Participatory Action Research for People with IDD:
Family & Caregiver Support Guide

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Welcome!

Dear family members, guardians, and caregivers:

I want to share an encouraging message with you. We have come a long way in how we work on research projects. In the past, people like me—self-advocates—were asked to share our ideas, but we were not paid for our hard work. Today, many groups understand how important our voices are, and they pay us for our time and ideas.

I would like to tell you about my own experience. I know everyone’s story is different, and that is okay. I just hope this Guide can help you and your loved one in the way that works best for you.

More grantors now ask researchers to hire and pay self-advocates when they do projects about people with disabilities. This matters a lot to me. When I get paid, it shows that people see my gifts and talents, and value what I bring. The money I earn, along with my federal benefits, helps me pay my bills, be independent, and take care of myself.

Six years ago, I was given a chance to work on a research project. I knew a lot about the topic, and it felt really good to be part of the team. I started as an independent contractor, and later they hired me as a part-time employee. They saw my talent and hard work. That made me feel proud and accomplished.

I know you might worry about the rules and reporting for federal and state benefits. But with patience, support, and the help of this guide, you can help your loved one work successfully on research projects. My circle of support has helped me do well in both jobs—as an employee and as an independent contractor. The resources in this Guide can help you keep up with any changes to your loved one’s benefits while they work.

I am proud to be a contributing member of my community. I am happy to see more people with disabilities getting chances to do this kind of work. Our voices are important, and we make research stronger.

I hope this Guide encourages you to support your loved one in their work.

Sincerely,

James R Meadours

James R. Meadours
Advocacy & Outreach Lead
Strategic Education Solutions

How to Use the Family Support Guide & Toolkits

You Are Not Alone

This guide is for families, caregivers, and others who support a self-advocate working on a project. When a loved one is hired to work on a project, you might have worries about safety, pay, and other issues. You should not have to figure it out on your own. The Research Lead should support your loved one every step of the way. This guide will help you know what to expect, what to ask, and how to support your loved one—without taking over or being asked to do more than you should.

Using this Guide

This guide is made up of short sections about 9 common challenges families and caregivers face. Each one-pager:

- tells what you really need to know and why
- helps you know who to talk to and what to ask
- tells you where to find more information if you want it

You do not need to read the guide from start to finish. You can read just the sections that matter right now. You can skip sections and come back later if new questions come up.

Using the Toolkits

After you read a section, you might have more questions or want more information. That's why we created toolkits for each section. Each toolkit includes:

- A Closer Look: more details about the section, with helpful examples
- practical tools, such as Q&As, checklists, forms, and other tools

You only need to use a toolkit if and when it's helpful. The toolkits are there to support you—not to give you extra work.

A Final Note

We respect your time. We know families and caregivers already do a lot. We do not want to create more work for you. This guide and the toolkits are meant to:

- help you feel more confident and less alone
- make it easier to work with the Research Lead
- support your loved one's independence and success

Use what helps. Skip what doesn't. Ask for support when you need it. You don't have to do this alone—and you don't have to do everything.

1. Talking with Researchers

Why Is This Important?

Good communication makes projects successful. It helps self-advocates work on their own. It helps families know that their loved ones are safe and supported. Roles, responsibilities, and payment details should be clear. Everyone's choices should be respected. Everyone should get and give respect and trust.

What Do I Need to Know?

- Self-advocates and families should know what the project is about before they agree to do it. This can include the goal of the project and what the self-advocate will do. It can include meeting schedules and support. It can include details about pay and benefits.
- Families and caregivers should not have to provide a lot of support. Researchers should plan ahead to do this. This could include tools, training, scheduling, and transportation. Support should be based on what the self-advocate needs.
- Self-advocates may be paid as employees, 1099 contractors, or with gift cards. Families should know how and when loved ones will be paid. They should know how pay might affect tax benefits. This could include SSI, SSDI, Medicaid, and more.
- Once a self-advocate agrees to the work, everyone should treat it as a real job. They should be on time for all meetings. They should respond to emails and other messages. Everyone should respect the self-advocate's role.
- Many research projects now include self-advocates. More self-advocates can work, build skills, and earn money. Programs and services for the IDD community get better.

