

Adult AMC Registry Newsletter

AMC Registry update: A note from the project leader

Hello to all our readers who are interested in life and living with AMC as adults. It's been a strange year and I'm sure many of you have adapted to a new normal yet again. This time it is not related to AMC but the world has changed. I hope you are managing ok. In this issue we will provide 1) a brief update on the research study, 2) an article on how COVID may increase work opportunities for people with disabilities, and 3) an article by a counselor on tips for coping in our current world situation.

Firstly, I wish to thank all those who have agreed to participate in our AMC registry for adults and have entered their first year's data. This data includes information about people's demographics, health, description of AMC types, work, education, social life, surgery history, pain, fatigue, parenting, mental and sexual health. It's a lot of information and we are grateful for your time!

We have 70 completed entries from people from all over the world. This is fantastic. I have also received many requests for links to enter data but some people either have not finished or didn't in the end choose to participate. If you still want to, please go to the original link or email me again, and I will send another link (bonita.sawatzky@ubc.ca).

We are all living in very uncertain and strange times so your time to participate in this work is even more special to the team. We acknowledge that your life is about much more than being born with a type of AMC.

At the end of the survey, there is a place to enter comments. One common point mentioned is that the questions don't capture it all. There IS more to life than their AMC. This is so definitely true and we acknowledge that no matter what questions we'd ask, there would always be aspects of life we will not find out about. For example, we asked about fatigue. We cannot assume your increasing fatigue is directly related to your AMC. You may have other issues like taking care of elderly parents or a sick spouse that is confounding your life at the

moment. We cannot ask you all these details. Instead, by doing a study with a large enough sample size, we will get a big picture of what life is like for people with AMC, not specifically you as an individual. Your individual data tells us one small piece of that big picture. Your input is invaluable to making this study work. Thus, if you feel we are missing points, please do enter comments as they do help put information into context.

Another comment is about "health". How do people with AMC think about their health and their disability? Some questionnaires sound like the two are interlinked, meaning your health is dependent on "what" you can do; however, many suggest that health is completely separate from disability. We agree on this point. However, because we are using standardized questionnaires that are used worldwide with all sorts of populations, we kept these questions unchanged. Please accept the limitations of our study, but also provide your feedback in the comments as they are very helpful. Thank you.

Since our last newsletter in July 2019, we have developed the "Annual Questionnaire" that will be completed beginning January 2021. For all participants, we will ask you to complete this much shorter update questionnaire to "check in". We had hoped to start it January 2020, but with technical delays and other COVID priorities it was pushed down the timeline. Thank you for your patience on this.

Again, thank you all for helping us with this study. On behalf of the team, I wish you well in our COVID world and hope we come out of these challenges a stronger and more caring humanity.

Sincerely, Bonnie
(Dr Bonita Sawatzky)

Registry team:

Bonita Sawatzky, PhD; Noemi Dahan-Oliel, PhD; Ann Marie Davison, PhD; Judith Hall, MD; Ben Mortenson, PhD; Tracey Schalk, BA; Harold vanBosse, MD; Nicole Sidebottom, MA

Research topics?

Anything you are interested in knowing about people who live with AMC ?

I personally am interested in why many people with AMC function so well despite having a significant physical challenge. Did you all just have such awesome parents? Were we born with a higher Intellectual and Emotional Quotient? Are people with AMC more resilient?

Any thoughts on these questions, or do you have questions of your own?

Please send your ideas to me and we will see how we can study these further....

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How COVID-19 is Changing Remote Work for People with Disabilities

By Marco Pasqua

[ACCESS & INCLUSION](#) (REPRINT FROM RICK HANSEN FOUNDATION, VANCOUVER CANADA)

We're living in an interesting time—the COVID-19 pandemic seems to have flipped our world, and how we function in it, upside down. Personally, I have felt the impact. As a professional speaker and accessibility consultant, a large portion of what I do requires me to travel—to events, conferences, and public spaces—all of which are at a standstill for the foreseeable future.

Social distancing, the closure of parks and playgrounds, and the insistence that we all stay and work from home can seem like scary things, but is there an upside? As an optimist and entrepreneur with a disability, I can tell you there absolutely is—in fact, I've actually been able to do the majority of my business tasks from home for over eight years now. With that in mind, not only are the changes we're seeing in our society a good thing from a business perspective, but they are going to revolutionize the ways we live and work forever.

I know, you're probably thinking "But Marco, how can this possibly be a good thing?" Well, if you happen to have a disability (and even if you don't) there are many benefits that we'll see as a result of our current socioeconomic situation.

Before I get into it, I want to acknowledge that this still isn't an opportunity every person with a disability has. While it is terrible that it took a pandemic to make working from home a more viable option, my hope is that it will continue to become more accessible and benefit more people with disabilities.

