

Accessible Community Forum: Accessible Healthcare in BC

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PART I: Panelists

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- Engagement Leader on the Patient & Public Engagement Team at Health Quality BC (Patient Voices Network)

Joanne Smith – Toronto jes.smithy@gmail.com

- Certified Nutrition Practitioner at Fruitful Elements Nutrition (SCI and identified nutrition missing in the rehab program)

Pascale Jendral – Richmond Pascale.Jendral@pathwaysclubhouse.com

- Program staff at Pathways Clubhouse, in the Public Education department

Heather Lamb – Prince George hlamb@sci-bc.ca

- InfoLine Services Lead at SCI BC

Vanessa Lim – Vancouver vanessalim@talltreehealth.ca

- Occupational Therapist at Tall Tree Integrated Health

PART II: Forum

- 73 total EventBrite registrants
- 52 total Zoom attendees (including ConnecTra staff, panelists and hosts)

PART III: Survey Response Summary

104 total respondents participated in the survey.

- Respondents' relationship with the disability community
 - 49 respondents have a visible disability
 - 30 respondents have a hidden/invisible disability
 - 8 respondents have a family member or a care aid of a person(s) with disabilities
 - 4 respondents are a health care professional or other aid for a person(s) with disabilities
 - 6 respondents are an advocate for people with disabilities
 - 7 respondents put Other / do not have a disability
- Respondents' ages
 - 0 respondents Under 18
 - 5 respondents between the ages of 18-30
 - 38 respondents between the ages of 31-50
 - 49 respondents between the ages of 51-70
 - 12 respondents are ages of 71+
- Respondents' location: All respondents are currently located in BC
 - 10 respondents are in Victoria, BC
 - 7 respondents are in North Vancouver
 - 5 respondents are in Kelowna
 - 5 respondents are in Burnaby
 - 4 respondents are in New Westminster
 - Other responses included Port Coquitlam, Maple Ridge, Surrey, North Delta, Williams Lake, Denman Island, Port Moody, West Vancouver, Mackenzie, Richmond, Grand Forks, and Fort Fraser
- Types of disabilities respondents live with
 - Most common disability among respondents was a mobility impairment (68) followed by mental health (27) and cognitive disability (26)
 - Several respondents also indicated having a
 - Memory impairment (19)
 - Communication impairment (18)
 - Degenerative disease (16)

- Visual impairment (15)
 - Hearing impairment (9)
 - Indicated Other (4)
 - Prefer not to say (3)
- 59% of Respondents live with chronic illnesses
- Healthcare services respondents access at least once a year
 - Doctor's appts/check-ups (95)
 - Dentist (84)
 - Physiotherapy / Massage Therapy (53)
 - Optometrist (47)
 - Emergency Care (32)
 - Counselling/Therapy (25)
 - Occupational Therapy (25)
 - Neurologist (25)
 - Other (24)
 - Audiologist (8)
 - Dermatologist (8)
 - Surgeon (8)
 - Nutritionist (7)
- How frequent respondents access the health care services listed above
 - A few times a year or less (48)
 - Monthly (15)
 - Weekly (11)
 - Bimonthly (8)
 - Everyday/every few days (4)
- 63% of respondents say that health care services are somewhat accessible in the area they live in
- 25% of respondents say that health care services are easily accessible
- 9% of respondents say that health care services are not accessible

- Why health care services are not accessible in their area
 - No family doctor, or specific therapy available (physio, massage etc.)
 - Lacking doctors/nurses in their area
 - Cannot go to ER (due to shortage) without waiting 4+ hours
 - Transportation issue
 - Most appts are too far away (1.5 hrs) and a bi-annual appt is 12hrs away
 - Wait times are ‘ridiculous’
 - Medical care buildings are not accessible (physio, dentist, doctor’s office)
 - Lack of transfer systems/abilities to have a physical exam in most spaces (eg. Can’t transfer onto an exam table)
 - No automatic door, heavy doors to open
- If respondents' needs were met when they sought out healthcare in the last 12 months
 - My needs were met (25%)
 - My needs were sometimes met (45%)
 - No, my needs were not met (25%)
- Why respondents feel like their needs were not met
 - Health concerns were not resolved (16)
 - Services used did not accommodate their disability (14)
 - Appointment/practitioner was not available at the time required (11)
 - Felt like doctor was not taking them seriously (8)
 - Didn’t understand what doctor was telling them (2)
 - Language barrier (2)
 - Appointment/practitioner not available in the area required (1)
- Health care offices/buildings accessibility for respondents and their needs
 - Yes, they are accessible (39%)
 - They are sometimes accessible (49%)
 - No, they are not accessible (9%)
- Online health services (eg. Online appts, digital prescriptions) accessibility for respondents
 - Yes, they are accessible (44%)

