

# **PLAIN LANGUAGE REPORT**

*Challenging the Use of Algorithm-driven Decision-making in Benefits Determinations  
Affecting People with Disabilities*

*The Center for Democracy & Technology*

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## **Meet Bradley Ledgerwood**

Bradley Ledgerwood is a 39-year-old man who lives in rural Arkansas. He is a member of the county Republican committee. He is also an alderman, or town council member, for the town of Cash.

Bradley also has cerebral palsy. His cerebral palsy makes it hard for him to move his body by himself. He needs help from other people to eat, dress, or change his position. Bradley's parents are his support people. They can help Bradley because Arkansas' Medicaid program pays for the cost of his family members providing care at home.

Arkansas' Medicaid program used to have nurses figure out how much care people need. Medicaid used to pay for 56 hours of care each week for Bradley. That is a lot of hours because Bradley needs a lot of help. Bradley's mom even left her job to help Bradley more.

But then Arkansas started using a new "**algorithm**" to make decisions about people's care hours. Based on the new algorithm, Arkansas cut Bradley's hours from 56 to 32. Bradley still needed the same amount of help. But Arkansas wasn't going to pay for it anymore.

### **What are algorithms and how are they used in benefits?**

Algorithms are sets of "if, then" questions. They help people answer hard questions by breaking them down into lots of easier questions. Algorithms can look like flowcharts. People start with one question. The answer to that question tells them which question is next.

Many state governments use algorithms to make decisions. One way state governments use algorithms is to help figure out who should get benefits.

State governments run programs that provide many kinds of benefits. Some benefits help people get health care or disability services, like Medicaid or Medicare. Unemployment benefits give money to people who lose their jobs. Social Security benefits help people who can't work. State governments can use different kinds of algorithms to provide benefits.

Algorithms can be very simple. For example, a short algorithm can help someone figure out if they can get unemployment benefits. The first question would be (1) "Are you unemployed?" If the person says no, they can't get unemployment benefits. But if the person says yes, they go to the next question. The next question would be (2) "How did you become unemployed?" If the person says they were laid off, then they can get unemployment benefits.

Algorithms can also be very complicated. Some algorithms might use hundreds or

thousands of questions. It's easier to have computer programs to figure out these algorithms. Computer programs can use algorithms to help make complicated decisions faster and easier. "Computer-run algorithms" are algorithms that computer programs use to make automatic decisions.

Sometimes, state governments worry that people are lying to get benefits they shouldn't have. They use computer-run algorithms to try to catch people who they think are lying.

For Medicaid, computer-run algorithms can help figure out if people need support. They also can help figure out how much supports people need.

Medicaid has a program called Home and Community-Based Services (HCBS). HCBS helps people with disabilities live in their own homes instead of institutions. People who live in institutions lose their independence. People who live in institutions have very little say in their lives. People who live in their own homes are more independent and have more say in their lives. HCBS helps people have more say over their lives. HCBS can help people with disabilities with eating, cooking, cleaning, and more while living at home.

People are unique. Every situation is different. So state governments are supposed to make unique decisions for each person. Every state government uses different tools to figure out how much help people need from HCBS. Some state governments make their own tools. Other state governments buy tools from companies. Some tools are just a state government staff person figuring out on their own how much help someone needs. Other tools use a computer-run algorithm to figure out how much help someone needs automatically. Sometimes, algorithms try to guess what one disabled person needs based on what lots of other people with disabilities needed in the past.

### **An example: Idaho**

In 2011, Idaho started a new program to decide how much money every person in HCBS should get for the year. In this program, people had to go to a medical center. At the medical center, staff filled out a special form that gave people scores for their needs. Then the staff had to type the scores in a spreadsheet. The state's computer-run algorithm used the scores in the spreadsheet to figure out a budget.

A private company made the algorithm and spreadsheet for Idaho. The company came up with the algorithm using information it didn't want to share.

