
Respite Care Association of Wisconsin

A CASE STUDY IN ORGANIZATIONAL CHANGE WITH CO-
OCCURRING STATEWIDE LONG-TERM CARE SYSTEMS
CHANGE.



RCAW
Respite Care Association
of Wisconsin

Overview

RCAW will provide a brief overview of its 30-year history and how taking a hard look back helped us determine how to move forward.

Having a fresh set of eyes and a new perspective set against the backdrop of changes in the long-term care and support delivery system to individuals across the lifespan enabled RCAW to look at itself under a microscope, make difficult decisions and implement changes with the goal of producing better outcomes, inter-weaving its efforts into an changing systemic statewide delivery system where we add value, impact, and increase our sustainability - with a very limited budget.

Objectives

Objective 1. * Attendees will learn how RCAW sought cross-sector collaborations to identify opportunities, establish organizational relevance, and become integral part of Wisconsin's LTC respite service and support delivery system.

Objective 2. * Attendees will learn the significant changes in Wisconsin's LTC service and support systems, which resulted in identifying respite care services as one of the top requested services; and how RCAW and the Wisconsin Department of Health Services (DHS) closely working together to meet the respite care needs of family caregivers for adults and children with disability across the lifespan.

Objective 3. * Attendees will learn how to conduct their own organizational self-assessment and the benefits of doing so.



A little history

- Respite Care Association of Wisconsin (RCAW) is a 501(c)(3) non-profit charitable organization organized in 1987 to support and advocate for quality systems of respite care for Wisconsin families.
- In 1999, Wisconsin adopted state Lifespan Respite Care legislation, authorizing Wisconsin DHS to issue state lifespan respite care grant funds to RCAW to administer the program.
- At that time, Wisconsin led the nation in recognizing the need to establish funding to support lifespan respite activities.
- From 1997 to 2000, Wisconsin was one of three states that enacted legislation to implement Lifespan Respite Programs, along with Oregon and Nebraska. This legislation established state and local infrastructures for developing, providing, coordinating and improving access for respite services to residents regardless of age or disability.



Timeline of change

- **1987:** RCAW formed
- **1999:** Wisconsin Legislature approved Statute funding respite care; Wisconsin became third state in the nation to implement a lifespan respite program
- **2000:** Family Care waiver program was approved by Centers for Medicare & Medicaid Services (CMS); phased implementation begins in 5 counties operated by managed care organizations
- **2004:** Children's Long-Term Support (CLTS) Waiver Program approved by CMS, implemented statewide and operated by county departments of human, social, or community services
- **2006:** Five pilot lifespan respite programs (1 in each of the 5 regions of the state) serve seven counties across the state and help family caregivers access quality, affordable respite care
- **2008:** Include, Respect, I Self-Direct (IRIS) waiver program approved by CMS and implemented in Wisconsin's counties, as the alternative self-directed option to Family Care
- **2011:** Five pilot lifespan respite programs expand to cover 25 counties
- **2012:** RCAW created free online respite care registry to access list of trained respite workers
- **2017-2018:** Governor's budget provides funding to eliminate waiting list for CLTS services by the end of FY18
- **2018:** IRIS and Family Care waiver programs expanded statewide, covering all Wisconsin counties
- **2019-2020:** CLTS Waiver Program implements federally mandated uniform statewide rates



Wisconsin Snapshot

- Located in upper Midwest, bordered by Lake Superior (North) Michigan Upper Peninsula and Lake Michigan (East), Illinois (South); Mississippi River, Iowa and Minnesota (West)
- 23rd largest state by area; 20th most populous state (2018 population: 5,814 million), State capital: Madison, largest city: Milwaukee (30th most populous city in the nation)
- Milwaukee County largest population (956,586) Florence County smallest population (4,354), State has diverse urban and rural areas
- Divided into 72 counties; Wisconsin Constitution – counties serve as arm or political subdivision of the State, County departments statutorily required to perform delegated program operations at the local level and frequently contribute local funding for their residents.
- Progressive Wisconsin Idea: - among the nation's first states to establish:
 - Kindergarten (1856 - Watertown, WI)
 - University of Wisconsin's statewide expansion through extension system (1907)
 - Worker's compensation program (1911)
 - Unemployment compensation program (1931)
 - Community Options Program - state alternative for adults to remain home instead of nursing home placement (1981)
 - Wisconsin Works – welfare reform program (1996)



