



*Strengthening the Delivery of  
Family Caregiver Education  
through Partnerships*

**Assessing strengths and weaknesses in  
meeting the educational needs of Wisconsin's family caregivers**

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# Executive Summary

## *Strengthening the Delivery of Family Caregiver Education through Partnerships*

The Wisconsin Alliance for Family Caregiving is a statewide organization of educators, social workers, health-care providers, aging-network professionals and others dedicated to offering education, resources and support to professionals who work with family caregivers.

Last year the Alliance held 12 listening sessions across the state to assess Wisconsin's strengths and weaknesses in meeting the educational needs of family caregivers. 168 professionals from 33 counties attended the sessions, sharing information on:

- existing caregiver resources and support,
- gaps in caregiving resources and support and
- ideas on how the Alliance can fill some of those gaps.

During listening sessions caregiving professionals identified six major concerns:

- family caregivers not identifying themselves as caregivers and consequently not participating in educational programs;
- family caregivers' reluctance to accept help and thus not recognizing education as a potential coping strategy;
- gaps in family caregiving education;
- lack of visibility of existing community services;
- overall lack of adequate services and funding; and
- lack of community support for family caregivers.

The Alliance will use data gathered during listening sessions to develop a strategic plan to meet the educational needs of family caregivers throughout Wisconsin.

### **Recommendations**

The Wisconsin Alliance for Family Caregiving identified the following recommendations, which a newly-expanded board of directors will use to develop a strategic plan:

1. Grow a statewide network of trainers who conduct educational programs, institutes and seminars for family caregivers throughout Wisconsin.
2. Connect with professionals, agencies and organizations in a noncompetitive forum to identify the educational needs of family caregivers. Review existing programs and create others to fill identified gaps in educational programs for family caregivers.
3. Build on the existing strengths, networks and experiences of Alliance partners to develop, distribute and evaluate caregiving education.
4. Offer a central resource for educational programs with links to regional coalitions, such as the Caregiver Support Network of Ashland and Bayfield Counties, the Chippewa Valley Family Caregiving Alliance and others.

5. Develop the Alliance web site into a one-stop service where professionals can learn about national, state and local caregiving education; best regional and local practices; and programs whose funding may have expired but have relevant content.
6. Develop statewide educational programs that address basic caregiving issues and concerns, complemented by content that recognizes Wisconsin's geographic and cultural diversity.
7. Identify potential partners and serve as a technical resource for partnerships, alliances and coalitions that deliver educational programs to family caregivers.
8. Expand the Alliance's current leadership committee into a board of directors with additional partners.
9. Develop a strategic plan, with accompanying action steps, based on this report's recommendations.
10. Leverage resources for the Wisconsin Alliance for Family Caregiving to ensure long-term sustainability.

The Wisconsin Alliance for Family Caregiving would like to thank the many dedicated, caring individuals who participated in the listening sessions. Their willingness to share their knowledge, insight and ideas will enable us to fulfill our vision of helping family caregivers maintain their health and well-being throughout Wisconsin.

To learn more about the listening sessions or the Alliance, contact Mary Brintnall-Peterson at [mary.brintnall-peterson@ces.uwex.edu](mailto:mary.brintnall-peterson@ces.uwex.edu), D'Anna Bowman at [DBowman@aarp.org](mailto:DBowman@aarp.org), Linda Marty Schmitz at [marsch@chorus.net](mailto:marsch@chorus.net), or visit the Alliance's web site at <http://www.uwex.edu/ces/flp/caregiving>.

# Summary

## *Strengthening the Delivery of Family Caregiver Education through Partnerships*

### **Purpose: caregiver education**

The purpose of the listening sessions was to gather data for a strategic plan on how the Wisconsin Alliance for Family Caregiving can boost the level of caregiving education in Wisconsin by providing educational resources for professionals who work with family caregivers across the state.

A one-year planning grant from the UW Medical School's Partnership Fund for a Healthy Future funded the strategic planning process. During 12 listening sessions throughout Wisconsin, we asked individuals who work with family caregivers this question: How can the Alliance help you provide education, information, resources and support to family caregivers?

### **33 counties represented at listening sessions**

Listening sessions were held at: Stevens Point (April 15), Janesville (April 26), Green Bay (April 28), Appleton (April 29), Ashland (May 4), Hayward (May 5), Rhinelander (May 6), Eau Claire (May 16), La Crosse (May 17), Platteville (May 18), Madison (May 24), Brookfield (June 14), Kenosha (June 15) and Milwaukee (June 16). Sessions in Hayward and Platteville were cancelled due to low registration.

A total of 168 people attended listening sessions. Members of the Alliance's core committee, representatives from area agencies on aging and Project Coordinator Linda Marty Schmitz accounted for 23 attendees. Of Wisconsin's 72 counties, 33, or 46 percent, were represented. Agencies and organizations include Wisconsin County Aging Units/Departments (42), County Departments of Health & Human/Social Services (4), UW Extension (6), faith-based agencies (10), Alzheimer's Association network (13), Hospice organizations (11), health agencies/hospitals/Visiting Nurse Associations (8), adult day centers (4) social service agencies (14), tribes (2), United Way (2), AARP (2), private agencies—respite, home care, disability programs, etc. (21), Wisconsin Department of Health & Family Services (2) and family caregivers (1).

### **Existing resources & support**

#### **Caregiving education consistent across state**

During listening sessions we discovered that counties offer similar educational programs. For example, 22 counties and seven types of agencies teach the curriculum, "Powerful Tools for Caregivers." Eleven counties use the curriculum, "Caregiving Relationships for People Who Care for Adults." In one county seven agencies offer the curriculum, "Caregiving Near Life's End."

Other curricula used by counties include "Partner With Your Doctor," "Skillful Caregiving" and the Red Cross's "Coping With Chronic Disease."

## **Resources include support groups, nurses, web sites**

In addition to the above curricula, other local caregiving resources include:

- support groups
- newsletters for caregiver
- information, assistance and referral
- resource libraries and centers
- web sites
- conferences, teacher training, seminars, senior fairs, health fairs
- counseling
- resource directories
- adult day care
- faith-in-action programs
- parish nurses
- benefit specialist programs in all counties
- respite programs (paid & volunteer)

## **Gaps in caregiving education**

### **Many don't see themselves as caregivers**

Participants at all 12 listening sessions identified the concern that family caregivers do not “self identify” or do not think of themselves as being a caregiver. Participants also pointed out gaps in caregiving education, information, resources and support.

### **Educational gaps**

Educational gaps centered on two themes. Given that most curricula are not available on-line, participants cited a lack of understandable printed materials, difficulty accessing classes and adapting existing curricula. They also noted a lack of caregiving curricula tailored to employers, the medical profession and individuals with developmentally disabled children.

### **Informational gaps**

Informational gaps centered on the lack of visibility of existing services. Many caregivers, medical providers and employers are not aware of local support services for family caregivers. Employers are also unaware of the burdens created by caregiving roles and responsibilities and the resulting effect on productivity. Participants identified a lack of caregiver knowledge – and places to go for help – regarding financial planning, legal issues, power of attorney and wills. They expressed concern that cultural differences are not recognized in educational efforts. And they noted that, in some cases, family caregivers may need interpreters.

### **Resource gaps**

Resource gaps centered on a lack of services. Some communities identified a lack of case managers, available and affordable intervention services, and lack of respite, both paid and volunteer. Underlying a majority of resource gaps is a lack of funding to develop or support development of needed resources. In some communities, long waiting lists keep family caregivers from accessing resources. On the other hand, another concern is getting family caregivers to use community support when it *is* available. This may be because families aren't aware of resources due to a lack of outreach or the stigma connected with asking for help. Medical professionals not recognizing the needs of family caregivers and the medical

profession's lack of knowledge of community resources for family caregivers are also major concerns. Listening session participants recognize that medical professionals are crucial in reaching family caregivers who need support in order to maintain their caregiving roles and responsibilities.

### **Support gaps**

Support gaps include a lack of communication and collaboration between medical providers, and agencies and organizations acting in isolation. With many medical professionals unaware of local resources, communities often fail to recognize caregivers' emotional needs, causing family caregivers to fall through the cracks.

### **Where caregivers go for help**

Participants say they rely on a variety of sources for caregiving education, information, resources and support. In order of importance (ranked according to the number of times participants referenced a source during listening sessions), caregiving resources include:

- UW-Extension and the Internet (12);
- disease-specific associations (9);
- educational programs such as conferences, seminars and professional associations (7);
- faith communities and parish nurses (5);
- libraries, universities, technical colleges and aging specialists (5);
- aging network and area agencies on aging (4);
- senior centers, CWAG Elder Law Center; AARP, Elder Care Locator, public health departments, medical providers, state agencies and Hospice (2); and
- advocacy organizations such as the Wisconsin Alliance of Family Caregiving, Family Caregiver Support Network, National Family Caregiver Organization, Badger Aging ListServ, the Administration on Aging and the American Society on Aging (1).

## **How the Alliance can help bridge gaps**

### **Suggestions grouped into nine topics**

During listening sessions, participants listed ways the Alliance can help. Suggestions fell into the following topics: advocacy, caregiver assistance, curriculum, other educational programs, marketing/outreach, funding, regional alliances, web site/Internet and miscellaneous.

### **Advocate for family caregivers**

The Alliance can encourage family caregivers to advocate for themselves and then support them in their advocacy roles. Also the Alliance can keep legislators – and caregiving professionals – abreast of family caregiving issues.

### **Create survey and assessment tools**

Participants said the Alliance could help family caregivers by:

- creating an assessment tool for professionals;
- conducting a survey to identify caregiver needs,
- creating a uniform way to identify a person as a caregiver; and
- creating programs that link caregivers with mentors or a “navigator” program that helps caregivers access community resources.

