Development of IncludeMe™ - A Starting Point for Dementia Caregivers

April 2024

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Development of IncludeMe™

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Our Goal is to synthesize, generate, translate, adapt, and mobilize scientific evidence in the co-design, implementation, and evaluation of person- and family-centred health and social care services.

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Executive Summary

As lead organization, Iris the Dragon received funding from the Public Health Agency of Canada's Dementia Strategic Fund for the project titled, 'IncludeMe™ Dementia Edition for Caregivers: The engaging, interactive and transformative educational experience that prepares Canadians facing caregiver responsibilities for someone diagnosed with Dementia'. The content of the IncludeMe™ learning resource would be focused on 1) reducing stigma and encouraging dementia-inclusive communities, and 2) educating caregiving populations on person-centred support, communication, and care. The overall objective of the proposed IncludeMe™ learning resource was to improve access, understanding, and implementation of high-quality dementia guidance using accessible technology not limited by time and place.

In this report the SE Research Centre team describes the development process employed by Iris the Dragon and Addiev Corporate Training, the co-leading partners responsible for creating the 'IncludeMe™ - A Starting Point for Dementia Caregivers' learning resource. This report describes the three phases of the ADDIE method for instructional design employed by Iris the Dragon and Addiev Corporate Training, specifically the *Analysis, Design,* and *Development Phases*.

Partner organizations and individuals bringing unique expertise to the development and design of the IncludeMe™ learning resource included representatives from Iris the Dragon (lead), Addiev Corporate Training (co-lead), Alzheimer Society of Lanark Leeds Grenville (subject matter experts); a caregiver expert-by-experience (subject matter experts); Indigenous Diabetes Health Circle (subject matter experts); The Perth District Community Foundation (subject matter experts); and SE Research Centre (evaluators). These collaborators participated in a two-day Training Board (*Analysis Phase*) and provided feedback on the Qualification Standard with Curriculum (*Design Phase*) and storyboard (*Development Phase*).

After the Training Board component of the *Analysis Phase*, collaborating partners decided that the project would address the informational needs and uncertainty new caregivers face. The target audience for the IncludeMe™ learning resource would therefore be adult caregivers (e.g., family member, friend, neighbour, or other community member) to people living with dementia (PLWD) or to persons showing signs of dementia, who are new to the caregiving role and want to learn online. A curriculum was developed through an iterative process during the *Design Phase* that focused on learning in four areas:

1. Knowledge about dementia including the correct terminology to communicate to others about the condition;
2. Navigating the healthcare system and local community supports to initiate a circle of relational care for the person living with dementia;

3. Preparing a care plan, plus a circle of relational care for the person living with dementia; and

4. Develop a plan for personal self-care and social connectedness.

After the *Development Phase*, the final version of the evaluation-ready pilot learning resource consisted of four modules, with two to four lessons in each, designed to allow people to navigate the program in a "choose your own adventure" format (see Image 1). The outline of the pilot for IncludeMe™ included the following modules with corresponding lessons:

1. Home: The caregiver's role
   - Lesson 1: What does it mean to be a caregiver?
   - Lesson 2: What is relational care?
   - Lesson 3: How do I communicate better as a caregiver?
   - Lesson 4: How do I communicate with friends and family?
2. Alzheimer Society: What is dementia?
   - Lesson 1: Introducing dementia
   - Lesson 2: What does the diagnosis mean?
3. Clinic: Build a care plan
   - Lesson 1: What should I know to better navigate the healthcare system?
   - Lesson 2: What goes into arranging a care team?
4. Park: Self care tips
   - Lesson 1: Burnout
   - Lesson 2: The emotional rollercoaster
   - Lesson 3: Best practices for mental health

Outline of Pilot for IncludeMe™
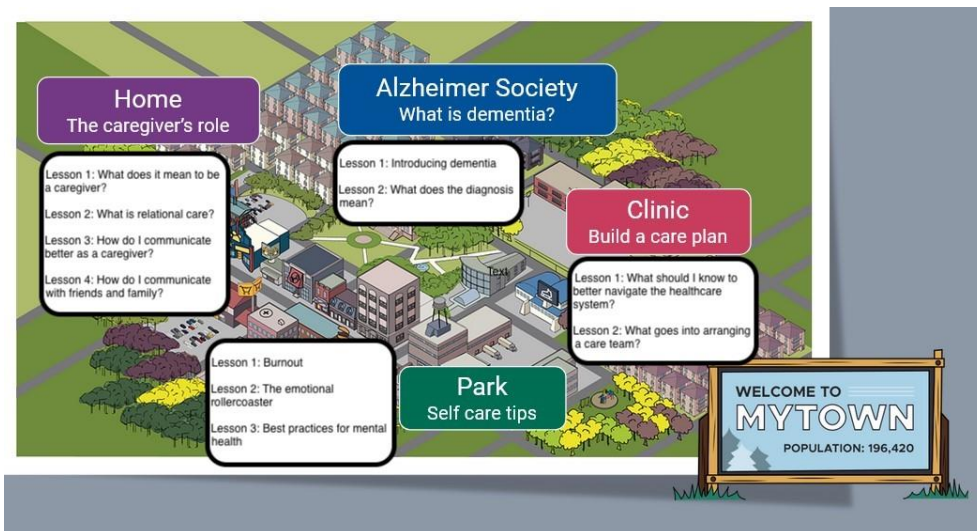
Development of IncludeMe™

Key challenges identified by project partners in the development of the IncludeMe™ learning resource include: 1) missing key perspectives (e.g., caregivers from equity deserving groups, and caregivers from diverse groups regarding race, ethnicity, and gender identity) to inform the curriculum content, design, and development of the resource, and 2) a lack of clarity around roles and obligations for partners to ensure active participation and detailed feedback on the content of the learning resource in the *Development Phase*.

Recommendations for adaptation identified by the SE Research Centre team in collaboration with Iris the Dragon and Addeiv Corporate training include:

1. Engagement with diverse caregiver experts-by-experience to ensure curriculum is relevant and meets the educational needs of the target audience.
2. Dedicated subject matter experts assigned to the project with clearly defined roles and responsibilities, such as meeting regularly with project leads during the *Development* Phase to ensure timely feedback on curriculum content and providing recommendations for evidence-based information.

