Loyola University Chicago Law Journal

Volume 52
Issue 2 *Winter 2021*

Article 8

2021

Difficulty of Care: Aligning Tax and Health Care Policy for Family Caregiving

Christine S. Speidel
Villanova University Charles Widger School of Law

Difficulty of Care: Aligning Tax and Health Care Policy for Family Caregiving

Christine S. Speidel[*]

In the United States millions of people live with disabilities, many of whom require assistance with activities of daily life to remain in their homes and communities. However, financial support for this assistance is limited. Many caregivers forgo working outside the home in order to provide care to a family member. And while state and federal programs provide some compensation for caregiving, caregivers frequently face problems including poverty, lack of health insurance, lack of Social Security and Medicare credits, and lack of retirement savings. Our nation's paltry support for caregiving threatens the practical ability of people with disabilities to choose community integration over institutional living.

This Essay examines the little-known and little-used "difficulty of care" gross income exclusion under I.R.C. § 131 as a possible vehicle to improve this picture. While § 131 originated as an exclusion for foster payments, it was reinterpreted in IRS Notice 2014-7 to apply to contemporary programs for in-home services and supports. Unfortunately, the impact of this reinterpretation was complicated and hotly contested. This Essay juxtaposes the evolution of home and community-based health care services, the Affordable Care Act, and the evolution of tax expenditures for low-income taxpayers to explain how the tax and health care systems collided in the aftermath of Notice 2014-7.

This Essay reveals tensions and contradictions between tax and health care policy, informed by case examples and by ground-level considerations of program administration. It suggests that a gross income exclusion is an ineffective means to implement policy preferences and that policymakers should undertake a broader examination of the interactions between health

* Assistant Professor and Director of the Federal Tax Clinic, Villanova University Charles Widger School of Law. My sincere thanks to the participants of the 2019 Critical Tax Conference at Pepperdine Caruso School of Law and to Stephanie Hoffer, Leslie Book, Wayne Turner, Kathryn Sedo, and Francine Lipman for their insights and encouragement. I am grateful to the organizers of the 2020 Loyola Chicago Tax Policy Symposium and to Becky Bavlsik. I benefited from discussing "difficulty of care" issues with several of my fellow tax clinic directors including Caleb Smith, Daniel Kempland, and Sarah Lora. I received research assistance from Anna Gooch, Katherine S. Smith, Michael Cardone, Charles Butrico, Lisa Riley, William Cowen, and Alexandra Santulli. Any errors or omissions are mine alone.

and tax provisions when considering financial supports for caregiving. Finally, the Essay offers preliminary considerations for redesigning tax supports for caregiving, both to better reflect the values of dignity and autonomy that underlie home-based services, and to prevent unintended harm to low-income families.

INTRODUCTION

The coronavirus pandemic has exposed inequities and hardships faced by disabled people and those who care for them.[1] The inaugural Family Caregiving Advisory Council is poised to deliver its first annual report to Congress pursuant to the RAISE Family Caregivers Act of 2017.[2] The time is ripe for a reexamination of national disability and caregiving policy, as disability activists recently celebrated the thirtieth anniversary of the Americans with Disabilities Act (ADA)[3] and the twentieth anniversary of the U.S. Supreme Court's seminal *Olmstead* decision.[4]

Nationwide over forty million people live with disabilities,[5] with over fourteen million reporting difficulty with independent living.[6] In order to live at home or in community settings, individuals with disabilities may need help with activities of daily living—such as bathing, dressing,

1. *See, e.g.*, *COVID-19 Poses Unique Challenges for People with Disabilities*, JOHNS HOPKINS UNIV.: HUB (Apr. 23, 2020), https://hub.jhu.edu/2020/04/23/how-covid-19-affects-people-with-disabilities/ [https://perma.cc/RHZ7-64ES]; Kristi L. Kirschner et al., *The Invisible COVID Workforce: Direct Care Workers for Those with Disabilities*, COMMONWEALTH FUND (May 21, 2020), https://www.commonwealthfund.org/blog/2020/invisible-covid-workforce-direct-care-workers-those-disabilities [https://perma.cc/Z9MJ-2MKK]; Roni Caryn Rabin, *Developmental Disabilities Heighten Risk of Covid Death*, N.Y. TIMES (Nov. 10, 2020), https://www.nytimes.com/2020/11/10/health/covid-developmental-disabilities.html [https://perma.cc/DMN2-F26A]; *see generally COVID-19 Outbreak and Persons with Disabilities*, UNITED NATIONS DEP'T ECON. & SOC. AFFS., https://www.un.org/development/desa/disabilities/covid-19.html [https://perma.cc/5VYT-WF5G] (July 24, 2020) (collecting resources).

2. *See* Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017, Pub. L. No. 115-119, § 4(d), 132 Stat. 23, 26.

3. *See* Americans with Disabilities Act of 1990 (ADA), Pub. L. No. 101-336, § 2(b)(4), 104 Stat. 327, 329 (stating Congress's purpose for the Act was, in part, "to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.").

4. Olmstead v. L.C., 527 U.S. 581, 582 (1999) (holding that unjustified isolation of persons with disabilities is discrimination in violation of the ADA).

5. *2018 American Community Survey (ACS) 1-Year Estimates: Disability Characteristics*, U.S. CENSUS BUREAU, https://data.census.gov/cedsci/table?q=S1810&g=0100000US&tid=ACSST1Y2018.S1810 [https://perma.cc/5WBW-HDRW] (last visited Jan. 12, 2021) [hereinafter *2018 ACS*]. Individuals with disabilities are 12.6% of the civilian, noninstitutionalized population of the United States. *Id*. Disability is not simple to define, and figures vary some from study to study. The Centers for Disease Control and Prevention, for example, reports that 61 million adults in the United States live with a disability. *Disability Impacts All of Us*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html [https://perma.cc/QY8M-MP3Z] (last visited Dec. 21, 2020).

6. *2018 ACS*, *supra* note 5. *See also American Community Survey and Puerto Rico Community Survey 2018 Subject Definitions*, U.S. CENSUS BUREAU 59–62, https://www2.census.gov/programs-surveys/acs/tech_docs/subject_definitions/2018_ACSSubjectDefinitions.pdf [https://perma.cc/4PAQ-SJJM] (last visited Jan. 12, 2021).

moving around within the home, eating, and taking medications.[7] In 2013, the national Commission on Long-Term Care reported that over twelve million people receive care at home to support their quality of life and their independence.[8]

The National Academy for State Health Policy recently analyzed hundreds of recommendations from over two dozen multi-stakeholder reports relevant to family caregiving.[9] The resulting report distills overlapping recommendations for improving our national caregiving strategy. Among the top recommendations was strengthening financial supports for caregiving.[10] As policymakers consider expanding financial supports for caregivers, this Essay offers a cautionary tale from the world of tax.

We begin with a real-world example.[11] Kerrie Reilly's daughter, K.R., was born with a developmental disability. Although K.R. is an adult, she requires constant supervision to live safely in her home. K.R. requires care similar to that needed by a three-year-old, "that is, anticipating everyday hazards and intervening to avert harm."[12] Ms. Reilly does not

7. Peter F. Edemekong et al., *Activities of Daily Living*, STATPEARLS, https://www.ncbi.nlm.nih.gov/books/NBK470404/ [https://perma.cc/XU42-S6P4] (June 26, 2020). In the 2018 American Community Survey, nearly eight million people reported difficulty with self-care activities. *2018 ACS*, *supra* note 5. It is important to note that the nature and severity of disabilities vary widely. The Census Bureau acknowledged the difficulty of measuring this "complex concept," noting that "disability is a dynamic concept that changes over time as one's health improves or declines, as technology advances, and as social structures adapt. As such, disability is a continuum in which the degree of difficulty may also increase or decrease." *American Community Survey and Puerto Rico Community Survey 2018 Subject Definitions*, *supra* note 6, at 59–60. While this Essay focuses on individuals who require in-home care, many individuals with disabilities do not require caregiving to live and work independently.

8. STAFF OF S. COMM'N ON LONG-TERM CARE, 113TH CONG., REP. TO THE CONGRESS 3 (Sept. 30, 2013) [hereinafter COMM'N ON LONG-TERM CARE, 2013 REPORT].

9. Wendy Fox-Grage, *Inventory of Key Family Caregiver Recommendations*, NAT'L ACAD. FOR STATE HEALTH POL'Y 1 (Apr. 14, 2020), https://www.nashp.org/inventory-of-key-family-caregiver-recommendations/ [https://perma.cc/EM4R-8KAQ].

10. Similarly, the Family Caregiving Advisory Council has recognized the need to protect and enhance financial security for caregivers and adopted a recommendation to "decrease the negative financial impacts for family caregivers on both a short- and long-term basis." *Family Caregiving Advisory Council: Final Recommendations*, ADMIN. FOR CMTY. LIVING 5 (Nov. 18, 2020), https://acl.gov/sites/default/files/raise_sgrg/raise%20recommendations%20final%20web.pdf [https://perma.cc/6FMK-KF89].

11. This example is taken from a recent California case, *Reilly v. Marin Housing Authority*, 472 P.3d 472 (Cal. 2020). Examples of families in similar circumstances may be found in other cases including *In re Hite*, 557 B.R. 451 (Bankr. W.D. Va. 2016) (examining a bankruptcy claim made by a couple providing full-time care for their adult son who "is wheelchair-bound and has autism, cerebral palsy and Lennox-Gastaut syndrome, a rare and debilitating form of epilepsy") and *Ray v. United States*, 993 F. Supp. 2d 760 (S.D. Ohio 2014), *vacated*, No. 2:12-cv-677, 2014 WL 12852321 (S. D. Ohio Feb. 11, 2014) (involving a tax refund claim by a mother who cared for her adult son who "cannot walk, talk, or feed himself, is unable to provide for his needs and requires round-the-clock care").

12. *See Reilly*, 472 P.3d at 477.

work outside the home because she cannot afford paid care for K.R. Instead, Ms. Reilly is paid through a state and federally funded In-Home Supportive Services (IHSS) program.[13] Although K.R. requires twenty-four-hour supervision, her mother's paid caregiving hours are statutorily capped at 283 hours per month,[14] making her income about $40,000 per year.[15]

This Essay examines the supports available to the families like the Reillys through the health and tax systems. Common problems identified for family caregivers include poverty, lack of health insurance and access to health care for themselves, lack of Social Security and Medicare credits, and lack of retirement savings.[16] For care recipients, challenges often include lack of agency and choice in how to live their lives.[17]

Several articles have examined federal tax supports for caregiving.[18]

---

13. In the Reillys' home state of California, IHSS is funded partly through a Medicaid waiver. *Id*. at 485.

14. *See* CAL. WELF. & INST. CODE, §§ 12303.4(b), 14132.952(g) (West 2020) (capping in-home caregiving hours and reimbursement rates).

15. The average hourly wage under IHSS in California for 2019 was about $12 per hour. *See County IHSS Wage Rates*, CA.GOV, https://www.cdss.ca.gov/inforesources/ihss/county-ihss-wage-rates [https://perma.cc/U54Q-2W6C] (last visited Nov. 16, 2019 via Wayback Machine) (estimating Ms. Reilly's income at $12 × 283 × 12 = $40,752 ($12 per hour compensation multiplied by the 283-day cap multiplied by a standard twelve-hour day)). The record does not disclose Ms. Reilly's actual income. *See generally Reilly*, 472 P.3d. 472.

16. *See, e.g.*, Richard L. Kaplan, *Family Caregiving and the Intergenerational Transmission of Poverty*, 46 J. L. MED. & ETHICS 629, 630 (2018) [hereinafter Kaplan, *Family Caregiving*]; *Economic Impact of Family Caregiving*, *in* FAMILIES CARING FOR AN AGING AMERICA 127–28 (Richard Schulz & Jill Eden, eds., 2016) ("Researchers, advocates, and observers have raised concerns that the demands of caregiving can negatively impact caregivers' ability to stay in the workforce and thus jeopardize their income, job security, personal retirement savings, eventual Social Security and retirement benefits, career opportunities, and overall long-term financial well-being."); CDC Caregiver Brief, *infra* note 24, at 4, 7 (noting that 92.9% of caregivers aged forty-five years and older have health insurance but only 79.3% of them reported having had a routine checkup in the past year and 17.6% reported experiencing fourteen or more physically unhealthy days in the past month).

17. *See, e.g.*, Michael Ogg, *Remaining at Home with Severe Disability*, 38 HEALTH AFFS. 1046, 1049 (2019); *see also About* Olmstead, ADA.GOV, https://www.ada.gov/olmstead/olmstead_about.htm [https://perma.cc/VSX8-HY5N] (last visited Jan. 31, 2021) (documenting personal stories of a few of the thousands of beneficiaries of the *Olmstead* decision and the subsequent Department of Justice actions).

18. *See, e.g.*, Richard L. Kaplan, *Federal Tax Policy and Family-Provided Care for Older Adults*, 25 VA. TAX REV. 509, 561–62 (2005) [hereinafter Kaplan, *Federal Tax Policy*] (advocating for tax credits for family caregivers); Nancy E. Shurtz, *Tax, Class, Women, and Elder Care*, 43 SEATTLE U. L. REV. 223 *passim* (2019) (advocating changes to the tax system including a refundable credit for both care receiver and provider, among other changes, to protect marginalized groups including women, the poor, and the elderly); Katie Wise, *Caring for Our Parents in an Aging World: Sharing Public and Private Responsibility for the Elderly*, 5 N.Y.U. J. LEGIS. & PUB. POL'Y 563, 585 (2002) ("The federal dependent care tax deduction, in place since 1976, allows individuals to claim a deduction against federal income tax liabilities for caregiving-related expenses in excess

Scholars examining tax supports for family caregiving—including the dependency exemption, tax-advantaged savings accounts, and the medical expense deduction—have widely concluded that the tax code provides very poor support for caregiving.[19] This Essay does not dispute this overall conclusion. Instead, it offers a close look at one largely overlooked provision, the "difficulty of care" gross income exclusion under Internal Revenue Code § 131, and posits that this benefit provides a useful prism through which to examine the points of friction that have emerged as health and disability law and federal income tax law and administration have developed on separate trajectories over the last forty years.

The difficulty of care exclusion is an income tax break for community caregivers of disabled adults who are "placed" with a "foster care" provider.[20] It is a little-known and little-used provision, perhaps because it is built on top of an exclusion for foster child payments, also found in § 131.[21] Eligibility for the exclusion has also been unclear. Parental caregivers' attempts to access this benefit were unsuccessful for decades. Then in 2014, the Internal Revenue Service (IRS) reinterpreted § 131 in a manner that attempted to recognize the realities of modern state programs for community care of adults with disabilities, which often support family caregiving under a beneficiary-directed model. Unfortunately this reinterpretation came via subregulatory guidance without the benefit of public comment or formal input from those best positioned to inform the IRS about the full ramifications and complexities of its interpretive shift. This well-motivated move by the IRS set off a conflict between caregivers who benefited from the exclusion and caregivers who were financially harmed by it due to Congress's gradual

---

of 7.5% of their gross income."); John Jankowski, *Caregiver Credits in France, Germany, and Sweden: Lessons for the United States*, 71 SOC. SEC. BULL. 61 *passim* (2011) (examining the caregiver credit systems in European countries and considering their potential in the United States); Alexandra M. Ferrara, Note, *Incentivizing the Care of Adult Family Members Through a Two-Part Tax Credit*, 94 N.Y.U. L. REV. 819 *passim* (2019) (advocating for government subsidies for family adult care).

19. *See, e.g.*, Kaplan, *Federal Tax Policy*, *supra* note 18, at 560–61 ("[T]he tax code's existing provisions for personal exemptions and medical expense deductions provide relief to only a limited extent and under fairly uncertain conditions."); Shurtz, *supra* note 18, at 264–83 (detailing "tax system failures"); Ferrara, *supra* note 18, at 841 ("[T]he current federal tax code does not provide a broadly accessible incentive that addresses the positive benefits created by family adult care or the unique characteristics of the adult population, justifying the creation of a new tax incentive."). *Cf.* Setting Every Community Up for Retirement Enhancement (SECURE) Act of 2019, Pub. L. No. 116-94, § 116(a)(1), 133 Stat. 3137, 3161 (defining "difficulty of care" payments to foster care providers as "compensation" when considering 401(k) and IRA contribution requirements, allowing caregivers to contribute to a retirement account).

20. I.R.C. § 131(c).

21. This Essay does not address the exclusion for foster payments to caregivers of minor children under I.R.C. § 131(b).

expansion of income-based refundable tax credits.

This Essay uses the difficulty of care exclusion to illuminate little-known but consequential interactions, frictions, inconsistencies, and uncertainties that adults with disabilities and their family caregivers face. It offers preliminary suggestions for lawmakers to better align our federal tax system to support family caregiving and community living for adults with disabilities.

The Essay proceeds in the following way. Parts I and II trace the evolution of selected[22] health and tax policies impacting family caregivers over the past fifty years. Part I focuses on Medicaid and the growth of supports for home and community-based care. Part II describes the difficulty of care exclusion and the administrative and policy complications that have developed since its enactment. The story shows the entwining of health and tax policy and the need for advocates and policymakers to consider unified rather than siloed solutions.

Part III critiques the difficulty of care exclusion as currently administered on both procedural and substantive grounds. Finally, the Essay reveals what lessons the difficulty of care saga might offer for legislators considering how to design financial caregiving supports in the context of a national caregiving strategy. Ultimately, this Essay argues that Congress should reconsider tax laws supporting community integration and care in light of the realities of modern health programs and in light of contemporary health and disability policy. The IRS's 2014 reinterpretation of § 131 attempted to correct course, but ultimately, only Congress can fix siloed, outdated, and paternalistic policies.

22. There are myriad federal and state policies impacting adults with disabilities and family caregivers. This Essay focuses on Medicaid on the health care side and the difficulty of care exclusion on the tax side.

I. MEDICAID, DISABILITY RIGHTS, AND THE DEVELOPMENT OF SUPPORTS FOR IN-HOME AND COMMUNITY CARE

Most paid long-term care[23] services and supports in the United States are funded by the Medicaid program.[24] This Part briefly describes the structure and evolution of Medicaid as it relates to adults with disabilities and their caregivers.[25]

Medicaid is a needs-based, federally funded health program historically serving eligible families with children, older adults, and persons with disabilities.[26] For individuals with disabilities who require

23. Long-term care consists of services and supports (commonly referred to as LTSS, long-term services and supports) "for older adults and people with disabilities who need support because of age; physical, cognitive, developmental, or chronic health conditions; or other functional limitations that restrict their abilities to care for themselves." *LTSS Overview*, CTRS. FOR MEDICARE & MEDICAID SERVS., https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/ltss-overview [https://perma.cc/NQ4D-3DY4] (Sept. 30, 2020). *See also What is Long-Term Care?*, NAT'L INST. ON AGING, https://www.nia.nih.gov/health/what-long-term-care [https://perma.cc/NL8Q-PLD3] (May 1, 2017) ("The most common type of long-term care is personal care—help with everyday activities, also called 'activities of daily living.' These activities include bathing, dressing, grooming, using the toilet, eating, and moving around—for example, getting out of bed and into a chair.").

24. Molly O'Malley Watts et al., *Medicaid Home and Community-Based Services Enrollment and Spending*, KAISER FAM. FOUND. (Feb. 4, 2020), https://www.kff.org/medicaid/issue-brief/medicaid-home-and-community-based-services-enrollment-and-spending/ [https://perma.cc/C9V8-GBYW]. However, it should be acknowledged that the vast majority of caregivers (tens of millions of people) are unpaid or underpaid family members. There are more than two million paid home care workers in the United States, according to estimates based on census and Bureau of Labor Statistics data. *See U.S. Home Care Workers: Key Facts*, PHI 2 (2019), https://phinational.org/wp-content/uploads/legacy/phi-home-care-workers-key-facts.pdf [https://perma.cc/5UBF-9HT2]. In contrast, studies suggest that around forty million people provide uncompensated care. *See Caregiving Statistics: Demographics*, FAM. CAREGIVER ALL. (Apr. 17, 2019), https://www.caregiver.org/caregiver-statistics-demographics [https://perma.cc/UXX7-58J6]; *see also* GARY SMITH ET AL., OFF. OF THE ASSISTANT SEC'Y FOR PLAN. & EVALUATION, U.S. DEP'T OF HEALTH & HUM. SERVS., USING MEDICAID TO SUPPORT WORKING AGE ADULTS WITH SERIOUS MENTAL ILLNESSES IN THE COMMUNITY: A HANDBOOK 10 (2005) [hereinafter ASPE HANDBOOK] ("It is estimated that between one-quarter and one-third of adults with serious mental illnesses reside with their family, usually a parent."); *Caregiving for Family and Friends—A Public Health Issue*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/aging/caregiving/caregiver-brief.html [https://perma.cc/GGD2-Y2TR] (July 30, 2019) [hereinafter CDC Caregiver Brief] (discussing the health hazards associated with providing unpaid caregiving services to a friend or family member and its impact on public health).

