Virginia’s Care Coordination Program for Individuals with Dementia

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Disclaimer

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Dementia and Caregiving Snapshot

Dementia:
- 140,000 individuals aged 65 and older with Alzheimer’s disease
- ~92,106 FFS Medicare beneficiaries (9.2%) with Alzheimer’s disease/dementia
- ~6,427 Medicaid beneficiaries with cognitive impairment or dementia (conservative estimate)
- 1 in 11 (8.9%) individuals aged 45 and older are experiencing memory loss/confusion

Caregiving:
- 458,000 Alzheimer’s disease and dementia caregivers
- 20.7% of Virginians providing care or assistance to a friend or family member with a health problem or disability
- 7.5% selected dementia or other forms of cognitive impairment as the main health problem of the care recipient

The Alzheimer’s Disease and Related Disorders (ADRD) Commission

Established in 1982 by the Virginia General Assembly

§ 51.5-154 of the Code of Virginia

15 Members; Quarterly Meetings

Advises the Governor and General Assembly on policy, funding, regulatory and other issues related to dementia
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<tbody>
<tr>
<td><strong>1</strong></td>
<td>Examine the needs and ways that state government can most effectively and efficiently assist in meeting those needs;</td>
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<tr>
<td><strong>2</strong></td>
<td>Develop and promote strategies to encourage brain health and reduce cognitive decline;</td>
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<td><strong>3</strong></td>
<td>Advise the Governor and General Assembly;</td>
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<td><strong>4</strong></td>
<td>Develop the Commonwealth's plan for meeting the needs;</td>
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<td><strong>5</strong></td>
<td>Submit annual reports on activities to the Governor, General Assembly, and DARS; and</td>
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<td><strong>6</strong></td>
<td>Establish priorities for programs among state agencies and criteria to evaluate these programs.</td>
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Timeline: Dementia State Plan

2009-2010
• Reviewed other state plans

2010-2011
• Drafted DSP
• Public listening sessions and comments received

December 2011
• Publication of the 2011-2015 DSP

2014-2015
• Drafted update to DSP
• Public listening sessions and comments received

October 2015
• Publication of 2015-2019 DSP
Goals of the **Dementia State Plan**

- **Goal 1**: Coordinate Quality Dementia Services in the Commonwealth to Ensure Dementia Capability
- **Goal 2**: Use Dementia Related Data to Improve Public Health Outcomes
- **Goal 3**: Increase Awareness and Create Dementia-Specific Training
- **Goal 4**: Provide Access to Quality Coordinated Care for Individuals with Dementia in the Most Integrated Setting
- **Goal 5**: Expand Resources for Dementia-Specific Translational Research and Evidence-Based Practices
Work Groups

- Training
- Data & Research
- Coordinated Care
- Legislative
Dementia Services Coordinator

- Outreach & Education
- Data
- Collaboration & Partnerships
- Grant Writing & Administration
- Tracking Policy
Virginia Alzheimer’s Disease and Related Disorders Commission

DEMENTIA
STATE PLAN

Virginia’s Response to the Needs of Individuals with Dementia and their Caregivers

2015-2019

www.alzpossible.org

GOALS

Goal I: Coordinate Quality Dementia Services in the Commonwealth to Ensure Dementia-Capability.
A. Support and maintain a dementia services coordinator (DSC) who oversees Virginia’s dementia-capability by recommending policy and coordinating statewide data collection, research and analysis, and training and awareness efforts in conjunction with the Commission.
B. Expand availability and access of dementia-capable Medicaid and other state-level administered services.
C. Review all state-funded services to ensure dementia-capable approaches and policies based on principles derived from the Person-Centered Care and Culture Change movements.

Goal II: Use Dementia Related Data to Improve Public Health.
A. Collect and monitor data related to dementia’s impact on the people of the Commonwealth.
B. Collaborate with related public health efforts and encourage possible risk-reduction strategies.

Goal III: Increase Awareness and Create Dementia Specific Training.
A. Provide standardized dementia specific training to individuals in the medical, health- and social services-related fields and require demonstrated competency.
B. Provide dementia specific training to professional first responders (police, fire, EMS and search & rescue personnel), financial services personnel, and the legal profession.
C. Support caregivers, family members and people with dementia by providing educational information about dementia and available resources and services.

