Title VI Caregiver Programs: Expanding Services for Innovation & Success
Overview

• What?
• How are things different now?
• What are the possibilities?
• How do I go about setting this up?
• Success stories.
• Next Steps.
What?

• When Title VI –C was added, it seemed like an odd choice for funding.
  – Title VI Elders programs are under-funded and they are designed to serve ELDERS, not their caregivers.
  – Indian People have always cared for and held elders in high regard, so why do we need a program for it?
  – Because elders are already cared for, let’s just add this money to our Title VI programs and serve more roast beef and less macaroni...
Nope!

• Unfortunately... That is not the intent of the resource allocation.
• There are ways where services funded through these resources can help elders and their families provide the best care possible.
• And that is good for the elders!
Things are Different Now

- In many communities, elders have their own homes and do not live with extended families.
- Both parents work.
- Children go to day care, or occasionally to Grandma’s house for care.
What is Different?

• Title VI Programs gather elders together.

• There are programs to support elders stay in their own homes.
  – Many of these services are not currently used on reservations....but should be!

• ICWA allows children to stay in tribal communities, but the elders may be the only homes for them--so elders may be raising children.

• Tribal Communities are renewing their traditional ways.
What are the Possibilities?

• There are a variety of programs that have helped caregivers.
• When the caregiver is supported, knows what to do, and can get a break now and then, the elders do better.
• Look to non-Indian programs for ideas, and make them your own.
Medicaid Waiver Services

• Some states have homecare waivers where services are brought to the elders home.
  – Personal Care
  – Skilled Nursing
  – Client Training
  – Home-delivered meals
  – Home Modifications
Medicaid Waiver Services

- Using Title VI-C money to set up a service may make the service reimbursable under the Medicaid Waiver for elders who are eligible.
- The Medicaid money may help to sustain services.

- Connect with your State Unit on Aging or the Area Agency on Aging in your area to see how to get contracted to provide these services for your elders and their caregiver.
What are some of the services?

Five required areas:

1. Information for caregivers
2. Assistance for caregivers
3. Training, counseling, support
4. Respite
5. Supplemental Services
Information

• Information services for caregivers provide information for the caregivers of the elders about where to find help and how to access the help they need.

• To be effective, you need to know about resources in your area...not just those on the reservation or in your community!
Assistance

• Assistance means helping a caregiver to accomplish a goal
  – Help them fill out an application
  – Help them make telephone calls to fix mixed up bills
  – Help them to find a doctor who can help them help their elder
Training

- Caregivers need information about the needs of the care receiver.
  - Short term; catheter, wound care, transfer, bathing
  - Mid-term; range of motion exercises, ambulation

- Long term caregivers need information about what to expect.
  - Alzheimer’s
  - Congestive heart failure
  - Parkinson’s
  - Kidney Disease
  - Neuromuscular illnesses like ALS, MS
Caregiver Training

• Develop or “steal” a course the meets the needs of caregivers: use videos; classes; books; clinic staff.

• Begin “upstream”. Before the elder comes home from the hospital;

• If elective hospitalization, before they enter the hospital so all will know what care they will need.
  –May change their choice of caregiver.
Caregiver Training

- Offer classes through the year about common caregiver issues.
  - Stress
  - Cooking/using traditional foods
  - Danger signs
  - Home safety
  - Behavior problems
Caregiver Training

• Build a caregiver library with DVDs, books, tapes, and newsletters.
• Have games and tools to check out to try.
• Match caregivers with a caregiver mentor for them to call if they need to ask a question.
  – Might by another caregiver who has been there
  – Might use a clinic nurse or social worker
Support Groups

• Support Groups are a great way to provide emotional support and practical support for caregivers.
  – Listening to the needs of caregivers during a support meeting can lead you to design services specifically for your area or tribe.

• One positive outcome could be a caregiver conference; a special day for training and honoring their activities.
Caregiver Conference

- Pick a theme!
- Lead speaker
- Several “classes” from local experts
- LUNCH!
- Displays of medical equipment
- Door prizes/Raffle
Caregiver Honor Day

• A nice meal with a speaker
• Certificates of Honor for each caregiver
• Day Care for the elders or children
• Door prizes
• Words of appreciations
• Coupon Books for assistance with tasks
Care Planning/Case Management

- Very frail elders or those with families with problems may need a leader to assist them in the care of their elder.
- May be offered as part of the Medicaid Waiver for eligible elders.
Care Planning/Case Management

• Usually involves an assessment to evaluate the needs of the elder and the caregiver.

