



Ohio Respite Summit

Friday, March 4, 2011



Summary Report

Ohio Respite Summit, March 4, 2011

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On March 4, 2011, a steering committee made up of representatives from the Down Syndrome Association of Greater Cincinnati, Easter Seals, Epilepsy Foundation, Greater Cincinnati The Parent Group Collaborative of Greater Cincinnati and Ohio Department of Aging hosted an all-day Ohio Respite Summit at the Ohio Rehabilitative Services Commission office in Columbus. The Committee was supported by funding and/or technical assistance from the Administration on Aging, ARCH National Respite Network, and the Ohio Developmental Disabilities Council.

Over 90 participants from across Ohio attended the Summit representing a wide range of needs, caregivers, disabilities and organizations. Multiple state agencies participated including: Governor's Council on People with Disabilities, Ohio Department of Developmental Disabilities, Ohio Department of Mental Health, Ohio Department of Youth Services, Ohio Department of Aging, Ohio Department of Job and Family Services and Ohio Family and Children First Cabinet Council. A representative of Ohio's Aging and Disability Resource Center Network also participated.

The format for the Summit included plenary and breakout sessions. Plenary sessions included personal family caregiving stories (multiple caregivers), The Need for Respite in Ohio (Janet Gora, Executive Director, Down Syndrome Association of Greater Cincinnati and Member of Parent Group Collaborative of Greater Cincinnati), and Understanding LifeSpan Respite & Statewide Respite Models (Jill Kagan, MPH, Program Director, ARCH National Respite Network). Plenary session PowerPoints are available at <http://aging.ohio.gov/resources/nationalfamilycaregiversupport/>. In addition, at the conclusion of the Summit Bonnie Kantor-Burman (Director, Ohio Department of Aging) offered support and encouragement to the participants.

Participants worked together in morning and afternoon breakout sessions. In the morning five groups identified existing supports and services, and identified strengths, barriers and unmet needs. In the afternoon these same groups discussed building the Ohio Respite Coalition, identified the needs of the Lifespan Respite System in Ohio, and identified the characteristics of a "Dream system." A combined summary of the breakout discussions is attached.

After breakout report-outs and discussion participants were asked to sign-up (attached) for committees and a list-serve that will be used to move the Ohio Respite Coalition forward. Twenty-five participants volunteered to serve on the Ohio Respite Coalition's Steering Committee which will have their first meeting on April 7, 2011 at the Rehabilitative Services Commission.

Attached are the results of a participant evaluation conducted at the end of the Summit. Based on participant feedback the Summit was very effective and increased the participants' knowledge in the subject matter.

The results of the Ohio Respite Summit and this report will be used to help support the creation and work of the Ohio Respite Coalition, and inform and support Ohio's Lifespan Respite grant application to be submitted to the Administration on Aging in spring 2011.

For more information, on lifespan respite and caregiver support programs visit www.caregiver.org and www.archrespite.org.



Ohio Respite Summit

Friday, March 4, 2011

AGENDA



9:00 AM – 9:30 AM

Registration

9:30 AM – 9:45 AM

Welcome and Introductions

- Pat Luchkowsky, Co-Chair, Charter Ohio Respite Coalition
- Bonnie Kantor-Burman, Director, Ohio Dept. of Aging

9:45 AM – 10:15 AM

Respite....What a Relief

Personal family caregiving stories

10:15 AM – 10:45 AM

The Need for Respite in Ohio

Janet Gora, Executive Director, Down Syndrome Association of Greater Cincinnati & Member of Parent Group Collaborative of Greater Cincinnati

10:45 AM – 11:30 AM

Breakout Sessions

- Participant's share their respite connection
- Identify systems or help already existing to help families
- Identify strengths, barriers and unmet needs

11:30 AM – 12:00 PM

Report Back

12:00 PM – 12:30 PM

Lunch

12:30 PM – 1:45 PM

Understanding Lifespan Respite & Statewide Lifespan Respite Models

Jill Kagan, MPH, Program Director, ARCH National Respite Network

1:45 PM – 2:45 PM

Facilitated Breakout Workgroups

- Building the Ohio Respite Coalition
- Needs of the Lifespan Respite System in Ohio
- Service needs for Lifespan Respite

2:45 PM – 3:00 PM

Break

3:00 PM – 3:30 PM

Report Back

3:30 PM – 4:00 PM

Next Steps - Commitment

4:00 PM

Adjourn

Next coalition meeting is April 7, 2011 (9:00 AM – 12:00PM)



Special thanks to the Ohio Developmental Disabilities Council for generously supporting this event!



