# Top 10 Challenges to Meeting Brain Injury Survivors' Needs

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# System Navigation: What we do

We will work with anyone affected by ABI: survivors, families, and professionals

- Support & Referral
- Information & Advocacy
- Education & Training for Professionals
- Locally Focused Network for Consultation
- Collect Data & Share with LHIN



### When to consider brain injury:

- A diagnosis is provided
- There is a history of trauma or loss of consciousness
- Prolonged history of substance use and/or overdose
- Signs such as memory deficits, difficulty with follow through, and other symptoms not otherwise explained



#### The Human Brain: The Coles Notes Version

- Brain cells, called neurons are each connected to one another. They communicate by passing impulses through their chain of connections.
- The brain is divided into left and right hemispheres as well as four "lobes" (frontal, temporal, parietal and occipital) which are specialized in certain skills or functions.

## What is a Brain Injury?

- The term "Acquired Brain Injury" refers to an injury which occurs suddenly through a traumatic or non traumatic event
  - An injury can range from mild to severe
  - Concussions are mild brain injuries which cause a temporary disruption.
  - Repeated concussions, alcohol or substance use can cause permanent effects

#### What Affect Outcomes

The outcome of an injury is affected by many variables:

- Location of injury
- Severity of the injury
- Medical care
- Age
- Previous abilities
- Concurrent health problems
- Rehabilitation
- Support from family and friends

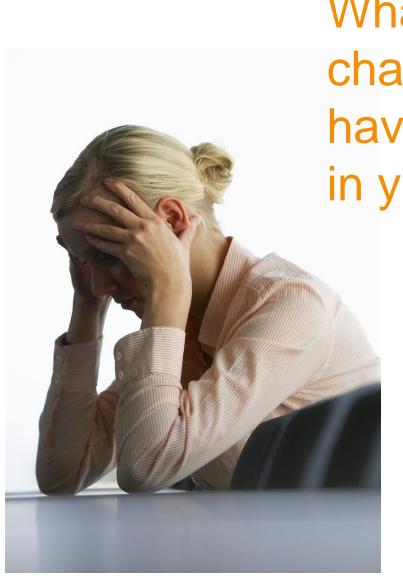


#### The Top 10 Challenges for Survivors:

#### RCBIS Clients Say:

- 1. Being forgetful
- 2. Being easily distractible
- 3. Difficulty setting realistic goals
- 4. Apathy
- 5. Poor concentration
- 6. Poor balance
- 7. Expressing self in wordy way
- 8. Difficulty finishing things
- 9. Fatigue
- 10. Doing things slowly





What are the challenges you have encountered in your work?



And now, the moment you've all been waiting for...

# The Top 10 Challenges to Meeting Brain Injury Survivors' Needs



# #1 - Recognizing Invisible Deficits

Certain skills and abilities may remain at the normal or even above average range, while other abilities are affected.

Challenges may only be revealed under particular circumstances over time.



#### Points to Consider:

- Good verbal skills can mask other impairments
- Examples of abilities which become apparent in particular circumstances include
  - Processing speed & attention
  - Memory
  - Problem solving
  - Verbal or reading comprehension
  - Planning and organization deficits



#### Where to look for direction:

- Ask your client, family members, and professionals involved questions to find out about your clients' particular needs.
- Request and read cognitive assessments, discharge summaries, or psychological reports
- Assume that the person is wanting to succeed – if you are not getting anywhere, try to change your approach.
- A little information gathering up front will lead to less time spinning your wheels later.

# Case Study: Mike

Mike is receiving Employment Supports. He meets with an employment counsellor and talks enthusiastically about his goal to work in landscaping. He is able to discuss the subject in detail and appears motivated. He shares that he has had worked as an assistant landscaper for nearly a decade. When his counsellor asks him to complete tasks such as updating his resume and applying for work, he is always agrees but does not follow through. This goes on for weeks without success....

What are the areas that Mike may have challenges in?



How might you learn more?

What might be done to address them?

