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Business Planning for Dementia Programs: Toolkit for Nonprofit and Government Agencies

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Executive Summary

Addressing the needs of individuals with dementia and their family caregivers living in the community is a key focus of states as they recognize the growing number of individuals with dementia. State Units on Aging, Area Agencies on Aging, and Aging and Disability Resource Centers are working to integrate services and create connected systems of care using business principles and practices. They are fostering funding sources to braid together a set of reliable revenue streams, developing marketing and communications plans, and engaging in collaborative partnerships, especially with the health care sector.

Using a basic business plan template as an organizing framework, this Toolkit walks the reader through key issues for consideration, offers examples, and provides resources for further exploration. The steps offered in this Toolkit provide a guide for writing the components of a business plan. Although this Toolkit is crafted to focus on dementia programs, the questions posed involve considering larger issues, such as an assessment of internal organizational capabilities and external constraints in the marketplace. These factors influence choice of the business model, operational approach, financing, implementation success, and sustainability. Preparing and using a sound business plan increases the likelihood that the program will be sustained.

A fundamental starting point is to set forth the purpose for the program, clearly describing the program's focus and intent and tying them to the mission and strategic priorities of the larger/parent organization. If the dementia program is not tied to organization priorities, it will be difficult to embed it. Likewise, if there is not a foreseeable way for the dementia program to be sustained, then it is questionable whether the organization should devote valuable resources to building the organization's capability and offering the program in the first place. Chapter 1 walks through identifying purpose, setting goals, attending to context, and understanding partnership considerations.

Once the overall purpose and goals are clear, specific dementia programs can be reviewed to meet goals. The task of selecting the program requires attention to the inputs (resources required), competencies, and steps necessary to offer the program with fidelity. Clarity around the components of the program and an understanding of requirements is critical. It is wise to learn as much as possible from other organizations that have successfully implemented the chosen dementia program(s). This helps address hurdles that are not easily anticipated.

Chapter 2 walks through program selection, investigating components and operational issues, and recognizing core competencies which will be needed.

Determining funding sources and charting a course for financial sustainability for the dementia program ideally should be done before the organization's leadership commits to developing the program. In general, greater diversity in payment/revenue sources is a goal to help ensure reliability of funding. There may be a mix of revenue sources including federal and state service contracts, Medicare, Medicaid, project grants, operating grants, individual donations, corporate contributions, fees for services, and endowments or investments. Building the budget and service forecast involves conducting a thorough cost analysis and making informed estimates about service capacity, service volume, and payment sources. Chapter 3 walks through the budgeting process and offers seven steps: calculating costs and a cost per unit of service, estimating program capacity, determining the total program cost, understanding potential service payment rates, investigating referral sources, creating volume scenarios, and choosing targets to finalize the forecast.

The marketing and communication strategy for the dementia program must be developed with the business model, program focus, and funding model in mind. Marketing and outreach takes time and money—resources must maximize referrals to the dementia program. The end user of the dementia program is the person with the disease or the caregiver, such as a spouse, adult child, or live-in friend. However, there are many other potential customers (intermediaries) who will be the actual purchaser of the service or who are key constituents in getting the service to the end user. Chapter 4 walks through clarifying customers, understanding distribution channels, connecting marketing methods to constituents, and attending to special populations.

Even with the best preparations, no business strategy is assured. An evaluation provides the information to determine whether the resources invested achieved intended results and is the final component of creating the business strategy. Chapter 5 walks through identifying key stakeholders, selecting indicators, and conducting the evaluation and communicating results.

Introduction

Addressing the needs of individuals with dementia and their family caregivers living in the community is a key focus of states and health and social service providers as they recognize the growing number of individuals with dementia. In particular, states are working to build dementia-capable systems of care (Tilly et al., 2011, 2014). Services for people with dementia include information about and referral to community services, assessment, counseling and care planning, caregiver education, caregiver self-care, respite, wellness, meaningful engagement, day care, transportation, transition support, and other programs. Many evidence-based service programs have been successfully developed, tested, and translated to community settings, although dissemination remains limited (Maslow, 2012).

State Units on Aging (SUAs), Area Agencies on Aging (AAAs), Aging and Disability Resource Centers (ADRCs), and aging services providers are increasingly recognizing the need to use business principles and practices as they develop and sustain programs (Bowers et al., 2004; Gage et al., 2004). Emphasis on incorporating business principles and practices has included creating a business plan, identifying and fostering a variety of funding sources to build or braid together a set of reliable revenue streams, developing marketing and communications plans, and engaging in collaborative partnerships and relationships to develop more formal agreements around referrals and reciprocal accountability.

Policymakers and experts in the field are encouraging providers of long-term services and supports (LTSS) (including dementia and caregiver programs) to build their capacity and business acumen to participate as a provider of services within a larger health care or social services network. Organizations seeking to foster dementia-capable networks or systems of care must consider the larger environment in which the dementia system or program will reside. External factors (for example state policies, funding priorities, community characteristics) influence what organizations can do in terms of developing and sustaining programs and service network systems (Durlak & DuPre, 2008). At the same time, internal factors (for example organizational culture, staff capability, administrative supports) heavily influence implementation of programs (Fixsen et al., 2009). In studies of implementation success of evidence-based programs, for example, factors such as program-to-organization fit, mission alignment, presence of a strong organizational champion or leader, strong technical support, and continuity of stable funding have been shown to be important (Aarons et al., 2009; Greenhalgh et al., 2004; Kaczorowski et al., 2011; Ory et al., 2010; Paone, 2015).

This report provides organizations with information about the five key components of a business plan that program managers can use to strengthen their chances of successfully meeting the needs of people with dementia and their caregivers and sustaining those initiatives over time.

How to Use This Toolkit

This Toolkit was written for public and private entities that provide or promote dementia programs and services as part of the LTSS system or aging and caregiver services network.

Using a basic business plan template as an organizing framework, the Toolkit walks the reader through key issues for consideration, offers examples, and provides resources for further exploration. Although this Toolkit is crafted to focus on dementia programs, the questions posed often involve considering larger issues, such as an assessment of internal capabilities and external realities in the marketplace. Internal and external factors ought to be taken into account, because they will influence choice of the business model, operational approach, financing, implementation success, and sustainability.

The key message of this Toolkit is that investing the time and energy to develop a business plan for dementia programs will provide useful benefits to the organizations making the commitment. The five chapters of the Toolkit mirror the key components of a business plan:

1. Purpose and Business Model
2. Program Components and Operations
3. Funding Strategies
4. Marketing
5. Evaluation

For each chapter, the Toolkit provides an overview of the chapter topics. A few key questions are posed and addressed. Case examples are offered, providing both illustrations of the content and practical advice and lessons learned from various agencies and organizations operating at the state or regional level in the field. Case examples from the field and illustrative case examples were developed by the author to clarify and provide guidance around technical methods or specific steps. The Appendix includes additional resources, with brief descriptions and electronic links to reports, articles, and other material.

Chapter 1: Purpose and Business Model

Key Questions

1. What is a business model?
2. What is the purpose for the dementia program, vis-à-vis the mission and purpose of the organization?
3. What are emerging core competencies for partnerships, particularly with health care systems?

Business Model Defined

A business model is an organization's approach to making and then delivering a product or service effectively. Every organization has a business model—even volunteer organizations—whether adopted consciously or not. For example, a volunteer scout troop may focus on *building young leaders through training, education, and team-building experiences* and rely on families who provide both in-kind labor and materials to the troop and voluntary fees. A dementia program may focus on *increasing self-care capacity of dementia caregivers* and rely on training programs and support groups funded by grants.

Business models identify the customer/client of a service or product and what that customer values about that service or product (Ovans, 2015). Parameters include the following:

1. Who will be our key partners or collaborators for the dementia program?
2. What key activities and resources will be required?
3. What is the value proposition of the dementia program, from the organization's perspective and from the perspectives of key partners?
4. What are the dementia products or services the organization is offering?
5. Who are the customers and what are the key customer relationships that need to be fostered?
6. What are the distribution channels through which the customer is reached?
7. What is the organization's cost and pricing structure?
8. What are possible revenue sources?

Step #1: Define Purpose

The starting point in business planning is to set forth the purpose for the product, program, or service, clearly and concisely describing the program's focus and intent and tying this to the mission and focus of the parent organization or system. For a dementia program (or network) at the state or regional level an illustrative purpose statement for its business plan might read:

To create and sustain a comprehensive network of information, referral, training, and person-centered support services for persons living with Alzheimer’s disease and related dementia and their caregivers as an integral part of the _____ (state’s/region’s) long-term services and supports provided to individuals, families, and caregivers.

And further,

To build this network as part of the home and community-based services system that is based on a single entry point/no wrong door approach that reaches underserved ethnic and other minority population groups and those in remote or rural areas of _____ (state/region).

This dementia network aligns with the mission and purpose of our department within the state, which is to “Help people meet their basic needs so that they can live with dignity and achieve their highest potential.”

For a dementia program at the organizational unit level (e.g., within one aging service provider or AAA), the purpose statement might read (illustrative):

To increase physical activity and meaningful engagement of individuals living with Alzheimer’s disease and to improve caregiver self-care through implementing with fidelity and sustaining the _____ (name of the program) in the geographic region covered by _____ (name of the organization or AAA) as part of the menu of services offered to individuals, families, and caregivers by this organization.

This dementia program aligns with the mission and purpose of our organization, which is to “Assist individuals to age with vitality and enrich the capacity of communities and families to care for the aging population in our region.”

Step #2: Clarify Goals

Following the purpose statement, the business plan will provide one or more goals and a set of objectives for the program. The program manager will need to clarify the organization’s goals for this dementia program(s). The business plan will also define the target user of the service and any intermediary agents that serve as third parties or are important in getting the service to the user. Illustrative goals and objectives follow:

GOAL: (1) To improve access to ADRC (or AAA) programs and services for *individuals and families*, particularly in underserved areas.

Objective 1a: Increase the number of ADRC/AAA programs serving minority, culturally/ethnically diverse, and rural communities.

Objective 1b: Ensure that ADRC/AAA program communication, marketing, outreach materials and methods, and informational resources are appropriately translated or redesigned to match the language, culture, and communication channels of minority and ethnically diverse communities AND that they are transmitted through informal and formal channels, building on the natural means of communication in the community.

Step # 3: Attend to Context/Environment

In writing the business plan, the program manager needs to take context into account. What is going on in terms of the geographic setting or marketplace? What is the demographic profile of the area the program will be serving? Are there unique challenges or characteristics of the market? How will people who are considered the ultimate end user come to find and use the dementia program? Who are possible competitors? Briefly, the business plan should describe the environment in which the program will be operating. Illustrative examples follow:

Example: Urban AAA

Our agency serves a densely populated ethnically and racially diverse urban area of more than 2 million people. The population is becoming more ethnically and racially diverse through immigration of individuals and families from more than 36 countries. In some schools more than 100 languages are spoken. Major employment is in the retail sector, manufacturing, and self-employment. Approximately 14% of the population is over age 65 (294,000). The average age is 30 and declining, as the proportion of households with young families increases. Although the economy is improving, many individuals are working two jobs. The major means of transit is through public subways, bus, and rail transportation systems, and some private shared ride programs.

Based on estimates from the Alzheimer's Association, one out of every nine individuals over age 65 may have Alzheimer's disease, representing 32,666 individuals in this geographic area. National estimates reveal that approximately two-thirds of caregivers are women and over one-third of caregivers are elders themselves. In this geographic area, almost 45% of all households with children are managed by single working mothers.

Thus, our dementia programs and dementia care networks need to address the needs of both working women with children and older women. These women are most likely to be caregivers of individuals living with Alzheimer's disease or dementia. We also need to work collaboratively with our partners across service areas, because caregivers may work in one area but live in another within our city. In addition, our dementia programs need to be tailored to immigrant and ethnic/racially diverse subgroups within our resident population, ensuring that our program design, materials, service format, and outreach methods are ethnically, culturally, and language competent.

