

BRI Care Consultation and Unmet Respite Needs of Family Caregivers

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*National Lifespan Respite
Conference ♦ Denver, CO
September 22, 2016*

Benjamin Rose Institute on Aging

Mission:

To advance support for older adults and caregivers

National Impact

- Research and Education
- Evidence-Based Programs
- Community Advocacy

Local Impact

- Home and Community-based Services
 - Rose Centers for Aging Well
 - Margaret Wagner Apartments
 - Conference Center



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Overview of BRI Care Consultation

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BRI Care Consultation

- A telephone-based information and support service for adults with physical and mental health challenges and their family caregivers
- Personalized coaching and advice to empower clients to manage their own care situations
- Ongoing support and assistance throughout the caregiving journey



Issues Prompting Development of BRI Care Consultation

- Fragmentation among services
- Mismatch between professionals' and consumers' readiness
- Lack of attention to caregivers
- Difficulty with follow-through by consumers
- Lack of coordination between formal and informal care
- Care situations change, but services are static and short-term
- Too much assessment; too few solutions
- Lack of attention to planning and prevention



How does BRI Care Consultation address these issues?

- Evidence-based method of coordinating healthcare and community services
- Personalized coaching by telephone and computer
- Targets persons with health problems and their caregivers
- Linkages to and monitoring of services
- Facilitates involvement of family and friends
- Ongoing long-term support



Four Types of Assistance

- **Health- and Care-related Information**
 - Empower clients to manage their own situations
- **Family and Friend Involvement in Care**
 - Support and strengthen the informal network
- **Awareness and Use of Community Services**
 - Help clients learn about formal services
- **Coaching and Support**
 - Coach caregiver and provide emotional support



Licensed Sites

There are currently 28 licensed BRI Care Consultation sites in the United States, many of which are managed in partnership with the Rosalynn Carter Institute for Caregiving

**Contact Branka Primetica at bprimetica@benrose.org or 216.373.1662 to schedule a demo and learn about how to become a licensed site*



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The Rosalynn Carter Institute for Caregiving



RCI: Supporting Caregivers through Advocacy, Education, Research, and Service

The RCI was established in 1987 at Georgia Southwestern State University (GSW) in Americus, Georgia. The Institute was formed in honor of Former First Lady Rosalynn Carter, an alumna of GSW, to enhance her long-standing commitments to human development, caregiving and mental health through its Advocacy, Service, Research and Education Programs

Mission and Philosophy

The Rosalynn Carter Institute for Caregiving (RCI) establishes local, state, national, and international partnerships committed to building quality long-term, home and community-based services.



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Key Components

Initial
Assessment

Action Plan

Maintenance
and Support



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Care Consultant as Interventionist

- Knowledgeable professional, experienced with people living with and caring for persons with a chronic condition
- Bachelor's or advanced degree in social work, nursing, or related field
- Knowledge of coaching, problem-solving, resources
- Excellent communication skills
- Ability to build and maintain relationships via telephone contacts



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BRI Care Consultation Implementation in Nevada

Celeste Graham, BS



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Overview

- I. Introduction
- II. Overview of Nevada's Implementation
- III. Care Consultation Information System (CCIS)
- IV. Sample Case
- V. Benefits
- VI. Conclusion



Introduction – Nevada Senior Services

❖ Non-profit Organization

Mission:

- ❖ Community agency providing compassionate care and services to adults and their caregivers, facing challenges of chronic diseases, disabilities, and aging to remain in the community with dignity

❖ Care Partner Institute

Range of Services:

- ❖ Community Based Programs
- ❖ Caregiver Support Services
- ❖ Southern Nevada Care Connection Resource Center

Who can access Services?

- ❖ Senior Adults
- ❖ Individuals with Disabilities
- ❖ Caregivers



State of Nevada Implementation

- ❖ State Demographics
- ❖ Implementation
- ❖ Successes
- ❖ Caseload
- ❖ Future Plans



Care Consultation Information System (CCIS)

BRI Care Consultation Evidence-Based Components:

- ❖ Initial Assessment
- ❖ Action Plan
- ❖ Maintenance and Support



Initial Assessment

❖ Domains

- ❑ “Yes” or “No” screening questions that cover a variety of problem areas for care
- ❑ Planning for the future, arranging services, etc.