### **Develop additional curricula**

The Alliance can establish criteria for endorsing and evaluating caregiving curricula. Participants said the curriculum, “Powerful Tools for Caregivers,” should be simplified and requested additional training on the curriculum, “Caregiving Relationships for People Who Care for Adults.” A need exists, they said, to summarize caregiving curricula, possibly with fact sheets that tell how to use various components. They would like to see a curriculum on legal and financial caregiving issues and a “Caregiver 101” manual.

### **Feedback on other educational programs**

This category had the most diverse feedback, with suggestions on how to deliver educational programs, types of training and educational resources, along with specific ideas on content.

### **Hold more listening sessions, build networks**

Participants cited e-seminars, fact sheets, chat rooms, newsletters (access to the Mather LifeWays newsletter), videos, training, resource packets, PowerPoint presentations, libraries and distance education as ways to deliver education. They said training should include:

- simple statistics/demographics on family caregiving for families and employers;
- best practices in family caregiving; and
- updates on what’s new in family caregiving.

Content should include family caregiving and health care, creating Internet and phone support groups, how to work with physicians, caregiver self-identification and planning for the future. Participants at six listening sessions mentioned the need for a statewide speaker’s bureau. They would also like to see ongoing listening sessions and networking.

### **Reach out to partners**

Much discussion centered on developing partnerships. Participants said the Alliance should connect with health-care providers through their publications, such as nurses’ publications, the State Medical Society newsletter, and publications put out by the Wisconsin Council of Churches (locally, the ministerial association), nursing homes, assisted living facilities and the Coalition of Wisconsin Aging Groups.

At four listening sessions, participants spoke of a need for a statewide media campaign with public service announcements. Other ideas included:

- newsletter articles;
- caregiver materials in doctors’ offices;
- family caregiving marketing tools that could be used by all agencies and organizations;
- a brochure called, “You Might Be a Caregiver If...”;
- specific marketing tools for long-distance caregivers, young caregivers and physicians; and
- a system for recruiting volunteers to help family caregivers.

### **Help find grants, technical support**

Participants focused on monetary concerns at all listening sessions, with a plea for more resources to support family caregivers. They also expressed a need for technical support in grant

writing and identifying potential grants. Finding funds to support regional caregiver specialists and respite workers is another concern.

### **Build regional alliances**

Participants said the Alliance could help build local and regional alliances and coalitions. The Alliance could develop guidelines on how to form a coalition, purpose, operation and ongoing support. The Alliance could also expand links between existing caregiving coalitions and develop criteria for educational programs supported by the Alliance.

### **Link Alliance to web sites**

Participants suggested linking the Alliance's web site to other agency web sites. The Alliance web site could also link to community support groups, state agencies and curricula, and provide referrals, such as to the Eldercare Locator, for caregivers. They suggested the Alliance link with Aging and Disability Resource Centers. The Alliance's web site should be user friendly. The need for a ListServ through the state office on aging was another issue.

### **Find ways to connect caregiving players**

Participants shared so much, it's hard to capture everything. Comments that don't fit into the other categories include:

- making sure the Alliance doesn't duplicate existing services;
- ensuring that local entities can access Alliance support and resources;
- finding ways to connect counties, providers and others with caregiving information; and
- addressing the Alliance's need for long-term sustainability.

### **Participants prefer Internet education**

Asked how they prefer to receive educational materials, the most popular answer, mentioned at 11 of 12 sessions, was via the Internet or a web site, followed by printed material in the mail. Other preferences included hands-on training, an 800 number and ListServes.

### **Alliance leaders react to listening sessions**

Alliance core committee members who helped lead listening sessions offered additional insights. Their thoughts include the following:

- A need to clarify differences between the Wisconsin Long-Term Care Workforce Alliance, which is for paid caregivers, and the Wisconsin Alliance for Family Caregiving. How do these two entities connect and what are the possibilities of working together?
- More time should have been spent describing Alliance-supported curricula during listening sessions since many participants didn't appear to know about "Caregiving Relationships for People Who Care for Adults" and "Caregiving at Life's End."
- It would have been helpful to hear more about various funding sources and how they support family caregivers. Some programs that could have been explored include the state's Alzheimer's Family and Caregiver Support Program, adult day care, respite care, home and community-based service programs such as COP, CIP, COP-W, etc.

- Participants appreciated the opportunity to meet and some expressed a desire to meet again. One suggestion was to make time at the annual Caregiver Institute for regional groups to update each other on caregiving issues in their communities. Some indicated they wanted to explore working across county borders, which might involve negotiations between counties because of funding sources and perceived barriers.
- Several commented on the extent of shared information, common needs and concerns, and a willingness to work together. They noted that participants came looking for resources and knowledge about educational programs, resources and support to help them in their work with family caregivers.
- Concern over a lack of recognition of the Alliance as a source of family caregiving information, despite the fact that Alliance-based curricula such as “Powerful Tools for Caregivers,” is used throughout the state.
- A majority of the participants wanted a copy of the listening session report and the Alliance’s strategic plan. They suggested posting reports on the web site.
- Some listening session participants plan to meet again. One group indicated they would like guidance from the Alliance on next steps for starting a regional family caregiving coalition.

## **Recommendations**

The Wisconsin Alliance for Family Caregiving identified the following recommendations, which a newly expanded board of directors will use to develop a strategic plan:

1. Continue to grow a statewide network of trainers who conduct educational programs, institutes and seminars for family caregivers throughout Wisconsin.
2. Work with professionals, agencies and organizations in a noncompetitive forum to identify the educational needs of family caregivers. Review existing programs and create others to fill identified educational gaps of family caregivers.
3. Build on the existing strengths, networks and experiences of Alliance partners to develop, distribute and evaluate caregiving education.
4. Offer a central resource for educational programs with links to regional coalitions, such as the Caregiver Support Network of Ashland and Bayfield Counties, the Chippewa Valley Family Caregiving Alliance and others.
5. Expand the Alliance web site into a one-stop service where professionals can learn about national, state and local caregiving education; best regional and local practices; and programs whose funding may have expired but have relevant content.

6. Develop statewide educational programs that address basic caregiving issues and concerns, complemented by content that recognizes Wisconsin's geographic and cultural diversity.
7. Identify potential partners and serve as a technical resource for partners, alliances and coalitions that deliver educational programs to family caregivers.
8. Expand the Wisconsin Alliance for Family Caregiving's current leadership committee into a board of directors with additional partners.
9. Develop a strategic plan, with accompanying action steps, for the Wisconsin Alliance for Family Caregiving based on this report's recommendations.
10. Leverage resources for the Wisconsin Alliance for Family Caregiving in order to ensure long-term sustainability.

### **Thanks to listening session participants**

The Wisconsin Alliance for Family Caregiving wants to thank the 168 individuals who took part in the listening sessions. Without their collective insight into caregiving resources, gaps in those resources and suggestions on how the Alliance can help bridge the gaps, the recommendations that will guide our strategic planning process would be meaningless. Their willingness to share their knowledge, experience and thoughts on how to build a better system will enable us to fulfill our vision of helping Wisconsin's family caregivers maintain their health and well-being.

We also want to thank Linda Marty Schmitz, program coordinator for the grant, Strengthening Family Caregivers Through a Statewide Coalition, for her time and commitment in conducting listening sessions. This report was written by Mary Brintnall-Peterson, UW-Extension, and Linda Marty Schmitz, and edited by Marla Maeder of maeder design. The Alliance's core leadership group provided input and review. The report is posted on the Alliance web site at <http://www.uwex.edu/ces/flp/caregiving/>

# APPENDIX I

## Listening Session Agenda

### Introductions

### Overview of Purpose of Meeting & Agenda

### Description of WI Alliance for Family Caregiving

- Overview of Alliance's Mission
- Programs of the Alliance
- Partners involved with the Alliance
- Accomplishments of the Alliance

### Description of the UW Grant

### Highlights of Family Caregiving Information, Resources & Support in the Region

#### Group Work

1. What educational programs, information, resources and support are you providing to family caregivers?
2. What educational programs, information, resources and support are being provided for family caregivers in your community?
3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?
4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?
5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, list serves, other)?
6. How would you like to access the items identified above?

#### Next Steps

- Compilation of data from regional sessions
- Formation of local and regional alliances

# APPENDIX II

## Data Summary from Listening Sessions

### Stevens Point – April 15, 2005 Lincoln Center

**Participants:** Kristy Bridenhagen, Stevens Point Area YMCA, Darcy Dickman, Marathon Co. Long-Term Care Workforce Alliance, Julie Genrich, Portage Co. Dept. on Aging, Ann Habband, Epilepsy Foundation, Angie Johnson, Marathon Co. Aging & Disability Resource Center, Jeannie Pientka, ASPIRUS Comfort Care & Hospice Services, Korrine Rietz, Community Industries Corp., Betsy Sachs, Trinity Lutheran Church, Russ Schultz, Marathon Co. Aging & Disability Resource Center, Leslie Smith, Community Industries Corp., Judy Steinke, Aging Resource Center of Wood Co., Rita Straub, UW Extension-Marathon Co., Sasha Vieth, Interfaith Volunteer Caregivers and Jane Weddig, Merrill Senior Center.

14 people attended plus 3 leaders (Dana Cyra, Alliance Core Committee; Judy Olmanson, NAAA; Linda Marty Schmitz)

#### **1. What educational programs, information, resources and support is your agency providing to family caregivers?**

Wood Co Aging Resource Center (age 60+)

- Powerful Tools class – every 6 months

- Support Groups

- Home visits/assessments – what do people need?

