

# Overnight and Weekend Respite:

Critical to Family Survival

October 15-17, 2013



# What is the House of Possibilities?



- Multi-use model with respite as a component
- Opened its doors in 2009 in Easton, MA
- Situated on the campus of Stonehill College
- Supports children and adults with developmental delays
- Offers weekend and overnight respite for children



# Who Participates in HOPE's Programs?

HOPE serves children with all types of cognitive, physical challenges with exception of medically fragile or severe behaviorally challenged children

- 2012 We served over 500 repeat clients from 63 towns

- 2012 We provided more than 37,000 hours of service to children and adults



# Objectives of Today's Presentation

## Objective 1:

Discuss the importance of having overnight and weekend respite as a critical component in the care plan for children with special needs.



## Objective 2

Look at how an effective partnership between the public sector and the private sector can be enhanced by involving non-profit or educational institutions.



## Objective 3

Recognize that although the recipe for success in running children's respite has the same ingredients, the amount of each ingredient needs to be adjusted based on your particular model.



# The Need

## **Families' experiences:**

- Lack of overnight programs for children with developmental disabilities
- Recharging from the demands of caretaking is critical to family's well being
- The siblings of children with special needs require one on one time with their parents and other siblings
- Consistent, sustainable relief is critical to family's well-being



# Benefits

## For Children:

- Enhanced independent daily living skills
- Some separation from family is necessary in order to attain one's full potential
- Increased chance to participate in fun activities
- Connection to peers and/or bonding with mentors
- Increased confidence and self esteem





# Benefits

## For Families:

- More emotional balance within family
- Predictable help allows for planned respite
- When kids are having fun during time apart there is less guilt involved
- Improved relationships with spouse and other children
- Time for self-care



# Why is Overnight Respite Important?

- Respite care can delay or prevent a child from being institutionalized.
- According to Dept. of Developmental Services, it costs the state \$501/day to \$548/day for someone to live in an institution (between \$180,000 and \$200,000 per year)
- 74% of families with a child with a disability said respite made a significant difference in their ability to provide care at home.

•Knoll, James, Human Services Research Institute, March 1989



# Why is Overnight Respite Important?(Cont.)

- Caregivers of children having physical, cognitive and or social disabilities face a **life long challenge**.
- **Round-the-clock care – 365 days a year.**
- Recent surveys estimate there are 44 million caregivers over the age of 18. (Approximately **1 in every five adults**).

•National Alliance for Caregiving, AARP. Caregiving in the U.S. Bethesda, MD: National Alliance for Caregiving, AARP; 2004 Apr.



# Why is Overnight Respite Important?(Cont.)

- The divorce rate among families with a special needs child is 80%.<sup>1</sup>
- Declines in physical health and premature death among caregivers in general have been reported.<sup>2</sup>
- Declines in caregiver health have been particularly associated with caregivers who perceive themselves as burdened.<sup>2</sup>



<sup>1</sup> Thorpe, Jen, Divorce Rates Higher Among Couples With Special Needs Children.

<sup>2</sup> Schulz R, Beach SR. Caregiving as a risk factor for mortality: The caregiver health effects study.

# Why is Overnight Respite Important?(Cont.)

## Caregiver strain has been related to :

- Increased health risk behaviors
- Higher use of prescription drugs
- At risk for fatigue and sleep disturbances
- Lower immune functioning, slower wound healing
- Increased insulin levels and blood pressure & higher Risk for cardiovascular disease



# Why is Overnight Respite Important?(Cont.)

## Medication Use Among Caregivers and Noncaregivers

THERAPY CLASS	CAREGIVERS	NONCAREGIVERS	RELATIVE DIFFERENCE
High Blood Pressure/Heart Disease	44.5%	42.2%	5.5%
High Cholesterol	31.9%	33.2%	-3.9%
Depression	19.9%	18.2%	9.1%
Ulcer Disease	19.9%	18.1%	9.9%
Hypothyroidism	15.5%	12.9%	20.6%
Anxiety	12.5%	9.7%	28.5%
Allergies	10.6%	10.2%	3.9%
Diabetes*	9.2%	8.6%	6.5%
Asthma	8.5%	8.5%	0.8%
Seizures	6.0%	5.6%	7.7%

\*Oral anti-diabetes medications only

# Why is Overnight Respite Important?(Cont.)

## Financial Challenges:

- One study by the National Center on Women and Aging found that, on average, **caregivers lose \$659,130 over their lifetime** in reduced salary and retirement benefits.
- Overnight respite saves the government billions of dollars every year
- 50 million family caregivers nationwide provide at least **\$375 BILLION** in uncompensated services.