WI DHS Respite Funded Programs

Programs serving Children with Disabilities

- **Children's Long-Term Support (CLTS) Waiver Program:** Federally approved Home and Community-Based Services (HCBS) Medicaid Waiver program. DHS administration includes program oversight, monitoring, enforcement, guidance and technical assistance. Wisconsin's county waiver agencies (CWAs) operate the program at the local level.
 - January 2019 Statewide **CLTS enrollment** - **8,874** participants; **CLTS Wait List** - **1,069 children**
 - Website: <https://www.dhs.wisconsin.gov/clts/index.htm>
- **Children's Community Options Program:** Effective January 2016, Wisconsin merged the Family Support Program and Community Options Program funding to form the Children's Community Options Program (CCOP), under state statutory authority Wisconsin's county human/social/community service departments operationalize CCOP at the local level.
 - January 2019 Statewide **CCOP Enrollment:** **855** participants
 - Website: <https://www.dhs.wisconsin.gov/ccop/index.htm>



WI DHS Respite Funded Programs...

Programs Serving Elderly or Adults with Disabilities

- **Family Care:** Statewide long-term care program for frail elders (65 and older) and adults with disabilities that delivers appropriate services to remain in their homes whenever possible. **There is no waitlist for Family Care applicants.**
 - **Statewide Enrollment:** As of January 1, 2019, **52,891** participants enrolled in Family Care, Partnership, and PACE
 - **Website:** <https://www.dhs.wisconsin.gov/familycare/index.htm>
- **IRIS (Include, Respect, I Self-Direct):** Statewide self-directed program for Wisconsin's frail elders and adults with disabilities. IRIS is the alternative to Family Care, built on principles of self-determination and self-direction. IRIS applicants do not have a waitlist.
 - **Statewide Enrollment:** As of January 1, 2019, **40,809** participants enrolled in IRIS
 - **Website:** <https://www.dhs.wisconsin.gov/iris/index.htm>



DHS Bureau of Children's Services 2019 Initiatives

- CLTS Waitlist Elimination
- CLTS Waiver Provider Directory
- CLTS Statewide Uniform Rate
- Provider Outreach and Communication

Good time to check in

- A lot of positive change over the past 18 years.
- Still had growing direct care workforce crisis.
- What cumulative impacts have these changes had on our programming as an organization?
- Good time to take a look at the big picture. Lets see where we are we at. What tools did we use?



The Non-Profit Lifecycle Tool

- Having a clear understanding of your organization's "life stage" can help frame:
 - critical conversations
 - inform strategic decisions
 - offer new or different starting point for capacity-building.
- When discerning the particular stage that a system is currently in, it does not depend on the age of the system. Rather, it depends on the nature of its current activities.



Overview of Lifecycle of Non Profit

Stage	Key Question	Duration	Obstacles	Opportunities
Grass Roots - Invention	Is the dream feasible?	0 – 5 years	<ul style="list-style-type: none"> • Resistance to forming • Lack of funding/expertise • No outside support 	<ul style="list-style-type: none"> • Creativity • Energy for the dream • Excitement to join
Start-Up - Incubation	How do we get this started?	1 – 2 years	<ul style="list-style-type: none"> • Fear of formalizing • Sustaining initial enthusiasm • Focusing the founder and energy 	<ul style="list-style-type: none"> • Excitement of funders • Charismatic leader • People wanting to belong
Adolescent – Growing	How can we build this to be viable?	2 – 5 years	<ul style="list-style-type: none"> • Absence of systems & accountability • Overwhelmed with change • Change may alienate funders, clients, staff and board • Danger of becoming isolated in the system 	<ul style="list-style-type: none"> • Sense of accomplishment • New faces, 'arms and legs' • Diversification in all areas of the organization • Rejuvenation for the founders
Mature - Sustainability	How can we ensure sustainability?	7 – 30 years	<ul style="list-style-type: none"> • Lack of or too much control • Lack of risk taking • Board & staff too operational • Unable to transition in to a governance board • Conflict between old and new 	<ul style="list-style-type: none"> • Feeling secure • Adequate resources • New staff/board – fresh ideas • Ability to try something new
Stagnation & Renewal	How, if any, can we renew?	2 – 5 years	<ul style="list-style-type: none"> • Resistance to change • Inability to address key challenges • Declining excitement • Isolation of the agency 	<ul style="list-style-type: none"> • Wisdom from past • Strategic Partnership opportunities • Chance to take risks again and think 'out-of-the-box'
Decline And Shut-Down	Should we close?	1 – 2 years	<ul style="list-style-type: none"> • Financial crises • Inappropriate leadership • Loss of staff and volunteers • Lack of any passion 	<ul style="list-style-type: none"> • Commitment to complete turnaround • Graceful 'sunset' or merger