Who Should I Talk To?

Talk to your loved one first if you have questions. You can also talk to research staff. But the self-advocate should be involved in all conversations about their work.

For More Information

If you still have questions or concerns, you may find one or more of these helpful:

- Talking with Researchers Toolkit (A Closer Look, plus forms and checklists)
- Free Online Participatory Action Research Courses (Self-Advocate Network Academy)
- PAR Resource Hub (videos, learning games, blog posts, and more)

2. Keeping Benefits Safe

Why Is This Important?

Many self-advocates get local, state, and/or federal benefits such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, or housing subsidy. These benefits are affected by earned income. Families, caregivers, researchers, and self-advocates must work together to help the self-advocate earn money while keeping their benefits safe.

What Do I Need to Know?

- Pay can affect benefits. Families should discuss payment with the Research Lead before work begins. Ask how much the self-advocate will earn, when payments will be made, and whether the self-advocate will be an employee or 1099 contractor.
- Wages must be reported monthly. SSI wages must be reported by the 6th of the month. SSDI wages should be reported as soon as possible. The Social Security Administration (SSA) recommends reporting by the 10th. You can report by phone, online, app, or in person. The Research Lead should provide clear pay details to make reporting easier.
- Income and asset caps affect benefits. SSI has strict monthly income limits and a $2,000 asset cap. SSDI uses Substantial Gainful Activity (SGA) to decide whether someone is working too much. Other programs, like Medicaid and housing subsidies, have their own rules. These should be considered when planning pay.
- Payment timing matters. Large, one-time payments may cause a loss or reduction in benefits. Smaller scheduled payments often work better. Families can ask the Research Lead to adjust timing when possible.
- Programs like Ticket to Work, Trial Work Periods, and wage subsidies let people with disabilities work while keeping some benefits. Work Incentives Program Assistance (WIPA) providers help with this. They are independent from the SSA. They are free for self-advocates. A Community Work Incentives Coordinator (CWIC) can explain options and create a plan. Find them here: https://www.ssa.gov/work/WIPA.html.
- Families can ask the Research Lead for a simple summary each time the self-advocate is paid. This helps with monthly SSA reporting.
- Rules for benefits reporting, earning limits, and asset caps change. The SSA and a CWIC should have the most up-to-date information.

Who Should I Talk To?

Talk to your loved one first. They should be included in all discussions about pay and benefits. Support them in asking questions and making choices. Ask the research lead about pay schedules, reporting needs, and any changes that might help protect benefits. You may also want to include a CWIC. They are the best source for up-to-date information about how income affects benefits. Finally, get to know the staff at your local SSA office. You can report income, ask questions, or request a Benefits Planning Query (BPQY).

For More Information

If you still have questions or concerns, you may find one or more of these helpful:

- Keeping Benefits Safe Toolkit (A Closer Look, plus forms and checklists)
- Free Online Participatory Action Research Courses (Self-Advocate Network Academy)
- PAR Resource Hub (videos, learning games, blog posts, and more)

3. Setting Expectations

Why Is This Important?

Families and caregivers want their loved one to be safe and supported. Researchers want self-advocates to succeed. To do that, everyone needs to know what to expect. Clear roles, responsibilities, and support help projects go well. Communication should be honest and respectful. Everyone's choices should be honored.

What Do I Need to Know?

- Researchers must explain tasks, learning goals, support, time commitment, and pay before the project starts.
- Support should be based on what the self-advocate needs. It should be provided by researchers, not just by families or caregivers.
- Families and caregivers should understand how and when the self-advocate will be paid, and how it may affect benefits.
- Self-advocates should be given credit if they want it.
- Families and caregivers should ask questions. They should always include the self-advocate in these conversations.
- Researchers should check in regularly. They should have a clear grievance process if problems come up.

Who Should I Talk To?

