

rest 

RESPIRE EDUCATION & SUPPORT TOOLS

Supporting Caregivers in Illinois

REST to the Rescue: Implementing a Comprehensive Volunteer Training for your Respite Program

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Delivering education and support to those offering a break to caregivers



The Caregiving Crisis

Over **65 million** US caregivers provide care for a chronically ill, disabled or aged family member or friend during any given year, spending an average of 20 hours per week providing care for their loved one.

National Alliance for Caregiving in collaboration with AARP; Nov. 2009

Estimated 2.4 million family caregivers providing 1.59 million hours of care across Illinois

AARP Public Policy Institute, 2011 Update



Illinois: Caring for Individuals with Disabilities



More than 1 in 6 adults has a disability

Est. 145,148 individuals with I/DD living with family caregivers

1 in 68 children has been identified with autism spectrum

Illinois Disability and Health Program, Data Brief, Issue 1, March 2011

Braddock et al. 2013. www.stateofthestates.org

National Center on Birth Defects and Developmental Disabilities; March 2014

Family Caregivers

Family caregivers are the foundation of long-term care nationwide exceeding Medicaid long-term care spending in all states. *Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving; National Alliance for Caregiving and Evercare. March 2009*

Three fifths of family caregivers age 19-64 surveyed reported fair or poor health, one or more chronic conditions, or a disability, compared with only one-third of non caregivers. Caregivers reported chronic conditions at nearly twice the rate of non caregivers. *The Commonwealth Fund: A Look at Working-Age Caregivers' Roles, Health Concerns, and Need for Support. August 2005*

64% of working parents caring for a special needs child believe that caregiving responsibility has negatively affected their work performance. *Care.com and National Family Caregivers Association: State of Care Index. 2009*

Over 90% of family caregivers become more proactive about seeking resources and skills they need to assist their care recipient after they have self-identified. *National Family Caregivers Association, Survey of Self-Identified Family Caregivers, 2001*

WHAT IS RESPITE???

Dictionary definition of “Respite”:

- a short period of time when you are able to stop doing something that is difficult or unpleasant or when something difficult or unpleasant stops or is delayed (Miriam Webster)

Respite Care:

- planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult. (ARCH – Access to Respite Care and Help)

Individuals Want to Stay at Home – Caregivers Need Help

- 80% of long-term care is provided by family in the home; 35% of respite users indicated that without respite services they would have considered out-of-home-placement for their family member. *(Knoll, James, Human Services Research Institute, March, 1989; Health and Human Services, Informal Caregiving: Compassion in Action, Washington DC: Department of Health and Human Services, based on data from the National Survey of families and Households, 2002.)*
- Respite allows caregivers to:
 - Bring their best self
 - Reduce stress related medical conditions
- Respite has been shown to improve:
 - Family functioning
 - Life satisfaction
 - Attitudes toward the care recipient
(Cohen and Warren, 1985)
- Respite widens the social network of the care recipient.



National Initiative to Delay or Avoid Long Term Care Placement

- Long Term Services and Support
 - Institutional Long Term Care
 - Community Based Long-Term Care Services and Supports:
 - Person-driven
 - Inclusive
 - Effective and Accountable
 - Sustainable and Efficient
 - Coordinated and Transparent
 - Culturally Competent
- Balancing Incentive Program authorizes grants to States to increase access to non-institutional long-term services and supports
 - Allows for partnerships with private sector
 - **Should** include respite as a home support



National Initiative to Delay or Avoid Long Term Care Placement

- Centers for Medicare & Medicaid Services
 - Supports initiative to improve quality of care and reduce cost
- Lifespan Respite Care Act of 2006 appropriates funds for:
 - Training paid and unpaid Respite Workers
 - Emergency Respite Services
 - Building Lifespan Respite programs in each state



Who Cares for the Caregivers and their Loved Ones?

