Social Work and Family Caregiving

• Ecological framework
  – Reciprocal relationship between individual & environment
  – Micro- & macro-level interventions

• Strengths perspective
  – Focus on goals, resources, and coping
  – Social justice, diversity, collaboration, self-determination
Goals of the NASW Standards

Advance support for family caregivers

- Enhance social work practice
- Educate the public
  - Family caregivers, older adults, & other consumers
  - Service providers
  - Employers
  - Policymakers
  - Media

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Development of the Standards

• Gerontological social work competencies
  – CSWE
  – SWLI (NYAM)
• State of the Science symposium (2008)
• Social work expert panel
• NASW member survey
• Public comment period
Content of the Standards

- Introductory material
- Ethics & Values
- Qualifications
- Knowledge
- Cultural & Linguistic Competence
- Assessment
- Service Planning, Delivery, & Monitoring
- Advocacy
- Collaboration
- Practice Evaluation & Improvement
- Documentation
- Workload
- Professional Development & Competence
- Resources
Dissemination of the Standards

- November 2010 release
  - National Family Caregivers Month (NFCA)
  - Launch of AoA’s *Year of the Caregiver*

- Use of multiple NASW channels

- Promotion by partners:
  - JAHF, AARP, AoA, FCA, NAC
  - Coalitions & sister SW organizations

- Central role of social work expert panel
Putting the Standards into Practice

- Presentations, publications, & Web
- National & international audiences
- Students & practitioners
- Supervisors & administrators
- Other professionals & service providers
- Family caregivers
- Social work curricula & field placements
- Continuing education & employee training
- GECs & other organizations
Social Work Expert Panel & Other External Advisors

Patricia Brownell, PhD, MSW
Catherine A. Clancy, PhD, LCSW
JoAnn Damron-Rodriguez, PhD, LCSW
Sandra Edmonds Crewe, PhD, ACSW, MSW
Lorraine Hedtke, LCSW, PhD
Forrest Hong, PhD, LCSW, C-ASWCM
Jamie Huysman, PsyD, LCSW
Phyllis Mensh Brostoff, CISW, ACSW, CMC
Nora O’Brien-Suric, MA, PhD
Miriam Sterk, LCSW, C-ASWCM
Cynthia Stuen, DSW/PhD, ACSW, LCSW
Amy Berman, BS, RN
Rita Choula, BS
Susan Reinhard, PhD, RN, FAAN
Accessing the Standards

• Single copy: www.socialworkers.org/practice

• Bulk copies: www.naswpress.org
Conclusion

“Attention to the contributions, strengths, needs, and goals of family caregivers of older adults is integral to social work practice.”

–NASW Standards for Social Work Practice with Family Caregivers of Older Adults (2010), p. 17
Professional Partners Supporting Family Caregivers Phase 2: New Jersey Care Partners Support Pilot Project

- Funded by The John A. Hartford Foundation
- Partners:
  - U.S. Administration on Aging
  - AARP Foundation
  - Family Caregiver Alliance
  - National Association of Social Workers (NASW)
  - Technical Assistance provided by The Lewin Group and the Hilltop Institute at the University of Maryland Baltimore County (evaluation)
Why New Jersey?

- History of caregiver support programs - state funded since 1980’s
- Tradition of using federal initiatives to shape system development efforts in state & leadership
- Process of developing ADRC’s in every AAA in the state
- Saw a need to integrate caregivers within all home and community based services shifting the paradigm to *person and family centered services*
The goal of the Pilot is to improve caregiver knowledge and skills through access to information, training and services for informal caregivers of those adults receiving HCBS waiver services.
New Jersey Care Partners Support Pilot: Design Parameters

- Pilot design recognizes the constrained resource environment facing state and local services
- Builds from the policy recommendation that caregivers should be integrated into health and social service systems - particularly if those systems rely on informal caregivers to provide LTC
New Jersey Care Partners Support Pilot: Design

- Pilot includes:
  - brief caregiver questionnaire (context, direct care, troublesome behaviors, self-care, informal supports)
  - tailored information and referral to services
  - one follow up call from Care Manager
How Does it Work?