Talk to your loved one first if you have questions. You can also talk to the research lead. If they cannot or will not help you, ask for another person on their team. The self-advocate must be involved in all conversations about their work.

For More Information

If you still have questions or concerns, you may find one or more of these helpful:

- Setting Expectations Toolkit (A Closer Look, plus forms and checklists)
- Free Online Participatory Action Research Courses (Self-Advocate Network Academy)
- PAR Resource Hub (videos, learning games, blog posts, and more)

4. Understanding Project Duties

Why Is This Important?

Self-advocates need to know what will be expected of them. This will help everyone plan ahead. Researchers must clearly explain what the person will do, and what support they will get. This helps everyone work together well. It ensures the self-advocate can do well in their role.

What Do I Need to Know?

- Researchers must tell self-advocates what to expect. They must share what they will be doing, when, and how. They must share this information in plain language.
- It is okay to ask for more information. It is also okay to ask the researcher to explain in another way.
- Self-advocates should have a real role on the project. They should not be a "token" participant.
- Families and caregivers can help researchers think outside the box. A self-advocate might be able to do more than everyone thinks.
- A project might be about sensitive topics. Informed consent may be required. Self-advocates have the right to say yes or no to some or all of what they are asked to do. They also have the right to change their mind.

Who Should I Talk To?

Talk to your loved one first if you have questions. You can also talk to the research lead. If they cannot or will not help you, ask for another person on their team. The self-advocate must be involved in all conversations about their work.

For More Information

If you still have questions or concerns, you may find one or more of these helpful:

- Understanding Project Duties Toolkit (A Closer Look, plus forms and checklists)
- Free Online Participatory Action Research Courses (Self-Advocate Network Academy)
- PAR Resource Hub (videos, learning games, blog posts, and more)

5. Overcoming Fears

Why Is This Important?

Families and caregivers often worry about their loved one's safety and well-being. They may fear that a research project will take advantage or push the self-advocate too far. These concerns are natural. But with the right support, self-advocates can share their experiences. They can build confidence and be valued as full members of the research team.

What Do I Need to Know?

- Families and self-advocates should talk with researchers about how the self-advocate will participate in a real and meaningful way, not as a token.
- Families should help the self-advocate set and keep healthy boundaries. These boundaries protect their emotional safety and dignity.
- Families should respect the self-advocate's wishes and let them take the lead, even when the task feels challenging.
- Guardians and group home staff should support the self-advocate's right to work on projects. They should help reduce barriers like transportation and benefits security.

Who Should I Talk To?

Talk with your loved one first. They should take the lead in all discussions about choices, respect, and boundaries. Talk with the research lead if a boundary is crossed or support is needed. If your loved one lives in a group home, include staff and guardians so everyone understands the plan and supports participation.

For More Information

If you still have questions or concerns, you may find one or more of these helpful:

- Overcoming Fears Toolkit (A Closer Look, plus forms and checklists)
- Free Online Participatory Action Research Courses (Self-Advocate Network Academy)
- PAR Resource Hub (videos, learning games, blog posts, and more)

6. Getting Paid

Why Is This Important?

Self-advocates should be paid fairly for the work they do. Getting paid helps build independence, develop new skills, and recognize real contributions. Families and caregivers need to understand how payment works. This helps them plan ahead for any effect on benefits.

What Do I Need to Know?

- Self-advocates should have a choice in how they get paid. This can include direct deposit, check, gift card, or even donating their time.
- Self-advocates should have a choice in when they get paid, so their income does not interfere with federal benefits.
- Families should help self-advocates set up a safe way to receive and manage their pay. This can include opening a bank account and learning how to use it.
- Researchers should support informed decisions about pay. They should not have access to a self-advocate's banking or financial information.
- Families can connect with a Community Work Incentives Coordinator (CWIC) to learn how paid work may affect federal benefits. These are independent consultants. They know a lot about working and social security benefits.

Who Should I Talk To?

Talk with your loved one first. They should decide how and when to get paid. Then talk with the research lead about payment methods, timing, and benefits planning. You can also contact banking staff to set up accounts or direct deposit. You can speak with a CWIC for accurate information about how pay affects benefits.