25. Medicaid is an incredibly complex program with volumes of arcane rules and many separate programs. This Essay will necessarily summarize provisions relevant to the difficulty of care exclusion; it does not attempt to provide a comprehensive description of Medicaid law or a complete history of the program.

26. *See Eligibility*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, https://www.macpac.gov/medicaid-101/eligibility/ [https://perma.cc/WM8E-8UU3] (last visited Jan. 15, 2021); *see generally* MEDICAID.GOV, https://www.medicaid.gov/medicaid/index.html [https://perma.cc/Q8UB-RT9C] (last visited Jan. 15, 2021). In contrast, Medicare is an old age and disability insurance program funded through payroll taxes. *How Is Medicare Funded?*, MEDICARE.GOV, https://www.medicare.gov/about-us/how-is-medicare-funded

long-term services, Medicaid provides a crucial safety net.[27] While Medicaid's eligibility limits exclude many people,[28] its programs for individuals with disabilities are a key component of the U.S.'s current caregiving supports, particularly for lower income families.[29]

[https://perma.cc/M6EX-EKP3] (last visited Jan. 15, 2021). For more information about the Medicare program, see generally MEDICARE.GOV, https://www.medicare.gov/ [https://perma.cc/XHH8-YYP4] (last visited Jan. 15, 2021). Medicare recipients may either be individuals who are disabled and meet certain conditions or individuals who have reached the age of sixty-five. *Who Is Eligible for Medicare?*, HHS.GOV, https://www.hhs.gov/answers/medicare-and-medicaid/who-is-elibible-for-medicare/index.html [https://perma.cc/F35N-A9CE] (last visited Jan. 15, 2021). Some individuals qualify for both Medicare and Medicaid. Approximately 20% of Medicare beneficiaries are also enrolled in Medicaid. *Eligibility*, *supra*; *see also Data Book: Beneficiaries Dually Eligible for Medicare and Medicaid*, MEDICARE PAYMENT ADVISORY COMM'N & MEDICAID & CHIP PAYMENT & ACCESS COMM'N (2018), https://www.macpac.gov/wp-content/uploads/2020/07/Data-Book-Beneficiaries-Dually-Eligible-for-Medicare-and-Medicaid-January-2018.pdf [https://perma.cc/6ZP7-JKQQ].

27. As noted above, *supra* note 24, Medicaid is the primary payer of long-term care in the United States. AARP PUB. POL'Y INST., ACCESS TO LONG-TERM SERVICES AND SUPPORTS: A 50-STATE SURVEY OF MEDICAID FINANCIAL ELIGIBILITY STANDARDS 1 (2010) [hereinafter AARP, LTSS ACCESS], https://assets.aarp.org/rgcenter/ppi/ltc/i44-access-ltss_revised.pdf [https://perma.cc/3QSJ-EC24]. Contrary to popular belief, Medicare does not generally cover nursing home care, although it does cover some home health care. *See, e.g.*, *How Can I Pay for Nursing Home Care?*, MEDICARE.GOV, https://www.medicare.gov/what-medicare-covers/what-part-a-covers/how-can-i-pay-for-nursing-home-care [https://perma.cc/8NM9-Y96R] (last visited Jan. 15, 2021). Private long-term care disability insurance is unaffordable or unavailable for many people and provides inadequate coverage in many cases even if purchased. *Long-Term Care Insurance Facts*, AM. ASS'N LONG-TERM CARE INS., https://www.aaltci.org/long-term-care-insurance/learning-center/ltcfacts.php [https://perma.cc/GD3A-YYMP] (last visited Feb. 1, 2021) (indicating that the average annual premium for a couple over the age of 65 was $4,675 and 44% of applicants between ages 70 and 79 were denied coverage); *see also* Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 25–26 & nn.95–101, 27 (2004) (noting that private insurance "fails to cover the services people with disabilities most need for independence and health").

28. *See* Stephanie R. Hoffer, *Making the Law More ABLE: Reforming Medicaid for Disability*, 76 OHIO ST. L.J. 1255, 1269–70 (2015).

29. For federal fiscal year 2013, 4.2 million people received Medicaid-funded long-term services and supports worth $171.7 billion. MEDICAID & CHIP PAYMENT & ACCESS COMM'N., MACSTATS: MEDICAID AND CHIP DATA BOOK 57 (2018) [hereinafter MACPAC MACSTATS], https://www.macpac.gov/wp-content/uploads/2018/12/December-2018-MACStats-Data-Book.pdf [https://perma.cc/L3HW-F7QP]. *See also CMS Fast Facts*, CTRS. FOR MEDICARE & MEDICAID SERVS., https://www.cms.gov/research-statistics-data-systems/cms-fast-facts/cms-fast-facts-mobile-site [https://perma.cc/7FMX-YJCA] (Aug. 20, 2020, 3:21 PM) (tabulating 1.6 million beneficiaries of home health services under Medicaid in 2014 worth approximately $4.8 billion for the states and territories that provided complete or partial information); *Medicaid Facts and Figures*, CTRS. FOR MEDICARE & MEDICAID SERVS. (Jan. 30, 2020), https://www.cms.gov/newsroom/fact-sheets/medicaid-facts-and-figures [https://perma.cc/BY4D-5VF4] ("In 2017, Medicaid paid for 30.2 percent of expenditures for nursing care facilities and continuing care retirement communities.").

A. Medicaid's Early Days

The Medicaid program was created in 1965,[30] providing federal financial support for health care services to qualifying poor, elderly, and disabled individuals.[31] Medicaid is a complex federal-state partnership program.[32] State Medicaid programs are designed and managed by state agencies within federal parameters. Federal law establishes mandatory coverage groups (like children), optional coverage groups (most recently, people who need COVID-19 testing[33]), and mandatory and optional services that can be provided to those groups.[34] Within this wide menu of options, states submit a "state plan" for approval by the federal Centers for Medicare and Medicaid Services (CMS).[35] States can also customize their Medicaid programs through various waivers, which provide further options to deviate from standard parameters.[36] Because states have such flexibility in designing their programs, Medicaid programs vary

30. Medicaid was enacted as title XIX of the Social Security Act (SSA), Social Security Amendments of 1965, Pub. L. No. 89-97, § 121, 79 Stat. 286, 343–52 (codified at 42 U.S.C. § 1396 et seq.).

31. *See* Diane Rowland & Rachel Garfield, *Health Care for the Poor: Medicaid at 35*, 22 HEALTH CARE FIN. REV. 23, 23 (2000).

32. For a comprehensive overview of the Medicaid program, see *Medicaid 101*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, https://www.macpac.gov/medicaid-101/ [https://perma.cc/64YW-FX5C]. S*ee also* Robin Rudowitz et al., *10 Things to Know about Medicaid: Setting the Facts Straight*, KAISER FAM. FOUND. (2017), https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-medicaid-setting-the-facts-straight/ [https://perma.cc/DTH6-3E46].

33. *CMS Issued New Guidance for States on the Medicaid Optional Uninsured COVID-19 Testing (XXIII) Group*, AM. HOSP. ASS'N (June 4, 2020), https://www.aha.org/special-bulletin/2020-06-04-cms-issued-new-guidance-states-medicaid-optional-uninsured-covid-19 [https://perma.cc/R25M-74HL].

34. *See Eligibility*, *supra* note 26 ("Some eligibility groups are mandated by federal law and others may be covered at state option."); *Benefits*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, https://www.macpac.gov/medicaid-101/benefits/ [https://perma.cc/7M7D-UHCP] ("As with Medicaid eligibility groups, some Medicaid benefits that states offer are mandatory and others are optional."); *see also* Joint HHS, HUD, & USDA Informational Bulletin, *Living at Home in Rural America: Improving Accessibility for Older Adults and People with a Disability* 4 (Aug. 19, 2020), https://www.medicaid.gov/federal-policy-guidance/downloads/cib081920.pdf [https://perma.cc/Y79T-E24W] (detailing the flexible options for states to cover a variety of optional in-home services through Medicaid).

35. *See* Joint HHS, HUD, & USDA Informational Bulletin, *supra* note 34, at 4; Social Security Act § 1902(a)(4), 42 U.S.C. § 1396a; 42 C.F.R. §§ 430.10–430.25 (2021); *see also State Plan*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, https://www.macpac.gov/subtopic/state-plan/ [https://perma.cc/9E5V-PVWP] (last visited Dec. 21, 2020); MaryBeth Musumeci et al., *Medicaid Financial Eligibility for Seniors and People with Disabilities: Findings from a 50-State Survey*, KAISER FAM. FOUND 1 (2019) http://files.kff.org/attachment/Issue-Brief-Medicaid-Financial-Eligibility-for-Seniors-and-People-with-Disabilities-Findings-from-a-50-State-Survey [https://perma.cc/3YVZ-MCC3] ("Aside from the core group of SSI beneficiaries, pathways to full Medicaid eligibility based on old age or disability are provided at state option.").

36. *See generally Waivers*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, https://www.macpac.gov/topics/waivers/ [https://perma.cc/7698-REVZ] (last visited Sept. 21, 2020).

significantly from state to state.[37]

Most institutional long-term care is a mandatory service within Medicaid and has been from the enactment of the program in 1965.[38] In contrast, equivalent care in community settings is still largely an optional service, and one frequently provided through a waiver.[39] Only two long-term services and supports must be provided under a Medicaid state plan: nursing home and home health services.[40] Mandatory "home health services" are medical services; they are not required to fund supports for activities of daily living, like dressing, eating, bathing, or toileting.[41] Practically speaking, this means that Medicaid cannot turn away a person who qualifies for Medicaid-funded nursing home care. But if that person prefers to stay in her home,[42] she may face an uphill battle getting all the supports that she needs. The state could potentially enact caps, wait lists, or even deny care altogether.[43] Thus, for eligible beneficiaries, federal

37. For example, childbirth education classes are covered for pregnant persons in some states but not in others. Kathy Gifford et al., *Medicaid Coverage of Pregnancy and Perinatal Benefits: Results from a State Survey*, KAISER FAM. FOUND., 4 tbl.1 (Apr. 2017), https://www.kff.org/womens-health-policy/report/medicaid-coverage-of-pregnancy-and-perinatal-benefits-results-from-a-state-survey/ [https://perma.cc/DPK2-P2DD].

38. State Medicaid plans were and are required to cover inpatient hospital services and skilled nursing home services, except that these services were optional if provided in a mental institution or tuberculosis facility. *See* Social Security Amendments of 1965, Pub. L. No. 89-97 § 121, 79 Stat. 286, 344, 351–52.

39. *See* Carli Friedman et al., *Aging in Place: A National Analysis of Home- and Community-Based Medicaid Services for Older Adults*, 29 J. DISABILITY POL'Y STUD. 245, 253–54 (2018) (discussing institutional bias within the Medicaid program, noting that services in nursing facilities are often mandatory while home and community-based services are mostly optional for states to cover); *see also* Joint HHS, HUD, & USDA Informational Bulletin, *supra* note 34, at 5–7 (describing seven optional Medicaid programs and benefits that help the elderly and people with disabilities remain in their homes).

40. MEDICAID & CHIP PAYMENT & ACCESS COMM'N, REPORT TO THE CONGRESS ON MEDICAID AND CHIP 50 (2014) [hereinafter MACPAC LTSS REPORT].

41. "Home health services must include nursing, home health aides, and medical supplies and equipment. States may choose to provide additional therapeutic services under home health (occupational or physical therapy, speech pathology, and audiology) and determine the medical necessity criteria by which home health service utilization is managed." *Id.* (citations omitted). Obviously, a much broader array of services and supports can be needed to manage activities of daily living.

42. Most people prefer to stay in their homes rather than move to a nursing home or other large institution. *See generally* Candace Howes, *Who Will Care for the Women?*, 30 J. WOMEN POL. & POL'Y 248, 249 (2009) ("Despite the fact that most people would prefer to remain in their homes, half of paid care takes place in institutional settings . . . ."); AARP RESEARCH, 2018 HOME AND COMMUNITY PREFERENCES SURVEY: A NATIONAL SURVEY OF ADULTS AGE 18-PLUS 4 (2018), https://www.aarp.org/content/dam/aarp/research/surveys_statistics/liv-com/2018/home-community-preferences-survey.doi.10.26419-2Fres.00231.001.pdf [https://perma.cc/9C6X-MMVW] ("Between 50 and 60 percent of adults age 18–49 say they want to remain in their communities and homes as they age, while nearly 80 percent of adults age 50 and older indicate this same desire.").

43. Advocates have argued with limited success that such denials are a violation of the ADA.

Medicaid dollars are automatically available for nursing home care, while care sufficient to remain in one's home and community may not be covered.[44]

B. Health Policy Shifts Toward Community Living and Self-Direction

Medicaid's development was influenced by the deinstitutionalization and disability rights movement.[45] In the 1950s through the 1970s, challenges and resistance arose to institutions housing individuals with disabilities.[46] By 1967, nearly 200,000 people with developmental disabilities and mental illnesses lived in institutions in the United States.[47]

Since the early 1970s, many states have moved away from institutionalization of individuals with disabilities in favor of community placements,[48] often recognizing that disabled individuals' autonomy and quality of life had been severely and unnecessarily limited under prior state

---

See Mark C. Weber, *Home and Community-Based Services,* Olmstead*, and Positive Rights: A Preliminary Discussion*, 39 WAKE FOREST L. REV. 269, 270 (2004) (using a Seventh Circuit decision as inspiration for a discussion of whether the lack of sufficient HCBS placements violates the ADA's integrated-settings duty); David Ferleger, *The Constitutional Right to Community Services*, 26 GA. ST. U. L. REV. 763, 795 (2010) (arguing that a denial of in-home services violates the U.S. Constitution, in addition to the ADA); Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 CARDOZO L. REV. 1, 6 (2012) ("[D]einstitutionalization advocates have moved from the due process theories on which they relied in the 1970s and 1980s to an anti-discrimination theory relying on the ADA and *Olmstead*.").

44. *See* Friedman et al., *supra* note 39, at 245, 253–54 (discussing institutional bias within the Medicaid program, noting that services in nursing facilities are often mandatory while home and community-based services are mostly optional for states to cover).

45. "The American disability rights movement is based on a philosophy of independent living. That philosophy supports policies that ensure that people with disabilities have the opportunity to participate fully in society and control the day-to-day and minute-to-minute aspects of their lives." Brief of the American Ass'n of People with Disabilities et al. as Amici Curiae in Support of Respondents at 2, Harris v. Quinn, 573 U.S. 616 (2014) (No. 11-681). A significant body of scholarship explores the disability rights movement. *See, e.g.*, SAMUEL R. BAGENSTOS, LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT (2009) [hereinafter BAGENSTOS, CONTRADICTIONS]. In-depth treatment of this scholarship or of the history of the movement is beyond the scope of this Essay.

46. *See Parallels in Time: A History of Developmental Disabilities*, MINN. DEP'T ADMIN.: PARALLELS IN TIME, https://mn.gov/mnddc/parallels/index.html [https://perma.cc/X677-57V6] (last visited Feb. 14, 2021). *See also* Deborah S. Metzel & Pamela M. Walker, *The Illusion of Inclusion: Geographies of the Lives of People with Developmental Disabilities in the United States*, 21 DISABILITY STUD. Q. 114, 126 (2001) ("[D]einstitutionalization began in the late 1960s spurred by lawsuits, exposes, and efforts by people with disabilities, parents, and professionals." (citation omitted)).

47. Metzel & Walker, *supra* note 46, at 125 ("People continued to be institutionalized with the number of people increasing from a little over 115,000 in 1946 to nearly 200,000 in 1967, 'nearly twice the rate of increase in the general population.' In the mid- to late-1960s, federal legislation provided funds for new construction of institutions. Eventually these residents were the ones who constituted the great deinstitutionalization movement in the next two decades." (citation omitted)).

48. DEWAYNE L. DAVIS ET AL., NAT'L CONF. STATE LEGISLATORS, DEINSTITUTIONALIZATION OF PERSONS WITH DEVELOPMENTAL DISABILITIES: A TECHNICAL

practices.[49] In 1981, Congress established the home and community-based services (HCBS) waiver program[50] under Medicaid, which permitted states to furnish a broad array of services in lieu of institutional care.[51] However, these community-based alternatives to institutionalization were not mandatory Medicaid services as most institutional services were.[52] They were also not incorporated into Medicaid state plans. Instead, states could offer HCBS services with CMS approval via a waiver process.[53]

Despite this starting disadvantage, over time the disability rights movement pushed policymakers at all levels, eventually accomplishing a major shift toward more community integration options and greater self-direction in programs for people with disabilities.[54] The disability rights

---

ASSISTANCE REPORT FOR LEGISLATORS 2 (2000), https://mn.gov/mnddc/parallels2/pdf/00s/00/00-DPD-NCS.pdf [https://perma.cc/28UD-MS2U]. *See* AARP, LTSS ACCESS, *supra* note 27, at 1 ("Most Medicaid spending for [long-term services and supports] to older persons and adults with disabilities is for nursing home services. States, however, are increasingly offering home and community-based services (HCBS) to persons who would otherwise be eligible for nursing home services."); ASPE HANDBOOK, *supra* note 24, at 7 ("Fifty years ago, government-funded mental health services principally consisted of large state-run mental institutions, funded solely with state funds. Community-based services—especially for low-income individuals—were scant and not well-organized. . . . In the 1970s, . . . the 'community support system' (CSS) was formulated to serve as a conceptual framework for supporting individuals with serious mental illnesses who are especially reliant on mental health and other community support systems to live successfully in the community.").

49. *See, e.g.*, *Oregon and Georgia: Closing Institutions and Building Community Support Systems*, NAT'L COUNCIL ON DISABILITY, https://ncd.gov/publications/2012/Sept192012/Oregon [https://perma.cc/RJ4E-6MAC] (last visited Feb. 5, 2021) ("Our system of community-based supports is not perfect. . . . However, Oregonians with disabilities have some things today they didn't have 30 years ago at Fairview: freedom, dignity and a sense of belonging." (quoting Sara Gelser, Oregon State Representative)). *See also* Mary Jean Duckett & Mary R. Guy, *Home and Community-Based Services Waivers*, 22 HEALTH CARE FIN. REV. 123 (2000) (tracing the growth of HCBS in the early 1980s and noting studies documenting unnecessary use of Medicaid institutional care).

50. Social Security Act of 1935, § 1915(c), 42 U.S.C. § 1396n(c) (authorizing waivers, within certain parameters, permitting states to include home and community-based services in their Medicaid programs).

51. *See* MACPAC LTSS REPORT, *supra* note 40, at 42. One important limitation on HCBS funding is Medicaid's prohibition on covering services provided in so-called "institution[s] for mental diseases" if the beneficiary is under sixty-five years of age. *See* SSA § 1915(a), 42 U.S.C. § 1396n(a). This means that HCBS cannot "serve as an alternative to mental health institutional services for working age adults with serious mental illnesses." ASPE HANDBOOK, *supra* note 24, at 53 (emphasis omitted). Despite this limitation, Medicaid programs are important mechanisms for supporting community integration of many previously institutionalized people.

52. *See* Friedman et al., *supra* note 39, at 245.

53. *See* MACPAC LTSS REPORT, *supra* note 40, at 51 (describing the waiver application, approval, and review process).

54. Consumer-controlled personal assistance services, in which individuals with disabilities hire, fire, and direct the individuals who provide services to them, are a key means of making

movement took a social and civil rights approach[55] to integration, scoring major litigation and legislative victories,[56] including the 1990 enactment of the landmark antidiscrimination law the Americans with Disabilities Act (ADA).[57] Congress declared, "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals."[58]

The values of community integration and self-direction for individuals with disabilities were incorporated into many state Medicaid programs during this time via a major boost from the Robert Wood Johnson Foundation.[59] As a condition of funding, the projects were required to

---

> the philosophy of independent living a reality and preventing unnecessary institutionalization. Responding to the urgings of disability rights activists, changes in federal funding rules, and this Court's decision in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), states have increasingly provided for consumer-controlled personal assistance services under their Medicaid programs.

