paper talks about Participatory Action Research (PAR). In PAR, people with intellectual and developmental disabilities (IDD) are not just studied. They are valued partners. The paper shows how researchers and self-advocates can work together using PAR.

PAR is good for self-advocates.

- They learn new skills.
- They feel valued.
- They build self-confidence.
- They can work on new projects in the future.

PAR is also good for researchers.

- They build stronger research skills.
- They learn more about the people they are researching.
- They get better results.
- They make a bigger impact.

Here are some ways to make PAR work well.

- Make the work accessible for all. Provide training and support.
- Give self-advocates choice and control.
- Build trust and respect.
- Communicate in ways that work well for all.
- Find the right people for the job. Build them into strong teams.
- Find new ways to gather data.

Here are some things that make it hard to do PAR well.

- Finding the right people to work on the project
- Making sure people can get to and from meetings
- Making sure people have the technology they need
- Handling different ways of communicating
- Getting family or caregiver support

## Executive Summary

Participatory action research (PAR) includes the people researchers are studying in their projects. This helps researchers and the people they want to learn about. For people with intellectual and developmental disabilities (IDD), this means they are involved as active partners. They have a voice in the process. 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 well together 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 others be successful. The team will create training and tools based on this work.

## Notes About This Paper

Often when researchers look at disability, they include people with all types of disabilities. But people with different types of disabilities all have different needs. When researchers combine them, they often miss important needs. For this reason, our work does not include research 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." For this paper's purpose, self-advocates are people with IDD.

## Recommendations

This paper looks at ways to help make PAR as successful as possible. The sections are divided into four main categories:

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

Here is a summary of these four sections.

### Benefits

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

**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 choice and control, they feel important and included. Trust and respect create a comfortable and safe environment. Everyone can share ideas and work together. When self-advocates are part of the research, they feel connected to it. Good communication and collaboration lead to better results.

**Effective Practice: Phases of Research Projects**

Both self-advocates and researchers need training to work well together in PAR. Most research talks about training self-advocates to do PAR. Research on training researchers to do PAR is harder to find. 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 must be fully included in the research. Their needs must be met. They should also be paid for their work. Creating a strong team makes the research successful. Researchers can build strong teams by:

- Sharing work,
- Seeing each other's skills and abilities, and
- celebrating progress.

There are some ways to help self-advocates collect data for a project. Self-advocates can take pictures to share real-life experiences. They can also use a two-person interview. Both of these ways help researchers understand self-advocates better.

Research must be 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 make PAR difficult. Being aware of these barriers ensures the research is successful. Holding meetings 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 do not know how to best communicate with self-advocates. Sometimes families and caregivers have concerns that make it hard for self-advocates to participate.

**Conclusion**

Participatory action research makes research inclusive and meaningful. It gives self-advocates a voice. It makes sure their needs and experiences are considered in work done about their lives.

This helps challenge stereotypes and biases. The recommendations in this paper will teach researchers and self-advocates:

- methods for working together successfully
- best practice
- benefits of including self-advocates
- importance of choice and respect
- importance of training and team building
- data collection methods
- how to include self-advocates meaningfully across the research process

PAR has many challenges for both self-advocates and researchers. But, knowing about them ahead of time can lead to more successful work.

## Research Summary

### Benefits

PAR benefits self-advocates and researchers. 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)
- causes self-advocates to value and use products created based on their lived experience
- prioritizes the most important needs, improving safety and wellbeing (Cargo & Mercer, 2008)

#### For Self-Advocates

PAR creates positive changes in self-advocates' attitudes and beliefs. It helps 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 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 and find gaps researchers might not see (Nind, 2014; O'Brien et al., 2014; St. John et al., 2018)
- avoid mistakes made guessing about people with IDD (Cargo & Mercer, 2008)
- recognize the boundaries and gifts of people with IDD (St. John et al., 2018)
- create better study questions (Cargo & Mercer, 2008; Strnadova et al., 2014)
- produce stronger findings and better outcomes (Cargo & Mercer, 2008; Nind, 2014)
- reach a wider audience
- teach other researchers to use PAR (Cargo & Mercer, 2008)
- recruit volunteers more easily
- create 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 into smaller pieces of information (Strnadova et al., 2014)
- understand more about their research (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 consider different needs and abilities. Choice and control helps self-advocates feel valued and involved. Trust and respect help them feel comfortable. That makes it easier to share 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. Some ways 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 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 (O'Brien et al., 2014; Phillips et al., 2022).
- Self-advocates should be part of getting funding, 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, researchers should:

