

Policy Challenges for Grandparents Caring for Grandchildren with Disabilities

Madonna Harrington Meyer, PhD, *Syracuse University*

Ynesse Abdul-Malak, PhD, *Colgate University*

ABSTRACT

Childhood disability rates in the US are increasing, but supports for families are not. As a result, US grandparents provide a great deal of care for grandchildren with disabilities. When they do, they face a myriad of social policy challenges. Here we explore three such challenges: (1) how access to employment benefits such as paid vacation, paid sick leave, paid parental leave, or affordable, high quality childcare shapes grandparent care work; (2) how access to poverty-based, social assistance programs, such as SNAP, SSI, and Medicaid, shapes grandparent care work; and (3) how access to disability policies and programs, such as those pertaining to accessible classrooms, parks, or apartments, shapes grandparent care work. We augment this assessment of policies with quotes from fifty interviews we conducted with grandparents caring for grandchildren with disabilities. We found that grandparents were providing childcare, bathing, feeding, transportation, and therapy; helping with homework; accompanying grandchildren for medical care; paying for everything from groceries to surgeries; and assisting with technical medical care. Several were also advocating for their grandchildren with administrators at SNAP, SSI, Medicaid, public schools, park districts, and landlords. Caring for grandchildren with disabilities gives many grandparents a great deal of joy, satisfaction, and purpose. Although most are eager and happy to help, doing so may adversely impact their financial, social, emotional, and physical wellbeing. Those with sufficient resources may be more readily able to absorb the impact, but those who provide the most care with the fewest resources are more likely to deplete their savings, incur new debts, reduce or end employment, restrict social lives, and forego travel plans. They are also more likely to experience anxiety and emotional distress, have disabilities of their own, and neglect their physical wellbeing through a lack of exercise, improper diets, and delayed medical and dental care.

Keywords: grandparenting, childhood disabilities, care work

Desafíos de política para los abuelos que cuidan a nietos con discapacidades

RESUMEN

Las tasas de discapacidad infantil en los EE. UU. Están aumentando, pero los apoyos para las familias no. Como resultado, los abuelos de los Estados Unidos brindan una gran atención a los nietos con discapacidades. Cuando lo hacen, se enfrentan a una miríada de desafíos de política social. Aquí exploramos tres de estos desafíos: (1) cómo el acceso a beneficios laborales como vacaciones pagadas, licencia por enfermedad remunerada, licencia parental remunerada o cuidado infantil asequible y de alta calidad configura el trabajo de cuidado de los abuelos; (2) cómo el acceso a programas de asistencia social basados en la pobreza, como SNAP, SSI y Medicaid, configura el trabajo de cuidado de los abuelos; y (3) cómo el acceso a las políticas y programas de discapacidad, como los relacionados con aulas, parques o apartamentos accesibles, configura el trabajo de cuidado de los abuelos. Aumentamos esta evaluación de políticas con citas de cincuenta entrevistas que realizamos con abuelos que cuidan a nietos con discapacidades. Descubrimos que los abuelos brindaban cuidado de niños, baño, alimentación, transporte y terapia; ayudando con la tarea; nietos acompañantes para atención médica; pagar por todo, desde comestibles hasta cirugías; y asistencia con asistencia médica técnica. Varios también abogaban por sus nietos con administradores de SNAP, SSI, Medicaid, escuelas públicas, distritos de parques y propietarios. Cuidar a los nietos con discapacidades les da a muchos abuelos una gran alegría, satisfacción y propósito. Aunque la mayoría está ansiosa y feliz de ayudar, hacerlo puede afectar negativamente su bienestar financiero, social, emocional y físico. Aquellos con recursos suficientes pueden ser más capaces de absorber el impacto, pero aquellos que brindan la mayor atención con la menor cantidad de recursos tienen más probabilidades de agotar sus ahorros, incurrir en nuevas deudas, reducir o terminar el empleo, restringir la vida social y renunciar a los planes de viaje. También son más propensos a experimentar ansiedad y angustia emocional, tener sus propias discapacidades y descuidar su bienestar físico por falta de ejercicio, dietas inadecuadas y atención médica y dental tardía.

Palabras clave: abuelos, discapacidades infantiles, trabajo de cuidado

祖父母养育残疾孙辈所面临的政策挑战

摘要

美国儿童残疾率正在上升，但对家庭提供的支持却没有增加。结果，美国祖父母为身患残疾的孙辈提供了极大的照顾。当他们这么做时面临着许多社会政策挑战。我们在此探究三种这类挑战：(1) 对例如带薪假期、带薪病假、带薪产假、或可负担的高质量儿童护理等员工福利的获取如何影响祖父母对孙辈的护理工作；(2) 对基于贫困的社会协助项目，例如补充营养援助计划（SNAP）、补充保障收入（SSI）、医疗补助（Medicaid）的获取如何影响祖父母对孙辈的护理工作；(3) 对残疾政策及相关项目，例如那些与残疾人教室、公园或公寓有关的获取如何影响祖父母对孙辈的护理工作。通过与那些养育残疾孙辈的祖父母们进行的50次面谈得出的引述，我们对该政策评估进行了阐述。我们发现，祖父母曾提供儿童护理、洗澡、喂食、交通和治疗；帮助完成家庭作业；陪同孙辈进行医疗；支付从杂货到手术等一切费用；协助技术医疗。几位祖父母还曾在SNAP、SSI、Medicaid、公立学校、公园区域和房东管理员面前公开支持孙辈。教养残疾孙辈为许多祖父母带来了极大的快乐、满足和目的。尽管大多数祖父母都乐意帮助，但这样做可能会对其经济、社会、情感和身体健康造成消极影响。那些拥有充足资源的祖父母可能更能准备好承受这些影响，但那些用最少资源提供最多护理的祖父母更可能耗尽其储蓄、引起新债务、较少或终止就业、限制社交生活、放弃旅行计划。他们也更可能经历焦虑和情感痛苦，并由于缺少锻炼、不协调饮食、医疗及口腔护理拖延而忽视其个人的身体健康。

关键词：祖父母教养，童年残疾，护理工作

When one of her twin grandsons was diagnosed with Down syndrome and the other was diagnosed with autism, Marsha and her husband moved to a new city and changed jobs so that they would be nearby to help. Now sixty-four, Marsha has become a real estate agent mak-

ing her job flexible and allowing her to care for her grandsons. She rearranges her schedule constantly to care for them days, evenings, and weekends. She and her husband take them to doctor and therapy appointments and look after them during sick or snow days (Harrington Meyer 2014).

When the second was diagnosed, it became imperative that we live close. They needed family I needed something very flexible, so I could help at various times of the day and week. I just can't do a Monday through Friday job. I gave up paid vacation and paid sick leave when I went into real estate. I needed to be available to help with the kids, especially because they have special needs.

