



I WANT YOU!

The Family Café CHANGE AGENT NETWORK THEY NEED YOU!

Volume 3, Issue 3

This Newsletter Is A Project Of The Family Café

April 2020

The Change Agent Network is a project of The Family Café and offers an opportunity for advocates and change agents to work collaboratively to transform the system by: combining abilities, skills, ideas, and talents; standing together for meaningful system reform measures; taking the lead in our communities and neighborhoods; sharing Information to help families become effective players within their communities; developing statewide networks to organize and discuss the issues that are most important to families and persons with disabilities; and creating a united position on critical disability policy issues.

We hope everybody is staying safe in this unprecedented time in our history. Several of you have asked about the status of The 22nd Annual Family Café. At this time, we are planning to host the event on June 5-7 at the Hyatt Regency Orlando as planned. We are certainly aware of public health concerns surrounding COVID-19 (coronavirus), and will continue to pay close attention as the situation develops over the coming weeks and months.

The Family Café's first priority is the health and well-being of the families we serve. We will follow guidance provided by the Centers for Disease Control, the Florida Department of Health, and the Orange County Health Department in determining how to move forward should COVID-19 impact the conference. In the event that there are any changes in our plans to host The 22nd Annual Family Café this June, we will notify all attendees via email as soon as possible.



Up-To-Date Information from the Florida Department of Health:



The Florida Department of Health is an excellent resource for the latest information on the Coronavirus. There is a lot of information floating around out there, not all of which is accurate. Please use this as your source for a factual breakdown of the latest news, data, and "do's and don'ts."

The Florida Department of Health website has a toolkit, contact information, and the latest press releases:

<http://www.floridahealth.gov/>



WWW.FAMILYCAFE.NET

The Florida Department of Health also has a “Data and Surveillance Dashboard” with the latest information by county:

<https://experience.arcgis.com/experience/96dd742462124fa0b38ddedb9b25e429/>

Staying Home from School:

At this time, schools throughout Florida are scheduled to be closed for the next month, and many school districts are developing plans for online classes. Don't forget that students with disabilities STILL have all the rights afforded to them under the Americans with Disabilities Act (ADA) and Individuals with Disabilities Education Act (IDEA), even when at home utilizing online learning during this break from classes. If your child needs help ensuring web accessibility in order to fully participate in classes it is the Department of Education's responsibility (in conjunction with your local School Board) to do just that. Most web sites are fully accessible, but if you are having problems do not hesitate to speak up!



Points to Keep in Mind for People with Disabilities:

Andrew Pulrang, a Contributor to *Forbes* magazine writes in his column “Diversity & Inclusion” an excellent article entitled: “Five points to keep in mind about how the coronavirus outbreak affects disabled people.” Pulrang examines the challenges specific to the disability community as it relates to the

1. The people most often cited as being at serious risk are largely, by some definition, people with disabilities.

While simply having a disability probably doesn't by itself put someone at higher risk from coronavirus, many disabled people do have specific disabilities or chronic conditions that make the illness more dangerous for them.



Unfortunately, any natural anxiety disabled people might have about the COVID-19 outbreak is likely made worse every time news reports and official statements go out of their way to reassure everyone by saying “only” elderly and chronically ill people are at serious risk. It feels awful to hear people reassure each other that coronavirus isn't that scary because it will mainly hurt and kill “high risk” people. Remember, that's us you are talking about, and we can hear you.

At the same time, the connection between people with

pre-existing medical and disability conditions could become blurred, and disabled and chronically ill people could be unfairly stigmatized. People of Asian ancestry have already experienced discrimination because of underlying prejudice and people's vague associations between COVID-19 and China. Everyone should be on guard against any fear-based impulse to ostracize or confine people who have, for example, chronic coughs or breathing difficulties that are normal for them, and are not by themselves evidence of exposure to COVID-19.

Because of all these and other factors ... both active and anticipated ... people with disabilities may be experiencing a higher level of anxiety about coronavirus. And anxiety poses risks of its own.

Symptoms of COVID-19

(coronavirus disease 2019)

Systemic:

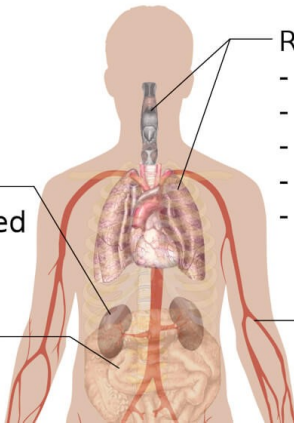
- Fever
- Fatigue

Kidneys:

- Decreased function

Intestines:

- Diarrhea



Respiratory:

- Sneezing
- Runny nose
- Sore throat
- Dry cough
- Shortness of breath

Circulatory system:

- Decreased white blood cells

2. It can be harder for disabled people to take prudent steps to protect themselves from the coronavirus outbreak.

Expert advice on preparing for an outbreak makes logical sense and should be followed as much as possible. But many disabled and chronically ill people's past experiences with medical bureaucracy and obtaining responsive, flexible assistance makes us skeptical that we will be able to follow all of the recommended advice successfully.

For one thing, some disabled people can't isolate themselves as thoroughly as other people, because they need regular, hands-on help from other people to do every day self-care

tasks. Also, laying in supplies of groceries can be difficult for some disabled people to do, when shopping of any kind is always extra taxing, and they rely on others for transportation. For some of us, even cleaning our homes and washing our hands frequently can be extra difficult, due to physical impairments, environmental barriers, or interrupted services.

Some people with chronic health conditions even worry that they won't be able to get the extra supplies of medications that are being recommended to the general public. Depending on the medications, and what kind of health insurance a disabled person has, just getting *regular* refills in a timely manner can be a challenge, even when there isn't a public health crisis.

