Volume 10 – Issue 3
March 1, 2021

The International Journal for Direct Support Professionals

THREE P'S IN THE POD: The Pandemic, the Professionals, and the People

By: Rick Rader, MD
Mark R. Macbeth, PhD

What impact has the pandemic had on the individuals you support?

Imagine waking up in the morning, looking forward to seeing your friends, going to work, practicing for your Special Olympics event, meeting friends for pizza, and finishing up the day shopping for things you were running low on ... and finding out, without warning, that you were unable to do any of those things. That is exactly what individuals with intellectual disabilities were told when the Covid pandemic reared its ugly head. To make matters worse, they were told it was not just for that day, or for the next day, and the day after that. In fact, no one could tell you when things could go back to normal. On top of that, you were told you could not high five, hug, shake hands, or give back pats to anyone around you. You have always enjoyed showing how much you enjoyed and appreciated your friends – and now you could not even do that. No one could easily explain what was going on, and why you were being told to just sit and wait it out. Without understanding the reason, the justification, and the rationale for this dramatic change to the way you were now allowed to live, there was only one simple explanation ... You were being punished ... and for no reason.

The individuals you support began to behave just the way you and I would behave if we thought we were being unjustly punished … they became anxious, depressed, angry, isolated, confused, lonely, and even aggressive. These are exactly the reactions that Direct Support Professionals (DSPs) have reported seeing in the individuals they support, work with, play with, assist, and guide. Adding insult to injury, they were taken to some sterile location where a stranger dressed like they were members of a bomb squad stuck a probe all the way inside both of their nostrils and, in a somber tone, said, "You will get your results in several days." The picture gets dimmer. You are given a mask to put over your face and wear at all times. You were instructed to raise both of your arms straight out and told to keep away from anyone that exact distance. You were informed that you needed to wash your hands after you touched anything and not just soak your hands but to scrub them for as long as it took for you to sing 'Happy Birthday' twice. A series of strange rituals even if you understood that they were for your own protection.

Imagine if you did not know why you were forced to follow these strange and disturbing behaviors. Even when you could not understand exactly what the DSP was saying, you could always understand, by looking at

their facial expressions, if things were okay, but now you could not see their faces. Were they smiling? Were they sticking their tongues out? Were they frowning? It was another connection that was being taken away from you. It was leaving you more confused, more afraid, and more anxious. You could tell that everyone around you was also confused, anxious, and afraid. You were placed in a bad place, and there was little to comfort you or to reassure you that things would be back to normal. You had no experience in anything like this before and, therefore, you had nothing to relate to, nothing to assist you, and nothing to lead you to a comforting place. The scenario is not over, not even close. You watched television and saw dead bodies being placed in parked vans, people in hospital beds hooked up to breathing machines, health care workers crying, and listened to important people that had no real answers.

Individuals with intellectual and developmental disabilities are at three times the risk of dying from Covid-19 disease. Many of the individuals you support have underlying medical conditions like diabetes, high blood pressure, heart disease, breathing problems, seizures, allergies, sleep disorders, mobility problems, dental decay, obesity, and dementia. In addition to that, you have also seen that they have problems with emotions, behaviors, psychiatric disorders, and reasoning. Each one of these co-occurring conditions decreases their ability to survive being infected with the Covid virus.

What impact has the pandemic had on the Direct Support Professional?

Imagine waking up in the morning, looking forward to helping the folks you have been connected to for years only to find out you had to stop them from living the way they have enjoyed. You were now required to keep them at home, away from family, friends, and the community to which they felt connected.

You were told by your supervisors that you had to enforce strict guidelines, were unable to make any exceptions, and were told to wear masks, and to make them last because there was a limited supply. Add to that, you were being asked to work extra shifts, and sacrifice being able to go to your own home to take care of your own family. You were also informed that, in the event anyone around you “tested positive,” you would be forced to be quarantined for two weeks.

Direct Support Professionals are attracted to their work for many reasons. Among the most significant is the ability to assist people in meeting and exceeding their goals, dreams, and aspirations. The pandemic has virtually removed that aspiration. In a “lock down” situation, we are unable to escort the people we support into the community, to provide them with new opportunities, novel choices, and options, and to assist them in exploring new friendships and connections.

You have been given few answers, and they change almost daily. Direct Support Professionals have experienced the same feelings that the folks they support have demonstrated: fear, isolation, loneliness, depression, and anxiety. But they have had to put their own feelings on the back burner and concentrate on helping, assisting, and monitoring the health (physical and emotional) of the folks with whom they have aligned.

Direct Support Professionals are tested every day; in part, that is what attracts many of them to devote their professional lives to this complex, demanding, and rewarding profession. They have had to rely on their faith, experience, peers, training, ethics, and intuition to help solve problems; problems that seem to never end. They have always been there, with ideas, trials, and suggestions to improve the lives of people who depend on them to assist, not to insist. As a physician, I appreciate the role that DSPs play in the everyday lives of people who have emerged from the shadows and have taken their long overdue place in the community. The Covid pandemic has impacted the lives of DSPs in much the same manner as it has the lives of the individuals they support.