- Connecting with medical & religious communities using the “Making the Link” program

- Chore service providers

- Library

Marathon Co. ADRC

- Powerful Tools class – 2 times per year

- Support groups

- Caregiver outreach – meet with employers and HR people

- Outreach: public awareness campaign

- Adult day services (60+)

- Community training for family & paid caregivers

- County Caregiver Alliance being formed

  - Bring caregivers together

  - Agency collaboration

  - Help avoid duplication

- Comfort Care and Hospice Services

  - Support & supplemental care

  - Bereavement support

Portage County

Powerful Tools  
Support groups  
    Dementia  
    Monthly caregivers  
    Chronic conditions  
I&A specialists  
Making the Link  
Chore services  
Library  
Adult Day Center

Portage Co. Community Industries

Training to respite provider

Portage Co Interfaith

Provide services to those without family in the area  
Look for areas not being services  
Services provided free-of-charge

Portage Co Epilepsy Foundation

Education toward epilepsy victims  
Work with Parents Helping Parents

Waupaca County

Church will be meal site  
Respite, support & education for families re: bereavement  
Parish nurses will fill in the gaps for those who fall in-between  
Referral to other services

**2. What additional educational programs, information, resources and support are being provided for family caregivers by other agencies in your community?**

Marathon Co.

Red Cross – hands on training  
Hospice – One-on-One training as needed

**3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?**

- Identifying problems, linking people to services (appropriate) at time of diagnosis re: things they want/need
- Identifying self as caregiving
- People don't identify or want to identify self as "caregiver"
- Fear of interference by outsiders

- Identifying self as caregiver and feeling OK about it (Alz Assn is now using term: care partner)
- Lack of visibility of services
- Stigma of referring people to county agencies
- Resources for long-distance caregiving
- Curriculum components are not on-line
- Special needs trusts-DO (legal & financial)
- Emotional supports for family caregivers of adults
- DD/PD – Planning for the future (How to support independence and feel OK about it)

**4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?**

National organizations (Epilepsy Foundation)  
 UW Extension (state level)  
 Aging Specialist such as Mary Brintnall-Peterson  
 Lots of books/videos (usually buy in response to mailings)  
 Public Library  
 Internet  
 Professional associations  
 Other organizations  
 Statewide conferences  
 Other caregivers

**5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, ListSerts, other)?**

- Curriculum on-line (Powerful Tools on-line as a self study)
- Provide curriculums suitable for on-line training
- County by county list of resources – both on-line & hard copy
- More listening/facilitation sessions
- Money
- Grant writing assistance
- Research assistance regarding specific curriculums
- Regional or statewide speakers bureau on caregiver issues/concerns
- Outreach/Marketing strategies
- Success stories – what makes a group successful
- Radio/TV public service announcements
- Billboard advertising
- Advertise AAAs as contact points—direct to county aging units
- Strategies/Resources for long distance caregiving
- Link to ElderCare locator on web site

**6. How would you like to access the items identified above?**

Internet/hard copy

Develop distribution/ mailing list for those without Internet or computer access

Training opportunities for professionals

## **Janesville – April 26, 2005**

### **Rock County Job Center**

**Participants:** Karen Barger, VNA of WI Senior Care Consultants, Mary Cagney-Pike, Independent Disability Services, Larisa Chmielewski, Alzheimer's Support Center, Anita Kerl, Assn of Elder Care Management, Lynn Kilvington, Independent Disability Services, Jayne Mullins, AgeAdvantAge Area Agency on Aging, Sharon Olson, Jefferson Co. Human Services Dept., Tammy Pence, Alzheimer's Support Center, Julie Seeman Rock Co. Council on Aging, Sue Torum Jefferson Co. Human Services Dept., Mari Vander Pal, Mercy Assisted Adult Day Center & Joanne Woodman, Mercy Health Center.

12 people attended plus 2 leaders (Barbara Robinson, Alliance Core Committee; Linda Marty Schmitz)

#### **1. What educational programs, information, resources and support is your agency providing to family caregivers?**

##### Rock County

Powerful Tools classes

Newsletters: County Council on Aging  
Alzheimer's Support Center  
Mercy Adult Day Center

Red Cross basic curriculum

Web site: [alzsupportcenter.org](http://alzsupportcenter.org)

Support groups

Lending library: books/ videos

Roundtables for professionals

Annual Caregiver Conference

Stateline Area Memory Clinic

Family Caregiver Training

Training of enforcement professionals

Training for dementia workers

Community educational series

Community partnership for older adults

Goal: better care for older adults

Senior Fair – reaches working caregiver

Fall 2005: Senior Fair African/American community in Beloit

Safe Return Registration Site (and other wandering)

##### Jefferson County

Family Impact Seminar

Powerful Tools classes

Information assistance

Support groups

Held two caregiver resource fairs

**2. What additional educational programs, information, resources and support are being provided for family caregivers by other agencies in your community?**

Rock County

Hospice programs  
Mercy Hospital chaplain conducts clergy programs  
Alzheimer's Support Center trains clergy  
Temporary respite facilities for wanderers, etc.  
Parish Nurses/VNA of Wisconsin (active in Walworth County for skilled care  
United Way First Call for Help

Jefferson County

Temporary respite facilities for wanderers, etc.  
Volunteer respite program through churches – "Reaching Out Respite"  
"Faith In Action" trains volunteers  
Parish nurses

**3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?**

- Not aware of "being a caregiver"
- Outreach/Marketing
- Where do I start?
- What do I/they need
- 800 #
- Gaps in "support"
- Not enough time
- Waiting lists
- False impression that Medicare will pay
- Getting to employees early on
- Not ready for information until a crisis
- Packets for caregivers earlier (dementia, stroke, diabetes)
- Not aware of hospital resources for caregivers
- Caregiving for disabled
- Physicians' lack of knowledge of resources for caregivers
- Medicare assessment for caregiver and receiver
- Professionals or groups not communicating with hospitals/physicians in regard to client's disease case management
- Social work support in clinics
- Financial information and planning early on
- Legal information
- Information on powers of attorney and living wills

**4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?**

Aging Offices  
Meal sites  
Senior Centers  
Alzheimer's chapters  
Rock County Senior Connection (Joanne Woodman)  
Legal & financial advice for older adults and caregivers  
Schools for special needs students  
Google/Internet  
Independent Living Centers  
Community groups such as the Lions  
Church Parish Nurses  
Library  
ECHO (Everyone Cooperating & Helping Others)  
Grocers  
Y's public health  
UW Extension  
CWAG Elder Law Center  
AARP  
ElderCare locator  
WAFC

**5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, ListServes, other)?**

- Curriculums on legal and financial issues
- Caregiver assessment tool that physicians and medical schools could use with caregivers
- Training for medical professionals on caregiving
- Signs for physicians' offices – "Caregiving Information Available Here"
- Develop one hour video
- Pamphlets – "Planning for the Future," "What to ask your physician"
- List of questions for caregiver to ask care receiver's physician+
- What can my caregiver do to help me?
- More listening sessions
- Resource packet for caregivers
- Statistics on number of caregivers in counties
- Conduct a caregiver survey

**6. How would you like to access the items identified above?**

800 #  
Web site

## **Green Bay – April 28, 2005**

### **Bay Area Agency on Aging**

**Participants:** Sunny Archambault, Aging Resource Center of Brown Co., Cheryl Ault, Oneida Elderly Services, Amie Bastian, NEW Curative Rehabilitation, Barbara Bauer, Florence Co. Aging Unit, Diane Bezella, BCHSD, Mary Bouche, Alzheimer’s Assn of Greater WI, Cindy Brabbs, Oneida Elderly Services, Diana Brown, NEW Curative Rehabilitation, Bonne Elias Planner, Outagamie Co. DHHS Aging Services, Ann Golueke, Aging Resource Center of Brown Co., Mary Hansen, NEW Curative Rehabilitation, Nicolette Jauquet, Alzheimer’s Assn of Greater WI, Sara Malay, Kewaunee Co HS-Aging Services, Becky Reichelt, Alzheimer’s Assn of Greater WI, Pam Sengstock, Hope Hospice, Jenny Staidl, Marinette Co. Elderly Services, Brenda Strzelecki, NEW Curative Rehabilitation, Dee Van Hoof, Helping Hands, Julie Van Klooster, Brown Co Human Services Dept, Bonnie Weyers, Shawano Co Aging & Disability Resource Center & Mary Ziong, Lutheran Social Services.

21 people attended plus 2 leaders (Judy Rank, Alliance Core Committee; Linda Marty Schmitz)

#### **1. What educational programs, information, resources and support is your agency providing to family caregivers?**

##### Outagamie County

- Collaborate to provide caregiver seminars
- Powerful Tools through Lutheran Social Services
- “Help, Home & Humor” caregiver seminar (Winnebago, Fox Valley area)
- Caregiver support groups
- Spousal and adult children support groups
- Offer web access and listing
- Post family caregiver information
- Send information to other tribes
- Adult day care
- “Partnering with your doctor”
- 24 hour caregiver helpline through Alzheimer’s Assn
- Newsletter: “Care Consultation”
- LSS Counselors provide one-on-one counseling
- Alz class provided by Dementia Care Specialist

##### Brown County

- 24 hour caregiver helpline through Alzheimer’s Assn
- Have 4 Master Trainers for “Caregiving at Life’s End”
- CAS – Children Are Supportive monthly support group
- Grief support groups for adults and children
- Volunteers who provide caregiver respite
- Family Resource Guide
- I&A through Aging Resource Center
- Web site data base that caregivers can access
- Alz Assn support groups

Tribe provides transportation  
N.E.W. Curative provides adult day care  
Powerful Tools classes  
Caregiver support groups  
Dementia crisis response  
LSS Counselors provide one-on-one counseling  
Lending library  
Alz class provided by Dementia Care Specialist  
Financial assistance provided by county benefit specialists & Catholic Charities  
WREA provides information on Powers of Attorney for Finances & Health Care  
Alz Assn newsletter  
Safe Return program through Alz Assn  
Project Lifesaver

