A Report of the COVID-19
Health Disparities
Statewide Leadership
Task Force

August 2023

RECOMMENDATIONS TO REDUCE COVID-19 HEALTH DIFFERENCES FOR PEOPLE WITH DISABILITIES

in Plain Language

COVID-19 HEALTH DISPARITIES AMONG THE DISABILITY COMMUNITY

PROJECT OVERVIEW

Our project brings together people who care about disabilities and health care to listen, talk and learn about how COVID-19 affects people with disabilities differently than other people. We will ensure that people with lived experience of disability and their families join the conversation and have their voices heard as we establish state and regional partnerships. These partnerships will bring public health, health care, disability, and non-health interventions together to meet the needs of people with disabilities, including those from different races, ethnic backgrounds, and who live in all places.

EXECUTIVE SUMMARY

With funding from the Pennsylvania Department of Health through the Centers for Disease Control and Prevention (CDC)'s National Initiative to Address COVID-19 Health Disparities Among Populations at High-Risk and Underserved, The Arc of Pennsylvania, with the help of the Statewide Leadership Task Force, has been working on finding answers to these questions:

- To what extent have we used a disability-inclusive approach to combat COVID-19?
- To what extent will we use a disability-inclusive approach to prepare for future emergencies?

A disability-inclusive approach means that the interests, ideas and needs of people with disabilities are included every step along the way.

The first thing we did was create a report called "COVID-19 Health Care Barriers Among People with Disabilities." We did interviews, surveys, and meetings to collect information about the problems people with disabilities faced during COVID-19. We see barriers as things that make it harder for people with disabilities to get health care and for that health care to help them.

This report to the Pennsylvania Department of Health is about ways to solve these problems with recommendations. We created the list of recommendations after collecting ideas from interviews, surveys, and meetings.

PROJECT BACKGROUND

The COVID-19 pandemic has been difficult on everyone, but for some groups, including and especially the disability community, its impact has been staggering. This is even more the case for those in the disability community who live in rural areas and those belonging to racial and ethnic minorities.

The Arc of Pennsylvania received funding from the Pennsylvania Department of Health to investigate and report on the difficulties faced by people with disabilities during the pandemic. We held "listening tours" by bringing together people who care about health care for people with disabilities to listen and talk. We learned about many issues that people with disabilities face in their health care such as:

- Difficulty getting information that was able to be understood (in plain language, in braille, in languages other than English)
- Less access to testing, vaccinations, and accommodations

- Health Care Providers lack of understanding how to work with people with disabilities
- Higher risk of severe illness or death from COVID-19

In August 2022, a group called the Statewide Leadership Task Force (Task Force) published a report about the problems that people with disabilities face when it comes to getting health care during the COVID-19 pandemic. The report is called [COVID-19 Health Care Barriers Among People with Disabilities](#).

With the information we learned from that report, the Task Force created ten main recommendations for the Pennsylvania Department of Health to help improve health care for people with disabilities during the pandemic and for future emergencies. These recommendations are the most important ones.

At the end of the report, the Task Force included fifteen more recommendations. Some of the fifteen recommendations might need more than one government department to work together, not just the Department of Health.

CORE RECOMMENDATIONS

1. Provide opportunities to involve people with disabilities, their families, and caregivers in policy making and health care decisions.
2. Restart the Governor's Cabinet and Advisory Committee for People with Disabilities.
3. Keep helpful policy changes from the COVID-19 Pandemic.
4. Expand health care to where people live, by using services such as telehealth and mobile clinics.
5. Include disability representatives in the Office of Health Equity Advisory Committee.
6. Provide disability-specific training for health care professionals.
7. Put people with disabilities in the category, Medically Underserved Population.
8. Collect information like standardized data on the health needs of people with disabilities.
9. Provide information in ways that everyone can understand, such as in plain language, braille, and in multiple languages.
10. Prohibit ranking of the life of a person with disabilities as less than a person without a disability when making health care decision during emergencies.

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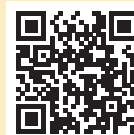
**If You Have an iPhone or Android Phone**
Every iPhone running iOS 11 or later and most phones running Android 9 or later can scan a QR code directly from the camera app.
1. Open the camera app.
2. Center the QR code you want to scan on the screen and hold your phone steady for a couple of seconds.
3. Tap the notification that pops up to open the link. (You will need to be connected to the internet to do this.)

