

**Review of the Adult Capacity
and Decision-making Act**

**Public Engagement:
What We Heard**

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Submitted by:



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The ACDMA Public Consultation: Main Points

About the ACDMA

The ACDMA stands for the **A**dult **C**apacity and **D**ecision-**M**aking **A**ct.

The ACDMA is a law that started in Nova Scotia in 2017. It replaced an old law called *The Incompetent Persons Act*.

The ACDMA means the court can choose a person to make decisions for an adult who cannot make some or all of their own important decisions. The person the court chooses to make decisions is called a representative.

We use the word 'rep' in this report. The rep helps the adult who needs help to make some or all decisions. The rep can only make decisions that the adult cannot make for themselves. In this report, when we say 'the adult', we mean the adult who needs help to make some or all decisions.

The ACDMA Review

The ACDMA is a new law. The Nova Scotia government wants to make sure it is a good law and that it works. They want to know if the ACDMA helps adults and their families. They also want to know how we can use supported decision-making with the Act.

In 2021, the government started to work with a company called Horizons. Horizons helped the government talk to people about the ACDMA.

Supported Decision-Making

Supported decision-making is when adults get help to make decisions from someone they trust. For example, a person they trust helps them to make decisions about money or health. This person might be an ACDMA rep or someone else.

The ACDMA Consultation

We had a consultation in June 2021. It was later than we wanted it to be because of COVID-19.

We had a lot of meetings. We asked people questions. People told us what they thought. We wrote down what we heard and put it in a report. This is the report.

We invited people to the meetings in 3 ways:

- Some people heard about the meetings on the internet.
- Many people got a letter in the mail. The letter asked them to do a survey on the computer or on the phone.
- Some people talked in groups to answer questions about the ACDMA. These group meetings were on Zoom because of COVID-19.

We heard from many people all over Nova Scotia. We talked to:

- Adults who may need help making decisions
- Organizations and people who work with adults who may need help making decisions (like doctors, nurses, lawyers, support workers and advocates)
- Family members and caregivers

We asked them:

- What they knew about the ACDMA
- If they had any problems with the ACDMA

- If they had ideas about how to make the ACDMA better
- If they had ideas about supported decision-making

What We Heard

Most people thought that what the ACDMA is supposed to do is good. They liked that:

- Adults have more rights under the ACDMA than under the old Act.
- Adults can make their own decisions about different parts of their lives.
- Adults can have help from someone they trust to make decisions.

Problems with the ACDMA

People told us about two main problems with the ACDMA. They were:

1. There is not enough information about the ACDMA

Many people said that:

- They did not have enough information about the ACDMA.
- They did not know about ACDMA before these meetings.
- There are other laws that are a lot like ACDMA.
 - It is hard to know when to use these other laws.
 - Even some lawyers and doctors do not know when to use all the different laws.

2. It is hard to apply to be a rep under the ACDMA

People who applied to be an ACDMA rep said that:

- It is very hard for people who have trouble using computers or do not have a computer.
- It is hard for people who can't read a lot.
- It takes a lot of time to apply.
- It costs too much money to make an application. They had to pay lawyers and many other fees.

People we talked to had ideas about ways to make the ACDMA better.

Some of those ideas were:

- Give more information to people all over Nova Scotia about the ACDMA.
- Make it easier to apply to be a rep.
- Give help to the people applying to be a rep.
- Make it cost less.
- Make sure everyone can access the ACDMA.

We asked people if they thought supported decision-making was a good idea.

They said that:

- It is a good idea for adults to have help making decisions when they need it.
- People need to learn more about how supported decision-making works.
- Adults who are not part of the ACDMA should also have help when they make decisions if they need it.

We asked people if there should be more in the ACDMA about supported decision-making. This way supported decision-making would become a part of the law.

We asked people what the ACDMA should say about supported decision-making. And how it would help adults who need support with making decisions.

They said that the government should:

- Learn more about supported decision-making and how it works
- Learn more about the laws in other provinces in Canada.
- Always remember human rights first. The person with a disability should be the person to direct their own life!

