OCTOBER 2024

To Make Technology Better for Disabled People, Start by Fixing Disability Data

Plain Language Report

CENTER FOR
DEMOCRACY
& TECHNOLOGY

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Miranda Bogen
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The **Center for Democracy & Technology (CDT)** is an organization that helps protect people's rights by thinking about technology.

It started in 1994. CDT has an office in Washington, D.C., and in Brussels, Belgium.

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To Make Technology Better for Disabled People, Start by Fixing Disability Data

Plain Language Report

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Plain Language Version by ***Reid Caplan***

Note: This paper was written for people with disabilities. We will use the pronouns “we” “us” and “ours” when talking about disabled people as a group.

Thank yous

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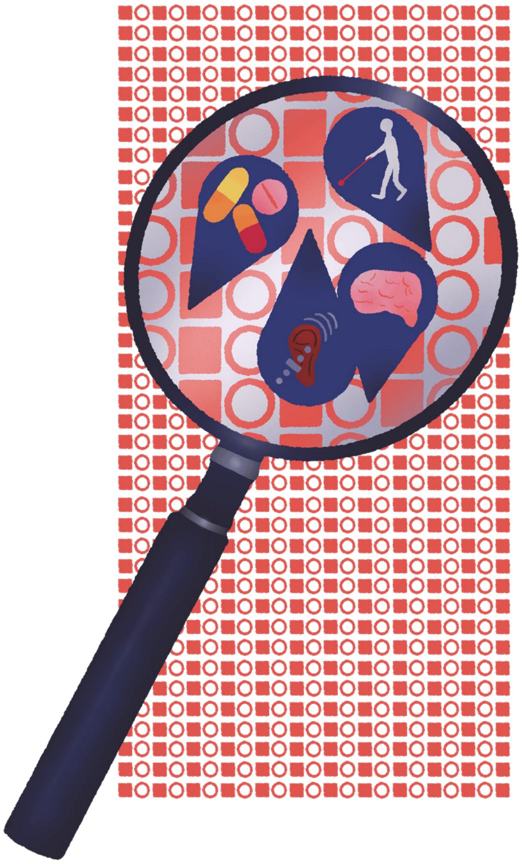


Ableism

Discrimination against someone for being disabled.

Algorithm

A kind of computer program people use to make decisions.

Algorithmic black box

The idea that it's impossible to fully understand algorithms.

Americans with Disabilities Act (ADA)

A U.S. law that protects disabled people from discrimination.

Census Bureau

The part of the government in charge of counting people.

Data

Information that gets read by a computer.

Data set

A group of data used for one project.

Demographic

A specific group of people in the world. For example, “people in their 20’s” can be a demographic.

Diagnosis

When a doctor says that someone has a disability.

Discrimination

Being treated unfairly because of who you are.

Internalized ableism

When people with disabilities feel ableism against themselves.

Model

A way that people think about something. Models also get called "frameworks" or "paradigms." There are 4 models of disability we talk about in this paper:

- **Legal model:** The idea that the law decides who "counts" as disabled.
- **Medical model:** The idea that disability is a problem with someone's brain or body. The medical model says disabilities should be cured.
- **Social model:** The idea that society causes disability by not helping disabled people get what we need. It says society should help disabled people instead of trying to cure us.
- **Identity model:** The idea that disability is part of who someone is. The identity model says people should be proud to be disabled.

Social Security Administration (SSA)

The part of the government that runs benefit programs like SSI and SSDI.

Stigma

Bad attitudes or beliefs about a group because of who they are.

Technology

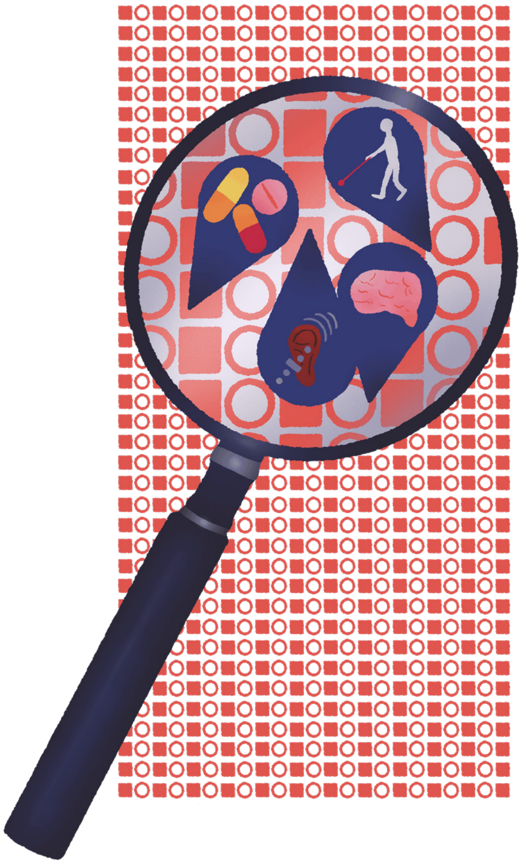
Tools that people use to make life easier.

Testing

When an algorithm is given data on real-life situations to see how it will act.

02

About This Paper



Technology means tools that people use to make life easier. There are all different kinds of technology. Many kinds of technology help people with disabilities. For example:

- Wheelchairs are a kind of technology. They can help people with disabilities get around.
- iPads are a kind of technology. They can help non-speaking people with disabilities. People can use an iPad to type what they want to say. Or they can point to pictures or words on an iPad to communicate.