Brief of the American Ass'n of People with Disabilities et al. as Amici Curiae in Support of Respondents, *supra* note 45, at 2–3. *See also* Everette James & Meredith Hughes, *Embracing the Role of Family Caregivers in the U.S. Health System*, HEALTH AFFS. (Sept. 8, 2016), https://www.healthaffairs.org/do/10.1377/hblog20160908.056387/full/ [https://perma.cc/3EY9-JLTD] ("One of the clear trends emerging from U.S. health reform is the transition from a provider and procedure focused system to one that puts the patient at the center of care. 'Patient-centered care' is defined as 'providing care that is respectful of, and responsive to, individual patient preferences, needs and values.'"); *see also* BAGENSTOS, CONTRADICTIONS, *supra* note 45, at 25 ("Independent living activists thus defined 'independence' as the ability of people with disabilities to make their own choices concerning how to live their lives, what services to receive, and how and where to receive them.").

55. *See* Mark C. Weber, *Disability Rights, Welfare Law*, 32 CARDOZO L. REV. 2483, 2485 (2011) [hereinafter Weber, *Disability Rights*] (explaining that activists and lawmakers justified the ADA on civil rights and antipoverty grounds); *see also* Samuel R. Bagenstos, *The Americans with Disabilities Act as Welfare Reform*, 44 WM. & MARY L. REV. 921, 926–27 (2003) [hereinafter Bagenstos, *ADA as Welfare Reform*]. As with any other coalition, disability rights activists are not a monolith. Within the movement (and within the disability community) are differing perspectives and policy positions.

56. *See Part One: The Reawakening 1950–1980: Litigation and Legislation*, MINN. DEPT. ADMIN.: PARALLELS IN TIME, https://mn.gov/mnddc/parallels/five/5d/1.html [https://perma.cc/Y58P-3ZYJ] (last visited Feb. 14, 2021) (listing selected legislative and litigation victories of the disability rights movement).

57. Americans with Disabilities Act of 1990 (ADA), Pub. L. No. 101-336, 104 Stat. 327 (codified at 42 U.S.C. § 12101). The ADA prohibits discrimination on the basis of disability in employment, public services, public accommodations, and telecommunications.

58. *Id.* § 2. Professor Bagenstos points out, however, that ADA reflects multiple goals including the less lofty desire to save the public fisc the "cost of dependency." Bagenstos, *ADA as Welfare Reform*, *supra* note 55, at 927, 957.

59. The Foundation funded "self-determination" pilot projects in eighteen states during the 1990s and later funded three "Cash & Counseling" demonstration projects. *See* JANET O'KEEFFE ET AL., NAT'L RES. CTR. FOR PARTICIPANT-DIRECTED SERVS., DEVELOPING AND IMPLEMENTING SELF-DIRECTION PROGRAMS AND POLICIES: A HANDBOOK 1-18, 2-2 (2010) [hereinafter O'KEEFFE, SELF-DIRECTION], https://www.appliedselfdirection.com/sites/default/files/Participant%20Direction%20Handbook.pdf [https://perma.cc/P5K6-9RGP]; *see also* Medicaid Program;

incorporate participant direction, giving more control over services to the care recipient.[60] Some states also adopted "consumer-directed" personal care services as an optional state plan benefit.[61]

Nine years later, another crucial step in the evolution of Medicaid for people with disabilities was the U.S. Supreme Court's decision in *Olmstead v. L.C.*[62] The *Olmstead* decision held that state services for disabled individuals must be offered in the least restrictive setting appropriate, under the ADA.[63] Many states now fulfill their *Olmstead* responsibilities through their Medicaid programs.[64]

The *Olmstead* opinion offers a compelling articulation of the values and social policy reflected in the ADA.[65] In oft-quoted language, the Court recognized two "evident judgments" by Congress:

> First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.[66]

After *Olmstead*, these policy judgments were reflected in the authorization of additional Medicaid options and demonstration programs. One of these was *Money Follows the Person*, a demonstration program to help people leave institutions.[67] States were also given new

---

Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling), 73 Fed. Reg. 57,854, 57,855 (Oct. 3, 2008).

60. O'KEEFFE, SELF-DIRECTION, *supra* note 59, at 1–13 (describing the Cash & Counseling Vision Statement); *id.* at 1–4 ("States that received C&C grants . . . agreed to make program design choices in accordance with the C&C Vision Statement.").

61. SSA § 1905(a)(24), 42 U.S.C. 1396d(a)(24).

62. 527 U.S. 581, 587 (1999) ("Specifically we confront the question whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions.").

63. *Id.* at 607.

64. *See* MACPAC LTSS REPORT, *supra* note 40, at 43 ("The *Olmstead* ruling on state LTSS policies has been a major factor in the increased use of HCBS.").

65. *See* Samuel R. Bagenstos, *Taking Choice Seriously in* Olmstead *Jurisprudence*, 40 J. LEGAL MED. 5, 5 (2020) ("*Olmstead* has often been called the *Brown v. Board of Education* of the disability rights movement.").

66. *Olmstead*, 527 U.S. at 600–01 (citations omitted).

67. *See Money Follows the Person*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/index.html [https://perma.cc/6FTV-QSDD] (last visited Jan. 16, 2021). *Money Follows the Person* has been extended several times, including in the CARES Act. *Id. See also* Pam Katz, *Important Step for Community Living for People with Disabilities: Congress Makes Overdue Investment in Money Follows the Person Program*, ARC

options to incorporate self-directed home and community-based services into their Medicaid programs.[68] The Centers for Medicare and Medicaid Services (CMS) acknowledged that the new options were "built on the experiences and lessons learned from the disability rights movement and States that pioneered self-direction programs."[69] The agency proclaimed, "self-direction is an important component of independence, as it promotes quality, access, and choice."[70]

Today there are seemingly endless options for states to use Medicaid funds or separate state funds to support community life for individuals with disabilities.[71] This is partly because the Social Security Act (SSA) allows for waiver and for some optional services to deviate from the normal Medicaid requirements, such as comparability of services.[72] This allows states to develop unique programs specifically for individuals with certain diagnoses, for instance developmental disabilities.[73] This can be beneficial for the individuals with a customized program available to them, but it creates mind-boggling complexity, as each Medicaid option has its own detailed scope and requirements.[74] Also, states may operate multiple programs under a single legal provision.[75] Moreover, it is still

(Dec. 22, 2020), https://thearc.org/important-step-for-community-living-for-people-with-disabilities-congress-makes-overdue-investment-in-money-follows-the-person-program/ [https://perma.cc/BQF3-YAMF].

68. These options are found in SSA sections 1915(i) (State Plan Home and Community-Based Services), (j) (Self-Directed Personal Assistance Services under State Plan), and (k) (Community First Choice), 42 U.S.C. § 1396n(i), (j), and (k). The section 1915(i) option was a particularly significant addition. Unlike section 1915(c) waivers, section 1915(i) waivers could serve people who did not (yet) need an institutional level of care. *See* Letter from Cindy Mann, Dir., Ctr. for Medicaid, CHIP & Surv. & Certification, to State Medicaid Dir. (Aug. 6, 2010), https://downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/SMD10015.pdf [https://perma.cc/Y7C4-873V]. In the Affordable Care Act, Congress amended SSA section 1915(i) to increase the HCBS services available and to provide greater flexibility in program design. *Id*.

69. *See* Medicaid Program; Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling), 73 Fed. Reg. 57,854, 57,854 (Oct. 3, 2008) (to be codified at 42 C.F.R. pt. 441).

70. *Id.* In this context, self-direction may include choice of setting and choice of care provider. As discussed below, it can also mean that certain management responsibilities are shifted to the beneficiary. *See infra* notes 83–85 and accompanying text. *See generally Self-Directed Services*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html [https://perma.cc/8MMK-D9MT] (last visited Feb. 2, 2021).

71. MACPAC LTSS REPORT, *supra* note 40, at 51–52.

72. ASPE HANDBOOK, *supra* note 24, at 27; MACPAC LTSS REPORT, *supra* note 40, at 51.

73. MACPAC LTSS REPORT, *supra* note 40, at 58.

74. *Id.* at 51–52, 61–62. *See, e.g.*, Medicaid Program; Community First Choice Option, 76 Fed. Reg. 10,736, 10,736-53 (proposed Feb. 25, 2011) (to be codified at 42 C.F.R. pt. 441) (explaining and proposing definitions, requirements, options, and other parameters for the Community First Choice State plan option under SSA section 1915(k)).

75. For example, California currently has six active waivers under SSA section 1915(c) alone.

up to each state to voluntarily amend its state plan or seek a waiver to take up any of the HCBS options. States choosing to take up an HCBS option have significant leeway in determining financial eligibility criteria for those programs.[76]

C. Administrative Complexity Grows as Community Care Programs Develop

As Medicaid programs shifted away from institutionalization and toward community care for people with disabilities, the administration of these programs changed and diversified.[77] Several developments are notable in the context of this Essay. They concern (1) who can be a paid caregiver, (2) who is the employer or responsible payer of the caregiver, and (3) how administrative tasks relating to the caregiver's hiring and payment are handled.

Originally, most Medicaid-funded home care was provided by professional employees of the state agency.[78] As Medicaid services increasingly reflected disability rights values of autonomy and self-direction, states grew more receptive to individuals (as opposed to agencies) being hired as caregivers, and eventually even family members were allowed to be hired.[79] Today, federal Medicaid law generally

---

State Waivers List, MEDICAID.GOV, https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html [https://perma.cc/5SRP-4HNU] (last visited Dec. 21, 2020). According to Medicaid.gov, there are currently more than three hundred HCBS Waiver programs active nationwide. *See Home & Community-Based Services 1915(c)*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html [https://perma.cc/23E6-96ZM] (last visited Dec. 21, 2020).

76. *See* AARP, LTSS ACCESS, *supra* note 27, at 3; *see also* Musumeci et al., *supra* note 35, at 21 ("While most states that expand financial eligibility for Medicaid nursing home and other institutional care also apply those same rules to HCBS, there are a few states in which HCBS financial eligibility rules are more restrictive and could be aligned with those for institutional care to eliminate bias in favor of institutional care.").

77. In addition to having flexibility around programs and services, state Medicaid programs have significant flexibility in administration. O'KEEFFE, SELF-DIRECTION, *supra* note 59, at 2-20–21.

78. Newcomer et al., *supra* note 79, at 518.

79. *Id*.; O'KEEFFE, SELF-DIRECTION, *supra* note 59 at 1-9–10. This policy change was made easier by studies finding that family caregivers were cost-effective for the state. A study of California's in-home services and supports (IHSS) program concluded, "[t]here were no financial disadvantages and some advantages to Medicaid in terms of lower average Medicaid expenditures and fewer nursing home admissions when using spouses, parents, and other relatives as paid IHSS providers. This argues in favor of honoring the recipient's and family's preference for such providers." Robert J. Newcomer et al., *Allowing Spouses to Be Paid Personal Care Providers: Spouse Availability and Effects on Medicaid-Funded Service Use and Expenditures*, 52 GERONTOLOGIST 517, 517 (2011), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3530315/pdf/gnr102.pdf [https://perma.cc/B4KB-KBG5].

permits states to pay family members to care for disabled adults.[80] While some states still restrict who can receive caregiver payments for adults, those states are now a minority.[81]

In addition to paying a broader range of caregivers, states' financial administration of their programs also changed as personal choice models grew in popularity and complexity. Two aspects in particular stand out. First, Medicaid agencies began to contract with third party companies not only to manage services, but also to manage caregiver payments, often including compliance activities like payroll and tax paperwork obligations.[82] Second, states shifted control and responsibilities to the person receiving services, to various degrees.[83] Generally, a contracted fiscal manager[84] would handle or assist the service recipient in handling the administrative obligations connected to their care.

Administrative obligations are not uniform across states because the employment status of Medicaid-funded caregivers can vary.[85] Even for caregivers who are treated as employees, the identity of the employer can

80. Newcomer et al., *supra* note 79, at 518; O'KEEFFE, SELF-DIRECTION, *supra* note 59, at 1-10.

81. Newcomer et al., *supra* note 79, at 518; O'KEEFFE, SELF-DIRECTION, *supra* note 59, at 1-9–10.

82. *See, e.g.*, Medicaid Program; Community First Choice Option, 76 Fed. Reg. 10,736, 10,742–43 (proposed Feb. 25, 2011) (to be codified at 42 C.F.R. pt. 441) (noting that under § 441.545, states may choose agency models or "agency with choice" models, which contain a requirement for an internal or contracted "financial management entity" to "collect and process timesheets of the individual's workers; process payroll, withholding, filing and payment of applicable Federal, State and local employment related taxes and insurance; maintain a separate account for each individual's budget; track and report disbursements and balances of individual's funds; process and pay invoices for services in the service plan; and provide to the individual periodic reports of expenditures and the status of the approved service budget"); *In re* Hite, 557 B.R. 451, 453 (Bankr. W.D. Va. 2016) (noting that the caregiver-parents received Medicaid benefit payments through the entity Public Partnership, LLC); Micorescu v. Comm'r, 76 T.C.M. (CCH) 796, 797 (1998) ("Petitioners were licensed . . . as Level III adult foster home providers and were . . . . an instrumentality of the State of Oregon that acts as a social service agency responsible for providing various services to individuals including determining eligibility for, and case management in, [M]edicaid for elderly persons.").

83. *See generally* SUZANNE CRISP ET AL., INTEGRATED CARE RES. CTR., SELECTED PROVISIONS FROM INTEGRATED CARE RFPS AND CONTRACTS: PARTICIPANT DIRECTION (2014). States generally use "a budget model, an employer authority model, or a combination of both" in participant-directed Medicaid programs for long-term services and supports. *Id.* at 2.

84. There are various terms for these companies, including "fiscal intermediary" and "financial management services" (FMS) entity, organization, provider, or agency. This Essay uses the term "fiscal manager" as shorthand to encompass both fiscal/employer agents and FMS entities in programs operating under an "agency with choice" model.

85. *See Certain Medicaid Waiver Payments May Be Excludable from Income*, IRS https://www.irs.gov/individuals/certain-medicaid-waiver-payments-may-be-excludable-from-income [https://perma.cc/8KNL-XU2C] (Feb. 23, 2015) [hereinafter *IRS § 131 FAQ*]; Amy B. McLellan & John Tripp, *Recovering FICA and Medicare Taxes for Family Caregivers*, 156 TAX NOTES 225, 226–27 (2017).

vary.[86] Some states contract with multiple fiscal management companies, who may handle payments differently.[87] Occasionally, caregivers may even be treated as independent contractors.[88]

The IRS accommodated this complexity with updated guidance on federal employment tax responsibilities related to caregivers. In Notice 2003-70, announcing a proposed revenue procedure, the IRS explained:

> The proposed revenue procedure also addresses questions that have arisen in light of another evolving aspect of the home-care service industry. States now often engage third parties to participate in various aspects of their home-care service programs, including processing federal grants and administering payroll for home-care service providers. . . . The Service recognizes that there are a variety of third parties involved in these arrangements, some for-profit, some nonprofit, and some public, and that the terms of the agreements between the states and the third parties also vary.[89]

Consistent with shifts in Medicaid policy toward greater beneficiary participation and control, many states adopt the posture that the beneficiary hires and employs the caregiver.[90] For beneficiaries with very limited capacity like K.R., this is a fiction; for others it is a meaningful and

86. O'KEEFFE, SELF-DIRECTION, *supra* note 59 at 7-4. In some states, caregivers are employees who receive a form W-2 from the state contractor that handles payroll for these programs statewide. *See e.g.*, *IRS Notice 2014-7, Difficulty of Care Payments Excludable from Income*, WASH. ST. DEP'T SOC. & HEALTH SERVS., https://www.dshs.wa.gov/altsa/irs-notice-2014-7-difficulty-care-payments-excludable-income [https://perma.cc/ZD8K-46KS] (last visited Dec. 31, 2020) (showing Washington DSHS uses contractor Public Partnerships Washington Individual ProviderOne (IPOne) program to manage its filing requirements for individual care providers).

87. *See* CRISP ET AL., *supra* note 83, at 7 (describing three main accountability responsibilities of financial management services providers, including managing tax requirements, and typical arrangements between states and providers ranging from delegation to collaboration). *See also infra* note 178 (describing agencies handling difficulty of care payments differently in the wake of IRS Notice 2014-7).

88. *See IRS § 131 FAQ*, *supra* note 85; McLellan & Tripp, *supra* note 85, at 226. The classification of an individual as an employee or an independent contractor is dependent on several factors, and the distinction has significant consequences, from workers' rights to tax treatment. *See* 19 RICHARD A. LORD, WILLISTON ON CONTRACTS § 54:2 (4th ed. 2020); Shu-Yi Oei & Diane M. Ring, *Tax Law's Workplace Shift*, 100 B.U. L. REV. 651, 666–79 (2020).

89. I.R.S. Notice 2003-70, 2003-43 I.R.B. 916, 916. The procedures were later finalized in Rev. Proc. 2013-39, 2013-52 I.R.B. 830.

90. I.R.S. Notice 2003-70, 2003-43 I.R.B. 916, 916; JANET O'KEEFFE ET AL., OFF. OF THE ASSISTANT SEC'Y FOR PLAN. & EVALUATION, U.S. DEP'T OF HEALTH & HUM. SERVS., UNDERSTANDING MEDICAID HOME AND COMMUNITY SERVICES: A PRIMER 195–98 (2010) [hereinafter ASPE PRIMER], https://aspe.hhs.gov/system/files/pdf/76201/primer10.pdf [https://perma.cc/26SM-KVDM]. In other programs, the fiscal manager is considered the caregiver's employer. *See* PAMELA NADASH & SUZANNE CRISP, CTRS. FOR MEDICARE & MEDICAID SERVS., BEST PRACTICES IN CONSUMER DIRECTION 31 (2005), https://aspe.hhs.gov/system/files/pdf/177236/CMS-CDBestPractices.pdf [https://perma.cc/PNS5-MZ9D].

important feature of the program. Regardless, IRS Notice 2003-70 addresses programs that designate the beneficiary as employer by adopting a principal/agent framework for the relationship between the person receiving care and the fiscal manager.[91] Under this framework, the person receiving care is legally responsible for the employment tax obligations that accrue to any employer (e.g., withholding income tax, withholding and paying FICA, and filing a W-2 for the caregiver), but these duties are delegated to the fiscal manager.[92] In reality, the state Medicaid agency contracts with the fiscal management company[93] as it is not reasonable to expect Medicaid beneficiaries to individually vet and hire payroll firms to deal with their caregivers' payments. Also, of course, the actual money to pay the caregiver comes through the state agency to the fiscal provider, not from the Medicaid recipient's personal resources.[94]

D. Medicaid Coverage for Caregivers

Medicaid originally was not available to nonelderly caregivers of disabled adults.[95] Since the implementation of the Affordable Care Act (ACA) in 2014,[96] however, Medicaid has become a path for low-income caregivers to access health care.[97] The ACA's expanded Medicaid coverage group includes most individuals with income up to 138% of the

91. I.R.S. Notice 2003-70, *supra* note 90, at 921.

92. *Id.* at 916. Medicaid programs are generally required to offer financial management services to beneficiaries in participant-directed programs. *See* ASPE PRIMER, *supra* note 90, at 182 tbl.7-1. As noted above, states may contract with outside vendors to serve as fiscal managers. *See* NADASH & CRISP, *supra* note 90, at 32.

93. *See* CRISP ET AL., *supra* note 83, at 2.

94. Medicaid generally does not allow cash payments to beneficiaries for use in paying providers directly. *See* ASPE PRIMER, *supra* note 90, at 182.

95. Rowland & Garfield, *supra* note 31, at 29 ("For adults who are not pregnant or disabled, eligibility is limited to parents with very low incomes . . . . Adults without children are ineligible for Medicaid coverage, no matter how poor, unless they qualify as disabled individuals."). Parents and caretakers of minor children could be covered, but not caretakers of adult children. *See Medicaid's Role for Women*, KAISER FAM. FOUND. 1–2 (Mar. 2019), http://files.kff.org/attachment/Fact-Sheet-Medicaids-Role-for-Women [https://perma.cc/58QM-Q92M] (describing Medicaid's categories of eligibility before and after the ACA). As there was no mandatory or optional coverage category for low-income adults without children, states could only cover those individuals through an SSA section 1115 demonstration waiver, resulting in relatively few such individuals enrolled. *See* ANDY SCHNEIDER ET AL., THE MEDICAID RESOURCE BOOK 10–11 (2002), https://www.kff.org/wp-content/uploads/2013/05/mrbeligibility.pdf [https://perma.cc/ND75-K2ZT].

96. The term "ACA" refers globally to the Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (PPACA) and the Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029, as amended. While the ACA was enacted in 2010, its provisions were gradually rolled out over the next four years, achieving full implementation of most provisions in 2014.