#### Shawano County

Resource Lobby provides computers  
Resource Center  
Caregivers Ride Free transportation program  
Adult Day Care at 2 locations  
Alz Support Groups  
Telephone Assurance Program  
24 hour caregiver helpline through Alzheimer's Assn

#### Kewaunee County

Powerful Tools classes  
Daybreak for caregivers  
Caregiver Tools box Resource Guide  
24 hour caregiver helpline through Alzheimer's Assn  
Memory Assessment Clinics

#### Marinette County

24 hour caregiver helpline through Alzheimer's Assn  
Volunteer Medical Escort Program  
Annual Caregiver Workshop  
Administer caregiver funds

## **2. What additional educational programs, information, resources and support are being provided for family caregivers by other agencies in your community?**

Hospital and other support groups  
Other education programs  
Door County: Neighbor to Neighbor program (go to home to give respite)  
Faith In Action  
Parish Nurse programs

**3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?**

- Money
- Outreach/Marketing
- Respite assistance
- Caregivers fear to leave care recipient with someone else
- Caregivers don't identify themselves
- Break the "routine"
- Literacy/Language differences
- Hearing
- Understanding cultural differences
- Interpreters needed
- Lack of federal/state tax support
- Education re: the future
- Lack of professionals in the geriatric & dementia fields
- Education of medical providers
- Affordable and available transportation
- Crisis intervention services

**4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?**

Internet

Other agencies/aging network

Education seminars

Technical college

UW Extension

Churches/Parish Nurses

**5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, ListSrvs, other)?**

- More networking sessions
- More fact sheets
- How to set up a regional coalition – What is the goal of having regional coalitions?
- Commentary on curriculums
- Establish criteria for endorsing curriculums
- E-seminars
- Develop criteria for local coalitions – guidelines, things to address
- Provide information for parents of children with disabilities
- Live chat room on Internet
- Link to aging & disability resource centers on Alliance web site

- PowerPoint presentation on caregiving
- Develop criteria for program (Alliance) inclusion

**6. How would you like to access the items identified above?**

Internet – current web site

Binders

Networking meetings

Listening sessions

E-seminar!!!

Tele-conferences

Bulletin board on web site

**Appleton – April 29, 2005**  
**Prince of Peace Lutheran Church**

**Participants:** Denis Ashauer, Home Helpers, Vicki Gehrke, Lutheran Social Services, Sue Haase, Lutheran Social Services, Jeanine Knapp, CAP Services, Inc., Christine Kniep, UW Extension-Winnebago Co., Jennie Kosko, Lutheran Social Services, Joy Lautenslager, Lutheran Social Services, Kim Marheine, Alzheimer’s Assn of Greater WI, Andrea Mitchell, Lutheran Social Services, Tami Morrow, Alzheimer’s Assn of Greater WI, Marie Rohrer, Lutheran Social Services, Sister Joy Rose, St. Paul Elder Services, Kelly Schliesmann, Caring Angels, LLC, Pat Valentyn, Lutheran Social Services, Dee Van Hoof, Helping Hands & Mary Wisnet, United Way Fox Cities.

16 people attended plus 3 leaders (Liv Arafat & Barb Robinson, Alliance Core Committee; Linda Marty Schmitz)

**1. What educational programs, information, resources and support is your agency providing to family caregivers?**

Workshops for families on levels of care/care plans and “Elder Care & Work: Finding the Balance”

Dementia: education, help groups, 24 hour helpline, I&R

Lutheran Social Services

Monthly support group

I&R: Senior Connection

Powerful Tools

Elder Match – volunteers visit homebound seniors; phone reassurance; peer counseling

Respite volunteers

Caregiver Burnout Prevention Program

Free mental health counseling

Co-sponsor caregiver education programs: “Caring for Those You Love As They Get Older”

Compassion Fatigue Day (pamper day for caregivers)

Workshops at churches – overview of caregiving

In-home assessments and provide resources

Community programs based on the UW-Extension site

Hmong elder program

UW-Extension

Living With Grief – satellite program

St. Paul’s Church

Dementia support groups

Provide services in churches in relation to end of life issues and Durable POAs

Alzheimer Assn

Conducted a program at Oneida Tribal School discussing memory loss with third graders  
Prevention piece for Safe Return program

#### United Way

A committee is looking at caregiving issues  
They fund respite programs for persons with disabilities  
Provide options counseling  
211 I&R  
Publishes directory

#### Oshkosh

Resource Fair is held for people of all ages  
Monthly support group  
3 workshops scheduled for May  
Red Cross conducts caregiving classes

#### Tri-County

Make the Ride Happen program provides transportation

### **2. What additional educational programs, information, resources and support are being provided for family caregivers by other agencies in your community?**

#### Red Cross-Fox Cities

Caregiver series  
Shopping & errand services  
Counties provide home care services and publish a directory  
Caring Today magazine – has a web site  
Elder Care Locator  
Senior Connections at Thompson Center  
Access workers in Winnebago County  
Collaborations among agencies  
Waupaca County uses senior nutrition programs/sites to educate  
A local bank sponsored a senior fair  
Community Care Notes newsletter published quarterly  
Home delivered meals  
Geriatric psychiatrist works at Theda Care; concentrates on dementia  
Clinic in Hilbert also works with dementia patients  
Memory Center in Oshkosh  
NAMI office in Appleton  
Inpatient hospice in area  
Waupaca County has county-wide caregiver conference

### **3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?**

- Transportation

- Money for respite
- Referral from physicians; end of life decisions; getting information to providers; information from family history; hospice referrals happen too late
- Programs that serve both caregiver and care receiver at the same time
- Lack of information caregiver at the time they need it
- User-friendly system in Winnebago County is lacking; unwilling to change
- Services to Hmong and Hispanic elders and families
- :Lack of employer support
- Caregivers will not self-identify
- Lack of volunteers to provide respite
- Caregivers ignore resources until crisis arises
- Perceived boundaries limit participation

**4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?**

Meetings/Conferences

Faith community

Networking

Internet

Alliance web site

Caregiver newsletters

UW-Extension

UW-Oshkosh, Fox Valley Tech, Green Bay Tech

**5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, ListSers, other)?**

- Mather newsletter
- Coordinate Powerful Tools and other class schedule
- ListServ
- Keep caregiving issues before the public/marketing
- Promotional piece: “You Might Be A Caregiver If....”
- Keep those fact sheets coming
- Blitz health care providers – Nurses publications; State Medical Society newsletter
- Positive approach to nursing homes, assistive facilities, etc
- Make use of local cable systems
- WI AARP & Coalition of WI Aging Group members sent Alliance information

**6. How would you like to access the items identified above?**

Web site

Printed materials

Public Service Announcements on radio/TV  
Keep providing educational programs

**Ashland – May 4, 2005**  
**Bad River Convention Center**

**Participants:** Chris Beeksma, Regional Hospice Services, Ann Marie Evan, caregiver, Debbie Hipsher, Ashland Co Aging Unit, Stewart Holman, North Country Independent Living, Marianne Johnson, Bayfield Co DHS, Bob Lynn, Iron Co Aging Unit, Joe Muench, Regional Hospice Services, Grace Nurkkala, Michigan AARP, Luann Teige, Aging Resource Center for Douglas Co., Dorothy Walaesewicz, Iron Co Aging Unit, Lynne Wiercinski, Friendship House, Larry Wilczewski, Friendship House & Deanna Yost, Lifespan Respite Network.

13 people attended plus 3 leaders (Lucia Patritto, Alliance Core Committee; Judy Olmanson, NAAA, Linda Marty Schmitz)

**1. What educational programs, information, resources and support is your agency providing to family caregivers?**

Bayfield County

- Support groups
- Lifespan Respite Program (Ashland & Bayfield counties)
- Combined trainings for caregiver providers & caregivers
- Presentations on family caregiving program
- Newspaper article/outreach to spouses
- Elder Choice Grant: developing video/in-home care (Ashland & Bayfield counties)
- Act as fiscal agent for families
- Powerful Tools classes
- Making The Link Program (Ashland, Bayfield, Douglas & Sawyer counties)
- Community Options Program
- Senior Caregiver Service Guide (Douglas County)
- Caregiver Conference

Iron County

- Assist long distance caregivers
- Recommend (?) care services
- Friendship House (Iron & Gogebic counties)
- Powerful Tools
  - Look for grant opportunities & resource information
  - Collaborative opportunities
- Transportation to Friendship House
- AARP does education on caregiving
- Funding for adult day care

Gogebic County

- Caregivers Fair
- Support groups/provide information & education
- Resource Library
- Outreach: newsletters

To non-caregivers – prepare for caregiving  
Free home safety inspections

North Country Independent Living (consumer based, run & directed)

Disability services  
I&A  
Skill training  
Public education  
Loan closet  
Teach advocacy skills  
NH transition project – into community

Ashland County

I&A/Senior Resource Directory  
Caregiver Conference  
Resource Library (books, videos, etc.)  
Support group  
Direct services: transportation, benefit specialists, nutrition, home safety  
Outreach & Education

Regional Hospice

Referrals to support services  
“Hands on” teaching of caregivers  
Respite program using staff & volunteers  
After death of care receiver: do caregiver follow-up  
Community outreach  
Caregiving at Life’s End curriculum for NH staff

**2. What additional educational programs, information, resources and support are being provided for family caregivers by other agencies in your community?**

Alzheimers’ Family Caregiver Support Program (AFCSP)  
Alzheimers’ Assn.  
American Cancer Society & other disease specific organizations  
Red Cross  
Food pantries  
Faith In Action volunteer program  
RSVP  
County Departments of Public Health  
Community Action Agency (Gogebic County)  
Parish Nurses

