Self-Determination

➔ Covid-19 is a complicated illness. Believe we are capable of understanding what's going on.

➔ We get it. Everyone wants us to be safe. Unfortunately the progress we have made as a movement for society to embrace self-determination is slipping away.

➔ Often people do not consider us smart enough to assess how risky a situation might be
Self-Determination

➔ We cannot just keep living as a hermit and hide from the world. We want to live our lives.

➔ We are tired of people telling us, what they want us to do. It's our lives.

Information

➔ We need clear information explaining the differences between the pandemic phase and the endemic phase.

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Mental Health

➔ We understand we need to focus on our physical health, but we also need information on how we keep ourselves healthy mentally.

➔ Technology helped but it does not make up for the loneliness. We need resources to recognize when to seek out mental health support.

➔ More information about depression. Are we just feeling sad and the sadness will pass, or do we need to see someone? Explain it in ways we can understand. We need to know what to do about it.

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Ever Changing Advice

➔ You get one set of rules from your family and often another set of rules from your support staff, and you also have your town telling you what to do to.

➔ Explain why the CDC switched from focusing on counting cases to counting hospitalizations. The US map was red for months and then it seemed like overnight it turned green.
Misinformation

➔ We need more tools on how to identify misinformation
➔ We still need to know what to say to stop misinformation about the pandemic and China. This has increased hate and discrimination of Asian people. We need to stop this misinformation.
Boosters

→ We are not getting a clear message from the disability community about our eligibility for a second booster.

→ Does everyone with a disability need to get a second booster or just people who are fragile.
Testing

➔ When you get a positive test and you have to isolate for five days, can you still, cuddle with your dog or cat?

➔ Do the at-home tests work equally on all the variants?

➔ Clarify the rules for when you test positive. Explain how you isolate for 5 days and then do another test
Provider Issues

➔ CMS should require providers to give us science-based information about boosters. When the vaccine first came out our providers were focused on helping us to get the vaccine. However, their response was slower with the booster. Often we had to be the ones bringing up the topic.

➔ People are reporting that their providers are not wearing masks. And with staff shortages, if we report them there is nobody to fill in.

➔ I don't know the status of my staff. Are they testing? Did they get a booster? That is something that needs to be addressed.
Masks

➔ We need more accessible videos and written information about finding the best mask that fit our faces.
➔ We need reminders about what kinds of masks to use and understand why.
➔ How often should you switch to a new mask and dispose of the old one?
➔ Make sure people know they do not have to take off their mask
Some disability groups are having large gatherings. They are saying “Masks are not required by the meeting venue” Some groups are not sure if they can require masks. We need examples of how to explain why they are required

We wonder why others do not wear masks. Churches are mask optional right now. Really?

Not wearing masks worries us. Some agencies and programs do not require masks.

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Advocacy Issues

➔ Make sure we have resources for patient advocates at local hospitals. We are at higher risk of going into the hospital and we need support to make sure we know what to do if they try to get us admitted to a nursing home once we are hospitalized.

➔ We need the universities to come out with a response when the CDC and others make comments that sound like new strains of Covid-19 are not that bad because only people with chronic medical conditions are being hospitalized and dying.
Education Issues

➔ Include role plays and real examples of people with disabilities making their own health decisions or getting help in making decisions that affect them.

➔ As much as it pains us to say so, there are still people asking if there is a microchip in the vaccine.

➔ It is worth repeating that if you test positive and do NOT have symptoms you still need to isolate.

➔ Many people said they don’t know how to use a self-test.
Covid Policy Concerns

➔ The CDC says it is okay to get your flu shot and Covid shot at the same time. But what if you have a reaction, how will you know what you are reacting to?

➔ Keep working on clearly showing the differences between general guidance and guidance if you have a chronic illness or have a weakened immune system.
Covid Policy Concerns

➔ Public testing sites are closing yet at home tests are not accessible to everyone. One concern is you need to test soon after getting symptoms because you only have 5 days to take the new medications to fight Covid-19.

➔ New information about new variants being more contagious – can we get specifics? Does it last longer in the air? Does it stay longer on surfaces?
Research

→ Share current guidance on how COVID 19 impacts different animals.

→ When is Covid going to come to a stop?

→ We heard a rumor that some people are refusing to go back to their day programs – can you research this? Is this a time to push for closing segregated programs?

→ Is there a reliable way to know if I had Covid and have natural immunity?
Research

➔ Can we have stronger vaccines, so we do not need to get constant shots? Why are they doing a secondary booster so soon? Why did they not make the first booster stronger?

Overall, Health Impacts

➔ Look at the long-term impacts of missing our OT & PT appointments for so many months

➔ Providers need to help us get caught up with missed medical appointments. Many of us have not been able to go back to the eye doctor and dentist.
We are concerned about people with IDD and their families not knowing that back in February, the CDC added IDD to the list of conditions at increased risk from Covid.

The list includes people with intellectual and developmental disabilities, birth defects, cerebral palsy, Down syndrome, attention-deficit hyperactivity disorder, learning disabilities, spinal cord injuries and “people with any type of disability that makes it more difficult to do certain activities or interact with the world around them, including people who need help with self-care or daily activities.”
This got more complicated when guidance about getting a second booster shot was released. We are concerned that people with IDD might be confused about whether they should get a second booster.

The CDC website says - Among people who are eligible for a second booster dose, the following people might consider getting the second booster dose as soon as possible (i.e., 4 months after their first booster dose):

- People with **underlying medical conditions** that increase the risk of severe COVID-19 disease…

Our experience is that providers and government agencies are not promoting getting a second booster to people with IDD and their families.

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