Next steps include an evaluation of the IncludeMe™ - A Starting Point for Dementia Caregivers learning resource, to be conducted by the SE Research Centre team, to answer two research questions: 1) How does participating in the training impact caregiver's a) attitudes towards dementia; b) preparedness for caregiving; c) knowledge of dementia; and d) self-efficacy?; and 2) To what degree do participants find the training: a) inclusive; b) usable; and c) acceptable?. The evaluation will provide additional recommendations for adaptations to this learning resource prior to it being launched to the public.

Development of IncludeMe™ - A Starting Point for Dementia Caregivers

April 30, 2024
Celina Carter *RN PhD*
Ryan McLeod *MA*

1. Background and Rationale

It is estimated that 600,000 people in Canada are living with dementia; by 2030, this number is projected to grow to 1 million (Alzheimer Society of Canada, 2018; Alzheimer Society of Canada, 2022). Caregivers are essential to ensuring effective care, support, and good health management, particularly for people living with dementia (PLWD) who wish to age in the place where they live. However, many caregivers of PLWD feel ill prepared, uninformed about dementia, and unsure where to turn to for help (Sztramko et al., 2021). With caregivers being at an increased risk for depression, anxiety, declining physical health, and financial stress (Sztramko et al., 2021) there is a need for accessible, acceptable education and support for these caregivers.

Many caregivers of PLWD have specific needs including emotional and social support, improved knowledge about dementia, improved caregiving skills, coping strategies, and balancing caregiving responsibilities with personal needs (Aledeh & Adam, 2020; Sztramko et al., 2021). Furthermore, caregivers want dementia educational resources to be stage-specific, so they receive meaningful guidance that is relevant to their experience to better support their caregiving knowledge and skills (Aledeh & Adam, 2020; Sztramko et al., 2021).

Educational resources have the potential to reduce caregiver distress and isolation, increase quality of life for caregivers, and make it more possible for PLWD to age in the place where they live (Sztramko et al., 2021). However, many caregiver/public dementia education programs for Canadians include informational and in-person workshops that are not always accessible to caregivers. Caregivers of PLWD often find it challenging to schedule time to be out of the home to attend face-to-face programs (Aledeh & Adam, 2020; Ottaviani et al., 2022). Additionally, caregivers living in rural areas have the challenge of limited community resources. Internet-based interventions can be accessible to caregivers and effectively deliver psychosocial and psychological support (Aledeh & Adam, 2020; Ottaviani et al., 2022).

These gaps in accessibility and services were recognized by the Alzheimer Society of Lanark Leeds Grenville in Ontario who expressed their challenge of supporting caregivers of PLWD in their rural area with limited community resources. Iris the Dragon, an organization specializing in using story to deliver psycho-education to caregivers, applied to the Public Health Agency of

Canada's Dementia Strategic Fund for a grant aiming to address this challenge by developing a stigma reducing tool for caregivers living in rural and remote communities that promotes a better understanding about the behaviours of those with dementia, ways to best support PLWD from a person-centered approach to caring, and catalyze a cultural shift towards more dementia-inclusive and aware communities.

2. Objectives

The proposal for IncludeMe™ expressed intention to focus content on 1) reducing stigma and encouraging dementia-inclusive communities, and 2) educating caregiving populations on person-centred support, communication, and care; with the overall objective of improving the access, understanding, and implementation of high-quality dementia guidance using accessible technology not limited by time and place. This report details the development of the IncludeMe™ learning resource that will be free, bilingual, and accessible, offering an alternative to traditional dementia education by employing a self-directed, online program employing a storied approach to learning.

3. Program Methodology and Andragogy

Led by Iris the Dragon and Addiev Corporate Training, the gamified, scenario-based learning approach used in the development of IncludeMe™ employs four fundamentals of knowledge, skill, and attitudinal transfer:

> 1. the empirically-validated Iris the Dragon Narrative Formula (using story to shape attitudes);
> 2. the empirically-validated IncludeMe™ Formula (using gamified, mission-based storylines to shape attitudes);
> 3. Prochaska's stages of change (Prochaska et al., 2013) (change theory); and
> 4. the rigorous ADDIE Instructional Design methodology for andragogy (Trust & Pektas, 2018) (adult learning).

This approach requires a collaborative participatory process, drawing on diverse sources of knowledge and perspectives from a group of individuals and organizations. With a desire to include and integrate perspectives into the program development from diverse Gender Based Analysis Plus (GBA+) (Canadian Institutes of Health Research, 2022) perspectives, partner organizations who represented perspectives of communities of interest were invited to participate.

4. Partner Participation in the Development of IncludeMe™

Iris the Dragon curated partnerships with subject matter experts in dementia; learning and development; health education; caregiver lived experience; and impact-oriented health services research and evaluation to develop the program. The partnership team included:

- Iris the Dragon (lead)
- Addiev Corporate Training (co-lead)
- Alzheimer Society of Lanark Leeds Grenville;
- A Caregiver expert-by-experience;
- Indigenous Diabetes Health Circle;
- The Perth District Community Foundation; and
- SE Research Centre.

Inclusion and representation of diverse perspectives were important factors in assembling the partnership team. These various perspectives, expertise and insights informed the development of the IncludeMe™ learning resource. Below provides a brief overview of partners' role and contribution with a focus on the development process.

Iris the Dragon
Iris the Dragon has over 20 years of experience developing proven health promotion and awareness raising tools to reduce stigma, specializing in using story to deliver key psycho-educational messages to create more accepting views and prosocial behaviors. The partnership team relied on Iris the Dragon's experience as lead partner for this project. Jessica Grass, Registered Psychotherapist, acted as Iris the Dragon's project manager and as a Subject Matter Expert (SME) during the development process ensuring that the content being presented is evidence-based and reflects the input of those with lived experience to deliver key psycho-educational messages.

Addiev Corporate Training
Addiev Corporate Training designs engaging, interactive, and gamified learning experiences that measure knowledge, skills, and behaviour change in large-scale training deployments. Addiev is an ISO 21001:2018 accredited continuing education company employing rigorous academic principles and multiple andragogical approaches in the development of education programs. Addiev's role in the project was to support Iris the Dragon to create an engaging online education program for caregivers of PLWD. ADDIEV implemented their rigorous design and development process to support the creation of the learning resource. Representatives from Addiev included Guy Paquette – Founder & CEO with lived experience of being a caregiver for two PLWD, Ashley Muldoon – Director of Operations in charge of production, and Karen Murphy – Project Manager, with lived experience of being a new caregiver of a PLWD. These dual roles and perspectives greatly added to the depth and diversity of knowledge in the group.