About the Consultation – Full Report

Introduction

Participation

People participated in this consultation in two main ways:

- By doing a survey online or on the phone
 - The survey was in English or French
- By participating in a focus group on zoom

Surveys

190 people did a survey.

These people were:

- Adults who may need help making decisions
- People who were interested in the ACDMA
- People who work with adults who may need help making decisions
- People who are ACDMA reps

Focus Groups

There were 18 focus groups.

130 people participated.

They were:

- People who work with adults who may need help making decisions.
 - These people were from many different organizations
- Adults who may need help making decisions
- Family members
- ACDMA reps

Reports from Other People

Three people gave us reports that they wrote. They wanted to share their ideas about the ACDMA.

What We Heard

What is Good about the ACDMA

The purpose of the ACDMA

The purpose of the ACDMA is to let adults make decisions about the things in their lives where they can. They can get help to make decisions about the things in their lives where they need help.

People told us that the ACDMA is good because it meets that purpose.

It lets adults:

- have more control over their own lives.
- make some decisions on their own if they can.
- have help making decisions that are hard for them.
- make mistakes and learn from them.

They also said that it is good that families can choose more than one person to be the ACDMA rep.

Human Rights

People liked that the ACDMA says that the rights of adults are important. They said it is better than the old act. Adults have more control over their own lives under the ACDMA. They are allowed to make their own choices whenever they can.

The Capacity Assessment

A capacity assessment is a test to find out what decisions people can make with or without support. These decisions might be how they spend money, where they work, where they live, or who they live with.

People said they liked that the ACDMA assessment is split up into different parts. For example, the person who gives the test may decide that the adult cannot make their own decisions about money, but they can make their own decisions about where they want to live.

This gives adults control over their lives.

Problems with the ACDMA

People said that the ACDMA seems good when they read it. The big problem is that many people are not able to access it or use it.

In this part of the report, we will talk about the problems people had with the ACDMA.

Not knowing about the ACDMA

Many people we talked to said they did not know about the ACDMA.

Some people knew a little bit about the ACDMA.

Almost everyone said they needed to learn more.

Ways people said they learned about the ACDMA were:

- Talking to family or friends
- From their care coordinator or social worker
- On the internet
- In the news
- From their doctor
- From their lawyer
- Because they need to know about it for their work

Applying to be an ACDMA rep

Many families who applied to be ACDMA reps said it was hard.

All of the people we talked to said it is hard to apply for the ACDMA.

People said the problems with the ACDMA application were:

- Understanding and filling in all the forms
 - They are hard for people to use.
 - There are a lot of forms to fill in. They are hard to read. They are not in plain language.
 - They are hard for people who do not use computers.
 - They are hard for people who do not speak English.
- It takes a long time to apply for the ACDMA
 - Sometimes it takes more than a year to do all the steps
 - Many family members said they did not apply to be ACDMA reps because the application was too hard.

Getting an assessment is hard

- It is hard to get an ACDMA assessment
 - It is hard to find someone who will do an ACDMA assessment
 - Sometimes the people who do the assessments do not have enough training

The time and order of the steps

Many people said that the ACDMA application takes too long. It does not work when there is an emergency.

- After you apply for the ACDMA, you have to wait at least 25 days before you go to court. It is very hard to make it go faster than that.
- Sometimes people need help quickly to make important health decisions. The ACDMA is not fast enough for this.
- The documents you need for the application are not all due at the same time. Sometimes one document expires before the other ones are due. It costs a lot of money to get new documents. It wastes a lot of time too.

Going to court

One of the last steps of the ACDMA application is going to court.

Adults and people who apply to be an ACDMA rep must go to court to meet with a judge. The judge decides if the adult needs the ACDMA rep or not.

- Many adults and their families said they did not want to go to court.
- They said that court can be a scary place for some people.
- Some people said that they should go to Family Court and not Supreme Court.

It costs too much money

The assessment costs a lot

- The lawyers cost a lot.
- Not everyone can get help for free from a lawyer.
- Many people cannot pay to do the application.

- If you want to be an ACDMA rep, you need to show that you have money.
 - This is called bonding.
 - Some people may not be able to be an ACDMA rep because they do not have enough money.
 - This is not fair to adults. They want people they trust to help them make decisions. If the person they trust does not have enough money, they cannot be an ACDMA rep.