In this paper, we mostly talk about computer technology. Today, most new technology is made with computers.

There are lots of ways technology can help disabled people. But there are also ways that technology can hurt disabled people. Technology can discriminate against people with disabilities. **Discrimination** means being treated unfairly because of who you are. Discrimination happens to people with disabilities all the time. **Ableism** means discrimination against someone for being disabled.

It may seem strange that computer technologies lead to discrimination. But these computer technologies are sometimes built in ways that discriminate against people. This happens to people with disabilities in a lot of important places, like:

- When applying for jobs
- When trying to get benefits, like SSI, SSDI, and Medicaid
- When trying to get healthcare

One of the main ways people get discriminated against by technology is with algorithms.

An **algorithm** is a kind of computer program people use to make decision. Computer scientists create the algorithm, and researchers give the algorithm data. **Data** is information that gets read by a computer. In this paper, we talk about data that comes from people. We use the words “data collection” to talk about how we get data from people.

An algorithm gets “trained” about what it should do with data. Then, when the algorithm gets new data, it can tell people what choices to make. But some of the decisions algorithms make can discriminate against people. Algorithms can discriminate against disabled people.

> *Algorithms get used in lots of places. Many jobs use algorithms to choose who to hire. These algorithms can look at people’s resumes. They can also look at videos of people interviewing.*
>
> *Some businesses use algorithms that will throw out the application of people who don’t make eye contact. If an algorithm sees an interview with no eye contact, the algorithm will say not to hire that person. This isn’t fair to blind, low-vision, or autistic people who want a job.*

Algorithms can also make it harder for people with disabilities to get the help they need. Algorithms get used to decide what kinds of government benefits someone gets. They also get used to decide how much care someone gets.

> *For example, Jean gets home care through Medicaid. She knows she needs 10 hours a day of home care. But her Medicaid program is using a new algorithm. They only look at the algorithm to decide how much care she needs. The algorithm says Jean only needs 5 hours a day of home care. So, Medicaid cuts half of Jean's home care. This makes it much harder for Jean to live her life.*

Hospitals are also starting to use algorithms. Hospitals use algorithms to choose:

- Who stays in a hospital vs. who gets sent home
- Who gets certain kinds of pain medications
- And many other decisions

These decisions can make it harder for disabled people to get the healthcare we need.

When algorithms cause discrimination, people with disabilities have a harder time living our lives. Technology discriminates against groups who already get treated unfairly by society. For example, a disabled person of color could get discriminated against for their race or their disability, or both. That's why discrimination in technology can be even worse for disabled people of color and disabled LGBTQ+ people.

Disabled activists have worked for years as part of the disability rights and justice movements. We have fought against discrimination that affects disabled people. Discrimination by technology is a new kind of discrimination. But it is not going anywhere. Algorithms and other technologies are becoming a part of everyday life. When people with disabilities use technology, there is more and more risk of problems happening. Disabled people could get hurt and discriminated against if technology does not think about us.

Even when people want algorithms to act a certain way, sometimes they act very differently. Some people think that it's impossible to fully understand algorithms. They think we can never really know how algorithms come up with their decisions. This idea is called the **"algorithmic black box".**

But this idea is not completely true. There are ways to change how an algorithm works. There are ways to make algorithms discriminate less. We just need to use better data to train the algorithm.

Right now, there isn't a lot of good data about people with disabilities. But having good data is really important, for lots of reasons. Data gets used in research that shows what disabled people need. Data helps disabled activists know what to advocate for. Data helps the government know how much money disabled people need for benefits. That's why we need to figure out the problems disability data has right now. Then, we can fix some of these problems, and also figure out how to make technology discriminate less against disabled people.

This paper talks about the things that need to be done, so that disability data can get better. A lot of the data we have right now leaves out disabled people. Or, it might not count disabled people the right way, or count enough disabled people. We also talk about why there isn't good disability data right now, and why good data is hard to get. Then, we talk about how we would fix these problems. We call the solutions we come up with the "disability data justice" approach.

Here is the list of things we think should change to make better disability data:

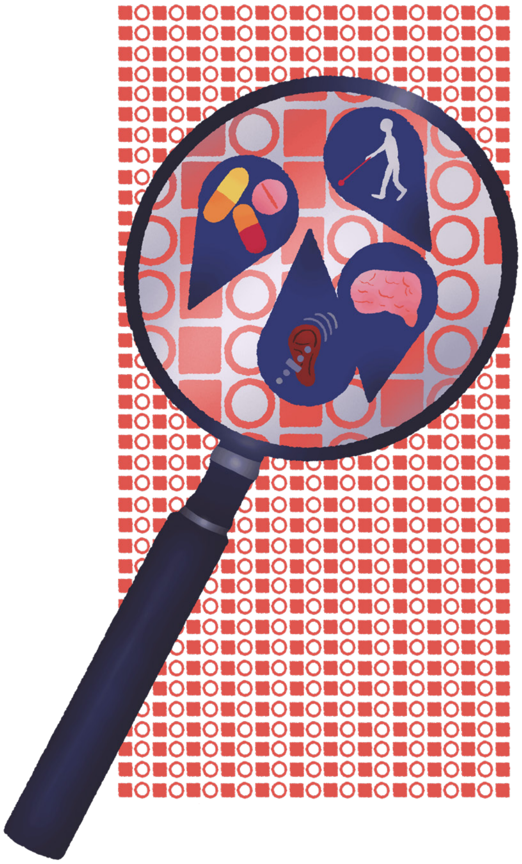
1. Disability data should get collected whenever other demographic data gets collected. For example, surveys asking about someone's age and race should also ask about disability.
2. Data should be collected and stored in ways that respect people's privacy.
3. New and better ways to decide who "counts" as disabled in data should get made. We also need to think of more inclusive ways to collect data.
4. People who work with disability data should keep trying to think of better ways to do their work.
5. People with disabilities should be a part of making and testing all technology.

