Charting our course in a changed world

NHCC Members’ Meeting
June 16, 2020
Conducted two surveys of members

- April 2020, NHCC surveyed member organizations about the impact of the COVID-19 pandemic in terms of serving clients and members and how they have adapted programs & services.

- Early June, NHCC surveyed member organizations about how the COVID-19 pandemic has directly impacted clients and members.
Results survey one

- Q1 - Has the COVID-19 pandemic and the need for physical distancing changed the way your organization functions
  - Yes, significantly - 81.82% (9 respondents)
  - Yes, somewhat - 18.18% (2 respondents)
  - No - 0.00% (0 respondents)
Q2 - How has your organization changed the way it is serving clients and members during the COVID-19 pandemic?

- We are offering programs by webinars - 72.73%
- We are offering one-to-one support sessions by telephone - 54.55%
- We are providing condition-specific information about COVID-19 on organization website, Facebook, Instagram, etc. - 81.82%
- Other - 54.55%
Q-3 Recognizing that it is still early, how successful have you been in carrying out the changed way of serving clients and members?

- It has gone well overall - 63.64%
- We had some glitches, but overcame them - 0.00%
- Still working to make programs and services available - 36.36%
Best practices and successes

• ... offering exercise programs via facebook live twice a week and Mindfulness Mondays (most Mondays) via webinar. It has worked well.
• ...very successful in establishing new emergency funding programs in a very short period of time.
• Those living with neurological conditions, illness and injury are often already socially isolated, so we could all actually learn best practices from them.
• ... have provided family education using zoom but clinics are seeing less patients so it is manageable
Results survey two

- **Q4** - Have your clients/members been negatively impacted by the pandemic and the shutdown and/or reduction of health care delivered by doctors and hospitals?
Q5 - How have your clients/members been negatively impacted by the shutdown and/or reduction of health care services delivered by doctors and/or hospitals.
Q5 - details

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
<th>RESPONSES</th>
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<tbody>
<tr>
<td>Appointments with doctors have been cancelled</td>
<td>91.67% 11</td>
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<tr>
<td>Procedures at hospitals have been cancelled</td>
<td>91.67% 11</td>
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<tr>
<td>Not able to access emergency services</td>
<td>50.00% 6</td>
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<tr>
<td>Lack of access to medical supplies, e.g., face masks, catheters</td>
<td>33.33% 4</td>
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<tr>
<td>Other (please specify)</td>
<td>58.33% 7</td>
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<td>Total Respondents: 12</td>
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- Other comments (selected)
  - appointments with doctors and other healthcare team members by phone or video.
  - anxiety re COVID restrictions
  - social isolation
  - care partners unable to visit long-term care homes or hospitals, anxiety/depression, isolation
  - afraid to have psws enter their homes
Q6: Have your clients/members been negatively impacted by the shutdown and/or reduction of health care services in the community?
Q7: How have your clients/members been impacted by the shutdown and/or reduction of health care services in the community?
Q7 - details

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<tr>
<td>Lack of access to rehabilitation services such as physiotherapists and occupational therapists</td>
<td>90.91% 10</td>
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<tr>
<td>Lack of access to social workers</td>
<td>45.45% 5</td>
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<tr>
<td>Lack of access to psychologists</td>
<td>45.45% 5</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>63.64% 7</td>
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<td>Total Respondents: 11</td>
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- Other comments (selected)
  - Some access...through tele-health but that is difficult for...individuals who have communication challenges.
  - ...shift in community programming to virtual does not benefit many... who are seniors and do not have access or knowledge to use technology ...
  - No access to recreation, mindfulness, camp, speech and language pathology, exercise programs, community pools, massage, acupuncture
  - children are not receiving education supports
Q8: Looking at your organization, have your revenues been impacted by the COVID-19 pandemic?
Q9: How has the impact on revenues affected your organization's activities?

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<td>We have had to reduce/stop services for clients/members.</td>
<td>41.67%</td>
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<tr>
<td>We have had to reduce/stop funding research.</td>
<td>25.00%</td>
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<tr>
<td>We have had to reduce/stop advocacy activities.</td>
<td>33.33%</td>
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<tr>
<td>We have had to lay off staff.</td>
<td>25.00%</td>
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<tr>
<td>Other (please specify)</td>
<td>75.00%</td>
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<tr>
<td>Total Respondents: 12</td>
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• Other comments (selected)
  ▫ Let contract staff go and implemented hiring freeze
  ▫ ...had to cancel our congress at a loss of $850,000 in revenue
  ▫ ...had to postpone conference and other revenue generating activities
  ▫ Fundraising events cancelled
  ▫ None... as we are solely funded by the provincial government
Q10: Has your organization been able to secure any government subsidies or supports?
Q10 - details

- Other comments (selected)
  - [received] CERB and a 10% payroll subsidy...looking into the rental subsidy with our property management and the charity subsidy.
  - have applied, and received our first month of payment subsidies for the 2 staff who are on payroll (approx $4500/month)
Final thoughts by two members

- COVID 19 has created angst and volatility in families that were already at risk. HD families are a low priority in the system and the added burden to help is put on the shoulders of HSC...Charitable nfps like ours seem to be misunderstood by a federal gov't that chooses to address small local charities rather than small-medium national charities impacting more families. If we do not survive the families will be left to their own and researchers will not be attracted to HD research.

- The charity subsidy looks to be quite difficult to access. It is being administered through the Red Cross and United Way.
Reaction?

Additional thoughts?
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