How to Scan with Google Lens
If your camera app doesn't seem to work for you, Google Lens is a good alternative. You can install the Google Lens app for free. Here's how to use it:
1. Tap the color lens icon in Google Assistant, or open the Google Lens app.
2. Select the Search mode.
3. Center the QR code that you want to scan on the screen and hold your phone steady for a couple of seconds.
4. Tap the notification that pops up to open the link. (You will need to be connected to the internet to do this.)
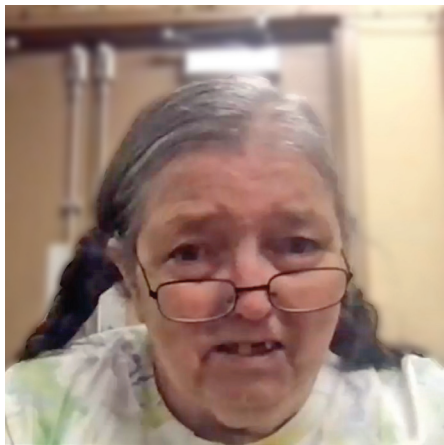
JANET MINICK

"We're not second-class citizens and we're not a menace to anybody.

We're just the same as everybody else, we just operate a little bit differently."

Self-Advocate
Allegheny County
[Janet's Experience](#)

INTRODUCTION

For more than 70 years, The Arc of Pennsylvania has been advocating for the rights of people with disabilities. Thanks to funding and support from the Pennsylvania Department of Health Grant through the Centers for Disease Control and Prevention's (CDC) National Initiative, The Arc of Pennsylvania has been able to learn about the differences in health for people with all kinds of disabilities across the state, during the COVID-19 pandemic.

The CDC says that health equity means everyone has a fair chance to be as healthy as possible. It's important to address the unfair treatment people have faced in the past and make sure everyone has access to good health care. We need to get rid of health disparities that can be prevented.[1,2]

Health equity relies on changing our health care systems, policies, and practices to include people with disabilities. People with disabilities have always faced unfair health problems, and the COVID-19 pandemic made these differences even clearer.

We need to focus on the wider differences faced by people with disabilities who also come from all races, ethnicities, and live in rural areas. During the pandemic, people with intellectual disabilities were almost 6 times more likely to die from COVID-19 than others.[3] This shows that we urgently need better solutions in Pennsylvania to make sure people with disabilities don't face these outcomes in the future.

During the first year of this project, The Arc of Pennsylvania worked with many individuals from disability and health care organizations to create a group called the COVID-19 Health Disparities Statewide Leadership Task Force. This group is called the "Task Force". The Arc of Pennsylvania collected information from hundreds of people with disabilities across the state about the problems they faced in getting health care during COVID-19. The Task Force published a report called "COVID-19 Health Disparities Among People with Disabilities" to share what they found.

Scan QR Code to access the report.

The solutions report is divided into two parts. The first part is called "Core Solutions" and gives ten recommendations for the Pennsylvania Department of Health to make changes within that department. The second part is called "Additional Solutions"

and includes fifteen recommendations. These recommendations might be for the Pennsylvania Department of Health, or might need more than one government department to work together, not just the Department of Health.

In this report, we use the words "health care professionals" to refer to all the people involved in providing physical and mental health care.

METHODOLOGY AND SAMPLE

METHODOLOGY

The Arc of Pennsylvania listened to many different people in Pennsylvania who have disabilities, their families, caregivers, and professionals who work in the fields of disabilities and health care. During the first year of the project, we wanted to find out what problems people with disabilities face when trying to get health care in Pennsylvania. Once we understood the problems better, we started looking for solutions to fix them.

We collected information by asking people questions online and in focus groups called listening tours. Everyone was asked the same two questions:

- What are the most important recommendations for using a disability-inclusive approach to combat COVID-19 and other health care emergencies?
- What are other recommendations for using a disability-inclusive approach to combat COVID-19 and other health care emergencies?

A disability-inclusive approach means considering the interests, ideas and needs of people with disabilities are included every step along the way.

The listening tours were like group discussions where people could talk about their answers. The Arc of Pennsylvania and local Arc chapters organized the listening tours.

We examined all the information received and organized it by the patterns we saw. We also made sure that different people reading the information and identifying the patterns agreed with one another. We asked regional groups of health care professionals and people with disabilities to review the ideas and choose the most important ones. From hundreds of ideas, the Task Force selected ten main recommendations and fifteen additional recommendations.