For More Information

If you still have questions or concerns, you may find one or more of these helpful:

- Getting Paid Toolkit (A Closer Look, plus forms and checklists)
- Free Online Participatory Action Research Courses (Self-Advocate Network Academy)
- PAR Resource Hub (videos, learning games, blog posts, and more)

7. Getting Work Support

Why Is This Important?

Work support helps self-advocates succeed on projects. Support people give help related to work, not personal or family needs. Clear boundaries keep everyone safe, respected, and successful. Families, caregivers, and researchers must agree on what help will be given, how communication will happen, and when.

What Do I Need to Know?

- Work support people help with job tasks only and should not be asked to provide personal or family support.
- Everyone should talk often and honestly about how work is going. The self-advocate should lead these conversations.
- Families, researchers, and support people should discuss private or uncomfortable needs before the project starts. This protects the self-advocate's dignity.
- Everyone should agree on when and how they will communicate, such as during work hours and by phone, text, or email.
- Support people should not be contacted about personal issues or outside agreed work hours.

Who Should I Talk To?

Talk to your loved one first if you have questions. You can also talk to the support person and research lead. If your loved one lives in a group home, you may also want staff to join the conversation. The self-advocate must be involved in all conversations about their work.

For More Information

If you still have questions or concerns, you may find one or more of these helpful:

- Getting Work Support Toolkit (A Closer Look, plus forms and checklists)
- Free Online Participatory Action Research Courses (Self-Advocate Network Academy)
- PAR Resource Hub (videos, learning games, blog posts, and more)

8. Using Technology for Work

Why Is This Important?

Many research projects use technology for meetings, communication, and sharing information. Self-advocates need the right tools to take part fully and do their best work. When technology is planned and supported, self-advocates can share their ideas. Researchers should not assume families or caregivers will provide or manage technology.

What Do I Need to Know?

- Technology is part of work support. It should be planned before the project starts. This includes both tools and training.
- Self-advocates may need devices like computers, phones, or tablets, as well as apps or software. The Research Lead should provide technology, help install apps and software, and help make sure technology is working the way it should.
- Some self-advocates use assistive technology or AAC tools to help them communicate. These tools should be respected and supported.
- Not everyone has reliable internet at home. Researchers should help find solutions, such as public spaces with Wi-Fi, hotspots, or flexible meeting options.
- Researchers should not assume you will set up technology or teach your loved one how to use it. Training and practice should be provided as part of the project.
- Researchers should not assume family or caregivers can be available to help a self-advocate log into an online meeting. The research lead, family/caregivers, and the self-advocate should agree on who will give this support when needed.
- If participating in meetings creates extra costs (such as phone data or internet use), this should be discussed ahead of time.

Who Should I Talk To?

Talk to your loved one about what tools help them most. Talk to the Research Lead about technology needs, internet access, and training. Your loved one should always be included in these conversations.

For More Information

If you still have questions or concerns, you may find one or more of these helpful:

- Using Technology for Work Toolkit (A Closer Look, plus forms and checklists)
- Free Online Participatory Action Research Courses (Self-Advocate Network Academy)
- PAR Resource Hub (videos, learning games, blog posts, and more)

9. Keeping Things Confidential

Why Is This Important?

When self-advocates work on projects, they may hear or see private information about other people or the project. They need to know what information must stay private and what can be shared. Families and caregivers also need to understand and respect these rules. Talking about confidentiality early helps everyone feel safe, respected, and trusted.

What Do I Need to Know?

- Self-advocates should get clear training about what information must stay confidential and who they can talk to about it.
- Some information should not be shared outside the project, including pay, personal details about other team members, and project data that is not ready to be shared.
- Families and caregivers should respect confidentiality rules, even if they know other people working on the project.
- Families and caregivers should talk with the Research Lead about what personal information their loved one is comfortable sharing and what should stay private.
- Some projects include emotional or sensitive topics. Researchers should plan ahead to provide support if the work brings up strong feelings.
- Sometimes a self-advocate may share a new or sensitive experience during the project. Families, self-advocates, and the Research Lead should work together to decide what support is needed and how to move forward safely.

