

To: Connecticut General Assembly Human Services Committee

re: Opposition to SB 116 AN ACT CONCERNING CAREGIVER AGREEMENT
REQUIREMENTS FOR MEDICAID APPLICANTS OR RECIPIENTS.

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Early in my legal career I represented a woman in Durham who operated a small family farm. Her husband had suffered a stroke, was in a convalescent home, and she had applied for Medicaid assistance. She could not support the farm on her income and we asked the Department of Social Services to allow her to keep more than the amount of the Community Spouse Protected Amount in order to pay her expenses. The DSS denied the request and the worker told me "Attorney Lang, I understand your client's position and am sympathetic. However, the rules are the rules and we have to follow the rules".

Ladies and Gentlemen - The legislature adopts the rules and the DSS must follow the rules. If you adopt SB 116 – An Act Concerning Caregiver Agreement Requirements for Medicaid Applicants or Recipients – you will be establishing rules that punish older adults in need of care as well as family members (people often referred to as the "sandwich generation") who provide the care. Not only is this bill bad policy, it is also drafted in a way that will make it extremely difficult for individuals to comply with its terms.

Currently, an individual who is applying for Medicaid is not penalized if they make a transfer for valuable consideration. This bill adds a new set of requirements when the services being purchased are for care provided by a "Family" member. Reports published by AARP and Genworth in 2015 indicate that many family members begin to provide assistance to a parent when the parent requires help with 1 activity of daily living. When a family member requires assistance with more than 1 activity of daily living, the amount of time spent by one or more family member increases.

The AARP study provides interesting statistics:

- An estimated that 34.2 million American adults have served as an unpaid caregiver to someone age 50 or older in the prior 12 months.
- 86% of 50+ caregivers provide care for a relative.
- On average, the care recipient is 74.7 years old.
- More than half of caregivers of someone 50+ are caring for someone age 75 or older.
- On average, caregivers of someone 50+ spend 24.1 hours a week providing care.
- Three in five are primary caregivers.
- 67% of the care recipients are female
- 60% of the caregivers are female.

In 2015, the Middlesex County Chamber of Commerce hosted a workshop titled “The Sandwich Generation – Partnering with Caregivers in the Workplace”. Information from participants at that workshop, personal experience, as well as published reports demonstrates that caregivers (mostly women) spend significant and generally uncompensated hours caring for adult parents. The caregivers often experience loss of income as a result of having to cut back their hours or having to take time off from work.

Services rendered by family caregivers include shopping, preparing meals, housework, managing finances, assisting with dressing and bathing, managing medication, dealing with pharmacies, medical professionals, care managers, and driving parents to visit friends and social events. Family caregivers often interact with various providers, agencies and professionals on the care recipient’s behalf.

The level of care that an individual requires changes as the individual ages or their medical condition accelerates. Most caregivers are focused on assisting the relative in need of care. The AARP study indicates that caregivers report that caregivers of a relative face a high level of physical strain and an increasing level of emotional stress.

Many family caregivers are working at the time that they begin providing care to a relative. The AARP study reports that “Caregivers sometimes make choices that change their work situations when caregiving demands become too much, such as cutting back on their working hours or taking a leave of absence.” Workplace support for caregivers is a major issue.

In many cases, the parent recognizes the loss of income that the family member suffers as a result of providing care and the parent offers to compensate the family member for those services. My experience is that the family member may include a child, grand child, step-child, niece, nephew, son-in-law, daughter-in-law, non-married partner of a child or grandchild, neighbor or friend. Services are rendered and compensation is paid without any consideration of qualifying for Medicaid in the future.

Families often attempt to compensate the caregiver through caregiver agreements that may provide for lump sum payments in advance based on the care recipient's life expectancy, lump sum payments secured by a mortgage on the care recipient's home, fixed weekly or monthly amounts as well as compensation on an hourly basis.

SB 116 provides that the DSS shall not impose a penalty for improper transfer of assets on a Medicaid applicant or recipient for payments made to a family member pursuant to a caregiver agreement provided the agreement meets the specific requirements established by the Bill.

In addition, the bill requires the applicant or recipient to establish that the services avoid or delay the applicant's or recipient's (1) placement in a nursing home facility or (2) need for home and community-based services provided under a Medicaid waiver.

Statistics, and real life experience, demonstrate that the level of services provided by caregivers to relatives is constantly changing to address the needs of the care recipient; and that the physical, emotional and financial impact on the caregiver changes over time. As families adjust to meet the needs of a care recipient, the family is often unaware of the services and financial assistance that may be available to them, particularly when care is being provided in the care recipient's home rather than in a nursing home facility. This Bill will result in disqualifying care recipients from receiving assistance in the many instances in which families are attempting to provide care for family members in need. I encourage you to consider the needs and well being of all of the caregivers and care recipients in the State of Connecticut and not adopt this very aggressive approach to a perceived problem.

