

Please Take Action: Lessons Learned and Moving Forward

By Yona Lunsky

"Please Take Action". This was the subject of the email I received on December 24th, notifying me that our paper on the accessibility of vaccine information during the pandemic, "They Need to Speak a Language Everyone Can Understand" had been officially published in the journal Vaccine, as part of its special issue on Canadian COVID-19 Experiences. The paper emphasizes that vaccine accessibility is not just about making vaccines available to everyone; it is also about ensuring that everyone can participate in the vaccination process. This includes making sure that information about vaccines and the vaccination process is easy to understand, regardless of one's ability.

Both the timing and the subject of this email got me thinking about the words, "Please Take Action"—what they meant during the pandemic as we worked on vaccine accessibility and what they could mean now, as we begin a new year, four years later.

Looking Back: Taking Action During the Pandemic

Publishing a paper and sharing new information over the holiday season is unusual; the H-CARDD team usually takes a break during this time. However, four years ago, we were working through the holidays as we faced a devastating wave of COVID-19. People with developmental disabilities were isolated in their homes, unable to access vaccines that were available only to prioritized groups. As is often the case, despite international evidence highlighting the disproportionate impact of the pandemic on people with developmental disabilities, Canada's National Advisory Committee on Immunization's vaccine prioritization guidance, published just before Christmas that year, made no mention of this marginalized group.

Across the country, agencies and advocacy groups supporting people with developmental disabilities were left scrambling, asking, "What does this mean and what can we do?" Together, we worked to find answers, present evidence to anyone who would listen, advocate, and prepare:

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- We published an <u>op-ed in *Healthy Debate*</u> and followed up with two <u>policy</u> briefs on vaccine prioritization.
- We worked with the Ontario Science Table to publish a brief <u>on accessibility</u> <u>for disabilities</u> more broadly, which saw nearly 3,000 downloads and over 20,000 views. Shortly after, <u>ICES</u> began reporting vaccination data as part of its provincial dashboard.
- We met with families, self-advocates, and community agencies to talk about vaccines and why they were important. We also taught about vaccines in virtual courses and created easy-read explanations and videos.
- We spoke to news outlets to explain why vaccines were so important to people with developmental disabilities, raising awareness and advocating for change.

Throughout this time, we rapidly learned from our friends and colleagues around the world, comparing notes and exchanging resources. Sometimes we just sat together-virtually-sharing our frustrations and giving each other hope. We certainly felt hopeless at times, but we never stayed still for long. We took action, and until then, I don't think we fully realized just how many actions we could take!

Lessons for Moving Forward

Our paper on vaccine accessibility represents the latest contribution to our pandemic-related research. In collaboration with Inclusion Canada and People First of Canada, we share what we learned about how accessible vaccine information was for people with developmental disabilities, their families, friends, and support staff, along with suggestions for improvement. We are excited that the article is open access and includes a <u>supplementary easy-read summary</u>, which we codeveloped with advisors with developmental disabilities.

But this little email, "Please Take Action", reminded me not only of our past efforts but also of what still needs to be done. New Year's resolutions often focus on future goals - what we will do. However, during the pandemic, I realized that we all can do something, big or small, to improve not only our own health and wellbeing but also that of those around us. Here is what I learned:

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- **Learn and share**. We need to take the time to read, educate ourselves, and share what we learn to help build awareness.
- **Listen to others**. We often underestimate the power of listening. It not only helps us to see things differently but also makes others feel heard and valued especially when they feel invisible or ignored. This can provide crucial support and encouragement to keep going.
- **Learn and adapt**. COVID-19 was an unprecedented crisis, and we didn't always have the answers or know what to do. But, we bravely kept trying, learned from our mistakes, and adapted our approach.
- Work together. The pandemic showed us the power of teamwork. Much of
 what we learned about vaccine accessibility applied not only to people with
 developmental disabilities but to many other groups as well. Together, we
 created a broader, more inclusive community under one big tent!

A Call to Action for 2025

As 2025 begins, here is how I'm taking action. First, I am reflecting on the past, acknowledging what went wrong and celebrating what went right. Second, I am sharing my thoughts through this blog, hoping to encourage you to challenge yourself and take action this year. Finally, I am focusing on connection. In 2025, I am committed to working collaboratively to make healthcare more accessible for people with developmental disabilities. Collaboration fuels creativity, validates our efforts, and empowers us. And it's fun!

Happy New Year, H-CARDD supporters. Thank you for reading. In 2025, let's keep working together and taking action–before, during, and after crises. "Please Take Action" can sound like a very polite Canadian request or a universal, desperate plea. The lessons we learned during the pandemic can continue to guide us in taking action. Don't look away or say "I wish I could help, but there is nothing I can do." You *can* do something. We all can. Please try.

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