6. Policies about technology need to get made by people with disabilities. Leaders in the disability rights and justice movements should be part of these decisions.
7. Data should be collected and stored in ways that are accessible to people with disabilities.

It will take a lot of work to change algorithms to be more inclusive of people with disabilities. But we think these changes are possible and that they need to be made.

03

What Are the Problems With Disability Data Sets?



There are many different kinds of data, and many people who collect data. A group of data used for one project is called a **data set**. Some data sets may say they have disability data. But that data might not actually show what it needs to for people to understand disability. Here is a list of ways data sets might not do a good job.

It does not actually have any disability data.

Some data sets don't collect any data about disability. This is a choice that the people collecting data made. These people may not think disability is a type of **demographic**. A demographic means a specific group of people in the world. For example, "people in their 20's" can be a demographic. "Black people" can be a demographic. Disability is a demographic, but some people collecting data don't count it that way.

Data collectors may also think disability data is too hard to collect. Or, they will say that information about disability is private, so they don't want to ask. But that means disabled people will probably still end up in the data set. The data collectors just won't know it. They won't be able to get good information from that data because they didn't ask about disability. So, they should just ask about disability anyway.

Not enough data about disability.

Here are some reasons data collectors can end up with not enough data about disability:

- Some data sets don't have enough disabled people in the set. The data collector might not have talked to enough disabled people.
- Sometimes, data sets decide what "disability" means in a way that leaves people out:
  - The dataset might ask people if they have certain disabilities, but not others.
  - The dataset might say disability means one thing, and leave people out who don't feel like they "fit" that meaning.
  - The dataset might leave out some people with disabilities, like people living in institutions or nursing homes.

Data gets collected the wrong way.

This means that the data is wrong. Here are ways that data can get collected the wrong way:

- Data about people's disability or disabilities can be wrong.
- Other data about a person can be wrong, even if their disability data is right. For example, someone's race gets written down wrong.
    - These mistakes can happen at 2 different times:
        - When collecting data
        - When going through the data to write about it

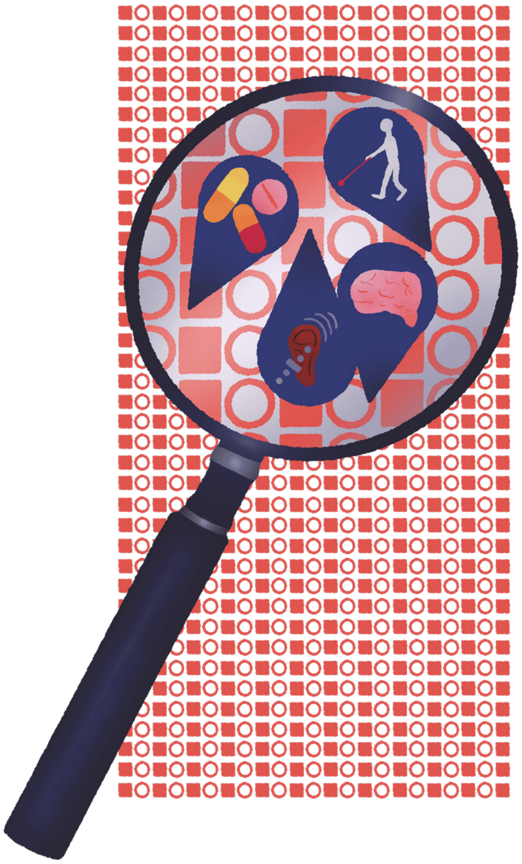
The ways we listed all make disability data sets less helpful for disabled people. When it comes to technology, algorithms that train on bad data sets do a worse job and make mistakes. They are more likely to discriminate against people. When disabled people don't get to be a part of data sets, algorithms don't understand people with disabilities. Then, when algorithms get used in places like jobs and hospitals, they might leave people with disabilities out. People with disabilities already get left out of society in many ways. This is another way that people with disabilities get discriminated against.

Many data sets don't have good disability data. That makes it harder to tell if an algorithm is discriminating or not. So, we need good disability data to fix how algorithms treat people with disabilities.

So far, we've talked about problems with disability data and data collection. Now, we will talk about why these problems happen, and how to make them better.

04

How Do We Decide What Disability Means? And How Does That Affect Data Collection?



When someone collects disability data, they need to decide what "disability" means. This is a big problem with disability data collection. People think about disability in many different ways. That means people collect different data about disability. They "count" who is or is not disabled in different ways. This makes it harder for people to know how many disabled people are actually in the data.

