

LEARNINGS

From the

2023 United Way British Columbia Family & Friend Caregiver Programs Co-Creation Sessions





ACKNOWLEDGEMENTS

We express our sincere gratitude to the numerous individuals and organizations whose contributions were essential to the success of the Family and Friend Caregiver Demonstration Project conducted between 2020 and 2023.

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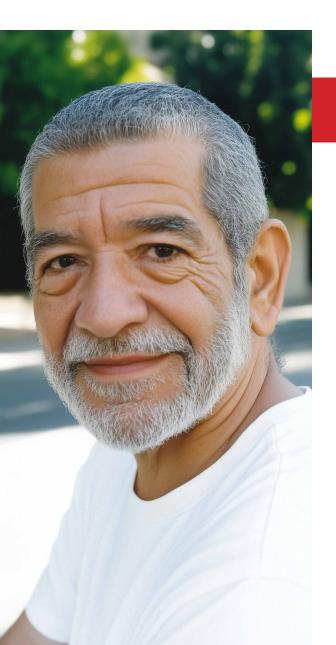


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INTRODUCTION & PURPOSE

This document outlines key data points that should be used to inform the development of the FFCG program manual. From October 2020 to April 2023, the Howegroup collected data from FFCG programs and participants to explore impacts for caregivers, as well as general program successes, challenges, and areas for improvement. Data was also collected from funded FFCG programs to inform the development of a stream-specific operating manual. Detailed findings from these data collection processes have been summarized in the following reports. Readers are encouraged to consult these documents for more contextual and in-depth information, if of interest.

Document	Purpose	Date of Completion
Higher Needs Interim Evaluation Reports #1 & 2	The interim evaluations assessed: program design and delivery; feedback on program supports; progress toward intended outcomes and impact; key successes, challenges, and areas for improvement; and factors supporting scaling and sustainability.	Report #1: June 2021 Report #2: April 2022
Summary Report: Informing the Development of a Manual for FFCG Programs	Data was collected from FFCG programs to inform the development of stream-based Program Guidelines, Best Practices, and Operating Procedures Manuals.	February 2023
FFCG Program Profiles	Individual profiles of FFCG programs were created to explore programs specific progress and areas for future support.	February 2023
Notes from 3 Co-Creation Sessions with FFCG Programs	Co-creation sessions were held to develop further consensus on FFCG program design and delivery, as well as to identify areas for future support.	Session 1: January 2023 Session 2: April 2023 Session 3: March 2023

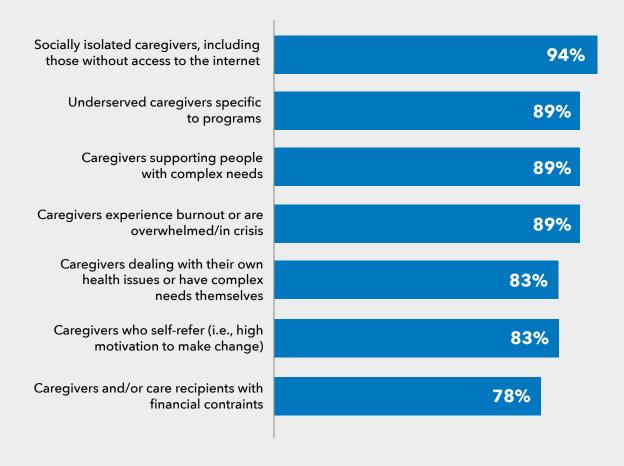
KEY DATA POINTS TO INFORM MANUAL DEVELOPMENT

1. Participants

Participants who benefit most

Programs had a high level of consensus on the characteristics of participants who benefit most from FFCG services and supports (Figure 1).

Figure 1. Agreement on characteristics of participants who benefit most from FFCG (N=18)



Short vs. long-term participants

Programs estimated that 90% of their participants are 'long-term' or have been involved for more than 3-months, while the remainder were considered 'short-term' or have been involved for 3-months or less.