In addition to giving up benefits such as paid vacation and sick leave, employer-based health insurance, and private pensions, Marsha paid for training to become a licensed real estate agent. Moreover, she and her husband help with some of the boys' expenses and plan to continue to do so. As a result, their incomes and retirement nest eggs are much smaller than they had expected they would be. Thus, they both plan to work for another ten years, until Marsha is seventy-four (Harrington Meyer, 2014).

I would have retired if I could have, but financially we could not. We needed more money, and we wanted to be able to help the kids with financial strain. It was a big financial strain on the kids to have two sons with special needs.

Marsha and her husband have learned what many other grandparents have learned: childhood disability rates in the US are increasing, but supports for families are not (Hogan, 2012; Zablotzky et al., 2019). Roughly 17 percent of US children have developmental

disabilities (Center for Disease Control, 2019; Hogan, 2012; Kraus, 2017; Zablotzky et al., 2017). As a result, US grandparents provide a great deal of care for grandchildren with disabilities. When they do so, they face a myriad of social policy challenges. Here we explore three such challenges: (1) how access to employment benefits such as paid vacation, paid sick leave, paid parental leave, or affordable, high quality childcare shapes grandparent care work; (2) how access to poverty-based, social assistance programs, such as SNAP, SSI, and Medicaid, shapes grandparent care work; and (3) how access to disability policies and programs, such as those pertaining to accessible classrooms, parks, or apartments, shapes grandparent care work.

Grandparents are often highly coveted sources of grandchild care because they tend to be more flexible, lower cost, and reliable (Silverstein & Lee, 2016). Grandparents are generally much more nimble than organized daycare in that they are able and willing to rearrange their schedules to care for grandchildren before school, after school, evenings, weekends, holidays, snow days, and sick days (Cherlin & Furstenberg, 1992; Harrington Meyer, 2012, 2014; Loe, 2011; NACCRRRA, 2008). They often provide care for free or at a very low cost. Moreover, they often share parenting styles and family values with their adult children (Barnett et al., 2012; Bengtson, 2001; Bengtson & Oyama, 2010; Hoang & Kirby, 2019; May et al., 2012; Musil et al., 2013; Silverstein & Giarrusso, 2010).

Grandparenting varies by socio-demographic factor, including gender, race, socioeconomic standing, and family composition. Grandmothers are more likely to provide care than grandfathers, Hispanic grandparents are more likely to live in multigenerational households and to stay in those households longer, and grandparents are more likely to provide care when their adult children are single parents (Harrington Meyer, 2014; Hayslip et al., 2019; Lou et al., 2012; Silverstein & Lee, 2016). African Americans are more likely to be custodial grandparents, and custodial grandparents are more likely to have lower incomes and to live in poorer housing in poorer neighborhoods (Baker et al., 2008; Livingston & Parker, 2010). Grandparenting is not for everyone; each year, about half of grandparents provide grandchild care, and the remainder does not (Harrington Meyer, 2014; Livingston & Parker, 2010).

To illuminate how social supports shape grandparent care work, we integrate excerpts from our forthcoming manuscript, *Grandparenting Children with Disabilities*.¹ We interviewed fifty grandparents who care for grandchildren diagnosed with disabilities. Interviews were transcribed verbatim; however, names have been changed to protect confidentiality. Like other studies, we found that the amount of support grandparents provide varies considerably (Hayslip et al., 2019; Livingston & Parker, 2010; Lou et al., 2012). Some live far away and help one weekend a month, some live nearby and help several times a week, some live in the same

house and help every day, and some have become custodial grandparents and provide around-the-clock care and supervision. The types of care they provide also vary considerably and often include assisting with feeding, bathing, dressing, medicating, and transportation. Many help with homework, therapies, lessons, and doctor visits. Some assist with medical procedures, oxygen and feeding tubes, specialized wheelchairs, and other medical equipment. They often pay for expenses, including groceries, rent, utilities, nurse's aides, private school tuition, therapies, and legal fees. Several also advocate for their grandchildren, taking on programs like Medicaid, public schools, and landlords to garner the services their grandchildren need.

During our interviews, we found a great deal of joy about their special relationships. For example, Colleen, a sixty-two-year-old married mother of four and grandmother of nine, cares for seven-year-old Sam and two-year-old Kit, who both are diagnosed with Down syndrome. She avowed, "We love each other immensely I love all my grandkids. But these two, I just love everything about them." We also found frustration that US social policies did not provide more supports for families. Lizzy is a fifty-year-old divorced mother of one and grandmother of three. Her oldest grandson, Mark, who is twelve and has ADHD, has lived in her custody since he was two months old because his mother was addicted to drugs and his father died of a heroin overdose. Like several grandparents we interviewed, she found that there were

far too few resources and programs for grandparents of grandchildren with disabilities. She explained, “There are not many programs around here for anything like special needs So there is not support.”

Lack of Federal Policies for Working Families

Studies suggest that grandparents in the US provide more care than grandparents in many other countries because the US does not provide federal policies that help families juggle work and childcare (Baker et al., 2008; Igel & Szydlik, 2011). Igel and Szydlik (2011) find that in countries where policies help young families juggle employment and parenting, grandparents provide less intensive childcare. In countries with few such policies, grandparents provide more childcare. The US does not guarantee paid vacation, paid sick time, paid parental leave, or high quality affordable daycare (Harrington Meyer, 2014; Igel & Szydlik, 2011). Some US employees have access to these benefits through their jobs, but employers are more likely to offer these benefits to their higher paid and full-time employees (Glynn, 2012). The lack of federal guarantees makes it hard for both parents and grandparents to juggle work and childcare.

Paid Vacation

Although 127 countries guarantee paid vacation to workers, the US does not (Glynn, 2012; Maye, 2019). Instead, 77 percent of US workers receive paid vacation benefits through their employer, but access varies markedly by hours

and pay (Maye, 2019). Just 40 percent of part-time workers, compared to 90 percent of full-time workers, have paid vacation days (Maye, 2019). Roughly 52 percent of workers in the bottom quartile, compared to 91 percent in the top quartile, have paid vacation (Maye, 2019). Women, blacks, and Hispanics, because they are more likely to be in part-time or lower-waged work, tend to be less likely to have paid vacation time (Glynn, 2012). Employed parents who do not have paid vacation may have little choice but to call on grandparents for childcare.

Paid Sick Leave

The US is the only developed country that does not guarantee workers paid sick leave (Boesch, 2018; Glynn, 2012). Instead, workers receive paid sick leave as an employee benefit, but access varies markedly. While most public sector employees receive paid sick leave, in 2018, 29 percent of private sector workers did not (Boesch, 2018). Currently, 61 percent of part-time workers, 69 percent of very low-wage workers, and 48 percent of service workers do not have paid sick days (Boesch, 2018). Hispanic workers are 27 percent less likely to have paid sick leave compared to white workers, and only 49 percent of Hispanic women have access to paid sick leave (Boesch, 2018). The lack of federal guarantees for paid sick leave makes it more likely that families will turn to grandparents for care.

