



Massachusetts Department of Public Health



Solving the Respite Crisis for Caregivers of Children & Youth with Special Health Needs

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King James

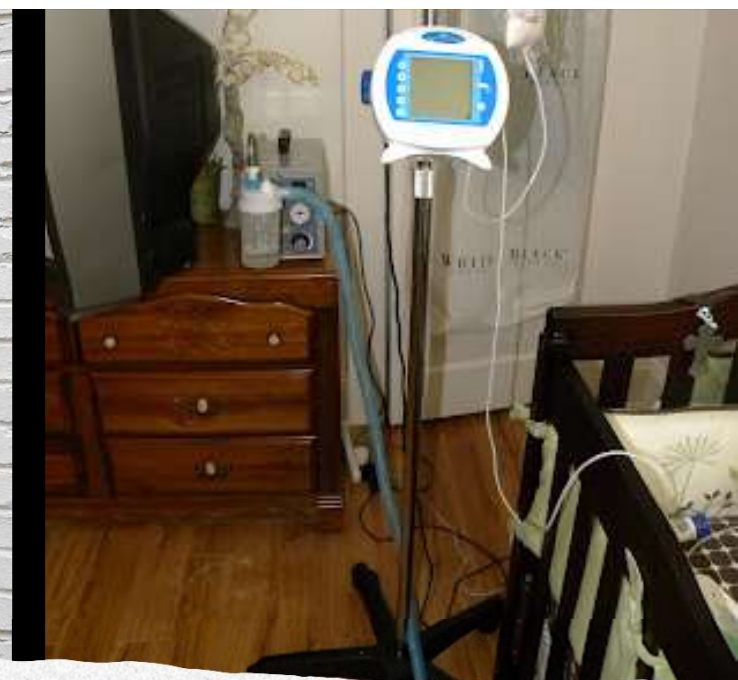
- Nonverbal
- Non-Ambulatory
- G-tube fed
- Hearing Impaired
- Little to no Volitional Movement
- Multiple surgeries
- Maximum Assistance for all ADLs



Many, Many Roles of a Caregiver of CYSHN

- Physical Therapist
- Occupational Therapist
- Pharmacist
- Case Manager
- Respiratory Therapist
- Medical Transport Provider
- Nurse
- Care Coordinator/Scheduler
- Medical Equipment Technician
- Supply Manager
- 24 hour on call emergency service provider
- Manager of “Team King James”





High burden of care

Agenda

- Define Children and Youth with Special Needs (CYSHN)
- Causes for lack of respite
- Impact of lack of respite
- The Solution
- Next Steps



Children and Youth with Special Health Needs (CYSHN)

Chronic Conditions

- Physical
- Developmental
- Behavioral
- Emotional



- 340,000 in Massachusetts
- 11,000 with Medical Complexity (CMC)
 - Substantial service needs
 - Chronic condition(s)
 - Functional limitations
 - Health care use

Caregivers of CYSHN in MA provide *at least \$4.1B* in uncompensated *skilled* care annually!

Causes of the Respite Crisis for Caregivers of CYSHN

Our Problem:

*Massachusetts' lack of comprehensive and accessible respite services incurs significant costs to its employers in loss of **productivity**, loss of **institutional knowledge**, and **employee turnover**.*

- Siloed bureaucracy - inconsistent funding and eligibility
- Direct Service Provider (DSP) Workforce crisis
 - Service availability
 - Transportation
 - Cost
 - Lack of knowledge where to access
 - Inconvenient service time

The Respite Crisis for Caregivers of CYSHN



Families

- Lower productivity at work
- Forced change in employment
- Impact on employability
- **\$17B** in lost income nationally/year due to missed work



Employers

- **\$25.2B** in lost productivity nationally
- Locally – **turnover, absenteeism and presenteeism** is costing MA employers of caregivers of CYSHN **\$573M**



State

- Loss of talent due to caregiving responsibilities
- Loss of income = loss of tax revenue