SAMPLE

The Arc of Pennsylvania talked to many people from all over the state. We talked to people with lived experience of disability, their families, caregivers, health care professionals, and leaders of advocacy organizations. We heard from people with different kinds of disabilities, like physical, intellectual, developmental, behavioral, emotional, sensory, and complex medical disabilities. We made sure to include people from all races and ethnic backgrounds to understand how disability and race are connected. We reached out to all kinds of people in Pennsylvania, and people from different races and ethnicities participated and paid special attention to those thought of as "underrepresented" groups, like Hispanic, Asian American, African American/Black, Indigenous, and LGBTQIA+ communities.
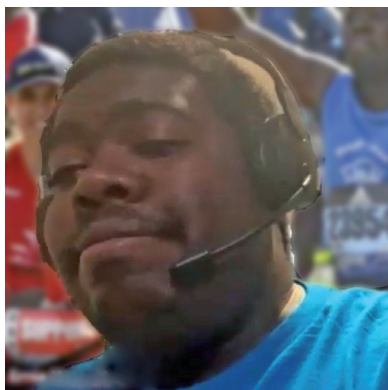
"You do not have lived experience, you leave stuff out, and in leaving stuff out you put people with disabilities' lives in danger, to the point where they can die."

Person Living Well with a Disability

Dauphin County

[Theo's Experience](#)

THEO BRADDY

ERNIE ROUNDTREE

"We're talking about inclusion and people with disabilities, sometimes we are not included in the conversations."

Special Olympic Athlete and Self Advocate

Monroe County

[Ernie's Experience](#)

RECOMMENDED CORE SOLUTIONS

CORE SOLUTION #1

Provide opportunities to involve people with disabilities, their families, and caregivers in policy making and health care decisions.

The Task Force suggests the Pennsylvania Department of Health involve people with disabilities and their families and caregivers to have a say in how health care is planned and carried out.

The Task Force suggests the Department of Health provide support for people with disabilities and their families and caregivers to participate at all levels, including their state and regional offices. The barriers to health care for people with disabilities are complicated and can be hard to understand if you haven't experienced them yourself. Even though people with disabilities face some of the biggest differences in health care, most decisions about their health care are made without them. If we don't involve people with disabilities and their families and caregivers when making decisions, we won't be able to fix these differences.

Examples of including people with disabilities and their families and caregivers in policymaking and decisions include hiring more people with disabilities for important jobs in the Department of Health and bringing back the Governor's Cabinet for People with Disabilities.

Other examples would be to learn from people with disabilities and their families and caregivers through listening sessions, panel discussions, discussions and working together with advocacy groups. For health care decisions made during health care emergencies, the focus should be to make sure health care professionals listen to and respect the voices of individuals with disabilities when making decisions, especially during health care emergencies.

Restart the Governor's Cabinet and Advisory Committee for People with Disabilities.

The Task Force suggests restarting everything in the Executive Order 2006-09 including bringing back the Governor's Cabinet for People with Disabilities and the Governor's Advisory Committee.

When rules are made or planning is happening for all people in the state, it is important that people with disabilities are involved and in-charge at every step along the way. The Task Force recommends appointing a person with a disability with knowledge about health care to the Governor's Cabinet and Advisory Committee. The Department of Health should help make this suggestion happen, so the needs of people with disabilities are considered wherever decisions are made.

The Governor's Cabinet for People with Disabilities and the Governor's Advisory Committee was created in 2006 when Edward Rendell was governor to give advice to the Governor on things that mattered for people with disabilities. This was an important step forward. However, right now, the Cabinet and Committee aren't meeting and there is no one running the Cabinet. It's important that people with all kinds of disabilities are part of the Cabinet and Committee so the specific problems they have can be understood and fixed.

"People with disabilities who have access needs weren't part of plans at the beginning - honestly, sometimes not even by the end."

Autistic Adult and Parent to Disabled Children

Allegheny County

Sharon's Experience

SHARON JANOSIK

Keep Helpful Policy Changes from the COVID-19 Pandemic.

The Task Force suggests keeping the policy changes and flexibility that were made during the COVID-19 pandemic. These changes helped people with disabilities in Pennsylvania get the care and services they needed. It's important to make sure these changes continue, and that health systems and professionals include the voice of people with disabilities.