Paid Parental Leave

Although 180 countries offer paid maternity leave and eighty-one offer paid

paternity leave, the US offers neither (Heymann, 2013). According to Bureau of Labor Statistics (BLS, 2018), only 17 percent of the civilian labor force had access to paid family leave, which includes maternity and paternity leave. Workers are more likely to be offered paid family leave if they are full-time, higher paid, and in larger firms (Glynn, 2012). The US guarantees unpaid leave through the Family and Medical Leave Act, and the BLS (2018) reports that in 2018, 89 percent of civilian workers had access to unpaid family leave. However, to be able to take unpaid leave, employees must have worked with the company for twelve months, worked at least 1,250 hours during the preceding twelve months, and worked for an employer with at least fifty employees within a seventy-five-mile radius (BLS, 2018; Heymann, 2013). Nearly 74 percent of workers earning over \$100,000 qualify, compared to 39 percent of earners making \$20,000 (Heymann, 2013). Even when workers qualify for the program, many cannot afford to take advantage because they cannot afford to go without pay (Glynn, 2012). In the absence of paid parental leave, families may turn to grandparents to help them balance work and family (Harrington Meyer, 2014).

Affordable High Quality Child Care

The lack of affordable quality daycare options puts tremendous stress on young families, particularly when children have disabilities. Among parents with a child under five, 83 percent reported that finding quality affordable

childcare was a serious problem in their area (Malik et al., 2018). The US offers childcare support via tax subsidies, tax credits, and subsidized childcare (Malik et al., 2018). However, of the low-income families eligible for subsidized childcare, only 15 percent receive it due to long waiting lists and insufficient funding (Malik et al., 2018). Many childcare facilities do not accommodate children with disabilities; many are inaccessible and relatively few provide needed therapies or assistants, facilitate integrated learning and play, or work cooperatively with parents on solving problems that may arise at daycare (Booth-LaForce & Kelly, 2004; Boyle et al., 2011; DeVore & Bowers, 2006; Gaines & Curry, 2011; Hogan, 2012). Who cares for children with disabilities is particularly important because studies show that they are more likely to suffer physical, sexual, and emotional abuse and neglect, which adversely affects wellbeing across the life course (Cicchetti & Valentino, 2015; Maclean et al., 2017; McDonnell et al., 2019; Spencer et al., 2005; Sullivan & Knutson, 2000). Adult children often regard grandparents as the most capable and trustworthy source of childcare for children with disabilities (Barnett et al., 2012; Bengtson, 2001; Bengtson & Oyama, 2010; Hoang & Kirby, 2019; May et al., 2012; Musil et al., 2013; Silverstein & Giarrusso, 2010; Silverstein & Lee, 2016). Given the dearth of affordable high-quality options for children with disabilities, working parents may have few options other than relying on grandparents for childcare.

High quality daycare is not only an issue for youngsters. When growing

children have disabilities, families often struggle to find after school and summer programs. Chris says they always expected to move closer to the grandchildren when they retired, but they never expected to provide this much grandchild care (Harrington Meyer & Abdul-Malak, forthcoming). Chris is a sixty-seven-year-old married mother of two. She and her husband, who is on the heart transplant list, moved across the country to provide care for their two grandchildren, Wendy, who is ten and diagnosed with anxiety disorder and has autism-like symptoms, and Mark, who is seven and diagnosed with ADHD and Oppositional Defiant Disorder. Mark is prone to violent outbursts, and as he grows stronger, Chris and her husband face growing difficulties containing the violence.

I was a bit surprised, once we moved here, that we have the kids so much I thought Mark would be in a structured after-school program; we thought he needed that, that it would be best for him. But he is not. I thought we would just have Wendy; she is much easier to watch. But we have them both. It's much more childcare than we expected.

Because of his violent outbursts, Mark has been expelled from several programs. Chris feels there should be many more programs for Mark that can accommodate his violence, provide him with the structure he needs, and provide his parents and grandparents with respite.

Reliance on Poverty-Based Social Welfare Programs

Grandparents in the US also tend to be called upon for help more often than in other countries because social welfare programs in the US are primarily poverty-based rather than universal (Igel & Szydlik, 2011). As such, benefits tend to be small and emphasize gatekeeping. Key poverty-based social welfare programs include Supplemental Nutrition Assistance Program (SNAP), Supplemental Security Income (SSI), and Medicaid.

SNAP is a poverty-based program that provides food benefits to low income people. Although the eligibility rules and benefit levels for SNAP are set federally, state variation is substantial (Center on Budget and Policy Priorities, 2019b). Generally, households of three qualify if gross monthly income is below 130 percent of the poverty line, although households with people who are older or have disabilities do not have to meet this qualification (Center on Budget and Policy Priorities, 2019b). SNAP limits assets to \$2,250 for households without and \$3,500 for households with people who are older or have disabilities (Center on Budget and Policy Priorities, 2019b). To obtain benefits, individuals must overcome substantial red tape, including attending interviews and providing required documents, such as pay stubs, house payments, birth certificates, immigration records, and deductible expenses (Center on Budget and Policy Priorities, 2019b; Herd & Moynihan, 2019). Beneficiaries may have to reapply as of-

ten as every six to twelve months (Center on Budget and Policy Priorities, 2019b). Nonetheless, SNAP take-up rates are high; 85 percent of individuals who qualify for SNAP receive it (Center on Budget and Policy Priorities, 2019b). Benefits are so meager that an estimated 50 percent of households on SNAP remain food insecure (Coleman-Jensen et al., 2018). When families struggle to put enough food on the table they may turn to grandparents to provide financial assistance, cohabit to combine resources or take custody of the grandchildren (Baker et al., 2008; Harrington Meyer, 2014; Luo et al., 2012; Silverstein & Lee, 2016).

Like many custodial grandparents, Elsie pays for absolutely everything but does not receive sufficient support from poverty-based welfare programs (Harrington Meyer & Abdul-Malak, forthcoming). Initially, Elsie, age sixty-two, had her daughter and grandson, Curt, both of whom have disabilities, living with her. When her daughter stole money to buy drugs, Elsie told her to leave and she became Curt's sole legal guardian. Curt, now age eleven, has ADHD and learning disabilities. Elsie is unemployed due to her own disabilities and is struggling to support them both on just \$23,000 a year. She has Social Security and Medicare, and Curt has SSI and Medicaid. They are in dire straits, but have not been able to qualify for SNAP.

I pay for everything, his clothes, school supplies, everything. As long as we are together and get both of our benefits, we will

make it I make \$100 a year too much to qualify for SNAP.