**3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?**

- Lack of money

- Caregivers won't self-identify – how to get them to accept services
- Outreach and marketing
- Get care receiver to accept services
- Lack of volunteers
- Geriatric case manager needed
- Coordination/Collaboration between agencies
- Training re: “pots of money”
- Lack of technology in rural areas
- Outreach to rural areas
- Transportation for rural residents
- Getting seniors to use resources/printed
- Training in immediate area
- Employer's lack of accommodation for caregiver needs

**4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?**

UW-Extension

AAAs

Aging units

Internet

Colleagues

Human Services Dept/Social Workers

Health care providers

Library

Research information

**5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, ListServes, other)?**

- Keep up-to-date on what's new
- Technical assistance to develop coalitions
- Training to recognize funds and resources and to recognize appropriate referrals
- Statewide awareness campaign/multi media, TV ad
- Education of legislators
- Keep information up-to-date on statistics and best practices around the state
- Info provided needs to be adaptable for local use
- User friendly web site as opposed to a ListServ
- Speakers Bureau
- Help to reach out to other agencies
- Resource sharing sessions
- Link caregivers and caregiver mentors

**6. How would you like to access the items identified above?**

Print

Internet

Face-to-face

    Resource sharing/annually

    Meet at facilities we want to reach

Personal testimony

## **Rhineland – May 5, 2005**

### **YMCA of the Northwoods**

**Participants:** Donna Barron, Vilas Co Commission on Aging, Connie Bessa, Ministry Home Care-Hospice Services, Patricia Brockman, Langlade Co Dept on Aging, Judy Durke, Alzheimer's Assn of Greater WI, Maureen Juras, Headwaters, Inc.-Birth to 3, Linda Mezel, Langlade Co Dept on Aging, Diane Niggemann, Taylor Co Commission on Aging, Peggy Nordgren, UW-Extension-Taylor Co., Myra Uttech, student intern & Geri Wallin, Oneida Co Dept on Aging.

10 people attended plus 3 leaders (Kim Marheine, Alliance Core Committee; Judy Olmanson, NAAA; Linda Marty Schmitz)

#### **1. What educational programs, information, resources and support is your agency providing to family caregivers?**

##### Taylor County

- Powerful Tools/hospital does respite
- Resource Library (books & videos)
- Caregiving Relationships (UW Ext)
- Monthly Caregiving Newsletter from Comfort Home
- Support groups developed from Powerful Tools
- National Family Caregiver Month (Powerful Tools Reunion)

##### Oneida County

- Headwaters (Birth to 3) (Developmental Disabilities)
- Service Coordination – I&A
- Powerful Tools
- Alz Assn in town
- Computer classes
- Resource Directory
- Talking books on issues
- Advance Directives – have classes at hospital
- Drug check-up day

##### Oneida County-Ministry Hospice

- Caregiving at Life's End
- Resource Library
- Grief & Loss Counseling
- Volunteers – 6 week training – do respite, etc
- Outreach/Marketing

##### Vilas County

- Powerful Tools
- I&A
- Resource Library

Home Support – link private duty workers w/families  
Will be doing: “Coping With Chronic Disease” (curriculum out of Stanford) for the care receiver but caregivers can participate  
Respite care

#### Langlade County

Resource Center (includes computer, videos, books)  
Computer Labs  
Monthly caregiver support group where respite is provided  
“Lifestyles” newsletter  
Resource Directory

#### AAA

Acts as umbrella providing resources, educational materials  
Making the Link – provides templates

#### All counties

Benefit Specialist program  
Chore services  
Health/senior fairs

#### Alzheimer’s Assn/Preceptorship

Health fair for students in Lincoln, Langlade, Oneida, Vilas, Forest & Florence counties  
Powerful Tools  
“Partner With Your Doctor” curriculum  
Dementia Care Specialist training  
Memory Diagnostic Clinic  
State convention & regional conferences  
Community workshops  
Newsletter  
Helpline (local and national after hours)  
Safe Return Program  
Support Groups  
Resource Library  
Care consultation  
Acute Care Training  
Law Enforcement Training

## **2. What additional educational programs, information, resources and support are being provided for family caregivers by other agencies in your community?**

#### Meals On Wheels

Energy Assistance/supplemental services  
Parish Nurses  
Human Services does case management  
Statewide: network of independent nurses (DD)

Faith In Action in Oneida, Vilas & Florence counties

Taylor County

Nursing home conducts Alzheimer's Support Group  
Respite  
Adult Day Care  
Palliative Care Coalition (respite volunteers)

Vilas County

Palliative Care Coalition (respite volunteers)

Lincoln County

End of Life Coalition

Oneida County

Community Link Coordinator  
Adult Day Care  
RSVP Interfaith Volunteer Respite

Collaboration: VOICES (Vilas Oneida Inter County Elder Services)

**3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?**

- Resources not being used
- Communication/Networking (staying current)
- Coordinate/not duplicate programs (private vs. county)
- Case managers/lack of – paid professionals
- Reimbursement for Services -- \$\$\$\$
- Lack of time/personnel
- Lack of adult respite services/flexibility
- Refusal to access services
- Transportation
- Long distance caregiving expectations
- Expectations: care receiver vs. availability and caregivers vs. care receiver vs. availability
- Lack of education/empathy in people who serve caregivers
- Reaching and educating doctors
- Outreach/Marketing – Who are they?
- Stigma
- Inability to plan for future
- Poor nutrition
- General knowledge re: aging
- Caregivers wait until there is a crisis
- Caregivers won't identify themselves
- Aging population growth puts stress on services

- Awareness of caregiver stress in work place
- Caregiver benefits at work
- Support for parent of adult disabled child
- Lack of community
- Lack of legal protections for agencies
- Lack of resources to pay caregivers
- COP waiting lists
- Overall caregiver wellness
- Cultural barriers: lack of education, language

**4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?**

Internet

UW Extension

Alzheimer's Assn

Area Agency on Aging

Public Health Departments

County Commissions on Aging

Medical providers

Colleges & technical colleges

Public library

Support groups/coalitions

State agencies

WisLINE

Satellite programs

Hospice organizations

DD organizations

Social Service Agencies

Advocacy Agencies (private)

Faith based groups

**5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, ListSerts, other)?**

- Fact sheets/pie charts – simple: statistics/demographics, families, employers
- User friendly web site providing referrals for caregivers
- Marketing Tools – public service announcements
- Speakers Bureau
- Tool Kit on Caregiving: binder, vide, handouts, etc – issue oriented
- Brochure: “You Might Be A Caregiver If...”
- Dual purpose video/Power Point on caregiving
- Warning signs brochure

- On Alliance web site: linkages to support groups/county offices/community resources/state agencies/Elder Care Locator/curriculums

**6. How would you like to access the items identified above?**

E-mail

Program Service Area meetings – come to area

Replicate key components in downloadable hard copy

U.S. Mail

800 number

**Eau Claire – May 16, 2005**  
**Dove Health Care Center**

**Participants:** Debra Anderson, Heartland Homecare Network, Bonnie Baskett-Harvey, Northwest WI Supportive Home Care, Karen Gunderlach, Alzheimer's Assn of Greater WI, Erika Robinson, Rusk Co Senior Services, Nancy Sailer, St Croix Co Dept on Aging, Erika Schendel, Hudson Hospital, Mary Jean Smith, Barron Co Office on Aging, Karen Swanberg, Polk Co Aging Programs, Dianne Weber, UW Extension-Washburn Co., Lisa Wells, Eau Claire Co Dept on Aging & Linda Zwicker, Respite Care Assn of WI.

11 people attended plus 2 leaders (Dianne Rhein, AgeAdvantAge; Linda Marty Schmitz)

**1. What educational programs, information, resources and support is your agency providing to family caregivers?**

Barron County

- Powerful Tools
- Alzheimer's Support Group
- Senior Review/lists workshops
- Monthly Workshops on topics pertinent to caregivers
- Resources/Lending Library
- Literature
- Loan Closet
- Hospital Support Groups/disease related
- Care consultation
- Maintain caregiver files

Eau Claire County

- Powerful Tools (advertise on their web site and in the Senior Review)
- Family Caregiver Support Groups (afternoon & evening)
- Sponsor many caregiving events
- Sponsor Caregiving Series in afternoon
- Dept on Aging Red Cross Caregiver Training (offered for loan)
- Caregiving Near Life's End
- Chippewa Valley Caregiving Alliance
- Community presentations
- Chippewa Valley Care Coalition (end of life issues)
- Family Caregiver Support Program
- Falls Prevention Program

Polk County

- Powerful Tools
- Resources for Caregivers sent to hospitals and nursing homes
- Senior Voices newsletter

Northwest WI Home Care (serves 11 counties)

- Skillful Caregiving Curriculum
  - Family Caregivers
  - Learning about hospice
- Volunteer Training
- Presentations at town hall meetings, support groups
- Bereavement Series
- Memorial services as families transition
- Holiday gathering for caregivers
- Geriatric Care Management

Washburn County  
County Extension

No support in Burnett County

St. Croix County

- Nutrition/Senior Dining
- Equipment loan program
- Incontinence Products
- Newsletter
- Home meals
- AFCSP
- Faith In Action – services to seniors
- Care Management/consultation
- Elder Choice Grant – consultant to explain
- Day Away Respite
- Transportation – in between major towns
- IRIS electronic data base
- Support Groups (for caregivers and visually impaired)
- Display in government center
- Caregiver Conference

St. Croix County—Hudson Hospital

- Health Resource Center
- Community Series on Health Care Pathways covers different topics
- Referrals
- Parkinson’s Support Group
- Medical equipment
- Meals On Wheels (but are not accepting new clients)
- Transportation (lift van) for those living 15 minutes from the hospital

St. Croix County—Heartland Hospice

- Emotional Support for individuals—training
- Coordinate with other caregiving programs
- Caregiving Near Life’s End
- Core staff does all-day training for individual caregivers