97. *See infra* notes 133–148 and accompanying text.

federal poverty line (FPL).[98] The ACA originally conceived of this as a new mandatory coverage group under Medicaid state plans. However, in 2012 the U.S. Supreme Court ruled that states could opt out of the Medicaid expansion.[99] As of February 2021, thirty-eight states and the District of Columbia have adopted a Medicaid expansion.[100]

E. Summary

Since Medicaid's enactment in 1965, state-sponsored programs caring for individuals with disabilities have evolved in several ways. States generally moved away from emphasizing medical and institutional care provided by state employees who were not related to the beneficiary, toward emphasizing participant direction and choice. Today, state programs frequently utilize family members as caregivers, depending on the care recipient's preference. In addition, a complex administrative system has evolved, wherein private fiscal managers may handle tax, payroll, and administrative obligations for a range of programs. Federal law provides incredible flexibility and options for a state to design its own Medicaid system, which provides opportunities for innovation but also presents many challenges.[101]

In the example of Ms. Reilly and K.R., depending on where they live and which program they enroll in, they could be treated very differently for tax and employment purposes. K.R. might be considered the employer

98. PPACA § 2001(a), 42 U.S.C. § 1396a(a)(10)(A)(i)(VIII). There are a few other requirements, such as citizenship and lack of Medicare eligibility. The income limit for the Medicaid expansion population is technically 133% FPL, but there is a five-percentage-point disregard, so the practical limit is 138% FPL. 42 U.S.C. § 1396a(e)(14)(I); 42 C.F.R. § 435.603(d)(1), (d)(4) (2019). See also the discussion in the Preambles to the Proposed Rule at 78 Fed. Reg.4,594, 4,625–26 (Jan. 22, 2013) and the Final Rule at 78 Fed. Reg. 42,160, 42,186–88 (July 15, 2013). For 2020, that limit was $23,791 ($17,240 × 138%) per year for a family of two. *See* Annual Update of the HHS Poverty Guidelines, 85 Fed. Reg. 3,060, 3,060 (Jan. 17, 2020) (setting the 2020 poverty guideline for the contiguous United States at $17,240 for a family of two).

99. Nat'l Fed'n of Indep. Bus. v. Sebelius, 567 U.S. 519, 588 (2012).

100. *Status of State Action on the Medicaid Expansion Decision*, KAISER FAM. FOUND., http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act [https://perma.cc/BXY9-ZLX2] (Feb. 22, 2021); *see also Status of State Medicaid Expansion Decisions: Interactive Map*, KAISER FAM. FOUND. (Feb. 22, 2021), https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/ [https://perma.cc/9P4R-Z8Y4] (mapping state Medicaid expansion status); Louise Norris, *Find Medicaid Coverage in your State*, HEALTHINSURANCE.ORG (Nov. 18, 2020), https://www.healthinsurance.org/medicaid/ [https://perma.cc/4X42-9SX3].

101. Researchers have observed that the current "patchwork of services and eligibility policies" is confusing, not well coordinated, and can lead to impeded access to services; fundamentally these legal and administrative complexities "complicate the task of designing a more rational and efficient system of LTSS." MACPAC LTSS REPORT, *supra* note 40, at 61–62. *See also* ASPE HANDBOOK, *supra* note 24, at 2 ("Because of the great flexibility afforded states in program design, there are essentially 51 unique state Medicaid programs.").

of Ms. Reilly, even if she does not have the cognitive capacity to hire and fire her caregiver. Or K.R. could be seen as a third-party beneficiary of a contract between the state agency (or its contractor) and Ms. Reilly. In addition, Ms. Reilly might be treated as an employee (of K.R., the state, or a contracted entity), or she might be treated as an independent contractor.

Although it was prompted in part by the desire to center the beneficiary and return some autonomy to people with disabilities, many of whom had previously been institutionalized, the legal and administrative complexity of government in-home care programs will prove to be a significant obstacle to providing uniform tax treatment for family caregivers. Part II of this essay explores these obstacles, and the relationship between tax policy, tax administration, and family caregiving, through the example of the § 131 difficulty of care exclusion.

II. AT THE INTERSECTION OF TAXATION AND CAREGIVING: THE "DIFFICULTY OF CARE" GROSS INCOME EXCLUSION

Parallel to the health care policy and disability rights story recounted above, we find a tax story.[102] As disability advocates were pushing for more community programs and greater involvement in decision-making regarding their care, the tax system was also changing.

This Part first describes the origins of the difficulty of care exclusion. Second, this Part reveals the changing impact of the exclusion on caregivers in the four decades following its enactment. Third, this Part reviews a series of attempts to apply the difficulty of care exclusion both to our contemporary system of disability supports and to family caregivers.

A. Early Development and Codification of the "Foster Care" Gross Income Exclusion

The difficulty of care exclusion grew out of the child foster care system. In addition to "standard" foster payments, some states provided additional payments to foster parents of children with disabilities who required special caregiving time and effort.[103] While we do not know the precise rationale for each program, it appears that in some cases payments were seen as an incentive to recruit needed foster families.[104] Payments

102. The line between health policy and tax is already somewhat blurred, as the developments examined in Section I.C., *supra*, show.

103. *See* James D. Culley et al., *Public Payments for Foster Care*, 22 SOC. WORK 219, 221 (1977) (showing wide variability among states and sometimes within states of payment rates and factors influencing payment rates, such as special mental or physical health needs).

104. *See* Alice Bussiere, *Federal Adoption Assistance for Children with Special Needs*, 19

may also have been in recognition of the time and of the physical, mental, and emotional labor that caregiving requires.

Since at least 1952, the IRS has provided guidance on the tax treatment of state payments to foster parents.[105] On the theory that the payments reimburse foster parents for the expenses incurred as a result of taking in a foster child, the IRS opined that foster payments are not gross income except to the extent they exceed foster care expenses.[106]

This guidance left foster parents vulnerable to an audit, where they would have to account for all their expenses connected with a foster child in order to exclude the payments from their income. In the 1970s, the IRS audited several of these foster care parents in the state of Minnesota.[107] In response to these audits, Senator David Durenberger proposed what is now § 131 of the Internal Revenue Code, creating an exclusion from gross income for certain foster care payments. On the floor of the Senate, Senator Durenberger decried the negative publicity from the audits as "damaging to the cause of foster care—they have a chilling effect on those considering being a foster parent of a handicapped child."[108] He went on to explain the legislation:

> With this bill the Senate is declaring that these payments made to foster care parents over and above those payments made for nonhandicapped children are not income to the parents, regardless of whether they, dollar for dollar only cover expenses. [These] parents are saving the taxpayers' money by preventing institutionalization of these children. But more importantly, they are providing a sense of belonging, a sense of love and family to society's most vulnerable children—those with handicaps but without parents to provide them this love.[109]

As initially enacted, § 131 created an exclusion from gross income for two categories of foster care payments: (1) payments made to reimburse foster parents for expenses, and (2) "difficulty of care payments"—compensation for providing additional care required by reason of the foster child's disability.[110] The original § 131 only applied to minor

---

CLEARINGHOUSE REV. 587, 587–88 (1985) (describing the financial demand of caring for a child with special needs as an impediment to adoption of foster children with disabilities). *See also* 128 Cong. Rec. S26905 (daily ed. Oct. 1, 1982) (statement of Sen. Durenberger).

105. *See* I.T. 4068, 1952-1 C.B. 7 § 22(a) (restated in Rev. Rul. 77-280, 1977-2 C.B. 14) (advising that where reimbursements to foster parents do not exceed expenses, "neither the expenditures nor the reimbursements need be reflected in the foster parents' Federal income tax returns").

106. *Id.*

107. *See* 128 Cong. Rec. S26905 (daily ed. Oct. 1, 1982) (statement of Sen. Durenberger) (noting IRS audits of families examined whether payments were to cover expenses or compensate for services).

108. *See id*.

109. *Id.*

110. Pub. L. No. 97-473, § 131, 96 Stat. 2605, 2606–07 (1983).

foster children. Also, if a foster parent were audited, they[111] would still need a detailed accounting of expenses for any foster payments not designated by the state or foster care agency as "difficulty of care" payments.[112]

However, within a few years, Congress amended the statute as part of the Tax Reform Act of 1986, eliminating the documentation requirements and extending the gross income exclusion to "adult foster care" in community settings with up to five care recipients.[113] The conference committee report succinctly explains:

> The conferees intend that this extension of the exclusion to adult foster care is limited to cases of individuals who provide foster care within their own homes to adults who have been placed in their care by an agency of the State or political subdivision thereof specifically designated as responsible for such function.[114]

This history of § 131 supports the interpretation that its purpose was to encourage community care of individuals with disabilities. However, the exclusion for "difficulty of care" payments was clearly built on the child foster care framework. Section 131 merely extends that framework to programs supporting in-home care of adults with disabilities. Because of the initial focus on foster care, it is unclear whether Congress anticipated providing any benefit to the biological parents of adults with disabilities. The legislative history also lacks any indication of whether Congress recognized the potential impact of the gross income exclusion on caregivers' ability to claim refundable tax credits, which Congress had recently begun to employ.[115] Both of these issues became important to individuals with disabilities and their caregivers as tax and health care law and administration changed in the ensuing decades.

B. Impact of Gross Income Exclusions Then and Now

1. The Evolution of Social Benefit Programs Toward Administration Through the Tax Code

When the difficulty of care exclusion was created, it was likely in most caregivers' interests to have an exclusion from gross income.[116] Since

111. This Essay intentionally utilizes the gender-neutral singular pronouns, *they* and *them*.

112. *See* § 131, 96 Stat. at 2606–07.

113. Tax Reform Act of 1986, Pub. L. No. 99-514, § 1707, 100 Stat. 2085, 2781–82.

114. H.R. REP. NO. 99-841, at II-838–39 (1986) (Conf. Rep.), *as reprinted in* 1986 U.S.C.C.A.N. 4075, 4927.

115. *See* Lily L. Batchelder et al., *Efficiency and Tax Incentives: The Case for Refundable Tax Credits*, 59 STAN. L. REV. 23, 25 (2006).

116. Except, perhaps, for caregivers who lacked sufficient Social Security credits to receive Social Security and Medicare benefits. Technically, income tax liability is independent of liability for Social Security and Medicare taxes. That is, one can be obligated to pay employment taxes on

then however, the impact of a gross income exclusion has changed, as Congress has significantly increased the menu and generosity of income-based refundable credits available through the federal income tax system.[117] The decision to structure refundable credits to benefit those with income would become a key factor in the dispute over the difficulty of care exclusion.

For tax year 1986, the earned income tax credit (EITC) provided a maximum benefit of $800, and a taxpayer received the maximum benefit with $5,714 of annual earned income.[118] In the late 1990s and even more in the 2000s, Congress began to shift the bulk of our nation's public benefits from direct social benefit programs administered by benefit agencies to the tax system.[119] Welfare and food stamp benefits were cut severely, as "welfare to work" and the "contract with America" became

payments that are excluded from gross income under § 61. *See* I.R.C. § 3121(a) (defining wages for purposes of FICA tax under § 3101); *IRS § 131 FAQ*, *supra* note 85. However, in practice employment taxes are not always properly paid if the income is not taxable, perhaps because of confusion over the legal requirements. *See, e.g.*, McLellan & Tripp, *supra* note 85, at 229 n.19 (apparently misreading IRS website FAQ, *IRS § 131 FAQ*, *supra* note 85). Lack of Social Security and Medicare payments contributes to the impoverishment of family caregivers, as they may not qualify for retirement, disability, or medical benefits later in life. Kaplan, *Family Caregiving*, *supra* note 16, at 630–31.

117. *See* Batchelder et al., *supra* note 115, at 25 ("Prior to 1975, all individual tax incentives were structured as deductions or exclusions or, occasionally, as non-refundable tax credits. Today refundable credits are more widespread, accounting for about 18% of the roughly $500 billion in tax incentives."); Susannah Camic Tahk, *The New Welfare Rights*, 83 BROOK. L. REV. 875, 876–77 (2018) [hereinafter Tahk, *New Welfare Rights*]; *see also* Susannah Camic Tahk, *Everything Is Tax: Evaluating the Structural Transformation of U.S. Policymaking*, 50 HARV. J. ON LEGIS. 67, 70 (2013).

118. Tax Reform Act of 1986, Pub. L. No. 99-514, § 111, 100 Stat. 2085, 2107. *See also* GENE FALK, CONG. RSCH. SERV., RL31768, THE EARNED INCOME TAX CREDIT (EITC): AN OVERVIEW 16 (2014). For reference, $800 in 1986 is about $1,837 in 2019 dollars, and $5,714 in 1986 is about $13,446 in 2019 dollars. *CPI Inflation Calculator*, U.S. BUREAU LAB. STAT., https://www.bls.gov/data/inflation_calculator.htm [https://perma.cc/2WDR-6QS6] (last visited Dec. 27, 2020). In contrast, for tax year 2019 both the maximum EITC available and the maximum income level were much higher. *See infra* notes 127–130 and accompanying text.

119. *See* Tahk, *New Welfare Rights*, *supra* note 117, at 878–79. *See also* MARGOT L. CRANDALL-HOLLICK, CONG. RSCH. SERV., R44825, THE EARNED INCOME TAX CREDIT (EITC): A BRIEF LEGISLATIVE HISTORY 6 (2018), https://fas.org/sgp/crs/misc/R44825.pdf, [https://perma.cc/HY6J-KS96] (showing growth in EITC dollar amounts and recipients over time).

catchphrases.[120] In contrast, refundable tax credits grew substantially.[121] Consistent with the "welfare to work" philosophy that partially motivated the expansion of refundable credits, Congress generally requires taxpayers to have "earned income" in order to qualify for (and to maximize) refundable credits.[122]

The shift to providing economic supports to low-income individuals and families through the tax code has been decried by some,[123] but others have pointed to benefits including efficiency and increased labor market participation by low-income single mothers.[124] The earned income tax credit has been described as the "single most effective means tested

120. *See* NEWT GINGRICH ET AL., CONTRACT WITH AMERICA: THE BOLD PLAN BY REP. NEWT GINGRICH, REP. DICK ARMEY AND THE HOUSE REPUBLICANS TO CHANGE THE NATION 66–67 (Ed Gillespie & Bob Schellhas eds., 1994) (outlining the key changes, including the restructuring of benefits programs, introduced in the Personal Responsibility and Work Opportunity Reconciliation Act—which, at the time, had yet to pass Congress); Kathleen Kost & Frank W. Munger, *Fooling All of the People Some of the Time: 1990s Welfare Reform and the Exploitation of American Values*, 4 VA. J. SOC. POL'Y & L. 3, 24–27 (1996) (discussing "welfare to work" programs and generally criticizing welfare reforms proposed in the 1990s). *See, e.g.*, Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, 110 Stat. 2105 (exemplifying the 1990s shift toward ending the "entitlement" status of welfare benefits by implementing work requirements and similar restrictions).

121. *Earned Income Tax Credit Overview*, NAT'L CONF. ST. LEGIS. (July 15, 2020), https://www.ncsl.org/research/labor-and-employment/earned-income-tax-credits-for-working-families.aspx [https://perma.cc/FT22-9MQ6]. In addition to the federal benefit, thirty states now offer their own EITC. *Id*. *See also* CRANDALL-HOLLICK, *supra* note 119, at 6 (tracking the significant growth of the number of EITC recipients since inception through 2015).

122. *See* I.R.C. § 32(c)(2) (defining "earned income" for the taxable year as "wages, salaries, tips, and other employee compensation" includible in gross income plus any "net earnings from self-employment"); *see, e.g.*, I.R.C. § 24 (considering earned income when calculating the refundable portion of the child tax credit). *See also* Elaine Maag, *Refundable Credits: The Earned Income Tax Credit and the Child Tax Credit*, TAX POL'Y CTR. 1–2 (Mar. 23, 2017), https://www.taxpolicycenter.org/publications/refundable-credits-earned-income-tax-credit-and-child-tax-credit/full [https://perma.cc/6BFW-5LMA]; *Value of Child Benefits at Various Income Levels, 2010*, TAX POL'Y CTR. (Aug. 2, 2010), https://www.taxpolicycenter.org/statistics/value-child-benefits-various-income-levels-2010 [https://perma.cc/LQ2P-ZABD] (showing that refundable benefits were maximized around $20,000 in earnings).

123. *See, e.g.*, Steve Johnson, *The 1998 Act and the Resources Link Between Tax Compliance and Tax Simplification*, 51 U. KAN. L. REV. 1013, 1051–52 (2003); Michael J. Graetz, *100 Million Unnecessary Returns: A Fresh Start for the U.S. Tax System*, 112 YALE L.J. 261, 274, 280–81 (2002).

124. *See, e.g.*, Chuck Marr et al., *EITC and Child Tax Credit Promote Work, Reduce Poverty, and Support Children's Development, Research Finds*, CTR. ON BUDGET & POL'Y PRIORITIES (Oct. 1, 2015), https://www.cbpp.org/research/federal-tax/eitc-and-child-tax-credit-promote-work-reduce-poverty-and-support-childrens [https://perma.cc/J99V-JY97] [hereinafter Marr et al., *EITC & CTC*]; Chuck Marr et al., *Expanding Child Tax Credit and Earned Income Tax Credit Would Benefit More Than 10 Million Rural Residents, Strongly Help Rural Areas*, CTR. ON BUDGET & POL'Y PRIORITIES (Aug. 6, 2020), https://www.cbpp.org/research/federal-tax/expanding-child-tax-credit-and-earned-income-tax-credit-would-benefit-more-than [https://perma.cc/4PVH-TFLR]. *See also* Batchelder et al., *supra* note 115, at 27 ("[U]niform refundable credits represent the most efficient type of tax incentive . . . .").

federal antipoverty program for working-age households . . . ."[125] This credit can result in significantly negative income tax liability for low-income families with earned income.[126]

For tax year 2019, the average EITC benefit was $2,476, and the maximum benefit was $6,557.[127] The EITC steeply increases with earned income, and then phases out for higher income earners. To maximize the 2019 EITC, a single parent with one qualifying child[128] would report earned income of between $10,370 and $19,030.[129] A married couple with three qualifying children receives the maximum 2019 EITC of $6,557 with earned income between $14,570 and $24,820.[130] The child tax credit is also tied to earned income, providing no benefit at the very lowest income levels.[131]

Today, it is possible for a low-income worker to have a lower effective tax rate with gross income than without it.[132] An exclusion from gross

125. *How Does the Earned Income Tax Credit Affect Poor Families?*, TAX POL'Y CTR., https://www.taxpolicycenter.org/briefing-book/how-does-earned-income-tax-credit-affect-poor-families [https://perma.cc/WAR8-DPSF] (last visited Jan. 21, 2021). *See also* U.S. H.R. COMM. ON THE BUDGET, DEMOCRAT CAUCUS, 115TH CONG., THE EARNED INCOME TAX CREDIT BOOSTS WORK, REDUCES POVERTY, AND PROVIDES OTHER BENEFITS FOR WORKING AMERICANS 1 (Comm. Print. 2018), https://budget.house.gov/publications/report/earned-income-tax-credit-boosts-work-reduces-poverty-and-provides-other-benefits [https://perma.cc/GF8H-CWVX] (citing CRANDALL-HOLLICK, *supra* note 119).

126. *See Federal Returns with EITC*, TAX POL'Y CTR. (Oct. 15, 2020), https://www.taxpolicycenter.org/statistics/federal-returns-eitc [https://perma.cc/XX9J-G77A].

127. *Statistics for 2019 Tax Returns with EITC*, IRS, https://www.eitc.irs.gov/eitc-central/statistics-for-tax-returns-with-eitc/statistics-for-2019-tax-returns-with-eitc [https://perma.cc/2NUN-P8V5] (last visited Feb. 12, 2021); *Earned Income and Earned Income Tax Credit (EITC) Tables*, IRS, https://www.irs.gov/credits-deductions/individuals/earned-income-tax-credit/earned-income-tax-credit-income-limits-and-maximum-credit-amounts [https://perma.cc/4YMV-REC7] (last visited Dec. 6, 2020).

128. Ms. Reilly is one such taxpayer. A son or daughter who is permanently and totally disabled may be a qualifying child for the EITC at any age. I.R.C. § 32(c)(1)(A)(i) (predicating one option for eligibility for the EITC on having a "qualified child"); § 152(c)(3)(B) (waiving the "qualified child" age requirements for individuals who are permanently and totally disabled).

129. *See Policy Basics: The Earned Income Tax Credit*, CTR. ON BUDGET & POL'Y PRIORITIES (Dec. 10, 2019), https://www.cbpp.org/research/federal-tax/policy-basics-the-earned-income-tax-credit [https://perma.cc/XG4Z-XNNA]. The maximum 2019 EITC for this taxpayer is $3,526. *Id.*

130. *Id.* The Feighs are one such family. *See infra* notes 184–189 and accompanying text.