SSI provides cash benefits to people who are older or have disabilities if they are sufficiently poor enough to qualify (Center on Budget and Policy Priorities, 2019a). Generally, incomes must be below 75 percent of the federal poverty line, and assets must be below \$2,000 for an individual and \$3,000 for a couple (Center on Budget and Policy Priorities, 2019a). Applicants must overcome administrative burdens, including attending interviews, proving immigration status, or providing financial records, such as pay stubs, lease agreements, or diagnostic records (Herd & Moynihan, 2019). The program has been shrinking for the elderly but growing for those with disabilities (Center on Budget and Policy Priorities, 2019a). The combination of strict asset limits, meager benefits, and administrative burdens means SSI raises relatively few above the federal poverty line. Family members must often turn to each other for income stability as they raise the next generation.

As a grandparent, Connie, age fifty-seven, has expended a lot of time and energy fighting with SSI about benefits (Harrington Meyer & Abdul-Malak, forthcoming). Connie cares for Andy, who is two-and-a-half-years old and diagnosed with cerebral palsy. Andy and his mother live with Connie, and she cares for him about fifty hours a week. Andy receives \$125 a month from SSI. Connie is paid a small stipend for caring for Andy, and her daughter has a full time job. In total they have

less than \$60,000 a year to cover all of their expenses, which Connie says is not enough. Connie and her daughter have worked to obtain more SSI benefits, but in fact, their benefits have been reduced. She wishes SSI benefits were larger and more readily obtained. She becomes alarmed whenever she hears politicians propose reductions.

I don't want to see any cuts at all. It's just, people are barely getting by now and for them to cut even more for people that depend on that, my daughter being one. Then what are they going to do? They're going to have all these people needing this stuff and not being able to get it and no place to get it from. So, it's kind of scary I fought with them, and I'm not fighting any more. If they cut it out, they cut it off, fine. What can you do with \$25 a week? You can't even pay diapers.

Medicaid has expanded in recent decades and now covers more people with disabilities than ever (Musumeci & Foutz, 2017; Shea, 2016). Private insurance is often less desirable for people with disabilities because they may need specialized care such as attendant care, medical equipment or supplies, ongoing physical or speech therapy, assistance with feeding tubes, or IV medications, which are often excluded under private health insurance (Musumeci & Foutz, 2017; Shea, 2016). Medicaid coverage of those services is more robust; thus, it is often the preferred source of health insurance for people with disabilities. Medicaid expanded under Children's

Health Insurance Program (CHIP) and the Affordable Care Act (ACA). Currently 20 percent of the US population, and one-fifth of all healthcare expenses, are covered by Medicaid. The expansion for children has been pronounced. Currently, 43 percent of Medicaid enrollees are children, and Medicaid covers 83 percent of children in poverty (Rudowitz et al., 2019). However, eligibility and benefits vary widely by state. In Louisiana, newborns on Medicaid funded programs are eligible with incomes up to 142 percent of the federal poverty line. By comparison, in Iowa, they may have income up to 380 percent of the federal poverty line.

Currently, Medicaid/CHIP covers 48 percent of children with special healthcare needs—only some of whom are diagnosed with disabilities. Medicaid covers a wide range of health services, including doctor's visits, hospital visits, prescription drugs, prenatal care, home and community-based services, assistive technologies, and mental health services. Medicaid also provides healthcare services that are particularly important for children with disabilities. Early Periodic Screening Diagnosis and Treatment (EPSDT) provides medical, vision, dental, and hearing screenings and interventions; physical, occupational, and speech therapies; and other health-related services to over 13 million children who have special needs (Bruder, 2010; Musumeci and Chidambaram, 2019a 2019b). EPSDT also covers private nursing, medical transportation, personal attendants, and some assistive technologies. Long-Term Services and Supports (LTSS),

through Home and Community-Based Waivers, provide services to keep people with disabilities in the community rather than in long-term care facilities. Generally, LTSS covers services including attendant care, medical equipment, and assistive technologies, but services vary tremendously by state and in some states, waiting lists for services are long (Eiken et al., 2018; Kaiser Family Foundation, 2017; Lewis et al., 2018; Reaves & Musumeci, 2015; Thach & Wiener, 2018).²

Although coverage is often comprehensive, Medicaid beneficiaries must overcome considerable administrative burdens (Herd and Moynihan 2019). Families who pursue care through Medicaid often face difficulties obtaining prompt appointments, garnering Medicaid approval of procedures or prescriptions, securing transportation to healthcare facilities, and coordinating care services (Chien et al., 2017; Kaye, 2019; Medicaid.gov, 2017; Musumeci & Chidambaram, 2019a; Musumeci & Foutz, 2017; Okoro et al., 2018; Rudowitz et al., 2019). Currently, 32 percent of US physicians will not accept Medicaid patients (Herd & Moynihan, 2019; Holgash & Heberlein, 2019; Rudowitz et al., 2019). In addition to completing financial paperwork to prove that they are sufficiently poor, those with disabilities must undergo physical examinations and additional paperwork reviews to prove that they are sufficiently disabled. As a result, some applicants endure delays in eligibility and services (Candisky, 2019; Harrington Meyer & Stevens, 2020; Hirschi et al., 2019; Whittle et al., 2017).

In part due to these administrative burdens, only 75 percent of those who are eligible receive benefits (Moynihan & Herd, 2010; Rudowitz et al., 2016)

Hanna feels that Medicaid and other disability benefits should be more readily available, easier to obtain, and focused on early intervention (Harrington Meyer & Abdul-Malak, forthcoming). At seventy-one, Hanna is a Middle Eastern retired married grandmother who cares for her grandson Danny, now nineteen and diagnosed with autism. Danny missed out on most early intervention programs because he was not able to qualify for Medicaid benefits in time.

I think the government should have made sure that teachers and doctors ... help much earlier. My daughter went to hell navigating the system to get him Medicaid. He didn't get Medicaid until, I think, a couple of years ago.

Whatever headaches are created by Medicaid's administrative burden, not being eligible for benefits can create nightmares (Harrington Meyer & Abdul-Malak, forthcoming). Since the birth of her granddaughter, Jill and her family are drowning in debt. Jill is a forty-eight year-old married mother of three and grandmother of three. She cares for her youngest granddaughter, Minnie, age three months, who is diagnosed with Down syndrome, a heart defect, and an intestinal disorder. Jill works full time from home and also cares for Minnie around the clock several days a week when Minnie's mother is at work. Jill says her daughter and

son-in-law earn \$30 a month too much to qualify for Medicaid in their state, and they now have a \$580,000 medical bill for Minnie's care, a bill that is growing almost daily. None of them have the resources to cover such an enormous bill; Jill is dismayed they are not receiving Medicaid assistance for her granddaughter's considerable medical needs.

Because my son in law makes \$30 too much a month, she will not qualify for supportive Medicaid or anything really as far as the state goes. So their medical bills, they've got a \$580,000 medical bill that's now going to be the responsibility of us, both of us, to try and figure out how to pay ... even though it's a disability, it's not enough a disability for his income to allow her the extra medical coverage to make up the difference for what insurance doesn't cover. \$580,000, right now, and growing. Yeah, we don't even have the latest hospital visit bill back yet ... and, that was only one hospital. She was in two when she was born, so.