Rusk County

AFCSP

Direct services including chore services

Resources/Library

Loan Closet

Respite

Statewide—Wisconsin Respite Association

Provide respite services in targeted areas

Database of respite services (60 counties)

Respite Co-op information

Lifespan Respite Provider Training Manual

Alzheimer's Association

Lending library

Resources: fact sheets, books, brochures

Fall educational conference

State conference

Helpline (24/7)

Care consultation

Safe Return Program

Maintain Your Brain

**2. What additional educational programs, information, resources and support are being provided for family caregivers by other agencies in your community?**

Interfaith Caregivers

Faith In Action

Triniteam

Employee Assistance Program

Area hospital support groups

Family Resource Center

Aging & Disability Resource Center

Healing Place

Center for Independent Living

Food Resource Collaborations

Resource Fairs

Parish Nurses

Trainings & Seminars

Grandparent Parenting Classes

Extension Office Teleconferences

**3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?**

- Caregivers won't identify
- Language and culture
- Gaps in technology
- Elder abuse & follow-up – gaps with follow-up & reporting self neglect
- Transportation
- Funding for in-home services
- Caregivers don't accept help
- Small volunteer base in small communities
- Limited paid caregivers
- Gap to find adult children (working or distance caregivers)
- Agency names and service
- Those a “cut above” in income cannot afford \$50/week for services
- Bureaucracy

**4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?**

National Family Caregivers Assn  
Alzheimer's Assn  
Internet – Hartford Institute  
First Call for Help  
State aging offices  
Universities  
Chippewa Valley Family Caregiving Alliance  
State and local conferences  
Geriatric health  
Extension Offices

**5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, ListServes, other)?**

- ListServ through state office on aging
- Sponsor regional learning sessions
- Facilitate access and outreach to physicians and health providers
- PSAs
- Get AARP with money to define “Care Partner” and get information out
- United Way to identify “caregiver”
- Identify caregiving in health care and management
- Money to hire agency sponsored respite workers
- Marketing to long distance caregivers

- Alliance would connect counties and key providers, pharmacies and distribute information
- Free Speakers Bureau
- Information and support on “how to form an alliance”
- Ongoing “Listening Sessions”
- Look at long-term sustainability
- Don’t reinvent wheel/overlap

**6. How would you like to access the items identified above?**

Attend regional area agencies on aging  
State Associations: WADD, WASS, WABS  
Internet  
Teleconference

**La Crosse – May 17, 2005**  
**Western WI Technical College**

**Participants:** Edie Felts-Podoll, UW Extension-Adams Co., Peggy Harbeck, Resource Center of La Crosse Co., Marsha Konichek, Prairie du Chien Hospice, Noreen Kuroski, La Crosse Co. Aging Unit, Lola Longyhore, Buffalo Co Aging Unit, Scott Omernick Jackson Co Aging Unit, Pat Peterson, Vernon Co Unit on Aging, Barbara Robinson, WI Dept of Health & Family Services & Pam Saley, Jackson Co Aging Unit.

9 people attended plus 3 leaders (Barb Lawrence, Alliance Core Committee; Dianne Rhein, AgeAdvantAge; Linda Marty Schmitz)

**1. What educational programs, information, resources and support is your agency providing to family caregivers?**

Adams County-UW Extension

- Powerful Tools (for caregivers and professionals)
- Caregiving at the End of Life
- Support groups
- Outreach press releases
- Network with county departments of aging
- Train on Red Cross caregiving curriculum
- Train on POA—Finances & Property and Advance Directives
- “Who gets grandma’s pie plate?”

Crawford County-Hospice

- Training with UW Extension on grief and loss
- Taking Care of the Caregiver
- Support group for grieving

Jackson County

- 3-day caregiver workshop
- Alzheimer’s Support Group
- Resource Center
- Radio outreach

La Crosse County

- Powerful Tools
- Provide books
- Provide assistance
- Do PSAs/advertising
- Provide scholarships for caregivers to attend classes & social events
- Provide respite
- Producing a video on community care/services
- Make presentations to health care providers re: community services through an Elder Enhancement Grant

I&A – direct people to services  
Wellness Expo

#### Vernon County

Elder Enhance Grant to update resource directory and web site  
Contract for national caregiver \$\$ for training  
CAP agency contract to provide grandparent support groups

#### Buffalo County

Chronic Disease Self Management program  
Care Package – Alzheimer’s Assn – caregiver issues  
Alzheimer’s Support Group  
Medication Management Program  
Foot care  
Nutrition education  
Powerful Tools  
Caregiver Newsletter  
Resource Center: books, videos, etc

## **2. What additional educational programs, information, resources and support are being provided for family caregivers by other agencies in your community?**

Parish Nurses

Faith in Action groups

“Sunday with Friends” in Adams County

Nutrition sites

New Senior/Community Center in Adams

Loan Closet

Resource Directory

Mound View Memorial Hospital does programs, has an Adult Coordinator and Memory Clinic

“Dining at Five” program at a hospital

Family Resource Center in Crawford County

Circle of Life Celebration on Memorial Day

Hospice – service for caregivers at Christmas

Disease specific support groups and printed materials

Independent Living Centers

Housing authorities

CAP agencies

Cooperative housing

Food pantries including “Lighted Schoolhouse” in Adams County

Promotion of advance directives

Alzheimer’s Assn chapters

**3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?**

- Help at home – bonded services other than health
- Find the caregiver
- Getting caregiver to accept services
- Professionals who don't know what's available
- Funding
- Medical system doesn't acknowledge caregivers
- Lack of hospice coverage in rural counties (Adams, etc.)
- Distances between classes offered
- Transportation, lack of
- Language issues
- Cultural issues
- County government doesn't understand the issue
- Lack of case managers
- Caregivers won't self identify

**4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?**

Internet/web pages

AAAs

Alzheimer's Assn

County senior newspapers

PSAs

Senior Center newsletters

Word-of-mouth

Bulletin boards

UW Extension

Daily newspapers

Badger ListServ

On-line newsletters

Home health agencies

Conferences: aging network, Alzheimer's Assn state & regional, Transportation, hospitals

**5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, ListServes, other)?**

- Explore distance education options for professionals and caregivers
- Expand Caregiving Relationships offerings
- Reach medical providers – inform them of caregiving/caregivers
- Educate professionals

- Outreach/Marketing
- Determine “Best Practice” Sequence – how to embrace caregiver
- Reach ministerial associations
- Maximize Mary Brintnall-Peterson
- Speakers Bureau
- Develop “Caregiving 101” Manual
- Develop guide on how to form coalitions
- Expand linkages between alliances
- Web site Links should explain why to link
- Best practices suggestions on web site development
- Write grant to support regional caregiver specialists
- Provide newsletter articles

**6. How would you like to access the items identified above?**

Internet

Face-to-face meeting

ListServ

Newsletters

**Madison – May 24, 2005**  
**Lussier Family Heritage Center**

**Participants:** Diane Bright, Oakwood Village Care Ministry Team, Mary Collet, Catholic Charities Aging Services, Wendy Fearnside, WI Dept of HHFS, BALTCR, Shannon Finger, Rainbow Hospice Care & Faith In Action, Nicole Gamble, HospiceCare, Marilynn Ley Lawler, Independent Living, Jayne Mullins, AgeAdvantAge Area Agency on Aging, Mary Reines, Alzheimer's Assn-SC WI Chapter, Mary Jo Rimkus, Chris Rode, HospiceCare, Yolanda Salazar, North/Eastside Senior Coalition, Rob Wilkins, United Way-First Call & Chris Ziemba, HospiceCare.

13 people attended plus 3 leaders (D'Anna Bowman, Alliance Core Committee; Claire Culbertson, Dane County AAA; Linda Marty Schmitz)

**1. What educational programs, information, resources and support is your agency providing to family caregivers?**

South Central WI Alzheimer's Assn

- 3-part ABCs of Alzheimer's disease

- Behavior workshops

- Late stage series

- Making transition from home to \_\_\_\_\_

- Legal & financial decision making series

- Answer requests from groups

- 24/7 Helpline

- Web site

- Lending library

- Quarterly newsletter

- Family consultations

- Provide information on request

- Monthly packet of new information for support groups

- E-mail newsletter to area case managers

- Brochures

- State & area conferences

- Dementia specialist training for workers

- Chore service trainings

- Program: "Crossing Bridges" for those experiencing early memory loss & their caregivers

Independent Living

- Provide direct care/in-home services

- Connect caregivers to resources

- Web site

- Newsletter

- Aging Parents Seminar for employed caregivers

## Hospice

- Provide direct care
- Individually provide resources
- Caregiving Near Life's End
- One-time programs for caregivers
- Caregiver in the work place presentations
- Grief in the work place

## Oakwood Village/Care Team Ministry

- Work with churches to develop teams of volunteers
- Train team volunteers on confidentiality, signs of depression, listening skills
- Refer to resources
- Provide transportation
- Printed resources
  - Care Notes
  - Dane County caregiver packet
  - Reminiscing

## Rock Co United Way First Call for Help

- Info & referral service (8-5, M-F)
- Web site
- Publish support manuals

## Catholic Charities Aging Services

- Direct care/respite care
- Info on workshops
- Quarterly newsletter
- Link caregivers to resources
- Training on aging & caregiving issues
- Volunteer programs through congregations
- Elder Mentor Program

## AARP Faith In Action

- Recruiting volunteers around the state
- Provide indirect resource materials
- Legislative activities
- SeniorCare

## NE Madison Senior Coalition

- Latino caregiver support group
- Grandparents Program (4Cs)
- Work with Latino Support Network
- Provide information on health fairs, etc
- LaSupa meets monthly
- Conduct annual health fair
- Work with WI Well Women Program to provide annual physicals