- Respite is currently underfunded (recently cut in Illinois).
- Leads to a reliance on social service agencies, community supports and volunteer organizations as entitlement programs decrease.
- Caregivers prefer to have people they know provide respite for their loved ones.
 - They often rely on untrained family , friends, or neighbors.
 - REST-trained volunteers feel more comfortable providing respite.



How do we Create a Vast Network of Trained Volunteers?

- Educate agencies and organizations about non-traditional avenues of respite, and how they can increase resources and availability.
- Mobilize trained volunteers and workers through a variety of agencies and organizations to increase the availability of planned and emergency respite.

REST Program Structure

- REST is a Train-the-Trainer format that equips and prepares trainers to conduct an 8-hour volunteer respite training program.

- Similar structure/goals of national CPR Training programs:

- Provide effective, standardized training to as many individuals across the nation as possible
- Training structure resulting in high numbers of volunteers trained



- REST entered into a 3-year pilot program with the IL Department of Human Services – Division of Developmental Disabilities to provide the training and materials free to anyone living in Illinois and working with or caring for an individual with developmental disabilities.

Key Components of REST

Includes 10 Core Competencies aligned with
the National Respite Guidelines

*What is Respite?
The Role of the Respite Worker*

*Coping Strategies
Caregiver Assessment*

Confidentiality

*Communication
Tips*

*First Visit
Leisure Activities*

*Valuing Differences
Caregiver Thoughts*

Activities

*Universal
Precautions*

*Crisis Intervention
Handling Injuries*

*Understanding
Behaviors*

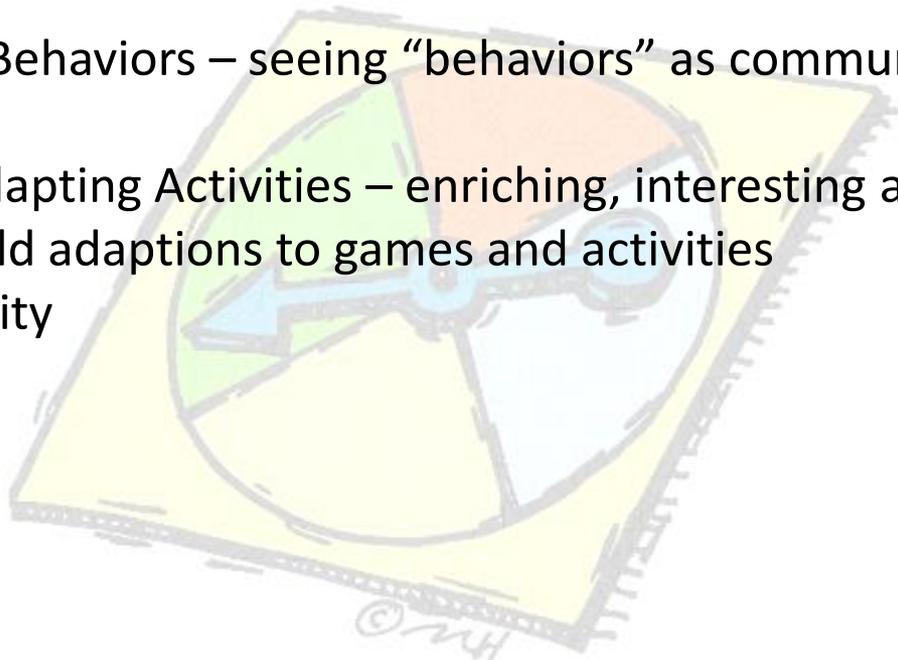
Volunteer Training Agenda

PREPARE	
20 minutes	Introduction
20 minutes	Respite: Definition/Value/Your Role
15 minutes	Crisis Intervention
25 minutes	Introducing the Caregiver and their Care Recipient
35 minutes	Building Your Relationship with the Caregiver and Care Recipient
15 MINUTE BREAK	
CARE	
10 minutes	Universal Precautions
15 minutes	Disability Awareness
25 minutes	Understanding Behaviors
CONNECT	
55 minutes	Assistance
LUNCH / SESSION BREAK	
25 minutes	Activities
40 minutes	Feeding
5 minutes	Hygiene/Grooming
15 minutes	Confidentiality
15 MINUTE BREAK	
FORMS	
55 minutes	First Visit
5 minutes	Leisure Interests
15 minutes	Coping Strategies
REFERENCES	
15 minutes	ARCH/ Volunteers
15 minutes	Closing/Next Steps

