

SUPPORTING INDIVIDUALS TO PARTICIPATE IN THE INCLUDE ME SURVEY PROCESS

Nearly **6,000** individuals have already participated in the **include Me!** survey process and most have found it to be a very positive experience. It gives the people we collectively serve a chance to let us know how they feel about their quality of life and gives us information about how we can make a positive impact on their experience of independence, social participation, and well-being.

Our past experience has taught us a lot about how to ensure that the process goes smoothly for you and the individuals you support. The service providers who participated in the 2010-11 demonstration project as well as those who took part in the subsequent rounds of surveys gave us great suggestions to pass along to others. Here are some of the things we have learned.

OWN THE PROCESS

Even though this is a CLBC-led initiative, the overall purpose is to provide you with valuable information that you can use to improve the quality of life of the individuals you support. The people you serve, their family members and friends, your staff, and your other partners want to know that this is something that you believe in, support, and are excited about. They will generally follow your lead. So ... let them know that you are looking forward to the process. Remember that this is just one more opportunity for you to formally connect with the individuals you serve. It will give you another piece of information that can be used for your own continuous quality improvement efforts.

BEGIN DATA COLLECTION AS SOON AS POSSIBLE

Once you have decided to participate, the next step is to generate a comprehensive list of the individuals you serve under CLBC-funded contracts. We will provide you with a spreadsheet that you will need to review and complete. We can get you started by providing the names of individuals you serve residentially. You will have to verify / correct this information and add individuals who access your non-residential services.

To prepare, it is really useful to reference the contracts you have with CLBC. We will be asking you to tell us what service(s) each individual receives and you will need to use the terminology that is on the header of your contract. The following are the only possible options:

- residential – staffed residential, shared living (home sharing or live-in support), supported living (outreach support or cluster living)
- community inclusion– employment, skill development, community-based, home-based
- respite
- support for individuals and families – psychological, behavioural, home-maker, support coordination

Most service providers invite all individuals to participate. However, if you support more than 200 people, Malatest can help you decide on a number that would give you reliable and valid results. If you are using the sampling approach, it is extra critical for you to complete this step as soon as possible so Malatest can generate a random list that is representative of the individuals you serve.

As soon as CLBC validates the information you have provided, we send it to Malatest so that it can be loaded in their on-line scheduling system. Our secret insider tip on data collection is that this step always seems to take longer

than you would expect and has caused delays in the past because the survey process cannot begin until this step is complete.

Oh ... one other thing to pass along is that we use a Microsoft Excel spreadsheet to collect this information so it is best to assign this piece of work to someone who is comfortable with that software program. Alternatively, a member of the *include Me!* team can come out and help you complete this exercise. If you will need assistance, we encourage you to book an appointment with us in early-July as the team gets quite booked up during that time period.

MAKE SURE YOUR LEADERSHIP TEAM IS WELL-INFORMED

It's really important to ensure that your leadership team knows as much about the initiative as possible so everyone can confidently answer questions that may come their way from individuals, their family members and friends, staff, and other partners. We have developed many different tools to ensure that people know what *include Me!* is all about – background reports, discussion papers, FAQ documents, videos, helpful links, etc. We have put just about everything we ever developed on our website so check out the link below:

<https://www.communitylivingbc.ca/provincial-projects/include-me-a-quality-of-life-focus/>

Even though there is a lot of material on the website, nothing beats having a conversation with someone who can answer questions as they come into your mind or who can help you brainstorm how things will work for your agency. Members of CLBC's *include Me!* team are always happy to talk about the initiative. Their contact information is on the website ... just follow the link above. They can also help connect you with service providers, individuals, and families who have already participated. If you are wondering about the technical

aspects of survey administration or data analysis, the project team at Malatest is available to answer all of your questions. Their contact information is also on the website. Let us know what we can do to help.

MAKE SURE EVERYONE IN YOUR AGENCY HEARS ABOUT IT ... A LOT

One of the most effective ways to ensure that people in your agency understand what this is all about is to invite a member of CLBC's *include Me!* team to present detailed information about the initiative. We can develop a presentation and an approach that meets your specific needs. One of the most popular parts of our presentations is a live demonstration of the survey in which our Self-Advocate Project Assistant or another experienced *include Me!* surveyor walks a volunteer through some of the survey questions. This helps people see the types of questions that are going to be asked and see that it isn't a scary process.