Tool to conduct analysis

	Grass Roots - Invention	Start-Up - Incubation	Adolescent – Growing	Mature - Sustainability	Stagnation & Renewal	Decline and Shut-Down
Program and Services	<ul style="list-style-type: none"> Extremely informal or not yet a concern Perceived need for a program or service 	<ul style="list-style-type: none"> Simple programs are initiated or a mix of diverse and non-integrated activities. Strong commitment to delivering services 	<ul style="list-style-type: none"> Programs begin to establish themselves in the market Often demand is greater than capacity More consistent program delivery More focus 	<ul style="list-style-type: none"> Core programs are established and recognized in the community Long range program planning New programs are added & deleted as market dictates Programs functioning well 	<ul style="list-style-type: none"> Organization loses sight of market Programs developed primarily to attract funding Difficulty in delivering services and reaching goals Inconsistent program quality 	<ul style="list-style-type: none"> No longer meeting market needs Loss of credibility with funders and clients Decline in product quality Major reduction in referrals Licensing or accreditation in jeopardy
Staff Leadership/ Management	<ul style="list-style-type: none"> Entrepreneurial and visionary leader 	<ul style="list-style-type: none"> Single minded founder whose vision drives the organization Sole decision making - little or no hierarchy 	<ul style="list-style-type: none"> Beginning strategic division of labor Executive Director still primary decision maker and is less accessible to staff Both external and internal demands 	<ul style="list-style-type: none"> Need for well-rounded Executive Director Sometimes 'Founder's Syndrome' Delegation of authority and clear accountability 	<ul style="list-style-type: none"> Founder likely to leave Change agent needed 	<ul style="list-style-type: none"> Major conflict between ED and board ED makes key decisions w/out board ED is inaccessible and unable to meet deadlines
Staffing	<ul style="list-style-type: none"> All volunteer driven No paid staff 	<ul style="list-style-type: none"> Most work completed by volunteers Small (if any), enthusiastic staff Sense of "family" and cooperation among staff 	<ul style="list-style-type: none"> Staff size increases – still join primarily for mission Deepening organization chart, with more centralized management No job descriptions & personnel policies 	<ul style="list-style-type: none"> Even larger, and more culturally diverse and specialized staff Professional managers are hired Vertical, hierarchical organization chart 	<ul style="list-style-type: none"> Low staff morale; staff turnover Focus is on individual programs, instead of organizational goals Fiefdoms develop Volunteers leave 	<ul style="list-style-type: none"> Departure of key staff Key positions difficult to fill Staff grievances bypass ED to board High conflict among staff Low # of volunteers
Governance/ Board	<ul style="list-style-type: none"> Not yet a real concern 	<ul style="list-style-type: none"> Formal governance structure in place Small, passionate, and homogenous board Members tend to be volunteers or hand-chosen by executive 	<ul style="list-style-type: none"> Board expansion – first 'outsiders' New board members are added who are professionals with expertise Less focus on operations, more on 	<ul style="list-style-type: none"> Board size and diversity increases Main function is policy and oversight Fundraising becomes a more important role Good committee structure – most work 	<ul style="list-style-type: none"> No or very high board turnover Sluggish and less involved Bogged down in structure that may be outdated 	<ul style="list-style-type: none"> Very low board attendance No new board members Key board members may leave Eventually dissolves itself