- This agenda allows for two 15-minute breaks and a 30-minute lunch.
- The course can be conducted in one 8-hour session or in two 4-hour sessions (session 1 would cover the morning topics, session 2 the afternoon topics).

REST Curriculum Examples

- Leisure Interest Survey – to gather in-depth information on the care recipients likes/dislikes, hobbies, activities, etc.
- Connections – to educate volunteers/workers and care recipients on appropriate interpersonal relationships
- Understanding Behaviors – seeing “behaviors” as communication
- Planning and Adapting Activities – enriching, interesting activities and simple household adaptations to games and activities
 - Group activity



Customizable Curriculum

- REST curriculum is applicable across the lifespan for individuals with special health care needs.
- Core Competencies must be included in all REST Volunteer Respite Worker classes.
- Trainers/organizations can add individualized content (placeholders in Instructor Guide)
 - Personal stories
 - Policies/procedures
 - Enhanced disability education
- Development of “Essentials of REST”, a four-hour course for supervised, group respite programs, including all core competencies.

What is Unique about the REST Program?

- Standardized training:
 - Aligns with National Respite Guidelines
 - Allows for customization
- Active learning:
 - Discussion
 - Group exercises
 - Experiential learning
 - Student-led presentations
 - Peer evaluation
- Modeling of Volunteer Respite Course



What is Unique about the REST Program?

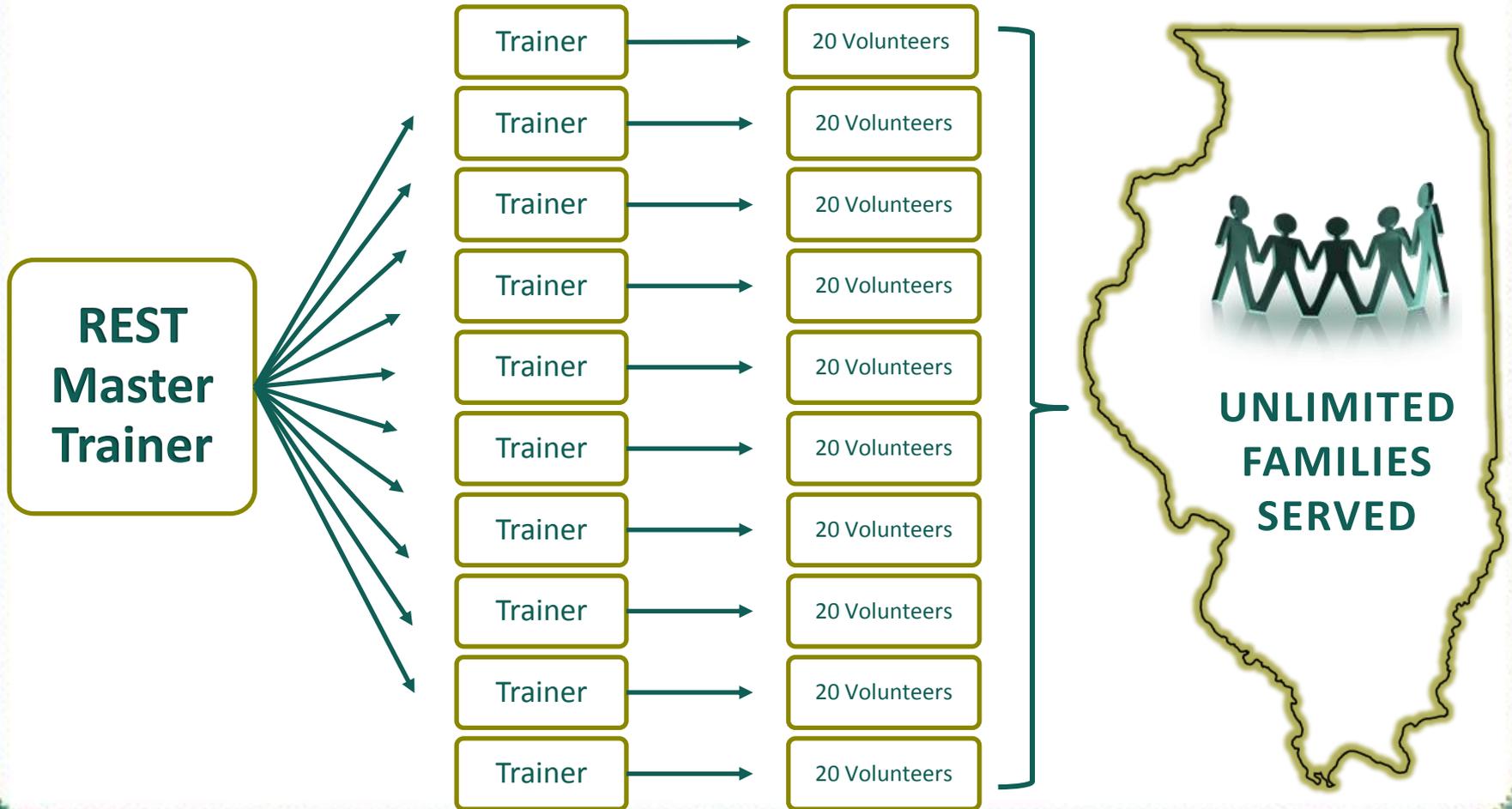
- Interactive training:
 - Experience of participants enriches course
 - Creates close, lasting connections
- Ongoing support from REST Team – successful mobilization