This project is supported, in part, under a grant from the U.S. Department of Health and Human Services, Administration on Aging. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. These contents, however, do not necessarily represent the policy of the U.S. Department of Health and Human Services and endorsement by the Federal Government should not be assumed.

FINAL

COMBINED WORKGROUP DISCUSSION

What are some of the strengths of the respite system in Ohio?

Availability of Resources and Supports – beginning volunteer programs, waivers include in home and institutional respite care, AoA has some money/funding for respite, families in Ohio are providing the lion's share of respite services currently, faith-based community recognizes the need and is willing to help with respite, inventive families, program giving (gift cards).

Choice and Responsiveness – Self-determination, recipients come back, there is flexibility in what constitutes respite, counties are doing creative helpful things, choice - can choose family and friends as providers, definition of respite has expanded, there is flexibility in the waiver system and with County board funds.

Leadership and Collaboration – People here today are working on this and will stick with it, this coalition is a multi-faceted group with a lot of experience in respite, people are willing to partner with each other to improve supports, efforts are currently being made to make the various state systems more compatible and easier to navigate - in the future there will be a "front door" for everyone..

Awareness of Supports and Services – Good word of mouth, aging and disability resource centers (networks in Ohio, more county board fairs that provide face to face interaction with families who need respite, awareness of respite is improving, people in general are willing to help when they know of the need, families/caregivers have access to more information today because of the internet.

Population and Location Specific Strength – Knowledge of Long-term care consultants (Adults), some counties are flexible with supported living dollars, funding for family support for Department of Developmental Disabilities, funding in Media Counties agencies SHC-ARC, provider agency availability (Adults), caregiver education and support in the Alzheimer's system.

What are the barriers, weakness and unmet needs of the current respite system in Ohio?

Lack of or ineffective use of funding – funding not set up for one time or sporadic nature of respite, potential double dipping (waivers), funding allocated in silos, lack of funding for training, funding not being used to maximum potential, disparity between rates of reimbursement, funding and portability is confusing, everything is based on money and funding.

Lack of effective coordination of care - lack of coordination within and across systems – caregivers have to be their own case managers, not consistent from one county to the next, cross agency cooperation is infrequent, limited coordination and linking of services across silos, services coordinators not universally informed about what’s available and who’s eligible.

Lack of quantity and quality of providers - lack of qualified providers, inconsistent training of providers, no standardized provider training, lack of out of home respite, need more “Quality” Providers vs. “Qualified” providers, provider training is confusing and complex, low pay for providers, limited access to training for volunteers, no career paths/matrix, limited use of volunteers, in some areas specialty of providers is not known or recognized, complicated provider certification process with ODDD, need for localized specialization or experts, government employees (county board staff, teachers, etc.) currently cannot work for families on their off time.

Gaps in Services – needs of individuals with behavior issues/disorders, widespread waiting lists, especially for county levy services, no services for the near eligible or on waiting lists, kids with high support needs, in-home respite, age-out of programs/services (e.g., camps), lack of qualified/trained specialist for out-of-home respite and in-home respite for specific populations, lack of emergency respite, lack of holiday and weekend respite.

Gaps in Coverage – age, disease/disability (TBI), rural areas (seniors), no statewideness, aging parents supporting aging children with developmental disabilities, juvenile justice system releases youth from incarceration and expect parents/foster parents to deal with their issues without respite.

Lack of information/knowledge – lack of training across systems and programs, limited awareness of independent contractors, limited knowledge of how Medicaid really works, no provider registries, the term respite is not clearly understood, benefits and need for respite not recognized, respite not marketed effectively, families do not know how to access respite/providers, some consider it negative, lack of a single point of access (e.g., 800 number) for respite, lack of media attention/champion, relying too much on internet for information and access, more needs to be done to tell the positive stories of respite.