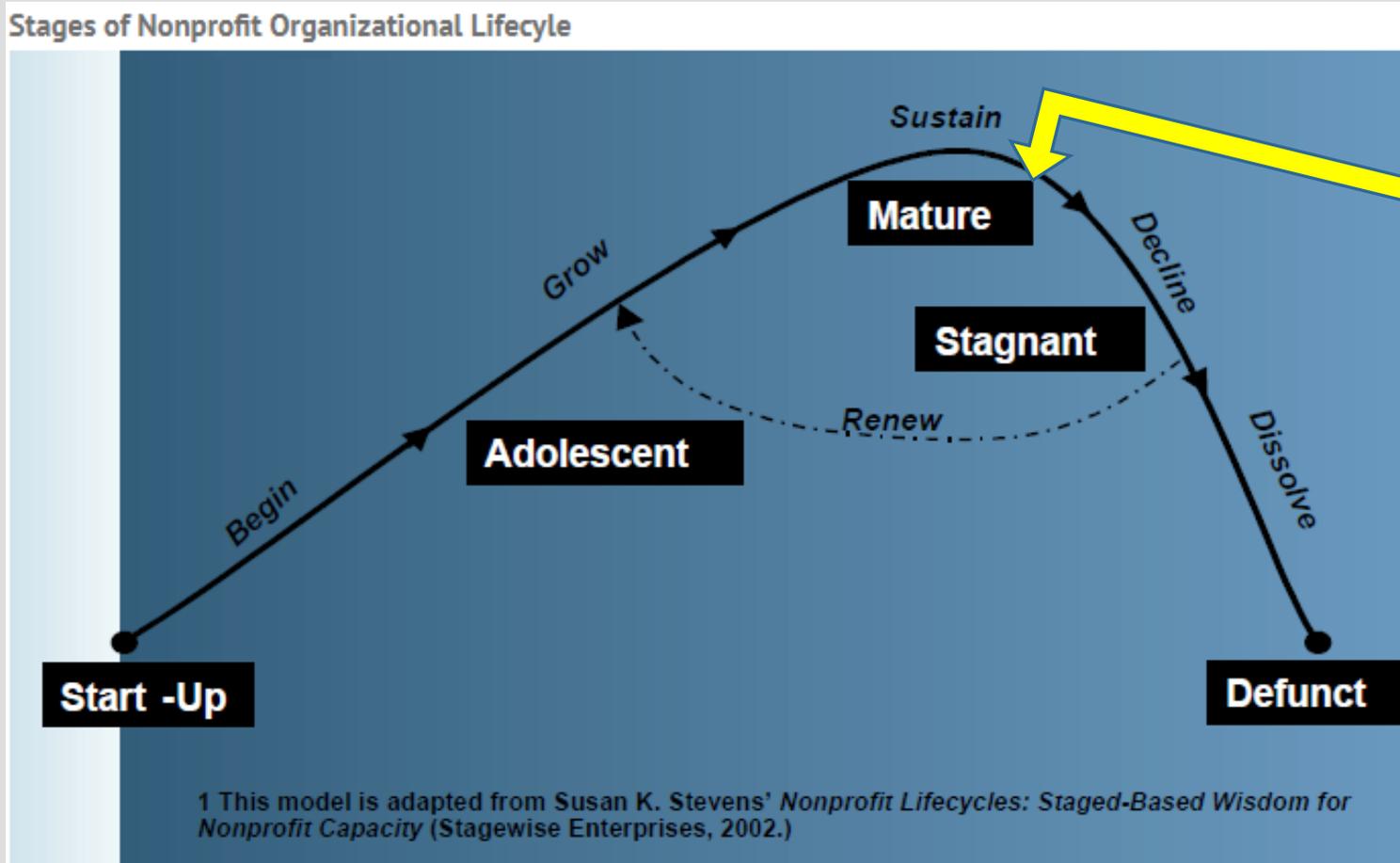


Tool to conduct analysis

	Grass Roots - Invention	Start-Up - Incubation	Adolescent – Growing	Mature - Sustainability	Stagnation & Renewal	Decline and Shut-Down
		<ul style="list-style-type: none"> director • Operating board. • Strong emotional commitment and motivation to the mission 	<ul style="list-style-type: none"> planning & oversight • More reactive than strategic in policies • Transitioning to governance board. 	<ul style="list-style-type: none"> done in committees • Better board accountability • Key board role is to ensure organization longevity 		<ul style="list-style-type: none"> • Major disagreement among board on mission and future • Board members making derogatory statements in public
Administrative Systems/ Operations	<ul style="list-style-type: none"> • Not yet a concern • No real 'home office' 	<ul style="list-style-type: none"> • Few formal systems • Operations are agile and flexible • Informal management infrastructure • Few operational routines or systems in place • Frequent informal communication 	<ul style="list-style-type: none"> • Unsophisticated operating systems • Unstable operations • Purchasing technology • Permanent home office with new admin support • Begin development of operational systems • Internal communication is challenging 	<ul style="list-style-type: none"> • Program and operational coordination through formal planning • Systems, policies & procedures in place • Standardized and efficient operations • Better integration of technology • More data management • Formal communications 	<ul style="list-style-type: none"> • Well-developed systems become "red-tape" • Poor planning 	<ul style="list-style-type: none"> • Departure from systems to crisis management • Poor internal controls or too much red tape • Cannot provide accurate picture of financial situation