OR

Example: Rural AAA

Our organization serves a rural and remote area of more than 15,000 square miles in the southwest corner of the state with about one household for every 3 miles. Major employment is in agriculture. The population of approximately 9,900 has declined as young people and families move to suburban and urban areas. Thus, the average age has increased and the proportion of residents over age 65 is now nearly 30%. Of these 2,970 elders approximately 35% live alone (1,039 individuals). Service providers are few and far between. Transportation is by private automobile. There is almost no public transit. Some shared ride programs and shuttle services exist but serve less than 5% of the area. Based on estimates from the Alzheimer's Association, approximately 330 older residents (1 out of every 9) in our service area may have Alzheimer's disease or a related dementia. We estimate that between 50 and 115 older residents with ADRD are living alone.

Given the nature of our service area, we have considered how to craft our dementia program to reach those in need. We are exploring the use of remote technology that provides clear audio and visual information and allows for communication in real time as part of our dementia and caregiver education and support, including caregiver consultation. In addition, our programs need to be connected with all sectors. We are exploring how to link our dementia programs with any organization (public or private) to raise awareness and inform the community at large about dementia and caregiver supports we provide. This would include faith communities; community service centers such as libraries, nursing homes, retail and agricultural businesses; and civic/volunteer groups. Our goal is to build both informal and formal communication channels and support systems that can help reach persons with dementia and caregivers living in our rural area.

Step #4: Identify Partnership or Network Strategies

However large the organization is, it will likely need to partner with other organizations to meet the needs of people with dementia and their caregivers. Over the last 10 years, partnering with other aging/social services providers or with health care entities has been promoted by experts as a way to increase reach, extend service availability and choice, and improve the potential for financial sustainability.

Case Example #1: Structure, Purpose of the Dementia Program:

Rosalynn Carter Institute for Caregiving, Georgia

This example is offered to highlight business purpose and model/strategy and is based on a key informant interview conducted in July 2015 with Executive Director, Leisa Easom, PhD, RN, and Gayle Alston, MA, Director of the RCI Training Center for Excellence. Information from the RCI website was also used (see <http://www.rosalynncarter.org>).

Brief Introduction to RCI

The Rosalynn Carter Institute of Caregiving (RCI) is part of Georgia Southwestern State University, located in Americus, Georgia. The mission and philosophy of RCI is to:

Establish local, state, national, and international partnerships committed to building quality, long-term, home and community-based services ... that begins with providing caregivers with effective supports to promote caregiver health, skills, and resilience (http://www.rosalynncarter.org/about_rci/).

There are four strategic priority areas for RCI: (1) advocacy, (2) education, (3) research, and (4) service. RCI currently focuses primarily on two types of caregivers: (1) those who are assisting a person with dementia, and (2) those assisting a person who has served or is currently serving in the military.

Discussion With RCI

The discussion with RCI representatives focused on the following:

- How RCI structured its dementia programming and services and created its business model that aligns with the overall strategy and business model of the organization
- What assumptions were made in setting up the program
- How any partnerships or networks were developed/fostered
- What worked in terms of creating and implementing the dementia program and strategy
- Key lessons learned and sustainability

Structure/Model

Everything we do within RCI lines up with our four strategic priorities (listed above). Our work around dementia focuses on training and education, based on scientific evidence and research about what is effective.

Our “business purpose” for the dementia program is to enhance the organizational capacity and effectiveness for implementing these evidence-based programs through best practices in training and technical assistance. As part of a university, we also espouse the principle that research and evaluation—that is, measuring the results—must be woven into what we do. We provide guidance to the community agencies and organizations in the field for how to do that with the dementia programs. Critical to evidence-based program implementation is fidelity to

the intervention. Licensure for training programs is available to ensure that technical assistance support is continued as are updates on training.

Assumptions, Development

When we started (about 7 years ago), we brought in research scientists to talk about caregiver support programs that had been tested through a clinical trial and proven effective in improving caregiver health, burden, depression, or other measures. This research approach—the randomized control trial—is tightly controlled by the scientist. Although this is an excellent study design, it does not yield a practical approach for implementing in the field of direct service.

This led to an understanding that there was a significant need for translation of the research-based effective practices/interventions. We took on the role (with others) to translate these effective interventions so that they can be implemented in community agencies, AAAs, and other service organizations in the field—the direct service organizations. We spent some time with these direct service organizations learning with them.

Our assumptions were that the focus in the future would be on evidence-based programs. This has turned out to be true. Creating robust technical assistance and helping to translate these programs to be used in the field was clearly a gap. We saw that was aligned with our mission and purpose. So we went about creating our training, technical assistance, and fidelity support service, which is what we are now disseminating beyond Georgia, nationwide. The RCI REACH program is a recent and continuing effort to support dementia caregivers.

We also saw that all organizations needed to move from a passive offering of programs and counting number of units provided to a more active recruiting/outreach and measuring value of what was provided. The measures have to be objective and all organizations need to build that capability to prove that what is being done is working. Further, achieving similar program outcomes to the original clinical trial outcomes is an indication of successful adherence to fidelity. The external environment was starting to push this, and we crafted our approach with the commitment to do this.

Partnerships/Networks

We had multiple research partners and collaborators, and funders, to develop our service and approach. This included Johnson & Johnson, the Administration on Aging/Administration for Community Living, Area Agencies on Aging, Councils on Aging, the Alzheimer's Association, AARP, Easter Seals, and other organizations that have caregivers as a focus. We worked with the Georgia state unit on aging, and providers statewide, including residential care providers, hospitals, home care agencies, and home and community-based services providers. We held expert panels and encouraged all these stakeholders to meet and talk with one another. In a real way we became a conduit for these stakeholders to share information and ideas.

The university is a key partner as well. We are able to tie this work to both the mission of RCI and the mission of the public university where we reside—its mission supports learning and teaching. This is the focus of our dementia training and technical support (<https://gsw.edu/about-gsw/mission-statement>).

What Worked

The timing. We were focusing on evidence-based programs and on measuring value precisely when the external environment was also moving in that direction. There was agency buy-in and a willingness to change from its usual approach.

Our approach. Our approach was grounded in on-site, hands-on learning with the organizations at the community level. We saw first-hand the struggles on the ground that some of the community agencies had with evidence-based programs, identifying where it needed adaptation or where additional resources and technical support were needed. For example, some programs had never followed an evidence-based program protocol before and were unfamiliar with fidelity monitoring.

Researcher buy-in. The researchers were supportive in recognizing this need for translation, implementation, and dissemination guidance. In most cases, this was not something they could take on themselves. We found that robust training and technical assistance is much more than a day or two of training on the intervention/program—it is working with the agency along its implementation journey.

Lessons Learned

Service agencies are not the same. They have different sizes, staff training, capacity, organizational orientation, even geographic and market characteristics. We learned that not every program is going to be a good fit. Also, the community service provider that is implementing the dementia program will sometimes need additional help to get it to a place of readiness. Our technical assistance needs to be flexible and meet providers where they are.

Any agency will have staff turnover. Program directors don't want their program walking out the door when a staff member leaves. Therefore, we built in retraining as a part of our service support under the licensure. We focused on doing this in an affordable, accessible way. We are bringing training to directors in the most effective way we can that still follows fidelity to the program and helps ensure the outcomes expected (e.g., reduction in caregiver depression, burden). We learned this was very important to the agency directors. They also came to see that we are not there simply to audit them. We are there to support them and build on their strengths.

Sustainability

We have been building program capacity in the field through providing affordable, effective training and technical assistance on evidence-based dementia programs. We sustain our organization and this program through (1) being part of the university, (2) renewals and licensure fees, and (3) additional service payments for the training and technical assistance through subcontracts with organizations (increasingly we are being written into another organization's grant application as it seeks funding for starting its dementia program).

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Chapter 2: Program Components and Operations

Key Questions

1. What factors should be considered in choosing among options for dementia programs?
2. What are the dementia system or program components?
3. What are the infrastructure and operational requirements (the inputs) necessary to host/provide the program?

Program Choice

Organizational leaders must ensure that the dementia program developed is consistent with the mission and strategic priorities and capabilities of the entity. Moreover, if there is no foreseeable way for the dementia program to be sustained over time, the organization must consider whether it is worth investing the time and effort to implement a new initiative. A scattered “start and stop” programming approach is difficult for both staff and potential clients/consumers.

If the organization is considering offering more than one dementia program, those planning the program menu will want to unpack the program components for each service and then compare across services. New program ideas should be compared to what already exists. Can economies of scale be achieved? Are the programs so similar that they compete with each other—both for staff time and for clientele? What does the market need? Are there gaps? What programs best fit with the capacity and strategy of the organization?

Organizational leaders designing the approach may wish to conduct a Strengths, Weaknesses, Opportunities, and Threats (SWOT) analysis regarding their organization’s ability to deliver the dementia program/package and meet defined goals. This approach can help crystalize the discussion and pinpoint areas that will need attention for the program to be successful. In some cases the “threats” can be turned into “opportunities.” An example is provided in **Table 1** where potential dementia program competitors could be approached as partners. This would be the case if a program that targets only the person with dementia and a program that targets only the caregiver were linked, for example, if a respite care day program and a caregiver educational workshop and support group were held concurrently and cross-marketed.

Table 1. SWOT Example for Dementia Program

SWOT	Examples
Strengths	<ul style="list-style-type: none"> • Organization is well known in the community. • Experienced staff with credentials. • Active volunteers (more than 100). • Strong Board of Directors. • Strong collaborative relationships with local providers and service organizations. • Low-rent space with good visibility. • Stable core programs. • Dementia programs tie to existing core programs in caregiver education and support, wellness, meaningful engagement, information and referral. • Infrastructure—database, financial management, policies and procedures, other operations—is solid.
Weaknesses	<ul style="list-style-type: none"> • Small size. • Do not have evening/weekend hours, except for first Saturday of the month. • Limited marketing/outreach budget or capacity. • Grants have been harder to get and almost all focus on new programs; very little grant funding for core support. • We have tested various funding streams and they are limited—insurance does not cover our dementia programs. We rely on Title III funding (which is capped). We have developed a sliding fee scale and provided a fee-for-service schedule to every client to build our private pay. The market is not responding to fee-based programs. Seniors do not want to pay. • Medical care providers (hospital, clinics, home care, and private physician offices) are not referring patients once a person is diagnosed with Alzheimer’s disease or related dementia, despite our outreach to clinics. Most clients find us through word of mouth or through referral from other sources (e.g., the Alzheimer’s Association).
Opportunities	<ul style="list-style-type: none"> • Growing awareness of Alzheimer’s disease and dementia issues in our community. More calls for information. May be able to create a market niche to be recognized as a full-service program provider. • Could perhaps set up a direct-connect referral process with two local physician groups that have a once-a-month “memory assessment clinic.”
Threats	<ul style="list-style-type: none"> • Other providers are developing programs and in dementia—more competition. <ul style="list-style-type: none"> – <i>Note that some do not offer respite and may be interested in partnering with us to enhance their support to caregivers.</i> • The marketplace is full of assisted living providers emphasizing that people with dementia should be in a memory care unit; this is affecting caregivers, because they come to believe that is the only or the best option for their loved one.

Step #1: Select the Dementia Program(s)

Once the overall purpose and goals are clear, specific dementia programs can be selected that best meet those goals. The task of selecting the program to develop requires attention to the inputs (resources required), organizational competencies, and steps necessary to offer the program with fidelity to the designers' intent. Clarity around the components of the dementia program and an understanding of requirements is critical if the organization is to successfully implement and sustain the program.