Limited Disability Policies and Programs

In addition to employer-based benefits and poverty-based benefits that are available to all, the US provides numerous pieces of legislation and programs designed specifically for people with disabilities. Although such policies aim to increase access and inclusion for people with disabilities, critics point out that disability policies are often dif-

ficult to use and poorly enforced. For example, the Individuals with Disabilities Education Act (IDEA) provides early intervention for infants and toddlers with disabilities until age three and special education for children over three (NECTAC, 2011; Stuart, 2018; US Department of Education, 2018). Legislation allows parents a role in creating annual Individual Education Plans (IEPs) with schools for students with disabilities, but many families struggle to get the services they need. These procedures are complicated and time-consuming and can be expensive. They are underused, particularly by those with less education and experience navigating paperwork (Araujo, 2009; NECTAC, 2011). At twenty-four months, only 12 percent of eligible children receive early intervention services, and eligible white children receive benefits at five times the rate of eligible black children. Those who are older than three, have families with lower socioeconomic status, and for whom English is not the first language often have more difficulties participating in, and maximizing the usefulness of, IEPs (Araujo, 2009; NECTAC, 2011).

During our interview, Mary noted how poorly this legislation functions for some families (Harrington Meyer & Abdul-Malak, forthcoming). Mary is a sixty-three-year-old mother of two and grandmother of three who attended some college and works part time. Four days a week, she provides childcare for her youngest, Alice, who is four and has been diagnosed with Williams syndrome, autism, and ADHD. At age three, Alice enrolled in public school

for early intervention. Although federal law requires them to do so, and although the family worked with specialists to develop programs that would be beneficial for Alice, the public school did not implement the supports that would encourage Alice's verbalization.

At the time, Alice could only speak five words ... not a good situation. The school had no concept. We brought in pictures of her, lists of her strengths and needs, but they paid no attention. We might as well have burned them. We had taken her to specialists telling them how to create a program for her, saying you are going to have to hire a person to develop a program for her, but it was a nightmare in the school.

Mary says that Alice stayed at public school for four months, and then they moved her to a small private school that emphasizes teaching children to talk. In an ongoing effort to make sure that Alice's needs are met, Mary and her husband have paid for private school. They also hired a lawyer.

Initially, my husband and I paid for part of it. Then we hired an attorney so the public school would have to help pay. We had to demonstrate that the public school was not giving her what she needed. They did an evaluation, but we wanted an independent evaluation. But they said no and tried to take us to due process. They declined an independent evaluation. We were challenging the evaluation the school

had done. We hired an attorney to settle in mediation, and the school gave us a financial settlement so that we could pay for her schooling for two years, plus to pay for the co-pays for the PT and OT in addition to the speech therapy from the school.

For now, Alice's progress is good, but next spring, the two years will end, and the family will have to go back to the public schools for new evaluations and a new education plan. Paying for lawyers to help arrange educational services is challenging for Mary and her family, and utterly impossible for families with fewer resources.

Since 1990, the Americans with Disabilities Act (ADA) guaranteed equal treatment in, and equal access to, employment and public accommodations. Although all businesses and service providers are required to provide reasonable accommodations to employees and consumers with disabilities, many do not. Many of the grandparents we interviewed have no accessible parks in their areas or find that the accessible parks are minimalistic and not well developed. Several grandparents we interviewed talked about traveling long distances to playgrounds that are appropriate for their grandchildren with disabilities (Harrington Meyer & Abdul-Malak, forthcoming). Doris is advocating for more convenient and accessible parks. A fifty-five-year-old retired mother of two, Doris cares for her only biological grandchild. John, age eleven, has been diagnosed with atrophy of the brain, Lennox-Gastaut sei-

zures, and visual and hearing impairments. Doris lives just a few minutes away, and despite her multiple sclerosis, assists with John's feeding tube, ventilator, tracheotomy, and catheter. She wishes that there were more and better equipped accessible parks.

There's all kinds of playgrounds and city parks. And one of them should be, one of them. We shouldn't have to travel out of state to go to a park that is handicap accessible We have some that have handicap accessible swings, but there might be one, one swing. There needs to be more activities for disabled children.

Even when they expend a great deal of time and resources to achieve equitable access, people with disabilities often find their needs are unmet or denied (Dunn & Andrews, 2015; Harlan & Robert, 1998; Priestley, 2003). Andy and his mother live with Connie, and she cares for him about ten hours a day Monday through Friday and then also sits for him occasionally on evenings and weekends (Harrington Meyer & Abdul-Malak, forthcoming). Because he is not mobile, Andy travels in a special wheelchair; additionally, his care requires several heavy pieces of medical equipment. To leave the apartment, Andy and the equipment must all be carried down flights of steps. Connie is not strong enough to do it all. While federal law requires public spaces to be made accessible, the owners of their apartment building have refused to put in ramps on the grounds that the building is private space. Connie and Andy

are typically housebound unless Andy's mom is also there to help get him out of and back into the building.

We don't go out as much because we live in an apartment building and we have stairs ... there's no ramps and that apartment complex doesn't want to put in ramps. We are pretty much stuck in the house so we go out on our deck and get some sun and air and stuff like that. Pretty much stay in all day. During the weekends when his mama's here, we go out. She carries him outside, and we'll either go to this grocery store or we'll go out to the mall or just, we've gone out to dinner with him. But, it's, his equipment is really heavy, and I have to be the one to carry his equipment down the steps to her car, and she carries him. And, I just can't do that by myself.

Thus, in addition to all of her other duties, Connie also spends a great deal of time and energy fighting for a much-needed ramp. So far her efforts have been unsuccessful.

I've looked, and we want to get out of this apartment because it's been fighting tooth and nail with them to trying to approve ramps, and they go, "Oh, no, we're not going to pay for that. You have to."

Connie says that the entire family would readily move to an accessible apartment if they could find one they could afford. She dreams of winning the lottery.

Discussion

The US welfare state provides very little support for children with disabilities or their families. As a result, grandparents provide a great deal of support. The US does not provide federally guaranteed paid vacation, paid sick leave, paid parental leave, or affordable high-quality childcare. When providing assistance for working families, the US relies almost entirely on poverty-based social welfare programs, including SNAP, SSI, and Medicaid. Due to the dearth of federal supports for families, unmet need is substantial, and families turn to grandparents for much needed assistance. In our interviews with fifty grandparents caring for grandchildren with disabilities, grandparents were providing childcare, bathing, feeding, transportation, and therapy; helping with homework; accompanying grandchildren to medical care; paying for everything from groceries to surgeries; and assisting with technical medical care. Several were also advocates for their grandchildren, fighting with administrators at SNAP, SSI, Medicaid, public schools, park districts, and landlords to garner the services their grandchildren need.