A **model** is a way that people think about something. Models also get called "frameworks" or "paradigms." We are going to talk about 4 different models of disability. Each model thinks about disability in a different way. The way people think about disability affects who gets "counted" as disabled.

Understanding each model of disability can help us understand how to collect better disability data. The 4 models of disability are:

1. The legal model

This model says that the law decides who is or isn't disabled. The legal model uses laws like the **Americans with Disabilities Act (ADA)**. The ADA is a U.S. law that protects disabled people from discrimination.

The ADA says that someone is disabled if:

- Part of their brain or body works differently from most people.
- They have trouble doing certain things, like: eating, sleeping, learning, reading, hearing, seeing, working, and breathing.
- It is hard or impossible for someone to do one or more things on the list above (seeing, reading, etc.).

The ADA also counts people who used to be disabled. It also counts people that other people think are disabled.

> *For example, Charles does not have a disability. He applies for a job at a supermarket. At his job interview, the interviewer says that Charles "looks disabled." The interviewer says he doesn't think disabled people can do the supermarket job. So, Charles doesn't get the job.*
>
> *It doesn't matter that Charles isn't really disabled. The interviewer still thought Charles was disabled. The interviewer still discriminated against Charles. So, Charles still gets rights from the ADA.*

The ADA is a really important disability law. But there are other laws that say what disability means. The **Social Security Administration (SSA)** has their own idea about what disability means. SSA runs benefit programs like SSI and SSDI.

The SSA says that someone is disabled if:

- They can't work because of problems with their physical or mental health.
- Their disability will last their whole life, or for more than a year.

The way that the ADA and SSA talk about disability are pretty different. That makes it harder for data collectors to decide who counts as disabled in their data. They can have a hard time even if they try to follow what the law says. On top of this, there are even more models of disability:

2. The medical model

This model thinks that disability is a problem caused by someone's brain or body. It sees brains and bodies that work differently than most people's as a problem. It says that the best way to deal with disability is to find a cure for it. It also says people with disabilities should try to seem "less disabled" to fit in better.

The medical model doesn't think about the reasons why disabled people have trouble getting by in society. It doesn't talk too much about things like discrimination. The medical model can make ableism worse for disabled people. If non-disabled people think all disabled people should get cured, they might not help disabled people live good lives. Disabled people shouldn't need to change who we are.

Many people also think that technology can solve the whole world's problems. They think technology can be used to cure disabilities. The idea that technology can "fix" disability is ableist. Disability is not a problem to be "solved." Using technology to try and cure disability is not what many disabled people want.

3. The social model

This is the opposite of the medical model. The social model says that society causes disability. Society makes it harder for people to get by if their brains or bodies work differently from others. The government may make it hard for disabled people to get what we need. And disabled people deal with all kinds of ableism and discrimination. These experiences are what make someone "disabled," not the things that may make their body or brain different.

The social model says we should not try to cure disability. Instead, others should help disabled people get what we need in society. They should make it easier for disabled people to live our lives.

4. The identity model

This model believes many of the same things as the social model. But the identity model also says that disability is part of who someone is. Disability is important to who you are, in the same way as race, gender, and ethnicity. That is why more people want disability data collected as part of demographic data.

All of these models "count" disability in different ways. The medical model usually only counts someone as disabled if a doctor said they were disabled. This is called getting a **diagnosis**.

But other models of disability let people decide themselves if they are disabled. For example, the Autistic Self Advocacy Network is a disability rights organization. Their website talks about who is a part of the autistic community. It says that, "Autistic people who were diagnosed by a doctor, and autistic people who figured out they were autistic on their own" are both part of the autistic community.

Thinking about disability like this makes things more inclusive. It welcomes people who might not be able to get to a doctor to get a diagnosis. It welcomes people who don't want a diagnosis. It also lets people see their disability as a part of who they are. The social and identity models let disabled people see themselves as a demographic. The medical model doesn't give people that same freedom.

The social and legal models might seem very different from each other. But the social model of disability is the closest model to what the ADA says. That's because the ADA doesn't just protect disabled people. It also protects people that others think are disabled.

Andrew Pulrang is a disabled activist and writer. He wrote for *Forbes* about the ADA, and how it counts disability. He said that the ADA thinks of disability more like an experience. Under the ADA, if someone goes through ableism, they have rights. This is very different from what the medical model says.

When there are so many different ideas about what counts as disability, people can get confused. Data collectors may not know that disability can mean so many different things. They might make data sets that use one meaning of disability, when a different one would be better. For example, a data collector may try to get disability data based on the medical model, when the social model would make more sense.

When data leaves out disabled people, it affects things in real life. It makes it harder to tell who needs services. And it makes it harder to tell if an algorithm is discriminating against disabled people. That's why data collectors need to work together to make better disability data sets. They need to decide what counts as disability. They need to make sure as many disabled people count as possible.

The Census Bureau is the part of the U.S. government in charge of counting people. Recently, the Census Bureau said it was going to change who counts as disabled in their data. They were planning on making some changes to their old survey questions to do this.

The Census survey questions ask if someone has trouble doing certain things. For example, getting dressed or taking a bath. All the old survey questions were "Yes" or "No" questions. If someone answered "yes," then they got counted as disabled.