To clarify and align consumer/client needs, organizational goals, and program expectations for the dementia program(s), organizational leads will want to determine program focus, intent, and delivery. Maslow (2012) offers several characteristics to consider:

- Type and stage of condition (e.g., Alzheimer's disease, other dementia, and early/mild, mid/moderate, late/severe)
- Where the practice/program can be delivered (e.g., home, office or clinic setting, nursing home, workplace)
- How the practice/program is to be delivered (e.g., in person, telephone, Internet, support group)

The choice of what the organization does is based on the purpose, funding, and partnership criteria or preferences of key stakeholders/leaders. That is why purpose and goals are so important to establish first. It is also important to understand potential competitors. What existing programs or services in the marketplace are similar or may be service substitutes? Look for existing memory programs and investigate what other organizations are offering. How might the dementia program of this aging services provider be differentiated?

Step #2: Identify Necessary Infrastructure/Inputs

The manager will need to research and define all of the necessary components and infrastructure, what it takes for the organization to offer the chosen dementia program(s). This may include one or all of the following:

- Personnel (staff with specific clinical or educational background, or with specific training, skills, etc., and sometimes trained volunteers)
- Additional training and skills development using a set curriculum
- Certification/testing with recertification requirements
- Clinical monitoring or oversight by an expert
- Information systems with specific database or computer application programs

- Written and audiovisual materials and other physical resources (e.g., program workbooks, DVDs, CDs, art supplies)
- Meeting room space and other equipment or facilities (e.g., computer, projection equipment, Wi-Fi access, sound system)
- Travel time/mileage reimbursement for staff/program volunteer to provide the service
- Additional professional or business insurance, fidelity bonding, legal review for contracts or agreements, and other corporate costs arising as a result of the dementia program

Step #3: Learn From Others

It is wise for program designers to learn as much as possible from other organizations that have successfully implemented the chosen dementia program(s). This information will help the manager address hurdles that are not easily anticipated. An organization implementing its first dementia program will face additional startup issues as compared to an organization that already has a set of programs for persons with dementia and their caregivers. Operational issues in program implementation might include the following:

- Lack of leadership around partnership and collaboration to build linkages and funding relationships
- Difficulty balancing staff workload; staff deployment; dependency on one or two trained staff members (leaves the program vulnerable to staff turnover)
- Need for staff with different background/education/skills than exists within the workforce
- Initial and ongoing staff training needs around specialized dementia programs
- Need for ongoing and intense recruitment efforts to build demand, such as staff-dependent outreach, to reach end user participants or answer questions posed by possible referral sources
- Need for tailored communication and marketing in all formats (including using social media)
- Challenges arising from organizational issues, such as shifting or competing organizational priorities, budget cuts, internal approval processes, resource limitations, lack of necessary infrastructure (e.g., billing systems, electronic databases matching the data needs of the program)
- Resistance to using new technologies requiring additional administrative support time (e.g., required by a tailored database, new software or cloud-based electronic data and information management systems), or new hardware (e.g., tablet or handheld devices for staff members in the field)
- Need for easy-to-follow fidelity monitoring methods (for evidence-based programs)

Lessons learned from implementation pilots and demonstrations of evidence-based dementia programs are available. For example, the experience of more than 60 grantees of the *Alzheimer's Disease Supportive Services Program (ADSSP)* grants is presented in the ADSSP Completed Grants Final Report (Gould et al., 2014). This report presents information about the dementia

program components, implementation activities, partners, populations served, and fidelity monitoring used (as in the case of evidence-based programs). There are in-depth case examples from program implementation providing practice-based information about program components and operations.

For example, a process evaluation of Minnesota's implementation of the New York University Caregiver Intervention (NYUCI) across 14 program sites offers lessons related to the importance of external and internal factors. The implementing sites were located in metropolitan, suburban, and rural areas. Most did not have preexisting services for people with Alzheimer's disease and dementia care partners, but almost all had existing programs for older people and caregivers. Challenges in implementation for these program sites included the amount of time needed for required training and ongoing oversight to maintain fidelity to the protocol, the difficulty in recruiting participants—despite the extensive time the trained staff member spent in personally pursuing many avenues to increase visibility and referrals—and the lack of a reliable funding source to support the cost of the program (Paone, 2010, 2014). These challenges, particularly recruitment and funding, affected sustainability (Gould et al., 2014; Paone, 2010, 2014). Ways that delivery organizations, AAAs, and state offices have addressed these challenges since that implementation experience have included streamlining the data collection tools and training requirements, adding information about the program and where to find providers on the state's website and database, and including the program as an option under National Family Caregiver Support Program (Title III-E of the Older Americans Act [OAA]) funding.

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Chapter 3: Funding Strategies and Considerations

Key Questions

1. What financial strategies can be derived or explored for dementia programs?
2. What are two basic considerations in evaluating revenue sources?
3. What calculations need to be performed to build a budget and service forecast (a financial plan) for the dementia programs?

Financial Strategy Defined

Determining the financial strategy for how the program will be funded is an important part of the business plan. Aging service providers typically rely on a mix of revenue sources including federal and state service contracts, Medicare, Medicaid, grants, individual donations, corporate contributions, fees for services, and endowments or investments.

Advice to nonprofits in developing a strong funding model includes the following (Foster et al., 2009):

- Begin planning for sustainability immediately, in the earliest stages of program development.
- Have clarity around goals for the funding model and the programs that the organization is committed to offering. For example, the organization may not expect the program to break even but act as a feeder to other revenue-producing programs.
- When building the funding model, focus on possible funder motivation and incentives and funding sources.
- Investigate all possible funding sources, even beyond those already tapped by the organization. Allow time to become familiar with possible financing sources. Seek advice from public and private funders, experts, and third-party payers.
- Reflect on the organization's strengths and weaknesses of current approaches to funding.
- Have a well-developed financial plan.

Step #1: Consider Revenue Sources

Organizations should consider specific factors when evaluating potential revenue options, such as the *reliability*, the *autonomy*, and the *size* of the source of funds (Pratt, 2004). Providers should consider each possible funder/payer for the dementia program and evaluate that source based on the following:

- What is the reliability of the funding source (high, medium, low)? High reliability provides advantages for planning and is desirable.
- What is the effect of the revenue source on organizational autonomy (high, medium, low)? Government benefit programs usually have compliance requirements;

organizations need to be prepared for these requirements including additional oversight and reporting.

- What is the likely to be the largest source of funding? For example, in low-income areas, Medicaid may account for most of the potential funding.

Many sources of funding can be explored, including the following:

- Government Funding
 - Federal Service Contracts and Grants—grants, service contracts, or agreements (e.g., federal OAA Title III-E funds for caregivers support services, ADSSP and ADI-SSS grants)
 - Federal/State Insurance Programs—Medicare or Medicaid reimbursement for eligible services (fee-for-service, managed care, bundled payments, etc.)
 - State/County/Municipal Programs—state discretionary funding for caregiver programs or behavioral or mental health services
- Philanthropy
 - United Way
 - Private foundation grants
 - Nonprofit foundation grants
 - Individual giving
 - Corporate charitable giving programs
- Corporate or Health Network Service Agreement
 - Corporate/Business—establish a service agreement or contract with a company to provide dementia program education or caregiver services as part of an employee assistance program, employee wellness program, or the corporation’s workforce continuing education and training
 - Health Network—establish a service agreement or contract with a health care system as an approved provider of caregiver consultation and support and dementia care education/training
- Private Pay
 - Individual—bill individuals receiving care/support at full or reduced cost, offering a sliding fee scale
 - Insurance—bill insurance for services as an approved service provider for eligible services under an individual’s long-term care or health insurance policy

Step #2: Build a Budget and Service Forecast

To be viable (at a minimum) over the long run, the sum total of revenues earned or received by the organization must cover expenses. To evaluate the potential viability of a dementia program, the organizational manager builds a budget and service forecast. Assuming that the organization has a variety of service lines that it offers to clients/consumers, the dementia program budget can be developed to cover *all* of its own programmatic and distribution costs or to be *part* of an overall package of services. In this second case, the dementia program funding may be less than or more than its direct and indirect costs. Leaders and managers will want to *make explicit their assumptions and expectations* about where the dementia program will land among these financial scenarios. In other words, leaders in the organization determine financial goals. The dementia program may:

- Be a *loss leader or flagship program*—where revenue sources do not cover funds, but the program is of such significance that it ties to other related services that are fully funded
- Bring in enough funds to cover *direct* costs
- Bring in enough funds to cover *direct and indirect* costs
- Attract funding beyond that which is required to cover direct and indirect costs (offer a surplus), to allow the organization to *build reserves* or cover costs of other programs/ services that do not have adequate funding support

The dementia program may be one of several programs and services offered by the organization. If it has more than one caregiver or dementia service, the manager will consider how all of the programs relate to one another. By being purposeful in creating this dementia program menu, the organization can more effectively build competency and maximize efficiency. It also offers the opportunity to cross-market the programs and offers more choices to potential referral organizations and partners.

Management will need to estimate and then track the direct and indirect costs of each service and the dementia/caregiver program as a whole. A forecast of service utilization and calculations about rates and service volume by payer will be used to compare to actual experience. The goal is to predict, as accurately as possible, whether the dementia program menu as a whole (or each individual dementia service) can cover the total costs needed to operate these programs.

Building a Budget and Service Forecast

Building the budget and service forecast for a dementia program involves conducting a thorough cost analysis and making informed estimates about service capacity, service volume, and payment sources. Using an example that was crafted for this Toolkit, we walk through seven steps for building the budget and service forecast for a dementia program. This dementia program is one that relies on a trained social worker to provide consultation, education, and guidance to persons with dementia and their caregivers. Steps are:

1. *Calculate costs* (direct and indirect, fixed and variable) of the program/service, and a *cost per unit of service*
2. Estimate service/program capacity
3. Calculate total *dementia program cost* to the organization
4. Understand the *potential service payment rates*, by payer source
5. *Evaluate referral sources*—estimate referrals per unit of time (e.g., month) by source
6. Set up scenarios using different estimates for *demand/volume by payer source*
7. *Finalize* budget and service forecast

Example—Aging Services Organization A

As an illustration, let us assume that Aging Services Organization A is implementing a dementia program that involves an upfront investment (fixed costs) of \$12,000 for training, online electronic database access, and licensure. The centerpiece of this exemplary dementia program is a trained expert licensed social worker who provides caregiver counseling, information, and referral and family meetings, and sets up an action plan with trigger points for follow-up. This particular program requires multiple interactions with the caregiver and family. It is evidence based; therefore, the consultant must follow a protocol with specific service components and data collection/reporting requirements.

We begin with three assumptions:

- The dementia program is consistent with the strategic direction and service complement of the organization (i.e., is part of a set or menu of programs and services focused on caregivers and persons with dementia offered by an organization).
- The organization can fund the startup costs to build the key components and capacity of the organization to launch the dementia program (e.g., through grants, reserves).
- Direct and indirect costs, service units, and referral sources can be tracked; for example, participants in the dementia program will be asked how they came to find out about and use the program (e.g., through referral from a health care or social service agency, friend, or through self-direction).

Step 1: Calculate Costs and Cost per Unit of Service

The first step the manager needs to take is to calculate or estimate direct and indirect costs of the dementia program.

Direct and Indirect Costs

The program costs such as staffing (including fringe benefits), workbook materials, and mileage to clients' homes are direct costs of the dementia program—that is, they arise only because of the program. Some costs will be incurred by fidelity to an evidence-based protocol. As an example, in the translation and implementation experience of the NYUCI program in Minnesota (2008–2012), each organization was required to have at least one trained memory care consultant. As part of the program protocol, the consultant:

- Conducted multiple in-home or in-office assessments of the primary caregiver through one-on-one visits, using a designated set of validated instruments
- Entered the assessment data into a state-mandated database system
- Facilitated family meetings—up to four family sessions
- Responded to calls and e-mails when questions or concerns arose
- Provided information and referral to supportive services

All of the expenses arising from the consultant's direct service, and his or her travel time to clients' homes, the consultant's data entry of the assessments, and his or her participation in required training/certification and clinical monitoring, were direct costs of the program. In addition, the consultant was expected to conduct the marketing and outreach for this specific program. Thus, the outreach time spent by the consultant and the promotional materials were also direct costs (Paone, 2010).