We have done presentations for individuals, families, staff, management, boards of directors, and others. We can do something that is organized specifically or as part of an event (picnic, dance, AGM, etc.) or meeting that you have already set. Service providers that have invited us to do these kinds of presentations tend to have a very high percentage of people who want to be part of the process.

In addition to inviting us to do a presentation, we recommend talking about the process with all of your stakeholders. Service providers who have already participated recommend:

- including information on your own website and in your own newsletters (etc.)
- putting up posters about the initiative ... we've had some very creative and beautiful graphics developed by service

providers and would be happy to share those with you

- handing out *include Me!* stickers (available from the CLBC *include Me!* team)
- providing people with the link to the CLBC website
- including information about the survey process as an agenda topic at regular meetings (for staff, individuals, etc.)
- asking for a staff person to "champion" the initiative ... this person can help spread the word with your various stakeholder groups and can act as a point person when the survey process begins

ASSIGN THE RIGHT POINT PERSON

Service providers recommend choosing a staff member (ideally someone from your leadership team) who is known to and liked by the individuals and families you serve to act as a point person. It should be someone who has the authority to make necessary things happen (booking meeting space for the surveys, sending out communication material, etc.). Service providers who participated in the past have told us that personal contact from the right person goes a long way to encourage participation.

The point person will need to reach out to many people and should ideally have some administrative support to assist with sending out communication materials, following-up through phone calls, scheduling interviews, etc. We strongly recommend a team approach, especially having learned from service providers who participated in the past that the administrative requirements can be difficult for a single person to manage.

If possible, try to support your point person to defer some regular duties when the survey is in full swing. This allows them to communicate effectively with everyone involved and to deal with any unexpected things that come up. It is also critical to ensure that the point person

doesn't change once the process gets going. So try to choose someone who can see the process through to the end. This provides continuity for those who are involved on your end and also means there are no gaps caused by having to reorient someone new to the on-line scheduling system.

ACTIVELY ENCOURAGE PEOPLE TO PARTICIPATE

This is one of the most important parts of the process and only you can accomplish this piece of work. Over 95% of individuals who say they want to participate end up completing the survey process. Many people have told us that they enjoyed the experience and appreciated being given the opportunity to talk about things that are critical to their quality of life. So ... it's really important to actively focus on getting verbal agreement from individuals to participate. Although it is a completely voluntary process, we don't want anyone to miss out on the opportunity to take part. Remember ... individuals can stop the survey at anytime throughout the process. So ... encourage people to give it a try.

Service providers who have already participated recommend:

- getting verbal participation agreement right after CLBC's *include Me!* team has done their presentation or at other events that you are hosting
- getting people to sign up in person (your staff teams can help) rather than just mailing things out
- engaging in follow-up, follow-up, follow-up

It may also help to mention to individuals that Malatest will be asking those who complete the survey if they want to have their name entered into a prize draw (in the past we have offered things like iPads, iPods, and Tim Horton's gift cards). This may encourage the people you support to participate. Another tip we have found for encouraging participation is

to use the word "discussion" or even an informal term like "chat" rather than "interview" when talking about the survey. For some individuals, the word "interview" sounds like something scary like a "test".

Remember that increasing the number of people who participate will increase the validity of your results. To have confidence in your results, you want to make sure that you have invited as many people as possible to share their thoughts and to have their voices heard.

BUILD ON MOMENTUM

Once you have held your launch presentation, it's good to get going on the survey process as quickly as possible so people remember what it is all about. Malatest has a team of trained surveyors ready to go. So ... try to start the survey process as soon as people have heard about the initiative. If you wait much more than a week or two, we have noticed that people's interest fades and they start to forget what it's all about. As mentioned above, we have even surveyed during launch events so that the information is fresh in everyone's minds and to capitalize on the enthusiasm that is generated by these presentations.

TAKE ADVANTAGE OF TELEPHONE AND ON-LINE SURVEY OPTIONS

Some individuals have told us that they don't want to disrupt their days by scheduling a 30-minute in-person interview. While the face-to-face experience is still the most common way to complete the survey, some prefer to complete the survey by phone or on-line. Both of these options are available. The phone interviews can be scheduled anytime between 8:30 AM and 9:00 PM Monday through Friday, 10:00 AM till 6:00 PM Saturday, and noon till 8:00 PM. on Sunday. The on-line option is available 24 hours a day, seven days a week during the

active survey period. Service providers have told us that these options are especially attractive to individuals who are independent and who access limited or outreach-type service (employment, skill development, etc.).