The Solution:
Caregiver to Caregiver Respite Network

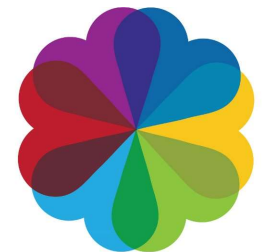
#RestedCaregiver

C2C Respite Network

#RestedCaregiver

Parent to Parent (P2P) peer support – successful evidence-based methodology/approach for caregivers of CYSHN

- Utilizes an untapped, fully trained workforce
- Caregivers provide respite to other caregivers of CYSHN with similar health care profiles
- Compensation – private pay, PCA hours, barter
- Mimics Personal Care Assistant (PCA) model – consumer driven, family directed model
- Fosters community/combats isolation
- Low cost – registry, family engagement specialist



PARENT_{TO}PARENT
USA

The Key to C2C Success – Reciprocity!



Benefits:

Provide respite (give and receive)

Provide confidence in care due to similar lived experience and skillset

Build/foster community

Combat isolation

Create social connections and opportunities for children and families

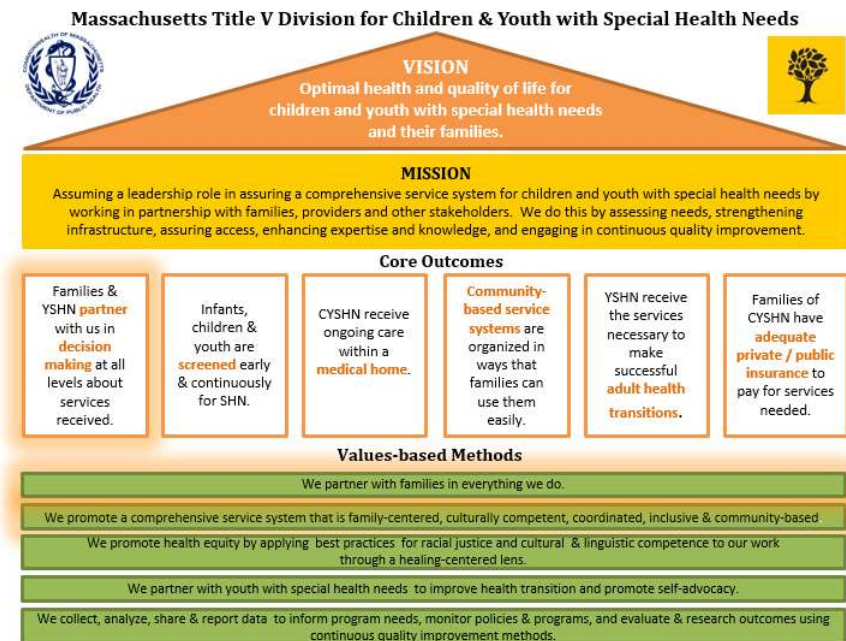
Highlights of SWOT & PESTEL Analyses

DCYSHN SWOT

- Commitment to CYSHN & their families
- Family Engagement
- Racial Equity Lens
- Strong CLD Community Engagement
- Growing Cross Agency Partnerships
- Limited resources/funding
- Bureaucratic workflows

C2C Respite Network PESTEL

- Political: AARP, MA Business Roundtable
- Social: Respite as a concept is culturally irrelevant to many CLD families
- Legal: Bartering is taxable income
- Legal: No respite regulations



Return on Investment



	0	1	2	3	4	5
Number of families served		200	300	400	500	600
Savings - Reduced Turnover/Absenteeism		\$ 380,000	\$ 570,000	\$ 760,000	\$ 950,000	\$ 1,140,000
Investment needs (registry buildout)	\$(125,000)					
Expenses:						
Family Engagement Specialist (.5 FTE)		\$ (50,000)	\$ (50,000)	\$ (50,000)	\$ (50,000)	\$ (50,000)
Registry Maintenance		\$ (7,000)	\$ (7,000)	\$ (7,000)	\$ (7,000)	\$ (7,000)
Rewardingwork Registration Fees		\$ (1,000)	\$ (1,500)	\$ (2,000)	\$ (2,500)	\$ (3,000)
Cash Flow	\$(125,000)	\$ 322,000	\$ 511,500	\$ 701,000	\$ 890,500	\$ 1,080,000