Goal IV: Provide Access to Quality Coordinated Care for Individuals with Dementia in the Most Integrated Setting.
A. Create a statewide network of interdisciplinary memory assessment centers with specialized, dementia-capable services for individuals with dementia and their caregivers from assessment and diagnosis through end-of-life.
B. Provide a system of services that are integrated, coordinated and diverse to meet the varied needs of individuals with dementia and caregivers during the disease trajectory.
C. Identify needed supports for informal and family caregivers and coordinate them to ensure positive caregiving experiences.

Goal V: Expand Resources for Dementia Specific Translational Research and Evidence-Based Practices.
A. Support Alzheimer’s and Related Diseases Research Award Fund (ARDRAF), especially projects that have a specific emphasis on “methods of treatment, ways that families can cope with the stresses of the disease, and the impact of the disease on the citizens of the Commonwealth” (§ 51.5-153).
B. Provide support to researchers and interested stakeholders across the Commonwealth through data sources and networking opportunities.
C. Promote the advancement of translational research, evidence-based practices and research participation in Virginia.
Dementia State Plan
GOAL 4A:
Create a statewide network of interdisciplinary memory assessment clinics with specialized, dementia-capable services for individuals with dementia and their caregivers from assessment and diagnosis through end-of-life.

Patient or family have concerns about memory.

The patient's primary care provider (PCP) conducts a basic assessment. If needed, the PCP makes a referral for further evaluation.

Memory Assessment Clinic

Interdisciplinary Clinical Teams
Strategically located throughout the Commonwealth
Placed within health systems

The MAC team provides a full evaluation that may include:
- a review of the PCP's records;
- clinical interviews with the patient, family and friends;
- neuropsychological and cognitive testing;
- blood and lab work-up; and neuromaging.

Diagnosis and Care Plan

Patient, family and PCP receive a clinical diagnosis and collaborate on a treatment plan.

Dementia Care Manager

The DCM supports the patient, family and PCP with in-person and telephone assistance and connects them with information, education, and resources for an extended period.

Long-Term Care
Support Groups
Eligibility Assistance

Home and Community Based Services
Caregiver Support
Other Resources

OUTCOMES:
- Delayed Institutionalization
- Fewer Hospitalizations
- Caregiver Satisfaction
- Decreased Depression
- More Family Supports
Care Coordination Program
&
Effective Strategies Program
United States Agency for Healthcare Research and Quality:

"...the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services.

Organizing care involves the marshaling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care."
Care Coordination

In Essence:

• Care coordination programs emphasize coordinated and comprehensive approaches to improving quality of care
Care Coordination

Most effective for diseases that are:

- High-volume and primarily managed in the outpatient setting
- Substantial variability in treatment
- Rely on coordination with community agencies/social services
Care Coordination: Positive Impacts

- Severity of patients’ symptoms
- Patient’s quality of life
- Social support
- Level of unmet caregiving needs
- Quality of caregiving
- Caregiver distress
- Adherence to published dementia care guidelines
Care Coordination: Positive Impacts

• Appropriate use of medications
• Use of community services
• Satisfaction with care and community service use
• Use of acute care services
• Institutionalization rates
Care Coordination: What Works?

Factors for success

• Expert knowledge of the care coordinators

• Investment in a strong provider network

• Coherent conditions for effective inter-organizational cooperation to deliver integrated care
Care Coordination: Costs

- Effects of interventions off-set start-up costs
  - Reductions in hospitalizations and other acute/unplanned health care

- Programs with substantial in-person contact that target moderate to severe patients can be *cost-neutral* and improve aspects of care
• Payer Perspective: Mean monthly adjusted costs of healthcare and caregiving services during were $219 less for those in CC
Care Coordination at UVA

UVA Memory and Aging Care Clinic

• A multidisciplinary clinic providing patient/family centered care
Health care provision is better as a “team sport”

Multi-Disciplinary Care
- Improves patient outcomes
- Decreases hospitalizations
- Increases patient satisfaction
UVA’s Memory and Aging Care Clinic

Initial Evaluation

- Neuropsychological testing
- Neurological evaluation
- Neuroimaging
- Advanced imaging/biomarker work-up
UVA’s Memory and Aging Care Clinic

Subsequent Care

- Ongoing coordinated care
- Re-assessments of cognition, behavior, and functioning
- Non-pharmacological management of symptoms
- Speech evaluations and therapeutic strategies
- Social work services
- Medication management
Care Coordination UVA/JABA

• A model program of coordinated care for individuals and their primary care partners

• Open to all Virginians with a recent diagnosis of MCI or dementia

• Collaboration:
  • Virginia Department of Aging and Rehabilitative Services
  • UVA Health System
  • Jefferson Area Board for Aging (JABA)
JABA–Jefferson Area Board for Aging