CONSIDER THE PROXY FACTOR

This survey and the interview process have been designed to allow most individuals with developmental disabilities to complete the survey themselves. During the 2012-13 year, approximately 71% of the results were based on the self-reports of individuals. In subsequent years it has ranged from 75% to 82%. However, there are some individuals who are not able to or who would prefer not to complete the survey on their own. We still want to ensure that their voices are included in the overall results so we look for people who can complete the survey on their behalf. In this case, surveys are captured as "reports of others" (instead of as "self-reports"). When an individual requires or requests this, we ask for 2 people who know the individual well and who have known the person for at least one year to complete the survey on the person's behalf. The 2 scores are averaged to give a score for the individual.

You know the individuals you support and probably have a good sense of who may want or need two people to report on their behalf (although ... we do encourage you to err on the side of caution and support as many individuals as possible to participate themselves). It's a good idea to start identifying and connecting with people who might need to act in this role as soon as possible. Make personal contact with people who have asked to respond in this role (in-person and by phone is way more effective than mail / e-mail) and give them lots of information so that they know what this is all about. They should be informed that their participation won't negatively impact the individual's services in anyway, that their answers will not be shared with anyone, and that you are supportive of the initiative.

"Report of other" surveys are typically completed by phone with a trained surveyor from Malatest's call centre. The phone interviews can be scheduled anytime between 8:30 AM and 9:00 PM Monday through Friday, 10:00 AM till 6:00 PM Saturday, and noon till 8:00 PM. on Sunday. The on-line option is available 24 hours a day, seven days a week during the active survey period (typically September to December). Ideally, "report of other" surveys should be occurring at or close to the time that you are scheduling in-person interviews. This makes the process more manageable for you and ensures that individuals and others reporting on their behalf are going through the process together.

Whenever possible, encourage and support individuals to choose who they want to complete the survey on their behalf. Family members and friends are preferred over staff who work directly with the individual. Remember that the individual's results cannot be counted unless 2 "report of other" surveys are completed. These individuals have to give the service provider their permission (either verbally or in writing) to allow someone from the Malatest team to call them to complete the survey process.

BLITZ, BLITZ, BLITZ

We've already tried just about everything you can think of in terms of scheduling. We've had providers who have stretched the survey process over several months. We've had providers who have done a batch of surveys, taken a break, and then started up again. What works best (for many reasons) is to blitz the process. Get it done as quickly as possible. The Malatest survey team can send more than one surveyor out at once so consider scheduling several interviews at the same time. We can even do the surveys during events that you have organized (as long as you have

private space available and people are willing to spend about 30 minutes with the surveyor).

We have had very large service providers (supporting more than 100 individuals) who completed the whole process in about a week. Many providers are able to complete all surveys in 1-3 days.

CHOOSE THE RIGHT TIME

We actively survey from September to December. Ideally, you should have all self-report surveys (in-person, phone, on-line) and all proxy surveys complete by the middle of December. The month of January is reserved to finish up interviews that had to be rescheduled and to take care of other last-minute details. So ... given that it is best to take advantage of the momentum that is generated by your launch event and that we recommend blitzing, choose your survey window carefully. Once you start ... it's best to finish as quickly as possible. Look at your fall schedule and pick the time you will be best able to devote to the process. If you have strong preferences, we encourage you to book your surveys as soon as possible to avoid scheduling conflicts with other service providers who may be trying to book for that same time.

PS ... have we already mentioned that we strongly recommend inviting a member of the *include Me!* team to do a launch presentation and blitzing the survey process? ☺

KEEP US IN THE LOOP

This is a very fluid process and we are learning much as we expand our implementation. If you have questions or suggestions as you move through the process, please get in touch with us. We have been able to accommodate many provider requests and can probably accommodate yours. Please keep in touch

and let us know if there's anything we can do to make the survey process a positive experience for you and the individuals you support. Remember ... you can find our

contact information on the *include Me!* section of the CLBC website.

<https://www.communitylivingbc.ca/provincial-projects/include-me-a-quality-of-life-focus/>