Finances and Fundraising	<ul style="list-style-type: none"> • Not yet a concern • All resources are in-kind. 	<ul style="list-style-type: none"> • Focus on gathering resources • Limited financial resources; • Small budget with limited to no financial/ accounting systems • Overly dependent on a few funding sources and in-kind donations of expertise • Hand-to-mouth 	<ul style="list-style-type: none"> • Established relations with key funders but still unpredictable funding resources • Efficient at in-kind and volunteer resources • Cash flow problems - organization is undercapitalized • Cost considerations are more important • Revenue generation options considered 	<ul style="list-style-type: none"> • Reliable and diverse funding streams • Significant cash reserves • Expanded major giving program • Have, or are considering, planned giving and an endowment • Additional fundraising staff support • Revenue generation 	<ul style="list-style-type: none"> • Insufficient cash reserves • Falling behind on financial obligations • Loss of financial support • Not bringing in new funding sources 	<ul style="list-style-type: none"> • Unable to meet payroll & behind on payables • Relies on lines of credit for basic bills • Possible bankruptcy • Major funders withdrawing or threatening • High % of funds from only a few sources
Marketing/ Community Awareness	<ul style="list-style-type: none"> • Not yet a concern 	<ul style="list-style-type: none"> • Poor external communication • Word of mouth referrals and marketing • No formal public relations 	<ul style="list-style-type: none"> • First official promotional material • Word of mouth still primary marketing channel 	<ul style="list-style-type: none"> • Marketing plan developed • Professional image and promotional material • In-house Communication & Marketing expertise 	<ul style="list-style-type: none"> • Reactive to each crisis • No real proactive marketing and community relation building • Spending less on marketing 	<ul style="list-style-type: none"> • Negative rumors in the community and/or bad press • Key stakeholders cannot clearly define mission & purpose • No marketing



Another way to look at it.