There is not enough training for people who work with adults who may need help making decisions

- Many people who work with adults who need help making decisions do not know a lot about the ACDMA.
 - They need to learn more about the ACDMA so they can help people better.
 - They need to learn more so they can give better assessments.
 - They need to know how to help ACDMA reps do their jobs.

Caregivers do not use the ACDMA

People told us that they do not want to apply for the ACDMA because it is too hard to use and too expensive.

Instead, caregivers just make decisions for adults without using the ACDMA.

This means that many adults do not get the chance to make some or all decisions on their own.

The ACDMA and other laws

People said that:

- It is hard to understand how the ACDMA is different from other laws about making decisions.
- It is confusing when an adult is under another law too.

People told us it is important that:

- people who apply to be ACDMA reps do it because they want to help adults who need help making decisions.
- people must not apply to be reps because they want to control the adult's life.

Problems with the system

A system is all of the different people and programs that are supposed to work together.

People said that they had two main problems with the system in Nova Scotia.

1. They did not understand how the system works.
 - It is hard to know where to go to find help.
2. The people in the system do not understand how the ACDMA works
 - Places like banks, health care, and nursing homes do not understand the ACDMA.
 - They need to understand what the ACDMA capacity assessment means.

People also talked about problems with the Public Trustee.

The Public Trustee of Nova Scotia:

- can be a rep for someone who does not have someone who wants to be their rep.
- looks into problems people have with the ACDMA.
- gives people information about the ACDMA.

People said the problems are:

- The Public Trustee is too busy. People have to wait more than a year to get help.
- The Public Trustee website is hard to use. It is hard to find the ACDMA forms.

Ideas about independence and human rights

The ACDMA says that adults can do many things with help and without help. This is a good thing.

We heard that the people who help adults sometimes do not understand how to help. ACDMA reps are supposed to help people make their own decisions.

But the ACDMA reps do not always know how to do this. They may need more information.

People told us that for a long time many parents:

- made decisions for their adult children with disabilities.
- did not follow any law that said they could do this.
- did this because they want to protect their adult children.

These parents do not think it is fair to have to go to court now to be a rep for their sons and daughters. They have been helping their children all their lives.

But many adults say that:

- the Act has to be on the side of the adult
- they want the chance to make decisions on their own.
- they want the right to make mistakes.
- they do not want their parents or other people to make decisions for them.
- they want help sometimes, but they want to be independent too.

These different ideas can be hard for parents and hard for seniors and adults with disabilities.

Ways to Make the ACDMA Better

People gave us good ideas for how the ACDMA could be better. In this part of the report, we will talk about those ideas.

Give people more information about the ACDMA

Almost everyone said that people need more information about the ACMA. They had ideas about how the government could share the information to people across Nova Scotia.

They said:

- Change the name of the ACDMA.
 - Make the name something that does not have as many words and is easy to understand.
- Make a website just for the ACDMA. The website should:
 - be easy for people to use.
 - have everything people need to know about the ACDMA in one place.
 - have answers to the questions people ask most about the ACDMA.
- Make a short book for reps under the ACDMA.
 - Reps can use this book to understand their duties.
 - This book should be in plain language.

- Make the Public Trustee website better. Make it:
 - easy to use.
 - easy to find the information you are looking for.
 - easy for people to get the ACDMA forms off the Public Trustee website.
- Make a chart that helps people decide when to use the ACDMA and when to use another law instead.
- Give workshops about the ACDMA to adults who need help making decisions and the people who work with them. Make sure the leaders of these workshops talk about human rights.
- Give information about the ACDMA to families who have children with disabilities.
 - Give them this information early. Do not wait until the child turns 19.
- Hire a person to help people apply for the ACDMA.
 - This person could be called a Navigator.
 - No one should have to pay to get help from the Navigator.
- Give more money to community programs so they can be Navigators.
 - For example: Seniors' Safety programs
- Give extra help to adults who may have a harder time getting information and help than others. Understand that there are some adults who have problems like:
 - No money.
 - No internet.
 - Can't read.
 - Do not live in the city or live far away from people and programs that can help them.
- Give people who can't read a phone number to call to get someone who can help them.
- Make sure people know that it is important to ask the court to choose a back up rep in case something happens to them. If they get sick or die, there will be someone ready to help the adult right away.