131. *See* Maag, *supra* note 122, at 3 ("Those with earnings under $3,000 cannot get any ACTC, while others have too little earnings to get the full credit."). Congress has changed the income threshold several times, but as of February 2021, it has never been zero. This may change with the 2021 economic stimulus bill. *See* Jason DeParle, *In the Stimulus Bill, a Policy Revolution in Aid for Children*, N.Y. TIMES (Mar. 7, 2021), https://www.nytimes.com/2021/03/07/us/politics/child-tax-credit-stimulus.html [https://perma.cc/658Z-UTQU].

132. *See T17-0124—Tax Benefit of the Earned Income Tax Credit, Baseline: Current Law, Distribution of Federal Tax Change by Expanded Cash Income Level, 2017*, TAX POL'Y CTR. (Apr. 18, 2017), https://www.taxpolicycenter.org/model-estimates/individual-income-tax-expenditures-april-2017/t17-0124-tax-benefit-earned-income-tax [https://perma.cc/N9A3-DAZM].

income is no longer necessarily a benefit. To the extent § 131's exclusion is intended as a benefit or a behavioral incentive, subsequent changes to the rest of the tax code now undermine that purpose for some taxpayers.

2. The Affordable Care Act Connects the Tax Code to Health Insurance Eligibility

When considering the changing landscape of social welfare programs between 1980 and 2020, it is impossible to overstate the importance of the Affordable Care Act.[133] The ACA effected broad changes to national health care policy, touching every aspect of the health care system from Medicaid to private employer-sponsored insurance. Its policies are effected through a range of carrots and sticks under the purview of several federal agencies.[134] Two ACA developments are particularly important for family caregivers: (1) changes to the Medicaid program and (2) the creation of Marketplaces for individuals to purchase subsidized health insurance.

The ACA made two major changes to the Medicaid program, effective in 2014. First, it created a new eligibility category for poor adults.[135] This is the "Medicaid expansion." Previously, nondisabled nonelderly adults without minor children (like Ms. Reilly) were not eligible for Medicaid, no matter how poor they were.[136]

The second major change the ACA made to Medicaid was to revise how financial eligibility is calculated for most children and adults.[137] For

133. The fate of the ACA is currently in doubt; the Fifth Circuit Court of Appeals struck down the individual mandate and with it the entire statute, and the Supreme Court is considering the case on appeal. *See* Texas v. United States, 945 F.3d 355 (5th Cir. 2019), *cert. granted sub nom.* California v. Texas, 140 S. Ct. 1262 (2020).

134. Samantha Galvin & Christine Speidel, *Understanding the Affordable Care Act and Its Impact on Low-Income Taxpayers*, *in* EFFECTIVELY REPRESENTING YOUR CLIENT BEFORE THE IRS, 29-6 (T. Keith Fogg ed., 7th ed. 2018) ("The ACA includes carrots as well as sticks. Positive incentives for consumers to get coverage include an expansion of the Medicaid program and subsidies available for insurance plans purchased through the exchanges. Small businesses also have access to a tax credit for providing insurance to their employees. . . . The implementation of the ACA requires participation from many different federal agencies, including HHS, the Department of Labor (DOL), and the Department of the Treasury. State insurance departments continue to have a role as well."); *see also* Brian Galle, *The Tragedy of the Carrots: Economics & Politics in the Choice of Price Instruments*, 64 STAN. L. REV. 797, 805 (2012).

135. Patient Protection and Affordable Care Act (PPACA), § 2001(a), 42 U.S.C. § 1396a(a)(10)(A)(i)(VIII).

136. *See supra* note 95 and accompanying text.

137. *See* PPACA § 2002, 42 U.S.C. § 1396a(e)(14). *See also* MaryBeth Musumeci, *The Affordable Care Act's Impact on Medicaid Eligibility, Enrollment, and Benefits for People with Disabilities*, KAISER FAM. FOUND. (Apr. 2014), https://www.kff.org/wp-content/uploads/2014/04/8390-02-the-affordable-care-acts-impact-on-medicaid-eligibility.pdf [https://perma.cc/9U7B-SVFJ]. The basic Medicaid financial eligibility framework for individuals with disabilities was unchanged by the ACA. The new rules do not apply to individuals who qualify for Medicaid based on old age or disability. *See* PPACA § 2002, 42 U.S.C. § 1396a(e)(14).

the new expansion population, Medicaid financial eligibility is now based on a person's adjusted gross income (AGI) under § 62 of the Internal Revenue Code, with a few modifications.[138] Therefore, gross income exclusions now directly influence one's eligibility for health insurance. Before the ACA, Medicaid had very different income eligibility rules, which were not aligned with considerations of income for tax purposes.[139] For many categories of eligible individuals, including newly eligible poor adults, access to Medicaid is now tied to the federal income tax return in a way that it never was before.

The ACA works a similar effect for middle-income adults. The law created Health Insurance Marketplaces in each state, which provide a venue for individuals to purchase private insurance.[140] The plans are subsidized on a sliding scale through two mechanisms: by advance payments of the premium tax credit,[141] and by cost-sharing reductions for lower-income consumers.[142] The premium tax credit benefits individuals whose income is not low enough to qualify for Medicaid, but who do not have medical insurance available through an employer.[143] As Marketplace insurance is subsidized through the federal income tax system, it also uses modified AGI as its measure of financial eligibility.[144] Thus, for both very low-income and moderate-income adults, having a

138. *Id.*; 42 C.F.R. § 435.603(e) (2019).

139. *See* ASPE HANDBOOK, *supra* note 24, at 35 (explaining the concept and rules for countable income and resources); *see generally* SCHNEIDER ET AL., *supra* note 95, at 5–41.

140. PPACA § 1311, 42 U.S.C. § 18031; 45 C.F.R. § 155.20. Statutes and regulations use the term "exchange," but in communications with the general public, the government uses the term "marketplace." *See*, *e.g.*, HEALTHCARE.GOV, www.healthcare.gov [https://perma.cc/EF8D-7R6N] (last visited Jan. 21, 2021); I.R.S. Pub. 974 (Nov. 20, 2019) (discussing the Premium Tax Credit). The terms are synonymous.

141. PPACA § 1401, I.R.C. § 36B. For an analysis and critique of the Premium Tax Credit, see Mary Leto Pareja, *Inviting Everyone to the ACA (Risk) Pool Party: Using Advanceable, Income-Based Tax Credits to Subsidize Purchases*, 20 FLA. TAX REV. 551 (2017).

142. PPACA § 1402, 42 U.S.C. § 18071. *See generally* Lawrence Zelenak, *Choosing Between Tax and Nontax Delivery Mechanisms for Health Insurance Subsidies*, 65 TAX L. REV. 723 (2012).

143. I.R.C. § 36B(b)(2). Premium Tax Credits are available to consumers with income up to 400% of the federal poverty line. I.R.C. § 36B(c)(1)(A). Note that the ACA refers to the "poverty line," but HHS prefers the term "poverty guidelines." *See Frequently Asked Questions Related to the Poverty Guidelines and Poverty*, DHHS: ASPE, http://aspe.hhs.gov/frequently-asked-questions-related-poverty-guidelines-and-poverty [https://perma.cc/EB94-KLSQ] (last visited Feb. 5, 2021). The poverty guidelines are available at *HHS Poverty Guidelines for 2021*, DHHS: ASPE, https://aspe.hhs.gov/poverty-guidelines [https://perma.cc/5G7G-JB2G] (last visited Feb. 5, 2021).

144. I.R.C. § 36B(d)(2)(B); Treas. Reg. § 1.36B-1(e)(2) (2020); 42 U.S.C. § 18071. *See also* NAT'L HEALTH L. PROGRAM, THE ADVOCATE'S GUIDE TO MAGI 3 (2018), http://www.healthlaw.org/publications/browse-all-publications/agmagi [https://perma.cc/62QN-LWU6] ("MAGI has two principal components: income counting and household composition. First, MAGI counts income according to federal tax law. Second, MAGI rules determine household composition and family size, with different rules applying in Marketplaces and Medicaid."). Galvin & Speidel, *supra* note 134, at 17.

low AGI is now a pathway to affordable health insurance.[145]

For some caregivers, this could be a lifesaving result. Access to affordable health insurance is more than a perk. For example, having affordable insurance with low out-of-pocket costs can allow a person with diabetes to manage their condition and avoid extremely serious health complications.[146] It is important to note that Medicaid requires much lower cost-sharing than Marketplace plans do.[147] Partially due to the low costs imposed on participants, it appears the Medicaid expansion "has improved access to care, utilization of services, the affordability of care, and financial security among the low-income population."[148] Financially,

145. There is a significant exception to this statement for very low-income adults in the twelve states that have not yet adopted the Medicaid expansion. In those states, access to health insurance through Medicaid is not available for adults like Ms. Reilly. Because the ACA presumed that all states would expand Medicaid coverage, Premium Tax Credit eligibility does not start until one's income is at least 100% of the FPL. *See* I.R.C. § 36B(c)(1)(A). Therefore, a low-income caregiver in a non-expansion state would prefer to have higher gross income to increase their chance of qualifying for affordable Marketplace coverage.

146. One study found a significant rise in preventative care such as immunizations, blood pressure and cholesterol screenings, and mammograms following the ACA's implementation, particularly among low-income women. Carol Potera, *Women Benefit from the Affordable Care Act*, AM. J. NURSING, July 2019, at 15, 15.

147. *See* Sherry A. Glied et al., *How Medicaid Expansion Affected Out-of-Pocket Health Care Spending for Low-Income Families*, COMMONWEALTH FUND (Aug. 22, 2017), https://www.commonwealthfund.org/publications/issue-briefs/2017/aug/how-medicaid-expansion-affected-out-pocket-health-care-spending [https://perma.cc/VB6F-K4JA] ("Medicaid coverage in most states requires low or no premiums, deductibles, or copayments. In expansion states that have adopted traditional Medicaid, as well as in most waiver states, premiums and cost-sharing may total to no more than 5 percent of income."). *See also* Sophie Beutel et al., *How Much Financial Protection Do Marketplace Plans Provide in States Not Expanding Medicaid?*, COMMONWEALTH FUND (June 16, 2016), https://www.commonwealthfund.org/publications/issue-briefs/2016/jun/how-much-financial-protection-do-marketplace-plans-provide [https://perma.cc/V3Q4-68ET]; *Cost Sharing*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/cost-sharing/index.html [https://perma.cc/PNT6-ATXD] (last visited Feb. 5, 2021) (noting that states can establish limited cost-sharing requirements for some Medicaid enrollees). In contrast, the Marketplace out-of-pocket maximum for an individual with 2020 self-only coverage ranged from $8,150 to $2,700, depending on the individual's income. *See* Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2020, 84 Fed. Reg. 17,454, 17,541–42 (Apr. 25, 2019). This out-of-pocket maximum is in addition to the monthly premium that consumers must pay for a Marketplace plan. For 2020 marketplace plans, an affordable premium was defined as costing no more than 9.78% of income. Rev. Proc. 2019-29, 2019-32 I.R.B. 620. *See also Average Marketplace Premiums by Metal Tier, 2018-2021*, KAISER FAM. FOUND., https://www.kff.org/health-reform/state-indicator/average-marketplace-premiums-by-metal-tier/ [https://perma.cc/Y2ZW-KXYN] (last visited Feb. 5, 2021) (tracking average monthly Marketplace premiums across states and tiers).

148. MADELINE GUTH ET AL., KAISER FAM. FOUND., THE EFFECTS OF MEDICAID EXPANSION UNDER THE ACA: UPDATED FINDINGS FROM A LITERATURE REVIEW 2 (2020), https://www.kff.org/medicaid/report/the-effects-of-medicaid-expansion-under-the-aca-updated-findings-from-a-literature-review/ [https://perma.cc/7UFW-3UWG]. *See also* Dalia Sofer, *Low-Income Adults Report Better Health, Other Benefits, with the ACA*, AM. J. NURSING, Aug. 2017, at 14, 14; Matthew Buettgens, Fredric Blavin & Clare Pan, *The Affordable Care Act Reduced Income Inequality in the US*, HEALTH AFFS. (Jan. 5, 2021), https://www.healthaffairs.org/doi/10.1377/hlthaff.2019.00931 [https://perma.cc/SFU8-5WB5].

a caregiver like Ms. Reilly would be much better off forgoing her $171 EITC[149] in order to qualify for Medicaid through the gross income exclusion of her caregiving wages.[150]

C. Attempts to Expand the Difficulty of Care Exclusion to Family Caregivers

Prior to 2014, case law[151] and IRS guidance[152] were uniform in denying a gross income exclusion to taxpayers caring for their adult family members with disabilities. The IRS asserted that biological or adoptive parents could not be "foster" parents or provide "foster care" as a matter of ordinary meaning, and therefore the plain language of § 131 bars these caregivers from the exclusion.[153] In addition, the IRS argued that self-directed in-home care programs were not "foster care programs" under § 131.[154] In the case of *Alexander v. Commissioner*, the U.S. Tax Court agreed.[155]

Mr. and Mrs. Alexander attempted to exclude payments from the Washington State Medicaid Personal Care program, which they received as caregivers for Mr. Alexander's elderly parents, Konstantin and

149. *See infra* note 197.

150. *See also* Jennifer Lav, *Top 10 Threats to People with Disabilities Under Graham-Cassidy ACA Repeal Bill*, NAT'L HEALTH L. PROGRAM (Sept. 19, 2017), https://healthlaw.org/resource/top-10-threats-to-people-with-disabilities-under-the-graham-cassidy-bill [https://perma.cc/7DSU-87U6] ("[T]he home care workers that actually provide HCBS for individuals with disabilities often rely on Medicaid for their own care. One-in-three home care workers live in households that qualify for Medicaid expansion. Medicaid expansion indirectly supports individuals with disabilities by making health care available to their parents and the workers who provide HCBS.").

151. Case law on § 131 is sparse. There is only one case precisely on point, *Alexander v. Commissioner*, T.C. Summ. Op. 2011-48, 2011 WL 1422015 (2011), and there are two Tax Court cases in which parental caregivers argued unsuccessfully for the general welfare exclusion: *Bannon v. Commissioner*, 99 T.C. 59 (1992) and *Harper v. Commissioner*, T.C. Summ. Op. 2011-56 (2011). *See also* John C. Zimmerman, *Excluding Qualified Foster Care Payments from Income*, 93 PRAC. TAX STRATEGIES 112, 114–15 (2014).

152. *See* I.R.S. PMTA 2010-07 (Mar. 29, 2010), https://www.irs.gov/pub/lanoa/pmta_2010-07.pdf [https://perma.cc/NQV6-ADVE]. No final regulations have been promulgated under § 131. Proposed regulations were published in 1985, but they were soon out of date due to 1986 statutory amendments and were never finalized. *See* Exclusion from Gross Income for Certain Foster Care Payments, 50 Fed. Reg. 4,702, 4,702 (Feb. 1, 1985).

153. PMTA 2020-007, *supra* note 152.

154. *Alexander*, T.C. Summ. Op. 2011-48, 2011 WL 1422015 at *4. The government generally took a strict approach to the statutory language prior to 2014. For example, in *Micorescu v. Commissioner* the government argued, and the Tax Court held, that payments made by a for-profit company contracted by the state to administer its caregiving program did not qualify for the exclusion. 76 T.C.M. (CCH) 796, 802 (1998). Congress subsequently amended § 131 to permit the use of for-profit agencies. *See* STAFF OF THE JOINT COMM. ON TAXATION, 108TH CONG., GENERAL EXPLANATION OF TAX LEGISLATION ENACTED IN THE 107TH CONGRESS 243 (Comm. Print 2003).

155. *Alexander*, T.C. Summ. Op. 2011-48, 2011 WL 1422015 at *4.

Tatiana.[156] Under this program, Konstantin and Tatiana had chosen to remain at home, living independently with assistance from their chosen caregivers, their son and daughter-in-law. Konstantin and Tatiana were considered the employers of Mr. and Mrs. Alexander under the state program, although an agency paid the Alexanders with Medicaid funds.[157]

The court found this self-directed arrangement inconsistent with a foster care relationship, and particularly inconsistent with § 131's requirement that the care recipient be "placed by . . . an agency" in the care provider's home. The *Alexander* opinion highlights the jarring contrast between Medicaid's promotion of independence and self-direction for adults who need care to live independently, and the entirely passive foster care framework of § 131.

In early January 2014, one court rejected the IRS's relationship-based argument, acknowledging that the plaintiff, a caregiver mother, "could have let [her son] become a ward of the state when he turned age 18."[158] However, the court then ruled against the mother on the grounds that she had become her son's legal guardian, and thus she had a legal duty to provide for his care under state law.[159] Shortly after the government won this decision, it reversed course with Notice 2014-7.[160]

1. IRS Notice 2014-7

In early 2014, perhaps not coincidentally around the time the ACA was being implemented and as Congress was considering the creation of ABLE accounts,[161] the IRS issued subregulatory guidance applying § 131's difficulty of care exclusion to Medicaid's HCBS waiver program under section 1915(c) of the Social Security Act.[162] In a major interpretive shift, Notice 2014-7 concludes that parents of adults with

156. *Id.* at *1.

157. *See supra* notes 85–94 and accompanying text (discussing administration options and Notice 2003-70).

158. Ray v. United States, 933 F. Supp. 2d 760, 768 (S.D. Ohio 2014). The government had argued that the existence of a blood relationship between mother and son "is what eliminates it from being a foster care relationship . . . ." *Id*. at 766.

159. *Ray*, 933 F. Supp. 2d at 767.

160. As a result, the Rays' motion to alter or amend the judgment was granted, and they were awarded a refund of $31,880 in taxes they had paid for 2006 and 2007, plus interest. Ray v. United States, No. 2:12-cv-677, 2014 WL 12852321 at *1 (S.D. Ohio Feb. 11, 2014). The record does not reflect the Rays' health insurance status, but the reversal would have qualified them for significantly reduced health insurance costs as well, if they did not have access to other insurance.

161. ABLE accounts are tax-advantaged savings accounts held for the benefit of individuals with disabilities. These accounts may counteract to some extent the impoverishment of people with disabilities who must qualify for public benefits to receive adequate care. *See* Hoffer, *supra* note 28, at 1261 (explaining ABLE accounts and their importance for people with disabilities).

162. I.R.S. Notice 2014-7, 2014-4 I.R.B. 445, 446. The IRS did not seek public comment before the notice was issued.

disabilities receiving caregiving payments through HCBS fall within the difficulty of care exclusion. The IRS further decided that the "home" in question could be owned by the care recipient, as opposed to solely by the caregiver.[163]

The IRS based its decision on the purpose and design of the programs, reasoning that HCBS serves the same function today as adult foster care programs did in the early 1980s.[164] The purpose and function of the program trumped the "foster care" label in the eyes of tax administrators.

This subregulatory guidance raised new possibilities for caregivers to benefit from the gross income exclusion. Notice 2014-7 was publicized by health care advocates who saw it as a means for family caregivers to obtain affordable health care through the ACA.[165] The § 131 income exclusion meant that caregivers were more likely to qualify for Medicaid or for lower Marketplace premiums and cost-sharing subsidies.[166]

Unfortunately for caregivers eager to claim the exclusion, Notice 2014-7 is specific to HCBS waiver programs authorized under section 1915(c) of the SSA.[167] The Notice thus left many unanswered questions for caregivers receiving payments under other Medicaid and state law programs.[168] The complexity of Medicaid was a significant stumbling

163. *Id.*

164. *Id.* ("Under state foster care programs, a state . . . may assist in locating a home that meets the qualified foster individual's needs, negotiate or approve the foster care payment rates, and contract with the foster care providers for the provision of foster care. . . . States perform similar activities with respect to individuals participating in Medicaid waiver programs. Under a Medicaid waiver program, a state . . . may assist in locating a home for an eligible individual or approve the eligible individual's choice to reside in the individual care provider's home, approve an eligible individual's plan of care, assess the suitability of the home for fulfilling the eligible individual's plan of care, and enter into a contract or other arrangement with the individual care provider for services provided to the eligible individual.").

165. *See, e.g.*, WAYNE TURNER & MICHELL LILIENFELD, NAT'L HEALTH L. PROGRAM, LESSONS FROM CALIFORNIA: HCBS PAYMENTS TO CAREGIVERS AND MAGI (2016), https://healthlaw.org/resource/lessons-from-ca-hcbs-payments-to-caregivers-and-magi/ [https://perma.cc/KN5D-N6FS]; WAYNE TURNER, NAT'L HEALTH L. PROGRAM, FACT SHEET: IRS UPDATED GUIDANCE ON HOME AND COMMUNITY BASED SERVICES AND EXCLUDING 'DIFFICULTY OF CARE' PAYMENTS FROM GROSS INCOME 4 (2016), http://procedurallytaxing.com/wp-content/uploads/2019/02/NHeLP-Factsheet-on-exclusion-of-difficulty-of-care-payments-Final-4.9.15.pdf [https://perma.cc/8MPT-PL7J].