Alzheimer Society of Lanark Leeds Grenville

The Alzheimer Society of Lanark Leeds Grenville (ASLLG) offers education and supportive services to over 4,000 residents and their caregivers impacted by dementia. ASLLG functioned as a subject matter lead, sharing their expertise regarding gaps in services related to educational needs of existing urban and rural caregivers of PLWD. Representatives from this organization included Melinda Coleman - Executive Director, Sean Fadden – Education and support coordinator, and Robin Hull - Education Coordinator.

Caregiver Expert-by-experience

Hanni Dzubas was part of the development process bringing expertise as a caregiver of a PLWD. The inclusion of a caregiver as a project partner provided an important perspective as an expert-by-experience. Partnering organizations relied on the experiences and knowledge of Hanni to ensure the IncludeMe™ learning resource resonated with her experiences and was relevant to her initial challenges while taking on caregiving responsibilities. As an expert-by-experience, Hanni contributed to the development process by challenging assumptions and providing innovative ideas that helped guide program development.

Indigenous Diabetes Health Circle (IDHC)

IDHC provides programs focusing on diabetes education, prevention, and management in Indigenous communities in Ontario, both on and off-reserve. The IDHC develops educational health programs and acts as a resource for other health and education service providers. The IDHC's Knowledge Program Manager, Jessica Pace, has a specialization in dementia and provided subject matter expertise and perspective during the project.

The Perth District Community Foundation

The Perth District Community Foundation is a charitable public foundation dedicated to strengthening the quality of life in the Lanark, Leeds, Grenville area for older adult residents. Victoria Gibb-Carsley, the foundation's Executive Director participated in the development of the project by drawing on a vast knowledge of community resources from over 40+ community organizations. She also commented on common gaps and struggles in meeting the needs of caregivers and PLWD from a community perspective.

SE Research Centre

The SE Research Centre conducts impact-oriented health services research and evaluation to synthesize, generate, translate, adapt, and directly apply scientific evidence in the design, delivery, and evaluation of person and family-centred health and social care services. Throughout the process, Celina Carter RN, PhD, and Ryan McLeod MA, from the SE Research Centre, provided insights from an evaluative perspective. These researchers participated in the learning resource development to ensure evaluation metrics were informed by learning objectives and offered insights on equity related issues.

Most project partners were subject matter experts with knowledge of diverse caregiver experiences and presented as white women. Project partners also included persons with Métis and mixed French Canadian and Indigenous lineage who also had expertise and/or lived experience with dementia. Representation from the IDHC enabled the group to consider social determinants of Indigenous health. The IDHC's perspective also informed how elements within the program might best resonate with Indigenous participants. Additionally, three project partners had personal experience with caregiving, two resided in rural areas, and one was new to the caregiving role. The representation of project partners included:

- Women and men;
- Persons with Indigenous heritage;
- Rural caregivers with lived experience;
- Professional expertise; and
- A new caregiver.

5. Learning Resource Development

The development of the learning resource was structured on the academic and industry standard for instructional design known as the ADDIE method (Trust & Pektas, 2018). The ADDIE method is a five-phase process that provides a well-structured approach to building the right training solutions that balances the needs and resources of the organization to that of the learners to achieve positive experiences and outcomes (Trust & Pektas, 2018). The phases include *analysis, design, development, implementation, and evaluation*. Each phase consists of a series of steps with activities, actions, and deliverables that lead into the next sequence of tasks resulting in a learning resource that can be delivered repeatedly to the same standard. This report highlights the creation of the IncludeMe™ learning resource, describing three phases of the ADDIE method, the analysis, design, and development phases. All partner organizations were included in the *Analysis Phase* of the process and consulted during the *Design* and *Development Phases* to ensure a well-informed design-to-delivery process and learning resource adoption.

5.1 Analysis Phase

The *Analysis Phase* identifies the training needed to meet a desired level of competency defined as a mix of subject awareness, knowledge intake, competency and performance, attitudinal change and/or demonstrable behaviour within a specified population.

Iris the Dragon and Addiev Corporate Training led and facilitated a Training Board with all the listed project partners to inform the learning resource design and desired outcomes. A Training Board is a structured set of activities that guides the formation of a curriculum by soliciting input from specific representatives that can inform program design for a larger population.

Development of IncludeMe™

Addiev's process includes Gender-Based Analysis Plus (GBA+), a requirement of the Government of Canada for public-facing funded projects to ensure end-user intersectionality is considered to promote inclusion and equity (Government of Canada, 2022).

Twelve participants from partner organizations (see above) representing diverse expertise and perspectives were invited to the Training Board and received pre-session training from Addiev to facilitate active participation.

The hybrid (in-person/virtual) Training Board process took place over two days with a day in between to reflect on what was accomplished on Day 1. Day 1 focused on scope, and Day 2 focused on curriculum development (see Table 1 and Table 2). Attendees received workbooks to support the activities and notetaking. The facilitators created an environment where participants felt safe to share and voice opinions by welcoming diverse viewpoints. While the Training Board did have an agenda, facilitators were flexible with the process in order to gather the information required in ways that suited participants.