The new survey questions were going to be written differently. People would be asked how difficult it was to do certain things, instead of a Yes/No question. Here is an example of what a question would look like:

How much trouble do you have taking a bath?

- No difficulty
- Some difficulty

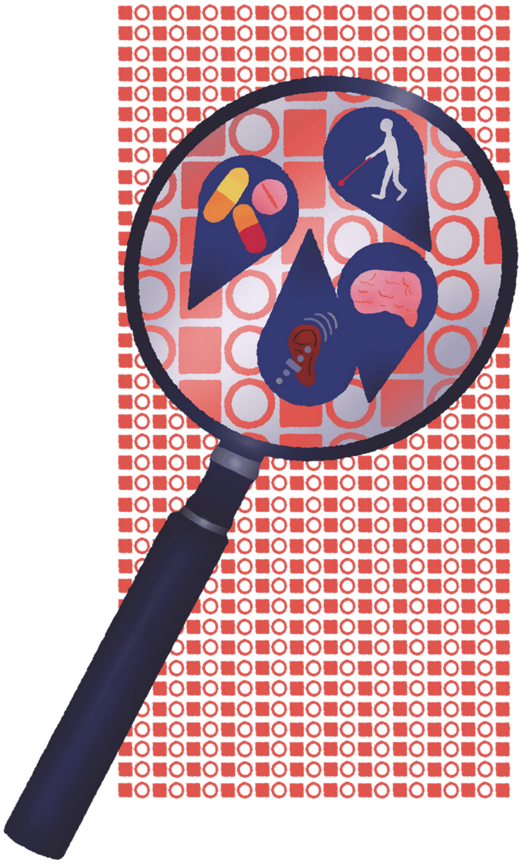
- A lot of difficulty
- I can't do this at all

These new questions would have changed who counted as disabled. Only people who answered "a lot of difficulty" or "I can't do this at all" would count as disabled. This would have made it look like there were 40% fewer disabled people in the U.S. But researchers and activists fought against the change. The Census decided to keep things the way they were before.

This situation shows how changing what disability means changes who gets counted in disability data. It can make it seem like there are a lot less disabled people than there are. This can mean less money gets set aside for benefits and services. It also makes it more likely for disabled people to get discriminated against by technology.

05

How Does Stigma About Disability Affect Disability Data?



Getting good disability data is also affected by stigma about disability. **Stigma** means bad attitudes or beliefs about a group because of who they are. For example, people with disabilities face a lot of stigma. People who aren't disabled may not understand that disability is not a bad thing. This might make some disabled people feel like they need to keep their disability a secret. That makes collecting disability data even harder.

There are other reasons someone might not want to say they are disabled, or even think they are disabled. If someone gets disabled later in life, it may be hard to adjust. They might not want to admit they have a disability. Others might feel guilty about needing help. They might not feel "disabled enough" to ask for help if they think others need it more.

People with disabilities might also be scared of facing discrimination. For example, many job applications ask about disability. But many people with disabilities don't say they are disabled on job applications. They know many bosses discriminate against disability. They think they won't get hired if they say they are disabled.

There is so much stigma about disability that some people won't even say the word "disability." They try to use replacement words, like "special needs" or "differently-abled." People use these words less now, but it still happens.

Most of these problems have to do with ableism. People with disabilities can feel ableism against themselves. This is called **internalized ableism**. Internalized ableism can make people feel grief and shame. It can make someone say they are not disabled, and make them ashamed of other disabled people. Ableism also leads to discrimination and stigma against disabled people. This all affects whether or not someone chooses to see disability as part of who they are.

In an essay for *Vogue*, Katie Baskerville wrote about ableism. She talks about how ableism affected her choice to say publicly that she is disabled. She uses a quote from disability activist Rachel Charlton-Dailey about internalized ableism. Charlton-Dailey says, "What we're taught in society is that to be disabled is the worst thing you can possibly be. So, of course people are not going to want to identify as disabled."

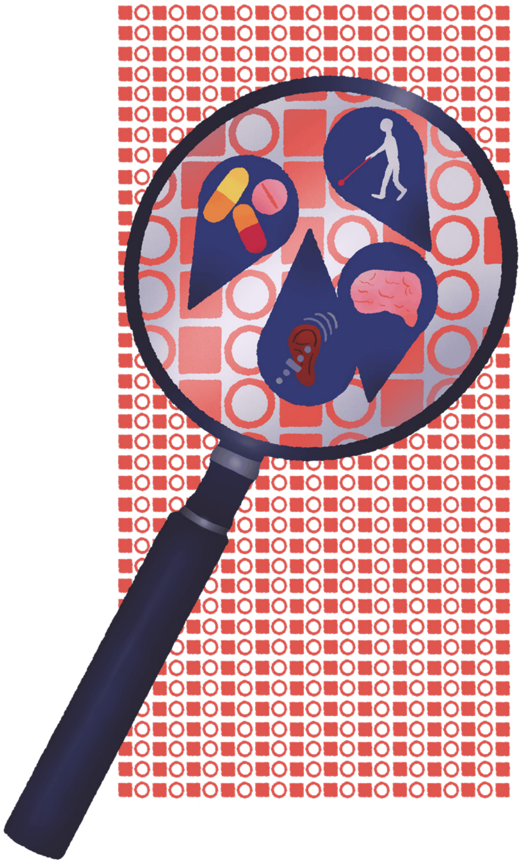
Baskerville wrote more about how disabled people experience ableism. She said that when others know about her disability, they might think she can't do things. She doesn't want people's opinions about her to change, or to face discrimination. So, she is careful about when she lets others know about her disability.