It is obvious from the history of natural science that this will not be the last pandemic that will emerge and serve to alter the way we live. The DSP will play a vital role in how we adjust, accommodate, respond, and react to the challenges that are being presented to us daily. Perhaps the best support that can be provided to DSPs is the support from other DSPs. They know what needs to be said. They know what DSPs need to hear, and they know what DSPs need. We (healthcare providers, policymakers, payers, administrators, families, and the community) need to do a better job of listening to them. Perhaps the pandemic has opened the avenues of communication.

Reversing the impact of the pandemic: Herd immunity

As discussed above, the Covid-019 pandemic has impacted all of us. It has changed the way we live our lives, how we do our jobs, how we interact and care for each other. It continues to test us, nearly a year after the first lockdowns. The tests we face now are more urgent, as if the clock is ticking. However, the path we face is clear. To save lives, to put an end to these grueling tests, to begin our return to ‘normal,’ we must turn the corner on this pandemic by establishing herd immunity.

Herd immunity is the protection given to a population against a contagious disease when a large enough number of the population are immune to it. One way to think about herd immunity is an actual herd of adult animals that forms a circle around a calf to protect it from a predator. Likewise, a virus needs a host to grow and spread. Without hosts to infect, due to most of the population being immune, the virus simply dies off, protecting those who are not immune from infection. In herd immunity, the population of those that are immune form the barrier to protect those that do not have immunity such as newborns and the immunocompromised.

How do we establish herd immunity to beat the Coronavirus? There are two ways. The first is let everyone get infected and develop immunity naturally. Obviously, this is unacceptable as too many lives have been lost already, and too many more are at stake. The second way to establish herd immunity is through an extensive vaccination program. When you receive a vaccine, you develop protection through your immune system, preventing infection, and the ability for the virus to grow and spread. When enough of the population has the protection from a vaccine – the virus cannot find a host and dies off as herd immunity has been established.

Establishing herd immunity through vaccination

How vaccines work is to 'trick' your immune system into *thinking* you have an infection, but the infection is not real. Vaccines rely on exposing your immune system to only a part of the virus, a part that is not able to cause an infection on its own. In addition to traditional vaccines using inactivated or dead virus, new technologies have been developed that are based on RNA. What is RNA and how is it used in these vaccines? In order to answer this question, we have to take a step back and talk about DNA. DNA is the instruction manual that makes us all who we are. These instructions were passed down from our parents and will be passed on from us to our children. What these instructions make are proteins, which perform most of the tasks that keep us alive. The issue is that DNA is written in a specific chemical language, while proteins use a different language. There needs to be a translator. That translator is 'messenger' RNA, or mRNA.

Humans have nearly 20,000 different DNA sequences that make 20,000 different proteins all passing through the 20,000 different mRNA sequences acting as the translator. The Coronavirus causing the pandemic is simple compared to humans. It only has 29 different RNA sequences, making 29 different proteins. One of these Coronavirus mRNAs carries the instructions for a protein called the 'Spike' protein. If you have seen a picture of the Coronavirus in the news, you will recognize the Spike protein as the studs that stick out from the virus. They give the virus the appearance of a 'crown,' or *corona*.

The mRNA that is in the Moderna and Pfizer vaccines carries the instructions for ***only*** the Spike protein. There are no other instructions for any part of the virus, and there are no whole viruses in the injection. Without the remaining set of instructions (the 28 other RNAs), the virus cannot be made, so it is impossible to get an infection from the vaccine. The RNA cannot change your DNA. DNA is in a separate compartment of a cell called the nucleus (which protects it from damage or changes), and the RNA from the vaccine cannot enter the nucleus. Also, RNA is very fragile, it will fall apart within hours of injection, which is one of the reasons why the RNA vaccines need to be stored at ultra-cold temperatures. The RNA that makes the Coronavirus spike protein just does not last very long.

When the mRNA is injected into your arm, it enters your cells, and the instructions are translated into the Spike protein. This is the only Coronavirus protein that is made, and it is harmless on its own. Still, it is recognized by your immune system as foreign, and you mount an immune response to it. This is the trick the vaccine plays – it does not matter if the Spike protein was part of an actual Coronavirus infection or if it was just made by itself as part of the vaccine. Your immune system senses it is foreign and targets it for destruction.

The first immune response that is made to an infection is mostly responsible for the symptoms you feel – some aches and pains, inflammation, fever, perhaps a rash. It is the same response we may feel after a vaccine, the big difference being there is no live virus. So, you may feel some side-effects of the vaccination – a sore arm, a low-grade-fever, mild body-aches. Unlike an actual infection, these will subside after a few hours as you are not constantly producing virus. These side-effects you feel are your immune system working to establish protection against future infection. The mRNA from the vaccine entered your cells, and the cells started making the Spike protein. It is a good sign that the vaccine is working.