Table 1: Day 1 - Scope

Agenda	Process and Activities	Outcomes/ Findings

Welcome & Introductions, Project Overview, Current Knowledge & Gaps, Managing Expectations	• **Current Knowledge:** 350,000 Canadians have identified as care partners. Within 7 years, 260,000 more citizens will become care partners. Care partner impacts include time away from work and socializing, out-of-pocket expenses, lower self-care, and an increase in personal mental health issues
	• **Managing Expectations:** What do we want this to be? What don't we want it to be? For example, people say their caregiving commitments will make it challenging to find time for learning.
	   ○ What exactly is it that we want our caregivers to be able to do at the end of the program?
	   ○ The desired learning outcome is for a [who] to be able to [what] when [activity] in a [condition]
		• Clarity on process and expectations

Needs Activity	• **Objective: State of Desired Learning Outcomes. What do the participants want to accomplish with this project?** • Participants were asked to write down their wants and needs for caregivers of PLWD • Each person then shared one idea. If they heard someone else share the same idea, they put a dot next to the idea if it was something they had listed as well • Participants shared three ideas each • This exercise explicates salient needs and wants, informing value/principle-based design	• Creating a shared understanding of the project goals • Goals included: Not dense; modularize, tailored to stage, tone, hope, reassuring, useful and practical, realistic; inclusive, focused on preparedness
Activity: Gaps in Care (Justification for Training)	• **Objective: Identify Gaps Areas for the Caregiver** • Participants got into groups of 3-4 to talk for 10-15 minutes about the gaps in care for PLWD	• Setting a foundation for the training need/justification, which

	• Each group was invited to write their top concerns on a paper • The facilitator and one team member reviewed each group's ideas – highlighting overlaps	informs the Qualification Standard • Key gaps: Funding; public awareness and education; system navigation; socioeconomic gaps in access to support; caregiver experience
Describe Target Learners and Context and Scale of Training	• **Objective: Create a Profile or Persona of the Caregiver** • The facilitator revisited the key stats • The facilitator engaged the group in creating a profile of a caregiver who will be using this training o How might we describe them? Can we form personas? Consider: age - race - identity - culture - languages - social life educational and work experiences - digital literacy - location - access - security - economics, etc. o Accounting for sex, gender, age, race, income, rural/urban (noted the use of intersectional lens)	• Need to account for what we know to be true from the perspectives in the room – rural, adults, predominantly white presenting individuals • Needed to clarify what makes someone a caregiver = increasing frequency, intensity, and duration of care • Target: new to caregiving journey, rural, seeking online learning to become more prepared for the role, for any gender and race/ethnicity
Envisioning Exercises: Blue sky	• **Objective: Participate in Envisioning Exercises:** Imagine this is "day one" on the job or what you'd put in the caregiver's Emergency Preparedness Kit. Our target audience is defined as someone who meets the criteria of being a caregiver. They either recognize the presence of dementia, sense a change, and/or have received a diagnosis o Participants wrote down what they'd like to see/wish-list for the training and shared them with the group one by one • A role play exercise was then used to further elicit potentially overlooked subject/topics during brainstorming activities about the content in the Emergency Preparedness Kit o Discussion of consent and disclosure of personal health information	• Those with lived experience were eager and quick to relay what they thought new caregivers should know right away. This is an important lesson in having a diversity of people at the table during conceptualization and design — it lowers the risk of subjective development • Key topics: Roadmap of clinical care and care planning; establish support network; build your team; how to communicate the news; how to advocate; safety plans; tools and tech; self-care; get educated; emotional preparedness
End of Day Impressions:	• Participants were asked to share end of day impressions	• Overall impressions from participants were positive, hopeful, and impressed by the amount

	• Facilitation encouraged discussion, supporting the inclusion and participation of virtual/remote participants	of work achieved and the level of expertise and thoughtfulness. • Reality of the complexities of navigating new diagnosis and the heterogeneity of potential target audience apparent, need to streamline intentions
Administrative notes: Due to timings, we skipped the activity that describes the caregiver's context as much ground had been covered. The Project Manager recorded 11 pages of notes. Imagery of the poster paper notes were taken as part of the Training Board's record.		

Between Training Board days, partners from Iris the Dragon and Addiev Corporate Training filtered Day 1 topics (e.g., needs, questions, wishes, and so on) into four sweeping themes that could be developed into curriculum in the *Design Phase* (see mage below):

Four Big Themes for the *Design Phase* of IncludeMe™

1. Dementia 101	2. Self-care module
4 Big Themes	
3. Skills to support the caregiver	4. Care planning

Day 2 focused on framing themes as either lessons or teaching points within a course for IncludeMe™ users to form an ability. A lesson would comprise knowledge, skills, or attitudinal scalars, which are the building blocks needed to form an ability.

Table 2: Day 2 - Curriculum development

Agenda	Process and Activities	Outcomes/Findings
Welcome	• Welcome to Day 2 & Re-motivation • Description of the day's agenda	• Clarity on process and expectations

Summary of Day 1	• Summary of ideas from Day 1 to inform curriculum development:
	  o A desire to prepare someone, who has accepted the reality of being a caregiver, with what they need to know right now to get started
	• Review of themes that emerged:
	  o The basics about dementia; what to expect from the healthcare system; connecting with caregiver support networks, care planning and the care binder, and self-care
		• These themes represented potential future lessons, depending on importance, frequency, and ability to translate the knowledge

Development of IncludeMe™

Reflection, Discussion, & Review of Target Audience	• Participants were given an opportunity to discuss anything on their minds following the summary of Day 1 activities	Key subjects raised included: • A review of the target audience • Ensure learning resource not overwhelming with too many different formats • The concept of a roadmap was brought up as a feature of an online learning resource – avoid being linear but rather able to navigate to content of immediate importance • Participants shared the importance of a learning tool that was easy to use, accessible, clear to follow the lessons, fillable PDFs, etc. • Idea to reinforce important topics throughout the learning resource and have bookmarks to save tangible information (virtual toolbox) • Normalizing feelings that a caregiver might experience
Review of Topics	• Iris and Addiev introduced the themes that emerged from Day One including the sub-topics • Participants were engaged in some consensus building around those themes and sub-topics	• 4 big themes emerged, with sub-topics captured within. They were 1) Dementia 101, 2) Self-Care, 3) Skills to Support the Caregiver, and 4) Care Planning

Focus on Curriculum, Desired eLearning Outcome, Big Categories & Themes	• **Objective: Sort out the learning objectives. Populate modules addressing caring for someone with dementia, enabling caregiver preparedness:**
	  o This 30-minute activity had participants form into 4 groups — with each team being assigned a theme. The task was to assess the topic, existing content ideas, and add in what was missing or needed for a caregiver to be able to engage in it, what resources might be needed, or if the topic was better suited for another category: navigating the system/care planning
	  o Each group then reported back to the larger team
		• Groups examined the topics captured within the larger themes and sought to identify whether all relevant content/information had been included. By identifying the most salient and important topics, the group could narrow down the learning objectives for that theme
		• Items that had been missed on Day 1 were captured, and the larger group was able to debate and build on ideas