Caregiver Questionnaire

- Self-administered questionnaire at time of care plan, monthly visit or yearly reassessment
- Four areas to query on questionnaire:
  - direct care of relative/friend;
  - management of troublesome behaviors;
  - caregiver self-care;
  - increasing informal supports
- Caregiver Action Plan - quick scan and check boxes
How Does it Work?
Caregiver Tailored Information & Referral

- Provided to caregiver: information and referral module(s) related to the four topic areas;
  - brief resource listing (includes local resource centers, national websites or call centers, web resources & support)
  - article(s) on identified topics
  - all materials used have permission for use
  - all materials are lodged on a website for use by staff

- Care Manager is to provide encouragement, information, recognition and to check back in with the caregiver over next two months
The pilot program was conducted and data was collected as follows:

- **Client Screening for Community Service (NJ)**
- **Clinical Assessment (NJ Choice) and Options Counseling (NJ)**
- **Plan of Care Development by Care Manager (NJ)**
- **NJ Delivers Services to Client**

During Home Visit:

- **Care Manager Identifies Caregiver and Requests Participation in Home Visit**
- **Self-Administered Caregiver Questionnaire and Tailored Response (FCA)**
  - 1 month

- **Care Manager Calls Caregiver and Records in Log (FCA)**
  - 2 months

**Survey Data (Hilltop)**

**Mail Survey to Caregiver (Hilltop)**

**Telephone Interviews with FCA, Agency/ADRC Directors When Caregiver Enrollment Completed (Hilltop)**

**Evaluation Analysis (Hilltop)**

**Caregiver Questionnaire Action Plan Client Assessment Data (WPA-1)**

**Call Log**

**Telephone Interview Findings (Hilltop)**
How Does it Work?

Staff Training

- Staff receive 6 hours of training on:
  - caregiver assessment and needs;
  - caregiver questionnaire;
  - how to use the results to tailor a response;
  - protocols of the evaluation component

- Staff technical assistance
  follow up call with supervisors
  follow up call with case managers
  available to answer phone or email questions
New Jersey Care Partners Support Pilot: Implementation Design

– Expectation that pilot will have 130 caregivers enrolled within 3+ months and the pilot test will take place in 4 counties: Warren, Mercer, Monmouth, Atlantic
Final Thoughts: New Jersey Perspective

Catherine Dailey

- 4 counties were asked to be a part of the pilot: 2 were Aging and Disability Resource Center/Area Offices on Aging and 2 were VNA's in order to have the perspective of 2 different organizations.

- The training was helpful for Care Managers because it increased awareness of the caregiver and their understanding of challenges facing informal caregivers.

- The consumer information was instructive for both Care Managers and the informal caregivers - the information on understanding dementia provided insight into the needs of the participant and the caregiver.

- In the future, we thought the program would be helpful to caregivers in the community who are without the benefit of being part of a Waiver that includes care management.
New Jersey Care Partners Support Pilot Project

Future Activities

- Finish evaluation activities
- Review project and evaluation with NJ administration
- Determine desire to incorporate cgr assessment and tailored response beyond pilot project
- If replicated, make adjustments to program components and staff training based on evaluation results
Contact Information for Pilot:

- Kathleen Kelly, MPA, Executive Director
- Family Caregiver Alliance, National Center on Caregiving
- 180 Montgomery Street Ste 900
- San Francisco CA 94104
- 415.434.3388
- www.caregiver.org
- kkelly@caregiver.org
The Evaluation of the New Jersey Care Partner Support Pilot Program: Preliminary Findings

September 13, 2011
Cynthia Woodcock
2011 National Home and Community-Based Services Conference
NASUAD
Overview of Presentation

- Overview of pilot program and data collection
- Profiles of:
  - Care managers
  - Care recipients
  - Caregivers
- Project status and next steps with the evaluation
The pilot program was conducted and data was collected as follows:

- Client Screening for Community Service (NJ)
- Clinical Assessment (NJ Choice) and Options Counseling (NJ)
- Plan of Care Development by Care Manager (NJ)
- NJ Delivers Services to Client
- During Home Visit:
  - Care Manager Identifies Caregiver and Requests Participation in Home Visit
- Self-Administered Caregiver Questionnaire and Tailored Response (FCA) 1 month
- Care Manager Calls Caregiver and Records in Log (FCA) 2 months
- Mail Survey to Caregiver (Hilltop)
- Telephone Interviews with FCA, Agency/ADRC Directors When Caregiver Enrollment Completed (Hilltop)
- Call Log
- Survey Data (Hilltop)
- Telephone Interview Findings (Hilltop)
- Caregiver Questionnaire
- Action Plan
- Client Assessment Data (WPA-1)
- Evaluation Analysis (Hilltop)
In addition, care managers were trained and later interviewed.
New Jersey’s care managers were experienced professionals.

- On average, the 16 care managers had more than 8 years of experience, with years of experience ranging from 1 to 17 years.
- 50% have been a caregiver to a friend or relative outside of their professional responsibilities.
- 88% have backgrounds in social work.
- 94% agreed or strongly agreed that the role of the care manager includes providing support to caregivers.
Who were the care recipients?

- 86 care recipients from 4 counties: Atlantic, Mercer, Monmouth, and Warren Counties
- 73% were Medicaid Global Options Waiver participants; 27% were Jersey Assistance for Community Caregiving (JACC) participants
- 65% had a cognitive impairment at the time of their last evaluation
Care recipients required assistance and supervision with at least three functional deficiencies.