Sometimes, a person thought their budget wasn't high enough. If they wanted a higher budget, a state government manager had to say they needed more money for "health and safety." But no one in the state government said what counted as "health and safety." This was confusing. Lots of people lost money for services they needed. They had to appeal to the state government.

People who lost money for their supports sued Idaho – they took Idaho to court. After listening to what everyone had to say, the judge said that the company didn't make the computer-run algorithm the right way. The company didn't use enough information to make the algorithm. Most people with disabilities couldn't trust the algorithm because it didn't help them. And the staff at medical centers could make mistakes when putting people's scores in the spreadsheet.

The judge also said that Idaho's government knew they needed to update the algorithm every year but they didn't. Disabled people who lost benefits in Idaho had no way to figure out what happened. Idaho didn't let people know what their scores were or how the medical center staff put down their information. And Idaho didn't check to see if people's budgets actually worked for them.

The judge said that Idaho's new program went against the Constitution. That means that the program violated people's rights under the highest law in the country.

Idaho isn't the only state government using computer-run algorithms. Other state governments use computer-run algorithms to make decisions about people's benefits, too. Some of those algorithms have used bad information or not enough information. Some of those algorithms have added more requirements for benefits than the law says should be there. And some of those algorithms make decisions just based on what people's disabilities are, instead of what they need help with.

It is unfair to use computer-run algorithms if people don't check what the algorithms are doing. Algorithms make guesses based on information about similar people. They look for patterns. They use average information about people to make guesses. They are not good at figuring out that individual people have different needs from each other. They are not good at figuring out that individual people have very specific needs.

People can help fix these problems. People can check the results from algorithms. People can figure out when algorithms make mistakes. People can use an algorithm with more information to make better decisions. People can ask people who need supports to give more information. People can treat people who need supports as individuals. And people who need supports can give more information to other people, but not to computer-run algorithms.

### **Using the law against algorithms that discriminate**

Advocacy is speaking up. Advocates can speak up for what they need. Advocates can also speak up for what other people need. Self-advocates are people who speak up for themselves.

For 10 years, advocates have gone to court to say that computer-run algorithms can be

bad for people who need benefits. Advocates usually go to court when computer-run algorithms make people lose their benefits. They also go to court if state governments take away benefits before telling people.

Sometimes, advocates appeal decisions they don't like. This means they go back to the state government or to court. Then they explain why they think the decision was wrong. They ask the state government or court to change the decision.

Here are 5 things advocates have said about algorithms for benefits:

1. People have the right to know in advance if the state government is going to cut their benefits. They also have to get a chance to appeal—to ask the state not to cut their benefits. Some computer-run algorithms start cutting benefits right away. This means that people don't get advance notice or a chance to appeal, even though they're supposed to.
2. People have the right to fair decisions about their benefits. State governments have to make decisions that make sense. If they use tools like computer-run algorithms to help make decisions, the tools have to work. Some of those algorithms don't work the way they should. This means that the algorithms can't make fair decisions.
3. Once people appeal, they must have a fair chance to win their appeal. The state government must tell them how it made the decision to cut their benefits. Some computer-run algorithms are secret or hard to find information about. This means that people don't get a fair chance since they can't figure out how these algorithms work.
4. State governments have to follow special rules when they change how things work. One of those rules says that state governments have to tell everyone what they plan to do before they make a change, like use a new computer-run algorithm. Some state governments started using computer-run algorithms for benefits without following the rules. This means that the state governments were wrong to start using the computer-run algorithms without giving people enough notice.
5. People with disabilities have a right to live in the community. Some computer-run algorithms cut people's benefits so much that they can't get all the help they need to live at home. This means people might be forced to go to institutions to get help. This is against the law.

Advocates say these things when they go to court. After advocates make their arguments, judges make decisions.

Judges often talk about problems with how state governments use computer-run algorithms. They tell state governments to make sure people have advance notice about new tools or programs. They tell state governments to keep giving people the same benefits as before, until they can give people enough notice first. They tell state governments not to use new tools at all until they can follow the rules.

Advocates should know what judges have already said about computer-run algorithms. This information can help advocates in future cases.