Centro Hispano & Centro Guadalupe  
Work with Wingra Clinic  
Bi-lingual staff includes a case manager  
Home chore programs that utilize high school Spanish students  
24/7 Helpline  
Provide meals at meetings and find food pantries  
Provide clothing  
Bi-monthly Spanish language newsletter  
Powerful Tools in Spanish

AgeAdvantAge Area Agency on Aging  
Refer people to resources  
Do information assistance training  
Distribute information to aging units  
Provide regional trainings/meetings  
Web site has links on caregiving  
Legislative Advocacy  
Power Point presentation on elder abuse

Jefferson County Faith In Action  
85 volunteers provide services  
Home modification & repair  
Provide transportation  
Meals on Wheels in 2 communities  
Assist with housework  
Newsletter  
Working with Alzheimer's Assn to open Memory Assessment Clinic

Jefferson Co Rainbow Hospice  
One-on-one support and education  
Volunteer program  
Bereavement and spiritual care programs  
Vast amounts of info/handouts  
Social Workers answer caregiving questions  
Share The Care group

WI Dept of Health & Family Services  
Administer MA, COP, SeniorCare, senior centers, etc programs  
Provide annual trainings for county staff

Dane Co AAA  
Senior Nutrition Program  
Elder Abuse Investigator Program  
Powerful Tools  
Caregiving Relationships  
NFCSP

Make presentations to employers & employees  
Conduct annual caregiver luncheon  
Elder Victim Advocate

**2. What additional educational programs, information, resources and support are being provided for family caregivers by other agencies in your community?**

Oakwood & Attic Angels SAIL program – independent living program where fee is paid and services are provided

Dane Co Case Management System – focal points

Rock Co Community Partnership for Older Adults (meet monthly to share information)

Parish Nurse programs (St Marys, Meriter, Oakwood, etc) – state & national network

Elderly Services Network of Dane Co

Dane Co Aging Network

Housing people

Elder Care of WI

Befrienders Ministry

Stephen Ministry

Attic Angel community

Access to Independence

UW Extension

**3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?**

- Lack of caregiver and care receiver connected programs (Living With Chronic Illness curriculum)
- Difficult to adapt existing curriculums for professional caregivers
- Hospitals, etc don't deal with caregivers thrown into caregiving
- Lack of services and programs for ages 50-60
- Lack of knowledge of benefit specialist program
- Lack of training for faith community leaders
- Lack of resources for long distance caregivers
- Lack of one-stop resource center/advocate
- Lack of education about caregiving/identity
- Caregivers won't self-identify
- Getting information to referral agencies
- Peer support for caregivers?
- Marketing
- Language—Hispanic community
- Keep It Simple Stupid
- Cultural gaps
- Lack of readable/low vision materials
- Private case management
- Transportation

- Volunteer base affected by increased energy costs

**4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?**

UW Extension

National Alzheimer's Assn office

All of the above in question #2

Internet

Easter Seal transportation manual

Over 60 Book

Disease/Disability web site

"Family Caregiving 101" web site

Administration on Aging

National Faith In Action office and web site

Conferences

UW Institute on Aging

AARP

**5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, ListServes, other)?**

- Find curriculums
- Caregiver navigator program
- Curriculums for professionals – implementing programs
- Identify best practices
- Connection with Wisconsin Council of Churches and pastors to provide resources
- Marketing tools – jointly with agencies
- Training for paid caregivers
- Tool for caregivers in crisis (videos, brochures) that could be provided to realtors, MDs, etc.
- How to employ caregiver guide
- Array/Spectrum of info on services

**6. How would you like to access the items identified above?**

Internet

Trainings

Snail mail

Caregiver ListServ

Provide tips on accessing

**Brookfield – June 14, 2005**  
**Best Western Midway Hotel**

**Participants:** Elizabeth Fossum, Vitas Hospice, Alice Kowalski, Milwaukee Co Dept of Aging, Veronica Naumann, Bugel, Alzheimer's Assn, Jennifer Nowak, Lutheran Home Adult Day Services, Judy Roehm, Waukesha Co Dept of SS, Prue Smith, Luther Manor, Janet Stikel, Aurora Adult Day Center & Cathy Young, Catholic Charities.  
8 people attended plus 2 leaders (Linda Dreyer, Alliance Core Committee & SE Wisconsin AAA; Linda Marty Schmitz)

**1. What educational programs, information, resources and support is your agency providing to family caregivers?**

Milwaukee Co. Dept on Aging

- One-stop shopping center for senior Services
- I&A
- Resources provide direct services
- Fund Family Caregiver Support Network
- Respite funding
- Living Well With Chronic Conditions

Aurora (statewide)

- Powerful Tools
- Danceworks Program teaches relaxation techniques
- Respite
- Senior Services Team has and Employee Assistance Program
- Try to get employees to identify as caregivers

Vitas Hospice (south to IL border; north to Rubicon)

- Offer respite
- Work with Alz Assn and other agencies to find resources
- Facilitate to meet needs (transportation)
- Grief Support Groups
- Other support groups
- Caregiver Agency lists
- Education employees of care facilities
- Educate doctors & health professionals

Luther Manor (Milwaukee & Ozaukee counties)

- Offer Partners in Caring program
- Adult Day Services
- Weekend Respite Services (Milwaukee County)
- Facilitate Alzheimer's' Support groups
- I&R with congregational partners thru Parish Nurse Program
- Facilitate work group in family care with Alzheimer's Assn and others
- Work with Portal Industries to provide support for caregivers of people with DD

Community events on planning for LTC (Ozaukee County)  
Produced a film – will offer tools, etc.

Waukesha Co Dept of Senior Services

I&A phone line  
Make referrals  
Conduct family meetings  
Powerful Tools classes  
Collaboration with a church  
Intermission Program—hands on intergenerational program  
Caregiver & receiver come together to interact  
Caregiver Library—books, CDs, equipment  
Collaborate with Adult Day Care centers to provide books, equipment, etc.  
Collaborate with County Library System  
Annual Caregiver Conference  
Caregiver Newsletter  
Respite Services – “Try It; You’ll Like It”  
Breakout workshop for male caregivers at conference

Alzheimer’s Assn (12 SE WI counties)

Education programs for families (disease specific), for professionals, general community—“Dementia Specialist Training”  
I&R (24/7 Toll Free #)  
Offer resources re: legal, financial, assistance  
Library at Milwaukee office connected with national office  
Support Groups—most for family caregivers  
Specialized: ladies only, men only  
Early Stage groups for receivers; caregivers at same time  
Support for facilitators—annual training  
Broad collaborations  
Conferences (state on down)  
Annual Family Conference  
Annual Nursing Assistant Conference  
Jefferson County Dementia Care Coalition  
Waukesha County Aging Consortium  
Opening Memory Care Clinic in Ft Atkinson

Catholic Charities (Milwaukee Archdiocese)

I&R in all counties  
I&R for outstate caregivers  
Aging people with DD/help aging caregivers with aging recipients  
Adult Day Care  
In-home support  
Respite care  
Four support groups  
Educational programs

Lifelong Wellness Conference  
Liaison for Parish Nurses  
Work with hospitals on end of life issues  
Powerful Tools  
Listening sessions for caregivers

Lutheran Living Services (Milwaukee County)  
Support groups (Parkinson's & Alzheimer's' diseases)  
Respite services  
Adult Day Center  
Family Spiritual Retreat  
Health Fair  
Education program  
Field trips for care receivers & caregivers  
Sep: will start Early Onset Alzheimer's day programs/classes  
I&R

**2. What additional educational programs, information, resources and support are being provided for family caregivers by other agencies in your community?**

UW-Milwaukee Age & Community Center  
Collaborations with police department (Waukesha County)  
RSVP of Waukesha County  
Family Caregiver Support Network of SE WI through Interfaith  
Dept of Vocational Rehabilitation  
YMCA  
American Cancer Society  
Dept of Motor Vehicles—When to take keys away?  
Funeral Homes—education programs  
Hospitals—education, support groups, assessments  
Some physicians  
Medical College of WI—caregiver support education  
Latino Aging Network (Milwaukee County)  
Waukesha Hispanic Collaborative Network—La Casa

**3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?**

- Caregivers won't self-identify
- Cultural issues (language, etc.)
- Caregiver support for DD population
- \$--money not there
- Where to start in finding resources?
- Respite (volunteers, agencies, services, funding)
- Affordable services
- Transportation (flexibility, cost, quality)

- Lack of willingness to coordinate/share by counties
- Health professionals inability to recognize caregiver issues

**4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?**

Family Caregiver Support Network  
 Alzheimer's' Assn.  
 County Departments on Aging  
 Family care I&R  
 Disease specific associations  
 Network with each other  
 Internet  
 Universities/Extension/Technical colleges  
 Churches/synagogues/faith communities

**5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, ListServes, other)?**

- Alliance as link on other agency web sites/two-way street
- Fact sheets on curriculums
- Educate caregivers to be advocates
- Support caregivers to be advocates
- Challenge caregiving assumptions/not only educate
- Program for volunteer recruitment
- Marketing/Outreach
- Education programs (caregiver related) on web site
- Review & certify curriculums
- Caregiver to Caregiver Mentoring Program

**6. How would you like to access the items identified above?**

Web site  
 800 # where a person answers the phone  
 TV (under utilized)  
 Physicians

**Kenosha – June 15, 2005**  
**UW-Parkside**

**Participants:** Ruth Ann Challis, Aging & Disability Resource Center of Kenosha Co., Christopher Czerwinski, Home Instead Senior Care, Ninna Frank, Caregiving & Aging Resource Center of Racine Co., Katherine Halaberda-Hinks, Aging & Disability Resource Center of Kenosha Co., Marilyn Joyce, Caregiving & Aging Resource Center of Racine Co., Bill Leon, Catholic Charities, Gail Lesjak, Parish Nurse-Aurora Health Care, Alice Schwalbe, Aging & Disability Resource Center of Kenosha Co. & Tedi Winnett, UW Extension-Kenosha Co.