- All care recipients had functional deficiencies* in at least 3 areas
- Nearly 21% had deficiencies in all 7 measured areas

*Seven functional deficiencies: bathing, dressing, toileting, transferring, locomotion, bed mobility, eating.

Source: NJ Form WPA-1.
Caregivers were most often female and the children or spouses of the care recipients.

- 50% of caregivers were children and 27% were spouses
- 13% of caregivers were parents of the care recipient
- 86% of caregivers were female

Source: The Hilltop Institute
The average age of caregivers was 60 years, but there was wide variation.

Source: The Hilltop Institute
More than half (58%) of caregivers were not working.

Source: The Hilltop Institute
Most caregivers (70%) reported that they were in excellent or good health ...
... yet 68% of caregivers reported health issues that got in the way of their caregiving duties.

Source: The Hilltop Institute
On average, caregivers reported caring for their relative or friend for 9 years.

Source: The Hilltop Institute
Caregivers’ average score on the Zarit Burden Scale (4 items) was 7, but many scores were significantly higher.

Source: The Hilltop Institute
Status and Next Steps

- Enrollment of caregivers ended on July 15, 2011

- Care managers are now completing a web-based survey to report their experience with the pilot

- Caregivers are now completing the 3-month follow-up mail survey to report on their experience with the pilot

- Telephone interviews are underway with New Jersey agency staff and key members of the project team on pilot implementation, perceived outcomes, and recommendations for replication

- Hilltop will complete the final evaluation report by the end of 2011
About The Hilltop Institute

The Hilltop Institute at the University of Maryland, Baltimore County (UMBC) is a nationally recognized research center dedicated to improving the health and wellbeing of vulnerable populations. Hilltop conducts research, analysis, and evaluations on behalf of government agencies, foundations, and nonprofit organizations at the national, state, and local levels.

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Professional Partners
Supporting Family Caregivers

Susan C. Reinhard, RN, PhD
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HCBS
National Home & Community Based Services Conference
September 13, 2011
Overview

- Highlights of AARP Caregiving Initiative
  - State of the Science: Professional Partners Supporting Family Caregivers
  - Professional Partners Supporting Family Caregivers – Phase II
  - Professional Partners Supporting Diverse Family Caregivers Across Settings
  - Long Term Services and Supports Scorecard

- NASW Standards for Social Work Practice with Family Caregivers of Older Adults

- New Jersey Care Partner Support Pilot Program

- Questions/Comments
Family Caregivers: The Backbone of the Long Term Services and Supports System

“Seventy-seven. How about yours?”
Valuing the Invaluable

• In 2009, about 42.1 million family caregivers in the U.S. provided care to an adult with limitations in daily activities at any given point in time
  – about 61.6 million provided care at some time during the year

• The estimated economic value of their unpaid contributions was about $450 billion in 2009
  – from an estimated $375 billion in 2007

Caregivers Need More Recognition and Support from Professionals

- The *caregiver* and the *care recipient* should be seen as a "unit of care"

- More preparation for transitions across settings

- Increase caregiver confidence and competence
  - Leads to better outcomes for the care recipient
  - Helps to lower burden and stress of the caregiver
Caregivers Need More Recognition and Support from Professionals

- Assessment of the caregivers’ needs
  - Rarely are family caregivers asked “How are *you* doing? How are *you* managing?”

- Understand the caregiving situation – including service needs, unresolved problems, and potential risks – in order to meet the needs of the caregiver
  - Identify services available and provide appropriate and timely referral for services
  - Provide specific and targeted resource referrals
In Their Own Words

“Nobody told us anything. All they said to us was, "do you have all your things? Do you need another pair of socks?" We had our things and we didn't need socks, we needed information. And the person did not have the time to give it to us. “

----Jackie, cares for her 85 year-old husband Phillip*

“We ask family caregivers to do things that would make first-year nursing students shudder”

----Susan C. Reinhard

Caregiving Gains Recognition Among Policymakers, Health Professionals

AARP Public Policy Institute Initiative

• Bring Professionals Together to Support Family Caregivers
  - Focus on Nurses and Social Workers
  - Numerous Partners
    • To recognize and better address family needs
      - Rarely are family caregivers asked “How are you doing? How are you managing?”
    • To work as “partners in care” with families
  - New Research
    • What are the health tasks that caregivers do?
  - Funding from The John A. Hartford Foundation and The Jacob & Valeria Langeloth Foundation
Bringing Professionals Together to Support Family Caregivers – Phase I