Who Should I Talk To?

Talk to your loved one first about what confidentiality means and what they feel comfortable sharing. You can also talk to the Research Lead about confidentiality rules, sensitive topics, and supports that might be needed. The self-advocate should always be part of these conversations.

For More Information

If you still have questions or concerns, you may find one or more of these helpful:

- Keeping things Confidential Toolkit (A Closer Look, plus forms and checklists)
- Free Online Participatory Action Research Courses (Self-Advocate Network Academy)
- PAR Resource Hub (videos, learning games, blog posts, and more)

Words to Know

1099 Contractor
A person who is paid directly. They handle their own taxes. The organization does not take out taxes or pay part of them.

Assistive Technology
Devices or software that help people with disabilities do tasks or communicate. Examples include tablets, special keyboards, or screen readers.

Augmentative and Alternative Communication (AAC)
Tools that help people who have trouble speaking or writing to share their thoughts. Examples include communication boards, picture symbols, or speech-generating devices.

Boundaries
The ways people behave with others based on their relationship. Work boundaries may be different from family or social ones. Clear boundaries help people work well together.

BPQY (Benefits Planning Query)
A report from the SSA showing what benefits a person gets and how work might affect them.

Close Circle
A small group of trusted people your loved one can share private information with. This usually includes close family, caregivers, a guardian, the Research Lead, and sometimes a work support person.

Confidentiality
Not talking about or sharing private information learned on a project.

CWIC (Community Work Incentives Coordinator)
A trained expert who helps people know how working affects their benefits. CWICs do not work for the SSA. They work for community agencies that receive SSA funding through the WIPA program. They work under a program called Work Incentives Planning and Assistance (WIPA).

Donation
A self-advocate may choose to work without pay. They choose to donate their time.

Direct Deposit
Pay is deposited directly into the self-advocate’s bank account.

Employee
A person whose employer takes out taxes. The employer pays part of the taxes. The employee gets a paycheck with taxes already deducted.

Gift Card
A gift card to a store or for cash (e.g., Visa, Mastercard) is used as pay. This type of payment is generally considered income, so it can still affect benefits.

Grievance
A problem the self-advocate might have with the researcher. This could be an issue with payment, boundaries, or something else. There should be a process that says who the self-advocate can talk to about problems with the work.

IDD (Intellectual and Developmental Disabilities)
Disabilities that affect thinking, learning, and daily life skills.

Informed Consent
Understanding what you are asked to do. Then agreeing to do it.

Lived Expertise
The real-life experiences of people with IDD. They are valuable to researchers.

Participatory Action Research (PAR)
A type of research where people with lived experience help study and solve problems that affect them.

Paycheck in the Mail
A physical check is sent to the self-advocate by mail.

Plain Language
A way of writing that uses short sentences and clear words. It might use pictures. It helps everyone understand.

Research Lead
The person in charge of the project.

Research Project
A study or project about a specific topic.

Self-Advocate
A person with an intellectual or developmental disability who speaks up for themself.

Self-Advocate (or Loved One)
The person with IDD hired to work on a project. These terms are used interchangeably.

SSI (Supplemental Security Income) and SSDI (Social Security Disability Insurance)
Federal programs that give money each month to people with disabilities who qualify. To keep these benefits, people must stay under income and asset caps.

Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI)
Federal benefits programs for people with IDD. Each program has earnings limits.

TTW (Ticket to Work)
A program that helps people with disabilities find jobs and connect with CWICs.

Token
Someone included in a project just for show. A token self-advocate does not get to share their ideas in a real way.

WIPA (Work Incentives Planning and Assistance)
The SSA program that funds CWICs. It gives free benefits counseling to people who work or want to work.

Work Support Person
Someone who helps a person with a disability do their job on a project. They may provide job coaching, technical help, or other work-related support.