

## 21 UT SNT Presentation

### Paying the Family Caregiver

#### *I. Introduction*

There are said to be three types of lawyers: philosophers, physicists and plumbers. While as practitioners we are basically plumbers, for a moment we may want to think like physicists, examining some of the properties of our environment: the legal, and particularly the financial, aspects of caring for a family member.

The pandemic has affected the willingness of people to place family members in congregate facilities and the ability of those facilities to provide care and, in some instances, to maintain operations.<sup>1</sup> The pandemic is also creating “COVID-19 long-haulers” in their 20s, 30s and 40s: 10% of those infected, according to UK study.<sup>2</sup> Many of these people may need special needs trusts as well as needs-based government benefits. All of these individuals will need assistance now and in the future.

Home health care has a supply-and-demand problem. Where will the people who provide the services come from? How will they be compensated? More will be expected of families of people of all ages who have special needs. We can only hope that many of those people also have loved ones who planned for their care and established and funded special needs trusts.

#### *II. The Conflict*

##### *II. A. Social Goods: Public Benefits and Tax Receipts.*

For at least the next 20 years there is likely to be even less money to pay for the public benefits on which our clients rely. Throughout the developed world, even before the pandemic, government and corporate debt were so high that the Peterson Institute for International Economics predicted a recession beginning in the first half of this decade. High government and corporate debt are compounded with low increases in productivity, in the U.S. improving less than 1% per year since 2008.<sup>3</sup> The low increases in productivity appear to be due largely to (1)

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<sup>1</sup> Harris Meyer, *Nursing Homes' Flawed Business Model Worsens COVID Crisis*, AARP (Dec. 7, 2020), <https://www.aarp.org/caregiving/health/info-2020/covid-19-nursing-homes-failing-business-model.html>.

<sup>2</sup> Trisha Greenhalgh et al., *Management of Post-Acute Covid-19 in Primary Care*, THE BRITISH MEDICAL JOURNAL, August 2020.

<sup>3</sup> Adam S. Posen & Jeromin Zettelmeyer, *Facing Up to Low Productivity Growth*, PETERSON INSTITUTE FOR INTERNATIONAL ECONOMICS, Feb. 2019.

uneven and very limited improvement in education, in contrast to the flowering in the years following World War II, and (2) the predominance of the service economy, in which, as we have all experienced, it can be very difficult to become more efficient, more productive.<sup>4</sup>

## *II. B. Economic Units.*

In an agrarian society, which predominated culturally before World War I, status determined the economic unit to which one belonged and on which one relied. Formal or informal, these economic units were based on being a member of a family, on worshipping at a particular Balinese temple, on residing in a certain Aztec altepetl or English parish. Duties and privileges flowed from one's position within that family, worship group, altepetl or parish, a position based on gender and age as well as broader family relations, financial position and line of work.

As a status-based economic unit the family, primarily the nuclear family, continues to be important in the U.S. culturally and, specifically, in the law. Parental and spousal duty are unquestioned. In Medicaid regulations filial duty is deemed to require performance of a broad array of household, personal service and medical tasks, regardless of skills or circumstances. Unlike in Europe, familial duty and bonds of affection, which are in any event far from universal, are not strengthened by forced inheritance; in the U.S. you can leave your property to anyone you please at your death. Everywhere the demands of familial duty and affection conflict with other demands.

In the current economy, status has largely been replaced by contract. We are employers and employees. We fund disability, retirement, and long-term care privately through employee benefit programs, insurance policies and investments and publicly through Social Security, Medicare and Medicaid.

## *II. C. Conflicting Cultural and Economic Imperatives.*

Medicare and Medicaid are part of the Social Security Act.<sup>5</sup> This conflict in the law – within the very same federal statute – reflects and reinforces the conflict our clients experience in trying to comply with a broad cultural imperative to take care of family members while the legally-imposed financial scheme assures that by

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<sup>4</sup> Kimberly Amadeo, *Components of GDP Explained*, THE BALANCE (June 26, 2020), <https://www.thebalance.com/components-of-gdp-explanation-formula-and-chart-3306015#:~:text=The%20four%20components%20of%20gross,being%20spent%20in%20that%20economy>.

<sup>5</sup> 42 U.S.C.S. §§ 1395-1396 (2020).

doing so they are permanently and irretrievably damaging themselves and their immediate family.

### *III. The Cost.*

Status-prescribed work which replaces or impinges on contract-based participation in the economy is costly.

#### *III. A. Direct Economic Cost.*

Family caregivers are rarely paid. They have no health or disability insurance, no paid sick or vacation days. They do not accumulate credits for Medicare or for Social Security disability and retirement benefits. Instead of receiving payment for work, both directly and indirectly they pay to work. A 2016 AARP survey of family caregivers of disabled people between the ages of 18 and 50 found that, on average, family caregivers paid \$7,000/year out of pocket. If they lived an hour or more away, they paid more, \$12,700.<sup>6</sup>

#### *III. B. Delayed Economic Cost.*

Whatever the number of hours of care they provide, whatever the number of months or years they forego paid full-time work, the harm family caregivers experience is lifelong. In 2020, half of married couples and 70% of single Americans relied on Social Security for at least half of their retirement income while 21% of couples and 45% of single Americans relied on Social Security for 90% or more of their retirement income.<sup>7</sup> Without paid full-time employment and Medicare and Social Security credits, family caregivers are likely both to over rely on Medicaid and on Social Security disability and retirement benefits and to have a lower dollar amount of Social Security benefits on which to rely.

Failing to address this dilemma is not merely kicking the can down the road. It is kicking the can into the ditch. It is a cost we will all pay for in increased Medicaid and Supplemental Security Income claims, in increased demand for subsidized senior housing and in increased use of public programs and public-private partnerships ranging from Meals on Wheels and food banks to Metropolitan Access to Physicians Services and subsidized public transportation.

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<sup>6</sup> *Surprising Out-of-Pocket Costs for Caregivers*, AARP (Oct. 1, 2019), <https://www.aarp.org/caregiving/financial-legal/info-2019/out-of-pocket-costs.html>.

<sup>7</sup> Social Security Fact Sheet, Social Security Administration, <https://www.ssa.gov/news/press/factsheets/basicfact-alt.pdf> (last visited Jan. 12, 2021).

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17<sup>th</sup> Annual Changes and Trends Affecting Special Needs Trusts session  
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