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FOCUS GROUPS FOR CLIENTS WITH MODERATE TO SEVERE ABI: BENEFITS OF WORKING MEMORY COMPACTION/GRAPHIC ORGANIZATION OF INFORMATION

ABI COALITION MEETING: JANUARY 6,
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INTEGRATED COMMUNITY BASED REHABILITATION SERVICES FOR PEOPLE WITH ACQUIRED BRAIN INJURY IN THE CHAMPLAIN LHIN

- ▶ In late 2015, a working group led by Dr. Laura Rees was given the task of proposing a model for integrated and enhanced community rehabilitation services in our region.
- ▶ The task involved various data gathering exercises, one of which consisted of consumer focus groups.
- ▶ Aimed to build in procedural safeguards to ensure that focus group findings not consist of an exhaustive wish list of resources out of keeping with current fiscal realities.
- ▶ Deemed important that focus group objectives include identifying the highest priorities for consumers in the Champlain LHIN



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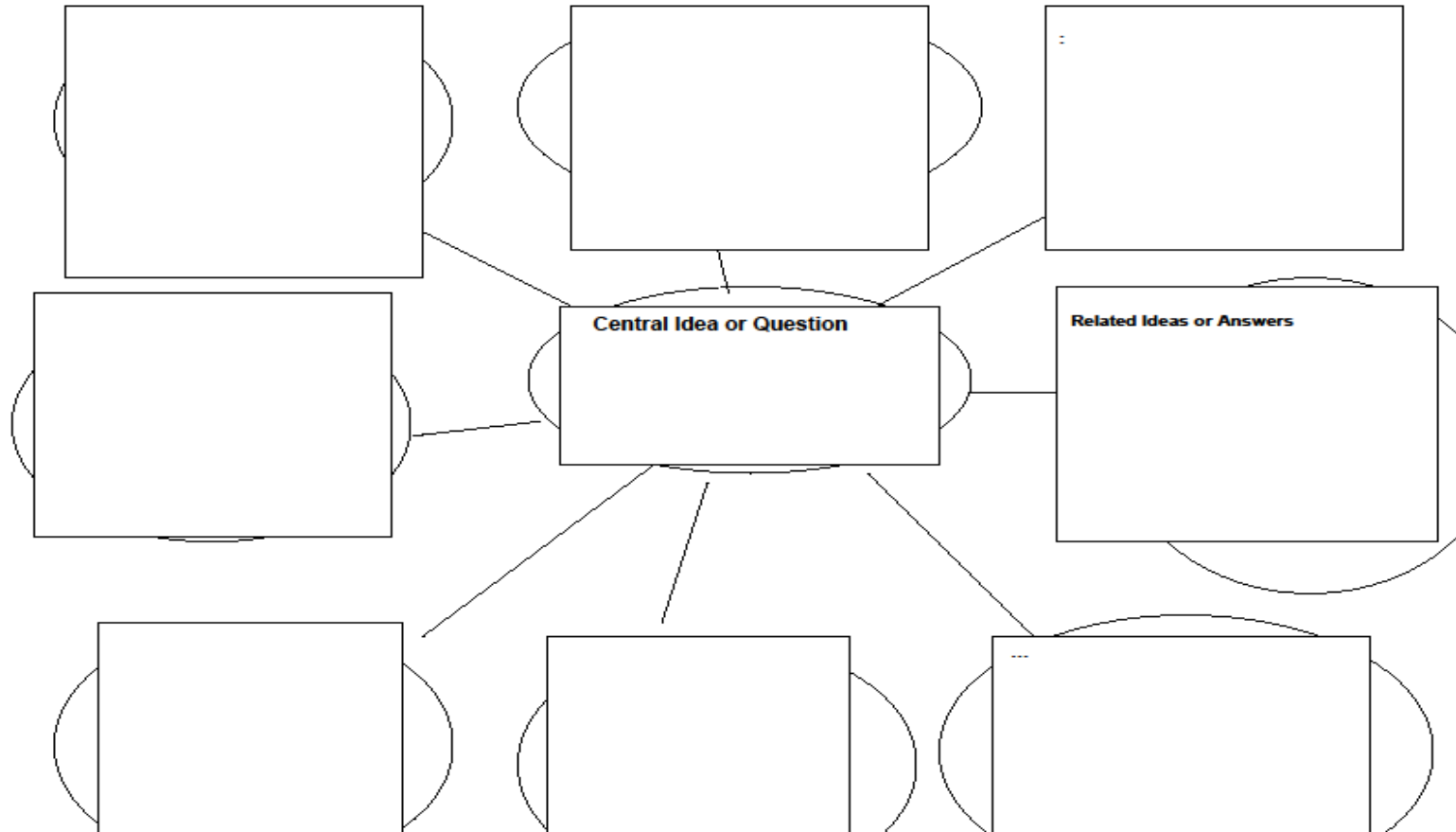
INTEGRATED COMMUNITY BASED REHABILITATION SERVICES FOR PEOPLE WITH ACQUIRED BRAIN INJURY IN THE CHAMPLAIN LHIN