306%
Internal Rate of Return

Massachusetts Response



- Respite Innovations Grant Program Applicants Conference
- EOHHS developed a \$20 million grant to test innovative Respite models to support family and natural support caregivers.
- Develop and implement a new or enhanced innovative model of Respite
- Grantees will not be penalized or required to return funding if the data reflects that the program did not produce expected results
- 42 organizations received awards ranging from \$40,000 to \$1.2 million.

The Federation was awarded the \$1.2 million for their proposal!



Caregiver to Caregiver Respite Network

A community of caregiving rooted in shared experience



www.fcsn.org/c2c email: c2crespite@fcsn.org





What is Caregiver to Caregiver/C2C Respite Network?

A statewide network of families of children with special health needs. The network will support connections between families who share similar experiences. Our goal is to create a system for families to provide and receive respite. The term "respite care" means an opportunity for a child's primary caregiver to take a break. Successful respite requires a trusting relationship between families and their respite provider. C2C will build a community of caregiving rooted in shared experience.





Current Participation Considerations

- ✓ Massachusetts residence
- ✓ Primary caregiver of a child/youth with disabilities and specialized support needs ages 0-26 years
- ✓ Wants to receive and/or provide respite care





How does Caregiver-to-Caregiver/C2C Respite Network work?

Caregivers apply to provide and/or receive respite.

Match criteria:

- child's medical and support needs
- where families live
- language and cultural identities and preferences

C2C staff will provide:

- CORI/SORI checks for each program participant
- Online Learning platform (courses, discussion boards, etc.)
- Monthly check-ins and access to bilingual support as well as ASL





Program Process Steps

1. Complete Match Request Application on C2C webpage
2. Submit CORI/SORI
3. Check references.
4. Initial Virtual Phone Call
5. Invitation to Learning Platform
6. Begin Match Search – FSCN
7. Identify match
8. Introduce caregivers via virtual meeting





Compensation options

- Barter
- Private pay
- PCA hours

The Personal Care Attendant program is available to people with disabilities who meet the following conditions:

- Have MassHealth Standard or CommonHealth or be enrolled with a Senior Care Option or 1Care Plan.
- Physical assistance must be medically necessary.
- Have a permanent or chronic disability that impairs their ability to perform activities of daily living without physical assistance.
- Needs physical assistance with two or more activities of daily living.





Bilingual Project Staff



Project Director

Project Associate

Project Coordinators (part time 20 h./week):

- ✓ Spanish speaking Coordinator
- ✓ Chinese speaking Coordinator
- ✓ Korean speaking Coordinator
- ✓ Portuguese speaking Coordinator
- ✓ Haitian Creole speaking Coordinator





Caregiver to Caregiver Respite Network Team



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One Page Information Flyers



Arabic



Chinese



English



Haitian Creole



Korean



Portuguese



Spanish



Vietnamese





Developing Culturally Responsive and Equitable Project Materials



Activities:

- ☐ Host focus groups to assess the need in various communities
- ☐ Assess accessibility of materials and trainings
- ☐ Provide language in written and video (audio) formats - including ASL.
- ☐ Share information about C2C through our established programs, networks and social media with multilingual and multicultural outreach specialists