2. Referrals

Referral sources to the FFCG Program

Table 1 provides an overview of referral sources for FFCG programs, as well as key activities participants are referred to.¹ The top 3 referral sources to programs were: programs' own organizations; self-referrals; and family/friends. Nearly half of the programs (47%) did not report any health care referral sources (e.g. primary care, health and community care, etc.) when selecting their top 3 sources.

On average, the programs estimated that 33% of their participants are self-referred (range 10% to 65%). The top 3 activities FFCG programs refer their participants to were: information and referral resources; support groups; and educational opportunities.

Table 1. Referrals

Top referral sources (to the program)	 Our own organization: 77% Self-referral: 62% Family/friend: 46% Home and community care services (case managers, allied health, nurses, etc.): 38% Other community-based agencies: 23% Health authority mental health services (physicians, allied health, etc.): 23% Primary care (e.g., physicians, nurse practitioners, nurses, etc.): 15% Advertisement: 15% Hospital discharge planning (nurses, social workers, etc.): 8%
% not reporting health care referral sources to the program in 'top 3' sources	• 47%

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¹ Note that the top referral sources to and from the programs add up to more than 100% since programs were asked to select the top 3 referrals sources, rather than just one.

Top programs the programs refers to	 Information and referral: 92% Support group: 77% Educational opportunities: 46% Allied health professional: 15% Exercise group or other physical activity opportunity: 13% Physician: 8% Arts program: 8% Other: 0%
Average % self-referrals	• 33% (range 10%-65%)

Developing relationships to support referrals

Community relationships

FFCG programs provided examples of what successful relationship building has looked like with their community partners.

- Programs reported having relationships with various community partners to support referrals, such as: individual and regional networks of senior service agencies; community centres; settlement organizations (e.g., MOSAIC); groups involved with emergency management; Stroke Recovery Association of BC; Meals on Wheels; Better at Home; SP & TAPS programs; and hospice.
- Partnerships between FFCG programs and community partners involved:
 - Receiving new referrals
 - Information exchange, sharing resources, and supporting each other to problem solve
 - Helping to extend reach into rural and remote areas and better understand needs of potential clients there
 - Coordinating with one another to ensure similar services are not offered on the same day
 - Having shared programs and participants (i.e., referring them back-and-forth)

Other less obvious community sources for relationship building and referrals

• Housing complexes; churches; libraries; seniors centres; rotary clubs; legions; veteran affairs; neighbourhood houses; retirement programs through colleges; municipalities;

volunteer groups; local news stations; banks; music programs for people living with dementia; and knitting groups.

- Connections with these types of community partners resulted in:
 - Increased awareness about programs and services offered, both for staff and caregivers
 - New referrals, at times for caregivers of higher need
 - Service provision in partners' spaces (e.g., one-on-one support at housing complexes)
 - Donations to organizations or caregiver support programs
- Different ways programs built/could build relationships with less obvious community partners:
 - In some programs, caregivers themselves made the connections through their pre-existing connections to community partners
 - Programs can look to a scan of affordable housing buildings in BC (completed by UWBC; researcher leading the work can be contacted at laurak@uwbc.ca)
 - Factors that supported relationship building: personal touch and being clear on what caregiver support programs offer
- Future idea: Reach out to senior management at municipal community centres to explore partnership (e.g., programs provide workshops to community centre staff to support referrals).
- Some programs highlighted need to further raise awareness of their programs in community

Health care professional relationships

FFCG programs also described successful examples of relationships that have been built with health care professionals and the factors that supported such relationships.

- Partnership with a PCN in Burnaby, including ongoing communication and collaboration with one of the social workers involved.
 - Factors that supported relationship: clear and succinct program description; being clear on what the program can offer; conscious effort to connect with PCN over time; history of relationship between program and PCN related to other work.
- Successful relationships with social workers as a source of referrals. Programs can also rely on them for help accessing information, resources, and supports when they need it (e.g., if participant is in crisis, social worker is quick to reach out and respond).