## Meet Larkin Seiler

Larkin Seiler lives in Idaho and works at an engineering firm. He is also a self-advocacy leader with cerebral palsy. Larkin needs support with moving his body. He also needs communication support. Usually his wife Jennifer supports him.

But people with disabilities should make their own choices about who supports them. Having paid support workers can give people more independence. Relying on family members sometimes makes people feel less independent. People need more money to pay support workers than to pay family members.

It costs a lot of money to give Larkin the support he needs. So he gets money from Idaho Medicaid to pay for his supports.

But starting in 2007, Idaho Medicaid began cutting Larkin's budget for supports. Larkin used to get \$52,000 every year to pay for supports. In 2012, Idaho only gave Larkin \$28,000. That means Larkin lost almost half his benefits!

Larkin was one of many people who called the ACLU about the cuts. The ACLU lawyer, Richard Eppink, got call after call from people like Larkin. People found out that Idaho cut their benefits. They didn't know why.

Richard took Idaho to court. Many of the people who called Richard asked a judge to say that all the cases were connected. This is called a "**class action**." It means that lots of people had the same thing happen to them for the same reason and they want to go to court about it together.

The case helped advocates find out why Idaho started cutting people's benefits. In Idaho's tool, the medical center staff put down people's information about their needs into spreadsheets. Then a computer-run algorithm used the information on the spreadsheets to decide people's budgets. Idaho didn't tell anyone what the algorithm was. But then advocates found out that Idaho's algorithm had a lot of problems. The algorithm couldn't figure out what people needed because it used bad information.

Algorithms will make bad decisions if they use bad information. Information is bad if people can't trust it. Information is bad if it isn't complete. Information is bad if it's wrong.

## What is due process?

The Constitution of the United States is the highest law of the land. Under the Constitution, the government is not allowed to take people's lives, freedom, or property without good reason. To follow the Constitution, the government has to follow "**due process**." This means that the government must follow specific rules that are supposed to make sure that its actions are fair.

Due process usually requires that people have advance notice and an explanation before the government takes their property. In 1970, the U.S. Supreme Court decided an important case called *Goldberg v. Kelly*. In this case, the Supreme Court said that people have the right to advance notice before the government cuts off their benefits, since benefits are a kind of property. The advance notice has to explain why the government plans to cut off their benefits. People also have the right to a hearing. At a hearing, people can argue that the government is wrong. They can ask to keep their benefits.

Some judges have decided that state governments have to give people an explanation about why they are getting less benefits, too. The Ninth Circuit Court of Appeals, an important federal court, said that due process means the government has to give people an explanation. The government has to explain the reasons for cutting people's benefits. People need an explanation so that they can defend themselves against the government's decision. [1]

There are also laws for specific benefits programs. The Medicaid Act and the SNAP Act (for food stamps) also give people specific due process rights.

Advocates have convinced judges to agree that computer-run algorithms sometimes violate people's right to due process.

Here are some things advocates said about how computer-run algorithms violate due process when they went to court:

1. State governments didn't give people enough notice about why their benefits were cut. State governments were supposed to explain how they decided what supports people needed. They were also supposed to explain how they figured out the amount of benefits people should get.

2. State governments used computer-run algorithms that made mistakes. These algorithms didn't use good information. They weren't designed well. And the state governments didn't do a good job using them. So the algorithms weren't reliable. The decisions the algorithms made were unfair and didn't make sense. People have a right to fair decisions about their benefits that make sense.

3. State governments didn't give people a chance to appeal before cutting or stopping their benefits. Their computer-run algorithms cut people's benefits right away. State governments were also supposed to help people appeal if they needed supports. But the state governments didn't help.

4. State governments didn't share any information about their computer-run algorithms. They didn't share the algorithms. They didn't share any explanations for how the algorithms worked. People can't have a fair appeal unless they understand how the computer-run algorithms work. People have to understand why their benefits got cut so they can have a fair appeal.