Other costs are indirect, such as the overhead costs for the organization's day-to-day operations. Rent/lease costs, utilities, and use of shared office equipment are examples of indirect costs. Additional indirect costs may include advertising or marketing/communication costs, to the extent that these are not associated solely with the dementia program. However, if the outreach and marketing strategy for the program depends on the dementia program staff, then these costs (staff time) should be included as direct costs.

Fixed and Variable Costs

Fixed costs are those that the program will incur regardless of volume or number of units of service produced. For example, the purchase cost of software that must be used to offer a licensed evidence-based program is a fixed cost. The purchase happens before the program sees any clients and is not dependent on the number of clients served. Regular salary costs are also fixed costs, although some of those costs may be covered by other program revenue, to the extent that the staff person's time can be shifted to these other programs. If the staff person is hired only for the dementia program (e.g., half-time occupational therapist hired for in-home didactic instruction and skills development of caregiver), then all of those costs are fixed costs attributed to the dementia program. Required training and certification costs for the staff person to meet the preparatory requirements of a dementia program (e.g., to be a certified trainer or instructor/facilitator, coach, or consultant) are also examples of fixed costs. The cost of printing fliers for a given program is another example of a fixed cost—the fliers have to be printed and distributed before any client is served. All of these types of costs (training, certification, and printed materials) have to be incurred before even one unit of service is provided by the organization.

Variable costs are costs that vary based on volume or units produced. Examples of variable costs include mileage costs for travel to a client's home (if no clients, no mileage costs incurred), meeting room and snack expenses (e.g., for support group and workshop classes), and supply costs where the supplies can be purchased in small units, based on service volume.

In our example, Organization A employs three licensed social workers in aging and caregiver services, but only one FTE is available for and trained in the specialized dementia program. To begin the calculations to create a budget and service forecast, the operations manager works down from 40 hours per week (52 weeks or 2,080 hours per year) to determine the time available for direct service.

There are hours devoted to other required non–dementia-related administrative and service activities that have to be performed by that social worker because she is a part of the organization (e.g., attending staff meetings and required trainings or continuing education, documenting progress notes in the database). She must do these things whether the dementia program exists or not. The paid time off, holiday, sick, and other leave of the social worker also must be subtracted from the total hours available.

In our example, this results in 20 hours per week available for the dementia program. This is the maximum amount of time/capacity that is available to produce the total units of service (defined as completed client experience) for this dementia program by Organization A. The manager could hire a second part-time social worker as well, but first calculates a budget and service forecast based on the one half-time social worker.

The social worker's salary is \$31 per hour inclusive of 22% benefits (\$64,480 per year). She is allocated half-time to the dementia program (20 hours per week), thus the organization is allocating \$32,240 of salary costs to the dementia program in year one (direct cost, considered "fixed" for year one). In this simplified example, the *total direct fixed costs* estimated for this program are \$44,240 to be "up and running." This includes the fixed costs of a required online database, program licensure, and the costs of training (\$12,000), together with the salary and benefit costs.

Other *variable* direct costs that will come into play for this dementia program include mileage costs and client materials. Reviewing current client records, and calculating that the social worker will do only one home visit per client but may have additional travel costs, the manager estimates a cost of \$58 per client for mileage (.58 per mile, 100 miles per client). Client educational materials that are printed/mailed are estimated to come in at a total cost of \$25 per client over the course of the experience.

In this example, the manager of Organization A includes as indirect costs the following: allocated overhead expenses of a portion of the administrative support staff member's time (e.g., 5 hours per month), some portion of the supervisor's time (1 hour per month), a portion of the IT data support team time (5 hours per year), and a proportion of the office rental/utilities and some risk management/insurance costs.

Cost Per Unit of Service

To reach an estimate of cost per unit of service, the manager needs information about how much time it takes to produce a complete caregiver program experience, as defined by the intervention protocol. The manager and social worker consider the activities that will be performed by the social worker, such as telephone consultation, in-person assessment, data entry, creating an action plan with the client, providing follow-up information to the client, and connecting that person to additional services. They take into account factors such as travel time, charting, or training that the staff member(s) will have to spend in related activities.

For illustration purposes, assume that the total time to serve one client is estimated to be between 12 and 20 hours. The manager chooses to use the estimate of 20 hours to create a conservative budget where she can feel confident that the resources required to produce the full “client experience” will be available.

The manager calculates the direct costs (taking into account salary/wages, materials, average mileage, etc.) to be \$703 for serving one client if each full client experience takes 20 hours. The indirect costs of administrative support time, a portion of utilities, data support, and supervision costs are all allocated proportionately (i.e., based on total staffing allocation). Note that these are fixed costs to the organization and do not vary by client.

However, in this startup year, the organizational leadership decides to treat the overhead and administrative costs as variable *to this dementia program*. Management decides that a cost of \$2 per hour for overhead will cover the indirect expenses that are reasonably allocated to the dementia program. By charging \$2 per hour to the program versus a set overhead fixed cost, these allocated expenses are treated as variable and thus go up or down based on volume of service units produced. In our example of Organization A, at a 20-hour of service program, the manager estimates the total cost to produce an “average” unit of service (which is the completed experience for that caregiver) to be \$743 for this dementia program. This includes \$703 of direct costs and \$40 of allocated overhead costs. This is the baseline cost before additional fixed or variable costs are added.

Step 2: Estimate Service Capacity

The next step the manager takes is to estimate the service capacity that is possible within the department/agency. In addition to personnel costs, the other required resources needed might include meeting space, resource materials, audio-visual equipment, or other supplies. Usually the staffing component is the limiting variable. That is, given the available trained staff, how many units of service can be produced?

The manager should calculate a low and high end for the possible service units that can be provided in a given time period. The more that the program is multidimensional and stretched over weeks or months, the more variable the time commitment per client will be. The most tightly scripted programs are the easiest to estimate in terms of time required per client and are therefore more predictable in terms of cost.

The service and time commitment to serve a client/family (e.g., as for this counseling type of dementia support) for this type of program typically takes weeks if not months. For an ongoing

service such as this, rarely will the time commitment be for one or two interactions. In addition, not every client will require the same amount of time, even for the same service. Some clients will require more follow-up, counseling, and guidance than others.

In our example, the social worker has about 20 hours per week, but 4 weeks per year are for paid time off and for required dementia-specific training, leaving 960 hours per year dedicated to direct service for the dementia program. The estimated time commitment per client will be between 12 and 20 hours. Therefore, the total number of clients she could serve in a year would be between 48 and 80. The manager chooses to use the low estimate of 48 clients (960 total hours available divided by 20 hours per client). Because this is a new program, the manager is being conservative. She knows that it is almost impossible to start at full capacity. Moreover, developing a relationship with the client in this kind of service is important. Relationships take time, as does building outreach and program visibility. In addition, service intensity is not constant, even with the same client/family. Thus, the social worker with more clients may feel stretched and have less ability to take on new clients. There will be a gradual ramp-up in year one for this program. As part of building a budget and service forecast, the operational manager will offer volume scenarios for management to consider as they set program targets.

Step 3: Calculate Cost to Produce the Program

Using our example, the total costs to Organization A to produce this dementia program at a client volume of 48 individuals served in year one will be \$50,144. This figure includes the fixed direct costs (\$44,240) and the variable costs to serve 48 clients (\$5,904). Dividing the total costs by 48 clients, we have a cost per unit of service of \$1,045.

The manager creates various volume scenarios, calculating total variable costs while keeping fixed costs constant. At greater than 48 clients, the manager adds first another 0.25 FTE at 60 clients and another 0.25 FTE at 80 clients to account for the time commitment of 20 hours per client. This has the effect of raising estimated fixed costs by the salary level and training expenses for an additional social worker.

Table 2 provides a simplified example using the cost estimates shown for the dementia program offered by Organization A. Note that the cost per unit of service is highest at lowest volume. The lowest cost per unit of service comes in at a volume of 48 clients, where the half-time social worker is working at maximum capacity (if it takes 20 hours to produce completed caregiver experience). For more clients, the manager needs to add an additional half-time social worker and the program will incur additional training costs, which bump up the costs per unit of service.

Table 2. Organization A Dementia Program—Cost/Volume Scenarios at 20 hours per client

	10 clients	30 clients	48 clients	60 clients	80 clients
Fixed	\$44,240	\$44,240	\$44,240	\$60,860	\$76,980
Variable	\$1,230	\$3,690	\$5,904	\$7,380	\$9,840
Total	\$45,470	\$47,930	\$50,144	\$68,240	\$86,820
Cost per Client	\$4,547	\$1,598	\$1,045	\$1,137	\$1,085

Table 3 shows the same volume scenarios, but this time the social worker time per client is estimated to be 12 hours. Thus, the one half-time social worker can serve a maximum of 80 clients over the course of the year. No new fixed costs are added in. This substantially reduces the cost per client. With this cost structure, the dementia program can be produced at a cost of \$676 per client if the social worker has a maximum caseload of 80 clients.

Table 3. Organization A Dementia Program—Cost/Volume Scenarios at 12 hours per client

	10 clients	30 clients	48 clients	60 clients	80 clients
Fixed	\$44,240	\$44,240	\$44,240	\$44,240	\$44,240
Variable	\$1,230	\$3,690	\$5,904	\$7,380	\$9,840
Total	\$45,470	\$47,930	\$50,144	\$51,620	\$54,080
Cost per Client	\$4,547	\$1,598	\$1,045	\$860	\$676

Step 4: Understand Service Payment Rates, by Payer

What outside revenue sources are available to the organization to help pay the costs for this dementia program? For purposes of this illustrative example, let us assume that the targeted payers include (1) Title III-E OAA funds, (2) a regional health care organization that includes the program within its service network at a defined payment rate, (3) health insurance plus copayments from clients, and (4) private pay fees.

With the list of potential payers, the manager has to determine what these different payers will reimburse the agency for this program. The manager selects among the volume scenarios (she uses the scenario of 20 hours per client). She determines that the price point to meet or exceed is \$1,598 per unit of service. This is the cost at a volume of 30 clients. The manager and social

worker agree that at fewer than 30 clients per year, the program is potentially financially vulnerable; the organization's leadership likely might choose to discontinue the program if volume was under 30 clients.

So with this target, the manager evaluates each payer source. Although it is true that producing one dementia program "unit of service" will cost the organization from \$1,045 to \$1,598, this does not mean that every payer will cover that cost. The price tag may be too high for some payers. However, over the long run, without subsidy from the organization, the dementia program cannot provide service for a price/payment below cost for all or even most of its clients served.

Private Pay. Starting with the private pay/fee for service market, the manager begins to estimate what price point might be viable. In most areas of the country few clients would be willing or able to pay \$1,598 out of pocket for this dementia program. However, if this dementia service were covered as a benefit under the client's private long-term care insurance policy, it might bring the cost into reach for the consumer. For example, the insurer might provide a set payment for the client's care management and counseling services—let's say \$100 per day—and the insured client can show the service was provided over 7 days; then the \$700 payment from the insurance company together with a \$500 copay from the client would represent a combined payment of \$1,200. Organization A might accept this amount as payment in full. (The organization would have set up billing and payment guidelines and exceptions in advance to assist the manager or billing office personnel with how to handle discrepancies in payments compared to billing amounts, by payment source.) The number of clients with long-term care insurance may be small, but this could be a market niche that Organization A seeks to address as a target.

The manager will want to conduct some market research to get a sense of what payment rates are being paid for similar services in the area. A similar service would be one that involves the same type of practitioner, addresses the same problem or issue, provides equivalent service, and has produced similar outcomes.