Stigma and discrimination keep many people from saying they are disabled. One study looked at a group of adults. It found out that 64% had a brain or body difference that could count as a disability. But only 12% of the adults said they had a disability. That means 52% of adults in the survey didn't say they were disabled, even though they could have. That's over half the people surveyed! This shows that the way disability data got collected did not work. Data collectors need to do better.

It will be really hard to fix disability stigma in our society. It takes a long time to change how people think. We hope that discrimination and ableism will end one day. In the meantime, we will talk about other ways to make disability data better.

06

When Disabled People Get Left Out of Data Collection



When people first started collecting data, they were not thinking about disabled people. The ways they came up with to collect data do not always work for people with disabilities. That means disabled people sometimes get left out of data collection. Because of this, the disability data we do have might not work for the real world.

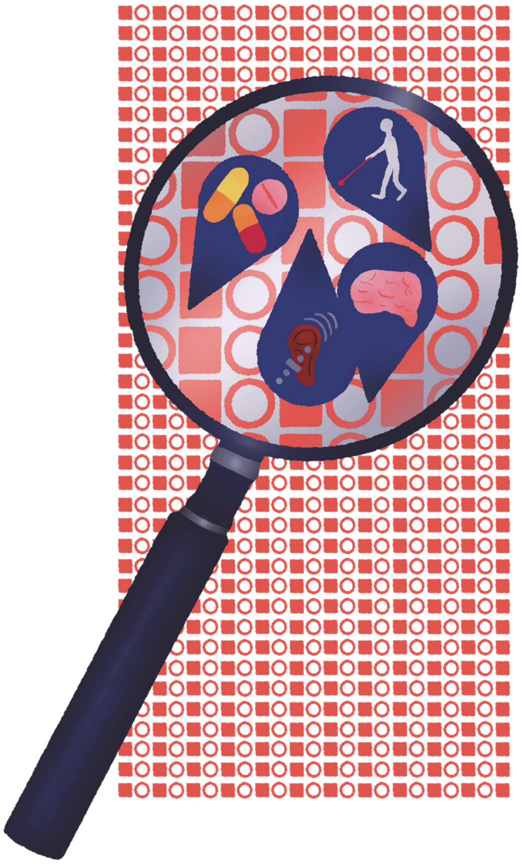
In all parts of data collection, there are ways disabled people get left out. People usually don't collect data from group homes, where many disabled people live. They also don't collect data at jails or prisons, even though many people in jails and prisons are disabled.

The ways that people collect data can also leave people out. For example, surveys are not always given out in accessible ways. The language might be too complicated, or it might not work with a screen-reader. This leaves out people with intellectual disabilities and blind or low-vision people.

Technology companies usually don't do a good job collecting disability data. They don't think as much about what disabled people need to use technology. But this leaves disabled people out. And there aren't enough laws or policies to make sure disabled people don't get left out.

07

The Cycle of Bad Disability Data



We talked about how disability data leaves people out, or gets measured the wrong way. These problems make it hard to know how many disabled people there are and what they need. And these problems make it even harder to start collecting good disability data.

The disability data we do have sometimes gets used in ways that hurt disabled people. But not having data on important subjects also hurts disabled people. For example, if there's no data about what services people need to access the community, the government won't pay for services.

Data collectors need to make sure disabled people are a part of their data. They need to make sure they collect data in accessible ways. If they don't, disabled people get left out. The data collectors may not even know they left disabled people out. They will make data sets and not know if disabled people are in it or not. This is a big problem, because now the data can't show the experiences of people with disabilities.

This problem gets even worse when people add in algorithms. Data sets without good disability data get used to train algorithms. If the algorithm doesn't understand disability, it is more likely to act in ways that discriminate against disabled people.

Then, the algorithm gets tested on bad data. **Testing** means that the algorithm gets given data on real-life situations to see how it will act. During these tests, it gets really hard to tell if the algorithm discriminates against people or not. That's because the algorithm didn't have good disability data to learn from. So, a researcher can't know for sure if the algorithm discriminates because of someone's disability. But even if the researcher can't know for sure, the algorithm could still be discriminating.

That means disabled people end up facing discrimination and may not know it. For example, earlier we talked about algorithms that reject job applicants who don't make eye contact. If a blind person didn't get a job there, they might think they just weren't good enough. But they were actually discriminated against.

