

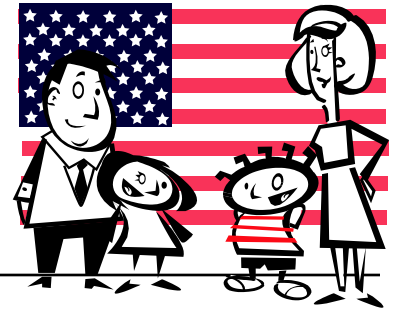


Paying Relatives Providing Supports

Practices, Issues, Lessons Learned

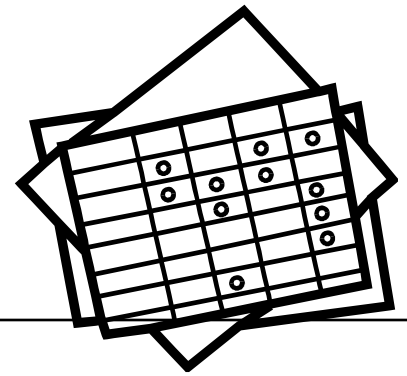
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Reinventing Quality
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We'll Cover



- What's happening nationally in compensating relatives to provide supports
- Federal and State policies
- Positives and concerns facing states, families and individuals with disabilities

State data**



- Of 48 states responding, 46 pay relatives to provide paid care
- 6 states pay parents of minor children
- 10 states pay a spouse
- 21 states pay a parent who is also a guardian
- 23 states pay guardians who are other relatives

**Survey conducted by NASDDDS, reported in Cooper *"Caring Families, Families Giving Care: Using Medicaid to Pay Relatives Providing Supports to Family Members"*, NASDDDS, June, 2010



State data

- 18 states pay guardians who are not relatives
- 36 states pay parents who are not legally responsible (parents of adults)
- 44 states pay siblings
- 45 states pay grandparents
- All 46 pay other relatives

Why Pay Families and Relatives?

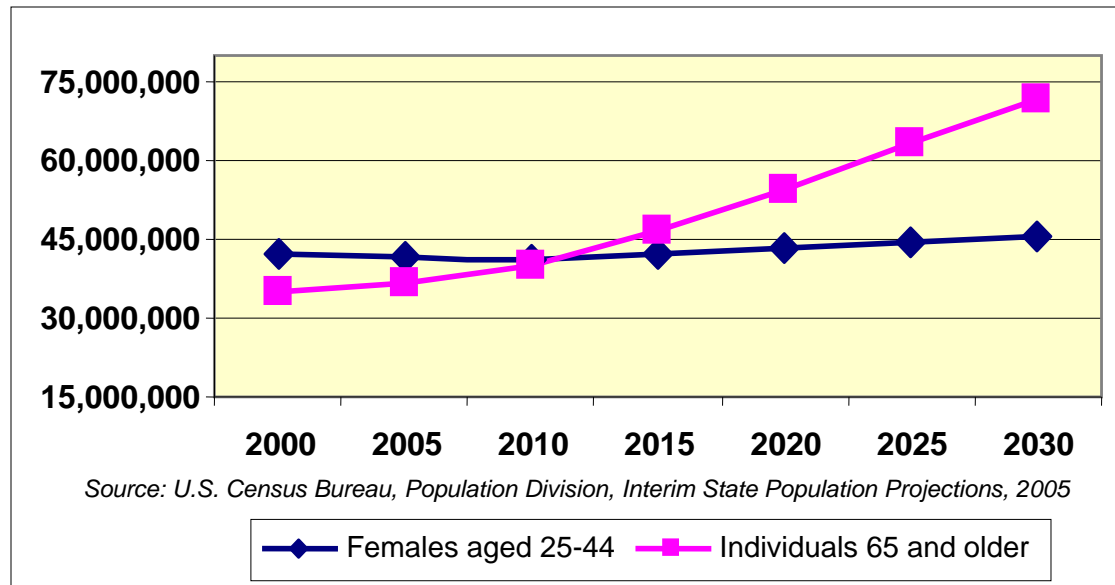
Caring and knowledgeable support



- Individuals report a high degree of satisfaction with living in the family home
- NCI data for 2009 indicate that of those living with family, 96% said they liked where they live. For those not living with family, 87% indicated they liked where they live.