- They are sometimes accessible (39%)
 - No, they are not accessible (8%)
- Information on healthcare services ease of accessibility for online or in-person
 - Yes, I can easily find info (20%)
 - I can sometimes find info (60%)
 - No, I can't find info (14%)
- Respondents can get in contact with their doctor/health specialists in a timely matter when needed
 - Yes, I can (27%)
 - I sometimes can (49%)
 - No, I can't (21%)
- Healthcare services respect respondents' autonomy in making their own medical decisions
 - Yes, they respect my autonomy (52%)
 - They sometimes do (32%)
 - No, they do not respect my autonomy (10%)
- Healthcare providers involve respondents' family/caregivers in making their medical decisions
 - Yes, all the time (8)
 - Yes, only when I want them to (26)
 - Sometimes they do (12)
 - No, they never do (36)
- Non-profit organizations support respondent's health care needs
 - Yes (24%)
 - No (43%)
 - Not sure (33%)
- Organizations respondents feel support their health care needs
 - 22 responses
 - A few of them include: ALS Society, SCI BC, SCIO ON, Provincial Respiratory Outreach Program (PROP) (BC), Muscular Dystrophy Canada, Tetra, REACH, ICORD, Arthritis Centre, Safe Care BC, Alcoholics Anonymous etc. (many more in Accessible Healthcare Resources!)

- What changes could be made to make healthcare services more accessible
 - 104 responses
 - Most common responses:
 - More doctors, GP, nurses, ER readily available (system is overrun, overworked, underemployed) (in rural areas too)
 - More doctors/nurses who understand/ receive training in disability and ableism
 - Online appointments for all services, Apps available
 - Websites with options for dyslexic fonts, larger text
 - Less wait times in general
 - Contact healthcare professional without making an appointment – Issue solved the phone
 - Contact doctors when needed (Eg. Not needing a referral every 6 months for specialists they will need for a lifetime due to spinal cord injury)
 - Physical access & accommodation in healthcare buildings
 - (eg. Ramps, automatic doors inside the building, elevators, accessible & height adjustable beds, chairs, lifts, fragrance free, washrooms, grab bars, moveable supports, more space for wheelchair, parking)
 - Accessible physical exams, examination tables too high (eg. Pap test had to be set to a specialist w/ can accessible table – requires wait time)
 - Dentist & Optometrist facilities not designed for people with wheelchairs
 - Information is accessible for people with visual disabilities
 - Issue: very few pharmacies offer service where the prescription sticker is compatible with a program that can read prescriptions out loud (script talk) - will take 2-3 days to get the tag put on the bottle with the info
 - Medical professionals will only speak to the family member/care giver and not provide a system for the individual with the disability to take their meds.
 - Testing labs, protocols, equipment need to be made more accessible
 - Info about clinic/testing lab/hospital services accessibility need to be centralized & accessible online (eg. Which clinic can perform a mammogram for wheelchair users, can perform ultrasounds)
 - Universal referral form (eg. Allow long term care residents to access physical rehabilitation services)

- Central hub from an organization that can be the spokes for healthcare needed for tailored needs in the community where accessibility is the central issue
 - Medical professionals using preventative medicine vs. Treating ailments only, until they become a bigger issue
- 64% of respondents have struggled with their mental health
- For 63% of respondents, their disability has impacted their mental health
- 68% of respondents know where to go when struggling with their mental health
- Only 32% of respondents attend regular therapy/counselling appointments
- 55% of respondents would like to attend therapy/counselling but feel limited due to lack of resources or finances, 15% of respondents have not been able to access therapy/counselling
- 21% of respondents feel mentally supported by the healthcare services they use, 35% of respondents do not feel supported, and 36% sometimes feel supported
- 74% respondents say accessing healthcare services cause stress/anxiety
- 96% of respondents agree that Mental health is an important component of healthcare
- 81% of respondents agree that ableism an issue in the healthcare industry
- 71% of respondents have witnessed ableism within the healthcare system
- Instance(s) respondents have witnessed ableism (60 responses)
 - Assume they can perform a task with their disability
 - Doctors making assumptions, instead of helping me
 - Discriminated against for their disability, weight, communication style, moving pace
 - Disregarded because of an invisible disability
 - Unsafe patient transfers, patient must bring an assistant to do patient transfers
 - Denied entry due to disability, “accessible” spaces aren’t accessible, charge more to provide wheelchair accessibility
 - When medical professionals want to share information, they talk to family member/friend/partner rather than to patient
- 63% of respondents say people with disabilities do not receive same level of care as people without disabilities, 15% say they do.
- Medical professionals ever tried to cure respondent’s disability
 - Yes (26%)
 - No (52%)