- Example of strong connections with various health care professionals linked to local health authorities (mental health, primary care, health and community care)
 - Factors that supported relationship: historical relationships; strong marketing materials (e.g. RX pads for physicians to handout to caregivers, welcome kits for health units/discharge planners, colouring books in kidney clinics, etc.); going through MOAs rather than busy physicians.
 - Sharing marketing materials widely so the program does not have to create/uphold individual relationships with health care professionals.
- One program reached out to a local municipality and was connected with a Community Liaison who supported connections to community centres, municipal councillors, local hospitals, social workers (HCC), and the local Division of Family Practice.
- Another program has applied for grants to run a hotline to support caregivers and is working in collaboration with Divisions of Family Practice to implement this.
- Other health care groups programs have established relationships with: NPs; discharge nurses; social workers; HCC; UPCCs; older adults mental health teams; recreation therapists; adult day centres; BC Association of Healthcare Auxiliaries; professional counsellors; pharmacists; and geriatric clinics.
- Other factors that supported partnerships: pre-existing relationships; persistence; handing out promotional materials; inviting HCPs to speak with caregiver participants; sharing information and doing presentations for HCPs; physician champions; and being connected to Better at Home.

Common referral form

Most FFCG programs supported the idea of a common referral form, however they suggested that it should not be mandatory to use such a form. Some suggested that a common referral form could streamline the referral and intake processes. Programs also discussed the importance of keeping the form brief and low-barrier (i.e., collection of minimal information from potential participants, such as name, phone number, and geographic location).



3. Program Elements

Core versus optional program elements of FFCG Programming

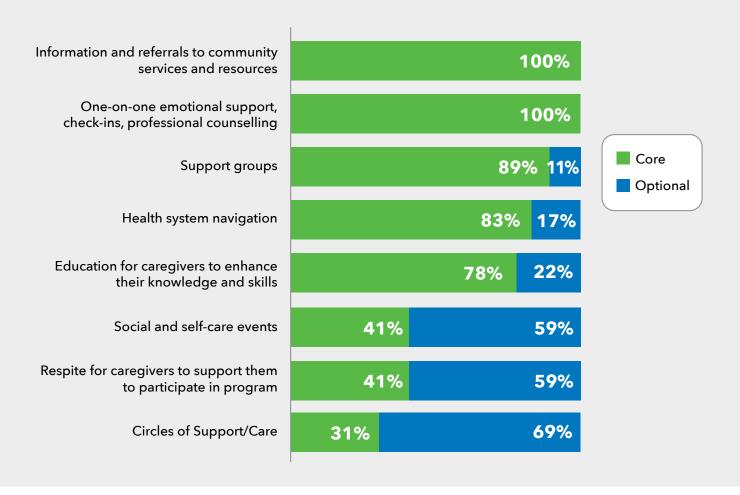
The majority of FFCG programs suggested that the following should be <u>core program</u> <u>elements</u> (Figure 2):

- Information and referrals to community services and resources
- One-to-one emotional support, check-ins, professional counselling
- Support groups
- Health system navigation
- Education for caregivers to enhance their knowledge and skills

Most recommended that the following should be optional program elements:

- Social and self-care events (e.g., coffee gatherings, walking groups, games)
- Respite for caregivers to support them to participate in programs (e.g., support groups, self-care). Could be provided by trained volunteers, simultaneous TAPS program, or private service.
- Circles of Support/Care

Figure 2. Program votes on core vs. optional FFCG program elements (N=18)



Intake process

Programs shared information about their current intake processes for the FFCG stream. Roughly half of the programs indicated that they collect most of the intake information on the first visit, while the other half gather the information over time. This was dependent on: the urgency of participants' needs; willingness to complete; and whether the participant was new to the program or pre-existing. Intake data is collected by programs over the phone, email, or in-person. The mode for collecting the data depends on participants' preferences and their involvement with program activities.

FFCG programs identified the following barriers to collecting demographic data (e.g., income, PHN) through the intake forms.

- Privacy concerns and general hesitancy sharing personal information. These concerns were heightened for those: living in rural/remote areas; of certain cultural backgrounds (e.g., Chinese); and those of older age.
- Relationship and trust not yet established with participants.
- Previous intake form included too many questions.
- Intake questions were considered invasive, particularly for those who are seeking a single service (e.g., piece of information, referral to another service, participation in an education series).
- Despite explaining that providing intake information is not required to receive services, some programs noticed that participants did not return after being asked for it.