Conflicts in care philosophies – active vs. nursing care, lack of family centered approach which meets interrelated family needs.

Stigmas/family dynamics – allowing strangers in the home, helping people understand/identify themselves are caregivers, people are reluctant to ask for help or don’t know how to get help, the person needing care does not want outsiders to be brought in for that care, reluctant to involve outside agencies for fear of children’s services or adult protective services, families feel isolated and don’t think the community understands their needs or their child’s issues – parents of children with behavioral issues are viewed as bad parents, stigma attached to using respite, the thinking

that no one can do it better than me, diverse opinions on needs and approaches among family members, especially those who do not live close by.

Other – lots of paperwork, compliance with eligibility requirements, siblings aren't allowed at in-home or center based respite so families have to find respite for them too, DD doesn't license respite homes anymore, who are the stakeholders.

Who else needs to be part of or partner with the Ohio Respite Coalition to ensure all family caregivers are served regardless of age or disability (please be as specific as possible)?

211 Systems, 4 C's, AARP, Acton for Children, advocacy groups, Aging and Disability Resource Network, all disability groups, Alzheimer's Associations Chapters, Area Agencies on Aging, ASILC, ASL Association (Amyotrophic Lateral Sclerosis), Association of Deaf and Blind/Visually Impaired, BCMH, Boys and Girls Clubs, Cancer Society, CareStar, Case Managers, Centers for Independent Living, Cerebral Palsy of Ohio, Children's Hospitals, Children's Sanctuary, Children's Services, Children's Trust Fund, Colleges and Universities, Cook Family Foundation, County Boards of Developmental Disabilities, County Commissioners, County Family and Children First Councils, Crisis Centers and Nurseries, CSB, Disability Network, Divisions of Nursing, Employers, Faith based organizations, Families, Funeral Homes, OLRS, Goodwill, Governor's Council for People with Disabilities, Governor's Council on Appalachia, Governor's Office of Faith-Based Initiatives, HAVAR, Health related Organizations, Hospital Associations, Join and Friends (Faith-based Ministry), Juvenile Courts, Kinship Navigators, Latchkey Programs, Local Health Departments, Maternal and Child Health, Media, Medical Associations, Mental Illness and Dual Diagnosis, Midwest Care Alliance, MS Society of Ohio, NAMI, National Association of Dual Diagnosis, National cancer Support Network, NECCOS, Nursing Homes, OACCA - Foster Care, Ohio Association of County Behavioral Health Authorities, Ohio Association of County Boards, Ohio Benefit Bank, Ohio Board of Regents, Ohio Commission on Minority Health, Ohio Council for Home Care, Ohio Department of Mental Health, Ohio Department of Health - Help Me Grow, Ohio Department of Aging, Ohio Department of Developmental Disabilities, Ohio Department of Education - Department of Special Education, Ohio Department of Job and Family Services, Ohio Family and Children First, Ohio Family Care Association, Ohio Federation for Children Mental Health, Ohio Legal Rights, Ohio Rehabilitative Services Commission, OPRA, Parent Mentors (OCECD), Parks and Recreation Departments, Physicians, PLANEQ, Politicians, Providers, Public Family's Serving Agencies of Ohio, Recreation Organizations, Red Cross, Salvation Army, State Support teams (regional centers on education, Stepping Stone (Cincinnati), The Arc of Ohio, United Way, Veterans, W/A.

Based on what you know and learned today, which overall infrastructure would be best for Ohio's Lifespan respite Program? What would a "dream" system look like?

Based on identified strengths, barriers and unmet needs, what services should the Ohio Lifespan Respite Program provide to overcome obstacles or build on strengths?

Principles – A system that crosses the lifespan, able to connect/coordinate services/supports, features blended/flexible funding, is consumer-directed, and offers one-stop access (online and by phone).