#### *What kind of notice are people supposed to have?*

Due process means people have a right to get advance notice before the state government cuts their benefits. The notice has to explain why the state government wants to cut their benefits. Having advance notice gives people a chance to try to stop the cut.

Judges have said different things about how much notice people are supposed to have. Here are some examples:

- A judge in Idaho said the state government has to tell people the reason their benefits are being cut. The state government has to say if someone who works for the state government decided that a person needs different supports. The state government also has to say how it decided that a person needs different supports.
- A judge in West Virginia said the state government has to explain how it figured out people's budgets for services. If people's budgets change for a new year, the state government has to explain why and how they figured out a different budget.
- A judge in Arkansas said that the state government has to say what information made the state government cut their benefits. For instance, the state government has to tell people if they got a low score for one type of need, and the low score counted against them. The state government doesn't

have to give people details about how the computer-run algorithm works overall.

### *How fair does a computer-run algorithm have to be?*

Due process means that the state government has to make fair decisions. The state government isn't allowed to make "arbitrary" decisions. Arbitrary means the decision is unfair because it isn't based on a good reason under the law. If the state government uses bad information to make its computer-run algorithm, then the decision will be based on a bad reason. This will make the decision arbitrary.

The state government has to make decisions with "ascertainable standards." Ascertainable standards means the state government has to explain in writing how it makes decisions. The state government also has to explain what tools it uses to make decisions. That way people can figure out if the decisions about them are fair. People can also figure out if an unfair computer-run algorithm made the decision.

Here are some examples of how this works:

- A judge in Idaho said the state government's computer-run algorithm for people's Medicaid HCBS budgets was not fair. The state government came up with its algorithm based on information about people who got services before. But the state government didn't use information about enough people who got services before. So the algorithm didn't know about all the different needs people could have. The computer-run algorithm made too many mistakes. It cut too many people's benefits.

The state government also had to have its staff type up many pages of information about each person to use the computer-run algorithm. The staff could make mistakes while typing, too, and the algorithm wouldn't figure it out.

The state government was also supposed to check every year to make sure its computer-run algorithm still worked right. But the state government didn't check.

The judge said the algorithm was unfair because it used limited information, staff could make lots of errors, and the state didn't check it every year.

- Right now, advocates in Oregon are asking a judge to say the same thing as the judge in Idaho. The advocates in Oregon are saying that the state uses a computer-run algorithm that is a secret formula. It automatically figures out how many hours of care each person gets. Staff can't give more information and/ or make changes. So the algorithm has been giving people different results that don't match their needs.

If the advocates succeed, the judge could say that Oregon isn't using "ascertainable standards" because the formula is unfair and secret. People can't figure out how it works, so they can't appeal.

### *What does it mean to have a fair chance to be heard?*

Due process means people have a right to ask the state government to change its decision before their benefits get cut. That means people can ask the state government for a chance to explain why their benefits shouldn't be cut.

Judges say different things about what makes a fair hearing. Here are some examples:

- A judge in West Virginia said that people need to be able to tell the state government about any mistakes with their budgets right away. People should get to tell the state about mistakes before they have to appeal.
- A judge in Idaho said that people need to understand what they can do when their benefits are going to be cut. The state government has to explain how it makes decisions in writing. That way people can explain why the decisions are wrong.

### *How do people get a fair shot at appealing?*

Due process means people have a right to argue that the state government's decision to cut their benefits is wrong. But to do this, people have to get enough information to know how computer-run algorithms work. If people know how the algorithms work, they can explain how the algorithms are making the state government make wrong decisions.

Judges have said different things about making sure people understand the government's computer-run algorithms. Here are some examples:

- A judge in West Virginia said that the state stopped people from being able to appeal because it used a secret computer-run algorithm. The state had to give people enough information to figure out why their budgets were being cut. After this, the state made a new system where everyone could find out how it made decisions.
- A judge in Idaho said that if people need help to explain why the state's decision is wrong, they have to have someone who can do a good job helping them with their appeal. This is important because a lot of people with developmental disabilities need extra support to appeal.