- ▶ Concern raised that some persons with moderate to severe ABI might have difficulty simultaneously generating response choices, narrowing down their personal priorities, as well as arriving at a consensus on priorities within a group.
- ▶ We know from the literature that persons with significant ABI can sometimes have challenges with working memory and organizing information to accurately reflect their values (Ylvisaker and Feeney 2000, Ylvisaker, McPherson, Kayes, Pellett, 2008)
- ▶ At REC, we have come to use mapping methods to help clients handle multiple pieces of information at once, and easily see more options at a glance.



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“BUBBLE MAPPING”



FOCUS GROUPS: OVERVIEW

- ▶ CLIENTS:
- ▶ 12 clients - 2 focus groups of 6 clients
- ▶ Mean # of years since injury/illness = 6 (Range = .5 – 20.5 yrs)
- ▶ F= 5, M = 7
- ▶ Adapted approach to focus group
- ▶ Duration approx. 1.5 hrs.
- ▶ FAMILY:
- ▶ 16 Family members - (2 focus groups)
- ▶ Mean duration of years since family member's injury/illness = 11.9 (Range = 2.5 to 36 yrs.)
- ▶ Did not use bubble mapping
- ▶ Duration approx. 1.5 hrs.



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CLIENT FOCUS GROUPS: ADAPTED METHOD

- ▶ Step I INITIAL GROUP DISCUSSION:
- ▶ Moderator provides a question
- ▶ “ THE THREE MOST IMPORTANT THINGS THAT WOULD MAKE A NON-FAMILY DAYTIME MEETING/ACTIVITY PLACE INTERESTING FOR PERSONS WITH AN ABI ARE ? “
- ▶ By analogy, the group is sensitized to the possibility that certain choices might provide “ideal” higher cost services for some but result in more protracted access to such services for all (e.g. choosing ingredients for a cake on a fixed budget).
- ▶ Group has 5-10 minutes to suggest potential responses
- ▶ Some ideas for best answers are jotted on a flip chart and left in view



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CLIENT FOCUS GROUPS: METHOD

- ▶ Step II- INDIVIDUAL EXERCISE :
- ▶ Moderator provides a bubble map with the same question at the Centre of the map, with some possible responses in the periphery as well as some blank bubbles
- ▶ The provided response options were generated based on previous survey questionnaires and clinical experience addressing such questions with clients
- ▶ Clients are instructed to individually identify her/his 3 preferred responses to the question, drawing from the choices already in the bubble map, or adding some or all new ones based on the flipchart or from their own reflections.
- ▶ They rate their preferred responses in rank order, # 1, #2, #3 on the sheet
- ▶ At this stage they are working individually and not discussing or sharing their choices



AN IMPORTANT ISSUE IS BEING ABLE TO HAVE A SEPARATE APARTMENT WITH SERVICES, EVEN IF NOT ALL PERSONS CAN HAVE ACCESS TO THIS SOON.....

**IT WILL TAKE TIME TO DEVELOP THIS TYPE OF HOUSING OPTION FOR EVERYONE.
COMMENT:**

**AN IMPORTANT ISSUE IF SHARING A HOUSE, IS THAT ONLY PERSONS WITH AN ABI ARE LIVING THERE:
COMMENT:**

**AN IMPORTANT ISSUE IS THE TRAINING OF SERVICE PROVIDERS IN THE HOUSE
COMMENT:**

**AN IMPORTANT ISSUE IS THE KINDS OF ACTIVITIES AVAILABLE WITHIN THE HOUSING
COMMENT:**

Regarding persons with ABI, the 3 most important housing issues are: (rate in order of importance #1 , #2, #3)

**AN IMPORTANT ISSUE IS AN IDEAL LOCATION OF THE HOME TO GET TO ACTIVITIES AND APPOINTMENTS EASILY
COMMENT:**

**AN IMPORTANT ISSUE IS HAVING A LOW RENT
COMMENT:**

OTHER...