Summary of Day 2	• Participants were asked to share end of day impressions • Facilitation encouraged discussion, supporting the inclusion and participation of virtual/remote participants	• Additional considerations that hadn't been captured in the sessions were offered, such as the opportunity for reflection activities within the course, scenarios where learners could identify themselves, and the opportunity to choose your path and tactic were all ideated

5.2 Design Phase

Iris the Dragon and Addiev led and facilitated the transition from the *Analysis Phase* to the *Design Phase*. The *Design Phase* began with a review of what the learning resource needs to be, referencing the Training Board output (Tables 1 and 2) as the guiding source of information to create a Qualification Standard with curriculum (Appendix A). The Qualification Standard serves as a training agreement and provides the framework for the project. It includes the description of the desired learning outcome and how it will be achieved, the training justification for the training and a high-level training plan complete with lessons and subjects, and instructional methodology. During this phase, Addiev's instructional designer was mindful of creating efficient and effective curriculum to guide program delivery and incorporated the 62 recommendations made during the Training Board into the development of the curriculum.

To generate a draft curriculum that imparts learnings to the target learners, the following process was followed in the *Design Phase*:

- Use of a scalar system (an instructional analysis methodology) to deconstruct desired abilities into knowledge, skill, and attitudinal blocks of learning, known as KSAs. This process distills the high-level learning objectives into smaller blocks of enabling objectives based on the competencies identified throughout the lessons.
- Consideration of cognitive, affective, and motor domains of learning.
- Consideration of andragogical approaches and learning theory to meet learners where they're at, to then learn competencies.
- Employment of Bloom's Taxonomy and Addiev's VAN Construct (that uses a verb-adjective-noun system) to properly describe the level of competency desired with the topic and how competency is demonstrated.
- Determine assessment and how learners will be measured.

Following this process, all Training Board participants were emailed a copy of the draft curriculum (see Appendix A) and asked to appraise the significance of the chosen topics to caregivers. Partners' feedback supported Addiev's instructional designer in allocating appropriate lesson times to each section. Participating partners were also encouraged to review the list of resources that the Addiev team captured as key references and add or make suggestions to guide the development of this content. The Addiev team noted that only one partner contributed additional resources to the repository.

The result of the *Design Phase* was a Course Design Blueprint (see in Appendix B). The Course Design Blueprint is a specification that informs the *Development Phase,* during which Addiev's instructional designer used the blueprint to build the course and Addiev's content developers drafted learning material.

Development of IncludeMe™

The curriculum was designed for adult caregivers (e.g., family member, friend, neighbour, or other community member) to PLWD or persons showing signs of dementia, who are new to the caregiving role and want to learn online. The curriculum focused on four areas of learning:

1. Knowledge about dementia including the correct terminology to communicate to others about the condition;
2. Navigating the healthcare system and local community supports to initiate a circle of relational care for the person living with dementia;
3. Preparing a care plan, plus a circle of relational care for the person living with dementia; and
4. Develop a plan for personal self-care and social connectedness.

5.3 Development Phase

During this phase of the project, Iris the Dragon and Addiev began the content generation and curation process of the learning resource, based on the desired themes that were identified by the participating partners and stories shared by project partners with caregiving experience depicting the emotional turbulence that new caregivers may experience. The learning resource was wireframed to capture the layouts and flow of content and ideate how to incorporate story into the learning resource to create engaging learning activities. The storyboarding process followed, in which case Addiev's instructional designer refined the content identified into digestible text for a learner and added narration.

Iris created scenarios that reflected the experiences of a caregiver in the four identified modules to engage the learners through the use of story. The storyboard was then shared with partners to encourage additional feedback and confirm that the content aligned with the expectations set in the Qualification Standard. Feedback was provided by three project partners who were subject matter experts. This feedback helped modify the stories and lessons included in the training. It was noted that the level of engagement of project partners decreased at this stage of developing the learning resource.

Example Storyboard

Following partner feedback, the IncludeMe™ prototype was developed by Addiev's learning technologies specialist. Participating partners were again given the opportunity to review and offer feedback (virtually and during an online meeting). Again, it was noted that engagement with partners was low, accentuating the disengagement in the later stages of development.

The final evaluation-ready version of the pilot for IncludeMe™, consisted of four modules, with two-four lessons in each module, designed to allow people to navigate the online learning resource in a "choose your own adventure" format.

Outline of Pilot for IncludeMe™
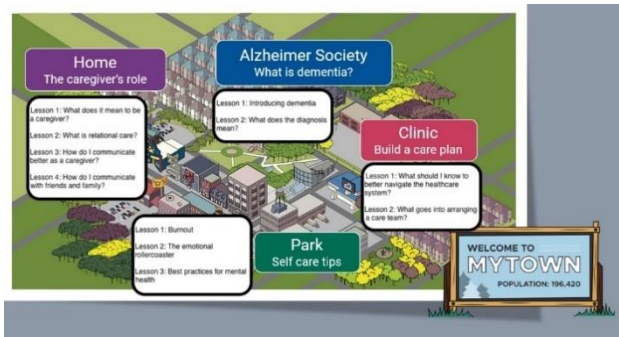
The pilot outline included the following modules with corresponding lessons:

1. Home: The caregiver's role
   - Lesson 1: What does it mean to be a caregiver?
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2. Alzheimer Society: What is dementia?
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   - Lesson 2: What goes into arranging a care team?
4. Park: Self care tips
   - Lesson 1: Burnout
   - Lesson 2: The emotional rollercoaster
   - Lesson 3: Best practices for mental health

6. Challenges Developing the Curriculum

Through the process of developing the IncludeMe™ - A starting point for dementia caregivers learning resource, several challenges arose that shaped the way the curriculum was developed in ways that may affect adaptation and scale:

1. One of the requirements agreed for the project as proposed to PHAC was to conduct a GBA+ analysis. We assessed the range of perspectives engaged in the project and found that while there were subject matter experts with knowledge of diverse caregiver experiences, the lived experiences and perspectives of caregivers from equity-deserving groups, including racial and ethnic minorities and diverse gender identities were missing.