- Not Sure (12%)
 - Do not have a disability (10%)
- 51% of respondents say that medical professionals have made them feel like a burden for seeking care with their disability
- Medical professionals given a treatment/procedure without respondents direct consent?
 - Yes (23%)
 - No (62%)
 - Not sure (14%)
- Respondents' response to ways ableism can be mitigated in the healthcare system
 - Education for healthcare staff (90)
 - More attention to physical design of buildings and services (79)
 - Further understanding of the autonomy of people with disabilities have the right to have (81)
 - Increasing awareness of what constitutes ableist language and behavior (86)
 - More accessible educational resources on healthcare services (71)
 - Employing more people with disabilities in the healthcare industry (79)
- 39% of respondents have received support from a case worker (person working for gov / dedicated organization who provides info, advocacy, resources)
- 47% of respondents do not know where to find a case worker, 38% of respondents do.
- 46% of respondents of someone they know use home/community healthcare services (long term care homes, assisted living homes, community nursing, home support), 53% of respondents do not.
- 45% of respondents know where to apply for home and community healthcare services
- 58% of respondents have made a claim to the Gov of Canada / respective Provincial government / Employer and received disability benefits, 32% have not and 5% do not know how to.
- Respondents believe Provincial Gov/Gov of Canada provides suitable assistance to help people with disabilities access healthcare services (eg. BC Disability Assistance)
 - Yes (8%)
 - No (66%)
 - Not sure (26%)
- Respondent's know which healthcare services in BC are free and which have partial costs

- Yes (27%)
 - No (51%)
 - Not sure (22%)
- Respondents interest / looking to be a part of improving the quality of the health care system and its accessibility
 - Yes (84%)
 - No (3%)
 - Not sure (13%)
- Respondent's interest in attending the Accessible Community Forum: Healthcare
 - Yes (63%)
 - Yes, but the time does not work for me (15%)
 - No (7%)
 - Not sure (14%)
- Questions respondents would like to be addressed during the forum
 - How can individuals improve the health care system / make it more accessible / share knowledge / share experience?
 - How could medical services make accessing health care easier for us?
 - Where is a centralized list of accessible options and can it be defined what "accessible" means? (Eg. It does not just mean no stairs. There are so many more components)
 - How do we ensure proper follow up and continuum of care for patients without family doctors?
 - Alternatively, how can we either stop relying on the family doctor system or fix that broken system?
 - Where can someone find free/low-cost services in BC, beyond solely relying on their family doctor (who may not have all the info)?
 - Is there a centralized online repository of easily digestible information around accessible healthcare in BC?
 - We often address the needs of unemployed disabled people but even employed disabled people are at a disadvantaged compared to their non-disabled counterpart.
 - What are some of the benefits/services offered to employed disabled people to support them in their quest to remain employed?

- (for instance, financial support for at home care services; financial support for mobility aids and/or other types of accessibility tools; etc...)
 - Are there any measures to incentivize or add legislative pressure to the private/semi-private healthcare sector in becoming more inclusive of disabled people?
- How could medical services better understand particular disabilities?
- Do health care professionals get training in general disability awareness and sensitivity?
- Please provide discussion and possible strategies to bring awareness and change to medical school training about disability issues.
- How can we ensure the topic of disability, inclusion and respectful care are part of post-secondary program curriculums?
- How can autonomy be respected, along with a need for communication assistance? Why are many doctors patronizing?
- How are healthcare providers being held accountable for discrimination?
- Where do you go if you have been discriminated against in the medical system?
- What can we do to establish a system of certified/trusted/qualified Medical Advocates?
 - Someone to go with you to appointments and intervene when medical staff talk over you, or help clarify things.
- Why are medical offices not mandated to have universal design?
- How can we advocating for funding to ensure access to affordable, wheelchair accessible transportation to medical appointments?
- How do we create incentives to ensure medical facilities and private medical office spaces are built or renovated using barrier free design principals?
- Is there an organization we can bring access issues to such as elevators that don't talk or have large print/braille labels by buttons, websites that are not accessible to the blind using screen readers? (like Life Labs)
- Why are medical services for physical disabilities primarily administered through the ministry of social development and poverty reduction instead of through the ministry of health?
- Why are most disability benefits are time-limited and have too many conditions?
- Why I can't have a health care team who all have electronic access to my file, why I don't have access to my file, why don't we have government staff assigned to PWD to help proactively get services, when will PWDs be treated equally?

- Why is financial income restricted and there are no facilities for work, and this is accompanied by weak health support?
 - Why is home visit OT (occupational therapy) a covered service, but home visit PT (physical therapy) is not?
 - Why are the provincial dental coverage/reimbursement rates so out-of-date? (2010?)
- People or organizations respondents would like to see represented on the panel
 - VCH, FVH, Primary Care, BCCH
 - Family Support Institute, Parents and Self Advocates, Community Living BC. DDMH. Service providers
 - Praxis, SCI BC, Spring Hawes, Tetra Society, Down Syndrome Research Society, PACE, Tobias House, March of Dimes, Urban Native Health Care Services, CMHA, Pain BC
 - Advocacy groups
 - Disability Alliance
 - The Ministry of Health (Federal & Provincial), The Ministry of Social Development and Poverty Reduction
 - Health Authority CEO's, College of Physicians & Surgeons
 - Ministry of Health (Adrian Dix)
 - VP of Regional Hospitals and Health Services (Laurie Leith)
 - BC College of Physicians and Surgeons, BC Paramedics, Community Living BC
 - CLBC, PLAN (Jule Hopkins)
 - Sociologist, Psychologist, Psychiatrist, Mobility Aid Specialist/Organization
- 59% of respondents were already on the ConnecTra Society mailing list, and 30% of respondents said they wanted to be added to the mailing list