Attributes of System –

- **One provider certification for all – general specialized training**
- **Recruits and develops providers**
- **Provides training to develop specialized services of behavior and medical respite providers**
- **Allows government employees (county board staff, teachers, etc.) to work for families on their off hours.**
- **Develops an elite respite corps where respite workers go through a series of trainings to reach higher levels and get paid more for their expertise**
- **Offers a clearinghouse/registry of names of those qualified to provide respite services so families can find ones that match their needs.**

- Offers holistic services that take into account the rest of the family: siblings, elderly parents, etc.
- Matches up needs of the family with experience of the respite provider

- **Offers the flexibility of vouchers**
- **Pools funds like Oklahoma model (but pooled funding makes some nervous)**
- **Access to a wide variety of funding sources for those who aren't on the waiver and need to pay out of pocket**

- Offers One-on-One Consultation
- Provides access to transportation
- Offers support groups and networking
- Provides more training on coping skills to caregivers to reduce stress and increase supports

- Offers a variety of respite services including: out of home respite, emergency respite, on demand respite, and weekend/holiday respite
- **Establishes a No Wrong Door system so that families are helped no matter where they start**
- **Provides an 800 number to call answered by an expert who understands funding streams, center-based and in-home respite**
- **Uses Ohio benefit Bank as a potential portal**
- **Uses Aging and Disability Resource Centers as a potential portal**
- **Provides web-based tool with a feature to walk parents through the maze of funding, services, etc.**
- **The person or 'coordinator' of the centralized system should have extensive training and knowledge re: all agencies and benefits**
- **Create a centralized benefit system – a central repository of information (ex: create a website, a 800#, and always speak to a real person who can direct you**
- **Should cut-through red tape and make services the key component**

Preferred Models -- Miami County Model, OASIS System, Oklahoma Model, No Wrong Door

Organizational - Hire a staff with grant money for follow through and expertise, advocates for funding and act as a liaison to coalition agencies, hold an annual respite Summit at state or regional levels, create a statewide Advisory Board made up of consumers, not agencies, Statewide Respite Coalition who is responsible for getting information to the local levels however they are organized. Need Governor's Office on Health Transformation to make a decision on which agency will lead the ORC and grant.

Commitment Responses from the Summit

Coalition Members/List Serve

Aimee Matusik*	Ohio Dept. of Health
Amanda Jividen	Anne Grady Corporation
Amy Clawson	Cincinnati Children's Hospital
Amy Willis	Logan Co. Board of DD
Amy Sealts	Family and Children First Council
Angela Sausser Short	Family and Children First Council
Angie Snell	Sandusky County Re-Entry
Ann Snyder	The ARC of Hamilton County
Barbara Igo	New Beginnings Behavioral Health
Beverly Laubert*	Dept. of Aging – Ombudsman
Brandi Nicholson	Ohio Dept. of Job and Family Services
Brenda Rock	Council for Union County Families
Carol Hemphill	Logan Co. Board of DD
Cheryl Wheeler	Goodwill Easter Seals Miami Valley
Cheryl Crawford*	Parent
Cheryl Weber	Spectrum Consulting Services
Chmala Schoeppel	Parent Advocacy Connection
Chris Link	Recreation Unlimited
Christine Keran*	Sunshine, Incorporated
Christine Reed	Spectrum Consulting Services
Colleen Miller	Ohio Coalition for the Education of Children with Disabilities
Darlene Vandine	Area Agency on Aging 8
David Hudler	Recreation Unlimited
Dee Bura	Abilities Resources
Despina Bourbakis	Respite Provider
Donna Owens	Ohio Center on Autism and Low Incidence
Eric Rathburn*	Assistive Technology of Ohio
Eve Fitch	Family & Children First Council – Franklin County
Frieda Barnhart	Parent/Support Group Coordinator
Harmony Hensley	Vineyard of Cincinnati (Faith-based org.)
Helen Chan	Independent Respite Provider
Holli Stetten	Easter Seals Central & Southeast Ohio
Jackie Kolesar	Montgomery Co. Board of DD
Janet Gora	Down Syndrome Association of Greater Cincinnati
Jeannie Stahl	Allen Co. Board of DD
Jennifer Wolford	Family Voices
Jessica Hawk	Parent
Jim Huntington	Ashland Co. Board of DD
Juanita Perry	Franklin County Office on Aging
Julie Hess	Family Care Options

