Got Respite?
Ask • Plan • Do

Amy Clawson
2013 National Lifespan Respite Conference
The Freedom Trail to Respite
Boston, MA
October 15-17, 2013
Got Respite?
Ask • Plan • Do

Learning Objectives:

1. Increase knowledge of the value of collaborative relationships to make an impact with family caregivers
2. Identify approaches to creating a strong respite awareness campaign
3. Share communication and outreach strategies
4. Inspire you

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What is a UCEDD?

“University Center for Excellence in Developmental Disabilities”

- funded by the federal government
- established 1963, guided by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act)
- part of a network of 67 UCEDDs with an umbrella organization, the Association of University Centers on Disabilities (AUCD)
- bridges families, communities, universities, and medical systems
University of Cincinnati (UC) UCEDD Mission

To be a leader in working with and on behalf of children and adults with disabilities and their families so they can lead the lives they want.

UC UCEDD accomplishes this mission through:
- education
- training
- research
- impact on policy and sharing information.
University of Cincinnati (UC) UCEDD Vision

All people, including children and adults with disabilities and their families, fully participate in society and live healthy, safe, self-determined and productive lives.
UC UCEDD’s Four Core Functions

- Community Education & Collaboration
- Impact on People with DD
- Information Sharing
- Interdisciplinary Training of Professionals

Respite
Role of UC UCEDD
Family Support Coordinator

• Parent of a child with a disability
• Intimately familiar with health and service systems
• Personal experience using respite and finding providers
• Participate and lead community efforts related to quality of life issues for people with disabilities and their families
Role of UC UCEDD Family Support Coordinator

• Host workshops and trainings on topics of importance to families caring for children with disabilities
• Information and referral
• Outreach to underserved populations
Key Relationships for Respite Efforts

• Parent Group Collaborative of Greater Cincinnati (PGC)
• Regional Respite Committee (County Boards of Developmental Disabilities)
• UC UCEDD Community Advisory Committee
• Health Professionals
Key Relationships for Respite Efforts

- Rubinstein-Taybi Syndrome Support Group
- Common Threads Network
- Parent Mentors in Southwest Ohio Schools
- PLANE0 (Hispanic Support Group)
- Family Members
- Family Advisory Council, Ohio Department of Developmental Disabilities
- Ohio Respite Coalition
Latino Parent Support Group (PLANO)

Do you speak Spanish and have a child with special needs? Want to get involved and help other families in Southwestern Ohio? Join PLANO!

Contact: Marbella Caceres at marbella@ocecd.org or 800-374-2806

Ohio Respite Coalition

Common Threads Network presents

The Affordable Care Act
"Bringing the Benefits to You!"

For families of children and adults with developmental disabilities

Wednesday, August 14, 2013
3:00pm-12:00pm

Butler, Clermont, Hamilton, and Warren counties

Featuring

Amy Ruhling McGuire, Health Policy Institute of Ohio

This is information you need to know as a family leader support locations and policy. The information will be presented in simple, easy-to-understand language. It will be provided in English and Spanish. Learn more about specific services and how to receive them.

Western Community Church
11110 New Canyon Road, Melbourne, Ohio 45256

Reserve a seat

1-855-369-6223 or ohio.affordablecareact.net

University of Cincinnati
Got Respite?

What is it?
• Respite Awareness Campaign
• Began March 2013

Who is it for?
• Families who care for children and adults with developmental disabilities in Southwest Ohio
Got Respite?

Why?

• Lack of information available to family caregivers
• Families, professionals, and community did not have accessible respite resources
• Reduce crisis and isolation
• Families could not find providers
• Teach families why it is important and how to build trust
Our Process

• Mobilize Collaborative Partners
• Build on Strong Foundations
  - Ohio Respite Coalition (2010)
  - Respite Speed Interview events (2012, 2008)
Our Process

- Parent Group Collaborative
  - 2009, Created online respite repository of existing respite resources for families
  - In Home & In the Community

- Collect Data
  - from past respite events
  - using focus group of families, professionals, community partners (2012)
Our Process

What did we learn?

- Family stories make a difference to impact change for new services
- Existing provider lists not helpful to families; they already had their own clients
- Families did not understand the word “respite”
Our Process

What did we learn?