For example, perhaps there are private home care agencies that have identified their social work expertise in working with caregivers of persons with Alzheimer's disease or dementia. These agencies charge a rate of \$180 per hour for their care manager consultation service (e.g., social worker or other practitioner). Clients, on average, use 5 hours of time at a total cost of \$900. If this service is seen as equivalent in the general layperson's mind, then the Organization A

dementia program will appear very expensive at \$1,600 per client. A way to differentiate the Organization A program might be to describe the components of the service, explaining that at least 12 hours of social worker time is involved and sometimes as much as 20 hours. Potential customers will quickly calculate that the cost from the private home care agency for that level of social worker time would range from \$2,160 to \$3,600, making the Organization A dementia program look like a bargain.

Service Contract. For a service network contract arrangement, the payer (Health Care entity) and the aging services provider (Organization A) will negotiate a payment per unit of service. The dementia provider will want and need to research payment rates that are being offered for these similar services in the area (if they exist). If no service contracts exist in the region for similar services, then the organizational manager will need to look to other regions. Any information about rates for a similar service can be helpful in negotiating a reasonable rate.

Assume that Health Care Entity B has negotiated a rate with Aging Services Organization A to provide service to up to 20 clients at a payment of \$1,800 per client, not to exceed \$36,000 for year one. For this payer, Organization A will experience additional costs to execute a business associate agreement and service contract and to enter data via a secure remote access system that this payer requires. So there will be some additional administrative costs. Despite determining that this will add \$2,500 to upfront costs, leadership from Organization A decides this is still a good course of action, because it is building the revenue sources for longer term sustainability and because this provider partnership is strategically important to Organization A.

OAA Funds. Organization A is an approved provider of Title III-E Caregiver Support services. The organization serves about 240 caregivers per year who qualify for Title III-E and receive services such as caregiver counseling, information, education, respite care, and assistance with access to needed services. The Organization A dementia program fits the service definition of an approved service under Title III-E. Organization A has to comply with the allowable costs and the 25% match of provider to federal funds that is required for Title III-E providers. In this case, the maximum the organization can receive per hour of social work time is \$85. Based on the estimated hours of service that would be provided to the average caregiver (between 12 and 20 hours), the total expected payment from OAA Title III-E is between \$1,020 and \$1,700 per client served. An average rate of \$1,500 is chosen for this payer. Again the manager notes that there are additional administrative costs to use a national database required by this payer. In addition, Title III-E providers are paid quarterly, following the quarter in which the services were provided. Therefore, the OAA Title III-E funds will be received up to 4 months following

the date of service. Despite these administrative challenges, leadership from Organization A recognize the value of participating in Title III-E to the market and to the organization. They determine that the OAA payment will be sufficient to cover costs of producing the program for caregivers under this funding source.

Step 5: Understand Potential Referral Sources and Estimate Volume

The next part of this equation is to estimate demand, which will drive actual service use. To do this, it is best for the manager to look at historical service utilization and current client service patterns. From where do clients come? How do they get referred or self-refer to the program? Are new patterns emerging? It is also wise to investigate the use patterns of other organizations offering similar programs. The actual experience of these organizations, particularly if they serve a similar population (e.g., they have similar geographic, demographic, and other market characteristics), is useful in setting estimates of demand.

For example, assume that the aging services provider (Organization A) examines its existing caregiver support and social work counseling services. It determines that most referrals (e.g., 20 per month) come through word of mouth (e.g., from past clients) and many qualify for Title III-E Caregiver Support. The manager then looks at a 1-month sample of clients served by the organization. Staff social workers who served these clients report that about half of them came to the organization with concerns about their loved one's memory loss and confusion. Thus, of the 20 clients served that month, 10 may have been candidates for the dementia program.

Based on discussions with the social workers and previous experience with client use of services, the manager determines that of the 10 possible dementia caregivers per month under Title III-E funding, only 2 are likely to use the program. The manager uses this to estimate that about 20 clients will likely use the program in year one.

In this way, for each referral source, the manager builds a sense of what volume could be expected for the dementia program. For the Health Care B service contract, the manager realizes that reaching 25 clients in year one with physician referrals will be ambitious and estimates that a reasonable target to set will be 15 for year one.

The manager can set up volume and payment scenarios, changing the mix of payer sources and volume projections to create a high and low end estimate of what type of demand will be expected for the dementia program. In our simplified example, the manager has set forth expectations for four possible payer sources and volume expectations as shown in **Table 4**.

Table 4. Organization A Dementia Program Payer Rates and Expected Volume, by Source

Payer Source	Expected Year One Volume	Potential Rate
#1—Older Americans Act Title III-E	20 clients	\$1,200 to \$1,700 (choose \$1,500)
#2—Health Care B Service Contract	15 clients	\$1,800
#3—Blended Insurance/Private Copay	3 clients	\$1,200
#4—Out of Pocket (discounted)	2 clients	\$1,000
Total:	40 clients	—

Step 6: Calculate Break-even Point(s)

The break-even point for a program is the level at which the volume of units of service produced at a specific price point (payment rate) covers the expenses to produce the service after which additional service units produced provide net revenue after expenses. (Note that this is true only up to a point; given staff capacity, eventually additional fixed costs have to be added to serve more clients, that is, another trained social worker).

In our example, the manager adds in the additional upfront administrative costs that will be required to work with the different payers and recalculates cost per client. **Table 5** shows that the manager has added in additional fixed costs that will be required to work with the payers. Thus, at 20 hour per client for social work time, the dementia program costs from \$1,117 to \$1,713 per client.

Table 5. Revised Costs per Client, by Volume—Year One

Volume:	30 clients	40 clients	48 clients
Fixed—Includes additional upfront costs which have been added to comply with payer requirements	\$47,690	\$47,690	\$47,690
Variable	\$3,690	\$4,920	\$5,904
Total Costs	\$51,380	\$52,610	\$53,594
Revised Cost per Client	\$1,713	\$1,315	\$1,117

The manager then calculates net revenue by payer source, using the assumptions about volume and price, by payer (**Table 6**).

Table 6. Net Revenue Gain/Loss, by Volume With Payer Source Assumptions

Volume:	30 clients	40 clients (expected volume)	48 clients
Fixed—Note that additional upfront costs which have been added to comply with Payer requirements	\$47,690	\$47,690	\$47,690
Variable	\$3,690	\$4,920	\$5,904
Total Costs	\$51,380	\$52,610	\$53,594
Cost per Client	\$1,713	\$1,315	\$1,117
Payer 1-OAA	18 clients @ \$1,500	20 clients @ \$1,500	25 clients @ \$1,500
Payer 2-HC B	10 clients @ \$1,800	15 clients @ \$1,800	18 clients @ \$1,800
Payer 3- Insurance + Copayment	2 clients @ \$1,200	3 clients @ \$1,200	3 clients @ \$1,200
Payer 4-Client	No clients	2 clients @ \$1,000	2 clients @ \$1,000
Total Payment	\$47,400	\$62,600	\$75,500
Net Gain/Loss	(\$3,980)	\$9,990	\$21,906

As shown, the program break-even point with this payer mix and this cost profile is between 30 and 40 clients served—about 34 clients. At the expected volume of 40 clients—averaging 20 hours of social work time per client and assuming this payer mix—the program has net revenue of almost \$10,000. At 48 clients, the program has net revenue of almost \$22,000. Note that if most clients who came to the program were covered at the rates shown by Payer 3 (insurance plus copayment) or Payer 4 (Private Pay Client), then the program would hardly produce any

net revenue or might lose money. Even at full capacity for the one .5 FTE social worker (48 clients), the payment rates for these two payers are low as compared to costs borne by the organization to produce that unit of service.

Step 7: Finalize Budget and Service Targets

The final step is to finalize the budget and service targets. In our example, the manager uses the revenue and expense estimates and the payer mix and volume assumptions. This analysis becomes the blueprint against which the program is measured and assumptions checked. The more that the demand/volume, operating costs, or payments received vary from the estimates, the more that the program's performance will vary. The manager may wish to set parameters for making mid-course corrections on the program if actual experience greatly deviates from the ranges that have been set. The volume of services delivered, the units by payer source, and the cost per unit of service are some of the metrics that determine whether the dementia program is viable. Each year of service provision provides more data points from which the manager is able to make more accurate forecasts. As data are collected about costs to produce a unit of service, volume by payer, and payment rates, the original assumptions made can be tested and revised. The manager will present this information to organizational leaders who determine whether it is worth continuing to offer the service. This assessment goes back to the business and financial model expectations and needs of the organization.

Case Example #2: Funding Strategies for a Dementia Program:

Aging and Adult Services Agency, Department of Health and Human Services, Michigan

This example highlights the *Creating Confident Caregivers*® Program in Michigan. It is based on a key informant interview conducted in July 2015 with Sally Steiner, Project Director, and Scott Wamsley, Division Director, Department of Health and Human Services, and information from ADSSP Grant (#90AE0341) and the *Michigan State Plan on Aging (2014–2016)*.

Background

The *Creating Confident Caregivers*® Program is the name used in Michigan for the evidence-based Savvy Caregiver Program (designates the implementation with state monitoring and oversight). The Savvy Caregiver Program was developed by researchers Kenneth Hepburn (formerly with University of Minnesota, now with Emory University) and Carey Wexler Sherman (Institute of Social Research, University of Michigan). The *Creating Confident Caregivers* Program delivers the Savvy Caregiver program using the manual, audiovisual and printed materials, and ongoing training, assistance, and fidelity oversight. The program is provided in six, 2-hour weekly sessions to caregivers of persons with dementia living at home. The program is provided by a trainer who has completed an approved training program.

Discussion

The discussion focused on the following:

- Funding options explored
- The budget and funding strategy used for the dementia program
- Assumptions made
- Conducting a cost analysis
- Financial sustainability and lessons learned

Funding Options

From the beginning, sustainability was our goal. We used the RE-AIM framework (Reach, Effectiveness, Adoption, Implementation, and Maintenance) to guide our program development and implementation. The AAA directors were encouraged to use National Family Caregiver Support Funds, including Title III-E dollars. The Administration for Community Living put out a transmittal to focus on evidence-based programs for Title III-D health promotion dollars, and the state of Michigan approved the use of these funds for the Savvy Caregiver/Creating Confident Caregivers program. The good news is that Michigan already had a strong history of implementing evidence-based health promotion programs.

The State of Michigan offers caregiver support funds in addition to the OAA dollars available. This is an important source of funding for these programs as well.

Private pay fees were never part of our model. With the federal funds, we do not charge caregivers. Of course through the OAA, a voluntary contribution is allowed. However, our programs have not built this in as part of their formal funding model.

Initially there were six AAAs involved. Then this expanded to all 16 AAAs. Fifteen AAAs are still offering the program. They see this as part of their normal funding model now, and this program is embedded within their caregiver services and health promotion programs. Some AAAs tried sponsorships (e.g., to do a program at the corporate office, or with underwriting from a business). However, such arrangements had limited success.

Chosen Budget/Funding Strategy

With regard to the budget development to support the grant program implementation and expansion of Creating Confident Caregivers®, each partner AAA developed its own project budgets during the proposal phase. Each AAA met the match requirement for the federal funds they received. We compiled the AAA budgets to create the overall project budget.

Cost Analysis

We conducted an analysis across the AAA program sites. In general, the direct costs were very similar across the sites. Under the grant funding we had to very carefully track costs. Going forward, while we continue to track funds and services provided, this level of cost tracking detail is not necessary.

We did look at the cost components. Staff time is the biggest component. The caregiver manual costs about \$20 per copy. There are session costs, handout materials, and supplies. Some AAAs do include a statement on their marketing that donations are welcome; however, that is not a sustainable funding source. We think the program should not be fee-based.

Financial Sustainability and Lessons Learned

Under the service definition, AAAs can use state caregiver funds, Title III-B, D, and E funds. Most AAA directors indicate that they are using a mix of these sources. Some use local millage funds. Having the service definition include this evidence-based program is key to financial stability. Those sources of funds will cover program costs.