2. The target audience agreed on at the outset of the project was broad. Project partners identified many topics that they felt were important/essential to include in the learning resource, and it became difficult for the developers of IncludeMe™ to narrow the scope of IncludeMe™. This challenge was exacerbated by 1) limited engagement of a diverse group of caregivers and subject matter experts to help guide decisions regarding the scope of the learning resource, and 2) having low input from project partners on these decisions. Ultimately, the developers felt the decision to keep so many lesson components meant that at times the curriculum content did not go into as much detail and depth as would have been ideal.

3. While there were subject matter experts involved as project partners, the most consistent involvement was in the *Analysis Phase*, during the Training Board and the *Design Phase*. During the *Develop Phase*, more engagement would have been helpful in shaping the final curriculum. In the early development stage, subject matter experts were asked to contribute to a list of evidence-based knowledge about dementia care; only one provided input. As the project progressed and the developers of IncludeMe™ needed to verify the evidence-base of the content, experts were not always readily available for input. Additionally, detailed feedback and input was required from subject matter expert partners during the *Develop Phase*, however there appeared to be a lack of clarity around roles and responsibilities and a lowered capacity for continued active participation.

7. Recommendations for Adaptation

1. Three project partners were caregiver experts-by-experience, and of the three, only one was exclusively representing this perspective as an experienced caregiver. Moving forward, inclusion of a diverse group of caregiver experts-by-experience (and in the case of new caregivers, experts with the recent experience of coming newly to the role) is recommended to ensure those experts can validate continually that the emerging curriculum is relevant and will meet the educational needs of those whom it is designed for.

2. Intentional project planning to manage partners' expectations, engagement and ensure equitable contribution to project objectives. To deliver an appropriate, timely and relevant learning resource, project leads can consider providing clarification on the roles and obligations of project partners, prompting partners of upcoming tasks at regular project check-in meetings. Particularly, emphasizing the need for, and importance of, robust feedback from subject matter experts during the *Design* and *Development Phases* could prime partners for robust engagement to ensure the learning resource is appropriate, relevant and evidence-based, drawing on their expertise regarding dementia and dementia care.

8. Next Steps

Next steps include an evaluation of the IncludeMe™ - A starting point for dementia caregivers learning resource, which will be conducted by the SE Research Centre, to answer two questions:

1. How does participating in the training impact caregivers':
   a. attitudes towards dementia;
   b. preparedness for caregiving;
   c. knowledge of dementia; and
   d. self-efficacy?
2. To what degree do participants find the training:
   a. inclusive;
   b. usable; and
   c. acceptable?

The evaluation will use a mixed-methods convergent design to address the two research questions using both qualitative and quantitative data to ensure a more complete understanding of the effectiveness of the learning resource (Doyle, Brady, & Byrne, 2016; Grant & Giddings, 2002). The evaluation will provide additional recommendations for adaptations to this learning resource prior to it being launched to the public.

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10. Appendices

10.1 Appendix A: Qualification Standard with Curriculum

IncludeMe^{TM} Training for Dementia Caregivers

Iris the Dragon's proposed Qualification Standard following the Addiev Training Board, March 2023

Background

600,000 Canadians are living with dementia. Currently, 61% or 366,000 of them live at home. By 2030, the number of people living with dementia in Canada will be 1 million. The number of caregivers is currently estimated to be 350,000. By extrapolation, within 7 years, 260,000 more citizens will become caregivers. Caregvier impacts include time away from work and socializing, out-of-pocket expenses, lower self-care, and an increase in personal mental health issues. The Alzheimer Society and the Government of Canada recognize the significant impact that this will have on workforces and productivity, not to mention the increased stress and cost to the health care system.

The Public Health Agency of Canada Dementia Strategic Fund (DSF) has awarded Iris the Dragon funding to develop, deliver, and measure the ffectiveness of a bilingual training program for caregivers of people with dementa in Canada. Iris the Dragon has consistently developed tools and products to improve mental health literacy, to reduce the associated stigma, and to encourage social inclusion and participation of those living with mental health conditions through the power of storytelling. Iris has earned 4.5 million readers globally and continues to expand its offering of resources.

Iris' pilot program will be tested in the Alzaheimer Society's catchment area of Lanark, Leeds, and Grenville, targeting caregivers who have just begun their journey in caring for someone with dementia. The course content will be informed by best practices, authored by credible sources, and vetted by subject matter experts and those with lived experience. Iris has partnered with Addiev Corporate Training, the Alzaheimer Society Lanark, Leeds, and Grenville, SE Health, Perth & District Community Foundation, the Indigenous Diabetes Health Circle, and the Mental Health Commission of Canada to produce the program.

A *Training Board* was convened to inform the program's currculum. The project partners identified gaps in the caregiving journey and determined a critical need to support those acknowledging their new role in life as a caregiver for someone with dementia. It was determined that an orientation, focused on early wherewithal across four key dementia topics, would enable a person to confidently begin their caregiving journey.

Qualifications Standard*:

Therefore, the desired learning outcome is for caregivers to be able to:
   1. Talk about dementia and use the correct terminology to accurately communicate to others about the condition.

2. Navigate the healthcare system and local community supports to initiate a circle of relational care for the person with dementia.
3. Prepare a care plan, plus a circle of relational care for the person with dementia.
4. Develop a plan for personal self-care and social connctedness.

* The Qualification Standard sets the expectation for the knowledge, skills, and behaviours that need to be transferred and then measured as instilled competencies. This program has a simpler expectation in order to meet participants where they're at. Learners will be able to freely navigate through the content or target topics of interest without measurement. Any positive shift in one of the 4 areas listed is a good outcome.

Proposed Curriculum

The proposed solution aligns with the third pillar of Canada's national objectives on dementia – to improve the quality of life of people living with dementia and caregivers. Moreover, it creates a well-structured package that consolidates what caregivers need to know, what to prepare for, and who to turn to when facing news of a dementia diagnosis, seeing early signs of cognitive decline or wantng to learn how to support those with dementia. It also addresses self-care, which is typically not promoted inline with caregiving activities. *IncludeMe^{TM} Training for Dementia Caregivers* is envisioned to be a 90-minute, eLearning program.