166. The exception, as noted above, is for individuals in non-expansion states whose gross income is under 100% FPL. *See supra* note 142 and accompanying text.

167. Even the term HCBS is not limited to programs under SSA section 1915(c). *See, e.g.*, MACPAC LTSS REPORT, *supra* note 40, at 42 (explaining that after the ACA's amendments to the SSA, states can "provide HCBS under the Medicaid state plan without obtaining a waiver under Section 1915(c)"); *id.* at 47, 51–52 (listing and describing various Medicaid pathways available to states to provide long-term services and supports in the community).

168. *See* Christine Speidel, *Information Letter Shows Need for Broader Guidance on Difficulty*

block to uniform implementation of the IRS's interpretive change. Two states submitted requests for IRS letter rulings[169] and received blessings to apply the difficulty of care exclusion to their in-home care programs in addition to their section 1915(c) programs.[170] For example, California requested guidance on four additional programs for in-home supportive care: three operated under Medicaid plus one solely state-funded program.[171] These requests reflect the legal complexities of our federalist health care system. In both cases, the IRS applied similar "purpose and function" analysis as in Notice 2014-7 and concluded that the other programs similarly qualified for "difficulty of care" treatment under § 131.[172]

Another stumbling block to implementation of Notice 2014-7 was administrability. There were administration challenges both for states and their contracted fiscal managers, and for taxpayers.

Because of the enormous variability in home care programs, there are a variety of caregiver situations and administrative structures.[173]

---

of Care Exclusion, PROCEDURALLY TAXING (Feb. 21, 2019), https://procedurallytaxing.com/information-letter-shows-need-for-broader-guidance-on-difficulty-of-care-exclusion/ [https://perma.cc/CTK3-AYUK]; Leonardo Castañeda, *Murky Rule Generates Expensive Tax Turmoil for California Caregivers*, INEWSOURCE (Mar. 28, 2016), https://inewsource.org/2016/03/28/rule-expensive-tax-turmoil-california-caregivers/ [https://perma.cc/3SEU-WFAT].

169. *See generally* Rev. Proc. 2020-1, § 2.01, 2020-1 I.R.B. 1, 8 ("A letter ruling interprets the tax laws and applies them to the taxpayer's specific set of facts."). A letter ruling is binding on the IRS only as to the taxpayer who requested it; other taxpayers are not entitled to rely on the analysis. *See id.* § 11, 2020-1 I.R.B. at 61–62; I.R.C. § 6110(k)(3).

170. *See, e.g.*, *Difficulty of Care Payments Excludable from Income*, *supra* note 86. The private letter ruling (PLR) issued to the State of Washington is available in redacted form only from the IRS. *See* I.R.S. Priv. Ltr. Rul. 131836-15, 7–8 (Mar. 11, 2016), https://www.irs.gov/pub/irs-wd/201624012.pdf [https://perma.cc/BUK8-9AAC]. *See also* I.R.S. Priv. Ltr. Rul. 127776-15, 8–10 (Mar. 1, 2016), https://www.irs.gov/pub/irs-wd/201623003.pdf [https://perma.cc/28HY-PXB7].

171. I.R.S. Priv. Ltr. Rul. 127776-15 at 3. The three Medicaid programs were (1) the Personal Care Services Program operated under SSA section 1905(a)(24), (2) the In-Home Supportive Services Plus Option operated under SSA section 1915(j), and (3) the Community First Choice Option program operated under SSA section 1915(k). *Id.* at 2–3. The other PLR requested guidance on its programs pursuant to sections 1905 and 1915(k) of the SSA. *See* I.R.S. Priv. Ltr. Rul. 131836-15 at 2.

172. I.R.S. Priv. Ltr. Rul. 127776-15 at 8–11 ("Whether certain payments under [California's] in-home supportive care programs will be treated as difficulty of care payments excludable from gross income of the provider under section 131 of the Code depends on an analysis of the purpose and design of the programs and the nature of the payments. . . . [T]he purpose and design of all four of State's in-home supportive care programs are similar to the purpose and design of foster care programs, and the nature of the described payments to providers is similar to the nature of difficulty of care payments under section 131 of the Code. Therefore, payments under all four of State's in-home supportive care programs to an individual care provider for in-home supportive care provided for an eligible recipient who resides in the provider's home will be treated as difficulty of care payments excludable from the gross income of the provider under section 131."); I.R.S. Priv. Ltr. Rul. 131836-15 at 7–10 (containing identical language as I.R.S. Priv. Ltr. Rul. 127776-15, *supra*).

173. *See supra* notes 83–88 and accompanying text.

Following the issuance of Notice 2014-7, the IRS posted a series of Frequently Asked Questions (FAQ) on its website as it became clear that implementation of this change posed difficulties.[174] These FAQ reflect the range of complications that taxpayers were facing. As reflected by the FAQ, caregivers were being treated in three ways: as employees of the agency issuing the payments, as employees of the care recipient, or as independent contractors.[175] There was confusion over withholding and reporting requirements for both income taxes and employment taxes.[176]

For fiscal management companies, there was another, practical complication: the capacity of their payroll software. An article coauthored by a home health agency administrator noted:

> Most small business software packages do not have the capability or flexibility to properly account for wages that are excludable from income taxes . . . . Payroll systems for larger businesses have the ability to properly account for wages that are excludable from income taxes, but for smaller employers these services can be cost prohibitive.[177]

Perhaps in response to lobbying from these companies, some states allowed fiscal managers to decide whether the agency would accommodate a caregiver's request that their payments not be reported as taxable income under the difficulty of care exclusion.[178] Some states also allowed fiscal managers to make different choices regarding the employment status of workers.

---

174. *See IRS § 131 FAQ*, *supra* note 85.

175. *Id.* at Q&A 12.

176. *Id.* at Q&As 16, 18–20.

177. William E. Wilcox et al., *Notice 2014-7: Issues for Home Healthcare Agencies*, 98 PRAC. TAX STRATEGIES 193, 196 (2017).

178. Minnesota permits each financial management service (FMS) to decide whether it will implement Notice 2014-7 or continue reporting "difficulty of care" payments as taxable income. *See* E-mail from Minn. CDCS Disability Servs. Div., Minn. Dep't of Hum. Servs., to Kathryn Sedo (Oct. 25, 2018) (on file with author). *See also Financial Management Services (FMS) Providers*, MINN. DEP'T HUM. SERVS., https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=DHS-307069 [https://perma.cc/4QLK-JZLC] (May 13, 2020) (showing DHS delegates its FMS services, which include payroll services, to providers). *See, e.g.*, *Is Your Income Exempt from Taxes As "Difficulty of Care Payments"?*, PARTNERS CMTY. SUPPORTS (Feb. 17, 2020), https://www.lssmn.org/pics/news/difficulty-of-care [https://perma.cc/VZ76-J92R] (inviting workers who qualify for the exemption to complete and submit an "IRS Notice 2014-7 Certification" and advising that PICS will "adjust your federal and state income tax withholding to zero for all future eligible payments"); ACCRA CARE, INC., 245D WAIVERED SERVICES POLICY HANDBOOK 128, https://www.accrahomecare.org/wp-content/uploads/2020/09/245D-Waivered-Services-Policy-Handbook.pdf [https://perma.cc/R4AM-RMC8] (last visited Feb. 8, 2021) (stating regarding the Notice 2014-7 exemption, "Accra does not pursue this for employees and Accra staff are not tax professionals.").

> For example, in Colorado, the Division for Intellectual and Developmental Disabilities oversees the Medicaid waiver program and originally required that caregivers be classified as employees. After the state became aware of Notice 2014-7, it removed the employee requirement from the regulations and allowed service agencies to treat caregivers as independent contractors. Thus, midway through the year, caregivers in Colorado that were considered employees during the first half of the year may not have been considered employees for the second half of the year. More than 300 service agencies were allowed to implement this policy change independently, so there was no uniform implementation of the change. Some service agencies continued to classify the caregivers as employees and issued Forms W-2 for their difficulty-of-care payments for the entire year. Other service agencies changed their reporting procedures and properly did not report the payments as wages or as Form 1099 expenditures for the last part of the year but issued Forms W-2 for the first part of the year.[179]

In the face of these obstacles, the IRS recognized that tax reporting and withholding for caregiver income would be inconsistent and sometimes erroneous.[180] Rather than wade into the morass of community care program administration, which would likely step on states' toes, the IRS placed the burden instead on each individual caregiver to correctly report their income and seek a refund of any erroneous withholding.[181]

2. *Feigh v. Commissioner*, 2019

To date, one case has challenged IRS Notice 2014-7, *Feigh v. Commissioner*.[182] Who would want to challenge a tax break for caregivers of disabled family members? Caregivers who did not view the gross income exclusion as a break, but rather as a deprivation of benefits. The conflict arose because of the requirement to show "earned income" to qualify for cash benefits provided through the tax code, namely the EITC and the additional child tax credit (ACTC).[183]

Mary and Edward Feigh have three children, one of whom was under seventeen years old in 2015.[184] Two of the Feighs' children are adults

179. McClellan & Tripp, *supra* note 85, at 228.

180. *IRS § 131 FAQ*, *supra* note 85, at Q&As 11–14.

181. *Id.* ("[Y]ou must first contact the agency that withheld the taxes for a refund. However, if the agency indicates an intention not to file a claim or adjust the overpaid social security and Medicare taxes, you may claim a refund of the erroneously withheld social security and Medicare taxes by filing Form 843, Claim for Refund and Request for Abatement."). This could partly explain why only two states sought guidance from the IRS regarding their non-1905(c) in-home care programs.

182. 152 T.C. 267 (2019).

183. The "additional child tax credit" is the refundable portion of the child tax credit. Low-income individuals who owe little if any income tax mainly benefit from the CTC through receiving the ACTC. Marr et al., *EITC & CTC*, *supra* note 124, at 4.

184. The facts presented in this Essay are derived from the U.S. Tax Court's opinion and from

with severe disabilities who lived at home that year. Mary earned $7,353 for care provided to her adult children through a Medicaid home care program.[185] The family would have been eligible for SNAP[186] benefits and some cash assistance from their state's Supplemental Aid Program.[187] At this income level, Mary and Edward also qualify for Medicaid.[188] Based on Mary's income from caregiving, the Feighs claimed an EITC of $3,319, and a refundable ACTC of $653, for a total refund of $3,972 for 2015.[189]

The IRS objected and challenged the Feighs' tax return. Before the Tax Court, the IRS argued that Medicaid waiver payments for care of the disabled adult children are not gross income under the rationale of Notice 2014-7, and therefore they cannot be "includible in gross income" for purposes of the EITC and ACTC.[190] For their part, the Feighs argued that

---

the brief filed by the Feighs. *See* Petitioners' Seriatim Answering Brief, *Feigh*, 152 T.C. 267 (No. 20163-17).

185. *Feigh*, 152 T.C. at 268.

The record does not reflect what other nontaxable income the Feigh family had. If we suppose that each of the adult children received disability benefits through Supplemental Security Income (SSI) in 2015, the family's household income would rise to about $24,945. SSI provides a subsistence level of income to individuals with disabilities who have little or no income and assets, and who do not have enough work credits to qualify for Social Security Disability benefits. The federal SSI benefit in 2015 was $733 per month, assuming each beneficiary paid their "fair share" of the family's living expenses. *See SSI Federal Payment Amounts*, SOC. SEC. ADMIN., https://www.ssa.gov/oact/cola/SSIamts.html [https://perma.cc/ V3DB-PSYL] (last visited Feb. 8, 2021) (laying out the monthly SSI payment amounts from 1975 to 2021). To calculate these figures, $733 × 12 months × 2 adult children = $17,592; $17,592 + $7,353 = $24,945. Note that the term "household income" is used here in the colloquial sense.

186. SNAP is the Supplemental Nutrition Assistance Program, formerly known as food stamps. *See SNAP Eligibility*, USDA: FOOD & NUTRITION SERV., https://www.fns.usda.gov/snap/recipient/eligibility [https://perma.cc/4D3K-HPS5] (last visited Dec. 30, 2020) (providing a Frequently Asked Questions resource regarding general program information and eligibility requirements).

187. MINN. STAT. §§ 256D.33–54, 256I.01–06 (2020). This cash benefit is not large. *See Minnesota Supplemental Aid (MSA): The Basics*, MINN. DISABILITY BENEFITS 101, https://mn.db101.org/mn/programs/income_support/msa/ [https://perma.cc/R6YU-KSAC] (Feb. 3, 2021) ("A person living alone and getting SSI will usually qualify for a MSA benefit of $81."); *Minnesota Supplemental Aid*, MINN. DEP'T HUM. SERVS., https://edocs.dhs.state.mn.us/lfserver/Public/DHS-1888-ENG [https://perma.cc/EPE5-9FDC] (last visited Jan. 8, 2021) (noting that the benefit for a single person can be up to $81 per month, for a couple, up to $111 per month, and for a person living in a facility, up to $74 per month).

188. The SSI payments are not counted as income for purposes of Mary and Edward's Medicaid eligibility, because the benefit recipients do not have an income tax filing requirement. However, Mary and Edward would still be eligible for Medicaid (as they lived in an expansion state) even if the SSI payments were counted.

189. *Feigh*, 152 T.C. at 269.

190. The IRS did not argue in the alternative that the Feighs' gross income should be increased to include the caregiver payments, likely because the payments were so small that including them in gross income would have zero tax consequences and therefore would not affect the outcome of the Tax Court case. The couple's taxable income will be zero whether the Feighs' gross income is

caregiving is work, Mary had earned income in exchange for her services, and the IRS had no authority to withhold a congressionally granted benefit for workers simply by issuing a notice.[191] The Tax Court sided with the Feighs.

In its opinion, the Tax Court found that "the plain text of section 131 renders it inapplicable to the care of biological adult children."[192] The Court gave short shrift to the "oversight and purposes" framework employed by Notice 2014-7, discounting its reasoning and giving the notice "little, if any, deference."[193] The Court was appropriately concerned with the denial of the refundable credits to the petitioners based solely on a subregulatory notice which lacks the force of law.[194] Thus, the Tax Court disregarded Notice 2014-7 and allowed the Feighs' EITC and ACTC.[195]

The *Feigh* case highlights the divergent interests that family caregivers have depending on their household income. Like Kerrie Reilly, Mary Feigh cares for her adult disabled children and receives state payments for this work. However, the Feigh household has a much lower income than the Reillys'. For the Feighs, losing the refundable EITC by excluding Medicaid waiver payments from income would be devastating. The Feighs' income is so low that they see zero income tax savings from

---

zero or $7,353; the outcome of the case hinged solely on whether the Feighs had qualifying "earned income" for the refundable credits. If there is a distinction to be drawn between "earned income" for refundable credits and "gross income" contributing to AGI and then taxable income, the Court did not reach it.

191. Petitioners' Seriatim Answering Brief, *supra* note 184, at 15–17. *See also* Caleb Smith, *Invalidating an IRS Notice: Lessons and What's to Come from* Feigh v. C.I.R., PROCEDURALLY TAXING (June 17, 2019), https://proceduralltaxing.com/invalidating-an-irs-notice-lessons-and-whats-to-come-from-feigh-v-c-i-r/ [https://perma.cc/E2ZS-29ZX]. In their brief, the Feighs also argued that the court should understand the earned income requirement in § 32 broadly, to encompass payments for services that are not gross income. Petitioners' Seriatim Answering Brief, *supra* note 184, at 16–17. The court appears to reject that argument, but technically it did not reach the question because, as noted above, the IRS did not argue that the payments should be included in gross income if the government lost the difficulty of care issue.

192. *Feigh*, 152 T.C. at 272.

193. *Id*. at 275.

194. Subregulatory guidance increases predictability, but its exemption from procedural rulemaking requirements is problematic under both administrative law principles and taxpayer rights grounds. *See, e.g.*, Christopher J. Walker & Rebecca Turnbull, *Operationalizing Internal Administrative Law*, 71 HASTINGS L.J. 1225, 1227–28, 1241–43 (2020) (identifying benefits and costs of subregulatory guidance and suggesting that agencies "should avoid injecting guidance with binding intent"); Kristin E. Hickman, *IRB Guidance: The No Man's Land of Tax Code Interpretation*, 2009 MICH. ST. L. REV. 239, 242 (2009) ("[IRS] guidance falls directly into a large doctrinal void of what it means for a rule to carry the force of law"); Leslie Book, *Giving Taxpayer Rights a Seat at the Table*, 91 TEMP. L. REV. 759 (2019) (proposing, *inter alia*, a requirement for pre-publication input by the National Taxpayer Advocate on the impact of subregulatory guidance on taxpayer rights). *See also* Smith, *supra* note 191 ("[T]he IRS can't magically decree that what was once earned income is no more through the issuance of subregulatory guidance.").

195. *Feigh*, 152 T.C. at 276.

a gross income exclusion, and they qualify for Medicaid already. On the other side of the equation, the EITC and ACTC are a large percentage of the Feighs' annual income, providing crucial financial support for the household. The Feighs may have alleviated a serious financial hardship by reporting their difficulty of care payments as earned income to claim the EITC and ACTC.

In contrast, Ms. Reilly's $40,000 caregiving wage[196] (without the application of § 131) only qualifies her for a very small EITC (about $171),[197] and she does not have a qualifying child for the child tax credit. If her caregiving wages are included in gross income, she could receive subsidized private health insurance through California's Health Insurance Marketplace, Covered California, thanks to the Affordable Care Act.[198] However, if Ms. Reilly's caregiving wages are excluded, she qualifies for the much more generous Medi-Cal program,[199] greatly reducing her health insurance and out of pocket healthcare costs.[200]

As the comparison between the Reillys and the Feighs illustrates, some families are better off with the § 131 exclusion and may even gain access to affordable health insurance and health care, but others lose crucial economic supports. Quantifying the benefits of one option versus the

196. *See supra* notes 14–15 and accompanying text.

197. *See Policy Basics: The Earned Income Tax Credit*, *supra* note 129 (showing that, in 2019, for a single filer with one child and $40,000 in household earnings, the EITC would be about $171).

198. *See* Section II.B.2, *supra*. With a family size of two, Ms. Reilly's household income is around 232% of the federal poverty line, making her eligible for a Premium Tax Credit and reduced cost-sharing. *See generally* Galvin & Speidel, *supra* note 134; Pareja, *supra* note 141.

199. *See Medicaid Income Eligibility Limits for Adults as a Percent of the Federal Poverty Level*, KAISER FAM. FOUND., https://www.kff.org/health-reform/state-indicator/medicaid-income-eligibility-limits-for-adults-as-a-percent-of-the-federal-poverty-level/ [https://perma.cc/D99R-CAUQ] (last visited Jan. 8, 2021) (showing that California sets its eligibility limit at 138% FPL).

200. *See supra* notes 147–148 and accompanying text. Ms. Reilly would pay a monthly premium of about $150 through Covered California. *Medi-Cal Eligibility & Covered California—FAQ's*, CA.GOV: DEP'T HEALTH CARE SERVS., https://www.dhcs.ca.gov/services/medi-cal/eligibility/Pages/Medi-CalFAQs2014a.aspx [https://perma.cc/N5K5-Z2J3] (Nov. 19, 2019); *Shop and Compare*, COVERED CAL., https://apply.coveredca.com/lw-shopandcompare/ [https://perma.cc/V7YG-J9R4] (last visited Mar. 2, 2021) (information entered for a forty-five-year-old individual for 2021, living in Marin County, California (zip code 94901), with $40,000 income needing medium use coverage). In addition to her premiums, Ms. Reilly would also be responsible for co-pays and cost-sharing when she used her insurance. These costs can add up, even for individuals with federal cost-sharing subsidies. For example, a Vermont resident with the same cost-sharing subsidy level as Ms. Reilly who has type 2 diabetes would pay about $1,400 per year in cost-sharing, in addition to their premium. *Summary of Benefits and Coverage: BCBSVT Silver Plan*, BLUECROSS BLUESHIELD VT., at 7, https://info.healthconnect.vermont.gov/sites/hcexchange/files/2017_ SBCs/Silver%20Standard%2087%25%20AV.pdf [https://perma.cc/5TXG-KAUC] (last visited Feb. 6, 2021). (Such estimates are not readily available for California plans.) In contrast, Medi-Cal premiums are minimal (between $0 and $39 per month), and so is cost-sharing. *Medi-Cal Eligibility & Covered California—FAQ's*, *supra*, at Question 2.

other is relatively simple when one only considers the Form 1040. However, the fact that access to affordable health care is now tied to AGI complicates the equation. The Feighs got their much-needed EITC, but did Kerrie Reilly lose her Medicaid?[201]

3. The IRS Responds to *Feigh*

After the *Feigh* opinion, the IRS appeared to reach an uneasy compromise. In the spring of 2020, it advised volunteer income tax assistance (VITA) programs that taxpayers are permitted to choose how they treat Medicaid waiver payments for income tax purposes:

> A taxpayer may choose to include qualified Medicaid waiver payments in the calculation of earned income for the EIC and the ACTC. The taxpayer may include qualified Medicaid waiver payments in earned income even if the taxpayer chooses to exclude those payments from gross income.[202]

Around the same time, the IRS published an ambiguous Action on Decision (AOD) notice. This notice appears to accept the Feighs' argument that payments can be both earned income for EITC and ACTC purposes and excluded from gross income under § 131.[203] However, at the same time the AOD calls into question the agency's continued commitment to Notice 2014-7. The AOD acquiesces in the result of the *Feigh* case, including that "Medicaid waiver payments received as wages for the care of the taxpayer[s'] disabled adult children in their own home are not excludable from income under I.R.C. 131 . . . ."[204]

Since then, the IRS has maintained this contradictory and limited position.[205] The IRS still uses the term "Medicaid waiver payments" and

---

201. The impact of this obviously depends greatly on Ms. Reilly's healthcare needs.

202. I.R.S. Volunteer Tax Alert, VTA-2020-03 (Mar. 3, 2020), https://www.irs.gov/pub/irs-utl/vta-2020-03.pdf [https://perma.cc/CK3X-232K].