The bigger issue for us in terms of sustainability is capacity—of trainers, program fidelity monitoring (done at the state level), and recruitment to fill classes—especially in remote areas of the state. Some AAAs have high program demand, while remote areas have high need, but low numbers. Staff turnover is unavoidable. Word of mouth is the biggest referral source—those who have taken the class tell others.

Our approach has been to play to the AAA strengths and determine with them what works best with their service approach and their regional needs. This program was very congruent with the AAA strengths and approach. The local budget control also played to their strengths. They know what it takes, what is needed operationally. The local implementation of this program was very important.

I feel we're sustainable. The program is embedded and there is local control and ownership.

Just since 2008, we've served nearly 5,000 caregivers, 10,000 if you include the person with dementia. That is success.

Chapter 4: Marketing

Key Questions

1. What is marketing?
2. Who are the customers?
3. What is the distribution channel?
4. What are marketing and outreach methods?
5. What marketing considerations arise when operating within partnership agreements?

What is Marketing?

Marketing is defined as a function of planning, pricing, promoting, and distributing the organization's programs and products (Kotler & Andraesen, 1991). The benefits of good marketing include (Holland, n.d.):

- Greater consumer satisfaction
- Increased consumer participation
- Better attraction of resources
- Stronger donor, staff, and volunteer loyalty
- Greater efficiency and effectiveness of services
- Stronger organization

The marketing and communication strategy for the dementia program must be developed with the business model, program focus, and funding model in mind. Because marketing and outreach takes time and money, the organization needs to decide where to allocate resources that will maximize referrals to the dementia program. The marketing must also differentiate this program from others that may be potential competitors in the marketplace so that consumers will choose this organization's services.

Step #1: Clarify Who the Customers Are

The end user of the dementia program is the person with the disease or the caregiver, such as a spouse, adult child, or live-in friend. However, there are many other potential customers (intermediaries) who may be the actual purchaser of the service or who are key constituents in getting the service to the end user. These purchasers or payers often influence who will be served, when and how that service can be provided, and what can be offered to the person and caregiver. The dementia provider organization needs to consider both the end user and these intermediaries.

Casting the net widely, the target audiences could include the following:

- The general public who are potential end users of the program (caregivers and persons with dementia and their families, friends, and colleagues)
- Professionals from potential referral sources and businesses providing health care or related products and services
- Staff members from elder advocacy and voluntary health organizations (e.g., Alzheimer's Association, Parkinson's Society, Stroke Association)
- Staff in regional or statewide helplines, ADRCs, or AAAs
- Those in helping or counseling professions, such as leaders from faith communities, therapists, or counselors
- First responders, such as emergency medical technicians, paramedics, fire, or police

Step #2: Understand the Distribution Channels

The program will need to consider the distribution channels—the potential pathways through which the person with dementia or caregiver and the service are connected. The intermediaries, such as payers or other providers, are part of these distribution channels. The manager will want to understand how caregivers and persons with dementia are most likely to find and access the dementia program and how professionals and others refer people to programs.

To map out the possible distribution channels, the program manager will need to investigate how people with dementia and their caregivers seek, find, and use dementia programs. Although there is some information in the literature about this pathway from identification of need to service use, the best source of information may be the organization's own staff serving older people and caregivers. If the dementia services provider is a member of a larger partnership or network, these collaborator organizations also can offer information and insight about these distribution channels and how people seek care.

The journey of care seeking to care finding can be a long one. There is not a clear path from the time the family or person with dementia identifies issues with memory loss/confusion to the time they receive help. Delays of years between noticing symptoms and seeking help are not uncommon. There are many reasons for this delay. Symptoms are not often recognized in the early stages of the disease. There may be denial that anything is wrong. Out-of-town family members may not be aware of changes in daily living or cognition. If there are indications of mild memory loss or confusion, family members may believe they are part of normal aging or because of fatigue.

Unfortunately, even once the person or family member begins seeking a medical diagnosis related to the memory loss, confusion, or other symptoms, he or she may not receive a diagnosis right away. Many individuals with Alzheimer's disease or related dementia experience delayed diagnosis.

After the diagnosis, the person and family may be in a state of shock or denial and can be reluctant to make the call for dementia/caregiver supportive services, even when their physician has advised them to do so. Thus, the person and his or her care partner might go for months or years before learning about supportive dementia and caregiver programs. Likewise, the dementia service provider is usually unaware of who has dementia or who is a caregiver in his or her service area until that person seeks help. For all of these reasons, the person and dementia services provider remain separated.

Eventually, some individuals find dementia programs through informal and formal distribution channels. Typical referral sources for these types of programs include the following:

- LTSS system in the state/region (e.g., "Senior Help Line," ADRCs)
- Word of mouth—general lay public (e.g., family, friends, neighbors, and previous clients)
- Advocacy organizations and voluntary health organization serving target population (e.g., Alzheimer's Association, Stroke Association, Parkinson's Society)
- Professional referrals from general or specialty medical or social service organizations (e.g., primary care physicians or neurologists)

The dementia provider will need to consider how the person and caregiver work through or are guided within each of these distribution channels. Each referral source may need a different approach in marketing, communication, and outreach.

Long-Term Services and Support System—The LTSS system in each state represents an important way to connect older people or caregivers to a service provider. The LTSS system largely depends on ADRCs and AAAs to help direct people in need to the appropriate services. Many states have been working to ensure a "no wrong door" approach to their LTSS systems. Using such processes as online screening, telephone and in-person intake and assessment, and self-directed web-based database, information, and referral systems, consumers (or professionals acting on behalf of consumers) are provided with lists and summary information about programs and services for dementia and caregiver education, counseling, or other programs. To effectively use this system, the dementia service provider has to ensure that the list of services it offers is in the LTSS database and is accurate. Providers may be able to include information that helps differentiate their program from others (e.g., offering services on evening

and weekends, providing services by a master's-level clinician, offering services in several counties).

The LTSS systems are an excellent starting point for getting the dementia program on the radar within the state and region and for reaching consumers. However, the system has limitations and can offer challenges, especially from the perspective of the consumer (end user), who may be either the caregiver of the person with dementia or the individual with dementia. A study of policy and field experts notes that the weaknesses in the LTSS system may be particularly difficult for persons with dementia (Shih et al., 2014; Tilly et al., 2011).

Strategies that dementia service providers can use to address the limitations of the current system include the following:

- Offer open information and educational sessions about dementia, where the whole community is invited for building general awareness about dementia, caregiving, and the benefits of seeking help early.
- Assist callers by being attuned to the primary need of the caller and synthesizing information in useable, manageable pieces.
- Follow up with a call to check on the consumer within a week or two, triggered by follow-up alerts in a database.
- Assist the consumer with finding relevant resources that meet current needs and preferences.
- Build awareness of service substitutes, when a particular program is not available but there is another service that might meet the need.

Word of Mouth—Direct recruitment of older adults (including those with dementia) and caregivers to gain their participation in evidence-based programs has proven to be challenging (Frank & Lau, 2013; Gould et al., 2014; Paone, 2014, 2015; Woodstock et al., 2013). Typically, word-of-mouth referrals—from friends, family, neighbors, or caregivers' work colleagues—represent the top referral source for aging services providers. This distribution channel is unfettered and not formally organized. This channel requires a marketing and outreach approach that maximizes visibility throughout the community. The approach should target specific groups or locations (physical or virtual), to focus in on people who are more likely to need the dementia program or caregiver services. For example, hardcopy fliers or electronic updates that describe dementia support services could be included in electronic announcements or bulletin boards used by caregiver support group participants.

Person-to-person outreach has been found to be most effective in reaching caregivers (Navaie, 2011). Distribution by mail has been found to be the least effective method. Timeliness of

recruitment—that is, meeting the caregiver with the information and invitation at the right time (just when he or she has self-identified as requiring help)—plays a key role in success.

Families and caregivers may not know where to go to find services or may be uncertain about the type of services available. Use of advertising, blogs, social media, and other methods can draw the attention of a general audience and drive them to an agency’s phone number or website. However, caregivers frequently do not identify as such, and the person with dementia may be trying to avoid being labeled. Therefore, simply advertising the availability of a dementia program may not yield self-referrals. Building some basic understanding of the symptoms/signs of dementia, and general awareness of caregiver issues faced, may be part of marketing the program. In your materials, include brief descriptions of the dementia service purpose and how a caregiver or person with dementia experiences/uses the service. This can be helpful to caregivers—making the service more approachable and understandable.

Often it is adult children, other family members, or close friends who seek out information about the disease and services. Building awareness may include advertisements, articles, or videos and placing them in newsletters, on websites, and in other virtual communities—targeting information to those who are more likely to have recognized assistance is needed. For example, there may be advocacy organizations, employee assistance programs, faith community forums, or therapists/counselor sites that could include links to websites of local providers, provide service definitions and guidelines, or offer tips to assist caregivers as they seek help. Testimonials or short vignettes from caregivers speaking about how the program helped them during a difficult time may be especially compelling.

Health Care and Social Services Professionals—An important distribution channel is professionals working in the health care and social services sectors; those who are likely to come into contact with older people and families dealing with dementia. In many cases, physicians do not have the time to provide the education and counseling that people with dementia and caregivers need.

Step #3: Connect Marketing Methods to Constituents/Customers

As the organization prepares a marketing strategy for the dementia program, it needs to reach the intermediaries and end users of the program. This will require deployment of many strategies and a variety of methods intended to reach a number of audiences. Recruitment and marketing/outreach methods can include:

- Personal phone calls to existing clients
- Brochures/print pieces mailed to existing clients and distributed at caregiver meetings or other gatherings, conferences, and events
- Personal visits made to local clinics, hospitals, pharmacies, and local social service and home health care agencies (leave print materials and business cards)
- Materials offered through the local Alzheimer's Association chapter
- Written announcements or bulletins in newsletters, local papers, e-bulletin boards, websites of cities/towns, senior centers, advocacy organizations, faith communities, schools, local businesses, legal and financial planning firms, etc.
- Presentations at health fairs, local festivals, educational events, etc.
- Facebook and Twitter announcements and ongoing feeds
- Articles, feature stories, case stories in local publications, cable-access channels, blogs

Effective recruitment strategies for building enrollment of persons with Alzheimer's disease and their caregivers into clinical trials offers some insight into how these individuals are reached and why they decide to participate. For example, one study by researchers from the University of Kentucky compared recruitment methods for an Alzheimer's disease research study, including methods that directly targeted potential subjects (e.g., family and friends) and those that targeted primary care physicians. Greater recruitment success came from directly targeting potential subjects than from going through primary care physicians (Carr et al., 2010). In this case a community outreach health fair event was held where 14 research teams participated as exhibitors and provided hands-on activities that highlighted research studies and offered free memory screens. The event was advertised through a number of media formats: a local magazine, a local TV news program, the local Alzheimer's Association chapter, and through direct mail to 600 community members who were already on a university mailing list.

Tools and methods for designing ways to reach consumers and professionals include the following (Holland, n.d.):

- Focus group discussions
- Analysis of demographic and census data
- Key informant interviews
- Surveys of consumers, sponsors, and referral sources

The dementia provider should:

- *Plan* specifically what it will do, why, how, and when as it delivers the dementia program
- Identify and describe the *products* that the various constituents value
- Ensure that *prices* are acceptable and provide sufficient revenue
- Make sure that the *places* that the end user and intermediary use (the distribution channels) are easily accessible and user-friendly

- Develop a *promotion* strategy that has two-way communication so that the intermediaries and end users of the service realize the benefits of engaging with this program and provider

Attending to Culturally Diverse Groups—In many U.S. markets, the population is increasingly diverse in terms of ethnicity, culture, language, race, and religion. A marketing manager who is not a member of a specific group may not be knowledgeable about the nuances of how that particular group copes with Alzheimer’s disease or about their values, needs, and preferences. It is useful to reach out to local social service or advocacy organizations with staff members who will have firsthand experience as members of and service providers to these specific groups. Review of the websites of these organizations and personal phone calls and interviews may help the manager gain some understanding about values, beliefs, preferences, messages, terminology, and images that are positive and respectful.