Karen Waddle	NAMI
Karen Ezirim	Parent
Karen Skeels	Lucas Co. Board of DD
Kathy Bachman	Family Voices/ Parent
Kathy Sell	Catholic Social Services Miami Valley
KB VonDerau	Green County Council on Aging
Kevin Shepherd	Dept. of Youth Services
Kathy Foley	Linking Employment, Abilities and Potential (LEAP)
Kim Humphrey	Dept. of Youth Services
Kim Weimer	ECRN
Kimberly Blanton	Oasis Choice Services
Larry Green	LCHI – Newark
Laurel DuBeck	Area Agency on Aging 9
Lauri Kaplan	Ohio State School for the Blind
Leigh Reed*	ALS Association
Lillian Hull	All Staff Medical
Linda Garrick	Ohio Dept. of Mental Health
Lynn Dobb	Central Ohio Area Agency on Aging
Lynne Fogel	Parent
Marc Molea	Ohio Dept. of Aging
Marge Barnheiser	Down Syndrome Association of Central Ohio
Marikate Leavens	Heritage Day Health
Mark Findley	Epilepsy Foundation of Cincinnati
Marla Root	Step by Step Academy
Mary Wright	Respite Connections
Melissa Ramey	Ross Co. Board of DD
Melissa Woehrman	Alzheimers Association
Michelle Caserta	Goodwill Easter Seals Miami Valley
Michelle Hoerig	Sunshine, Inc.
Michelle Merrill	Ottawa Co. Board of DD
Miriam Rose	Benjamin Rose Institute
Misty Milstead	Hocking Co. Family & Children First Council
Mozelle Mackey	Ohio Dept. of Aging
Nancy DeKatch	Joseph DeKatch Caregiver Association
Nicole Nagendram*	Parent
Nicole Thompson Mills	Ohio Rehabilitation Services Commission
Nina Wichard*	Council on Aging Southwest Ohio
Pamela Carter	Ohio Rehabilitation Services Commission
Pat Luchkowsky	Easter Seals of Ohio
Patti Love	Parent
Patty Callahan	Central Ohio Area Agency on Aging
Patty McMahon	The ARC of Hamilton Co.
Pauline King	Area Office on Aging NW Ohio
Peggy Clary*	ALS Association Central/Southern Ohio

Peggy Keener	Brain Injury Association of Ohio
Peggy Martin	Ohio Dept. of Developmental Disabilities
Rachel Perlstein	Clermont Co. Board of DD
Rebecca Wheelersburg	Scioto Co. Children & Family First Council
Renee Lammers	Greene Co. Children & Family First Council
Sally Clingman	Ohio Dept. of Developmental Disabilities
Sarah Kohls	Ross Co. Board of DD
Scott Campbell	Southeastern Ohio Center for Independent Living
Shania Allen	Lawrence Co. Board of DD
Sharon Honnert	Parent Mentor
Sheila Hall	Parent Mentor – Bridges to Transition
Stacy Borger	Family Care Options, Inc.
Sue Williams	Ohio Dept. of Job and Family Services
Teresa Cook	Area Agency on Aging 5
Teresa DiSalvo	Family Care Options, Inc.
Tom Lewins	New Avenues to Independence
Toni Glandon	Ross County Health District
Traci Sebastinas	Consumer Advocacy Model
Trevor Dunlap	The NuHop Center
Yvonne Tenant	Parent

* List Serve Only

Committee Sign Ups

Steering Committee/Structure

Renee Lammers – Greene Co. FCFC
 Marla Root – Autism Society
 Angela Sausser Short – Ohio FCFC
 Sue Williams – ODJFS
 Angela Schoepflin – NAMI/Parent Advocacy Conn.
 Dee Bura – Abilities Resources, Inc.
 Mary Wright – Respite Connections
 Patty Callahan – Central Ohio AAA
 Lynn Dobb – Central Ohio AAA
 Peggy Keener – Brain Injury Association
 Teresa Cook – AAA 5
 Jessica Hawk - Parent
 Cheryl Wheeler – Goodwill Easter Seals Miami Valley
 Sharon Honnert – Parent Mentor
 Kathy Bachman – Family Voices
 Jennifer Wolford – Family Voices
 Marikate Leavens – Heritage Day Health Centers