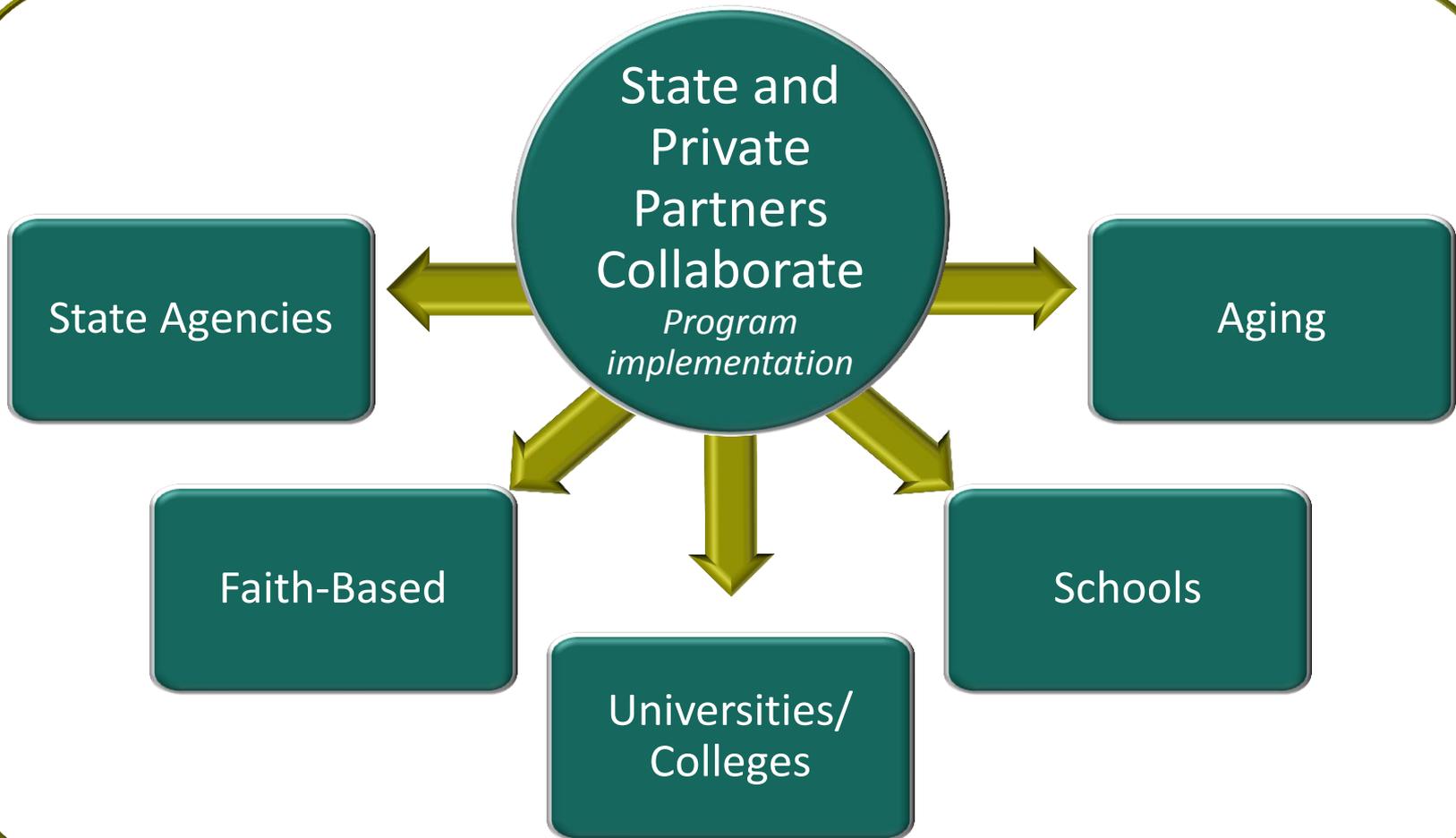
REST Program Impact

Impact of one Train-the-Trainer Course

1 Master Trainer → 10 Trainers → 200 Volunteers → Families Served



Volunteer Respite Models



Implementing the REST model Metropolitan Family Services, In-Home Senior Respite

- IHSR provides volunteers for families caring for an elder loved one in the home
- 472 families
- 35, 000 hours of Respite
- Over \$500,000 in salary value
- 3 hours a week for at least 6 months
- Social visits

Pre/Post -REST Training

- 4 Hours
- Covered Policies, procedures, aging, dementia, activities
- Agency produced
- Frankly, it was BORING
- 8 Hours
- Covered pre-REST subjects + boundaries, universal precautions, hands-on assistance, lifespan respite
- Adult learning techniques, interactive
- Professional participant/trainer guides, activity materials and supplies
- PowerPoint Presentation
- Website with access to document and network
- ENGAGING