C2C Focus Groups

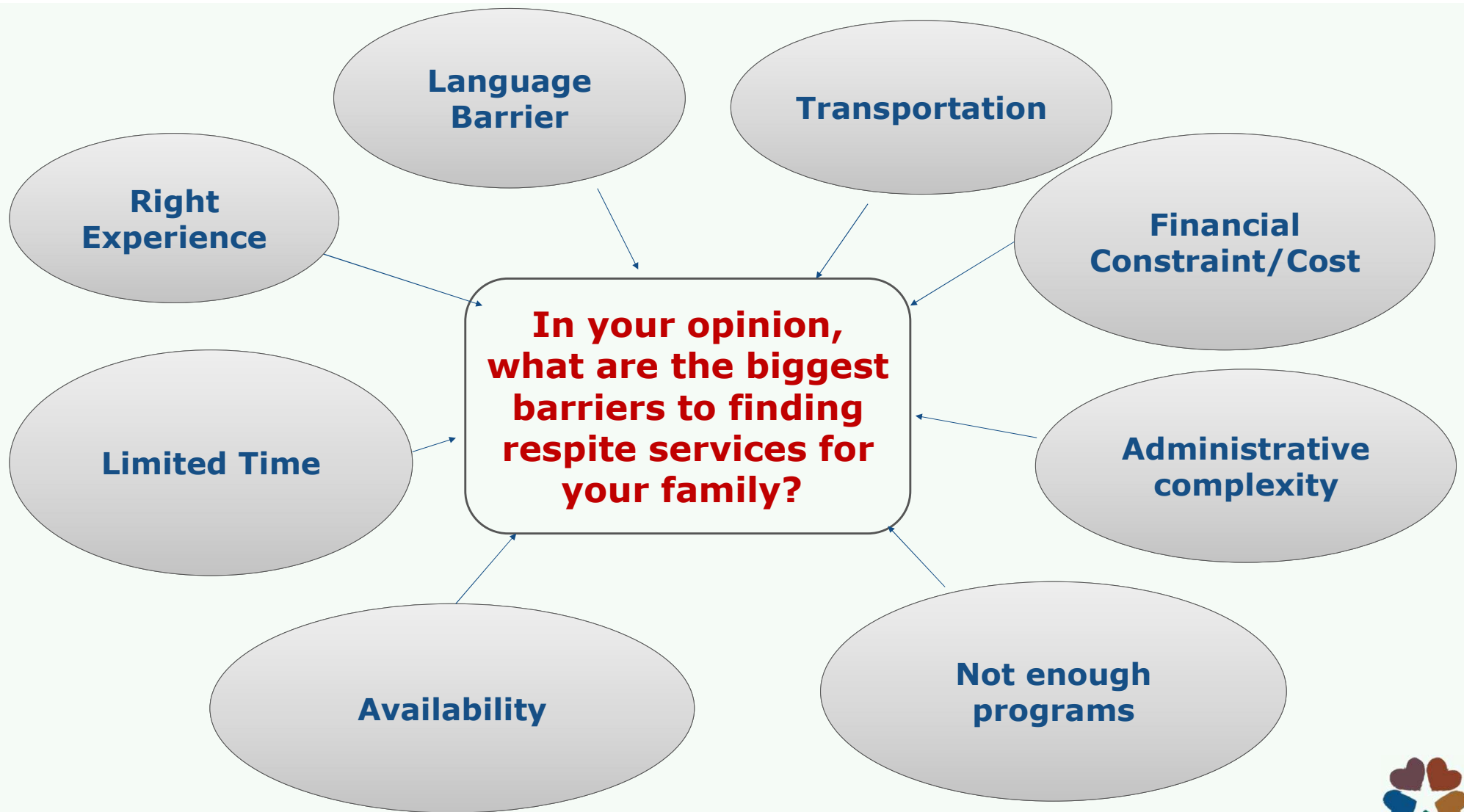
Purpose:

