Consumer-Directed Care and Its Implications for State and Federal Long-Term Care Policy

Randall Brown

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Key Medicaid Long-Term Care Issues for States

- States' overriding objectives:
  - Meeting needs of elderly and people with disabilities
  - Controlling costs
  - Maintaining consumers in least confining setting possible
- Reducing need for nursing home care can help
- Key: effective personal care benefits or HCBS

Problems with Medicaid Personal Care and HCBS

- Restricted access
- Poor quality
- Inflexible benefits don't meet needs

➡ Services may not be adequate substitute for nursing home care. Informal caregivers may burn out.

Cash and Counseling Helps Solve These Problems

- Consumers *love* the program—lives improved:
  - Fewer unmet needs
  - Quality of care same or better
  - Fraud/abuse was rare
- Informal caregivers' well-being improved; workers satisfied, not exploited
- Care costs were generally higher, but:
  - Mostly due to traditional program's poor access
  - Partially offset by savings in NH, other LTC
  - States learned how to avoid cost increases

Restricted Access to PC/HCBS

- Few/no providers in rural areas
- Worker shortages
- Shortages also can reduce care plan hours (GAO)

➡ Beneficiaries are unserved or underserved.

Poor Quality of PC/HCBS

- Some workers unreliable
- Some workers mistreat patients
- Lack of continuity (high turnover)
- Language/cultural competence

➡ Recipients get inadequate care.
Some eligibles opt out.
Caregiver burden increases.

Inflexible Benefits

- Can't choose times of day/week
- Transportation not covered
- Can't substitute equipment/devices
- Can't match workers to tasks
- Doesn't complement informal care

➡ Money spent inefficiently, ineffectively.

Consumer Direction Addresses PC/HCBS Shortcomings

- Access improved:
  - Increases worker pool
  - More dedicated, culturally compatible help
- Quality improved:
  - Control over who provides what care and how
  - Better coordination with informal care
- Benefits more flexible:
  - Consumer controls schedule and staffing
  - Can buy transportation/equipment/appliances

Concerns About to Consumer Direction

- Concerns about consumers/caregivers:
  - Fraud/abuse
  - Quality of care – untrained, unsupervised
  - Ability of elderly to direct own care
  - Workers' well-being
- Political concerns:
  - Substitution of paid for unpaid (family obligation)
  - Cost increases/induced demand
  - Agency/union opposition

Overview of Cash and Counseling Features

- Implemented in three states (AR, FL, NJ)
- Flexible use of benefit allowed
- Consumers could hire legally liable relatives
- No Medicaid contracting requirements
- Counselors helped develop spending plan, monitored it
- Fiscal intermediaries wrote checks, withheld taxes

Cash and Counselling Enrollment

- Enrolled Medicaid PCS/HCBS waiver eligibles (10/98 - 7/02)
- No screening of eligibles (representatives allowed)
- 1,800 – 2,000 adults in each state:
  - Included aged and younger adults
  - FL included 1,000 children with developmental disabilities
- Random assignment to treatment/control groups

Effects on Hours of Care

- Increased percent getting any paid services
- More hours of paid care (17% to 25%)
- Fewer unpaid hours (7% to 24%)
- Slightly fewer total hours of care:
  - Except AR, age 18-64 (–19%); FL 65+ (–12%)
- Little effect on other allowance uses

Effects on Consumers' Well-Being

- Large reductions in unmet needs
- Large increases in satisfaction with care
- Care-related problems/injuries same or lower
- Satisfaction with life increases greatly
- Works for children, adults <65, elderly
- Small/no effects if few get the allowance

Effects on Unmet Needs

- Many (30-65%) have unmet needs for:
  - Household help
  - Personal care
  - Transportation
  - Routine health care
- Large reductions (10 to 40%) in all 3 states
- Effects largest where access increased most

Effects on Unpaid Caregivers

- Reduced total hours of care provided
- Much more satisfied with care, less worried
- Much less emotional/physical/financial strain:
  - Fewer adverse work life effects
  - Fewer adverse health effects
- Much greater overall satisfaction with life
- No effects for group whose hours increased

Hired Workers' Experience

- Most were relatives, few were strangers
- Received same or higher wages as agency workers
- Much more satisfied with wages
- Report less physical strain
- Feel *more* emotional strain
- Report less respect from consumer's family
- Family ties cause greater strain and disrespect

Effects on Medicaid Costs--Year 1

- Cost of cashed-out services, per month of benefits:
  - Increased for younger adults (all states) and children
    - Control group underserved in AR and NJ
    - Allowance > care plan amount in Florida DD groups
- Annual cost per beneficiary in study:
  - Personal care costs: higher cost/month, higher percent receiving
  - Other Medicaid costs lower (mostly long-term care)
  - Total Medicaid cost higher, for most states and age groups
  - Results diverge in Year 2

Three-Year Effect on Costs: AR

- Increased access/flexibility/quality generates nursing home savings:
  - NH admissions and cost 18% below controls
- Comparable LTC savings for new and continuing consumers:
  - New: Can't offset large increase in PC access
  - Continuing: Fully offsets higher PC costs

Policy Issues

Results should allay concerns about CD care, but:

- **Higher costs may deter some states, but fixable, and LTC savings may offset**
- **Allowance may increase demand for PCS/HCBS**
- **Paying legally liable relatives is controversial:**
  - **Also, some substitution of paid for unpaid**
- **Hired relatives face emotional stress, lack respect**
- **Should states *push* consumer direction?**
- **Some agencies/unions likely to oppose it**

Implementation Issues: Eligibility and Allowance

- Eligible population
- Services to cash out
- Method to set and revise allowance amount
- Uses of the allowance
- Whether can hire spouses/guardians
- Whether to recoup unspent allowance

Implementation Issues: Program Structure/Monitoring

- Counselors' roles and responsibilities
- Solicitation and payment of a fiscal agent
- Monitoring of spending plans
- Monitoring of counselors' performance
- Monitoring of costs
- Monitoring time to receiving the allowance and disenrollment

Take Away Messages

- Better access, quality, and flexibility:
  - Consumers have fewer unmet needs, better lives
- Costs can be controlled through design
- Increased access raises care costs, but produces offsetting NH reductions
- Reduced informal caregiver burden could yield future savings