We determined we were here



Tool helps guide action steps

	Grass Roots - Invention	Start-Up - Incubation	Adolescent – Growing	Mature – Sustainability	Stagnant <u>And</u> Renewal	Decline and Shut-down
Program and Services	<ul style="list-style-type: none"> Identify key unmet client/community needs Develop a concept plan Identify and evaluate program options Clarify results & expectations of work 	<ul style="list-style-type: none"> Assess and begin to improve quality Establish criteria for what activities and programs to pursue 	<ul style="list-style-type: none"> Develop a strategic plan to clarify & integrate. ID and track client outcomes Learn to say 'no' to opportunities Develop collaborations to better serve client needs 	<ul style="list-style-type: none"> Explore new program delivery models Develop internal process for evaluating new opportunities Review strategic plan & develop a long-range program plan 	<ul style="list-style-type: none"> Undertake strategic planning to review activities – reduce and focus efforts Conduct formal program evaluation – survey clients Explore best practices and models New collaborative relations 	<ul style="list-style-type: none"> Reduce programs to core essence Explore partner to transfer programs Immediately improve quality
Management	<ul style="list-style-type: none"> ID someone with time, skills and energy to formalize the organization 	<ul style="list-style-type: none"> Provide a mentor or coach for development of the leader Assess ED's ability - maximize strengths and minimize weaknesses 	<ul style="list-style-type: none"> Clarify ED's primary roles Establish ED annual priorities Delegate and offer more admin support Begin succession planning for key staff 	<ul style="list-style-type: none"> Enhance ED annual evaluation process Clarify ED's roles related to staff management Explore additional coaching 	<ul style="list-style-type: none"> Develop succession plans for key leadership May need a new or interim Executive Director 	<ul style="list-style-type: none"> Coach current ED or recruit interim ED with turnaround and financial experience
Staffing	<ul style="list-style-type: none"> Estimate initial staffing needs ID and determine how best to utilize volunteers Create a basic staff orientation plan 	<ul style="list-style-type: none"> Use and recognize volunteers well Hire administrative support Consider contract or part-time for needed expertise – accounting, etc. 	<ul style="list-style-type: none"> Hire more admin support Develop job descriptions and work charts Refine volunteer management functions Expand volunteer base Create personnel policies 	<ul style="list-style-type: none"> Increase personnel management Provide more training, including management training Ensure proper volunteer programs Conduct salary review and comparison Prepare staff for diversity 	<ul style="list-style-type: none"> Prepare for major staff changes Push for enhanced internal collaboration Re-evaluate the volunteer program Explore ways to keep essential staff Reassign staff as needed Consider new staff structures 	<ul style="list-style-type: none"> Conduct staff retreat – input to address critical operational issues Engage third party to mediate conflicts Recognize challenge for staff – plan to address burn-out Explore severance packages if shutdown
Governance Board	<ul style="list-style-type: none"> Begin to ID potential board members Obtain information 	<ul style="list-style-type: none"> Expand the board Clarify board member roles & 	<ul style="list-style-type: none"> Conduct board retreats for planning & training 	<ul style="list-style-type: none"> Institute an annual board evaluation Enhance board 	<ul style="list-style-type: none"> Re-energize or develop new board Explore partnerships 	<ul style="list-style-type: none"> Board resign or build new board Engage third party to