Caring for grandchildren with disabilities gives many grandparents a great deal of joy, satisfaction, and purpose. Although most are eager and happy to help, doing so may adversely impact their financial, social, emotional, and physical wellbeing (Harrington Meyer, 2014; Harrington Meyer & Abdul-Malak, forthcoming). Those with sufficient resources may be more read-

ily able to absorb the impact, while those with fewer resources may not. Grandparents who provide the most care for grandchildren with disabilities and have the fewest resources are more likely to deplete their savings, incur new debts, reduce or end employment, restrict social lives, and forego travel plans. They are also more likely to experience anxiety and emotional distress, have disabilities of their own, and neglect their physical wellbeing through a lack of exercise, improper diets, and delayed medical and dental care.

Nearly all of the grandparents we interviewed need more social, medical, and financial support than they are receiving (Harrington Meyer & Abdul-Malak, forthcoming). They need policies and programs that will assist them as they care for their grandchildren with disabilities.

Federally guaranteed paid vacation days, sick days, and parental leaves would give all US families much needed support. If parents were more readily able to juggle work and family responsibilities, less would fall upon grandparents. Better access to high-quality affordable childcare that was much more responsive to the needs of children with disabilities would also provide much needed care for children and respite for families. Streamlining the application processes for poverty-based programs, such as SNAP, SSI, and Medicaid, and expanding the benefits would reduce challenges for families caring for grandchildren with disabilities. Finally, disability policies never seem to go far enough; a lack of responsiveness and accessibility often confounds grand-

parents. Better implementation and enforcement of a wide array of disability policies would enable children with disabilities to be more fully engaged. Because they have less income, education, and experience from which to draw, such policy reforms would make the biggest difference for families with relatively fewer resources.

References

- Araujo, B. E. (2009). Best practices in working with linguistically diverse families. *Intervention in School and Clinic, 45*(2), 116-123. <https://doi.org/10.1177/1053451209340221>
- Baker, L. A., Silverstein, M., & Putney, N. M. (2008). Grandparents raising grandchildren in the United States: Changing family forms, stagnant social policies. *Journal of Societal & Social Policy, 7*, 53-69. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2888319/>
- Barnett, M. A., Mills-Koonce, W. R., Gustafsson, H., Cox, M., & Family Life Project Key Investigators. (2012). Mother-grandmother conflict, negative parenting, and young children's social development in multigenerational families. *Family Relations, 61*(5), 864-877. <https://doi.org/10.1111/j.1741-3729.2012.00731.x>
- Bengtson, V. L. (2001). Beyond the nuclear family: The increasing importance of multigenerational bonds: The Burgess award lecture. *Journal of Marriage and Family, 63*(1), 1-16. <https://doi.org/10.1111/j.1741-3737.2001.00001.x>
- Bengtson, V. L., & Oyama, P. S. (2010). Intergenerational solidarity and conflict. In M. A. Cruz-Saco & S. Zelenev (Eds.), *Intergenerational solidarity* (pp. 35-52). New York: Palgrave Macmillan. https://doi.org/10.1057/9780230115484_3
- Boesch, D. (2018). *The uneven expansion of access to paid sick days*. Center for American Progress. Retrieved from <https://www.americanprogress.org/issues/women/news/2018/08/30/457309/uneven-expansion-access-paid-sick-days/>
- Booth-LaForce, C., & Kelly, J. F. (2004). Childcare patterns and issues for families of preschool children with disabilities. *Infants & Young Children, 17*(1), 5-16. https://journals.lww.com/iycjournal/Fulltext/2004/01000/Childcare_Patterns_and_Issues_for_Families_of.4.aspx

- Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M. Visser, S., & Kogan, M.D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics*, 127(6), 1034–1042. <https://doi.org/10.1542/peds.2010-2989>
- Bruder, M. B. (2010). “Early childhood intervention: A promise to children and families for their future.” *Exceptional Children*, 76(3), 339–355. <https://doi.org/10.1177/001440291007600306>
- Bureau of Labor Statistics (BLS). (2018). *Access to Paid and Unpaid Family Leave in 2018*. Retrieved from <https://www.bls.gov/opub/ted/2019/access-to-paid-and-unpaid-family-leave-in-2018.htm>
- Candisky, C. (2019, March 5). Medicaid backlog delaying care for needy and payments for health providers. *Akron Beacon Journal*. Retrieved from <https://www.beaconjournal.com/news/20190304/medicaid-backlog-delaying-care-for-needy-and-payments-for-health-providers/1>
- Centers for Disease Control and Prevention. (2019). *CDC’s work on developmental disabilities*. <https://www.cdc.gov/ncbddd/developmentaldisabilities/about.html>
- Center on Budget and Policy Priorities. (2019a). *Policy basics: Supplemental Security Income (SSI) Program*. <https://www.cbpp.org/research/social-security/policy-basics-supplemental-security-income>
- Center on Budget and Policy Priorities. (2019b). *Policy basics: An introduction to SNAP*. <https://www.cbpp.org/research/food-assistance/policy-basics-the-supplemental-nutrition-assistance-program-snap>
- Cherlin, A., & Furstenberg Jr, F. F. (1992). *The new American grandparent*. Boston, MA: Harvard University Press.
- Chien, A. T., Kuhlthau, K. A., Toomey, S. L., Quinn, J. A., Okumura, M. J., Kuo, D. Z., ... & Janmey, I. (2017). Quality of primary care for children with disabilities enrolled in Medicaid. *Academic Pediatrics*, 17(4), 443-449. <https://doi.org/10.1016/j.acap.2016.10.015>
- Coleman-Jensen, A., Rabbitt, P. M., Gregory, A. C., & Singh, A. (2018). *Household Food Security in the United States in 2017*, (ERR-256). U.S. Department of Agriculture, Economic Research Service. <https://www.ers.usda.gov/webdocs/publications/90023/err-256.pdf?v=0>

- Cicchetti, D., & Valentino, K. (2015). An ecological-transactional perspective on child maltreatment: Failure of the average expectable environment and its influence on child development. In D. Cicchetti & D. J. Cohen (Eds.), *Developmental psychopathology* (pp. 129-201). New Jersey: John Wiley & Sons, Inc. doi: 10.1002/9780470939406.ch4
- DeVore, S., & Bowers, B. (2006). Childcare for children with disabilities. *Infants & Young Children*, 19(3), 203–212. https://journals.lww.com/iycjournal/Abstract/2006/07000/Childcare_for_Children_With_Disabilities__Families.5.aspx
- Dunn, D. S., & Andrews, E.E. (2015). Person-First and Identity-First Language: Developing Psychologists' Cultural Competence Using Disability Language. *American Psychologist*, 70(3), 255–264. <https://doi.org/10.1037/a0038636>
- Eiken, S., Sredl, K., Burwell, B., & Amos, A. (2018). *Medicaid Expenditures for Long-Term Services and Supports in FY 2016*. Medicaid.Gov. <https://www.medicare.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpenditures2016.pdf>
- Gaines, K. S. & Curry, Z. D. (2011). The Inclusive Classroom: The Effects of Color on Learning and Behavior. *Journal of Family & Consumer Sciences Education*, 29(1), 46-57. <https://natefac.org/Pages/v29no1/v29no1Gaines.pdf>
- Glynn, J. S. (2012). *Working Parents' Lack of Access to Paid Leave and Workplace Flexibility*. Center for American Progress. <https://www.americanprogress.org/issues/economy/reports/2012/11/20/45466/working-parents-lack-of-access-to-paid-leave-and-workplace-flexibility/>
- Harlan, S. L. & Robert, P.M. (1998). The social construction of disability in organizations: Why employers resist reasonable accommodation. *Work and Occupations*, 25(4), 397–435. <https://doi.org/10.1177/0730888498025004002>
- Harrington Meyer, M. (2012). US grandparents juggling work and grandchildren. In S. Arber & V. Timonen (Eds.), *Contemporary grandparenting: Changing family relationships in global contexts* (pp. 71-90). Bristol, UK: Bristol University Press.
- Harrington Meyer, M. (2014). *Grandmothers at work: Juggling families and jobs*. New York: NYU Press.