- Tell adults how to appeal the judge's decision.
 - If adults do not agree with the judge's decision to give them a rep, they can tell the court they want to appeal the decision.
 - Appeal means that someone will look at the application again. They will make a new decision. It might be the same decision or a different decision from the first one.
 - Make sure adults know where to get free legal help to appeal.
- Make a list of all the people who work with the ACDMA. Make sure everyone can find that list easily so they can find the person they need to help them.

People also gave ideas about how where they could get more information about the ACDMA:

- Schools
 - Children with disabilities can learn about the ACDMA when they are in high school.
 - Parents who have children with disabilities can learn about it from their child's school too.
 - Students who want to work with adults with disabilities need to learn about the ACDMA in university.
- Community Services
 - Care coordinators / social workers should tell the people they work with about the ACDMA.
 - They should take time to talk about it and answer questions people have.
- Places that help adults who might need help to make decisions.
 - For example: day programs and community organizations.
- Libraries

Make it easier to apply to be an ACDMA rep

We heard many times about how hard it is for people to apply to be ACDMA reps. People shared about how to make the application easier. They said:

- The forms should be easier to read and understand.
- Some adults with disabilities who need an ACDMA rep do not have anyone who can be their rep. The government should help them find someone who is honest and who will do a good job.
- The Public Trustee should have enough staff to help people with ACDMA applications. People should not have to wait a long time to get help from the Public Trustee.

Many people said it is very important to make the application easier. When people are very sick, they may need a rep to help them make quick decisions about their health.

When there is an emergency, like during COVID-19, it is even harder to apply for the ACDMA. Other people said that it should not be too easy to for someone to become a rep. It has to be someone the adult trusts.

Make the assessment better

People had ideas about how the assessment could be better. They said:

- The adult should have another assessment after a year or more.
 - This is because people change. Maybe the adult cannot make their own decisions about money now. After a few years of practice, they might be ready to make these decisions on their own.
- A health care team should do the assessment.
 - An example of a health care team is a doctor, nurse, social worker, and therapist working together. They need to be fair and know the person well. They need to know the person's history and know what they can do.

- People who work with adults need to get training so that they can do the ACDMA assessments the right way.
- Some people who do assessments worry that they may make a mistake. They want the law to protect them in case they make a mistake in the assessment.
- The people who do assessments should sign their name on all the pages so no one else can lie and pretend they did the assessment.

Some people said that if the adult does not understand safety rules or talk at all, the parent or caregiver should not need to apply to be their rep when they turn 19. Other people said the court should agree that the adult will need someone to make decisions for them. An adult who cannot talk may still be able to make decisions and have ways to share their decisions.

Other people said the adult should always have the final decision, even if it seems like they do not understand. They still have the right to an assessment and the right to meet with a lawyer.

The assessment form is called Form 1. Form 1 is hard to understand. The people say it needs to be fixed.

People had more ideas for making the ACDMA better:

Make the time shorter. Make the order of the steps better

Make sure all the documents are due at the same time so that some do not expire before the other ones are due.

- Make the application go faster. It takes too long if someone needs a rep in an emergency.
- Make sure people know that if they cannot get all the forms ready in time for court, they can ask for more time. It should be easy to ask for more time.

Make going to court easier

- Give people the choice of going online to court - like on Zoom.
- The ACDMA should be in Family Court. It is faster and costs less money.
- Some people said that if adults get an assessment by a health care team, they should not need to go to court at all.

Make some or all of the steps free

- Give free help to people who need help with the applications.
- Lawyers should tell people at the very beginning how much it will cost.
- Make sure there are enough lawyers at Legal Aid to help people who do not have a lot of money.
- Assessments should be free. They should be part of basic health care.
- Look for people who can help adults make decisions. These people could be nurses or social workers who do not work anymore.
- If the senior or adult with a disability has a lot of money, use their money to pay for the ACDMA application.