To receive input and recommendations from caregivers

6 groups total, 90 minutes each







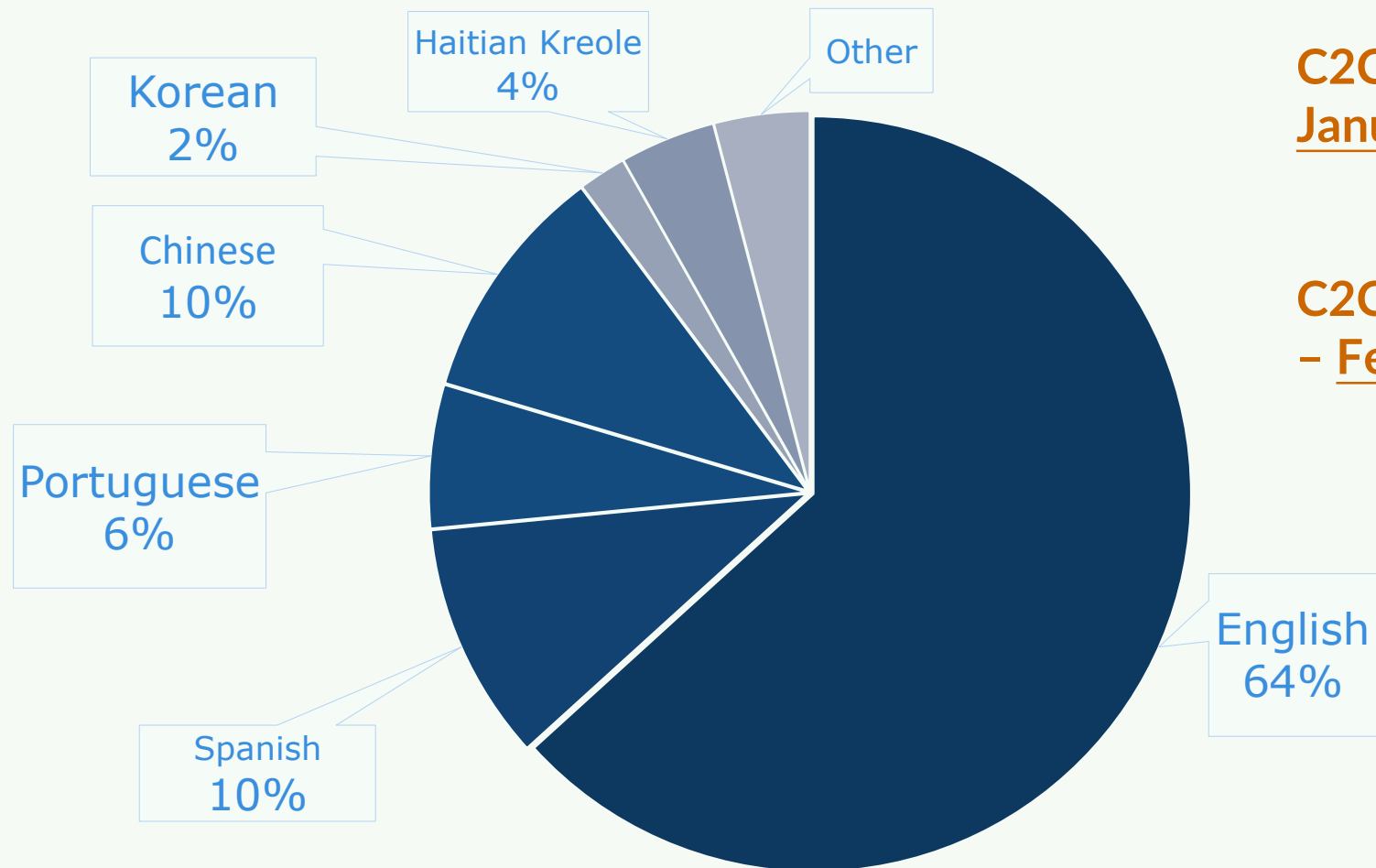


Building an Online Learning Community for Caregivers

- The Origin of Caregiver-to-Caregiver Respite Network
- Other courses include:
 - ✓ Introduction and Overview of the Respite Program
 - ✓ What to look for in a respite provider
 - ✓ How to Provide Respite for Another Family
 - ✓ The matching process
 - ✓ CORI process
 - ✓ Listening and Learning
 - ✓ Culturally Responsive Respite
 - ✓ CPR/First Aid
 - ✓ Other internal and external trainings
 - ✓ Compensation (PCA, bartering, private pay)
- Discussion board
- Multilingual Resource Library



Current C2C match requests data



**C2C “soft” launch –
January 29th, 2024**

**C2C official launch
– February 5th, 2024**



Use Project Metrics to Track and Review Progress

Quantitative (include demographics for each indicator)