- Harrington Meyer, M. & Abdul-Malak, Y. (Forthcoming). *Grandparenting children with disabilities*. New York: Springer Publications.
- Harrington Meyer, M. & Stevens, J. D. (2020). Medicaid for people with disabilities. In D. Lanford (Eds.), *Medicaid: Enrollment, eligibility, and key issues*.
- Hayslip, B., Fruhauf, C. A., & Dolbin-MacNab, M. L. (2019). Grandparents raising grandchildren: What have we learned over the past decade? *The Gerontologist*, 59(3), e152-e163. <https://doi.org/10.1093/geront/gnx124>
- Herd, P., & Moynihan, D. P. (2019). *Administrative burden: Policymaking by other means*. New York: Russell Sage Foundation.
- Heymann, J. (2013). *Children's chances: How countries can move from surviving to thriving*. Boston, MA: Harvard University Press.
- Hirschi, M., Walter, A. W., Wilson, K., Jankovsky, K., Dworetzky, B., Comeau, M., & Bachman, S. S. (2019). Access to care among children with disabilities enrolled in the MassHealth CommonHealth Buy-In program. *Journal of Child Health Care*, 23(1), 6-19. <https://doi.org/10.1177/1367493518777310>
- Holgash, K., & Heberlein, M. (2019). *Physician Acceptance of New Medicaid Patients* [PowerPoint Presentation]. Retrieved from MACPAC.gov: <http://www.macpac.gov/wp-content/uploads/2019/01/Physician-Acceptance-of-New-Medicaid-Patients.pdf>
- Hogan, D. P. (2012). *Family consequences of children of disabilities*. New York: Russell Sage Foundation.
- Hoang, N. P. T., & Kirby, J. N. (2019). A meta-ethnography synthesis of joint care practices between parents and grandparents from Asian cultural backgrounds: Benefits and challenges. *Journal of Child and Family Studies*, 29, 1-15. <https://doi.org/10.1007/s10826-019-01553-y>
- Igel, C. & Szydlik, M. (2011). Grandchild care and welfare state arrangements in Europe. *Journal of European Social Policy*, 21(3), 210–224. <https://doi.org/10.1177/0958928711401766>
- Kaiser Family Foundation. (2017). Waiting List Enrollment for Medicaid Section 1915(c) Home and Community Based Services Waivers. <https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

- Kaye, H. S. (2019). Disability-related disparities in access to health care before (2008–2010) and after (2015–2017) the Affordable Care Act. *American Journal of Public Health, 109*(7), 1015-1021. <https://doi.org/10.2105/AJPH.2019.305056>
- Kraus, L. (2017). *2016 Disability Statistics Annual Report. A Publication of the Rehabilitation Research and Training Center on Disability Statistics and Demographics*. Institute on Disability, University of New Hampshire. https://disabilitycompendium.org/sites/default/files/user-uploads/2016_Annual_Report.pdf
- Lewis, E., Eiken, S., Amos, A., & Saucier, P. (2018). *The Growth of Managed Long-Term Services and Supports Programs: 2017 Update*. Mathematica and Centers for Medicare & Medicaid Services. <https://www.medicare.gov/medicaid/managed-care/downloads/ltss/mltssp-inventory-update-2017.pdf>
- Livingston, G. & Parker, K. (2010). *Since the Start of the Great Recession, More Children Raised by Grandparents*. Pew Research Center Social & Demographic Trends. <https://www.pewsocialtrends.org/2010/09/09/since-the-start-of-the-great-recession-more-children-raised-by-grandparents/>
- Loe, M. (2011). *Aging our way: Lessons for living from 85 and beyond*. New York: Oxford University Press.
- Luo, Y., LaPierre, T. A., Hughes, M. E., & Waite, L. J. (2012). Grandparents providing care to grandchildren: A population-based study of continuity and change. *Journal of Family Issues, 33*(9), 1143-1167. <https://doi.org/10.1177/0192513X12438685>
- Macleon, M. J., Sims, S., Bower, C., Leonard, H., Stanley, F. J., & O'Donnell, M. (2017). Maltreatment risk among children with disabilities. *Pediatrics, 139*(4), 1081-1087. <https://doi.org/10.1542/peds.2016-1817>
- Malik, R., Hamm, K., Schochet, L., Novoa, C., Workman, S., & Jessen-Howard, S. (2018). *America's child care deserts in 2018*. Center for American Progress. <https://cdn.americanprogress.org/content/uploads/2018/12/06100537/AmericasChildCareDeserts20182.pdf>
- May, V., Mason, J., & Clarke, L. (2012). Being there yet not interfering: The paradoxes of grandparenting. In S. Arber & V. Timonen (Eds.), *Contemporary grandparenting: Changing family relationships in global contexts* (pp. 138-158). Bristol, UK: Policy Press.