3. COVID-19 coronavirus threatens not only disabled people's health, but their independence.

Some disabled people depend on regular help and support from others to maintain their independence — that is, their ability to live in their own homes rather than in nursing homes, group homes, and other institutional settings. Outbreaks of communicable disease can disrupt these services. Aides and caregivers may become sick themselves, or the risk of catching or spreading illness may require aides and caregivers to stay home, interrupting disabled people's services.

It is also worth considering that especially during an outbreak, congregate care facilities are not *necessarily* safer for elderly and disabled people. They are the opposite of isolated. Facilities may have access to more medical resources to treat and control the illness. But a single disabled person at home, with at most one or two careful and prepared aides, may actually benefit some from their relative isolation. Medically we can't say for sure which is the "right" setup for any particular disabled per-

son. That means we need to keep open minds, and set aside preconceptions we may have about what health and safety look like for people with various kinds of disabilities. We don't know exactly how this will play out. The important thing to remember is that the risks of COVID-19 for disabled people don't run only in one direction, or take only one form. And the greater risks may not be from actual disease, but from the disruptions in services and routines it can cause.

4. This outbreak has the potential to add new perspectives and urgency to a number of long-time disability issues.

Workplace accommodations and flexibility: People with disabilities and chronic illnesses regularly struggle to carve out flexible work arrangements, including reasonable accommodations and telecommuting. Such measures are now being looked at in a different light by many employers, in response to a problem affecting all workers, not just those with disabilities and ongoing health conditions.

Centralized care in institutional facilities vs. decentralized home and community-based services: As noted above, preconceived ideas about the relative health risks of centralized care and decentralized home care are being viewed now in new ways. Many disability activists have for years contended that the purported safety of nursing homes and group homes for elderly and disabled is overrated. COVID-19 highlights the fact despite the apparent advantages of more controlled, medically-supervised environments, there are also health risks involved in housing people with health vulnerabilities in hospitals and other kinds of care facilities.

Health care organization and affordability: Health care is one of the most intensely polarized issues in politics today. While everyone seems to have strong opinions about how to organize and pay for health care, the public health consequences of America's patchwork system have rarely been so clear. Controlling contagious disease requires immediate access to care, and a minimum of red tape and affordability barriers. When people have to weigh the possibility of huge bills resulting from taking prudent preventative steps, public health for everyone suffers.

5. You can help a lot just being aware and sensitive to the specific risks and obstacles faced by disabled people in an outbreak of contagious illness like COVID-19.

Panic is neither warranted nor helpful. But don't minimize the risks or try to talk disabled people out of being worried. For all of the factors outlined here, and taking into consideration many disabled people's past experiences, it's not unreasonable for us to be concerned. We are not just worried about getting sick, but about whether support systems we rely on will "have our backs" the way they should. Employers, teachers, health care providers, families, and friends can help by allowing disabled people as much practical and emotional leeway as possible to cope as recommended, and as they themselves may need. Now is not the time to tighten the reins, or try to impose what *you* think is best for disabled people.

If you live and work with a disabled person or if you assist, care for, or serve people with disabilities and/or chronic health conditions ... take the risks to us seriously and be extra careful with your own precautions so you can remain healthy and able to help."

As always, please do not hesitate to contact us at The Family Café, Inc. with any questions or concerns. Be safe, smart and we look forward to seeing you soon!



COVID-19

Protect Yourself in Gatherings & Crowds

Florida Department of Health • FloridaHealth.gov

Public health authorities suggest the cancellation of gatherings greater than 10 people and smaller gatherings that may bring people from multiple areas in the U.S. Gatherings and crowds also exist in other places—like work or stores—so know what to do.

Limit interactions if you are 65 or older and have underlying or chronic health conditions: compromised immunity, diabetes or heart or lung disease.

Know How to Protect Yourself in a Crowd

Keep Your Hands Clean



Wash your hands often with soap and water for at least 20 seconds. Throw used paper towels in the trash.

- Wash after going to the bathroom, before eating, and after blowing your nose, coughing or sneezing.
- Wash after you touch someone.

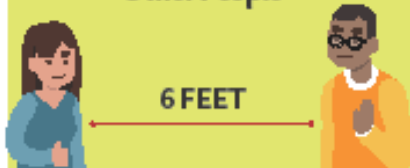
If you don't have soap and water, use a 60% or more alcohol-based hand sanitizer.

Cough and sneeze into your bent elbow or a tissue. Throw used tissues in the trash.

Limit interactions:

- Avoid shopping at peak hours and take advantage of delivery or pick-up services.
- Avoid public transit.
- Avoid areas with active outbreaks.
- Ask your employer if you can telecommute.
- Don't shake hands as a social greeting.

Keep at Least 6 Feet Between You and Other People



Know When to Protect the Crowd

Avoid Leaving Home If You:



- Have been in contact with someone who has or may have COVID-19.
- Have traveled internationally to places under level 3 advisories or visited an area with widespread COVID-19 transmission within the last 14 days.
- Have been exposed to someone with respiratory illness within the last 14 days.
- Currently have fever, cough or a sore throat.

Florida Health Office of Communications 05-17-20

Thank you to those who attended The 21st Annual Family Café this past June. With approximately 13,000 people in attendance. it was one of our largest ever! Pictures and video's from the event are available on our website now.

Please mark your calendars for The 22nd Annual Family Café which will be held on June 5th-7th in Orlando. Hope to see you there! Registration will open on Friday, February 14th.

See You Next Year!
AT THE
22nd ANNUAL Family Café
JUNE 5 - 7, 2020 • ORLANDO

HYATT REGENCY ORLANDO
9801 INTERNATIONAL DRIVE
ORLANDO, FLORIDA

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