Pauline King –Area Agency on Aging
Peggy Martin – ODDD
Amy Clawson – Cincinnati Children’s Hospital
Janet Gora – Downs Syndrome Assoc. Cincinnati
Mark Findley – Epilepsy Foundation Cincinnati
Marc Molea – ODA
Pat Luchkowsky – Easter Seals
Colleen Miller – Ohio Coalition for the Education of Children with Disabilities
Miriam Rose – Benjamin Rose Institute
Karen Waddle – NAMI/Parent Advocacy Connection

State Contacts to Support Proposal

Donna Owens - OCALI
Rachel Perlstein – Cuyahoga Bd. Of DD
Jackie Kolesar - MCBDD
Pauline King – NW Ohio AAA
Kevin Shepherd – Ohio Dept. of Youth Services
Karen Skeels – Embracing Diversity
Linda Garrick – ODMH

Membership/Communications

Michelle Caserta – Goodwill Easter Seals Miami Valley
Pamela Carter – Governor’s Council on People with Disabilities
Kathy Foley - LEAP
Ann Snyder – ARC of Hamilton Co.
Patty McMahon – ARC of Hamilton Co.
Karen Knavel – New Avenues to Independence
Sally Clingman – Ohio Department of Developmental Disabilities

Grant Writing

Kelly Kaupinis – Easter Seals
Linda Garrick – ODMH
Miriam Rose – Benjamin Rose Inst.
Marc Molea - ODA
Pat Luchkowsky – Easter Seals
Pamela Carter – Gov.’s Council on PWD

Ohio Respite Summit/Evaluation Results

Did the summit meet your needs by:	A Great Deal				Not at All
	5	4	3	2	1
1. Providing presenters who were knowledgeable about the subject matter and effective in presenting information?	Ave. 4.76 N = 51				
2. Introducing information in an understandable manner?	Ave. 4.71 N = 51				
3. Presenting material in an organized fashion?	Ave. 4.76 N = 51				
4. Providing effective handouts and/or visual aids?	Ave. 4.76 N = 51				
5. Increasing your knowledge of the subject matter?	Ave. 4.68 N = 50				
Please rate your confidence in the subject matter covered:	Very High			Very Low	
	5	4	3	2	1
6. Before participating in the summit, how would you have rated your knowledge of the subject matter?	Ave. 2.94 N = 51				
7. Now that you have participated in this summit, please rate your knowledge of the subject matter.	Ave. 4.27 N = 51				
Please rate your response to:	Very Effective			Not at all effective	
	5	4	3	2	1
8. Overall, how effective was this summit?	Ave. 4.59 N = 51				

Comments:

"How can you join coalition?" Cgreen0452@yahoo.com

"Great program, just need tables to set at, a lot of info just to hold on to. Real great information. I would like to help on committees"

"I would have like table to write or eat lunch."

"Please continue to provide this program, it was very helpful..."

"I really don't have much hope that anything will change as long as each county has their own rules that differ from county to county. Before there can be change and collaboration we must streamline the vast number of agencies we currently have."

"Great representation at mtg. & work done. Group 5 facilitator did great job leading discussions – we came up w/ a lot of great issues/ideas to take into consideration –"

"Inspiring! This is a fantastic group dedicated to their fellow man/woman and child."

"Had to stay awake after lunch"

"What is our scientific data on the wishes of families who need respite?"

"The Autism Society is very interested in supporting and being on a committee about this. Thank you." - Marla Root, Barb Yavorcik

"Thank you for organizing and presenting this program".

"Great information - Enjoyed meeting & learning about other organizations"

"The summit brought out the issues/problems -- And established the NEED"

"I am very new to respite – as in "institutional respite." Before today I did not know respite included so many services, ages, etc. Wonderful day and so informational & beneficial to me."

"I enjoyed this summit and the level of expertise of participants. As an advocate and a parent of a child with disabilities this is a very valuable initiative. I am committed to the coalition."

"Great job – All looking forward to working on this - Thanks to all!"

"A break between the presentation by Jill Kagan and the breakout groups would be helpful to review the "best practice" models etc. (I realize that this meeting was a "one shot" deal in terms of introducing the project.)"

“Please make sure that Centers for Independent Living are an integral part of the “system” model. Increasing the independence of people w/ disabilities impacts the caregivers and CILs can support and provide ILiving Skills training and support”

“Great spirit & energy! I think we could do anything”

“Need coffee in afternoon!! ☺”