During the pandemic, there were some good changes in how health care was given. For example, telehealth let people have their doctor's appointment in their home, which helped people who couldn't get to the office or who had an office that was not accessible. Another change was allowing support staff and families to be with someone in the hospital during the pandemic, even if there were quarantine rules. This change made people feel better and helped them get the right care.

Direct Support Professionals (DSPs) were also put in a category called "essential workers" during the pandemic, which meant they could keep helping people with disabilities. But in the beginning, there were problems understanding what "essential worker" meant so DSPs, did not get masks, gloves and did not get the COVID-19 vaccine early. It's important for the Department of Health to work with other agencies to make sure DSPs are categorized as "essential workers" in future emergencies.

The Task Force wants the helpful changes to stay in place after the pandemic is over. They also want future plans to include the voice of people with disabilities and their specific needs.

APRIL TUCKER

"I did end up quitting my job. We had gone through about seven nurses."

Mother of a Daughter with Multiple Disabilities

Allegheny County

April's Experience

Expand health care where people live, by using services like telehealth and mobile clinics.

The Task Force suggests adding telehealth services and mobile clinics to the Community-Based Health Care Program to make health care better for people with disabilities. People with disabilities have problems getting the health care they need. Many medical offices make it hard for people with disabilities to go there or to get the help they need there, and this causes a difference so the health of people with disabilities is worse than people without disabilities.[4]

Telehealth allows people to see their doctors through video calls, which means they don't have to go in-person. This helps when it's hard to get to the office by transportation, when wheelchairs can't get into the office, and when the office is too loud or confusing.[5] Mobile health care clinics bring health services to people everywhere, including rural places and cities, making it easier for people to get care. With mobile clinics, people go to the emergency room less and it saves money.[6,7]

It's important to remember that not all services can be done through telehealth or mobile clinics. Flexible health care should be available, which means in-person, telehealth, and mobile clinics should be choices. Lastly, the Task Force suggests making sure people follow the laws in the Americans with Disabilities Act and Affordable Care Act.

By making these changes, people with disabilities can get better health care and have less health differences from people without disabilities.

"Telehealth worked for me. I know it's difficult to help you make an egg over the phone, but you can talk about how your day went."

Person with a Mental Health Condition

Butler County

Jeffrey's Experience


JEFFREY DENNISTON PHD, CPS

Include disability representatives in the Office of Health Equity Advisory Committee.

People with disabilities often have worse health than people without disabilities, but their needs are often left out. To make things better, the Task Force suggests appointing a disability representative to the Department of Health's Office of Health Equity Advisory Committee.

The Office of Health Equity Advisory Committee helps the Secretary of Health by giving advice on health differences. But there is no one on the Committee who knows firsthand about the health differences for people with disabilities. This new representative should have lived experience of disability and know about the health care system.

And, because one person can't represent everyone with a disability, the Task Force recommends having local representatives in each regional Department of Health office. These representatives should be people with disabilities, family members, or caregivers. They can share important information about the needs of people with disabilities in their region. It's important for people from all races, ethnic groups, and cultures are included to make sure everyone's voice is heard. These local representatives will then share what they know with the disability representative on the Health Equity Advisory Committee.

By having disability representatives in the Department of Health, people with disabilities can get better health care and have less health differences from people without disabilities.
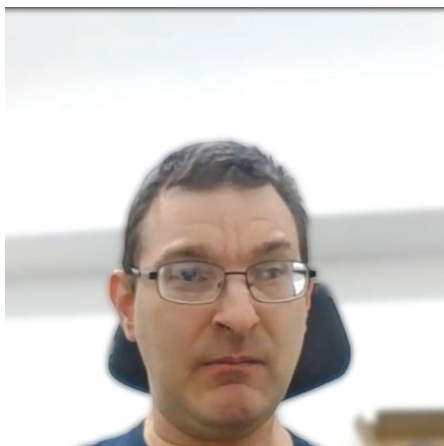
**BRIAN
HABERMEHL**

"The voices of people with lived experiences must be heard. We all have the right to share our stories."

Self Advocate
Susquehanna County
Brian's Experience

Provide disability, person-centered training for health care professionals.

The Task Force suggests that health care providers and community members be required to receive training on how to work with people with disabilities. This training should focus on the specific challenges and needs of people with disabilities so that health care professionals can provide the best care possible.

Health care providers and community members include medical professionals, mental health professionals, support staff, government officials, employers, police officers, community groups, caregivers, and family members. To help health care providers and community members learn, the Task Force is suggesting that disability-specific, person-centered training is required for new health care professionals and for license renewals.