# HOPe' s Overnight Respite Program



- Overnight respite 2 nights/month for 10 guests
- Must be overnight experienced (1 awake)
- Developmental and physical disabilities
- Child learns independence and self care
- Families time off to rejuvenate
- MAP certified
- 1:2 Staffing





# HOPe's Overnight Respite Program

**Results of our recent client family survey show :**

	Before Respite	After Respite
Would you rate your stress level due to caring from moderate to extreme?	91%	36%
Would you rate your relationship with your special needs child as moderately to extremely strained?	78%	11%
Do you believe that caring responsibilities moderately to extremely caused you health problems?	67%	33%



# Why isn't more Overnight Respite available?

- Rigorous state licensing requirements
- Need specialized facility for an overnight stay
- Subsidies are often necessary for families
- Cost prohibitive--facilities and other direct costs such as insurance and transportation alone are extremely expensive

# Why Isn't More Overnight Respite Available for Children?

- Little public revenue support available to enhance sustainability, thus dependent on fundraising and family contributions
- Complexity of program for short window of time
- Cost of staffing and training is expensive



# Effective Partnerships

Public + Private + Non-profit /Educational  
= Success



# Effective Partnerships

Are you asking yourself,  
why do I need a partner?



# Effective Partnerships

The Answer:

Each partner brings something different to the party!

# Effective Partnership

## **Non-profit and Educational Institutions can:**

- Provide volunteers
- Decrease staffing costs
- Provide peer to peer mentoring opportunities
- Provide complementary support services

# Effective Partnership

- Create “Strategic Alliances”
- Experts in the field lend instant credibility to your organization
- High Profile donors may give new donors confidence as well as visibility for the organization



# Effective Partnership

## **Diversify your sources of funding:**

- A source of funding may dry up and others will be needed to fill the void
- Supplement donations with state agency contracts and Medicaid payments
- To sustain your organization for the long haul

# Ingredients for Success

**For each organization, there is just the right recipe for success.**

Each recipe

- Uses similar ingredients
- Measures them in various ways
- Blends them differently
- Resulting in different finished products



# Ingredients for Success

Each organization adjusts their recipe to come out just the way they want it.



# Ingredients for Success

It is very important early in the process to determine the range and severity of the special needs you plan to serve.



# Ingredients for Success

## State Funding:

- Is there state funding available for the age group you propose to serve?
- How easily can this be accessed?

## State Regulations:

- What are the regulations pertaining to the population you will serve ?
- What needs to be done to meet these requirements?



# Ingredients for Success

## **Building /Facility:**

- There are many building code requirements such as ADA guidelines for handicap accessibility including special doorways, elevators and restroom facilities.

## **Program Staff:**

- All staff are certified in CPR and First Aid, trained on individual rights and health & safety.
- In MA, All overnight respite requires a MAP certified leader



# Ingredients for Success

## **Family Resources:**

- What is the ability for families to pay for services
- Do families have alternative sources of funding?

## **Volunteers:**

- It is very beneficial to have multiple sources of volunteers to supplement staffing needs. Popular sources are local colleges, high schools and religious communities



# Ingredients for Success

## **Financial backing and Fundraising capabilities:**

- Do you have access to major donors, foundations or corporations who could supplement your revenue stream?

## **Financial Requirements to Reach Sustainability:**

- Requires an annual cash outlay of \$200-300K to fund the program expenses depending on the size of your operation.
- You would also need an additional \$60-70K to pay for the annual housing and transportation costs.



# Conclusions

Have you heard of the TV show, “Restaurant Impossible”?

Chef Robert Irvine is given the “mission” of **making the impossible, possible** by renovating failing restaurants because he believes it is the right thing to do!



# Conclusions

We believe that Respite is the **most** important support for families having special needs children.

Without it families will experience: repeated physical and emotional crises, stressed family relationships and often additional expenses which can create serious financial burdens.

Eventually these experiences can lead to marital problems, sibling rivalry and even child abuse.

Overnight and weekend respite is a critical component of care for children with special needs regardless of its cost.