Give training and education to people all over Nova Scotia

- There should be more training and information about all parts of the ACDMA for:
 - People who do assessments
 - Doctors, nurses, and other people who work in health care
 - Lawyers
 - Care coordinators / social workers
 - Reps under the ACDMA
 - Community organizations
 - Seniors and adults with disabilities who need help making decisions
 - Community organizations are important places for seniors and adults with disabilities and their families.
 - People said that they trust the organizations they are part of.
 - They are good places for ACDMA reps, adults, seniors, and families to learn more about the ACDMA.

- Adults and seniors who have ACDMA reps should know more about their rights
 - One person said that adults and seniors with reps should get a “My Rights” card that tells them about their rights.
 - The My Rights card should tell adults what to do if they do not agree with decisions their reps make with and for them.

Always think about human rights

People we talked to said that the rights of seniors and adults with disabilities are very important. In Canada we follow two very important documents called:

1. The Charter of Rights and Freedoms
2. The UNCRPD (United Nations Convention on the Rights of Persons with Disabilities)

The ACDMA should always use these documents. These documents protect the rights of all people with disabilities.

The system working together

The people in government services should work together on the ACDMA assessment. These government services are:

- Community Services
- Health
- Justice (law)

Supported Decision-Making

Supported decision-making is when people get help to make decisions from someone they trust. For example, a person they trust helps them to make decisions about money or health. This person might be an ACDMA rep or someone else.

Dave Kent was the President of People First Nova Scotia until 2018. When we talked to the People First group about making decisions, they said that they wanted us to remember what Dave Kent said. He said, "*Help us. Don't do it for us!*"

When we asked adults about making decisions, almost all of them said that they did not want someone to make decisions *for* them. They said that they wanted someone to make decisions *with* them.

In this part of the report, we will talk what people said about making decisions.

We asked people what decisions were the most important to them.

They said that the most important decisions were:

- Money
 - How to spend and save money
 - How to pay bills

- Health
 - Having surgery
 - Getting a COVID vaccine
 - Decisions about what to do when they are dying

- Food
 - What foods to buy
 - What meals to make
 - Choosing healthy foods

- Work
 - What kind of work they do
 - What hours they work

- Where to live
 - Moving out of their parents' home
 - Living alone or with friends
 - Not living in an institution

- Having Relationships
 - Friends
 - Partners
 - Being married

Getting help to make decisions

We asked people what is good about getting help to make decisions. Most people said that it is good to have help, but they want to make the final decision on their own.

It is **good** to get help because the person who helps can:

- Give you more information.
- Explain things in words you understand.
- Answer your questions.
- Share their ideas.
 - One person said: "The more hands and mouths the better!"
- Make you less stressed.
- Give more time.
- Make people feel comfortable to say I don't understand.

Sometimes it is **not good** to get help because the person who helps might:

- Give you too many choices and make you stressed.
- Be bossy, or abusive, or too controlling.
- Tell you to make a decision you do not want to make.

Decisions people are not allowed to make

We asked people if there were any decisions they were not allowed to make.

Some people said that they can not make important decisions because they do not get enough money from the government. They can not choose where they live or what they buy if they only have a little bit of money.

One person said: *"I don't get enough money to make any real decisions. The government makes my decisions for me".*

Other decisions some people said they were not allowed to make:

- How they spend their money
 - Some people said that their support workers told them how to spend their money. They said they did not like this.
- Who takes care of their children
 - A couple of people said that they were not allowed to take care of their own children.
- Where they live and who they live with
 - One person said he wanted his girlfriend to live with him and not in a group home.

What helps people make good decisions

We asked people what helps them make decisions. Most people said that it is good to have someone to help them understand things. They said that it was good to “talk things over” with someone else and to share ideas.

Other things that help people make decisions:

- Learning from your own life.
- Time to think about it on your own.
- Someone to listen to you.
- Someone to give you a few choices to choose from.

How to help people make decisions

Doctors and nurses told us how they can help adults make decisions about their health.

They said:

- Understand what is most important to the person and their family.
- Understand the best way a person communicates.
- Be patient if the person needs more time to speak.
- Use pictures or other tools if the person needs them to communicate.
- Look together on the internet for tools about making decisions.