• ACL Grant provided an opportunity to collaborate with Memory and Aging Care Clinic

  • Joint hiring and training of Care Coordinators (one employed by each organization)
  • Care Coordinators work with clinic staff and JABA’s Options Counseling team
  • Able to access and refer to services provided by UVA hospital and JABA

• Dementia programs add to connections between JABA and largest area hospital
  Care Transitions Program       Community outreach
  Cross training               Research links
JABA–Jefferson Area Board for Aging

- Area Agency on Aging serving Charlottesville and five surrounding counties

- 42 years of providing services to older residents (60+)

- Programs defined by level of need:
  - Independent Seniors
  - Individuals needing Supports and Resources
  - Individuals needing 24-hour Assistance
  - Caregivers
JABA–Jefferson Area Board for Aging

• Wide range of services available at low or no cost

  • Information and Assistance
  • JABA Community Centers
  • Insurance Counseling (SHIP)
  • Volunteer Services
  • Affordable Senior Housing
  • Adult Care Centers
  • Options Counseling

  • Home Delivered Meals
  • Caregiver Support Groups
  • Chronic Disease Self Management Education
  • Ombudsman
  • PACE
Care Coordination Program

Goals

• Improve the quality of dementia care in Virginia
• Coordination of services
• Provide education about dementia
• Provide emotional support to patients and caregivers
Care Coordinators

Liz Boyd and Sam Fields

- Advanced degrees in fields related to area of work (psychology, social work)

- Knowledge of community services enhances cooperation and cross-referrals
  - (e.g., respite care available at JABA’s Adult Day Centers)

- Seamless connection between multiple agencies
Care Coordinators

Extensive training in:

• Aging and dementia
• Dementia-capability
• Options Counseling
• Person-centered care
• Future planning needs (e.g. Advance Directives)
Care Coordinators

- Form proactive relationships with patient and family
- Conduct at least one home visit
- Central continuous point of contact
- Key advocates
- Share knowledge of the range of health and care services
- Assist in navigation of complex health care and social services
- Monitor and review care services
Care Coordination Program

- Patient & Caregiver
  - Gov’t Resources
  - Medical Resources
  - Local Resources
  - AAA Resources
  - Non-Profit
  - OT, PT, SPCH
  - Durable Medical Equipment
  - Adult Care Centers
  - Transportation

Care Coordinator
Care Coordination: Outcome Measures

• Administer validated measures at the first visit and annually

• Outcomes 1:  
  (1) Decreased depression  
  (2) More steps to prepare for dementia  
  (3) Satisfaction with the Care Coordination program

• Outcome 2:  
  (1) Decreased use of emergency or unplanned health care
Care Coordination Program: Patients

- 54% Female; 46% Male
- 27% Veterans
- 85% Retired
- 87% Medicare
- 86% White; 10% Black
- 61% Rural; 39% Urban
- 71% Married
- 4% Medicaid
Care Coordination
Basic ADLs

Patients: .28 (Range: 0-4)
Caregivers: .44 (Range: 0-6)

<table>
<thead>
<tr>
<th>Dependency</th>
<th>Caregivers</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continence</td>
<td>17%</td>
<td>13%</td>
</tr>
</tbody>
</table>

Note: Caregivers = Caregiver report on patients
# Instrumental ADLs

**Patients:** 5.56 (Range: 0-8)  
**Caregivers:** 4.52 (Range: 0-8)

<table>
<thead>
<tr>
<th>Dependency</th>
<th>Caregivers</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping</td>
<td>79%</td>
<td>52%</td>
</tr>
<tr>
<td>Food Preparation</td>
<td>71%</td>
<td>45%</td>
</tr>
<tr>
<td>Transportation</td>
<td>60%</td>
<td>56%</td>
</tr>
<tr>
<td>Medications</td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>Finances</td>
<td>36%</td>
<td>21%</td>
</tr>
</tbody>
</table>

Note: Caregiver report on patient functioning
# Neuropsychiatric Symptoms

**Total Number of Neuropsychiatric Symptoms**
- **Caregivers:** 4.0 (Range: 0-11)
- **Patients:** 1.9 (Range: 0-8)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Caregivers</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delusions</td>
<td>18%</td>
<td>5%</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>13%</td>
<td>5%</td>
</tr>
<tr>
<td>Agitation/Aggression</td>
<td>43%</td>
<td>15%</td>
</tr>
<tr>
<td>Depression</td>
<td>42%</td>
<td>32%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>55%</td>
<td>33%</td>
</tr>
<tr>
<td>Apathy</td>
<td>46%</td>
<td>15%</td>
</tr>
<tr>
<td>Irritability/Lability</td>
<td>43%</td>
<td>32%</td>
</tr>
</tbody>
</table>