Actions to take based on where you are in the lifecycle

	<ul style="list-style-type: none"> on forming a board. • File articles of incorporation and by-laws • Recruit an initial board chair. • Obtain legal advice 	<ul style="list-style-type: none"> responsibilities – offer training • Create formal governance structure – including committees 	<ul style="list-style-type: none"> • Formalize board recruitment process • Culturally diversify board composition • Develop board orientation & mentor program • Focus on policies 	<ul style="list-style-type: none"> fundraising capacity • Enhance board committee structure 	<ul style="list-style-type: none"> with others • Board retreat -revise board and planning • Revitalize board nomination process • Clarify board roles 	<ul style="list-style-type: none"> mediate conflicts • Board retreat to develop plan to address critical issues
Administrative Systems/ Operations	<ul style="list-style-type: none"> • ID initial infrastructure and operation needs • Determine any compliance needs • Decide on 'home office' • Obtain accounting expertise 	<ul style="list-style-type: none"> • Formalize record keeping and • Begin to establish basic program polices and manuals 	<ul style="list-style-type: none"> • Automate data management • Purchase necessary technology and equipment • Develop maintenance & replacement plan • Improve internal communication 	<ul style="list-style-type: none"> • Develop a risk management plan • Upgrade technology hardware and software • Ensure adequate administrative staff • Formalize internal communication 	<ul style="list-style-type: none"> • Centralize key administrative functions • Look to revamp systems and equipment • Re-examine policies – reduce red tape 	<ul style="list-style-type: none"> • Shore up broken systems • Reduce red tape • Find external financial expertise
Finances	<ul style="list-style-type: none"> • ID initial funding sources, including researching targeted foundations • Develop a proforma budget • Develop an initial development plan 	<ul style="list-style-type: none"> • Expand funding sources • Institute formal accounting policies and procedures • Hire an experienced accountant • Begin to plan for future financial needs 	<ul style="list-style-type: none"> • Develop a multi-year budget – including capital budget • Establish formal financial controls • Create a development plan • Diversify funding streams – expand individual giving base • Hire a development person • Explore capital campaign feasibility 	<ul style="list-style-type: none"> • Develop an operating reserve & policies • Review fundraising plan • Start planned giving program • Enhance fundraising capacity 	<ul style="list-style-type: none"> • Expand funding sources • Detailed financial analysis • Explore short term cost reductions • Analyze current fundraising strategies • Add resources to development 	<ul style="list-style-type: none"> • External audit • Short-term budget and funding plan • Budget cutbacks • Emergency meeting with key funders
Marketing/ Community Awareness	<ul style="list-style-type: none"> • Explore a name – test with key audiences • ID and 'sell' concept paper to key potential stakeholders • ID initial marketing and promotional needs • Verify community need and interest in addressing need 	<ul style="list-style-type: none"> • Develop a condensed fact sheet • Create talking points for board/volunteers • Begin to develop an organization brand/identity • All staff and board to provide potential contact list (possible funders) 	<ul style="list-style-type: none"> • Have board more involved in community relations • Develop brand and image • Enhance professionalism of promotional material • Develop proactive PR plan 	<ul style="list-style-type: none"> • Enhance marketing capacity • Better utilize technology for communication • Develop a long-term marketing plan • Enhance public relations • Reassess logo and image 	<ul style="list-style-type: none"> • Proactive public relations campaign • Keep key stakeholders updated 	<ul style="list-style-type: none"> • Engage technical assistance in crisis communication



What did our analysis tell us?

It was time for change.



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What did we do?

- Reviewed all statewide LTC programmatic changes
- Learned how these changes affected the statewide delivery system
- Reviewed the programs we were offering and how we were delivering them to identify change in gaps, priority areas of focus, and opportunities for efficiencies and greater effectiveness
- Gathered year-long feedback via statewide caregiver listening sessions
- Changed program design criteria and delivery system to work with statewide programs and delivery systems to fill gaps, increase access, ensure consistency
- Identified priority strategies
- Communicated, Communicated, Communicated!
- Networked nationally, statewide, and locally to identify evidenced based practices to incorporate into our programs and delivery system
- Established new collaborations and identified opportunities to work together
- Consulted with DHS staff for input and direction to address identified respite related gaps and priority needs across the lifespan



RCAW's new strategy is born

- Data and results-driven focus on recruitment, training, and retention of respite workers
- Utilize existing delivery systems vs. having a separate system, or added layer
- Outreach and educate system providers (ADRCs, MCOs, county agencies, others) on how we can work in tandem
- Establish meaningful collaborations to build sustainable systems to meet Wisconsin's caregiver needs
- Expand the pool of trained quality respite care workers and provider agencies
- Develop comprehensive key performance indicator dashboard to monitor & measure programming effectiveness



Existing and **New** Programs

- Wisconsin Lifespan Respite Training
- Wisconsin Respite Care Registry
- **Mini-Grant Program - (recruitment, retention, business development)**
- **Caregiver Respite Grant Program**
- **Group Respite Grant Program**
- **Collaborative Outreach & Specialized Training Programs**
- Respite Resources