OTHER...

KEEPING A PERSON REGULARLY INFORMED OF WHERE THEY ARE ON THE LIST
COMMENTS:

PROVIDING A CLEAR AND EASILY ACCESSIBLE OPTION TO HELP IN CASE OF AN EMERGENCY WHILE A PERSON IS WAITING:
COMMENTS:

PROVIDING INFORMATION/STRATEGIES A PERSON CAN USE TO COPE WHILE WAITING
COMMENTS:

HAVING A WAY TO PRIORITIZE PEOPLE ON THE WAITING LIST BY NEED (EVEN IF SOME OF US MAY HAVE TO WAIT LONGER SOMETIMES)
COMMENTS:

There is often a waiting period to access ABI services (that is, you can be on a waiting list)
The 3 most important ways this can be more acceptable/bearable are: (rate in order of importance #1, #2, #3)

OTHER:

OTHER...

OTHER...

CLIENT FOCUS GROUPS: METHOD

- ▶ **Step III- Group Exercise:**
- ▶ **Each participant is asked to use the bubble map with their individual ratings to arrive at a consensus via group discussion about the overall 3 best responses, without rating them in order.**
- ▶ **So referring to their existing personal choices, the group engages in a 10-15 min discussion facilitated by the moderator.**
- ▶ **The moderator looks for evidence of converging viewpoints based on individual responses.**
- ▶ **When the moderator has exhausted the possibility of arriving at a consensus for all 3 best responses, then where necessary, responses with the highest number of endorsements as being among the best, are added to the top 3 list.**



CLIENT FOCUS GROUPS: METHOD

- ▶ So once we go through steps 1, 2, and 3 to arrive at group consensus or the closest possible to this for one question, we repeated the same process for the remaining questions.
- ▶ We posed 5 questions in all.



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CLIENT QUESTION 1: RESULTS

- ▶ *“ Regarding persons with ABI, the 3 most important housing issues are ? “*
- ▶ **Top 3**
 - a) **affordability (e.g. subsidized cost)**
 - b) **location (access to community services/resources)**
 - c) **trained staff (knowledge of ABI, safety, ability to assess client’s needs)**

Other response options that arose but were not among the top 3:

-having a separate apartment for self,

-if sharing, sharing only with persons with ABI

-types of activities available within the house

CLIENT QUESTION 2: RESULTS

- ▶ *“ If persons with ABI could have the assistance of a general “ helper person” for a few hours a week, what would be the three most important ways to use the service ? “*
- ▶ Top 3 group responses
 - a) Paperwork (bills, forms, mail etc.)
 - b) Problem solving (trouble shooting, solutions)
 - c) Organization (planning activities, time management)

Other response options that arose but were not among the top 3:

- *Setting up appointments for them*
- *Attending appointment with them*
- *Participation in social outings with them*



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CLIENT QUESTION 3: RESULTS

- ▶ “ If persons with ABI had access to a general ‘helper person’, then the most acceptable contexts to get that help are “
- ▶ Top 3 group responses
 - a) Home 1:1
 - b) Electronic communication (e.g. over the internet)
 - c) Outside home 1:1

Other response options that arose but were not among the top 3:

- *In a group context outside the home (whether in health care or community setting*



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CLIENT QUESTION 4: RESULTS

- ▶ *“ The three most important things persons with ABI tend to look for in non-family pastimes that can give meaning to life are “*
- ▶ a) Physical activities
- ▶ b) Volunteering
- ▶ c) Formal knowledge/academic opportunities

Not judged as part of the top 3 were:

- *Skill development (e.g. learning to sing, play pool etc)*
- *Work*
- *Social activities for the pure sake of the company of others*



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CLIENT QUESTION 5: RESULTS

- ▶ “ *There is often a waiting period to access ABI services (that is, you can be on a waiting list). The 3 most important ways this can be more acceptable/bearable are: “*
 - ▶ a) Regular accessible information about position on wait list
 - ▶ b) Support group for people on wait list
 - ▶ c) Strategies/information on how to cope via website
- Not judged as part of the top 3 were:*
- d) *Access to intervention/emergency services (perhaps considered already available)*
 - e) *Prioritization by need (deemed appropriate but not among the top 3)*



CLIENT SATISFACTION WITH THE FOCUS GROUP FORMAT AND CONTENT

▶ Clients were asked to provide their ratings regarding 6 questions.