Note: Caregivers = Caregiver report on patients
Behavioral Symptoms & Reactions

Total Number of Behavioral Symptoms:
- Patients: 4.98 (Range: 0-18)
- Caregivers: 8.19 (Range: 0-17)

- Ratings: Not at all, A Little, Moderately, Very Much, Extremely

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Caregivers</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Endorse</td>
<td>Bothers</td>
</tr>
<tr>
<td>Asking the same question</td>
<td>78%</td>
<td>63%</td>
</tr>
<tr>
<td>Forgetting significant past events</td>
<td>55%</td>
<td>36%</td>
</tr>
<tr>
<td>Starting, but not finishing, tasks</td>
<td>56%</td>
<td>45%</td>
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</tbody>
</table>

Bothers = moderately to extremely
### Behavioral Symptoms & Reactions

- Ratings: Not at all, A Little, Moderately, Very Much, Extremely

<table>
<thead>
<tr>
<th>Patients: Symptom</th>
<th>Endorse</th>
<th>Bothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling worthless or a burden</td>
<td>19%</td>
<td>32%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregivers: Symptom</th>
<th>Endorse</th>
<th>Bothers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appearing anxious or worried</td>
<td>56%</td>
<td>57%</td>
</tr>
<tr>
<td>Appearing sad or depressed</td>
<td>57%</td>
<td>55%</td>
</tr>
<tr>
<td>Irritability</td>
<td>47%</td>
<td>47%</td>
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</tbody>
</table>

Bothers = moderately to extremely
Depressive Symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Caregivers</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Could not shake off the blues</td>
<td>28%</td>
<td>23%</td>
</tr>
<tr>
<td>Felt depressed</td>
<td>40%</td>
<td>34%</td>
</tr>
<tr>
<td>Restless sleep</td>
<td>29%</td>
<td>29%</td>
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</table>

Note: Caregiver self-report
# Depressive Symptoms

<table>
<thead>
<tr>
<th>Patient Symptom</th>
<th>Frequency</th>
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</thead>
<tbody>
<tr>
<td>Trouble keeping mind on task</td>
<td>43%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregiver Symptom</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Could not get going</td>
<td>29%</td>
</tr>
<tr>
<td>Wished I were dead</td>
<td>3%</td>
</tr>
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Note: Caregiver self-report
Quality of Life

Patients: 40.51 (Range: 23-52)
Caregivers: 40.5 (Range: 23-52)

- Ratings: Poor, Fair, Good, Excellent

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Caregivers</th>
<th>Patients</th>
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</thead>
<tbody>
<tr>
<td>Ability to do things for fun</td>
<td>22%</td>
<td>22%</td>
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Note: Endorsing ‘poor’ or ‘fair’
Caregiver Wellbeing

Total Score: 66.4 (Range: 43-80)
• Ratings: Rarely/Occasionally/Sometimes/Frequently/Usually

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<thead>
<tr>
<th>Rarely to Sometimes</th>
<th>Caregivers</th>
</tr>
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<tbody>
<tr>
<td>Expressing anger</td>
<td>64%</td>
</tr>
<tr>
<td>Rewarding myself</td>
<td>57%</td>
</tr>
<tr>
<td>Having time to have fun with friends/family</td>
<td>45%</td>
</tr>
<tr>
<td>Participating in community events</td>
<td>45%</td>
</tr>
<tr>
<td>Making financial plans for the future</td>
<td>32%</td>
</tr>
<tr>
<td>Maintaining the home</td>
<td>24%</td>
</tr>
<tr>
<td>Attending to my own medical needs</td>
<td>13%</td>
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Care Coordination: Feedback

“I know I’m not alone.”

“I know if push comes to shove, I can call.”

“It’s been helpful to have somebody on your side to help expedite caregiver and future planning support.”

“How wonderful you have been to us.”

“I am so thankful you are involved.”