SEQUENCE	SUBJECTS & LESSONS	TEACHNG POINTS	TIMING
1	**WHAT YOU NEED TO KNOW ABOUT DEMENTIA**		20
1.1	What is dementia?	-All Dementias, including the Alzheimer's distinction -Recognizing dementia: the 10 warning signs	
1.2	What does the diagnosis mean?	-The diagnostic process and resources/tools to support diagnosis -The "stages" of dementia -Light overview of medications and therapies	
2	**PREPARING FOR THE CAREGIVER ROLE**		15
2.1	What does it mean to be a caregiver?	-The different "faces" of caregiving, including roles, routines, models -Managing expectations: Caregiving may take a lot of time and resources and it can fluctuate – monitoring, duration, frequency, and intensity -The necessity of preserving your own health throughout the caregiver journey (high-level msg) -It's OK not to be OK / or not to be able to do it all	
2.2	What is relational care?	-The person centered approach to compassionate caregiving -Recognizing the underlying needs and behaviours of a person with dementia -Techniques for managing behavioural symptoms (including creative problem-solving), practicing patient -Finding routines that work (leisure, medications, etc.)	

		-Remaining flexible in the face of change and uncertainty (high-level msg)	
2.3	How do I communicate well as a caregiver?	-The importance of effective communication as a caregiver -Effectively and patiently communicating with the person with dementia -Finding your assertive voice w/engaging the system -Managing ongoing communication with friends and family (including sharing the news) – it's a shared responsibility -The art of asking for help, expressing needs and wants (high-level msg).	
3	**PREPARING A CARE PLAN**		**40**
3.1	What do I need to know to better navigate the healthcare system?	-Overview of the clinical roadmap/spiderweb or concept of a trail map) -Distinguishing health provider roles -System navigation and patient advocacy -Developing a care strategy to get needs met	
3.2	What goes into arranging a care team?	-Creating partnerships wth care providers -Preparing for appointments with clinicians/HC providers -Community supports and access points for care -Arranging "the home team", composed of family, friends, and other supports -Build a patient binder with the documents, notes, numbers, medication list, etc. to bring to appointments (with circle of care centered decisions at every stage)	
3.3	What should I factor into a care plan for my loved one?	-Bringing structure and organization to your care routine (planning and prioritizing) -Identifying new tasks/roles to manage, i.e., paying bills, home maintenance, etc. -Listing support needs, checking for anything that can be delegated/outsourced -Non-medical planning (POA, SDM, financials, work, getting on long-term care lists, end of life care and decision-making) -Addressing safety – creating a safe space at home (comfort, cleanliness, safety, medication), planning for instances of wandering or delusions (intensity, duration, frequency), driving (sense of loss of freedom, getting lost, risk), protecting against scams, abuse, neglect, preparing for emergencies -Finding as many opportunities, where possible and practical, to get the individual socially engaged	
4	**TAKING CARE OF YOURSELF TOO**		**15**

4.1	Do I need to be concerned about burnout?	-Relate self-care as self-preservation. Self preservation, maintenance, & restoration while being cognizant of the barriers that may exclude some. -Describe top issues & impacts, support w/evidence, statistics (stress, burnout) -How to recognize when you've reached your limits (continuum of mental health)	
4.2	Is this "emotional rollercoaster" a common experience?	-Validation of the range of emotions you may feel -Navigating gulit and grief -Finding joy in the caregiving experience/using humour	
4.3	What are some best practices to help me sustain my own physical and mental health?	-Overview: examine best practices, select what's practical, create a self-care plan -Asking for help -Addressing loneliness as a reality for caregivers -Connecting with support networks (friends, family, therapists, community supports, religion) -Addressing sources of stress and balancing responsibilities -Navigating boundaries and changing family dynamics -Actions to help manage stress (journaling, exercise, meditation, sleep, spirituality, etc.) -Resources to help you (tool kit)	

Out of Scope for this Training Program

- No extensive resource lists. We will stick to well-situated, national organizations that can support caregivers and direct them to local supports if available.
- We will not provide comprehensive skill building in how to care for someone living with dementia. Instead, the program will provide high-level management techniques complemented by downloadables and links to national organizations that can provide methods that address the client's specific needs.

Sources of Dementia Content

Known SMEs (including lived experience) and vetted content:
- Project Team: Iris the Dragon, Addiev Corporate Training, Alzheimer Society, SE Health, MHCC, Perth and District Community Foundation, and the Indigenous Diabetes Health Circle.
- Content Repository: The Addiev Zotero database of publications and Iris the Dragon's repository of dementia resources.

Program Administration & Management

- Iris the Dragon is accountable for the project and will direct activities. Addiev Corporate Training is responsible for project management and for developing the program. The Alzheimer Society, Perth and District Community Foundation, the Mental Health Commission, and the Indigenous Diabetes Health Circle are responsible for testing the program internally and with their communities of interest. Finally, SE Health is responsible for measuring program effectiveness.
- The pilot program's launch is scheduled for January of 2024, following program testing in December of 2023.
- The program is to be offered in English and French.
- The program is to consider an alternative delivery format for those without access to digital services
- The program may be published on an HTML5-based Web server or SCORM-based Learning Management System.

Training Authorization

Jessica Grass, COO, Iris the Dragon	Guy Paquette, Director of Training, Addiev
	Guy Paquette

10.2 Appendix B: Course Design Blueprint

Course Design Blueprint

COURSE TITLE: IncludeMe™ Dementia Edition for Care Partners
COURSE MANAGER: Ashley Muldoon
QUALIFICATION STANDARD: dementia-care-partner-qs-ver-01
QS DATE: April 03, 2023
INSTRUCTIONS: Include course intro that recognizes the learner as a care partner—that acknowledges the truth and gravity of their situation. Acknowledge that not everyone will have the same situation, access to supports.