• A unique partnership among the AARP Foundation, the American Journal of Nursing, the Council on Social Work Education, the Family Caregiver Alliance, and Rutgers Center for State Health Policy

• Funding from the John A. Hartford Foundation and the Jacob & Valeria Langeloth Foundation
“State of the Science”

• 2008 interdisciplinary symposium of 50 RNs, SWs, family caregiver researchers, and others

• Presentations of peer reviewed papers summarizing the “state of the science”

• Final recommendations published as supplement to Sept. 2008 AJN and as special issue of the JSWE
Invitational State of the Science Symposium

- 2008 interdisciplinary symposium of 50 RNs, SWs, family caregiver researchers, and others

- Presentations of peer reviewed papers summarizing the “state of the science”

- Recommendations from the symposium circulated to all participants for feedback

- Report published as supplement to Sept. 2008 *AJN* and as special issue of *JSWE*
Bringing Professionals Together to Support Family Caregivers – Phase II

- Professional Partners Supporting Family Caregivers – Phase II
  - Funded by The John A. Hartford Foundation
  - In partnership with the U.S. Administration on Aging, Family Caregiver Alliance, National Association of Social Workers (NASW)
Bringing Professionals Together to Support Family Caregivers – Phase II

• Objectives
  – Establish standards of practice for social workers working with family caregivers
  – Seek to improve public policies related to support of family caregivers
  – Raise consumer expectations for caregiver support
  – Develop a caregiver assessment aimed at increasing caregiver skills
  – Develop a caregiver intervention that will train nurses and social workers to provide tailored information and referrals to caregivers.
NASW Standards for Social Work Practice with Family Caregivers of Older Adults

- Enhance social work practice with family caregivers of older adults
- Help the consumer understand the role of professional social work in supporting family caregivers across settings.
Professional Partners Supporting Family Caregivers In Diverse Settings

• Funded by The Jacob & Valeria Langeloth Foundation

• Partners:
  • New York University/Hartford Institute for Geriatric Nursing’s Nurses Improving Care for Healthsystem Elders program (NICHE)
  • American Journal of Nursing
Professional Partners Supporting Family Caregivers In Diverse Settings

• Themes:
  • Assessing the Needs of the Family Caregiver
  • Partnering with Family Caregivers by Recognizing Them as Partners in Care
  • Principles/Practices for Teaching Essential Skills to Family Caregivers
“Overall, I am fearful of being able to handle all of her needs. I am fearful that she could fall again. I am fearful that she could get hurt again and that I won’t be able to help her. More than anything it’s the constant fear.”

-Spanish-speaking Latina Caregiver, Los Angeles

Source: AARP Focus Groups with Diverse Family Caregivers, Los Angeles, 2011
Objectives

• Pilot and test family-centered practices at selected (NICHE) sites.

• Develop and disseminate a web-based toolkit based on established themes
  • Expansion of Evidence-Based Geriatric Nursing Protocol for Best Practice in Caregiving
  • Resource guide of family-centered practices
  • Interdisciplinary Training Module on Family-Centered practices
  • Registered Nurse Training Family Caregiving Module
Objectives

- Produce a qualitative research report highlighting the unique experiences of nurses, social workers and family caregivers in diverse communities
  - Using findings from focus groups

- Develop culturally relevant educational materials (training videos) to help nurses and social workers adopt best practices in partnering with family caregivers in diverse communities
State LTSS Scorecard

- States are ranked on five dimensions that approximate the five characteristics of a high-performing LTSS System.
- Scorecard calls attention to state variation and puts each state’s performance into context.
- Scorecard provides a mechanism to track progress in years to come.
Characteristics of a High-Performing LTSS System

- Support for Family Caregivers
- Ease of Access and Affordability
- Choice of Settings and Providers
- Quality of Care and Life
- Effective Transitions and Organization of Care
Support for Family Caregivers - Indicators

• % of family caregivers usually or always getting needed support

• Publicly funded respite care per person age 18+

• Nurse Delegation Tasks

• Legal and system supports for family caregivers
  – Including state use caregiver assessments
“It will take a movement to join the three corners of the care triangle: people who need care, families who care for and about their members, and people who give care for a living.”

Resources

AARP Resources
www.aarp.org/research/ppi
http://www.aarp.org/relationships/caregiving-resource-center/

American Journal of Nursing

Family Caregiver Alliance
www.caregiver.org

National Association of Social Workers
Standards for Social Work Practice with Family Caregivers of Older Adults
www.socialworkers.org/practice/standards/NASWFamilyCaregiverStandards.pdf
Resources cont…

Nurses Improving Care for Healthsystem Elders (NICHE)
www.nicheprogram.org

U.S. Administration on Aging

http://celebratingfamilycaregivers.org
Next Step: Developing Standards and Best Practices for Professionals