Survey Overview

In June 2020, we asked members of the Brain Injury Speaks Stakeholder Engagement Network about the impact of COVID-19 social distancing measures on their brain injury supports and services. Approximately 40% of the network (210 members) responded to the survey. Two open-ended questions were included at the end of the survey to provide respondents with the opportunity to comment further about their experiences, as well as what helped them the most during this challenging time. A total of 177 respondents used these open-ended questions to describe their experiences.

Question 1: Are there any support services that were not mentioned in the previous questions that you accessed/received during the COVID-19 social distancing practices? Please specify and provide as much detail as possible (for example, the type of service, the organization that provided the service, how you accessed/received the service).

63/177 respondents answered this question. Responses are sorted into three sections based on the type of responses received: 1) Brain injury supports and services accessed/received, 2) Barriers to accessing supports and services and 3) Other. Quotes from respondents are presented in Table 1 below.

1. **Brain Injury Support and Services** (n=23). Respondents described accessing both Online Services as well as services over the telephone. Most comments mentioned using online services such as Zoom and Facebook to connect with other individuals as well as access previous in person services. One individual highlighted how many individuals in the community did not have access to a computer and thus suggested having more phone services to include this group.

2. **Barriers to Service** (n=25). Comments about the barriers to accessing services varied widely. Some individuals experienced cancellation to their normal services with no alternatives, others had trouble with technology or were not able to tolerate computer screens to access services, and some did not know what was available to them/didn’t know where or how to access services.

3. **Other** (n=15). Responses in this section were more general about the survey rather than an explanation of specific services that individuals accessed.

Question 2: What has helped you the most during this challenging time of COVID-19 social distancing practices?

177/210 survey respondents answered this question. Five broad themes emerged in the analysis of responses: 1) Family, Friends & Social Support, 2) Online Support, 3) Physical activities and hobbies, 4) Rest, and 5) Mindfulness and yoga. 5 survey respondents answered the question by saying that nothing has helped them. One respondent described that “Nothing [has helped], I’m overwhelmed and struggling and have no supports available to me locally, and live alone.”

1. **Family, Friends and Social Support** (n=75). An overwhelming number of respondents mentioned that surrounding themselves with friends and family has helped them through
COVID-19. Some individuals were able to see their family/friends in-person while others were exclusively interacting virtually/over the telephone. Some respondents expressed that reminders from family/friends about taking the necessary precautionary measures for COVID-19 were helpful to them.

2. **Online Support** (n=53). 53 individuals were still able to access services that they used prior to COVID-19 that had transitioned to online/virtual platforms. Respondents described a variety of online supports that helped them, including brain injury support groups, virtual appointments with allied healthcare workers (e.g. physiotherapy), online events run through the local Brain Injury Associations, and online therapy with a psychologist/psychiatrist, among others. A few respondents mentioned being able to continue with in-person support from a PSW or RSW.

3. **Physical Activities and Hobbies** (n=26). Respondents expressed that exercise, such as walking, and hobbies like baking, sewing, and gardening was helpful to them.

4. **Rest** (n=22). Respondents described that they were taking extra time to rest which was beneficial to them. Some individuals expressed that COVID-19 social distancing practices allowed them to get some rest from their busy schedules of appointments and the pressure to socialize. A number of respondents described that the isolation from experiencing a brain injury had prepared them to cope with the isolation from the pandemic.

5. **Mindfulness and Yoga** (n=14). Respondents who were practicing yoga and/or mindfulness during COVID-19 social distancing said that their practice was very helpful. Some individuals suggested that the yoga/mindfulness was beneficial to their mental health and reduced their sense of isolation, while others expressed that online yoga/mindfulness helped them feel connected to their peers.

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<tr>
<th>Brain Injury Supports and Services</th>
<th>Theme: Barriers to Service</th>
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<tbody>
<tr>
<td><strong>(Online Services)</strong></td>
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<tr>
<td>“Online groups to keep up with social skills development”</td>
<td>“I was just unable to get my services necessary to manage my post symptoms, so I haven’t felt great. These include physio, chiro and osteopath (which is the most beneficial treatment for me) and massage.”</td>
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<tr>
<td>“Weekly physiotherapy video conferencing for my brain injury which involves regular exercises”</td>
<td>“Since COVID-19 put a halt to the two meeting groups, the two social workers who ran them phone each week to check in.”</td>
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<td>“Caregiver Conversation Group through Zoom for a period of 8 weeks offered by OBIA”</td>
<td>“A social worker from CMHA calls once a week.”</td>
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<td>“Mental health services online through Beacon/Mindbeacon (CBT)”</td>
<td>“Lack of community resources to find/assess abilities and identify resources. You have to know about something before you can access it.”</td>
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<td>“Phone calls from the [local Brain Injury Association] staff member. ”</td>
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<tr>
<td>“Did participate in a group for brain injury that continued to hold sessions post covid restrictions via Zoom but it is difficult to tolerate (screens/sounds). Many members turn off video but it is still a challenge.”</td>
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Table 1: Quotes that highlight the Brain Injury Supports and Services not captured by the quantitative survey questions

Table 2: Quotes that highlight what has helped people the most during COVID-19 social distancing measures

| Family and Friends (N=75) | Online Support (N=53) | Physical Activities & Hobbies (N=26) | Rest (N=22) | Mindfulness and Yoga (N=14) |
“Having friends and family, some of whom were able to truly share their time and space with me, as an individual who lives alone. Otherwise, it would have been intolerable and devastating mentally.”

“Conversations with friends and family members in order to digest information from national and local health authorities, and to share other trusted online resources re implementation of COVID protocols.”

“It has been important for me to have sisters near by. I live alone and they have been in my Bubble since the beginning!”

“Keeping in touch with family, taking different kinds of Webinars on Mental health and following up with my social worker”

“Family members continually/routinely reminding me to practice the necessary precautionary measures.”

“I think the Zoom support group sessions. Even though we were small, it was 'normalizing' for me to touch base with people who've been part of my support system for the past 2+ years.”

“My writing, drawing and painting, gardening, walking, and taking part in my online book club.”

“The isolation has actually helped as I don’t feel pressured to do things outside of the house. My activities are limited and I can concentrate on recovery. With so many things closed I don’t fill up my calendar with miscellaneous activities that do not benefit my recovery. I’m not pulled in fifty different directions that require immediate attention but have been enjoying the quiet. I feel that I have come farther faster than I did with my last concussion. I guess brain rest does actually help the healing process.”

“I found that my social isolation/social pacing that has been my new norm as result of my brain injury prepared me for the COVID 19 social distancing practices.”

“Previously learned techniques from therapies, as well as the fact that all expectations of socializing have been lowered during COVID which removes a lot of pressure & stress.”

“I actually felt healthier as I was not running to thousands of appointments.”

“Personal meditation practise and guided meditations”

“Meditation, yoga, belief that this period will come to an end”

“The Zoom yoga and mindfulness meditation sessions were very helpful in reducing that sense of isolation and feeling connected to peers.”

“Meditation has been a big help. Keeps a sense of calm.”

“Meditation. Trying to get outside for short walks in the sunshine”