- A judge in Texas said that the state used a secret computer-run algorithm that it wouldn't explain to fire public school teachers. The teachers didn't know what the algorithm was or how it worked. So they couldn't explain why the algorithm was bad during the appeal. (This is important because the teachers' pay counted as a benefit since they worked for public schools.)
- A judge in Arkansas said that it was okay for the state just to tell people how it figured out their individual budgets. But the state didn't have to explain how the computer-run algorithm actually worked.

*What is notice and comment? Why does it matter?*

The Administrative Procedure Act (APA) is a federal law that tells governments how they can make new rules. Some states have laws like the APA just for their state, too.

The APA says that when the government wants to make a new rule, it usually has to tell the public what the new rule will be. This gives people a chance to tell the government if they like or dislike the new rule. This is called "notice and comment." The notice is when the government says what it's planning to do. Comments are people's chance to express their opinion and speak their mind. The government has to listen to the comments before it makes a final decision.

State governments have to give people notice if they're going to use a new system for benefits. They also have to give people notice if they're going to change how benefits work in the state. After state governments tell everyone when they want to start using a new algorithm, they have to let people share their opinions about it.

*Arkansas, for example:*

In Arkansas, the state changed the way it figured out how many hours of care people in HCBS would get. Under the old system, nurses made decisions on their own based on their best judgment. The new system used a computer-run algorithm to decide automatically. Under the new system, lots of people began to lose benefits.

Even though Arkansas gave advance notice that it was changing the HCBS program, it didn't explain how it was going to make decisions about people's hours. So advocates went to court. They said that Arkansas broke the law because Arkansas didn't follow the APA. A judge told Arkansas to stop using the new algorithm until it followed the APA. Thousands of people got to keep their benefits!

Arkansas wasn't done yet though. Right after this happened, Arkansas used part of the APA called "emergency rules" to say it could keep using the same computer-run algorithm. The APA lets a government make a rule without notice and comment if there is an

emergency. In a real emergency, the state government wouldn't have time to give notice and wait for comments. But there was no emergency here. So a judge told Arkansas to stop using the new computer-run algorithm ... for the second time.

Five months later, Arkansas tried again and followed the APA the correct way.

But even though Arkansas followed the APA, advocates stopped the new computer-run algorithm. Advocates went to the state house, talked to the press, and told their stories. Advocates broke records for sending comments about a government decision. Arkansas started using a new computer-run algorithm that the state explained better.

### **Meet Lois Curtis and Elaine Wilson**

Lois Curtis is a Black woman with intellectual disabilities. Elaine Wilson was a white woman with intellectual disabilities. Lois and Elaine lived in Georgia during the 1990s.

Georgia put Lois and Elaine in an institution. They were locked inside a hospital and not allowed to leave. But Lois and Elaine wanted to live in the community in their own homes. Their doctors said they should get to live in the community. But Georgia didn't let them leave the institution.

Lois and Elaine met a lawyer who helped them go to court. They said that the Americans with Disabilities Act (ADA) says people with disabilities should be treated just as fairly as people without disabilities. This meant they should be allowed to live in the community instead of being separated from the community.

The U.S. Supreme Court agreed with Lois and Elaine. The Supreme Court said that putting people with disabilities in institutions is discrimination. The Supreme Court also said that state governments can't just say they don't have enough money to support people with disabilities in the community. This is an important case called *Olmstead v. L.C.*

Lois is still alive today. She is a self-advocate and artist.

### **Why is community integration important?**

**"Community integration"** means when people with disabilities live and work in the same community as people without disabilities.

The ADA says that people with disabilities can stay in the community instead of institutions. The government has to provide services, programs, and activities in the community as much as possible.

Sometimes computer-run algorithms cut people's benefits so much that they might have

to go to an institution to get care. This could mean that state governments are breaking the law. State governments aren't supposed to force people to go to institutions.