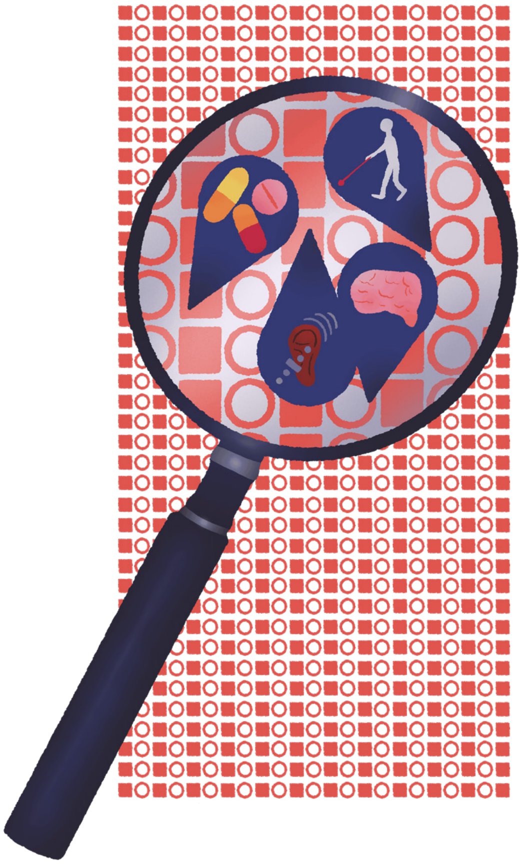
Other kinds of technology are also affected by disability data. Scientists need data about disabled people's experiences to make technology that works for them. Bad data can make it hard to know what things to change.

All of these problems make a cycle. Data collectors don't include people with disabilities. Then, people with disabilities choose not to share data about ourselves. That makes it so algorithms don't have good data and discriminate against disabled people.

This issue does not only affect disabled people. Disabled people come from many different demographics. For example, disabled people of color, or LGBTQ+ people with disabilities. It would hurt all these demographics if disabled people didn't get our data collected in the right way. We could lose out on data from other groups that get discriminated against. Then, algorithms might end up discriminating even more.

08

Disability Data Justice



In this last part, we will share what we think can help make better disability data sets. We call the solutions we come up with the "disability data justice" approach.

Disability activists have a saying: "nothing about us without us." Now, many people just say "nothing without us." This means that disabled people should be a part of all decisions, since everything affects disabled people. People with disabilities are affected by technology. Algorithms already affect many parts of the lives of disabled people. Problems with technology will keep happening as people use technology more in their everyday lives. The best way to fix these problems is to collect good disability data.

One of the goals of the disability rights and justice movements is to give more power to disabled people. We can use the disability data justice approach to give disabled people more power over disability data. We can help disabled people face less discrimination from technology.

Here are the parts of the **"disability data justice"** approach:

1. Disability data should get collected whenever other demographic data gets collected.

For example, surveys asking about someone's age and race should also ask about disability. Disabled people should have their data collected whenever other groups do. They should be a part of the data when it comes to:

- Voting
- Healthcare
- Jobs
- Schools
- Technology (like algorithms and artificial intelligence, or AI)

This idea is called "disability data in all places." Making sure data gets collected in more places will make data sets larger. The data will be more true to the real-life experiences of people with disabilities. That helps people working with data to understand what disabled people need.

Data collectors should never collect someone's data without asking. They need to make sure the person is okay with having their data collected. This is really important for people who usually get discriminated against. They might not trust data collectors again if their data gets taken without asking. Collecting data should also never get used to spy on what someone is doing.

Sometimes, demographic data gets collected for bad reasons. We don't think anyone should give out their demographic information when this happens. But there are lots of good reasons to give out demographic information. And when data collectors do get demographic information for good reasons, they should always get disability data.

2. Data should be collected and stored in ways that respect people's privacy.

Data collectors should have rules for collecting data. They should only collect the data they need and not any more. They should get rid of the data once they finish their project. They should also get rid of someone's data if that person asks.

Data collectors should only use their data for the reason they decided before collecting the data.

> *For example, Kiley starts a project about the flu. She collects data from people about their demographics. She also asks if they've had the flu and if they got the flu vaccine.*
>
> *Kiley should only use this data for her project about the flu. Kiley has other ideas for projects, and wants to use the data she already has. But if she starts a new project, she needs to get new data. That's because she didn't get permission from the people who gave her information about the flu. Those people didn't say Kiley could use that information for other projects.*

3. Data collectors need to make better ways to collect disability data.

They need to decide together who "counts" as having a disability. They need to make sure that as many people count as possible.

Data collectors should talk to people with disabilities. People with disabilities can show the problems that disability data has now. Disabled people can also share our experiences to help make better ways to collect data.

4. People who work with disability data should keep trying to think of better ways to do their work.

They should keep trying their best, even if they mess up. Disability data that doesn't have enough information is better than no data at all.

5. People with disabilities should be a part of making and testing all technology.

We should especially get to test things like algorithms and AI tools.

There are certain places where technology is extra important to disabled people. People with disabilities work with technology at school, jobs, in healthcare, and in benefit programs like SSI/SSDI. Disabled people need to play a big part in making technology for these places.

6. Policies about technology need to get made with people with disabilities.

Leaders in the disability rights and justice movements should be part of these decisions. This helps make sure these policies actually help disabled people, and solve some of technology's problems.