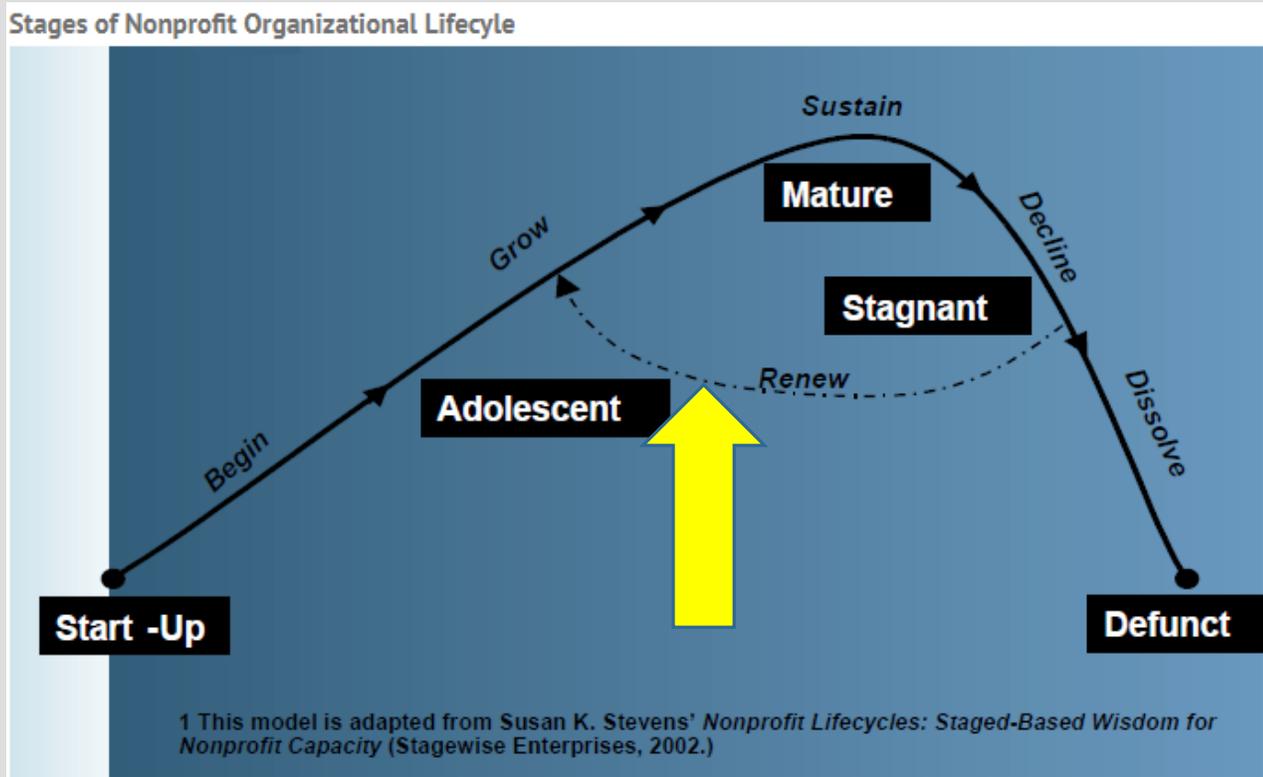


Cross sector collaborations formed

- UW Madison School of Nursing – CYSHCN Research
- UW Madison School of Nursing CARES Program (Dementia/Alzheimer's)
- Wisconsin Alliance of Family and Caregiver Support Alliance
 - Includes State departments, statewide non-profit organizations, MCOs, IRIS Consulting Agencies, Fiscal Employer Agencies, Fiscal Agents, Family Caregivers, ...)
- UW Oshkosh Center for Community Development, Engagement and Training (CCDET)
- Wisconsin Women's Council
- Next host of the International Short Break Association (ISBA) and National Respite Conference
- More in the works!



Where we are at now



Adolescent – Growing	How can we build this to be viable?	2 – 5 years
Mature - Sustainability	How can we ensure sustainability?	7 – 30 years



Here are some tools you can use

1. Non Profit Lifecycle Institute

<http://nonprofitlifecycles.com/>

2. Georgia Center for Non Profits - Free Online Nonprofit Lifecycle Assessment Tool

<https://ganonprofits.typeform.com/to/IYZAjE>

3. Basic Overview of Life Cycles in Organizations

<https://managementhelp.org/organizations/life-cycles.htm#understand>

4. Presentation Handout Materials



Change, Change, Change...

PROGRESS
is IMPOSSIBLE
WITHOUT CHANGE,
& those who cannot
CHANGE THEIR *minds*
CANNOT
CHANGE *Anything.*[®]
- George Bernard Shaw



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