

Appendix D: Best Practices for Participation Guides

What is a Participation Guide?

A Participation Guide is a tool. It is meant to help people. It can help them take part in a process. It can help them learn about a new thing. It can help them guide another person.

A Participation Guide should help families and workers to involve the person they are supporting. The guide has ideas about how to work together. It has tips on how to connect the topic to everyday life. It explains information in a way that is easy to understand.

Participation Guides are often available with other documents. They can come with application forms. Some Easy Read documents also have a guide.

Why are Participation Guides important?

Information comes in many different formats. It can be very accessible. But some people may still require support. They may not be able to find, understand, and use the information on their own.

Participation Guides are helpful to many groups. They help people with disabilities. They help people who work with newcomers to Canada. They help people to understand government information.

Our research confirmed that some people with intellectual disabilities get help with government information. They get help from family members. They get help from paid workers.

Family members help the person understand the information. They also help by making the person feel less worried about the information.

Paid workers help by offering resources. They also help by reading existing information.

More than half the time the help is given to simplify the language.

People are already getting help with understanding information in everyday life. A Participation Guide can help this process even more. Guides can give supporters ideas about how to explain complex information. Guides can give ways to encourage the person to be involved in the process.

Supporters want and need tools to help with this process.



What should be included in a Participation Guide?

Participation Guides must promote supported decision making. People with disabilities should be treated as capable adults. This means including them in the process. It means doing things with their consent.

Language in the guide should be about 'doing with' rather than 'doing for.' There should be plans and actions for how to involve the person being supported. All the information in a Participation Guide is based on these ideas.

Here are some key parts to include in a Participation Guide.

1. Tell supporters to prepare and explain the situation before they start talking.

Ask them to explain why the topic is important. Ask them to explain why it matters to the person. People like to understand **why** they're asked to do something. They want to know why it is important to them on a **personal level**.

Example: Disability Tax Credit

Scenario: A family member is helping someone apply for the credit.

The Participation Guide will encourage talking about the Disability Tax Credit. Discuss what the credit will mean for this person. Talk about the practical ways it will help. Explain what paying less income tax means. Explain how the person will have more money. They can use that money for groceries or rent or other things.

2. Make sure everyone understands the basics. Give supporters the information they need to explain ideas clearly. This could include a list of important words, a checklist, or answers to common questions. People advocating for themselves and those helping them can use these tools together to make sure they're on the same page.

The Participation Guide might have a glossary. This would explain terms like 'income tax' in plain language. It might have a Frequently Asked Questions section. This would have answers to the usual questions on the credit. This includes questions about whether someone has to apply for the credit each year.

3. Give advice on how to break the work into smaller parts. Present those parts over several sessions. This can be useful for things that are complicated or not very interesting. Start to talk about who should be part of the process.

The Participation Guide might suggest a pace to follow. It could start with talking about the idea of the Disability Tax Credit. This would include why it matters to the person. The guide might suggest showing the person the application form on another day. The next step might be talking about the medical visit.

The guide might suggest involving different people. Ask the person who they want involved in the process. Consider inviting the person's siblings. Or invite people from the person's support network. The process can be more than filling out the form. It can be a chance for social connection.

4. Give different ways to include the person in the process in a meaningful way. Supported decision making believes that everyone is able to make their own decisions. Participation Guides think everyone can and should be included. It doesn't matter if their disability is complex. It doesn't matter if their communication is not clear. They know that families or supporters who know the person well can often understand what they like and how they communicate.

The Participation Guide will suggest many ways to involve the person in the process. The person may be involved in all parts of the process. They may understand all the details. But other people may not. They may understand some of the process. For example, a family member may explain what they are doing for the person. They might explain that they are doing this to help the person save money and have a better life.

The guide highlights 2 important ideas. One is that it is important to inform the person of what is happening. The other is that it is important to get the person's consent or agreement.

5. Plan with universal design in mind. Government information should be easy for everyone to use. Lots of people could find a Participation Guide helpful. It's not just for people with disabilities and their supporters. Participation Guides help everyone get information easily. They should be set up so people can find them easily with forms or documents.

The Participation Guide may be valuable to other groups. It may be useful to people with dementia and their supporters. It may help to engage the person and explain complicated ideas.

6. Use plain language for everything. If your Participation Guide mentions other material to look at, make sure those are easy to understand too. Sending people to things with hard words or legal language might create more barriers. If the Participation Guide has to include those items, it can remind supporters to read them first so they can explain them better.

IMPORTANT NOTES

Participation Guides should be tested in many ways. They need to be tested for accessibility. They need to be tested with screen readers. They need to be tested with other assistive technology.

Other parts of the document also need to be tested, like the colour contrast and the font.

Plain language principles apply to Participation Guides too. Use short, everyday words. Explain any technical words or ideas.



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