# #2 - Understanding individual strengths and challenges

Each individual is unique and each brain injury is different. The approach you take must factor in the individuals strengths and challenges in order to be successful.



# Consequences of Injury to the Human Brain

- Motor strength, coordination, speed, balance
- Sensory sight, hearing, touch, proprioception, taste, smell, balance
- Cognition language, visualspatial perception, initiation, attention, memory, processing speed, executive function
- Behaviour/Emotion stability, control



## Strategies

- Reduce environmental distractions 3
- Speak clearly and concisely <sup>2</sup>
- Go slowly
- Monitor a person's attention span <sup>4</sup>
- Check in & summarize often to ensure understanding
- Avoid open ended tasks. Break down steps together and finish one before starting another
- Provide reminders like follow up phone calls or written step-by-step plans
- Take breaks & allow mental rest to avoid fatigue and overload

#### Strategies, Con't.

- Create organization assign places at home to put important things or keep copies of important paperwork at the office
- Involve family or friends as supports
- Implement routines and structure, such as keeping the same appointment time each week.
- Encourage day planner use <sup>3</sup>
- Maintain a record of work together for reflection and feedback.

# #3 – Pinpointing Goals

- Communication and cognitive challenges can make understanding goals difficult
- Discrepancies often occur between what we believe is achievable and what the client believes
- Memory deficits, lack of insight, and rigid thinking can complicate matters
- We don't have crystal balls sometimes you have to try and see!





## What helps?

- Make notes (words or pictures). Mind maps are a great way to collect thoughts. Refer to them each visit for clarity
- When possible, use the client's own words for goals
- If the client is unable to come up with ideas on their own, ask questions and suggest options
- Consider having the client sign a contract once goals are identified if there is significant memory issues as this will give you something to refer to at future meetings.

# #4 – Communication Challenges

- Can be caused by damage to communication areas of the brain as well as cognitive areas of the brain
- Word finding difficulty can be occasional or severe
- Affected by muscle control & coordination
- Disorganized thoughts
- Difficulty reading social cues



## Common problems:

- Talking too much
- Poor eye contact
- Not good at turn taking
- Being tangential
- Difficulty listening
- Difficulty starting conversations
- Getting stuck on one topic
- Inappropriate expression
- Not being aware of personal space
- Not reading cues to end conversation





# Strategies

- Go slowly and give plenty of time for a response.
- Encourage all attempts to communicate
- Try not to interrupt or answer for the individual
- Speak clearly and in short sentences
- Summarize and rephrase as needed
- Do not change the topic quickly.
- Encourage clients to take time to write down ideas ahead of meeting time (family or support workers may assist)
- Be aware of other factors such as pain or fatigue

# Keeping on Track

- Have a written work plan for both you and the client to refer to.
- Use transitional phrases like "Going back to my original question…" or "I wanted to ask you about…"
- If the behaviour is very intrusive, be polite but frank with the client, provide an example, and develop a plan together on how to keep focused

### Small Group Case Study: Carla



Carla has been receiving services from a physiotherapist related to her physical injuries after a car accident. During her appointments she is very

friendly and talkative, often focusing on stories about her pet dog. Although she is very pleasant, she often speaks at length and loses focus on her exercises.

Her physiotherapist struggles to return focus to the task at hand...

What factors might be related to Carla's talkativeness?

What challenges you can foresee?

How might you address your concerns?



#### #5 – Lack of Awareness

Limited awareness or insight can result from a number of factors:

- Adjusting to and accepting new abilities and limitations post-injury
- Damage to the brain can affect one's ability to perceive one's self and incorporate previous experiences
- Memory issues may interfere with the ability to draw on past experience
- Inability to think beyond one's self
- A lack of insight may cause people to attribute failures to external sources, including you!