▶ This scale was used for 3 of the questions

▶ 1 _____ 2 _____ 3 _____ 4 _____ 5

▶ Not at all

Moderately well

Very well

1. “ I found that the focus group leaders explained the purpose of the focus group and made the instructions clear to me “ mean score = 4.9

2. “ I found that I was able to understand the questions that we discussed in the focus group”
mean score = 4.6

3. “ I found that I was able to understand the suggested response options in the squares around the questions “ mean score = 4.5



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CLIENT SATISFACTION WITH THE FOCUS GROUP FORMAT AND CONTENT

- 4. *“When I chose to do so, I felt comfortable providing my own preferred best answers to the questions”*

1 _____ 2 _____ 3 _____ 4 _____ 5

Not at all

Moderately comfortable

Very comfortable

mean score = 4.8

- 5 *“I found that the overall duration of the focus group was “*

1 _____ 2 _____ 3 _____ 4 _____ 5

Significantly too long

Moderately too long

A good duration

(mean score = 4.5)

- 6. *I feel that my participation in the focus group allowed for a meaningful contribution*

1 _____ 2 _____ 3 _____ 4 _____ 5

Not at all

Moderately meaningful

Very meaningful

Mean score = 4.5



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FAMILY FOCUS GROUP: METHOD

- ▶ 6 questions posed. Some overlap but also differences with client questions.
- ▶ Each participant was first asked to consider a question individually and arrive at their own preferred responses in rank order, #1, #2, #3
- ▶ Then the question was discussed as a group; the group was asked to arrive at a consensus on the top 3 responses to the question, not in rank order though.



FAMILY QUESTION 1: RESULTS

- Housing

- 1) “*What do you feel are the three most important housing issues for persons living with ABI?*”
 - a) Affordable (e.g. subsidized costs)
 - b) Location (access to community services/resources)
 - c) Trained staff (knowledge of ABI, safety, ability to assess client needs)

FAMILY QUESTION 2: RESULTS

Family Resources

- ▶ 2. *“ For a family member who cares for someone with an ABI the 3 most important **resources** the family member would benefit from are: “*
- ▶ a) Respite
- ▶ b) Liaison/advocate for crisis situations (e.g. hotline) and to help with coordination of services
- ▶ c) Access to family support group

FAMILY QUESTION 3: RESULTS

- Helper person

- ▶ 3. “ *If you had the opportunity to have a general ‘helper person’ for a few hours a week to assist with care (e.g., hands-on assistance, supervision, etc.) of your family member, what would be the three most important ways you would make use of such a person’s services ? “*
- ▶ a) Support with personal care
- ▶ b) Take family member for social outings/activities in the community
- ▶ c) Assist with training in behavioral strategies

FAMILY QUESTION 4: RESULTS

Resources for Managing
Wait times.

- ▶ 4. *“ There is often a waiting period to access ABI services. What would be the 3 most important ways to make the wait more acceptable/bearable? “*
- ▶ a) Centralized ABI grief counseling to manage loss
- ▶ b) Check-in from a support person to ask for updates, answer questions
- ▶ c) Informal group sessions about ABI

FAMILY QUESTION 5: RESULTS

- Community Identity

- ▶ 5. *“Sometimes a caregiver can feel somewhat disconnected from their community (e.g. not feeling their life situation is understood, having different ways of living one’s family life, possible stigma toward ABI). The three most important ways that this feeling can be alleviated are: “*
- ▶ a) ABI education in the community to increase public awareness (similar to Mental Health Campaign)
- ▶ b) Access to group therapy/ centralized support provided by hospital and or ABI associations (e.g. website with ‘ask an expert’ and monthly newsletter)
- ▶ c) Ongoing consultation with families during treatment

FAMILY QUESTION 6: RESULTS

- Meaningful Activities

- ▶ 6 “ *What do you feel are the three most important non-family type of activities (e.g. schooling, adapted work, volunteering, social outings, socializing etc.) your family member with an ABI would find meaningful “*
- ▶ a) Schooling
- ▶ b) Meaningful activities (creative/vocational tasks/volunteer work)
- ▶ c) Social outings
- ▶

FAMILY SATISFACTION RATINGS

3) I found that the overall duration of the focus groups was: (Mean = 4.7)

▶ 1 _____ 2 _____ 3 _____ 4 _____ **X** 5

Significantly too long

Moderately too long

A good duration

4) I feel that my participation in the focus group allowed for a meaningful contribution. (Mean = 4.4)

1 _____ 2 _____ 3 _____ 4 _____ **X** 5

Not at all

Moderately meaningful

Very meaningful