203. Feigh v. Comm'r, 152 T.C. 267 (2019), *action on dec.*, 2020-02 (Mar. 30, 2020). This position is quite taxpayer-friendly, but it is curiously so, as the Tax Court did not adopt the petitioners' interpretation of "includible in gross income" in § 32. *See supra* notes 192–193 and accompanying text.

204. *Feigh*, 152 T.C. 267 (2019), *action on dec.*, 2020-02 (Mar. 30, 2020).

205. *See* I.R.S. Pub. 4012, No. 34183E, at D-59 (Oct. 2020), https://www.irs.gov/pub/irs-pdf/p4012.pdf [https://perma.cc/H6GS-CQWF]; I.R.S. 2020 Form 1040 Instructions, No. 24811V, at 87, https://www.irs.gov/pub/irs-pdf/i1040gi.pdf [https://perma.cc/63PC-KXEM] (last visited Feb. 2, 2021); *IRS § 131 FAQ*, *supra* note 85. The IRS has not published any guidance in the Internal Revenue Bulletin aside from the AOD. IRS publications, website FAQ, and form instructions do not bind the agency and may not be relied upon by taxpayers. Reed v. Comm'r, T.C. Memo 2014-41, 2014 WL 926908, at *3 (T.C. Mar. 10, 2014) ("Further, informal guidance, such as the FAQs posted to the IRS' Web site, is not an authoritative source of Federal tax law."); *see also* Miller v. Comm'r, 114 T.C. 184, 195 (2000) ("Administrative guidance contained in IRS publications is not binding on the Government, nor can it change the plain meaning of tax statutes."); Adler v. Comm'r, 330 F.2d 91, 93 (9th Cir. 1964) ("Nor can any interpretation by taxpayers of the language used in government pamphlets act as an estoppel against the government, nor change the

refers to SSA section 1915(c) in discussing § 131, even though it concluded in two letter rulings that other Medicaid and non-Medicaid caregiving programs can qualify for the difficulty of care exclusion.[206] To the extent that tax preparers, Medicaid agencies, and caregivers are relying on IRS statements to determine their options,[207] the current guidance is likely to result in underclaiming of the exclusion.[208]

Where does all this leave caregivers? The legal disputes have centered on the relationship between caregiver and care recipient,[209] but also on whether the structure of modern caregiving support programs fits within § 131.[210] These issues remain unresolved. Worse, the administrative complications that were brought to light as family caregivers pushed for the implementation of Notice 2014-7 have only grown with the IRS's current flexibility.[211]

For now, savvy and risk-tolerant taxpayers or their tax preparers will be able to maximize their tax and health care benefits. Ms. Reilly can exclude her waiver payments to get more affordable health care, thanks to a lower modified adjusted gross income (MAGI). The Feighs, on the other hand, can include their waiver payments to benefit from the EITC

---

meaning of taxing statutes."). These are less formal means of communicating to taxpayers than the IRS used in Notice 2014-7. The IRS's use of nonbinding and informal statements implicates some of the same fairness, informed decision-making, and democratic legitimacy concerns that Professor Kristin Hickman has identified in the regulatory context. *See* Kristin Hickman, *Coloring Outside the Lines: Examining Treasury's (Lack of) Compliance with Administrative Procedure Act Rule-making Requirements*, 82 NOTRE DAME L. REV. 1727, 1728, 1805 (2007) [hereinafter Hickman, *Coloring Outside the Lines*].

206. *IRS § 131 FAQ*, *supra* note 85.

207. *See* Hickman, *Coloring Outside the Lines*, *supra* note 205, at 1805 ("[M]ost taxpayers are inclined to adhere even to informal IRS interpretations of the law rather than risk an enforcement action.").

208. This is particularly true for caregivers of adults with serious mental illnesses, because SSA section 1915(c) waiver programs generally do not cover their care. *See* ASPE HANDBOOK *supra* note 24, at 13, 53.

209. *See, e.g.*, *Feigh*, 152 T.C. at 271–72; *In re* Hite, 557 B.R. 451, 458 (Bankr. W.D. Va. 2016) (examining whether caregiver-parents who lived with and cared for their disabled son were "qualified foster care providers"); Ray v. United States, 993 F. Supp. 2d 760, 761 (S.D. Ohio 2014) (finding that the mother-son relationship was not a foster care relationship and thus payments were not excludable).

210. *See* Alexander v. Comm'r, T.C. Summ. Op. 2011-48, 2011 WL 1422015, at *1 (2011); *In re Hite*, 557 B.R. at 460 (discussing the IRS's expansion of the definition of "foster care provider" in Notice 2014-7); Micorescu v. Comm'r, 76 T.C.M. (CCH) 796, 802 (1998) (finding that payments made by a for-profit company contracted by the state to administer its caregiving program do not qualify for the § 131 exclusion).

211. *See supra* notes 179–181 and accompanying text. *See also* ROBERT L. MOLLICA ET AL., AARP PUB. POL'Y INST., BUILDING ADULT FOSTER CARE: WHAT STATES CAN DO 23–28 (2009), https://assets.aarp.org/rgcenter/ppi/ltc/2009_13_building_adult_foster_care.pdf [https://perma.cc/M65G-P3AN] (noting that foster care providers do not understand § 131 exclusion and providing examples of state programs and funding models).

and ACTC, and still have MAGI low enough to qualify for Medicaid. Unfortunately, caregivers without the necessary information or counsel will likely follow the path laid out by the state agency or fiscal manager, reporting wages if they received a W-2, and forgoing the EITC if they did not receive a W-2.[212] To do otherwise risks a frozen refund and a letter from the IRS.[213]

III. TOWARD A COHESIVE FEDERAL CAREGIVING POLICY

The difficulties encountered by taxpayers and the IRS in trying to adapt the now outdated difficulty of care exclusion to current health care realities can spur a fresh look at tax supports for caregiving. This Part evaluates what current law lacks in light of the health and disability policy motivations underlying community care and the § 131 exclusion. It then closes with suggestions for new approaches that allow better achievement of these goals.

A. The Difficulty of Care Exclusion Illuminates Substantive Frictions and Procedural Shortcomings

The tale of the difficulty of care exclusion shows the need for better coordination between tax policy and health care policy for family caregivers. Lawmakers can draw three main lessons from the difficulty of care story. First, a gross income exclusion is no longer a simple way to enact a policy preference,[214] because of its interaction with the EITC

212. Of course, caregivers claiming the EITC without a W-2 (or otherwise taking a position conflicting with the state or FMS's reporting) will be subject to IRS compliance scrutiny. *See* U.S. GOV'T ACCOUNTABILITY OFF., GAO-18-224, TAX FRAUD AND NONCOMPLIANCE: IRS CAN STRENGTHEN PRE-REFUND VERIFICATION AND EXPLORE MORE USES 6–8 (2018) [hereinafter GAO, TAX FRAUD AND NONCOMPLIANCE] https://www.gao.gov/assets/690/689702.pdf [https://perma.cc/2YJ7-VGFL] (detailing role of W-2 in EITC refund hold and audit procedures). The IRS has attempted to address documentation issues related to Medicaid waiver payments through its VITA instructions, but not all low-income taxpayers use VITA services, and the IRS publications referenced in Form 1040 instructions are not as clear as the alert issued to VITA volunteers. *See* I.R.S. 2020 Forms 1040 and 1040-SR Instructions, *supra* note 205, at 23 (referring readers to additional pages and publications); *contra* VTA-2020-03, *supra* note 202 (explaining different scenarios and how to enter information into tax software used by volunteers). *See also* I.R.S. Pub. 4012, *supra* note 205, at D-6, D-59 (providing detailed instructions to VITA volunteers for how to enter payment information).

213. The IRS often "freezes" the refundable credits if a tax return claiming the EITC or ACTC is selected for review, paying out the refund only if the taxpayer prevails. GAO, TAX FRAUD AND NONCOMPLIANCE, *supra* note 212, at 20–21; NAT'L TAXPAYER ADVOC., 2 OBJECTIVES REPORT TO CONGRESS 87–88 (2018), https://www.taxpayeradvocate.irs.gov/wp-content/uploads/2020/08/JRC18_Volume2.pdf [https://perma.cc/6U32-ZKD6]; *see also* Leslie Book et al., *Insights from Behavioral Economics Can Improve Administration of the EITC*, 37 VA. TAX REV. 177, 205 (2018) ("[M]ost EITC audits are done before the refund is released . . . .") (citing CRANDALL-HOLLICK, *supra* note 119, at 10).

214. *See* David A. Weisbach & Jacob Nussim, *The Integration of Tax and Spending Programs*,

and ACTC. Second, a gross income exclusion is not necessarily simple to implement. In the home care context, it is anything but simple to overlay a targeted gross income exclusion on the multitude of Medicaid and state-funded home care programs across the country.[215] Even if federal policy is uniform and the IRS takes steps through forms and instructions to inform individuals how to claim the benefit of an exclusion, there will be inconsistent access to benefits if the burden is on the beneficiary to assert them, rather than on the state agencies and their agents to correctly report to the IRS. Third, there is a disconnect between the language and function of the tax system and the values of dignity and autonomy for care recipients adopted in participant-directed care programs.

We can also identify lessons for agency administrators. When a tax provision touches another area of law, particularly a complex area such as health care, it is especially important to solicit stakeholder input on the application and administration of that provision. The difficulty of care exclusion also highlights the divergent interests that taxpayers with different characteristics may have from each other and from other stakeholders. An interpretive position that was beneficial to middle-income taxpayers had very harmful effects on very low-income taxpayers. This suggests that the agency would benefit from soliciting a wide range of public comments, including from the perspective of marginalized taxpayers.

In evaluating caregiving supports in light of these points, it is useful to examine the policy considerations that drove the relevant laws. Traditionally, tax policy has been viewed through the prisms of efficiency, equity, and administrability.[216] However, this framework has

113 YALE L.J. 955, 980 ("An exclusion is an incredibly simple method of implementing policy . . . .").

215. Professors Abbe Gluck and Nicole Huberfeld recently demonstrated the complex and arguably incoherent ways that "federalist" aims of state autonomy interact with federal health policy. Abbe R. Gluck & Nicole Huberfeld, *What Is Federalism in Healthcare For?*, 70 STAN. L. REV. 1689 (2018); *see also* Abbe R. Gluck & Nicole Huberfeld, *The New Health Care Federalism on the Ground*, 15 IND. HEALTH L. REV. 1 (2018); Hoffer, *supra* note 28, at 1305.

216. *See* Reuven S. Avi-Yonah, *The Three Goals of Taxation*, 60 TAX L. REV. 1, 1 (2007) (calling these three principles "the traditional grounds for evaluating tax policy"); Anthony C. Infanti, *Tax ~~Equity~~*, 55 BUFF. L. REV. 1191, 1191 (2008) (referring to the three principles as "the triad of tax policy concerns"). In addition to these criteria, one might also examine the possibility that a gross income exclusion is appropriate in recognition of the fact that a caregiver realizes no accession to wealth by virtue of their caregiving activities. *See* Comm'r v. Glenshaw Glass Co., 348 U.S. 426, 431 (1955). *See also* Jasper L. Cummings, Jr., *The General Welfare Exclusion*, 169 TAX NOTES FED. 441, 441–42 (2020) ("The best income tax policy justification for the [general welfare gross income exclusion] is that the payees may not have enjoyed a net gain in wealth."). Unfortu-

been critiqued by scholars, who argue, among other things, that traditional tax policy analyses, including considerations of equity, reduce all concerns to economic factors and prevent real consideration of the lived experiences of marginalized individuals.[217] In the disability context, this is an apt criticism. This scholarly critique also has particular force when applied to tax provisions whose primary purpose is not connected with revenue collection but rather seek to advance social goals. The difficulty of care exclusion is founded in and intertwined with nontax policy.

What are the social goals and values that we should care about in the caregiving context? Here, tax must largely defer to health and disability policy.[218] Fighting poverty among individuals with disabilities and their families is one oft-cited goal of health and disability legislation, including the ADA.[219] Also, there is broad national consensus on the importance of honoring the dignity and autonomy of people with disabilities and providing maximum opportunities for individuals to participate fully in community and economic life.[220] Indeed, for disability advocates this is

---

nately, as programs are currently structured, family caregivers must acknowledge that they are being compensated for providing services. It is firmly established in our tax law that "[w]here the payment is in return for services rendered, it is irrelevant that the donor derives no economic benefit from it." Comm'r v. Duberstein, 363 U.S. 278, 285 (1960) (quoting Robertson v. United States, 343 U.S. 711, 714 (1952)). In fact, tax policy traditionalists would point out that caregivers are undertaxed to the extent that they are unpaid or underpaid, and thus benefit from imputed income. *See* Nancy C. Staudt, *Taxing Housework*, 84 GEO. L.J. 1571, 1577 (1996) (noting that scholars such as Richard Posner and A.C. Pigou have commented that an ideal income tax would tax nonmarket activities such as childcare).

217. Infanti, *supra* note 216, at 1201–02 ("[T]his is a powerful rhetorical move that simultaneously sanitizes the debate over tax fairness—cleansing it of uncomfortable discussions of racism, sexism, heterosexism, and disability discrimination—and allows that debate to be easily manipulated in favor of those with wealth and power."). *See also* Leo P. Martinez, *Tax Policy, Rational Actors, and Other Myths*, 40 LOY. U. CHI. L.J. 297, 298 (2009) ("[T]ax policy is a largely mythical concept, more akin to the Holy Grail than to anything else."); James Repetti & Diane Ring, *Horizontal Equity Revisited*, 13 FLA. TAX REV. 135, 136–38, 145–46 (2012) (describing the persistence of horizontal and vertical equity analysis despite repeated scholarly criticism).

218. It is not an easy task to divine a coherent set of goals and values from federal health and disability law, and different players in the system may have differing values. *See* Bagenstos, *ADA as Welfare Reform*, *supra* note 55, at 926–27 (arguing that the "basis premise" of the ADA can be seen as welfare reform rather than as a commitment to the social and civil rights of individuals with disabilities).

219. Weber, *Disability Rights*, supra note 55, at 2485 ("Supporters [of the ADA] also argued that by eliminating barriers to employment, it would reduce poverty among people who are disabled and diminish the need for governmental support."). Similarly, the goal of the ACA was "to increase the number of Americans covered by health insurance and decrease the cost of health care." Nat'l Fed'n of Indep. Bus. v. Sebelius, 567 U.S. 519, 538 (2012).

220. *See, e.g.*, *Disability Inclusion*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/ncbddd/disabilityandhealth/disability-inclusion.html [https://perma.cc/54AR-QSMT] (last visited Sept. 22, 2020); *supra* notes 58–70 and accompanying text. There is international consensus as well. For example, in 2006, the United Nations adopted

the minimum, not the ultimate goal.[221] Professor Mark Weber explains that "[t]he conceptual premise of the disability rights movement is the social model of disability, that is, the recognition that physical and mental conditions do not themselves disable, but disability results instead from the dynamic between those conditions and environmental and attitudinal barriers."[222]

However, pure cost-benefit analysis is also a realistic motivation for governmental support of community caregiving. The origins of § 131 reflect concerns of social welfare (ensuring that foster children with disabilities find good homes) but also concerns of government efficiency (saving states the cost of institutional care).[223] There is evidence that in-home supports can help people with disabilities maintain a higher level of functioning and postpone or avoid the need for more expensive care.[224]

---

the Convention on the Rights of Persons with Disabilities, which aims to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, 2515 U.N.T.S. 3, Art. 1, https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf [https://perma.cc/HN6A-CNDE].

Despite this clear policy shift, discussed *supra* notes 58–71, it has been difficult to transform the stated goals of participant control into reality. Programs that are participant-centered on paper do not always cede actual control and autonomy to individuals with disabilities. *See, e.g.*, Ogg, *supra* note 17, at 1049; Lisa I. Iezzoni, *A Backstory to Michael Ogg's Narrative Matters Essay: Why He Needed to Leave PACE*, HEALTH AFFS. (July 18, 2019), https://www.healthaffairs.org/do/10.1377/hblog20190717.505863/full/ [https://perma.cc/6VHY-YFVT]. *See also* Class Action Complaint at 1–3, Price v. Comm'r, No. 1:21-cv-00025 (D. N.H. Jan. 11, 2021) (alleging that the State of New Hampshire failed to adequately support its program for community services and supports, endangering plaintiffs' choice of community integration). However, these Medicaid programs are at least "talking the talk" and they have increased community services significantly compared to the pre-*Olmstead* days. *See also* Hoffer, *supra* note 28, at 1277–78 (noting that Medicaid services are only available to the very poor).

221. *See, e.g.*, Francine J. Lipman, *Enabling Work for People with Disabilities: A Post-Integrationist Revision of Underutilized Tax Incentives*, 53 AM. U. L. REV. 393, 410–13 (2003) (describing post-integrationism); Hoffer, *supra* note 28, at 1268 (explaining that integration via antidiscrimination laws is insufficient to mitigate structural barriers and provide full emancipation for people with disabilities).

222. Weber, *Disability Rights*, *supra* note 55, at 2484 (citing Paula E. Berg, *Ill/legal: Interrogating the Meaning and Function of the Category of Disability in Antidiscrimination Law*, 18 YALE L. & POL'Y REV. 1, 9 (1999)).

223. *See* 128 Cong. Rec. S26905 (daily ed. Oct. 1, 1982) (statement of Sen. Durenberger). This duality mirrors that reflected in the ADA. *See also* Bagenstos, *ADA as Welfare Reform*, *supra* note 55, at 926–27 ("[S]upporters of the proposed ADA argued that . . . a regime of 'reasonable accommodations' could move people with disabilities off of the public assistance rolls and into the workforce in a way that would ultimately save the nation money."). It is interesting to note that Notice 2014-7 also mentions institutionalization, but the text of § 131 does not actually require an institutional level of need.

224. *See Deinstitutionalization Toolkit: Costs in Detail*, NAT'L COUNCIL ON DISABILITY (2012), https://ncd.gov/publications/2012/ditoolkit/costs/indetail/ [https://perma.cc/2KKL-ET4E] (listing case studies that have examined varied reasons for cost savings); AARP, LTSS ACCESS,

Even the "double benefit" of gross income exclusion and the EITC may be warranted on this ground when one considers the enormous expenses of long-term care.[225]

This cost-benefit justification for § 131 is concerning from the caregiver's perspective. Taken too far, it could lead to the exploitation and impoverishment of family caregivers, especially those who cannot afford to supplement family caregiving with paid professional services.[226] There is a widespread recognition and expectation that caregivers who live with the care recipient will likely provide significant uncompensated care, especially if the caregiver is caring for a loved one.[227] Caregivers

supra note 27, at 14 ("In the long run, providing HCBS in lieu of nursing home care may be a more cost-effective approach to financing LTSS for the state.") (citing H. Stephen Kaye et al., *Do Non-institutional Long-Term Care Services Reduce Medicaid Spending?*, 28 HEALTH AFFS. 262 (2009)); *see also Deinstitutionalization: Unfinished Business (Companion Paper to Policy Toolkit)*, NAT'L COUNCIL ON DISABILITY (Sept. 19, 2012), https://ncd.gov/publications/2012/Sept192012 [https://perma.cc/RBR8-NDVN]. Also, some have suggested that health and social outcomes are better for people who are at home in a loved one's care.