• How to help families regardless of systems barriers
• Respite is not dependent on ‘waivers’
• Trust
• Take a break – normalize the message
• Respite options are available
• Natural supports
• Parent Co-ops & Networking opportunities
Our Process

Basic tips families needed to know:

1. Always get a background check
2. Start early, *Good for You AND Your Child*
3. Value of respite across the lifespan
4. Each county board of developmental disability had/has some form of respite resources
5. Some respite is FREE
Our Process

Four Priorities established with Key Collaborators:

1. Educate families about respite.
2. Encourage families to make use of respite.
3. Assist family caregivers in finding quality providers.
Our Process

Four Priorities established with Key Collaborators:

4. Develop a mechanism to share information among the county boards of developmental disabilities to learn about unique respite programs that are cost effective and successful.
What does our Community need to create a Strong Respite Awareness Campaign?
Three Major Activities

1. Create respite brochures, in English and Spanish

2. Develop respite website [www.ucuceddd.org/respite](http://www.ucuceddd.org/respite)

3. Raise respite awareness
Got Respite?
Develop Brochure & Website

Bring collaborators into every step - writing, reviewing, and editing:

• Messages
• Fact finding
• Layout
• Photos
• Quotes
• Contact information
Considerations

• Is it family friendly? Colorful? Informative?
• Content reviewed by families and professionals not involved in process
• Diversity considerations
• Accessibility (visually and readability level)

GOAL: Collaborative partners were invested in respite awareness
Respite Care is a Temporary Relief from the Responsibilities of Caring for a Loved One

Did You Know?
There are between 115,000 and 152,000 children in Ohio who have a disability.*

Data shows that families caring for a child with a disability have more emotional stress.*

We know that families caring for a child with a disability have less social support, more health care burdens, and financial worries.*

*Reported in the Impact of Caring for Children with Disabilities in Ohio (Goudie, 2010), a white paper prepared for the Ohio Developmental Disabilities Council.

You Have Options!
Respite In Your Home
- Ask a friend or neighbor for a break
- Hire a certified provider or recruit a college student
- Swap time with a friend who has a similar need

Respite Out of Your Home
- Recreation / social programs
- Day camps / weekend camps
- Community ‘Respite’ event
- Using time during your child’s therapy appointments

“I take yoga classes or go to lunch with a friend when my son is with a caregiver.”

“Respite - good for you and your child
We enjoy respite because our daughter gets a break from us! She gets to have fun with somebody new.”

“I use respite so that my husband and I can go to dinner without guilt. It’s a time to get refreshed and stay connected while my child goes to camp.”

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Respite: A Temporary Break for Families to “Refresh”

Family caregivers work hard every day to provide the best care possible for their loved ones. However, everyone needs a break from caregiving once in a while. Short-term breaks from responsibilities allow families to continue doing their best. If you are a family caregiver, an important part of being a good caregiver is taking care of yourself. Whether you have a child with a disability or an adult with special needs, using respite to refresh is one way to do this.

Who are Family Caregivers?
Parents          Siblings
Grandparents     Relatives
Close Friends

Family caregivers care for a child or adult with a disability or chronic illness on a regular basis.

“When my son is with a respite provider, my family has a chance to relax and enjoy time with each other. It’s the gift of time and peace of mind to know my son is safe and his needs are met.”

What is Respite?
Respite is the temporary relief from responsibilities of caring for a loved one. It is an important form of family support. Respite allows families to take a break, spend time together, or enjoy time alone.

Why is Respite Important?
Research shows that raising a child with a disability can be very stressful. Families face emotional, financial, social, and physical challenges.
Respite improves the family’s ability to cope. It can build the strength needed to cope with day-to-day challenges.
Respite is important because it allows families to spend time with friends and with each other. Respite can improve the overall health and well-being of caregivers.
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Respite can also help the child or individual to grow and form new relationships with other people outside their family.

Make a Plan for Respite

Once families understand the value of respite care services, many schedule it regularly. This can avoid a crisis or exhaustion. Respite should be helpful and enjoyable for family caregivers and the child.

Learn more about respite using the navigation below:

- Types of Respite
- How to Pay for Respite
- Types of Providers
- Finding a Provider
- Respite Brochure
- Respite Resources

Questions? Please contact Amy Clawson, Family Support Coordinator, UC UCEDD at amy.clawson@cchmc.org or 513-636-4723

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Outreach Strategies with Partners

• Over 1,000 brochures disseminated since March 2013

• Train parents and support groups

• Intake and referral to assist families in respite options

• Train community professionals in the field

• Promote information with key collaborators
Outreach Strategies with Partners

• County boards linked to website, posted on Facebook, newsletters, etc.

• Hospitals / clinic waiting rooms

• School programs

• Public libraries

• Help Me Grow (Birth to 3 Programs)
Next Steps

• Respite website launched, March 2013

• Continue to promote brochures and online resources

• Train professionals, including county boards

• Continue collaborations / problem-solving:
  - families whose children have the greatest needs
  - families who have the highest need for respite
  - match families with specialized providers
  - crisis and emergency options
Got Respite?

You have options
It’s good for you and your child

The first step is to ask.
Be inspired to plan it.
Do it!

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Questions
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www.ucuceddd.org/respite