Summary of SB 116

To be valid under this bill, the caregiver agreement must be:

- executed prior to the delivery of services
- be signed and dated by the applicant or recipient and the family member who provides the services
- be notarized
- allow for modification of the agreement only by written mutual agreement of the parties
- allow for termination of the agreement by either party at any time and only in writing

The agreement must:

- Include the frequency, location and duration of services that will be provided
- Provide for payment on a daily, weekly, biweekly or monthly basis
- Prohibit prepayment for the provision of such services
- Provide for payment for services at rates (A) not more than the average private pay rates for home and community-based services determined and published annually by Connecticut's Partnership for Long-Term Care through the Office of Policy and Management and (B) for those services for which no rate is published, not more than twice the state minimum wage at the time the services were provided.
- Require the provider of the services to maintain contemporaneous records of services provided
- Require the provider of the services to submit copies of such records and itemized bills to the recipient.

BURDEN OF PROOF

The bill places the burden of proof on the applicant to establish that the services avoid or delay the applicant's or recipient's (1) placement in a nursing home facility or (2) need for home and community-based services provided under a Medicaid waiver. This bill does not establish the standards that will satisfy this burden or indicate what proof must be submitted. The burden of proof will require the family to obtain medical and other professional evaluations on a continuous basis in order to comply with this requirement.

Problems with this language include the following:

Child provides caregiver services because parent is in need of assistance with activities of daily living. Parent breaks a hip, suffers a medical condition such as a stroke that significantly alters the parent's ability to function. Under this bill, the payments to the child prior to the onset of the new event will not meet the requirement that the services prior to the event avoided or delayed the applicant's placement in a nursing home facility or the applicant's need for home and community-based services provided under a Medicaid waiver.

COMPLYING WITH THE REQUIREMENTS OF THIS BILL

This bill permits the Department of Social Services to require an applicant or recipient to provide, *in addition to other documentation*:

Copies of the contemporaneous records of services provided by and itemized bills received from the provider of services pursuant to a caregiver agreement; and

Documentation establishing that the applicant or recipient of services has complied with state and federal tax requirements governing payments made to a provider of services pursuant to a caregiver agreement.

Comment

This bill does not define "contemporaneous" or "itemized"

As written, this bill will permit the department to deny benefits to a parent who fails to withhold social security, fails to provide the recipient with a 1099 form, or fails to file unemployment taxes for payments to a family member.

Since taxpayers have the ability to request extensions of time to file income tax returns, it is possible that a person who receives payments in any given year, will not report those payments until September of the following year.

This bill imposes a penalty on a person who may be otherwise eligible for Medicaid services because a person over whom they have no control, fails to report taxable income.

This bill permits payment for services only if they are not duplicative of services provided by others. The bill does not make clear if services that are the same as, but in addition to, services provided by others are permitted.

The bill prohibits payment for

Social activities

Companionship

Services provided while the applicant or recipient is in a nursing home or other health care facility. *In many cases, as the parent's health is declining, there are injuries, illnesses, or conditions that require temporary hospital or skilled nursing facility stays. This language would prohibit compensation to a family member who provides care and assistance during the temporary absence from the home.*

Travel by the provider of services to or from the residence of the applicant or recipient. *If the caregiver is driving the parent to medical appointments, emergency medical care, visits to professionals, or to social events, what is the policy for denying payment to the caregiver who is forced to be absent from their work or family.*

Problems with this bill include:

1. The unrealistic and unfair assumption that families who compensate related caregivers are contemplating a Medicaid application at the time that the family caregiver begins providing services. In real life, the level of services provided by a family caregiver is constantly changing.
2. The burden of proof that is placed on the applicant.
3. The record keeping and paper work burden placed on the caregiver
4. The unrealistic assumption that families are able to define future services at the time that a caregiver agreement is prepared.
5. The ability to deny Medicaid benefits to an individual in need of services because they were not aware of a requirement that the agreement be notarized.
6. The ability to deny Medicaid benefits to an individual in need of services because a care recipient or caregiver failed to comply with state and/or federal tax laws.
7. The bill specifies that compensation may not be paid to a family caregiver who provides social activities and companionship.
8. The bill specifies that compensation may not be paid to a family caregiver while the applicant is in a nursing home or other health care facility, regardless of the ongoing services provided or the length of stay.