9 people attended plus 4 leaders (JoAnne Kuehl & Paulette Kisse, Alliance Core Committee; Linda Dreyer, SE Wisconsin AAA; Linda Marty Schmitz)

**1. What educational programs, information, resources and support is your agency providing to family caregivers?**

Catholic Charities (10 counties)

- Annual Conference: Lifelong Adult Wellness
- I&A
- Education
- Counseling

Aging & Disability Resource Center (Kenosha County)

- Caregiver Newsletter (bi-lingual)
- I&A
- Loan Closet (durable medical equipment)
- Support Groups
- Workshops
- Powerful Tools
- Health Living Classes
  - Falls assessment
- Daybreak—day respite program
- Presentations through employers to caregivers
- Elder Reach—one-on-one support for caregivers
- Community Hospital Link Program
- Work Crew Program
- Grocery shopping program

Caregiving & Adult Resource Center (Racine County)

- I&A
- Support groups
- Powerful Tools
- One-on-one counseling
- Resource Library

Lincoln Lutheran (older adult services—Racine County)

- Support Group: Grandparents Raising Grandchildren

Respite services

In-home volunteer based

Respite Day Care—volunteer based (social model)

Day Care (medical model)

Home Instead Senior Care (Kenosha & Walworth)

I&A

Parish Nurse

Just starting—Healthy Living Program starts in July

Alzheimer's Assn ((12 SE WI counties)

I&R (24/7 helpline)

Education

Family Caregiver Conference—local & regional

Programs: Behavior & Communication

Dementia Specialist Training

Annual Professional Caregiver Conference for professionals

Direct Care Worker Conference

Care Consultation – one-on-one

Home Visits

Advocate re: legislation/both state and national

Network/Dementia Care

Teach how to work with physicians

Safe Return Program

Support Groups

Outreach Coordinators

Milwaukee County: multi-cultural outreach

Work with employers to reach employees

Dementia Basics Class

**2. What additional educational programs, information, resources and support are being provided for family caregivers by other agencies in your community?**

Disease specific support groups

Aurora: Caregiver Support Group (Racine County)

Geriatric Assessment Center (Racine & Kenosha Counties)

I&A

Society's Assets: Home Modification Assessment

Community Care for the Elderly (Racine County)

Senior Companion Program (Sienna Center)

Volunteer Escort

Friendly Visitor

Skill Care (seniors helping seniors)

Meals On Wheels

Care Management agencies

CAMP (social program for adults with physical disabilities)  
Parish Nurse – Aurora & All Saints  
Community education: All Saints & Red Cross  
Churches: social programs for seniors  
Senior Centers: social & support groups  
Drop-In for Caregivers  
Benefit Specialist Program

**3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?**

- Snow removal/affordable or free
- Lawn care/affordable or free
- Overnight respite/weekend/affordable
- Transportation/accessible & affordable
- Marketing
- Won't self identify as caregivers
- \$--Money
- Understanding of spiritual component for caregiver & care receiver
- End of life programs/organized
- Affordable independent senior housing
- Assisted living funding lacking on state & federal levels
- Lack of advance planning/acceptance—"wait for crisis to hit"
- Understanding of reverse mortgage, LTC insurance

**4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?**

Aging & Disability Resource Center  
Disease specific organizations  
Internet  
National Council on Aging & American Society of Aging web sites  
Dementia Care Network  
Conferences  
Health care systems including Hospice  
Other local agencies for collaboration  
Professionals/Network  
National Family Caregivers Assn.  
AARP  
WI Alliance of Family Caregiving  
Families of caregivers  
Helen Bader School of Social Work  
Colleges & universities

**5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, ListSerts, other)?**

- Speakers Bureau
- Funding
- Advocacy—keep updates on legislators and their support or lack thereof and updates on issues before the legislature
- Resource Library – including videos
- PSAs for radio & TV
- Web site: download certificate for classes
- Materials geared to faith communities to help caregivers self-identify. Put together a tool kit including bulletin announcements, etc.
- Sponsor more “listening” type sharing sessions/quarterly
- Work with “Family Readiness Programs” for Armed Services

**6. How would you like to access the items identified above?**

Internet/E-mail

Phone notification

Snail mail

Teleconference

Video conference

“Did you know?” messaging

## **Milwaukee – June 16, 2005**

### **Washington Park Senior Center**

**Participants:** Kathleen Arch, Comfort Keepers, Pat Bruce, Interfaith Family Caregiver Support Network, Jill Knight, Milwaukee Co Dept on Aging, Betty Lovinus, Aurora Health Care, Michelle Pike, Waukesha Co Dept of SS, Jeannine Rowe, UWM-Applied Gerontology, Meg Steimie, SE Regional Children's Program, Chris Thies, Family Caregiver Support Network, Marsh Vollbrecht, Aurora Health Care, Lorraine Henrickson, Alzheimer's Association & Laura Tice, Milwaukee Co. Dept on Aging.

11 people attended plus 2 leaders (Mary Brintnall-Peterson, Alliance Core Committee; Linda Marty Schmitz)

#### **1. What educational programs, information, resources and support is your agency providing to family caregivers?**

##### Interfaith/FCSN

Powerful Tools

Maintain data base—provide information on area agencies & support groups (older adults, young adults, children)

Newsletter

Legal, financial, emotional, social services, etc.—resources provided and/or referred

Respite referred & provided through a small grant

Telephone counseling

Advocacy & Best Practices

2 web sites (Living Options & Family Caregiving)

Recognition of Caregivers

Resource Library

Follow-up

Gap reporting & research

Long distance caregiving research

Trainings – coordinate and promote

Grandparent Support Program

Info & Outreach (bullet sheet)

##### Parish Nursing

Education

Health counseling

Advocacy

Referrals

Support Groups

##### Aurora

Powerful Tools

Caregiving Near the End of Life Curriculum/Alliance

Support groups

Caregiver education programs  
Conferences  
Employee Assistance Program  
Sponsorships & Partnerships  
System-wide Senior Service Strategy Team  
    Caregiver Awareness Program  
Discharge Planners provide referrals & links  
Home Care Agency-VNA  
Adult Day Care  
Pharmacies provide family caregiving info  
Senior Celebration  
Web site  
    Web page: Senior Resource Director

Milwaukee County Dept of Aging  
    I&A  
    Telephone counseling  
    Respite—Case Manager coordinates  
    Managed Care System—Case Manager coordinates  
    Outreach Coordinator  
    Newsletter  
    Web site

Waukesha Co Dept of Senior Services  
    Powerful Tools  
    Adult Day Care  
    Intermission Program  
    I&A  
    Respite-facility or in-home  
    Grandparenting Program  
    Refer to support groups  
    Annual Caregiver Conference  
    Monthly newsletter  
    Resource Library (it travels)—“Try Before You Buy”  
    Outreach  
    Web site

Special Needs Family Center  
    Resource Library  
    Support families with children with special needs  
    Support groups  
    Web sites  
    Trainings  
    Information referral & follow-up  
    Parent-to-parent support  
    WI First Step Hotline (statewide)

Resource House web site out of MN; covers WI

League of Experienced Family Caregivers  
Gather information on family caregivers  
Web site

Comfort Keepers  
Provide direct care  
Do errands to 24/7 service  
Telephone counseling

**2. What additional educational programs, information, resources and support are being provided for family caregivers by other agencies in your community?**

Alzheimer's Assn  
Independence First (persons with disability served)  
Respite Coalition in Milwaukee  
AARP  
Adult Day Center—St. Anne's  
Disease specific associations  
SET Ministry  
Luther Manor  
Home Health agencies  
Red Cross  
UW-Milwaukee Center on Aging  
Hospitals  
ARC of Milwaukee  
Waukesha Co Federated Library System  
Grant to get books for caregivers  
Chat Rooms through web sites  
IMPACT 211  
Public health departments  
School system social workers  
NAMI

**3. What are the gaps in educational programs, information, resources and support for family caregivers in your community?**

- Limitations of funding sources
- Lack of knowledge on all areas of family caregiving
- Publicity/Marketing
- Lack of outreach
- \$\$
- Audio resources
- Caregivers wait too long to ask for help
- Respite education

- Providers of respite—paid & volunteer
- Affordability of services
- Poor business awareness of need
- Caregivers will not self-identify
- Employee Assistance Programs
- Lack of education for social workers & medical professionals
- Access or understanding of legal system/affordability
- Lack of ministerial education
- Lack of interest/education by physicians

**4. Where do you go for family caregiver education, information, resources and supports to assist you in providing educational programs for family caregivers?**

Web/Internet/ListSers

FCSN

Dept on Aging

UW-Extension

Hospital

Disease specific associations

Library

CWAG Elder Law Center

Published materials on shelves

Other professionals/network

American Society on Aging

**5. What educational programs, information, resources and supports should the Alliance provide to you and others who provide family caregiving education (fact sheets, curriculum trainings, technical assistance and support in developing regional coalitions, newsletters, ListSers, other)?**

- Speakers Bureau
- Videos re: caregiving
- PSAs
- Web resource manual on what's available in caregiving
- Web site provide statewide links to resources available
- Help with fund raising—list of foundations, etc. that will provide funds
- Advocacy Assistance—legislative/funding
- Simplify Powerful Tools
- Evaluate caregiver materials—how to use which pieces
- Technical support for grant writing
- Reach out to “young careers”
- Mini Manuals on how to create Internet & Telephone Support Groups
- Help promote and define respite
- Train on curriculums
- Chart showing what agencies share programs (libraries, etc.)

**6. How would you like to access the items identified above?**

Web

Curriculums

Provide name & phone #

Mini workshops & conferences

Snail mail

ListServ