Step #4: Be Aware of Special Considerations Within Partnerships

When operating as part of a larger network, the manager from the dementia program will need to comply with partner parameters set around marketing, outreach, and communication. Each of the partner organizations will have its own logo, branding, website, and marketing/communications strategy. The manager from the dementia program should understand any written agreements that pertain to these issues. The astute manager will also find out about the unwritten or implicit expectations that other partners may have regarding how the partnership is described or promoted in materials. In some partnerships, the dementia program may be seen as “co-created” or “co-promoted” where any written or electronic materials about the program must be developed jointly and approved by the participating organizations. Any time the partner’s name (or logo) is used, that partner will expect review and approval. Some partners may request specific terminology to be used. Others may want input when the media format is especially visible (e.g., a television or local news feature story). With some evidence-based programs, the intervention owner/license holder expects the program to be described in a certain way. They may offer templates for advertising their program to the general public. Connecting information via web-links across partner websites is another good strategy for cross-site awareness and promotion. These issues, strategies, preferences, and constraints should be discussed prior to launching the marketing plan.

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Chapter 5: Evaluation

Key Questions

1. Who are the stakeholders in evaluating the dementia program?
2. What are indicators or measures of success in financial and nonfinancial terms?
3. How will data be collected and analyzed?
4. How will the evaluation help the organization to meet its goals?

Why Evaluate?

Even with the best preparations, no business strategy is assured. Without a systematic evaluation using meaningful measures, the organizational leader or manager is hampered in knowing if he or she is succeeding. Evaluation should include more than financial metrics. It should include nonfinancial information that captures key stakeholder perspectives. An evaluation provides the information to determine whether the resources invested achieved intended results. Outlining the evaluation plan is the final component of creating the business strategy.

Step #1: Identify Stakeholders

It is very important to identify key stakeholders—those who the organizational leadership consider integral to the program’s success—before designing the evaluation plan for the dementia program. From a business perspective, these stakeholders must be satisfied with the program if it is to continue. These stakeholders could include the following:

- Clients (persons with dementia and their caregivers)
- Leadership from the implementing organization
- Staff members and volunteers
- Payers and “intermediaries” using (referring to) the program
- Other funders
- Partners and collaborative organizations where there are programmatic or strategic ties
- Policy makers in state and federal agencies
- Consumer advocates
- Researchers (particularly for evidence-based programs)

Develop the evaluation plan to ensure that the type of information needed from and for each of these stakeholders is gathered in a systematic way. This information from the stakeholders could be gathered through informal or formal means; the type of information may be qualitative or quantitative. Methods and data sources could include telephone conversations, in-person interviews, electronic or mailed surveys, consumer/client data reports (e.g., on client referrals,

by organization, market penetration), or financial data. The goal is to capture and analyze information in a structured way that provides a systematic assessment of the results of the business strategy. The evaluation of the business strategy should be both internally and externally focused.

Step #2: Select Indicators/Measures

When selecting indicators and measures, consider choosing a set that captures different components. For example, include structure, process, and outcomes of the program, and attend to the different domains or focus areas (e.g., financial, marketing). Set out your analytic framework for the evaluation to ensure that all important domains are included.

Indicators—The evaluation plan for the dementia program could include a variety of types of indicators and focus areas, such as:

- *Visibility/Awareness/Marketing*—How are the different marketing and communication methods working? What type of outreach and marketing is generating the most return?
- *Volume/Demand*—Have the service volume projections occurred as expected? Who or what organization is sending the most referrals to the dementia program? Are referrals coming from word-of-mouth/previous client referrals or from professional service providers? What is the overall demand for the dementia program?
- *Geographic or Population Target Reach*—What target population groups are using the program? Is the programming reaching intended special populations?
- *Services Delivered*—How many “units of service” are being delivered? Are there waiting lists? Is there excess capacity? Are different services being requested? Are there patterns of service delivery emerging (e.g., do caregivers want evening and weekend hours)?
- *Operational Efficiency*—Are there duplications, gaps, or extra steps or processes that can be eliminated to make service delivery more efficient, reduce administrative burden, and ensure that the highest cost resource (usually the trained professional staff member) is performing duties at the top of his or her license or capabilities? Are there tasks or steps that can be delegated to others?
- *Cost*—How do actual revenue and cost experience match projections? Is the program losing or making money for the organization? By how much?
- *Service Effectiveness and Consumer Satisfaction*—How effective is the service that is being delivered? Are consumers satisfied? Are results, such as reduction in caregiver stress/burden, being achieved? How is the program performing on the specific outcomes that payers and partners are monitoring (e.g., clinical, functional, quality of life, and utilization)?
- *Partner, Payer, and Leader Satisfaction*—Are the key partners and payers, and internal managers and organizational leaders, satisfied with the quality and service outcomes and with the administrative processes and efficiencies?

Measures and indicators of success could include the following:

- *Structural measures*—such as having a full complement of trained staff; having signed partnership agreements
- *Process measures*—such as how the direct referral methods are working with partners; marketing outreach response; staff workflows for the program showing efficiencies
- *Output measures*—such as the number of caregivers served; the number of caregiver workshops held; the number of client counseling sessions provided
- *Outcome measures*—such as consumer satisfaction; pre/post workshop knowledge scores from caregivers; reduction in caregiver burden; decrease in emergency room visits or nursing home placement

Step #3: Collect and Analyze Data

All evaluations are only as good as the data they collect. You will be collecting your own data or using data already collected by others. For example, you may conduct caregiver satisfaction surveys, and your collaborative partner (e.g., partner health care system) may collect information on the number of Emergency Room visits made by patients/clients using the dementia program.

Collecting reliable and valid data is hard. Many organizations do not invest enough resources into collecting usable data. It is important to make sure that the data collection has been thought through and that you are using valid and reliable measures. Think through each instrument (collection tool) and through each data source. Consider what is most valuable in terms of decision-making. Do not collect data first and then figure out how you are going to use these data. Likewise do not get to the end of your first year of operations without information to report to key stakeholders.

With regard to outcome data—for example, the effect of your program on caregivers or persons with dementia—data that are integral to the provision of services are likely to be more complete and representative of service users than are surveys administered thereafter. For example, data collected when counselors are speaking directly to clients are likely to be more complete and have a higher response rate than mail surveys sent after the end of the service. Surveys with low response rates raise questions about the representativeness of the data and validity of any analyses.

If possible, embed the data collection into program operations. For example, include validated depression or burden instruments in your caregiver assessment; add some kind of feedback incentive in your marketing outreach or in a post-program survey; ensure that referral source

information is gathered at every intake call by including a request for the referral source on the telephone script for staff who receive calls. You will, of course, also have regular financial reports from accounting. Ensure that the costs and revenue for this dementia program are being coded correctly, through having added specific items (for this dementia program) to the Chart of Accounts used by your organization. This one action will save countless hours going back through records to determine what was spent or received that is attributable to this dementia program.

Once the information has been collected, the data need to be analyzed and written up in a way that can be communicated effectively to the organization's management and other stakeholders. The financial data is probably the most straightforward, as long as revenues and expenses have been properly coded. Other quantitative data could include such items as number of referrals by date, by source; caregiver burden/depression scores; staff hours per client; zip codes of clients served; growth in referrals and referrals sources, by month.

Quantitative data can be entered into a spreadsheet program for analysis. For example, a spreadsheet that shows the referral source that each client caller reported to the staff member at intake, by date could provide information useful for gauging the effectiveness of marketing and outreach methods. The manager might notice a spike in calls right after a particular outreach method was conducted. In the same way, the data may reveal that one or two physicians in the community represent a large percentage of total physician referrals to the program. It would be worth finding out why these physicians have been referring so many of their patients—perhaps a follow-up telephone call with a few interview questions would reveal important insight.

Qualitative data, such as from focus groups or interviews with partners, will enrich the financial, service, and quality data picture to “get behind the numbers” and determine strengths and weaknesses of the business and service approach.

Step #4: Make Program Adjustments Based on Evaluation

Ultimately, the purpose of the evaluation is to assess the strengths and weaknesses of the business strategy and to make improvements in program operations, if needed. The evaluation provides information and data for adjusting or reaffirming the course of action that has been set for this dementia program. Thus, the results of the evaluation should trigger response on the part of the organization to review procedures and to address identified problems or to enhance and recognize those components that are going well. It also offers opportunity for increasing visibility and ensuring support by payers. For example, if outcomes are successful and have been

credibly measured, the positive results can be used to help market the program to third-party payers and clients.

Conclusion

The key message of this Toolkit is that the process of writing a business plan for your dementia program is an effective discipline that will serve you well. A business plan that is based on clear purpose and goals will provide the information and a structure that you can use to plan, implement, and evaluate your program. The process of researching the information needed and clarifying parameters for the dementia program will provide you with a better understanding of possible pitfalls and opportunities. It should provide you with the tools to make the dementia program more successful and likely to be sustained.

Key takeaway messages in the Toolkit are the following:

- *Know the organization's purpose.* Organizations have many competing claims on their resources. Why does the organization want to focus on persons with dementia and their caregivers? Why implement a dementia program? How will doing so affect the organization? What are leaders and stakeholders expecting from the program? How does this program fit into the organizational strategy, funding model, and vision?
- *Clarify goals for the program.* Yes, there are operational, funding, and other organizational goals for the program. Hopefully the ultimate goal relates to how this program will affect people living with dementia and their caregivers. Be clear about expectations and outcome/impact measures that address how the lives of people with dementia and their caregivers may be improved as a result of the program.
- *Understand your market—demand, payers, competitors.* Geographic areas differ in terms of population density, demographics, characteristics, and service availability. In some locations, services for caregivers and persons with dementia are few and far between. In other areas, there are already other organizations addressing needs. Does this dementia program fill an unmet need or does it seek to reallocate market share? Are there opportunities for partnering or collaborating to co-produce or co-market your dementia program? What is the organization's market niche? How is this dementia program going to be different?
- *Determine your input costs and set a budget and service forecast based on sound information.* To stay in business, the organization has to take in enough funding overall to cover costs. As with most programs, the dementia program requires certain personnel, materials, and other resources. When creating a budget, be sure you've accounted for direct/indirect and fixed/variable expenses. Investigate all potential sources of revenue and be explicit in your rate and utilization assumptions. Create service volume and payer source scenarios that have a range of values for these variables to allow you to calculate reasonable (fact-supported) targets. As you learn more about payer requirements, build in the lead time necessary to be sure you've met the requirements (e.g., certification of provider status with a provider number).

- *Use a marketing approach, and methods/media, that match the target constituents.* Organizations cannot assume that clients automatically will use the program’s services just because they are offered. Clients must believe that they need or want the services, know that the program offers the desired services, expect that they can afford the services, and determine that the benefits of obtaining the services outweigh the difficulties of doing so (e.g., travel, filling out forms, and involving a stranger in their personal life). Dementia programs often overstate the number of clients that they will serve, at least initially. Your marketing approach will address both the “end user” (persons with dementia and caregivers) and the “intermediaries” who refer to the program. A good marketing strategy has taken into account the distribution channels or pathways for having your dementia program reach the end user customer. Your marketing plan will have identified the types of media, messages, and images that best match these constituents.
- *Evaluate your strategy.* Without evaluating your business/service strategy in a systematic way, you will not know if you are reaching targets—program goals. In your evaluation plan, you’ve identified all of the types of data and information that you need to determine if the operational, funding, marketing, and quality monitoring approach has been successful. You’ve selected valid and reliable measures and selected methods to obtain data that balance resource constraints with the need for credible results. You have a sound way to analyze the data and present the results. Your plan includes communication and presentation to key stakeholders including organizational leaders. The evaluation provides the information needed to adjust the strategy, marketing, funding, service, or other components of this program. You can use the results to attract additional funders as well.
- *Plan for sustainability from the beginning.* Many programs start with short-term grants or seed money and then end when the grant money runs out. This start and stop programming is hard on staff, clients, and the organization’s viability. Planning for sustainability of the dementia program begins before the first client is served. It requires the planning work as described in this Toolkit and engagement of leadership. If the result of the examination is that the dementia program cannot be self-sustaining (cover its own costs), then that message has to be brought to organizational and other community leaders. There may be such interest and commitment to the issue of increasing dementia and caregiver programs that new collaborators, funding avenues, or advocates emerge. Better to engage these stakeholders upfront in the pursuit of sustainable programs than to wait until the program is in its last year of funding.