“I love having a personal advocate during this difficult time.”
Effective Strategies Program
Fondation hospitalière Sainte-Marie

Mission: To increase and preserve autonomy to patients with neurological illness

• Inpatient and outpatient facilities
• 3000 patients annually
• Serves majority of the left bank
French MCI- Dementia Program Overview

Topics covered

• Memory
• Language
• Planning and organization
• Emotions
• Health and safety
• Social services
• Real world engagement – “field trips”

• Pre- and post- assessments
Effective Strategies Program

- Modeled after FSM in Paris

- Group education program for individuals with MCI or early dementia

- Programs are held in the community
  - Independently living facilities
  - Community centers
Effective Strategies Program

Goals

• To promote independence
• Provide strategies for anticipating and coping with changes
• Provide emotional support
• Develop a support system
Effective Strategies Program

• 20 sessions over 10 weeks

• 1 hour of interactive presentations followed by ½ hour of socializing over snacks

• Sessions are led by experts in their respective fields

  • Neuropsychology  • Physical therapy
  • Nurse practitioners  • Speech therapy
  • Social work  • Art therapy
  • Occupational therapy  • Music therapy
Effective Strategies Program

Topics include

- Education about dementia and memory
- Speech, language, and memory strategies
- Developing and practicing an exercise program
- Home safety
- Planning and participating in outside activities
- Using art and music therapeutically
- Emotional adjustment to memory changes
Effective Strategies Program

Session 3 - Memory

- It is easier to recall something when you hear parts first (triggers).

Why is Memory Important?

- Blood flow: Memory loss can lead to brain function decline.
- Nutrition: Proper diet supports cognitive health.
- Medication: Certain drugs can improve memory.
- Exercise: Physical activity enhances brain function.
- Socializing: Engaging in conversations stimulates the brain.

Flashbulb Memory

- Events that people are passionate about and feel strongly about are more likely to be remembered.

ENEMIES of Memory

- Depression: Can impair memory, interfere with daily functioning.
- Anxiety: Can cause forgetfulness.
- Sleep disorders: Can affect memory consolidation.
- Stress: Increases the risk of memory loss.

Bring Your Med lists

Supplements

- Herbs (e.g., ginkgo biloba, echinacea)
- Vitamins (e.g., B complex, vitamin D)
- Omega-3 fatty acids
- CoQ10

Session 4

Exercise

- Walking
- Yoga
- Dancing
- Swimming
- Tai Chi

Skating

Read More

Time

Better Memory SeLective

Sense of humor

Garden

Social Responsibility

Chores
Effective Strategies Program: Outcome Measures

Participants complete validated measures at the start and finish of each ESP course.

Outcomes:

1. Increased knowledge of & ability to use memory strategies
2. Improved mood & quality of life
3. Satisfaction with the program
Effective Strategies Program

• 5 cycles, 40 participants
• 25% male; 75% female
• 18% veterans
• 100% Caucasian
• 64% married; 28% widowed
Effective Strategies Program: Participant Profile

- Basic ADLs: 5.82 (out of 6)
- iADLs: 7.3 (Range: 5-8)
  - Shopping: 13%
  - Food Preparation: 18%
  - Transportation: 10%
  - Finances: 15%
Effective Strategies Program

- Quality of Life: 42 (Range 30-50)
- Depression: 6.9 (Range 0-28)
- # Neuropsychiatric Symptoms: 4.5 (Range: 0-14)
Effective Strategies Program: Lessons Learned

- Participants feel isolated and fear for their future
- Setting/context matters
- Significant heterogeneity in patient profiles and groups
- Greater than expected (invisible) impairments
- Variable awareness/acceptance of decline
- Institutional/staff relationships matter
Effective Strategies Program: Preliminary Outcomes

- High participant satisfaction
- Cohesive group membership
- Improved understanding of memory
- Improved understanding of memory strategies
- Improved coping skills
Effective Strategies Program: Preliminary Outcomes

“This is a great interactive program.”

“Lots of fun & excellent input.”

“Everyone could benefit from this program. It is comforting to know you are not alone.”
Music and Memories

When I hear the Beguine
I always see your face
You were in your tux
And I was wearing lace

Love was in the air
When I danced with you
You tutored me in math
And taught me to be true

Music... brings back memories
Music... brings you back to me

When I was in the dorm
I played my radio
My roommate complained
So I had to let it go

I played it in my heart
I held it close to me
The future held our love
As far as we could see

Music... brings back memories
Music... brings you back to me.
Future Replication

Manual for state- and nation-wide replication by end of three-year grant

- Documented comprehensive training program for Care Coordinators
  - Using on-line materials and in-person training supporting dementia capability
  - Community networking and outreach to enhance knowledge and awareness of available resources

- Fully-developed procedures and best practice for reproducing
  - Care Coordination Program
  - Effective Strategies Program
Thank you for your attention

Questions?