SEQUENCE	PERFORMANCE & ENABLING OBJECTIVES	LESSON & ACTIVITY TIME (MINS)	PRACTICE & ASSESSMENT TIME (MINS)	EXPECTED LEARNING OUTCOMES (TEACHING POINTS)	INSTRUCTIONAL METHOD	INSTRUCTIONAL MATERIALS (TRAINING & LEARNING AIDS)	LESSON & ACTIVITY CONCEPT NOTES	ASSESSMENT METHOD	ASSESSMENT PLAN FILE	PRACTICE & ASSESSMENT CONCEPT & RATIONALE NOTES
	Apply a scalar method along with Bloom's Taxonomy to determine the appropriate level of mastery that can be assessed afterwards	State the lesson + activity time (min). This should match what is stated in the Lesson Schedule given to learners.	State the practice + assessment time (min). This should match what is stated in the Lesson Schedule given to learners.	These are the KSAs stated as teaching points for each EO. "While implementing MyWorkplaceHealth Principles and Code of Conduct, the employee shall [what] by".	The IM will have learning styles associated with it: VIS=visual, AUR=aural, VER=verbal, PHY=physical, LOG=logical, SOC=social, SOL=solitary	List lesson specific equipment, digital files, instructional guidance, and hand-outs required by the instructor and learners (w/links where possible).	Use this space to draft concepts for the lesson & activities	Identify how this assessment is being delivered and explain rationale (column to the right)	Please link to or identify the file name of the Assessment Planner	Use this space to draft concepts for the practice & assessment
1	**EXPLAIN DEMENTIA IMPAIRMENT**	10	0			Learner's Journal	Map → Alzheimer Society	* No assessment required	n/a	public health awareness only
1.1	Differentiate Dementia Conditions	0	0	TP → The umbrella of dementia (including the difference between Alzheimer's and dementia) TP → Recognizing dementia: the 10 warning signs	Online Lesson w/Gamified Activity (VIS-LOG-SOL)	pdf/url resource				
1.2	Summarize Dementia Diagnosis		0	TP → The diagnostic process and resources/tools to support diagnosis TP → The "stages" of dementia TP → Light overview of medications and therapies	Online Lesson w/Gamified Activity (VIS-LOG-SOL)	pdf/url resource				
2	**DISTINGUISH CARE-PARTNER ROLE**	20	0			Learner's Journal	Map → Home Setting	* No assessment required	n/a	public health awareness only
2.1	Explain Caregiver Roles		0	TP → The different "faces" of caregiving (roles, routines, models) TP → The necessity of preserving your own health throughout the care partner journey (high-level msg)	Online Lesson w/Gamified Activity (VIS-LOG-SOL)	pdf/url resource				
2.2	Explain Person-Centered Care		0	TP → The person-centered approach to compassionate caregiving TP → Getting to the underlying needs and behaviours of a person with dementia TP → Techniques for managing behavioural symptoms (including creative problem-solving) TP → Practicing patience TP → Finding routines that work (leisure, medications, etc) TP → Remaining resilient and flexible in the face of change and uncertainty (high-level msg)	Online Lesson w/Gamified Activity (VIS-LOG-SOL)	pdf/url resource				
2.3	Highlight Communication Skills		0	TP → The importance of effective communication as a caregiver TP → Effectively and patiently communicating with the person with dementia TP → Finding your assertive voice TP → Managing ongoing communication with friends and family (including sharing the news) TP → The art of asking for help, expressing needs and wants (high-level msg)	Online Lesson w/Gamified Activity (VIS-LOG-SOL)	pdf/url resource				
3	**PREPARE CARE PLAN**	30	0			Learner's Journal	Map → Clinic Setting	* No assessment required	n/a	public health awareness only
3.1	Relay Health-System Challenges		0	TP → Overview of the clinical roadmap/spiderweb TP → System navigation, patient advocacy, The Binder TP → Starting a care plan (with person-centered decisions at every stage)	Online Lesson w/Gamified Activity (VIS-LOG-SOL)	pdf/url resource				
3.2	Arrange Professional Care-Team		0	TP → Distinguishing health provider roles TP → Creating partnerships with care providers TP → Preparing for appointments with clinicians/HC providers TP → Community supports and access points for care	Online Lesson w/Gamified Activity (VIS-LOG-SOL)	pdf/url resource				
3.3	Build Care Plan		0	TP → Bringing structure and organization to your care routine (planning and prioritizing) TP → Identifying new tasks/roles to manage, i.e. paying bills, home maintenance, etc. TP → Listing support needs, checking for anything that can be delegated/outsourced TP → Arranging "the home team", composed of family, friends, and other supports TP → Non-medical planning (POA, SDM, financials, work, driving, etc.) TP → Creating a safe space at home (comfort, cleanliness, safety, medication) TP → Planning for instances of wandering or illusions (intensity, duration, frequency) TP → Protecting against scams, abuse, neglect TP → Preparing for emergencies TP → Preparing for end of life care	Online Lesson w/Gamified Activity (VIS-LOG-SOL)	pdf/url resource				
4	**DEFEND SELF-CARE PRACTICES**	30	0			Learner's Journal	Map → Park Setting	* No assessment required	n/a	public health awareness only
4.1	Recognize Caregiver Burnout		0	TP → Relate self-care as self-preservation TP → Describe top issues & impacts, support w/evidence, statistics (stress, burnout) TP → How to recognize when you've reached your limits (continuum of mental health)	Online Lesson w/Gamified Activity (VIS-LOG-SOL)	pdf/url resource				
4.2	Validate Personal Emotions		0	TP → Validation of the range of emotions you may feel TP → Navigating empathy fatigue and resentment (including that of family members) TP → Navigating guilt and grief TP → Addressing loneliness as a reality for caregivers	Online Lesson w/Gamified Activity (VIS-LOG-SOL)	pdf/url resource				
4.1	Examine Self-Care Tactics		0	TP → Overview: examine best practices, select what's practical, create a self-care plan TP → Asking for help TP → Addressing loneliness as a reality for caregivers TP → Connecting with emotional support networks (friends, family, therapists, community supports) TP → Addressing sources of stress and balancing responsibilities TP → Navigating boundaries and changing family dynamics TP → Connecting with emotional support networks (friends, family, therapists, community supports) TP → Actions to help manage stress (journaling, exercise, meditation, spirituality, etc.) TP → Resources to help you (tool kit)	Online Lesson w/Gamified Activity (VIS-LOG-SOL)	pdf/url resource				

	LESSON & ACTIVITY TIME	PRACTICE & ASSESSMENT TIME	
add: training & assessment time	90	0	← automatic cell calculation, do not modify
add: project & admin time	0	0	← yes, enter applicable minutes in these cells
less: unsupervised & break time	0	0	← yes, enter applicable minutes in these cells
IACET credit value		0.2	← automatic cell calculation, do not modify