It is important to highlight that caregivers were particularly reluctant to share their PHNs due to various reasons identified by programs, such as media campaigns teaching seniors about scams and telling them not to share their PHNs.

FFCG programs clearly indicated that they would not benefit from additional support, coaching, or training on how to collect intake information in the future. However, they suggested that the following strategies can be used to support the process of collecting demographic information in the future:

- UWBC could provide a brief, easy to understand statement about why the information is being collected and how it will be used (e.g., 2 sentences maximum). A stand-alone statement should be created for why PHNs are being asked for.
- Build trust and relationship with caregivers prior to collecting intake information.
- Use motivational interviewing strategies.
- Do not read intake questions word for word. Ask questions in a conversational way.
- Do not deny participants access to services if they choose not to complete intake.

Programs were also asked to describe if, and how, iUnite acted as barrier in the intake process. Some identified barriers with iUnite, such as the steep learning curve to become familiar with the platform, some staff struggling with the database due to low computer literacy/data entry skills, and programs doing double data (on pre-existing databases and iUnite). Similarly,

programs frequently experienced issues using iUnite for reporting activities (e.g., limited ability to search data, run customized reports, inaccurate data when queries made, etc.).

When asked to describe what database would work better than iUnite, most FFCG programs explained that iUnite has a lot of potential, but modifications need to be made to make it useful for reporting purposes (e.g., ability to filter data, make customized reports, aggregate information, etc.). Some programs suggested that UWBC should consider shifting reporting and client management to Salesforce given the use of this platform for other UWBC-funded programs.

FFCG programs also raised the following issues with the intake process.

- The intake forms were a time-consuming administrative task for programs, which
 took time away from service delivery. For some caregivers, time away from their
 care recipients is limited and answering a series of intake questions is often not how
 they want to spend their time. Some programs described a disconnect between
 encouraging a person-centered approach alongside the focus on collecting detailed
 administrative data.
- Administrative expectations for programs to collect detailed intake information were not made clear prior to funding offer. Programs did not adequately plan for this time or budget for it.
- Difficulties collecting intake information from pre-existing clients, as FFCG program intake questions seem to be asked out of the blue.
- Lack of training offered by UWBC teaching program staff how to do data collection and entry. Programs explained that staff often lack skills in this area.
- Updated intake forms were challenging to locate. Programs were using out-of-date forms at times.
- Inconsistencies between questions and scales on paper intake forms vs. questions on iUnite.
- No automated reminders for programs to complete 6- and 12-month checkpoint surveys for participants. Difficult to track and manage.
- Uploading consent forms posed as a challenge for some program staff (had to scan them, send to email, then upload to iUnite).
- Some participants provided intake information prior to creation of consent forms.

Person-centered support & co-creation of plans

FFCG programs were asked to describe what it looks like to provide 'person-centered support' to their participants. While this approach seemed to mean different things to different programs, the following summarizes their interpretation of offering person-centred support:

- Listening and getting to know the participant as a person first. Recognizing their individuality and building relationships.
- Treating participants with dignity, compassion, and respect.
- Offering participants personalized and tailored supports depending on their needs, interests, and availability. Participants can pick and choose activities to be involved in.
- Helping participants to advocate for what they need and use their voices.
- Using a strengths-based approach where participants' strengths are focused upon.
- Building upon participants' networks and people they have in their lives (e.g., family members, friends, etc.)
- Linking participants to wrap around supports or other health and social services, if needed.
- Constantly learning and evaluating what works for participants and re-designing services in response.
- Co-creating service plans with participants, or even supporting them to take the lead. Participants are involved in decision-making about their care.

The programs explained that co-creating step-by-step plans with caregivers is also a component of providing person-centered care. Depending on the participants' desires, FFCG programs co-create service plans with participants, or support them to take the lead if they are able and willing. Participants are involved in decision-making about their care and services provided to them.