In Oregon, the state has started using a new computer-run algorithm that is cutting people's benefits. Self-advocates have gone to court. They are saying that the cuts will force them to stay at home all the time or go to group homes. But the judge hasn't said anything yet about whether the cuts force people to go to institutions. Right now, advocates are working with the state to try to fix the computer-run algorithm.

Idaho is also using a new tool that is cutting people's benefits. Self-advocates are saying that the cuts put them at serious risk of having to live in an institution.

Last year, Washington, DC, started using a new computer-run algorithm for home care hours. Hundreds of elderly people and people with disabilities who need home care have gotten their benefits cut. Other people had their benefits cut off completely. They aren't getting any home care at all. People are afraid that they will end up in nursing homes and institutions. They are afraid that if they live in institutions, they could get sick, be abused, or die early.

### **What happens if companies say computer-run algorithms are their private property?**

Sometimes companies say that they have a right to keep secret the computer-run algorithms used to decide who gets benefits. State governments sometimes say that if a company wants to keep its computer-run algorithm a secret, the state government can't show it to people or tell people what it says.

Advocates should know that they have good arguments against companies that want to keep their computer-run algorithms secret. These companies are making algorithms for state governments. They're using taxpayer money to make the algorithms. And the algorithms are making decisions that affect people's rights.

State governments that want to use new computer-run algorithms should be careful. They should decide if they get to own the algorithms or not. They need to make sure that people's due process rights will be protected.

Here are two examples:

- In Idaho, the state government used an interview booklet that told the staff how to score people's needs. Staff had to enter all of the information from the interview booklet into the computer program's spreadsheet. The computer-run algorithm used that information to figure out people's budgets.

When advocates went to court, they wanted to see the whole interview

booklet. The state government said it shouldn't have to share the interview booklet. The state government worried that people might just copy the questions and make up answers to get more benefits.

The judge told the state government it had to show people parts of the interview booklet. The state government had to show people which parts of the booklet it used to cut their benefits.

The judge also said that the court could give a special order (called a "protective order") to stop people from sharing more information from the booklet.

- In West Virginia, the state government used a computer-run algorithm to make decisions about people's services budgets. The company that made the algorithm said it didn't have to share the algorithm because the company had the right to keep it a secret.

A judge said that if people didn't know what was in the algorithm, they had no way of knowing if it was fair or not. If people couldn't tell if the algorithm was fair, then the state was breaking the law. The state was not following the rules for due process.

Here is some more important information for advocates to know:

- Courts' protective orders only help after people go to court. Protective orders don't help people when their benefits first get cut because they have to go to court to get the orders.
- Protective orders can also help private companies keep their computer-run algorithms secret. Protective orders only let one person at a time see the algorithm. Protective orders keep them secret for everyone else.
- The federal government and state governments have "open records" laws. These laws let people ask the government for information about what the government does. The government has to reply and share the information, unless they have a special reason that lets them keep it secret.

Advocates can use open records laws to ask for details about the computer-run algorithms. Some states' open records laws say that the state government has to share information about software.

## So what should we do next?

State governments have many reasons to like computer-run algorithms and to use them. Those reasons include:

- State governments want their systems to work faster and better. They think computer-run algorithms can use information about people and will make their systems better.
- State governments want to get better at figuring out if people are lying. They think computer-run algorithms will help figure out if people are lying.
- State governments want to spend less money on benefits. They think that computer-run algorithms will help cut costs.

Indiana's government said it wanted to use computer-run algorithms to figure out if people were lying. The governor went further. The governor said he wanted fewer people getting benefits. He wanted to use algorithms to cut people off from their benefits.

Computer-run algorithms that cut people's benefits hurt people who lose all of the benefits they need. These algorithms also hurt people who will receive less benefits than what they actually need.

In Arkansas, people lost a lot of hours of home care and supports. On average, people lost almost half of their hours. People had to get more help from parents and family members. People had less independence. Some people had to go to the bathroom in their pants. Some people couldn't eat. Some people thought about going to nursing homes or institutions.