Workforce issues

- National shortage of direct support professionals



Adults are living at home longer

- More adults ages 25-39 living in their parents' homes.
 - In 1980, only 11% of 25-to-34-year-olds were living in multi-generational households
 - By 2008, 20% were *before* the effects of the recession were felt*
- 25 states report that the number of individuals residing with their families equals or exceeds the total number living in provider-operated residential settings.
- 7 states (AZ, CA, FL, ID, NJ, SC) report that 70% or more of individuals served live with their families.

*Roberts, Sam, "Facing a Financial Pinch, and Moving In With Mom and Dad", *New York Times*, March 21, 2010



State budget pressures

- 46 states are struggling with deficits*
- States are seeking to delay costly out-of-home placements
- More than 23 states use “supports-type” HCBS waivers that provide a capped amount of supports to individuals living with families

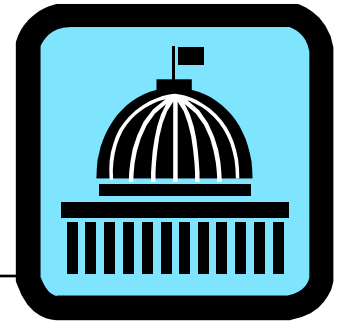
*Data from the Center on Budget and Policy Priorities, <http://www.cbpp.org/cms/?fa=view&id=711>

Positives in paying family members



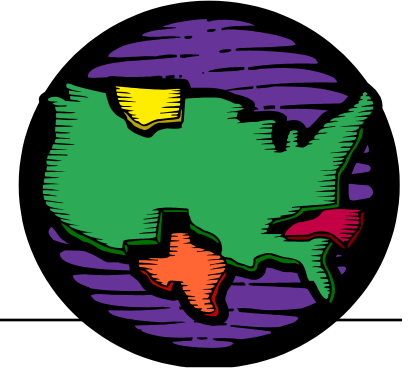
- Committed and caring pool of workers
- Have deep knowledge and understanding of the individual
- Already have long-term relationships
- The individual may prefer care from family
- May allow the individual to remain in the family home
- Can stabilize the living situation
- Can be a means to “extend” other unpaid care

Federal Medicaid Policies



- Under the HCBS waivers states can elect to pay relatives including “legally responsible” relatives such as the parent or a minor or a spouse
- May allow relatives to provide any type of services, but,
- When electing to pay for personal care or similar services from legally responsible relatives CMS has some additional requirements that relate to “extraordinary care”—care beyond what is typically expected by the parent or spouse

State policies



- Some states have crafted policies about when it makes sense to pay family members
- These policies are a part of person-centered planning and are intended to help the person and team make decisions

Issue: Keeping the focus on the individual

- Family needs may be complex and intertwined with the individual's needs
- Sorting out what's best can be challenging as family needs of course affect the individual
- Budget pressures can "skew" decision-making



Focus on the Individual



- Louisiana's planning protocol
 - Is the use of a family member age and developmentally appropriate?
 - Will using family members as paid direct service workers enable the person to learn and to adapt to different people and also to form new relationships?
 - Is the person learning flexibility and skills for increased independence?
 - Is this about the person's wishes, desires, needs, or about supplementing a family member's income?

Focus on the individual



○ Missouri

- The individual is not opposed to the family member providing services;
- The services to be provided are solely for the individual and not household tasks expected to be shared with people living in the family unit;
- The planning team determines which family member should be paid to provide the services that best meet the individual's needs; and,

Issue: What is “extraordinary” care?

○ Pennsylvania

- The service is considered extraordinary care, which means it is above and beyond the supports the legally responsible individual is ordinarily obligated to provide
- The service would otherwise need to be provided by a qualified provider of services funded under the waiver



What is “extraordinary” care?



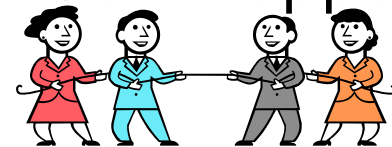
Minnesota

- A parent is legally responsible to meet the needs of a minor child, including the need for assistance and supervision typically required for children at various stages of growth and development. A parent can, however, receive payment for Personal Assistance Service when this support goes beyond what would be expected to be performed in the usual course of parenting, and when needed support exceeds what is typically required for a child of the same age.”