FFCG programs explained that offering person-centred support and co-creating plans with participants are important because caregivers are the experts with their respective lived experiences. Furthermore, these approaches improve the quality, relevance, and responsiveness of the services provided to participants. They also help caregivers receive the support they need, when they need it. Person-centered strategies encourage caregivers to be more active in looking after themselves and leading healthier lifestyles, which can reduce pressure on health and social services.



4. Benefits for Participants

The following participant benefits have been identified:

- Increased access to social, physical, and nutritional supports
- Improved physical and mental health (e.g. participation in physical activity, improved ability to feel seen and heard)
- Increased sense of belonging, social connectedness, and connection to the community
- Improved quality of life
- Increased their awareness of services in their communities, ability to access them, and confidence to participate
- Increased ability as a caregiver
- Increased confidence as a caregiver

Caregivers were asked to describe what changes the program made for them, such as differences in their physical health, mental health, and sense of connectedness. First and foremost, caregivers expressed their programs normalized their experience and helped them to understand both their experience and their situation. Caregivers further indicated the program increased their confidence to provide care, improved their mental health by increasing their understanding and acceptance, and increased their knowledge and skills in providing care. All caregivers acknowledged the program provided support unparallelled by any other, in terms of understanding, timeliness, kindness, and information. Caregivers also appreciated the grocery store gift cards, food delivery, and iPad provided through the program.

While family/friend caregivers reported accessing a range of Higher Needs services, they found the peer support groups, counselling/emotional support, respite services, and system navigation supports to be particularly beneficial.



5. Skills & Attributes for Program Leads/Coordinators

Table 2 provides an overview of FFCG program coordinators' educational backgrounds, training, experience, and skills. The majority of coordinators have a bachelor's degree (72%), followed by some who have college diplomas (13%), or graduate-level degrees (13%). Their degrees or diplomas were in a range of areas, from arts to education. Most coordinators have 5-years or more of work experience in a similar field (67%). FFCG programs most frequently reported that their coordinators maintain the following skills: (i) capacity to build trusting and meaningful relationships with vulnerable older adults (87%); and (ii) knowledge of community resources and programs (80%).

Table 2. Education, experience, and skills of current FFCG program leads/coordinators

Education	 Bachelor's degree: 72% College diploma: 13% Graduate (Master's/Doctorate) degree: 13% High school diploma or equivalent: 0%
Diploma/degree areas	 Bachelor of Arts: 23% Education: 23% Psychology: 15% Public health or social services: 15% Social work: 9% Sociology: 15%
Work experience in a similar field	Less than 5 years: 20%5 years or more: 67%None: 13%

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Coordinator skills

- Capacity to build trusting and meaningful relationships with vulnerable older adults: 87%
- Knowledge of community resources and programs: 80%
- Ability to build relationships with health providers: 73%
- Ability to identify programming gaps and figure out creative ways to address these gaps: 73%
- Ability to support the participant to try new things, move out of their comfort zone, take on new challenges: 73%
- Ability to help participant see the value in answering the questions needed for Outcome Reporting: 73%
- Ability to work with a group of volunteers to support their role: 67%
- Community development skills: 58%
- Motivational interviewing skills: 33%
- Other (Policing and adult guardianship): 20%

Programs identified a range of skills and attributes for FFCG coordinators to have in the future. These skills and attributes are illustrated in Table 3 and have been categorized into soft and hard skills.



Table 3. Important soft and hard skills for future FFCG program leads or coordinators

Soft skills/attributes	Hard skills/attributes	
 Active listening Communication and handling difficult conversations People skills Interview skills Flexibility Creativity Patient Critical thinking Problem-solving Organization Empathy Efficiency and time-management Setting boundaries Cultural competence Spirit of collaboration Lived experience Self-care 	 Technology skills (e.g., Zoom, participant databases, enhancing online engagement) Grant writing, reporting and evaluation Budget management Advocacy Ability to speak and write in different languages Knowledge of resources and supports in the healthcare system, ability to form partnerships, and system navigation skills 	

Training for program leads/coordinators

The top 6 training opportunities to support the delivery of FFCG programs were:

- 1. Service navigation (56%)
- 2. Dementia (56%)
- 3. Cultural sensitivity training (56%)
- 4. Care coordination (44%)
- 5. Trauma-informed care (39%)
- 6. Group facilitation (39%)

Most programs recommended that future training opportunities should be provided by preexisting experts in the field (e.g., Family Caregivers of BC, Alzheimer Society of BC, MOSAIC, etc.). They suggested that such training opportunities should be supported, promoted, and coordinated by UWBC.