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Appendix

The following resources provide additional tools, learning opportunities, and information related to business planning. Although not all resources are dementia specific, the content is applicable to dementia-related interventions and systems.

Resources Chapter 1: Business Model and Partnerships

Training Resources

- [*Integrating Community Programs Within Health Care: Building an Infrastructure and Partnering to Scale and Sustain Self-Management Programs*](#) (Elder Services of the Merrimack Valley, Inc. and Hebrew Senior Life)
Provides an example of the funding and partnership components of the Healthy Living Center of Excellence, an innovative partnership between a community-based organization and a medical provider in Massachusetts. Presentation slides also outline some steps of marketing plan development.
- [*Partnerships: Key to Behavioral Health Service Success*](#) (National Council on Aging)
Webinar that serves as a companion to the *Partnering to Promote Healthy Aging* manual referenced below. Shares factors in developing successful partnerships and the benefits of these partnerships, as well as case studies.
- [*Developing Service Packages that Appeal to Healthcare Entities of Various Sizes, Shapes and Motivation*](#) (Partners in Care Foundation, 2013)
Offers an example of a service provider that developed programs and a new business model to better meet the needs of clients and partners. Presentation emphasizes offering broad, diverse product lines for the diverse needs of payers and providers, identifying clear roles and expectations, and using metrics to support initiatives and purpose.
- [*Nonprofit Sustainability Clinic*](#) (CompassPoint)
This slide presentation walks through a simple matrix of profitability and impact for evaluating the business model and programmatic options for the nonprofit. The matrix includes four quadrants into which a program could fall: Upper left—high mission impact, low profitability; Lower left—low mission impact, low profitability; Upper right—high mission impact, high profitability; Lower right—low mission impact high profitability. Examples of each type of program are provided.

Further Reading

- [*Older Americans Behavioral Health Issue Brief 1: Aging and Behavioral Health Partnerships in the Changing Health Care Environment*](#) (Substance Abuse and Mental Health Services Administration and Administration on Aging, 2012)
Issue brief covers key components for health systems that choose to partner with aging service providers and behavioral health providers in order to reach populations and link

to community-delivered evidence-based services with the ultimate goal of improving care coordination and reducing cost. Useful sidebars list “Key Actions: Lessons Learned from the Field”: checklists for Aging Services Network, Behavioral Health Services, and Physical Health Services.

- [*Partnering to Promote Healthy Aging: Creative Best Practices Community Partnerships*](#) (National Council on Aging, 2007)
Manual that serves as a companion to the *Partnerships: Key to Behavioral Health Services Success* webinar referenced above. Provides ideas and strategies for building state and local partnerships and features case studies of seven best practice programs. Key “lessons learned” and contact information are shared for each study.

Resources Chapter 2: Program Operations and Business Planning

Tools and Templates

- [*Business Plan for Nonprofits and Social Enterprises*](#) (Nonprofits Assistance Fund)
An outline of a business plan developed from a nonprofit perspective.
- [*Aging & Disability Resource Center Technical Assistance Exchange*](#) (Administration on Aging, Administration for Community Living)
Set of business planning resources developed for ADRCs but potentially useful for other entities developing and providing dementia programs. Samples and templates include an ADRC Business Plan Template (Lewin Group), and the Alaska ADRC Operational Guide that includes a useful readiness checklist and a critical pathways flow chart (depicting stakeholders, referral and intake pathways, and funding sources).
- [*Business Plan template*](#) (National Council on Aging, Center for Healthy Aging)
A companion resource to the *Creating a Business Plan* webinar listed below; provides a template for a business plan.

Training Resources

- [*Creating a Business Plan for Evidence-based Health Promotion Programs*](#) (National Council on Aging, Center for Healthy Aging)
A 36-minute webinar showing the process of creating a business plan. Topics include ways to use a business plan; contents of a business plan; examples of Return on Investment.

Further Reading

- [*South Carolina's ABCs of ADRCs Replication Manual*](#) (Aging and Disability Resource Center in South Carolina, 2007)
A comprehensive “How To” manual, including information on purpose and background; definition of terms; business planning; management/staffing; information systems; marketing; evaluation; lessons learned. Illustrates how a dementia program can fit into a larger system/organization. A useful appendix contains examples of work plans, job descriptions, marketing tools, surveys, assessment tools, and more.

Resources Chapter 3: Funding Strategies

Tools and Templates

- [*Considerations for Conducting a Cost Analysis*](#) (Paone & Associates, 2009)
Memo and worksheets outline the approach used to conduct a cost analysis for the NYUCI implementation in Minnesota. Assumptions and definitions are provided, and instructions for filling out the worksheets. Materials can be adapted.

Training Resources

- [*Financial Stability Module*](#) (Minnesota Department of Human Services)
Developed for agencies that provide older adult services, this training module provides a step-by-step process to achieve financial sustainability for the organization or program.
- [*Business Planning as a Tool for Financial Sustainability*](#) (National Council on Aging, 2011)
Webinar highlighting business planning examples from Illinois, New York, and Maine. The importance of building relationships with funders is emphasized. Other key points: Grants don't last forever; determine the minimum reimbursement to be viable over the long term; have an exit strategy if key milestones are not reached.
- [*True Program Costs*](#) (Nonprofits Assistance Fund)
This program budget and allocation template and webinar guides readers as they allocate costs and calculate the true costs of programs and overhead. The video tutorial provides an overview of the concepts and practices of program budgets.
- [*Financing and Sustaining Behavioral Health Interventions*](#) (Older Americans Behavioral Health Technical Assistance Center, 2013)
A companion piece to the issue brief of the same name listed under Further Reading below. This webinar has four separate presentations on sustainability: (1) "Strategies for Sustaining and Financing Evidence-Based Programs and Practices"; (2) "The Older Americans Act: Behavioral Health Funding"; (3) "Financing Older Adult Behavioral Health Interventions Through Medicaid"; and (4) "Financing Evidence-Based Depression Programs for Older Adults."

Further Reading

- [*Financial Sustainability for Evidence-Based Programs: Strategies and Potential Sources of Financing*](#) (National Council on Aging (NCOA) and Centers for Disease Control & Prevention (CDC))
A four-page issue brief that reviews potential sources of revenue. The prospects for financial sustainability are improved through partnerships, and with conscious effort, accountability, and the development of tailored approaches which take advantage of a state's unique strengths and opportunities.

- [*Financial Strategies and Business Models*](#) (Nonprofits Assistance Fund)
This topic within Nonprofits Assistance Fund’s online Resource Library includes business model definitions; the financial strategy and structure of nonprofits; how nonprofits are changing their financial strategies; and emerging models. Four core financial components are presented for designing a new funding and business model: (1) program costs, (2) infrastructure, (3) capital structure, and (4) revenue mix.
- [*Financing and Sustaining Behavioral Health Interventions*](#) (Older Americans Behavioral Health Technical Assistance Center, 2013)
A companion piece to the webinar of the same name under Training section above. Materials include resource lists, and case studies. Factors within the program, the organization, and the community are described for consideration, including program impact and fit; organizational capacity; and community support. Potential funding sources are also addressed.
- [*Lessons Learned on Sustainability of Older Adult Community Behavioral Health Services*](#) (Substance Abuse and Mental Health Services Administration and The National Council on Aging)
This report offers two valuable products for service providers and funders: (1) A sustainability framework listing the ideal features of a program, the organization, and the community. Each factor is categorized within the framework diagram and also explained at greater length within the report text. (2) A financial resource guide reviews public, nonprofit, and private funding sources and financing streams.
- [*Cost Analysis: NYUCI Intervention in Minnesota \(“Family Memory Care”\), Year 2*](#) (Paone & Associates, 2010)
Summarizes costs experienced by nine NYUCI implementation sites in Minnesota, from startup through the second year related to their implementation. Study illustrates how (and which) costs vary and shift over the life of a program, particular costs being higher/lower during a startup phase, and then shifting during ongoing programming.

Resources Chapter 4: Marketing

Further Reading

- [*Business Planning Tools for Aging and Disability Resource Centers*](#) (Aging & Disability Resource Center, Technical Assistance Exchange, 2004)
ADRC-TAE Issue Brief prepared by The Lewin Group to assist ADRCs as they put together a business plan. Resource is structured so as to explain the purpose of each of the various components of a business plan (e.g., marketing plan, organizational structure, environmental scan) and then provide a pathway to developing each of these pieces for one's own plan.
- [*Issue Brief 12: Caregivers as Partners and Clients of Behavioral Health Services*](#) (SAMHSA and AoA, 2013)
This issue brief focuses on informal caregivers, describing characteristics, special issues of caregivers dealing with individuals who have behavioral health issues, evidence-based programs available for caregivers, key actions that the aging network and providers can take, and identifying resources.

Resources Chapter 5: Evaluation

Training Resources

- [*Introduction to Program Evaluation for Public Health Programs: A Self-Study Guide*](#) (Centers for Disease Control and Prevention, U.S. Department of Health and Human Services)

This document is a “how to” for planning and implementing evaluation activities. The authors offer four key areas for consideration: 1) utility of the evaluation results; 2) feasibility of evaluation activities; 3) propriety and protecting the rights of individuals; 4) accuracy of evaluation findings.

Further Reading

- [*Alzheimer’s Disease Demonstration Grants to States Program: Maine*](#) (Administration on Aging, 2006)

This case study offers an example of program evaluation, in this case that of a large-system federal grant recipient. The following strategies were identified as essential to achieving systemic and sustained change: designing and operating projects that can be implemented statewide; linking people and their families to existing services; building technical expertise at the state, AAAs, and consumer levels; establishing ongoing training programs using established curriculum; embedding initiatives in larger organizations; investing in funding research to demonstrate the value of grant-funded activities; leveraging ADDGS funding where possible.

- [*Evaluating Community Programs and Initiatives, Developing an Evaluation Plan \(Chapter 36, Section 5\)*](#) (Community Tool Box)

This resource includes basic information on developing an evaluation plan. It includes why and when you need an evaluation plan; different types of stakeholders; how to develop an evaluation plan; what to expect (products) as a result of evaluation; and standards to follow.

About the Author

Deborah Paone, DrPH, MHSA, is principal and owner of *Paone & Associates, LLC*, a company she founded in 2002.

Dr. Paone has worked in hospital, clinic, and community-based settings in operations, as an evaluator, and in the policy arena. She bridges these settings and disciplines and provides a unique perspective toward creating real-world strategies that can be sustained.

Dr. Paone has served as a researcher and evaluator and administrator in health care and community-based/aging services. She provided a 5-year implementation evaluation, including a cost analysis, for the NYUCI translation in Minnesota, and a 3- year formative evaluation of *ACT on Alzheimer's*—the collective action initiative to create “dementia-capable communities” in Minnesota. She served as Executive Director of a community-based aging and caregiver services organization for 11 years, where she guided implementation of evidence-based programs and fostered their sustainability through partnerships and service contracts.

Dr. Paone holds a Doctor of Public Health from the Gillings School of Global Public Health, University of North Carolina-Chapel Hill, a Master of Health Services Administration from the University of Michigan, and a Bachelor of Arts in Gerontological Issues in Community Health and in English Literature from the University of Rochester, NY.

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