The training should cover the disability experience for people of all races, cultures, ethnicities and those that have mental health needs. During the barriers listening tour, people with disabilities shared that there are not enough health care providers who understand and can meet their needs.[8] This can cause health care providers to refuse to help the person or diagnose them with the wrong problem and give the wrong treatment.[9]

The Task Force recommends including people with disabilities and their families to design the training or as a teacher. They have firsthand knowledge of the problems people with disabilities have and face and can share important information. The training should include using plain language, understanding the history of people with disabilities, laws and rules, person-centered approach, understanding that behavior is a form of communication, understanding, and good communication with people with disabilities.

By providing this training, we can help health care providers better understand and meet the needs of people with disabilities, improving the quality of care they receive.

"Training, professional development, and awareness for providers would be helpful so that they're able to meet and serve everybody and understand how everybody has unique needs."

Parent Of A Beautiful, Unique, and Magnificent Daughter with Down Syndrome, an Intellectual Disability

Philadelphia County

[Marjorie's Experience](#)

MARJORIE ANDERSON

Put people with disabilities in the category, Medically Underserved Population.

The Task Force recommends that People with Disabilities be put in the category, Medically Underserved Population so they will get more attention and funding for their health care. It would encourage health care professionals to learn more about this group and take away financial problems that make it harder for health care systems to give the care people with disabilities need.

To be put in the Medically Underserved Population, a group must not have enough health care professionals. People with disabilities across the country do not have enough health care professionals.[10] For example, in a survey of doctors, only about half felt they welcomed people with disabilities and even less felt they provided good care.[11] Another study learned that some doctors suggested sending patients in wheelchairs to places like supermarkets, grain elevators, zoos, or cattle processing plants to be weighed.[12]

These studies clearly show that people with disabilities find it hard to find health care professionals who can meet their needs. Putting them in the category of Medically Underserved Population would be an important first step in putting their health care first and making sure there is enough support to end health differences for people with disabilities.
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"You let them know your needs ahead of time, then the staff themselves don't know how to meet those needs."

Person with a Physical Disability
Erie County
Kelly's Experience
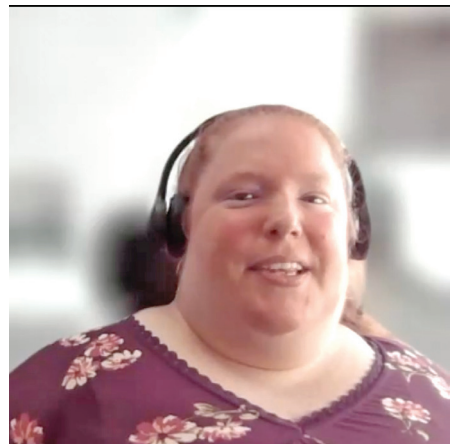
KELLY BARRETT

Collect information on the health needs of people with disabilities.

The Task Force suggests that the Pennsylvania Department of Health gather information in a way that helps them understand the health needs of people with disabilities. Currently, there are different ways information about disability in medical and health records is collected. Having information is important because it helps health systems understand the specific needs of people with disabilities and find ways to improve access to health care.

To collect this information, it's important to ask the same questions about disabilities so that everyone understands the same thing. Collecting information about different types of disabilities, where people live, and how race, ethnicity, and a person's financial health will help people understand how disability looks for different types of people. The Department of Health can require this information to be collected in all its programs and services and encourage other organizations to do the same. It's very important to collect information that is honest, responsible, and to report it correctly. When someone with a disability dies or has a bad health experience, it's important to record the actual cause, not just disability. This information will help support the Task Force's other recommendations and provide evidence for advocating for the disability community.

Lastly, changes need to be made to the Department of Health's website, such as changing outdated language like "mental retardation" to more inclusive language. The Task Force also recommends that the Office of Health Equity within the Department of Health specifically focus on including the disability community in their work to address the needs of all people at high risk for poor health in Pennsylvania.

SHARON JANOSIK

"Not everyone that needs those services fits into a category we predetermined decades ago."

Autistic Adult and Parent to Disabled Children

Allegheny County

Sharon's Experience

Provide information in ways that everyone can understand, such as in plain language, in braille, and in multiple languages.

The Task Force suggests that the Pennsylvania Department of Health should make sure that all the information about people's health care and well-being be shared in plain language, and in different languages, so all people in Pennsylvania can understand important health information.