6. Communication

Programs provided key messaging for participants, community, and healthcare providers:

Program participants & community

- Aim to be clear about what the programs can support, and what they cannot (see below)
 - Describe the range of services available (participants can pick and choose)
 - Can provide: services for family/friend caregivers; emotional support
 - Cannot provide: services for seniors themselves; housework help; respite; and support for younger adults who require extra help (e.g., adults with disabilities)
- Explain that the programs are there to support them
- Low barrier programs, no judgement, free of cost
- Use the term older adult rather than senior
- Include the term higher needs
- Highlight helping with health care system navigation support
- Emphasize supporting vulnerable groups in Canada
- Focus on hope and opportunity and social connection
- Use term of 'supporting' rather than 'caring'
- Point of tension related to 'caregiver' language: some participants do not see themselves as caregivers but as individuals caring for the people they love vs. the importance of calling participants 'caregivers' to honour the role
 - Focus on explaining/educating what a caregiver is, rather than using the term
 - Focus on self-identifying/enhancing self-awareness
 - Are you struggling looking after a loved one? You're not alone.
 - To help participants identify as 'caregivers', some programs have had success in talking about the proportion of time people are spending on caregiving (e.g., 'In life, you have may roles as a wife, mother, caregiver. When the caregiver role becomes 50% or more, then you are likely starting to need some help. You are getting to the tipping point.')

- Focus on emerging caregivers with multiple roles (i.e., caregiver and spouse)
- Consider cultural perspectives (for Indigenous families, and other cultures they are not a caregiver, they are 'doing what families do')
- Sometimes 'caregiver' term is associated with paid care (i.e., respite). Be clear that program is for family/friend caregivers
- Messaging that is avoided:
 - Connection to hospice services
 - Deficit-based language. Focus on hope and opportunities (e.g., self-care, social)
 - Use of the term un-paid caregiver



Health care professionals

- Recognizing that health care professionals are busy and have little time to learn about community programs, focus on: (i) idea that programs will reduce their workload and support them; (ii) being brief and clear; and (iii) having print resources and materials to share
- Share feedback and success stories from caregiver participants
- Be clear that program is separate from the health authorities
- Be clear that programs offer support for unpaid family/friend caregivers

- Emphasize that caregivers are 'partners in care'
 - Emphasize their key role in care planning/discharge planning
 - (i.e. Co-planning with family/friend caregivers)
- Focus on describing menu of services and when doing so, it can be helpful to use more technical terms (e.g., prevent burnout, navigation support, etc.)
- Emphasize the program supports health care system navigation and community support (i.e., community supports can augment health care)
- Indicate that it is a free program
- Highlight that materials and programming are available in multiple languages
- Key words when describing the target population: caregivers of people with: 'higher needs', 'complex needs', 'comorbidities', and providing disease-related examples (e.g., chronic diseases, dementia, degenerative diseases, frail seniors); experiencing burnout, needing self-care, emotional support, socialization

Marketing tools

- Programs would like a general brochure for the whole province that had some room for local information.
 - Programs liked the content and wording included in some of the materials from
 the Caregivers Network for East Kootenay Seniors (e.g., description of who would
 benefit from the program, key components of programs). However, programs would
 like to see more diverse participants reflected in the images (i.e., Indigenous, people
 of colour should be represented).
- Agreement that the brochure couldn't have a common title like SP and BAH because all the programs have a different name and groups should be able to use the name they are known by in their communities.
- In terms of having some room for a local description, programs want to be able to include some local information (e.g., optional program elements, recognition for funders in addition to UW)
- Programs would also like to see a Rack Card that was a pared down/simpler version of the brochure for libraries, community centres, presentations, etc.