- # of overview participants
- # of applications received
- # of orientation attendees
- # of matches completed
 - # of members who provided respite
 - # of members who received respite
 - # receiving respite for the first time
- Compensation type



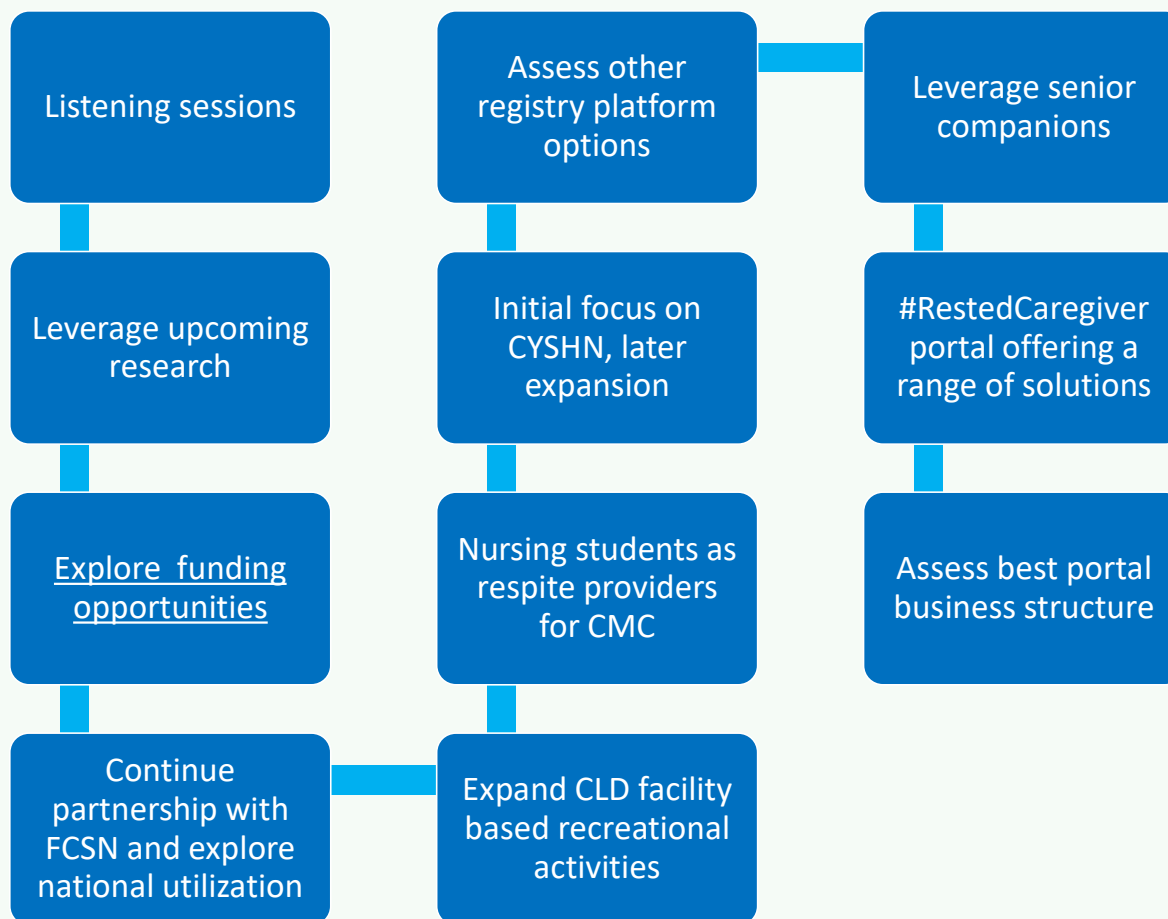
Qualitative

- Surveys following each training
- Survey following each match





Next Steps!





Conclusion

The Caregiver-to-Caregiver Respite Network:

- Accesses untapped *skilled* workforce
- Low cost/high rate of return
- Addresses serious unmet need
- Potential for national utilization



“This is who we are, this is what we do!”