Sometimes, lawyers and advocates can help people fight cuts to their benefits. Going to court can help people keep the benefits they need. But state governments can keep trying to use computer-run algorithms that are dangerous because they take away people's benefits. Advocates might need to try to stop state governments from using computer-run algorithms that are too dangerous.

Disabled self-advocates like to say "Nothing About Us Without Us." This means that people with disabilities should always get a say when governments do things that affect us.

We have done our best to listen to people with disabilities. We want all advocates to listen to people with disabilities. So here are some guidelines for advocacy about algorithms and benefits.

## State governments:

- State governments have to understand that decisions about algorithms are policies. Policies are how state governments choose to make or follow laws. State governments have responsibilities to know what computer-run algorithms they are using. They have to follow laws about computer-run algorithms.
- Buying a computer-run algorithm isn't the same as buying office supplies. Computer-run algorithms affect people's lives. So state governments are making decisions about policy when they use computer-run algorithms. They are telling people what the state government thinks is important.
- State governments shouldn't use computer-run algorithms for all decisions. State governments should also make sure people check decisions that computer-run algorithms make.
- State governments have responsibilities to the people. State governments need to use technology to help them with their responsibilities.
- State governments have to follow the law. State governments have to follow the APA, which tells them how they can make rules. State governments have to give people advance notice when they want to change the rules. They have to tell people when they want to start using computer-run algorithms. They have to give people a chance to let them know how they feel about the algorithms.
- State governments have to make plans for using computer-run algorithms. They have to follow the law when making, buying, and using computer-run algorithms. State governments have to go back and check their computer-run algorithms while using them.
  - State governments should check contracts before signing them. This means making sure the state government can see the algorithms. It also means making sure the state government can tell the public about them, how they work, and what information they use.
  - State governments should make sure their algorithms use enough information. They need to use correct information. They should use information that makes sense for why they want to use an algorithm. When state governments don't use enough information, or use wrong

information, the algorithms won't work and people can take them to court.

- State governments need to be careful and test their algorithms. They should check that
  - Algorithms make sense and work for what people need,
  - Algorithms don't put people at risk for going to institutions,
  - Algorithms aren't discriminating against people with disabilities.
- State governments need to check their algorithms on a regular basis. They have to check how the algorithms work, the information the algorithms use, and the decisions the algorithms make. State governments have to make sure the algorithms are working the way they should.
- State governments have to update their algorithms.
- State governments have to protect people's right to due process.
  - State governments have to give people advance notice before changing their benefits. State governments have to give people a chance to appeal before changing their benefits.
  - State governments have to explain changes to people. State governments have to explain why they decided to change the benefits. They have to explain how they used algorithms to make their decisions based on people's individual information.
  - State governments have to make sure that people get the help they need to appeal. A person's disability might make it hard to appeal by themselves. When this happens, it is important for state governments to make sure people have enough help.
- State governments should take steps that help people trust them more.
  - State governments should give the public information about their tools. They should give this information before anyone has to tell them to.
  - State governments should have public meetings about the tools. They should let people express how they feel about the tools at public meetings.

- State governments should listen to what people think about the tools. State governments should work with self-advocates and their family advocates, lawyers, and advocacy groups. State governments should keep learning from them.

## Attorneys:

- When attorneys agree to help people with their cases, the people are their "clients." Attorneys should get to know their clients and let their clients lead.
  - Self-advocates talk about what they need and how the tools affected them. Attorneys should listen to what they say.
  - Attorneys should work with disabled people who are experts about technology, policies, and laws.
- Attorneys should read what courts and experts have written.
  - Attorneys can find a lot of reports and articles about algorithms. These reports and articles talk about experts. Attorneys should get advice from the experts.
  - Attorneys should pay attention to what experts are writing. Experts write about whether states are using algorithms in ways that are fair.
- Attorneys should find ways to help their clients outside of court, not just in court. They should help people share their stories with the public. People should share their stories the way they want to.
  - Attorneys should find places where self-advocates can share their stories. These places can be websites, newspapers, and magazines. Attorneys should find people who can help stories reach these places.
  - Attorneys should talk to advocacy groups with their clients. Attorneys should ask these groups to share their clients' stories.
  - Attorneys should help their clients share their stories with people who make the laws. Attorneys can help self-advocates share why laws should stop state governments from using bad algorithms.
- Attorneys should think about who else lost their benefits because of the same algorithms.