## Strategies:

- Provide any feedback gently<sup>1</sup>, being respectful that the person may still be grieving the abilities they lost
- Explain your reasoning for suggestions and go through steps together<sup>1</sup>
- Allow for reality-testing where safe
- Pose questions to explore ideas together



# Strategies, Con't.

- Explain concerns/anticipated negative consequences clearly but without passing judgment on the person
- Praise successes and use failures as learning experiences to discuss alternative actions for the future





# #6 – Emotional and Behavioural Difficulties

There are a multitude of reasons for difficulties following an ABI

- Altered brain chemistry
- Reduced ability to self-regulate
- Loss of social supports
- Altered family dynamics
- Loss of control
- Emotional reaction to situation
- Pain



#### Mental Health

- ABI can cause increased vulnerability to developing a mental health disorder <sup>5</sup>
- The severity of the ABI is not correlated to the likelihood of a concurrent mental illness.
- Caused by neurological changes, reaction to stress and loss, or pre-existing conditions
- Collaborative and holistic approaches achieve the best outcomes. Both ABI and Mental Health need specialized treatment.
- Untreated mental health conditions can lead to difficulty in rehabilitation or maintaining level of functioning

#### **Ask Questions:**

 History of mental health or addictions issues prior to the brain injury



- New behaviours or emotional triggers
- Changes to appetite or sleep
- Engagement in regular activities
- Changes in relationships
- Flashbacks or fears resulting from trauma

#### Substance Use

- Substance use is a factor in many ABI's, and leaves survivors more susceptible to addiction issues <sup>6</sup>
- Loss of vocation or activity, stress, pain, and poor impulse control contribute
- Continued use can cause further harm to the healing brain
- Tolerance may be lower following ABI



## Strategies

- Provide education on the affects of alcohol and drug use after an injury
- Consider altering the environment to support the individual and remove them from the temptations to use 4
- Address underlying triggers such as isolation, pain, or mood
- Enlist support from family and friends
- Work with an addictions counsellor if ongoing support needed
- Develop a plan to avoid using
- Identify intrinsic reasons to stop

#### **Behavioural Difficulties**

- Some outcomes of ABI cause survivors to display behaviour which may be inappropriate or even aggressive at times.
- Don't assume someone is making a choice to act in a certain way.<sup>4</sup> Address concerns up front, and explain what is expected.
- Emotions such as anger can be secondary feelings, consider what is at the root <sup>2</sup>

# Common Challenges

- Disinhibition
- Emotional Lability
- Denial
- Egocentrism
- Low Mood, Depression and Anxiety
- Low Frustration Threshold & Irritability
- Impulsivity
- Difficulty Identifying Accurate Expectations
- Difficulty with Motivation
- Dependency on Others
- Pain & Loss of Ability



# We all have them – identifying triggers:

#### **Internal**

**Fatigue** 

Grief & sadness

Medication

Illness & pain

Hormones

**Blood sugar** 

Hunger

#### **External**

Lack of choice & control

Changes in routine

Noise

Holidays

Weather

Other's expectations

People around us



#### Turning it around:

- Identify behaviour and emotional triggers and "early warning signals" 2
- If possible, avoid triggers. If not be sensitive and respect that it may be overwhelming. Stop for breaks to recompose.
- Slow down and reduce pressure
- Avoid surprises involve the person in planning
- Write things down to increase understanding
- Be clear and direct in giving feedback to unwanted behaviour or comments
- Provide the opportunity to be successful
   & give praise
- "Roll with resistance" instead of being confrontational 4

### Case Study: Jack

Jack is a resident in a long term care home, where he was forced to move after experiencing a brain aneurysm. He is 40 years old and separated from his wife. Staff express difficulty in managing Jack's behaviour when he becomes upset, which can include yelling, swearing, and grabbing at them. Some feel he shouldn't be allowed to remain at the home.

## Think of Jack, or another case you may be dealing with in your own work:

- What do we know about the client that might be contributing to his/her behaviour?
- What don't we know?
- What needs investigation?
- What could the staff do to try to support the client and reduce the behaviours?

#### #7 – Don't Take it Personally



- Dealing with challenging behaviour can take its toll – even the best professional can get worn down
- Monitor your own feelings and reactions
- Although you may feel under fire, the behaviour is not necessarily directed at you.