225. AARP PUB. POL'Y INST., VALUING THE INVALUABLE: 2019 UPDATE 1 (2019), https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf [https://perma.cc/PC8R-MTBG] ("In 2017, about 41 million family caregivers in the United States provided an estimated 34 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contributions was approximately $470 billion."). Long-term services and supports "users accounted for 5.9 percent of Medicaid enrollees but 41.9 percent of all Medicaid spending" in federal fiscal year 2013. *See* MACPAC MACSTATS, *supra* note 29, at 38. The Commission on Long-Term Care similarly found that "[a] small percentage of Medicaid enrollees (6.4 percent) use LTSS, although this group (half aged and half disabled) account for nearly half (45.4 percent) of total Medicaid spending (counting both medical and LTSS expenses)." COMM'N ON LONG-TERM CARE, 2013 REPORT, *supra* note 8, at 31.

226. *See* Kaplan, *Family Caregiving*, *supra* note 16, at 633 ("Our collective failure to include in-home healthcare as a key component of our system's provision of long-term care results in family caregivers facing substantially diminished financial well-being—and in many cases, impoverishment—when their caregiving responsibilities end.").

227. *See* Courtney Roman et al., *Strengthening Family Caregiving Policies and Programs Through State Collaboration*, HEALTH AFFS. (Nov. 12, 2020), https://www.healthaffairs.org/do/10.1377/hblog20201112.860149/full/ [https://perma.cc/JDB3-E5VV] ("Family caregiving is worth an estimated $470 billion annually, providing substantial savings to the health care system."); James & Hughes, *supra* note 54 ("According to the Institute of Medicine, there are somewhere between 29 and 52 million unpaid caregivers nationally."). Even where government programs compensate caregivers, statutory caps can effectively require significant unpaid caregiving hours. *See, e.g.*, Reilly v. Marin Hous. Auth., 472 P.3d 472, 485 (Cal. 2020) ("However, an IHSS provider is limited to a statutory cap of 283 hours of compensation. (§§ 12303.4, 14132.95, subd.(g).) The discrepancy between a parent provider's actual hours of service and compensation belies any assertion that IHSS payments, at least with respect to protective supervision, are intended to represent wages the parent would have earned outside the home, where compensation would be based on every hour worked."); COMM'N ON LONG-TERM CARE, 2013 REPORT, *supra* note 8, at 118 ("Family caregivers, including relatives, friends, partners and neighbors, are the backbone of long-term services and supports in this country—they provided an estimated $450 billion in unpaid contributions in 2009—more than total Medicaid spending that year.").

are more likely to be female,[228] so the exclusion may perpetuate the gender pay gap as women forgo outside employment or educational opportunities to care for family members.[229] The cost-benefit justification may be compelling to Congress, but it can easily become problematic.

Finally, the language of the law also matters as a mechanism for communicating values.[230] The current "foster care" framework disempowers and infantilizes care recipients. It assumes that ownership and control belong to the care provider and to the state program funding the care.[231] As the Tax Court recognized, the framework of "foster care" is incompatible with participant-directed care, in which the care recipient has the ability to choose their caregiver, and where the care recipient may be the common law employer of the caregiver.[232] The "difficulty of care" exclusion in its very name centers the experience of the caregiver and reminds us of the "burdens" imposed by the individual receiving services.

228. *See* AARP FAM. CAREGIVING, CAREGIVING IN THE U.S. 2020, at 10 (2020), https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf [https://perma.cc/6RJ9-ZVYH] (reporting that 61% of caregivers are female).

229. *See* Shurtz, *supra* note 18 (arguing that long-term care is a women's issue and a class issue).

230. *See* Kitty Richards, *An Expressive Theory of Tax*, 27 CORNELL J.L. & PUB. POL'Y 301, 305 (2017) ("[T]he law not only shapes behavior via penalties and rewards, it also serves to express societal values and approval of (possibly contested) social norms in a way that is valued by citizens and policymakers independent of the instrumental function of the law."); Alice G. Abreu & Richard K. Greenstein, *Rebranding Tax/Increasing Diversity*, 96 DENV. L. REV. 1, 39 (2018) (arguing that framing tax law language as focused on raising revenue necessarily places issues of social justice outside of the field). *See also* Lydia X.Z. Brown, *The Significance of Semantics: Person-First Language: Why It Matters*, AUTISTIC HOYA (Aug. 4, 2011), https://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html [https://perma.cc/SK6A-AX68].

231. In this way, the language of § 131 encourages dignitary harms such as those experienced by people who are the supposed principals in a principal-agent relationship with their fiscal manager, yet who have no power to change how payments to the caregiver they hired are reported to the IRS. *See supra* notes 90–94 and 178–179 and accompanying text. *See also* Hoffer, *supra* note 28, at 1307–08 (exploring concerns of dignitary harms related to ABLE accounts).

232. *See, e.g.*, Alexander v. Comm'r, T.C. Summ. Op. 2011-48, 2011 WL 1422015, at *4 (2011). *See also* NAT'L TAXPAYER ADVOC., 2001 ANNUAL REPORT TO CONGRESS 76 (2001) (proposing legislative changes to simplify the tax code for "family status issues," including a proposal to create a uniform definition of a "qualifying child"). A major challenge for current § 131 is to recognize the diverse abilities of individuals with disabilities. Caregiving programs certainly help people like K.R. whose intellectual development is very limited. It may seem strange to some that we would speak of advancing her autonomy. But the same program may also help someone whose disabilities are purely physical, and who, like Mr. Alexander's parents, exercise the choice to live independently rather than in an institution.

This is antithetical to the social model of disability and perpetuates disability stigma.[233]

B. Updating the "Difficulty of Care" Exclusion

There are both social policy and economic cost-benefit justifications for supporting community-based services and supports for adults with disabilities, including family caregiving. However, the current § 131 exclusion is an ineffective mechanism for advancing any of these motivating goals. Tax provisions supporting community caregiving could more effectively advance the social policies and fiscal concerns that motivate them if they were designed to better reflect the values of dignity and autonomy for people with disabilities, and if they were reconciled with other expenditures targeted at low-income households.

To this end, five preliminary suggestions emerge from our "difficulty of care" example. First, a caregiving tax break can recognize and empower the care recipient's choice of living arrangement and care provider by applying equally to related and unrelated caregivers. Second, any caregiving support provisions should be available to individuals enrolled in participant-directed programs who choose their home and their caregivers. Third, a caregiving tax break should not make lower-income families worse off in absolute terms.[234] Fourth, a caregiving program that piggybacks on state-controlled programs should be flexible enough to adapt to innovations in program design, to maximize consistency between residents of different states and the ability of the tax system to keep up with changes in health policy. Fifth, the provision should be administrable to minimize dignitary harm and allow beneficiary families to maximize their personal welfare.

Whatever the structure of a tax expenditure for caregiving, Congress might avoid the policy conflict shown in *Feigh* by de-coupling the EITC and ACTC from the requirement to have earned (taxable) income. Other eligibility provisions could target those credits at needy taxpayers.[235]

It is not obvious that financial supports for caregiving should be run

---

233. *See* Jasmine E. Harris, *Processing Disability*, 64 AM. U. L. REV. 457, 464 (2015) (identifying "the root of the disability stigma" in "the cognitive-affective associations of disability with incapacity and inhumanity").

234. For example, by depriving them of the EITC. Though the legislative purposes of the EITC are complicated, the credit has a strong antipoverty effect. *See supra* note 125 and accompanying text; Michael B. Adamson, Note, *Earned Income Tax Credit: Path Dependence and the Blessing of Undertheorization*, 65 DUKE L.J. 1439, 1443–44 (2016) (noting that the EITC has "become the country's most significant federally administered anti-poverty program" and that "[l]argely due to the enactment and growth of the EITC, the IRS has become one of the government's principal welfare agencies" (citations omitted)).

235. For example, the EITC is not available to those with substantial income from investments. *See* I.R.C. § 32(i).

through the tax code.[236] However, congressional appetite for tax expenditures continues unabated, and it is significantly more common for legislators to adopt technical fixes to problems than to align broad priorities or fix fundamental inconsistencies in national policy. So, it is worth considering improvements to § 131.

To provide nationwide clarity on eligibility, a statutory revision should recognize the diversity of today's in-home community care programs. The receipt of funds through a state-sponsored program with a similar purpose as either HCBS programs or foster care could replace the current technical requirements for a foster care placement. Essentially, this proposal would adopt the IRS's "purpose and design" approach to provide future flexibility given the underlying variation in state programs.

Another laudatory aspect of Notice 2014-7 is its embrace of participant-centered programs. Congress should codify the IRS's conclusion that it does not matter whether the care recipient or the provider owns the home in which they reside, or whether the provider and care recipient are related. These changes would recognize the agency and dignity that participant-centered care programs aim to enable. Finally, as long as refundable credits remain tied to earned income, any reform of § 131 should permit individual caregivers to elect the tax treatment they prefer, maximizing the antipoverty effects of the EITC.

This narrow fix admittedly fails to touch some troubling aspects of state programs, including administrative complications, horizontal inequities,[237] and dignitary harms. While it is administratively complicated and potentially inequitable to rely on state programs or their contractors to determine which payments qualify for the difficulty of care exclusion under § 131, moving these determinations to the IRS would likely be even worse. The IRS has not embraced its de facto role as a benefits administrator, and requiring it to handle greater complexity in the eligibility or compliance aspects of administering a caregiving credit

236. For example, Professor Stephanie Hoffer has argued that expanding financial eligibility for habilitative Medicaid services is a normatively superior option. *See* Hoffer, *supra* note 28.

237. Perhaps the most troubling feature of caregiving programs from a horizontal equity perspective is states' and fiscal managers' disparate treatment of caregivers' employment status. *See supra* notes 85–88, 178, and accompanying text. Disparities in caregiver treatment are even greater when one broadens the picture to compare Medicaid-funded caregivers with those supported by the Veterans Benefits Administration. *See* Karen Syma Czapanskiy, *Disabled Kids and Their Moms: Caregivers and Horizontal Equity*, 19 GEO. J. ON POVERTY L. & POL'Y 43, 46–47 (2012) (noting that the lack of public benefits available to children with disabilities and their co-resident caregivers results in "unjustifiable differences in the standards of living among caregivers"). Many points illuminated by this Essay could be explored through a horizontal equity lens. *See generally* Ira K. Lindsay, *Tax Fairness by Convention: A Defense of Horizontal Equity*, 19 FLA. TAX REV. 79 (2016).

does not fit well with the IRS's capabilities.[238] Complexities in our health care system will not be solved by adding complexities to our tax system.

There is one context in which Congress has addressed the problem of an existing gross income exclusion unintentionally harming low-income beneficiaries by denying them access to refundable credits. In 2004, the General Accounting Office reported that the gross income exclusion for combat pay under § 112 was making lower income servicemembers worse off by denying them the EITC.[239] As a result, in the Working Families Tax Relief Act of 2004, Congress amended §§ 24 and 32 to allow servicemembers with combat zone income to opt into taxation in order to receive refundable credits that require earned income.[240] The legislative history of this amendment indicates that before 2004, Congress was not attuned to the tension between the gross income exclusion in § 112 and the refundable credits.[241] As with § 131, a well-meaning gross income exclusion became outdated and harmful to its intended beneficiaries due to the evolution of the national welfare system into the tax code. Here, Congress harmonized the tax provisions' benefits by creating an election.

To improve the administration of the EITC for servicemembers, Congress also required nontaxable combat pay to be reported on Form W-2.[242] Consistent and complete third-party reporting improves taxpayers' access to benefits by concisely informing them and their tax preparers of the relevant facts.[243] Improved third-party reporting also

238. The National Taxpayer Advocate has repeatedly pressed this issue. *See, e.g.*, 3 NAT'L TAXPAYER ADVOC., SPECIAL REPORT TO CONGRESS, EARNED INCOME TAX CREDIT: MAKING THE EITC WORK FOR TAXPAYERS AND THE GOVERNMENT (2020), https://www.taxpayeradvocate.irs.gov/wp-content/uploads/2020/08/JRC20_Volume3.pdf [https://perma.cc/7XV6-3EUE]; 1 NAT'L TAXPAYER ADVOC., ANNUAL REPORT TO CONGRESS (2016), https://www.taxpayeradvocate.irs.gov/wp-content/uploads/2020/08/ARC16_Volume1.pdf [https://perma.cc/LUU2-498Q].

239. *See* U.S. GEN. ACCT. OFF., GAO-04-721R, MILITARY PERSONNEL: ACTIVE DUTY COMPENSATION AND ITS TAX TREATMENT 2–3 (2004). The General Accounting Office's name was changed to the Government Accountability Office in July of 2004. *See* GAO Human Capital Reform Act of 2004, Pub. L. No. 108-271.

240. Working Families Tax Relief Act of 2004, Pub. L. No. 108-311, § 104, 118 Stat. 1166, 1168–69. The EITC election was made permanent in 2008. *See* Heroes Earnings Assistance and Relief Tax Act of 2008, Pub. L. No. 110-245 § 102, 122 Stat. 1624, 1625 (codified at I.R.C. § 32(c)(2)(B)(vi)).

241. *See* Theodore Paul Manno, *Federal Income Taxation of Soldiers, Sailors, Airmen and Marines*, 50 S.D. L. REV. 293, 308–09 (2005) (noting that the combat zone pay exclusion had "unintended consequences" by reducing the servicemembers' adjusted gross income and thereby affecting their eligibility for the EITC).

242. *See* Uruguay Round Agreements Act, Pub. L. No. 103-465, § 721(b), 108 Stat. 4809, 5002 (1994) (codified at I.R.C. § 6051(a)(10)).

243. *See, e.g.*, S. REP. NO. 103-412, at 147 (1994) ("By including on a W-2 the amount of nontaxable earned income paid during the year by the Department of Defense, the increased information reporting is intended to allow members of the Armed Forces claiming the EITC to determine more accurately the actual amount of EITC to which they are entitled.").

assists the IRS in administering the benefits and allows the IRS to grant benefits to taxpayers with less fear of fraudulent claims and thus with fewer audits.[244] Similarly, any technical fix for the difficulty of care situation should address inconsistent third-party reporting by requiring reporting of nontaxable caregiver payments.[245]

As noted above, Congress could allow opt-in taxation for those low-income caregivers who would benefit more from having taxable income, similar to the option available for combat pay.[246] To the extent that untaxed payments currently go entirely unreported, this option would also allow family caregivers to build Social Security and Medicare credits, and ameliorate the generational poverty that caregiving can produce.[247]

A purely optional exclusion, however, is problematic on administrability and antipoverty grounds. Lower income taxpayers who *should* opt to include difficulty of care income are less likely to understand the forms and instructions and may underclaim their benefits. Researchers Gleason and Tong at the Office of Tax Analysis, U.S. Department of the Treasury, found that the election for combat pay "makes certain personnel worse off because it adds more complexity to the EITC calculation"[248] and EITC optimization rates were lower for servicemembers who should have opted in to taxation. The gross income exclusion election increases compliance costs and taxpayer confusion and will likely lead to underutilization of benefits. Rather than an option, Gleason and Tong advocate for a mandatory inclusion of combat pay in gross income, which would ensure that the neediest families receive the EITC. Congress could consider this approach for difficulty of care payments as well, assuming the EITC remains tied to income.

There are other options. First, Congress could expressly provide that difficulty of care payments be considered earned income for EITC purposes but not be included in gross income. Congress chose this option for the child tax credit when fixing the problem of military combat pay.[249]

---

244. *See* I.R.S. Pub. 1415, at 14 (2019) (graphically showing the "Effect of Information Reporting on Individual Income Tax Reporting Compliance, Tax Years 2011–2013").

245. In order to standardize tax reporting and reduce confusion, Congress may want to also address worker classification in the caregiving context.

246. *See* I.R.C. § 32(c)(2)(B) (providing sources of funds that "shall [not] be taken into account" for the calculation for earned income).

247. *See* Kaplan, *Family Caregiving*, *supra* note 16, at 631. *See also supra* note 116 (discussing the extent to which payments not subject to income tax may be mistakenly excluded from employment tax).

248. Suzanne Gleason & Patricia K. Tong, *Nontaxable Combat Pay Election and the Earned Income Tax Credit*, 2015 IRS-TPC RSCH. CONF. 207, 214.

249. *See* Working Families Tax Relief Act of 2004, Pub. L. No. 108-311, § 104(a), 118 Stat.

This solution would avoid the complexity of an election, and it would ensure that families would not accidentally lose the EITC. However, this subsidy design would not be targeted to those most in need and could provide substantial benefits to moderate-income taxpayers.[250]

Second, Congress might direct the IRS to automatically determine the option that would maximize a taxpayer's refund.[251] This automatic optimizing strategy could potentially be employed both for combat pay and for difficulty of care income, as well as for any other gross income exclusion that Congress might enact. However, the IRS could not easily take the interplay with caregiver eligibility for health insurance into account when making this calculation.[252] Therefore, a taxpayer would need the option to deviate from the EITC-maximizing decision in order to avoid collateral harm. This is an imperfect solution for the same reasons that an election is problematic.

The solutions proposed above all require legislative action. If Congress does not act, could the IRS take action on its own to act in better conformity with the values supporting community care for adults with disabilities? The disorienting whiplash between PMTA 2010-07, Notice 2014-7, and *Feigh* was in part caused by a process failure: the IRS did not seek public comment prior to changing its longstanding position in 2014. It is possible that a public comment process might have alerted the government to the conflicts and uncertainties that awaited after Notice 2014-7 and warned the Treasury of the need for legislative harmonization of policy.[253] With input from stakeholders, Notice 2014-7 might also have anticipated more of the administrative problems that occurred and tried to better address inaccurate and inconsistent reporting. However, given the clashing and outdated provisions and language of the Code,

1166, 1168–69 (codified at I.R.C. § 24(d)(1)) (stating that for the purposes of calculating a taxpayer's earned income to determine the amount of the taxpayer's child tax credit, "any amount excluded from gross income by reason of section 112 shall be treated as earned income which is taken into account in computing taxable income for the taxable year").

250. *See* Petitioners' Seriatim Answering Brief, *supra* note 184, at 24–25.

251. Thanks to Professor Leslie Book for this suggestion.

252. The IRS has knowledge of taxpayers' health insurance status after the fact, based on information in returns filed under I.R.C. §§ 6055, 6056, and 36B(f)(3). *See generally* I.R.S. Notice 2020-76, § 2, 2020-47 I.R.B. 1058, 1058. However, this retroactive information is not sufficient to understand a taxpayer's *current* circumstances relevant to their health insurance status and options.

253. Benefits of stakeholder participation in the development of guidance include giving the agency better information so that it makes better rules. Leslie Book, *A New Paradigm for IRS Guidance: Ensuring Input and Enhancing Participation*, 12 FLA. TAX REV. 517, 525 (2012) ("Rulemaking that fails to benefit from the collective wisdom of those whom the agency is regulating can have significant adverse effects."). Also, public participation in the guidance process bolsters the democratic legitimacy of administrative agencies. *See* Hickman, *Coloring Outside the Lines*, *supra* note 205, at 1805.

even the best-informed IRS guidance could not have pulled § 131 into the twenty-first century.

CONCLUSION

While technical fixes such as those adopted for servicemembers in combat zones would undoubtedly help family caregivers, policymakers should take a deeper look at how the tax code can support community integration and care. Opt-in or targeted taxation and improved third-party reporting would not fix the problematic foster care framework or fully incorporate the values recognized by the Supreme Court in *Olmstead*. The development of our national caregiving strategy should involve a review of federal laws to identify areas, like § 131, where the laws are outdated and fail to reflect contemporary values.[254]

Siloed policymaking hurts people with disabilities and their caregivers. The outdated paternalistic language of the tax code is inconsistent with contemporary values of autonomy and self-direction expressed in Medicaid and in national disability policy, particularly since the Americans with Disabilities Act of 1990. Better coordination between tax and health care policy can further these values and the goals of community integration and mitigate some of the hardships facing family caregivers by making financial supports more accessible.

254. It is notable that the Family Caregiving Advisory Council, established by the RAISE Act to develop a "Family Caregiving Strategy," includes individuals who are care recipients as well as care providers. *See* RAISE Family Caregivers Act, Pub. L. No. 115-119, §§ 3, 4(b), 132 Stat. 23, 23–25 (2018); *RAISE Family Caregiving Advisory Council*, ADMIN. FOR CMTY. LIVING, https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council [https://perma.cc/8AJD-LQNR] (last visited Dec. 4, 2020) (providing biographical information on each of the members of the Advisory Council, including their experiences as caregivers and care recipients). Including marginalized voices in policymaking is a significant step toward living our professed values.