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

Here are some specific ways self-advocates can 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).
- Self-advocates can run focus groups. Two self-advocates can run the groups. Or a self-advocate and a co-researcher can work together. Or a co-researcher can coach a self-advocate (O'Brien et al., 2014).

### **Choice and Control**

All self-advocates should have a choice in and control over 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 is 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 help plan how they will do the research
- ask them to help decide how research findings will be used (Cargo & Mercer, 2008)

### **Trust and Respect**

Trust and respect create a safe and welcoming place to work together. Everyone feels empowered and that 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 get 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 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
  - meaningfully uses 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 give longer and better answers to questions from other self-advocates (St. John et al., 2018).
  - Self-advocates are more honest with other self-advocates. This can create more accurate results (O'Brien et al., 2014).
  - Some topics might make self-advocates uncomfortable. Researchers should plan ahead to give 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 give 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. They learn about trust, respect, and boundaries. They are able to stay safe during the research.

**Topics.** 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 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. There is little information on what topics should be included. It may include how to create non-leading questions. It may also 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 protects people in the study. Researchers carefully think about ways to avoid hurting people.

Researchers should:

- learn about 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)

In an ethical study, self-advocates understand 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 keep them working 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, including:

- Who will benefit from the research?
- How does their participation make the research better?
- What subjects should be part of the research?
- Who should help make sure everyone's values are respected?
- Who should help make sure that the research findings are used well?
- Who should keep the balance of scientific, social, and cultural importance?
- Who should gather information from stakeholders?
- Who should make sure the research goes smoothly?
- Who else could help the partnership reach its goals (Cargo & Mercer, 2008)?

It can be hard to find self-advocates to participate. Advocacy groups and groups that support self-advocates can often help (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 (The All of Us Research Program Investigators, 2019).

It is helpful to include self-advocates early in the research process. Everyone can feel they are working together and have a common goal (INVOLVE, 2012). It is also important to think about self-advocates' 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:

- Tell what the study involves.
- Provide contact information for all participants.
- Sign a consent form.

- Keep copies of the form.
- Tell what happens if 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\\_0qVkNRkjhK6hJb](https://jhmi.co1.qualtrics.com/jfe/form/SV_0qVkNRkjhK6hJb)

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 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](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 over time.
- 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

Having a strong team that works well together on shared goals is important. There are ways to ensure strong teamwork across the project.

**Teambuilding.** 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 (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).
- Make sure self-advocates and researchers can spend time together. They can go to classes, community events, and book clubs.

- Make sure self-advocates learn together. They can share research, use online learning, and recommend books (University of Cumbria, n.d.).
- Plan ahead 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 short to stay focused and engaged.
- Create a safe space where everyone feels comfortable talking.
- Encourage respectful debates (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 to ask questions.
- Give extra time for solving problems.
- Use the same format to start and end the meetings.
- Stick to the schedule and manage time well (O'Brien et al., 2014).

## Data Collection

Data collection is an important part of a study. Researchers should use many different methods to meet the needs of self-advocates. This will produce more and better data. There are some methods that work particularly well for self-advocates.

**Photovoice.** Photovoice helps people participate in community research. It helps include people who often get left out of research. Self-advocates take pictures to show their experience. Then they talk with researchers about the pictures. Chinn and Balota (2023) describe how photovoice can be used successfully.

**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. They can choose how meaning and new knowledge is created. They can make changes in their communities.

Photovoice is helpful because helps people who communicate without words share their stories. Self-advocates can share their ideas, feelings, and issues easily. It helps people remember ideas and makes group discussions easier. It empowers people who have been left out of research because of their level of disability.