• After the assessment of needs, the case manager will assist the family to start necessary services, get equipment, and provide the care.

• A Care Plan is written to tell the caregiver who will do each task.
Family Care Management

• In some tribes, family meetings are held to get the whole family involved with the elders care.

• A social worker, clinic nurse, or case manager evaluates the elder to see what the care needs are.

• The whole family comes to the same place, usually with the elder.

• Staff prepare a meal, while the family discusses who will do each task to help the elders.

• They sign a contract!
Don’t Forget the Grandparents!

Conferences Included

- ICWA Rules
- Making Play dough
- Internet Dangers
- The Choking Game
- Access to services
Respite Care

- Caregivers need a break.
  - Makes them better caregivers
  - Helps them manage stress
  - Gives them time to care for themselves

- Programs that provide Respite may find that it is the best program for the money.
In-home Respite

• Provides care for the elder in the home where they live.

• Begins with an assessment of the needs of the elder
  – Write down a daily schedule
  – Medications and times to provide them
  – Special diet instructions

• Pay Caregivers to provide the care on a schedule so the primary caregiver gets a break.
Special In-home Respite

• Sometimes a team of helpers can come in to do special activities that caregivers struggle to do.
  – Bathing/shampooing/foot care
  – Preparing meals for the freezer
  – Tuck in Service!
  – Night watch for sundowners
Out-of-Home Respite

• Negotiate a special daily rate for a local skilled nursing facility to allow coverage for the elder if a caregiver needs an extended time away.
  – Can also work for bathing
  – Excellent opportunity for sundowners; they can be awake all night with supervision and the caregiver gets a good night’s sleep
Adult Day Services

• Usually of two kinds
  – Social Day Care
  – Adult Day Health

• Both are possible with tribal clinic; if no clinic, only social model is affordable
Social Day Care

- Elders come to a center, much like a senior center.
- Activities are provided for the elders:
  - Simple crafts
  - Cooking
  - Music
  - Plays
  - Exercises
  - Stories
  - Games
  - Dancing
  - Movies
  - Anything they want!
- You may have the beginnings of a day care center already if caregivers drop their elder off at the senior center.
- Expand on this
Social Day Care

- Usually the day service operates 4-6 hours per day.
- May need to provide some additional coverage for working caregivers.
- Senior Center
- May find that the service can be reimbursed from Medicaid Waiver Program.
Adult Day Health

• Like social daycare, but includes therapies and treatments to help rehabilitate elders.
  – Physical & Occupational Therapy
  – Music & Recreational Therapy
  – Skilled Nursing
  – Social Worker
  – Case Manager

• Must have a clinic to do this and may want to look at a PACE program as an option
• Expensive to operate.
• Needs a large population to make it work.
Supplemental Services

• These are the “supportive services” which can assist caregivers provide the care the elders need.

• Materials developed for caregivers
  – Rearrange existing materials but put traditional ways in the materials

• Transportation to day services

• Meals

• Lending Closet of caregiving supplies, games, and activities for home care;
  – Elders and children
Where Do I Begin?

• First stop is to assure that elders are connected to and receiving as many of the services available as possible.
  – Don’t use tribal or Title VI resources if you don’t have to.
  – Find a champion in town or an advocate in State government to assure that you have a part in designing services.
What Can I Do?

- Seek to participate in advisory boards or committees that plan services to assure that they are appropriate in Indian Country.
- Request tribal members employed by AAA’s or the State to act as elders advocates.
- Seek contracts for Medicaid Waiver services.
  - Use these contracts as a springboard to support services for caregivers in your community.
Don’t Accept “No”

Indian Elders need the same things as other elders

– Might be presented in a different way.
– Need a culturally sensitive person to do the assessment and present the options.
– Offer to do the training!
Elders Are Precious

- They deserve our best care.
- Strive to support their caregivers in order to support the elders’ needs.
- Keeping elders in their homes means keeping them in the community where they can continue to provide leadership and wisdom to the community.
- Don’t let your lack of understanding be a barrier to their health and well-being.