People said that it is important to include all adults even if they do not use words or use their body to communicate.

How do we do make sure all adults who need it get support making decisions?

People said that it is important for all adults to get help making decisions when they need it.

The helpers can be:

- Reps under the ACDMA (often family members)
- Doctors

- Nurses
- Care coordinators
- Staff at day programs
- Staff at group homes
- Other people in the community

To make sure that helpers get the support they need to do their job, the government should:

- Give the helpers training about supported decision-making.
- Hire more people to help seniors.
- Help families and caregivers understand supported decision-making.

To make sure that adults get the best help they need to make decisions, the helpers should:

- Find ways to include all adults in making important decisions about their lives.
- Make sure adults make all final decisions about their health with support from their reps. The doctor should not make these final decisions.

Making supported decision-making a bigger part of the ACDMA

Supported decision-making is only a tiny part of the ACDMA. People said that the government needs to make supported decision-making a much bigger part of the ACDMA and the law. We asked people how the government can use the ACDMA to make sure adults get good help making decisions.

They said:

- The first thing is to make sure more people understand what supported decision-making is
- It is important always include the UNCRPD and the Charter of Rights and Freedoms.

- The government must give people the help they need to live, work, and play in the community. This is the law. It is called *duty to accommodate*.
 - An example of duty to accommodate is letting adults with disabilities and seniors have a person they trust help them make decisions they cannot make alone.

People said that the government should give money to help supported decision-making in different ways. These different ways would be listed in the ACDMA.

Ideas people gave us for ways government could create supported decision-making:

- Create a Decision-Making Office that does research on the best ways to help adults make decisions.
 - The people in this office can be part of making all the laws about decision-making.
- Make a training program for reps under the ACDMA and staff who work with adults who might need help making decisions.
- Hire Navigators. Adults should have a Navigator too, not just the reps. The Navigator's job would be to find out what the adult has and what the adult needs.
- Support micro-boards.
 - A micro-board is a small group of people that works together to help the adult make decisions.
 - The adult chooses the people on the micro-board.
 - These people may be neighbour, friend, family member, or staff.
 - The adult is the most important member of the micro-board.
- Make sure that the adults direct their own lives. The help they get should always be person-directed.

- Check in on adults with disabilities and their reps every year to make sure things are going well.
 - The person who checks in should spend time with the adults and their reps. They should give them information about supported decision-making when they need it.
- If there are problems with the rep, find ways to talk about it first before going to court. Make sure adults and reps have free legal advice if they need it.
- Make sure that the people who write and review the ACDMA understand that many adults can change. They may be able to make more decisions on their own with time and practice.
- Look at the ways other provinces like BC and Alberta do supported decision-making and learn from them.
- Instead of only the rep making the final decision, the rep and the adult can make final decisions together.
- Use these ideas about supported decision-making in other acts too, not just the ACDMA.

We asked reps under the ACDMA about making supported decision-making a bigger part of the ACDMA. These reps were all family members of adults with disabilities.

They said:

- They were worried that their sons or daughters may make decisions that are dangerous.
- That their sons and daughters were not able to make big decisions even with help.
- They wanted to make the decisions for them to keep them safe.

Many parents talked about Landon Webb's story. Landon Webb was in the news in 2016 because he wanted to make his own decisions about where to live, but he was not allowed. Parents we talked to said that they did not want this to happen in their families or in other families. One parent said that there should be a way to talk things over with someone first, so you do not have to go to court.

The reps we talked to all said that they wanted their sons and daughters to have rights. They wanted them to be able to make decisions like what to wear and what to eat.

They liked that the ACDMA lets them choose more than one rep:

- They said it is good because if there is only one rep, they might make a bad decision.
- If there are two reps, they can talk about it together to make sure they do what is best for the adult.

Many people said that making supported decision-making a bigger part of the ACDMA is a good idea because:

- We will understand more about how adults with disabilities can make their own decisions.
- We will learn more about the tools adults with disabilities need to make decisions on their own and with help.
- We will understand that adults with disabilities have rights like everyone else. They need to be treated with respect.