The true magic (It's not really magic! It's biology!) of vaccines is the long-term protection they provide. Two weeks after the first dose, your immune system starts to make antibodies specifically against the foreign Spike protein. Antibodies do two things: 1) Neutralize the Spike protein by blocking it from doing its normal job, and 2) Target the spike protein for destruction. The length of time antibodies last is still being studied; however, your immune system keeps the instructions (DNA) that make them. If you are ever exposed to the virus in the future, your immune system will recognize the Spike protein on the virus, and you can quickly produce these same antibodies to fight off the infection without getting very sick.

A few aspects of the mRNA based vaccines:

- You need two doses several weeks apart to build up a strong immune response. The second dose acts like a booster to make more Spike protein that the immune system can recognize.
- No corners were cut in testing. Yes, the vaccines were brought to the public quickly, but that is a result of an enormous amount of financial and human resources that went into making it. The vaccine went through the same rigorous standards as all vaccines, for example, the Pfizer trial had 38,000 participants in three phases of testing.
- Even if you tested positive for Covid-19, you should still receive the vaccine. It will generate a strong immune response to protect from future infection.
- The effectiveness on the newly developing strains is still being tested. Some of the vaccines are not as effective at preventing mild illness from infection; however, they remain very effective at preventing severe illness and hospitalization. This brings to mind an important quote from Dr. Anthony Fauci, "If the virus can't replicate, it can't mutate." What this means is the sooner we can establish herd immunity, the less likely a new strain will develop that can evade the protection given by the vaccine. Time is of the essence. More good news? The laboratory science used to make the RNAs for the vaccines is relatively easy, and the companies making them are developing new RNA sequences that will trigger an immune response to the Spike proteins found in the new Coronavirus variants.
- The timeline for protection from the virus is about a month from the first dose of the RNA vaccine, and 1-2 weeks after the second dose (depending on the vaccine). However, it is still possible to transmit the virus after that month even if you are protected from it. You should still wear a mask and social distance after receiving the vaccine.
- The chances of a severe allergic reactions are very low. The reactions seem to be in response to poly-ethylene glycol, a molecule that is used make the RNA more stable and to help it enter your cells. For the Pfizer vaccine, this severe response occurred in 1 of every 90,000 vaccinations and usually within 20 minutes of the injection.

While the introduction of several promising vaccines has provided us with some positive looking outcomes, it will be months until the restrictions will be lifted, and we can begin to reconnect where we were before the pandemic. We must remember it is up to all of us, that we all share a responsibility in establishing the herd immunity that will turn back this pandemic. The best ways to do this are to continue wearing masks, practice social distancing, and by receiving the vaccine when it is available to us.

About the authors

Dr. Rick Rader is a physician responsible for the creation of innovative medical programs for people with ID/DD at the Orange Grove Center in Chattanooga, Tennessee. He is the Editor in Chief of Exceptional Parent Magazine and has published over 350 articles on health and disability. He was a founding member of the American Academy of Developmental Medicine and Dentistry and currently serves as the VP for Public Policy and Advocacy. He was a consultant to five former US Surgeon Generals in the area of health and disability. He serves as the Medical Consultant to the NADSP. He is a researcher in sensory processing disorders and serves as a member of the Steering Committee at the National Task Group on Intellectual Disabilities and Dementia Practices. He was a member of the Task Force that created the NADSP Code of Ethics and was the first appointed Special Liaison for Family Health Concerns at the President's Committee for People with Intellectual Disabilities. He is a member of the Global Medical Advisory Committee at Special Olympics International.

Dr. Mark Macbeth earned his bachelor's degree in Biological Sciences from the University of Vermont and his doctorate in Biochemistry and Molecular Biology from The University of Chicago. His 20 years of experience in the field of RNA biochemistry began with his doctoral thesis on how messenger RNA is translated into protein. His specific research interests include the study of molecules that can change the sequence and structure of messenger RNA, and the effect of these changes on the nervous system. He is currently an Assistant Professor at Butler University where he teaches chemistry, biochemistry, their affiliated laboratories, and this spring semester he is teaching a course on the development of the SARS messenger RNA vaccine. He and his research team of six undergraduate students are developing a testing program to detect antibodies to the SARS-CoV-2 virus in students, faculty, and university staff. He resides in Indianapolis with his spouse, Dr. Malgorzata Gonciarz and their cat Teddy.

Answers to FAQ's about the journal

1) The journal is intended to be widely distributed; you do not need permission to forward. You do need permission to publish in a newsletter or magazine.
2) You may subscribe by sending an email to dhingsburger@vitacls.org
3) We are accepting submissions. Email article ideas to either the address above or to anethercott@handstfhn.ca
4) We welcome feedback on any of the articles that appear here.