Here's my take:

1. Telecommuting and Remote Work Will Become Standard Practice:

For years, members of the disability community have been promoting the benefits of remote work. Not only does it support a reduced carbon footprint, but it opens up opportunities for people who wouldn't otherwise be able to get to a physical location, and gives them the ability to

share their talents in new ways. Plus, if you're telecommuting, you might be able to get a few more minutes of valuable sleep and still make it on time to that important meeting.

2. The Introduction and Regular Use of Accessible Technology:

The ability for all team members to be seen and heard during meetings is vital—particularly in an effort to remove distance bias from the equation. Companies have come to realize this, and last year, Microsoft introduced the option to have live captions turned on through Microsoft Teams. Working from home also supports employees to use their own at-home computer setup for features like magnification, screen readers, and specialized lighting if they have certain preferences or photosensitivity.

3. Creating Consistent Schedules with Support Staff:

Some individuals with disabilities require additional supports from care workers for things like eating, bathing, and other hygiene routines. In some cases, this can prevent people from working in an office or elsewhere because these support workers are only able to be with them within their homes. Now, entirely new and predictable schedules can be created so that these folks can apply for jobs they wouldn't have previously—all in a safe and healthy environment.

4. Proper Planning and Execution of Tasks

Do you find yourself easily distracted or pulled into conversations that make you lose track of time? If you're working from home, you'll have the benefit of not being distracted by co-workers, the constant buzzing of the vending machine, or the clicking of someone else's pen. This may be particularly beneficial for some individuals with autism or ADHD. My caveat to this is that there are many other things that can distract you in

your home, so be sure to close the office door during periods that you're working, set chunks of time in your calendar for working on specific tasks, and close your emails during those times so that you're not tempted to jump on to something else prematurely.

5. Allowing Yourself to Have Meaningful Breaks

Being in isolation can take its toll on our mental health; conditions like anxiety and depression along with other forms of mental illness are the leading cause of disability leave in Canada. However, being at home puts us in a place of familiarity and comfort, so be sure to take advantage of that. Yes, social distancing is important, but when possible, go for a short walk, rest your eyes from your screen, and even take a few moments to have mindful meditation. It may sound silly, but it can have a profound impact on our mental health and the work that we produce. For me, taking a few minutes to listen to my favourite music and placing my hand on the plasma globe that sits on my desk completely recharges me. Remember, you're at home, so do whatever works for you.

Regardless of what you do for work, we are on the precipice of a changing world. We might not be able to be in the same room as some of our co-workers, but that doesn't mean that human connection isn't important, so remember that, and make time for it. For people with disabilities, this can open up opportunities for earning an income and changing perspectives in ways that didn't exist before. This is our opportunity to re-write the rules, do things a bit differently (arguably better), and envision a place where everyone can go everywhere—even if that means staying exactly where you are.

Coping with Loneliness and Isolation During the COVID-19 Pandemic

By Nicole Sidebottom
(a counselor of the Clarity Group,
Denver, CO USA)



COVID-19 seems to have impacted all of us, directly or indirectly, in one way or another. Perhaps you or a loved one are experiencing financial insecurity due to a job loss, perhaps physical distancing and stay-at-home orders have left you isolated and lonely, and maybe you're tired of hearing about the pandemic and are waiting for life to get back to "normal." Whatever your experience, as people with a disability, we often have experiences or layers of complication with which our nondisabled counterparts can be unfamiliar.

Here are a few tips to help you navigate the COVID-19 crisis:

Practice Gratitude: Whether it is keeping a gratitude list in a journal or engaging others in conversation about what you're grateful for, practicing gratitude is a great way to refocus our perspective and decrease our anxiety. People who regularly practice gratitude by taking time to notice and reflect upon the things they're thankful for experience more positive emotions, feel more alive, sleep better, express more compassion and kindness, and even have stronger immune systems. Despite the difficulties of this present time, what are you grateful for?

Stay Connected: Loneliness takes a huge toll on mental and physical health, and we might engage in all kinds of destructive habits to escape the emotions stirred by loneliness. Spend time each day with those you love. Devote at least 15

minutes each day to connecting with those you most care about. When you're with someone, focus on each other. Forget about multitasking and give the other person the gift of your full attention, making eye contact and genuinely listening. Also, consider helping others who might be feeling lonely. Doing good is good for our mental health, so now could be a great time to help someone else who is experiencing loneliness.

Get Creative and Pivot: As people with a disability, we learned early on that getting creative about obstacles and perceived limits was going to be a survival skill. Problem-solving often seems to be in our DNA, and we are required to get creative and pivot, or often go without. The coronavirus pandemic is no different. Pivoting around obstacles could be taking this time to learn a language, take a free online class, experiment with painting or another artistic outlet. Use the innate qualities you already possess to help get you through this difficult time.

There is a lot of uncertainty as we begin to wonder what life will look like in the future and what the rest of 2020 and 2021 will bring us. As we learn what life is like on the other side of the virus, may we see in greater ways how resilient we truly are, discover something wonderful along the way that surprised us, and be a people full of hope.

**On behalf of the Project Team,
I thank you!**

Bonnie and service dog, Gucci!