❖ Detail Questions

- ❑ Corresponding questions that are asked when a care partner identifies a domain as a problem



Action Plan

A roadmap, charting a path to propel care partners to address their priorities one step at a time

❖ Developing Goals

- ❑ General statements representing desired change

❖ Developing Action Steps

- ❑ Small, discrete tasks that gradually address unmet needs



Maintenance and Support

Ongoing Contact

- ❖ Maintains support during periods of stability
- ❖ Allows clients to provide updates
- ❖ Prevents serious concerns

Reassessment

- ❖ Re-administering domains and detail questions
- ❖ Helps address changing concerns
- ❖ Allows for development of new action steps

Case Example – Patrice

- ❖ Husband has early stage Alzheimer's disease
- ❖ Caring for her husband for 4 years
- ❖ Works full-time
- ❖ No formal or informal supports
- ❖ Oftentimes feels stressed and overwhelmed



Case Example – Initial Assessment

Domains Triggered

- ❖ Arranging Services
- ❖ Quality of Informal Supports
- ❖ Emotional and Physical Health Strain

Detail Questions

- ❖ Finding services to help you when family members are not available?
- ❖ Do you have supports in your life?
- ❖ Have you had less pep or energy?

Case Example – Action Steps

Domain: Arranging Services

- ❖ Contact home modification program at 555-555-5555 to out more information about home safety, such as grab bars
- ❖ Follow up with Adult Day Care Center 555-555-4444 to find out hours of operation
- ❖ Fill out paperwork for financial assistance programs to help defray cost of Adult Day Care

Domain: Quality of Informal Supports

- ❖ Reach out to Sally, neighbor/friend, to see if she would be willing to provide respite during the week

Domain: Emotional and Physical Health Strain

- ❖ Provide educational articles for Patrice to gain insight on ways to reduce frustrations
- ❖ Try to go to the gym more each week to attend yoga and spend time with Gary doing other activities
- ❖ Each day, find a way to change negative into positive thoughts when thinking about the care situation using the strategies discussed with Celeste, the Care Consultant

Case Example – Maintenance and Support

Reassessment

- ❖ Completed at 12 months
- ❖ Maintains frequent communication
- ❖ Previous concerns have been addressed and maintained
- ❖ No other concerns were presented

Domain Update

Arranging Services

- ❖ *Husband attends Adult Day Care*
- ❖ *Patrice has participated in Alzheimer's education/caregiver workshops*

Quality of Informal Support

- ❖ *Neighbor assists in transportation and respite*

Emotional and Physical Health Strain

- ❖ *Exercises regularly*
- ❖ *Retired*

Program Benefits

- ❖ *Improved care*
- ❖ *Decreased symptoms of caregiver depression and strain*
- ❖ *Reduced caregiver stress and burnout*
- ❖ *Improved access to information*
- ❖ *Improved quality of life*

- ❖ *"This program keeps me encouraged, it is nice to know I have someone to talk to who is so refreshing and positive."*
- ❖ *"I am so glad I have people like you to talk to. It makes me feel like I am not alone."*
- ❖ *"I had no idea I needed to lean on someone like this. Thank you so much for all of your support"*

Conclusion

- ❖ Proven to be effective
- ❖ Beneficial program for care partners
- ❖ Provides caregivers with ongoing support
- ❖ Allows care partners to address concerns
- ❖ Provides helpful tips and solutions for managing care
- ❖ “No Wrong Door”



Live Demo of CCIS Case Record

Initial
Assessment

Action Plan

Maintenance
and Support



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Thank you for your time!

Questions?