- Maye, A. (2019). *No Vacation Nation, Revised*. Center for Economic and Policy Research. <https://cepr.net/images/stories/reports/no-vacation-nation-2019-05.pdf>
- McDonnell, C. G., Boan, A. D., Bradley, C. C., Seay, K. D., Charles, J. M., & Carpenter, L. A. (2019). Child maltreatment in autism spectrum disorder and intellectual disability: Results from a population-based sample. *Journal of Child Psychology and Psychiatry*, 60(5), 576-584. <https://doi.org/10.1111/jcpp.12993>
- Medicaid.gov.(2017). *Health Care Experiences of Adults with Disabilities Enrolled in Medicaid Only: Findings from a 2014-2015 Nationwide Survey of Medicaid Beneficiaries*. <https://www.medicaid.gov/medicaid/quality-of-care/downloads/performance-measurement/namcahpsdisabilitybrief.pdf>
- Moynihan, D., & Herd, P. (2010). Red tape and democracy: How rules affect citizenship rights. *The American Review of Public Administration*, 40(6), 654-670. <https://doi.org/10.1177/0275074010366732>
- Musil, C. M., Jeanblanc, A. B., Burant, C. J., Zauszniewski, J. A., & Warner, C. B. (2013). Longitudinal analysis of resourcefulness, family strain, and depressive symptoms in grandmother caregivers. *Nursing Outlook*, 61(4), 225-234. <https://doi.org/10.1016/j.outlook.2013.04.009>
- Musumeci, M., & Chidambaram, P. (2019a). *Medicaid's Role for Children with Special Health Care Needs: A Look at Eligibility, Services, and Spending*. Kaiser Family Foundation. <https://www.kff.org/medicaid/issue-brief/medicaids-role-for-children-with-special-health-care-needs-a-look-at-eligibility-services-and-spending/>
- Musumeci, M. & Chidambaram, P. (2019b). *How Do Medicaid/CHIP Children with Special Health Care Needs Differ from Those with Private Insurance?* Kaiser Family Foundation. <https://www.kff.org/medicaid/issue-brief/how-do-medicaid-chip-children-with-special-health-care-needs-differ-from-those-with-private-insurance/>
- Musumeci, M., & Foutz, J. (2017). *Medicaid Restructuring Under the American Health Care Act and Nonelderly Adults with Disabilities*. Kaiser Family Foundation. <https://www.kff.org/medicaid/issue-brief/medicaid-restructuring-under-the-american-health-care-act-and-nonelderly-adults-with-disabilities/>

- National Association of Childcare Resources and Referral Agencies (NACCRRRA). (2008). *Grandparents: A Critical Childcare Safety Net*. http://www.Naccrra.Org/Sites/Default/Files/Publications/Naccrra_Publications/2012/Grandparentscriticalchildcaresafetynet.Pdf
- NECTAC. (2011). *The Importance of Early Intervention for Infants and Toddlers with Disabilities and Their Families*. <http://www.nectac.org/~pdfs/pubs/importanceofearlyintervention.pdf>
- Ohio Department of Health. (2020). *Family Handbook: For Families of Children with Special Health Care needs in Ohio*. Retrieved from https://odh.ohio.gov/wps/wcm/connect/gov/76444e92-b5c4-43bf-afc9-9fb9ec1e1972/parenthandbook2018-ONHOLD.pdf?MOD=AJPERES&CONVERT_TO=url&CACHEID=ROOTWORKSPACE.Z18_M1HGGIK0N0JO00QO9DDDDM3000-76444e92-b5c4-43bf-afc9-9fb9ec1e1972-miPgxnj
- Okoro, C. A., Hollis, N. D., Cyrus, A. C., & Griffin-Blake, S. (2018). Prevalence of disabilities and health care access by disability status and type among adults—United States, 2016. *Morbidity and Mortality Weekly Report*, 67(32), 882-887. doi:10.15585/mmwr.mm6732a3
- Priestley, M. (2003). *Disability: A life course approach*. Cambridge: Polity Press.
- Reaves, E., & Musumeci, M. (2015). *Medicaid and Long-Term Services and Supports: A Primer*. Kaiser Family Foundation. <https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/>
- Rudowitz, R., Artiga, S., Damico, A., & Garfield, R. (2016). *A Closer Look at the Remaining Uninsured Population Eligible for Medicaid and CHIP*. Kaiser Family Foundation. <https://www.kff.org/uninsured/issue-brief/a-closer-look-at-the-remaining-uninsured-population-eligible-for-medicaid-and-chip/>
- Rudowitz, R., Garfield, R., & Hinton, E. (2019). *10 Things to Know about Medicaid: Setting the Facts Straight*. Kaiser Family Foundation. <https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-medicaid-setting-the-facts-straight/>
- Shea, A. (2016). *Ticket to Work and Health Care: Incentivizing Employment with Medicaid and Medicare*. Administration for Community Living. <https://acl.gov/news-and-events/acl-blog/ticket-work-and-healthcare-incentivizing-employment-medicaid-and-medicare>

- Silverstein, M., & Giarrusso, R. (2010). Aging and family life: A decade review. *Journal of Marriage and Family*, 72(5), 1039–1058. <https://doi.org/10.1111/j.1741-3737.2010.00749.x>
- Silverstein, M., & Lee, Y. (2016). Race and ethnic differences in grandchild care and financial transfers with grandfamilies: An intersectional resource approach. In M. Harrington Meyer & Y. Abdul-Malak (Eds.), *Grandparenting in the United States* (pp. 19-39). New York: Baywood Publishing.
- Spencer, N., Devereux, E., Wallace, A., Sundrum, R., Shenoy, M., Bacchus, C., & Logan, S. (2005). Disabling conditions and registration for child abuse and neglect: A population-based study. *Pediatrics*, 116(3), 609–613. doi:10.1542/peds.2004-1882
- Stuart, Annie. 2018. *Early Intervention: What You Need to Know*. <https://www.understood.org/en/learning-thinking-differences/treatments-approaches/early-intervention/early-intervention-services-who-pays-for-what>
- Sullivan, P. M., & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect*, 24(10), 1257–1273. [https://doi.org/10.1016/S0145-2134\(00\)00190-3](https://doi.org/10.1016/S0145-2134(00)00190-3)
- Thach, N. T., & Wiener, J. M. (2018). *An Overview of Long-Term Services and Supports and Medicaid*. US Department of Health and Human Services. <https://aspe.hhs.gov/basic-report/overview-long-term-services-and-supports-and-medicaid-final-report>
- US Department of Education. (2018). *Individuals with Disabilities Education Act*. <https://sites.ed.gov/idea/>
- Whittle, H. J., Palar, K., Ranadive, N. A., Turan, J. M., Kushel, M., & Weiser, S. D. (2017). “The land of the sick and the land of the healthy”: Disability, bureaucracy, and stigma among people living with poverty and chronic illness in the United States. *Social Science & Medicine*, 190, 181-189. <https://doi.org/10.1016/j.socscimed.2017.08.031>
- Zablotsky, B., Black, L. I., & Blumberg, S. J. (2017). *Estimated Prevalence of Children with Diagnosed Developmental Disabilities in the United States, 2014-2016*, (NCHS Data Brief No 291). National Center for Health Statistics. <https://www.cdc.gov/nchs/data/databriefs/db291.pdf>
- Zablotsky B., Black, L.I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko,

R. H., Blumberg, S. J., Kogan, M. D., Boyle, C. A. (2019). Prevalence and trends of developmental disabilities among children in the US: 2009–2017. *Pediatrics*, 144(4), 1-13.

Notes

- 1 Our sampling and methods are described in detail in Harington Meyer and Abdul-Malak (forthcoming).
- 2 States provide a wide variety of policies and programs for children with disabilities and space limitations prevent us from addressing these variations. One example, however, is Ohio where the Department of Health (2020) provides a *Family Handbook* that describes programs for children with special healthcare needs, including programs for children with medical handicaps and programs designed to help families integrate services.