During the COVID-19 pandemic, some information was not accessible to everyone. It is important to release information in different ways and in a timely manner, both online and in print. This includes making information available in braille, large print, American Sign Language, with closed captioning, using interpreters who interpret language correctly, and having bilingual consultants in health care settings.

Using plain language is important because it makes information clear and easy to understand. It uses simple words, helpful pictures and graphs, describes images, and explains hard words. The Department of Health should show people how to help people understand complicated information. They can also share information about social stories, which help people get comfortable and know what to expect for their medical appointments and vaccinations. Social stories can help with being nervous or anxious

The Task Force recommends that all information from the Department of Health be translated into multiple languages before it is shared and is shared at the same time the English versions are shared. This ensures that people who don't speak English as their first language can get information at the same time as everyone else.

During the health care barriers listening tour, The Arc of Pennsylvania talked to people who spoke Spanish and Mandarin to understand their specific problems. Many of them said that the lack of translated information caused panic and confusion about COVID-19 and vaccinations. It was a threat to their family's safety and health.

The Pennsylvania Department of Health needs to release information that is easy to understand and translated into different languages, so that all Pennsylvanians can get important health information at the same time.

"That health information is so critical, any kind of inaccuracy or discrepancy in information could lead to something significant."

Parent and Advocate of a Child with Autism

Montgomery County

Jenny's Experience
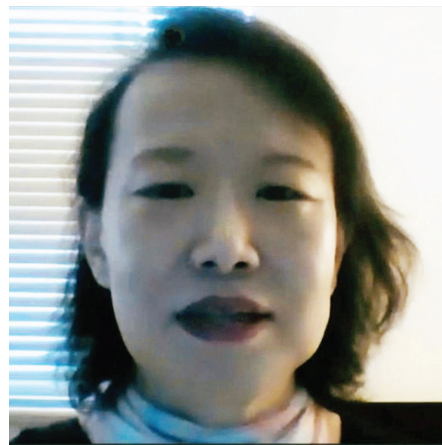
JENNY

> *"People thinking that people with disabilities are not worth living, they don't bring value to society, and therefore if it comes to an abled bodied person and a person with a disability, let's treat the able-bodied person."*

THEO BRADDY

Person Living Well with a Disability
Dauphin County
[Theo's Experience]

CORE SOLUTION #10

Prohibit ranking the life of a person with disabilities as less than a person without a disability when making health care decision during emergencies.

The Task Force suggests that disability should not be used as a measure when making decisions about who receives care during times when not enough health care resources are available.

During the COVID-19 pandemic, hospitals faced a sudden increase in patients needing care, including those with severe cases of the virus who required life-saving measures like ventilators. Because there weren't enough ventilators for everyone, hospitals had to make difficult decisions about who would receive the ventilators.

Some hospitals used a measure called Quality-Adjusted Life Years (QALYs) to help make these decisions. Unfortunately, QALYs ranks the life of a person with disabilities as less than a person without a disability because it incorrectly believes that their quality of life is lower.

The Task Force recommends that having a disability should not be part of deciding who receives life-saving support.

ADDITIONAL RECOMMENDATIONS

Below are additional recommendations from our listening tours, with different types of people. While they are not in the top ten core recommendations, they are still important for addressing health differences for people with disabilities and their families. Some of these recommendations might need more than one government department to work together, not just the Department of Health.

1. Make technology more available and accessible.
2. Work together with different agencies to tackle health disparities.
3. Improve the accessibility of health care facilities and equipment for people with disabilities.
4. Expand transportation services.
5. Increase pay and rewards for qualified staff who provide direct support to people with disabilities.
6. Develop a statewide curriculum, which is an education plan, used to teach about disabilities and cultural diversity and include what should be taught and a give a certification.
7. Increase funding for Direct Support Professionals, care providers, support staff.
8. Look for ways to hire various health care workers, such as nurses, social workers, and mental health workers.
9. Give training on telehealth and technology for support staff, caregivers, and people with disabilities.
10. Have health care cover more health services and provide more people health care insurance.
11. Provide more resources for health care and wellness in the community where people live.
12. Make sure people can get housing.
13. Make sure that staff working with people with disabilities are well trained.
14. Add additional health care practices and policies.
15. Add more money for emergencies and to help with money problems during emergencies.

END NOTES

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VIDEO LINKS

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August 2023