- People don't all have the same chances to share their stories. Attorneys should find ways to work with them. When more people talk about the same problem, the problem gets more attention.
- Attorneys should find the places where people go to ask for help. These places can be websites or offices for advocacy groups.

### Self-Advocates and Family Advocates:

- Self-advocates should share their stories on websites and in their community.
  - Many government meetings are public. Self-advocates can go to these meetings to share their stories and how they feel. They can find these meetings by looking for these words:
    - Town, City, or County Council
    - Town or County Disability Commission
    - State Developmental Disabilities Council
    - Health and Human Services Department
  - Social media websites are websites like Twitter, Instagram, and Facebook. Self-advocates can find other self-advocates on social media who have the same problem. They can teach people about how state governments used algorithms to cut their benefits. Self-advocates can join groups related to their problem.
  - They can also use "hashtags" on social media websites. Hashtags are words with the "#" symbol in front of them. When self-advocates write something and add a hashtag to it, more people can find it. This is because the hashtag puts everything with the same hashtag in one place. Some examples of hashtags are #CripTheVote, #DisabilityRights, and #DisabilityVisibility.
- Self-advocates should share their stories in news articles. They can send letters to websites, newspapers, and magazines about how algorithms cut people's benefits. They can also ask reporters to write about the problem. Many reporters write about benefits, health care, and disability issues. Self-advocates can look online to find out how to contact these reporters.

- Self-advocates should write, call, or send messages online to people who make the laws. Self-advocates can find out how to contact these lawmakers through websites like this: <https://myreps.datamade.us/>. They can tell lawmakers about themselves. They can tell lawmakers about the problem and what lawmakers should do.
- Self-advocates can ask lawyers for help. Self-advocates can find help if they don't have money for a lawyer by looking for these words:
  - "State protection and advocacy organizations"—They help people for free. They have names like Disability Rights California or Disability Rights Center of New Hampshire.
  - "Legal Aid" or "Legal Services"—These groups give free help if people don't have enough money to hire a lawyer.
  - "Law Clinics"—They are usually a part of law schools. They give free help if people don't have enough money to hire a lawyer. They have names like Health Law Clinic or Disability Rights Law Clinic.
  - "State pro bono programs"—States have groups where lawyers help for free. These lawyers volunteer some of their time to help people who don't have enough money to hire a lawyer. The groups have names like the Maryland State Bar Association or the Kansas Bar Association.
- Self-advocates should save everything they have that is related to their benefits. They should save all of the letters and emails related to their benefits getting cut. They should save all of their notes from their phone calls with people from the state governments. These things will help self-advocates and their lawyers when they appeal or go to court.
- Self-advocates should remember that they're not alone! They can join groups of other self-advocates. In these groups, they can get help on their cases. They can get support. They can work together to get state governments to change their tools. There are many groups like this:
  - "People First organizations"— Self-advocates with intellectual and developmental disabilities make these groups for people with the same disabilities.
  - "Autistic self-advocacy organizations"—Autistic self-advocates make these groups for other autistic self-advocates.

- Groups for the National Federation of the Blind and the American Council of the Blind
- People who live with mental illness make groups for other people like them. They help by talking about their mental illness and supports they use.
- Groups for a community called American Disabled for Attendant Programs Today, or "ADAPT"
- Family advocates can also join groups that support them, like:
  - The Arc
  - A Parent Training & Information Center
  - The Sibling Leadership Network
  - The Autism Society

**[1]** "Due process requires notice that gives an agency's reason for its action in sufficient detail that the affected party can prepare a responsive defense." *Barnes v. Healy*, 980 F.2d 572, 579 (9th Cir. 1992), citing *Goldberg v. Kelly*, 397 U.S. at 267-68.