7. Data should be collected and stored in ways that are accessible to people with disabilities.

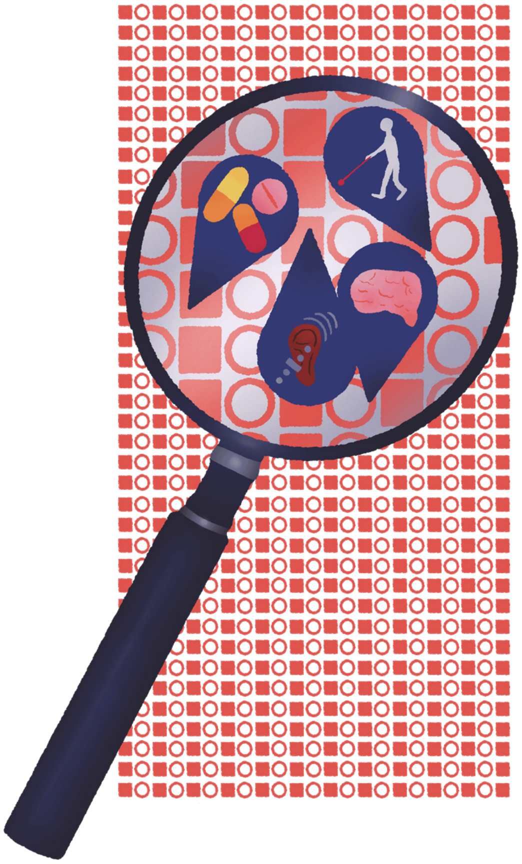
For example, people who are blind should be able to read data with a screen-reader. This makes sure people with disabilities can understand the data about their lives.

Algorithms and other technologies keep getting made without thinking of disabled people. These technologies don't use data that counts disabled people or their experiences. These choices lead to disability discrimination and ableism.

Technology is very powerful, and can help or discriminate against disabled people. Data gives power to technology. People with disabilities need to be able to use this power. Collecting better disability data is an important place to start.

09

Learn More



A Need for Disability Data Justice

This article gives a basic list of Disability Data Justice tips. https://www.healthaffairs.org/content/forefront/need-disability-data-justice

Civil Rights Standards for 21st Century Employment Selection Procedures

This report talks about hiring for jobs. https://cdt.org/insights/civil-rights-standards-for-21st-century-employment-selection-procedures/

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

This report talks about how algorithms get used to decide who gets benefits. https://cdt.org/insights/report-challenging-the-use-of-algorithm-driven-decision-making-in-benefits-determinations-affecting-people-with-disabilities/

‘You’re not God’: Doctors and patient families say HCA hospitals push hospice care

This news report shows how some hospitals use algorithms to decide who gets to stay there. https://www.nbcnews.com/health/health-care/doctors-say-hca-hospitals-push-patients-hospice-care-rcna81599

AI’s mysterious ‘black box’ problem, explained

This article talks more about the algorithmic black box. https://umdearborn.edu/news/ais-mysterious-black-box-problem-explained

Disability Rights Timeline

This resource from Temple University talks about the history of disability rights. https://disabilities.temple.edu/resources/disability-rights-timeline

What is Disability Justice?

This webpage by Sins Invalid explains what disability justice is. https://www.sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice

Count Everyone, Include Everyone

This report talks about making sure disabled people are a part of government data. https://www.ndrn.org/wp-content/uploads/2021/10/NDRN_Count_Everyone_Include_Everyone_2021.pdf

Comparing Measures Of Functional Difficulty With Self-Identified Disability: Implications For Health Policy

This study found out that many people that could "count" as disabled don't think they are disabled. https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00395

Introduction to the Americans with Disabilities Act (ADA)

This government webpage has lots of information about the ADA. https://www.ada.gov/topics/intro-to-ada/

Social Security Administration (SSA) Red Book – How do we define disability?

This resource from the SSA says how they decide who is disabled. https://www.ssa.gov/redbook/eng/definedisability.htm?tl=0

Medical and Social Models of Disability

This webpage explains the differences between the medical and social model. https://aec.uoregon.edu/content/medical-and-social-models-disability

Technosolutionism

This article talks about the idea that any problem can get solved with technology. https://digitalrightswatch.org.au/2021/03/25/technosolutionism/

Ask Disabled People What They Want. It's Not Always Technology

This book chapter talks about disabled people's difficult experiences with technology. https://www.sciencefriday.com/articles/against-technoableism-excerpt/

Disability Culture and the ADA

This article talks about how things have changed in the years since the ADA passed. https://dsq-sds.org/index.php/dsq/article/view/4936/4062

The Census Bureau is dropping a controversial proposal to change disability statistics

This article talks more about the changes the Census Bureau planned to make. https://www.npr.org/2024/02/06/1229547255/census-bureau-survey-disabled-people-with-disabilities

The next Census could undercount the number of disabled Americans by 20 million.

This article also talks more about the changes the Census Bureau planned to make. https://www.statnews.com/2023/11/27/disabled-americans-estimate-census-acs-washington-group-questions/

Disability Language Guide

This guide teaches people how to talk about disability. https://disability.stanford.edu/sites/g/files/sbiybj26391/files/media/file/disability-language-guide-stanford_1.pdf

Destigmatizing Disability.

This article talks about disability stigma and how to fight back against it. https://www.ncall.us/2021/07/19/destigmatizing-disability/

The Pros And Cons Of Identifying As Disabled.

This article talks about reasons why disabled people may or may not choose to say we are disabled. https://www.forbes.com/sites/andrewpulrang/2023/01/19/the-pros-and-cons-of-identifying-as-disabled/

Disability – The Prison Policy Initiative.

This webpage has research and data about disabled people in prison. https://www.prisonpolicy.org/research/disability/

Disability and COVID-19: who counts depends on who is counted.

This article shows how little disability data got collected during COVID-19. https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(20)30161-4/fulltext

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