7. Peer Support Networking and Communities of Practice

- Chairing COPs
 - Most FFCG programs expressed interest in having the content experts chair the COPs. They suggested that content experts should have on-the-ground experience. Programs have limited time/capacity to co-chair the meetings
- Frequency & meeting types
 - Monthly with a break in the summer months (i.e., 10 meetings per year)
 - Two meeting types suggested
 - (i) Mandatory meetings led by content experts (5 meetings/year)
 - (ii) Optional meetings that are dedicated to peer sharing and problem solving (i.e., opportunity to share challenges/failures and discuss troubleshooting) (5 meetings per/year). Meeting topics should be pre-determined
 - Rotate monthly schedule between mandatory and optional meetings

Topics

- Programs expressed interest in discussing a range of topics at future COPs, such as: service navigation; respite; one-to-one support; coordinator burnout; setting service boundaries; training for volunteers; strategies for getting programs established in HA referral processes, etc.
- Training on care co-ordination was reported to be lower priority
- With regards to service navigation, programs want to learn more about the following:
 - Concrete understanding of roles and responsibilities within the health authorities and who to contact for different issues
 - Helping caregivers navigate the healthcare system, including long-term care
 - How to build relationships with health authority staff (e.g., champions, social workers)
 - Strategies to breakdown silos in services
 - More information on the financials of care (e.g., caregiver tax breaks)
 - Navigating long-term care (e.g., steps to getting loved ones in)
 - Policies and processes to support caregivers experience safety issues



- Consider facilitating regional meetings with health authorities so programs can learn about services available and who to connect with
- Programs would like all COP meeting topics to be pre-determined at the start of the year
- To prioritize COP topics for the year, some suggested that possible topics should be voted upon in advance of the first meeting
- Cowichan Family Caregivers Support Society has various training modules that could be leveraged for future training opportunities (e.g., module on service navigation). FCBC's trainings should also be used

Logistics

- Programs would like to have schedule for meetings to be determined asap
- Consider having one meeting per year in-person given benefits of connecting with each other face to face
- Record COPs so programs are able to listen if they are unable to attend. Store recordings on CORE

Other recommendations for future COPs

- Focus on providing space for program-to-program learning
- Vulnerability to discuss challenges
- Prevent programs from reinventing the wheel (i.e., avoiding duplication of work)

8. Balancing Standardization with Local Flexibility

FFCG programs were generally supportive of UWBC developing a standardized reference manual for the FFCG stream. They explained that the manuals will likely be helpful for new staff and during staff transitions. Some programs suggested that the FFCG manual should be similar to the design of the Better at Home Program Handbook. Others specifically mentioned that the manual should include: guiding principles; participant eligibility criteria; description of services in and out of scope; evaluation and reporting requirements and tools; clear expectations of funded programs; key definitions; and templates.

While standardization of the FFCG stream is important, programs highlighted the need for flexibility with service design and delivery to ensure their offerings are responsive to their local contexts and diverse needs of their participants. Factors that influence the need for flexibility in programs' communities include: geographic location and community spread (rural vs. urban); target population background; socio-economic status; living situation; services already offered by other agencies within communities; longevity of pre-existing caregivers support programs; and engagement of local health authorities.

Programs recommended that room for local flexibility should be provided in the following areas:

- Program design (e.g., ability to create hub and spoke or centralized model depending on needs)
- Mode of delivering programs (e.g., in-person, online, hybrid, etc.)
- Flexibility with offering some program activities, so as long as program objectives are met (e.g., walking groups, transportation for caregivers, educational offerings, etc.)
- Frequency of offering program activities
- Referral sources
- Extent to which peers and volunteers are used to support service delivery
- Involvement of community partners
- Reach of service delivery (i.e., # of participants served)
- Budget amounts per category (e.g., printing costs, translation costs) and flexibility to make shifts
- Ability to adapt service delivery model and budget based on emergent needs and learnings

Some expressed concern that if the funding stream becomes overly prescriptive it will be challenging to retrofit pre-existing models to meet new service delivery requirements. This concern was most often raised by caregiver programs that existed prior to Higher Needs funding.