Seeing self-advocates' photos raises awareness of social barriers. It 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. It is important to make sure family and friends keep their views separate from the self-advocate's views.
- Researchers might get wrong ideas based on self-advocates' pictures. They can write in journals to help them avoid bias against self-advocates.
- Researchers should use plain language to give instructions for taking pictures and using cameras. They can also use slide shows to help self-advocates learn.
- Researchers should teach self-advocates about asking permission to take pictures of other people.
- Researchers should let self-advocates decide what pictures are important to take. They can also give self-advocates specific topics, but include many different choices within that topic.

There are different ways self-advocates can use photovoice:

- Some self-advocates use their own smart phones to take pictures. Some researchers give simple digital cameras to self-advocates.
- Some researchers teach self-advocates in groups. Some researchers teach one-on-one.
- Self-advocates can take photos on their own or in groups.
- Researchers might talk only to the person who took the photo. They might talk about the photos in groups. Talking about the photos with self-advocates can help researchers understand what the photos mean.

Some self-advocates communicate without speech. Researchers use other ways to learn about the photos, such as:

- meeting the self-advocate many times to get to know them
- making notes while the self-advocate takes the photos
- asking friends, family, or caregivers 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 need family or caregivers to help talk about their photos. These people 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 technique 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.

A series of three different interviews includes the self-advocate and their chosen support person. This makes sure the self-advocate's voice is the most important one.

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

During the interview with the support person:

- 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.
- Tell self-advocates they can interrupt during interview if the support person is not getting their thoughts right.
- From time to time, stop and ask the self-advocate if the support person is answering correctly.
- At the end of the interview, ask the self-advocate if the support person answered as they would have.

This interview technique helps in two ways:

- Some self-advocates communicate with words. The support person can add a new a new perspective on what the self-advocates have already said.
- Some self-advocates communicate with fewer or no words. The support person can add information for which the self-advocate might not have words.

Answering for the self-advocate from their perspective can be emotional. The support person should understand this. They should agree 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 shows that the people the research is about work on the project. The bottom of the thermometer shows that the research is inaccessible to people. It has unclear or confusing goals. The thermometer was used for a healthcare project. But it could be adapted and used for any project.

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**

Researchers should prepare for the end of the project. They should:

- 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, researchers should:

- share the results widely to make the biggest impact
- 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 projects to work on (INVOLVE, 2012)

### **Reflection**

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

- 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. It is important to overcome these barriers. Planning ahead to address them improves the research. It ensures self-advocates are meaningfully included.

### **Meeting Logistics**

There are barriers to having effective meetings, such as:

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

Meeting together early in the project can sometimes be challenging. Researchers may need money to recruit self-advocates. They also need funds to create tools like consent forms. Often, ethics committees want to know about the research before they approve payment. This can delay recruitment of self-advocates (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 meeting schedule may not work with transportation options. 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 are logistical:

- Recruiting friends to join a project can make a group biased and less diverse (O'Brien et al., 2014).
- In-person meetings can be hard for some people to attend. That means fewer people can participate (Ouellette-Kuntz et al., 2013).
- It can be 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 relate to the people involved. These are some barriers:

- Recruitment criteria leave some people out. These might include speaking English or meeting other special requirements.
- Researchers might not understand the culture of people they are trying to recruit. They may miss these people because of that.
- Sometimes self-advocates do 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 might get people interested. But not all 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 be afraid they will be bullied for being different if they join a project
- 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 sometimes speak for the person they are helping. That stops self-advocates from sharing their own opinions (O'Brien et al., 2014).
- Self-advocates may distrust police and care providers. They may be afraid to be honest. They may 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).
- Self-advocates might have learned to do what others tell them. They may not trust their own opinions. They may be afraid to share their own ideas (Strnadova et al., 2014).

### **Family and Caregivers**

Families' support can affect the participation of self-advocates. Addressing family concerns can make it easier to recruit self-advocates. 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)

Families also 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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