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Ohio Partners in Dementia Care

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Studies of BRI Care Consultation

1. Cleveland Alzheimer's Managed Care Demonstration, 1997-2001
2. Chronic Care Networks for Alzheimer's Disease, 1998-2004
3. Integrated Care Management, 2005-2007
4. Wellness Network for Older Adults with Depression and Their Caregivers, 2006-2009
5. Partners in Dementia Care for Veterans and their Family Caregivers, 2006-2011
6. BRI Care Consultation in Cleveland, Ohio, 2009-2011
7. BRI Care Consultation in Tennessee, 2009-2012
8. BRI Care Consultation in Georgia Area Agencies on Aging, 2010-2013
9. Ohio Replication of Partners in Dementia Care, 2011-2015



Benefits Found in Research Studies (Evidence Base)

- Improved satisfaction with formal care
- Reduced hospital admissions
- Delayed nursing home placement
- Fewer Emergency Department visits
- Decreased symptoms of caregiver depression and strain
- Reduced caregiver stress and burnout
- Reduced relationship strain
- Decreased embarrassment and isolation
- Improved access to information



Ohio Partners in Dementia Care

VA and Community Organization Partnerships

Benjamin Rose Institute on Aging
(Evaluation and Study Oversight)

Greater Cleveland
Veterans and Caregivers

Louis Stokes Cleveland
Veterans Administration
Medical Center – Wade
Park Campus and
Cleveland Area Community
Based Outpatient Clinics

Western Reserve Area
Agency on Aging

Greater Akron and
Canton Veterans and
Caregivers

Louis Stokes Cleveland
Veterans Administration
Medical Center – Akron and
Canton Area Community Based
Outpatient Clinics

Greater East Ohio Area
Alzheimer's Association Chapter

Translational Study

- Utilized Advanced CCIS software
- Effective information sharing across organizations
- Diverse areas - greater Cleveland, Akron, Canton
- Similar outcomes as original controlled trials
- Served Veterans with and without caregivers
- 12-month implementation period
- Funded by Administration for Community Living, Dementia Capable Grant Funding (administered by the Ohio Department on Aging)



Ohio Replication of PDC Study Sample Description

- Research interviews with 200 caregivers of veterans with dementia before and 12 months after enrolling in PDC/ BRI Care Consultation
- Sample for analysis of unmet respite need: 148 of these caregivers
 - Average age: 68 (range, 28 – 92); 95% female
 - Ethnicity: 74% white
 - Average caregiving tenure: 6 years (range, 1 month – 65 years)
 - Average age of veterans they care for: 81 (range, 60 – 91); 98% male



Unmet Respite Need Scale

Need more information about or help with:
(yes/no)

1. Getting someone to stay with the veteran so he/she would not be left alone
2. Getting a break from care
3. Finding services to provide care when family help is not available



Caregiver Characteristics that Might Predict Unmet Respite Need

- Age
- Ethnicity
- Income
- Share household with veteran
- Satisfaction with help and support from family and friends
- Depression
- Caregiver strain:
 - Emotional health strain
 - Social isolation
- Stressors related to veteran's characteristics:
 - Need for help with activities of daily living (personal self-maintenance)
 - Cognitive impairment
 - Behavior problems



Caregiver Characteristics Predicting Unmet Respite Need at Baseline

- Age
- Ethnicity
- Income
- Share household with veteran
- **Satisfaction with help and support from family and friends**
- Depression
- Caregiver strain:
 - Emotional health strain
 - Social isolation
- Stressors related to veteran's characteristics:
 - Need for help with activities of daily living (personal self-maintenance)
 - Cognitive impairment
 - Behavior problems



Change in Unmet Respite Need

Statistically significant change from

1.6/3 - Average score at baseline
to

1.1/3 - Average score after 12 months in PDC/
BRI Care Consultation



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Caregiver Characteristics Predicting Decrease in Unmet Respite Need after 12 months in PDC/ BRI Care Consultation

- Age
- **Ethnicity**
- **Income**
- Share household with veteran
- Satisfaction with help and support from family and friends
- Depression
- Caregiver strain:
 - Emotional health strain
 - Social isolation
- Stressors related to veteran characteristics:
 - **Need for help with activities of daily living (personal self-maintenance)**
 - Cognitive impairment
 - Behavior problems



Caregiver Characteristics Predicting Decrease in Unmet Respite Need after 12 months in PDC / BRI Care Consultation

Conclusions:

- Coaching from care consultants enabled caregivers to find solutions to respite needs
- BRI Care Consultation worked well in situations where veterans were more impaired
- Economic resources may facilitate caregivers' ability to meet respite needs



Thank you for your time!

Questions?



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