## Keeping your cool

- Keep in mind: behaviours are often not intentional but the result of deficits
- Reframe the behaviour
- Keep your focus on addressing the underlying problem
- Recognize your feelings and seek support for yourself
- Maintain control in the situation, avoid compounding the issue by mirroring hostile behaviour
- Develop a consistent approach to address ongoing behavioural issues



#### #8 - Concerned Others

- After a brain injury, others may assist with or assume decision making on the survivors' behalf
- These individuals are often well intentioned, but may have differing views from the survivor or you as a professional
- It can be difficult to provide service without buy-in; how can all be comfortable with the plans?

#### Strategies:

- Often family members have also experienced trauma. Respect their emotions.
- Link family members to support groups or ABI education
- Look at the client and family as a whole. Solicit feedback from the client about their feelings and thoughts on family member's opinions.
- Don't make assumptions.

#### Strategies, Con't.

- Communicate empathy with the significant other's concerns. Allow them to feel they have been heard.
- Provide family members with an explanation for why you are recommending a particular approach.
- Remember that gains are not possible without some risk

## #9 – Recognizing Undiagnosed Brain Injuries

- Undiagnosed brain injuries are common, particularly in the criminal justice system, homeless individuals, and those with substance abuse concerns
- While some ABI's are easily diagnosed if investigated, others will not show up on typical CT scans or MRI's.
- Some individuals engage in behaviours or lifestyles which place them at risk of sustaining brain injuries or further harm

### Red Flags

- Symptoms not otherwise explained such as poor memory, concentration issues, planning difficulties, inability to transfer knowledge, difficulty initiating new things
- Remember some cognitive abilities may be unaffected while others are different from developmental disability

#### Red Flags, Con't

- History of being able to achieve a greater level of independence (if sustained injury in adulthood)
- Injuries in childhood which may not have shown symptoms until developmental stage approached – sometimes not traced back to injury





#### Why does it matter?

- It is likely that you are already working with people with some form of ABI but just don't know it
- Understanding the origin of the behaviour leads to insight and understanding
- Conceptualizing ABI symptoms enables the ability to plan intervention approaches
- May be eligible for ongoing support

## #10 – Finding help when you need it

Working with someone with a brain injury requires specialized skills. Some challenges may not be able to be fully addressed by you alone. If you need support, ABI System Navigation of Southeastern Ontario can assist in connecting you to services in your community. We will also track the types of requests we receive to help plan for the future.





#### braininjuryhelp.ca

Acquired Brain Injury System Navigation of Southeastern Ontario

- Local resource directory
- Links for professional resources
- Information on brain injury effects
- Call 613-547-6969 ext. 165Or 1-800-871-8096



#### Time's Up!

- Brain injuries are complex conditions, each unique to the individual
- If you are having ongoing concerns, seek support from rehabilitation professionals for insight
- Be patient & optimistic for the future!





# Thank you for making time to learn about this important issue

Questions & Comments?



#### Sources:

- 1. Working with People with ABI www.abistafftraining.info
- Working with People with TBI <u>www.tbistafftraining.info</u>
- Ontario Association of Speech-Language Pathologists and Audiologists Acquired Brain Injury www.osla.on.ca
- Ohio Valley Center for Brain Injury Prevention and Rehabilitation <u>www.ohiovalley.org</u>
- Evidence Based Review of Moderate to Severe Brain Injury <a href="http://www.abiebr.com">http://www.abiebr.com</a>
- Substance Use/Brain Injury Bridging Project <u>www.subi.ca</u>
- 7. Understanding Acquired Brain Injury (ABI) and Intellectual Disability, Don Salmon, M.A., Psychological Associate

  <a href="http://www.communitynetworks.ca/Uploads/Files/Slide%20Handouts%20-%20Acquired%20Brain%20Injury%20and%20Intellectual%20Dis.pdf">http://www.communitynetworks.ca/Uploads/Files/Slide%20Handouts%20-%20Acquired%20Brain%20Injury%20and%20Intellectual%20Dis.pdf</a>
- Brain Injury Basics and Strategies, RCBIS PowerPoint Presentation
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