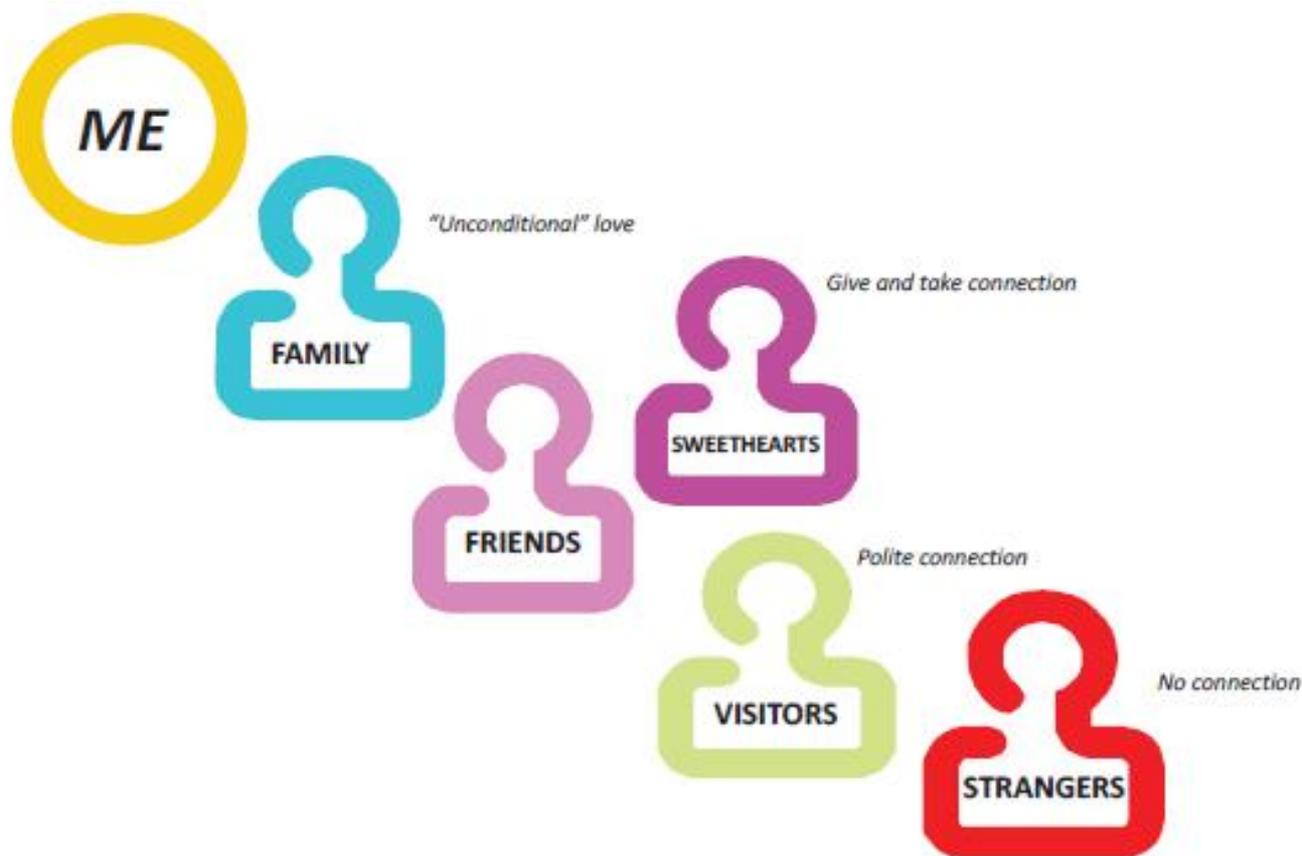
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- IHSR does not generate revenue of any kind
- Very few funding opportunities for Respite
- No evidenced based models
- Evidenced based outcomes from the REST program may lead to funding opportunities
- REST network may lead to partnerships and additional funding

Respite Grows Up

- REST is professional, standardized, and designed with knowledge and expertise
- REST training means being part of a larger network of respite professionals/volunteers
- REST brings legitimacy and professionalism to respite programs and volunteers by bringing the pieces together

Connections Exercise



Trainer Partnerships and Work Groups

- REST Team works to connect trainers from different organizations and disciplines to form partnerships and work groups
 - Partnerships between organizations that train volunteers and organizations who serve caregivers
 - Ex. Benedictine University and Metropolitan Family Services
 - Work Groups between trainers with different resources to mobilize a successful program by working together or sharing ideas
 - Ex. Schaumburg Work Group includes the Alexian Brothers Autism Spectrum and Developmental Resource Center, Bethel Baptist Church and Schaumburg Township

To learn more about REST visit our website at www.restprogram.org

Are you interested in:

Becoming a Trainer?

- **Kelly Fitzgerald**
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Becoming a Host Agency or learning about how to implement REST in your organization?

- **Lisa Esposito**
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- **Jody Kanikula**
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More information on the IL State Pilot?

- **Jenna Olznoi**
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Creating an international network
of organizations that prepares
individuals to support caregivers
through respite.



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