Issue:

Conflicts of interest/choice and control

- 23 states do not pay legal guardians
- **Washington** and **Virginia** require someone else to act as a monitor or representative
- In 18 states the paid guardian cannot be a relative
- Some states do not allow the paid relative caregiver to live with the individual supported



Issue:

Conflicts of interest/choice and control

- **Connecticut** requires a review by a Prior Approval Committee to assure that provision of services by a family member is in the best interests of the individual and also comports with their policies regarding the use of relatives as providers



Paying Relatives and Consumer-Directed Services

- Who's in charge?
- Employer of record issue: family member being paid cannot act as employer of record
- Need an alternative representative if the individual cannot fulfill employer functions



Issue: How much care?

- Missouri
 - A family member cannot be paid over 40 hours per week. Any support provided above this amount would be considered a natural support or unpaid care that a family member would typically provide.
- Some states allow only one family member living with the individual to provide paid care

Issue: Qualifications



- Many states require family members to have the same qualifications as any paid provider
- Some states require family members to be an employee of an agency
- Some states allow the planning team to use “alternate” qualifications and document why the relatives is qualified

Lessons Learned

- Clearly establish your policy aims when paying family members. This means being explicit as to under what conditions you compensate family members. For example:
 - always,
 - only when no other caregiver is available,
 - cost-effective alternative, and/or
 - preferred by the individual supported?;
- Based on your policy aims, decide which family members you compensate and for what specific services;



Lessons Learned

- Develop a written planning protocol to use in your person-centered planning process for making decisions as to if and when family members should be paid for providing supports;
- Establish clear guidelines as to how many hours per week you will pay an individual family member and how many family members you pay who reside in the same home with the individual;



Lessons Learned

- Consider potential conflicts of interest when paying the parents of adults, guardians, or individuals who also act as a representative in both traditional and self-directed options;
- If compensating legally responsible individuals such as parents of minors, a clear, objective assessment that helps ascertain what care you will pay for is helpful in order not to replace age-appropriate natural caregiving;



Lessons Learned

- Assure that the issues of choice and control are directly addressed in the person-centered plan for adults being supported by family members through such actions as providing opportunities for self-advocacy, developing competent circles of support, and/or the use of a non-related representative or advocate in the planning process; and
- Develop quality compliance and quality assurance processes that specifically address the unique concerns in that arise when paying family members and guardians

Resources

- *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria, Release Date, January, 2008; www.hsbswaivers.net*
- Cooper, Robin *"Caring Families, Families Giving Care: Using Medicaid to Pay Relatives Providing Supports to Family Members"*, NASDDDS, June, 2010, www.NASDDDS.org
- Minnesota's Developmental Disabilities HCBS Waiver Application: Appendix C-2 (e), pages 6-7: Other State Policies Concerning Payment for Waiver Services Furnished by Relatives / Legal Guardians
- Louisiana Office for Citizens with Developmental Disabilities: Policies for paying family members as staff under the New Opportunities HCBS" (*Louisiana Register*, Vol. 30, No. 6, June 20, 2004 §13901. Individualized and Family Support and §13907 Residential Habilitation, Supported Independent Living)

Resources

- San Antonio, Patricia, et al., "Lessons From the Arkansas Cash and Counseling Program: How the Experiences of Diverse Older Consumers and Their Caregivers Address Family Policy Concerns", *Journal of Aging & Social Policy*, January 7, 2010,
- Simon-Rusinowitz, Lori, et.al., "*Hiring Relatives as Caregivers in Two States: Developing an Education and Research Agenda for Policy Makers*" *Social Work in Public Health*, 25:17-41, 2010.

Legally responsible relatives and paying for personal care



- CMS characterizes personal care by legally responsible relatives as ***extraordinary care***
- “The State must ensure that the provision of services by a legally responsible individual is in the best interest of the participant; and,
- Controls are employed to ensure that payments are made only for services rendered” *

* *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria, Release Date, January, 2008, p. 119*