MEDICAID COVERAGE FOR AUTISTIC INDIVIDUALS: COVERAGE, GAPS, AND RESEARCH NEEDS

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ABSTRACT

The Medicaid program, a federal-state partnership administered by each state with oversight and funding contributions by the federal government, covers more people—including almost 40% of all children—than any other health insurance program in the United States. It is the primary means of coverage for specialized services needed by children with autism spectrum disorder, a range of developmental impairments including autism. This coverage is accomplished through legislation that permits the federal government to waive various statutory limits on state flexibility in benefit design. Research focusing primarily on children has found that Medicaid programs play an important role in supporting individuals on the autism spectrum in gaining and maintaining needed services and supporting their families and caregivers. However, there are important differences in the way states structure and implement their Medicaid programs that have not yet been fully cataloged. Moreover, research on enrollment and service use within the Medicaid program as these children age into adulthood is limited. Studies in this area are needed to ensure adequacy and equity in service availability and to guide states on policy and practice to meet the needs of these patients.

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INTRODUCTION

The Medicaid program is a health care lifeline for more than sixty-eight million Americans—more than one-fifth of the population.[1] It covers almost 40% of all children and more than 40% of all births in the United States.[2] Because of its wide reach, Medicaid also underpins the financial viability of thousands of

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[1] MEDICAID AND CHIP LEARNING COLLABORATIVE, MEDICAID AND CHIP ENROLLMENT TRENDS SNAPSHOT THROUGH JULY 2020 at figure 4, https://www.medicaid.gov/sites/default/files/2020-10/july-medicaid-chip-enrollment-trend-snapshot.pdf.

[2] *See* JOYCE A. MARTIN, BRADY E. HAMILTON, MICHELLE J. K. OSTERMAN & ANNE K. DRISCOLL, BIRTHS: FINAL DATA FOR 2018, NAT'L VITAL STAT. SYS. 2 (2019), https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_13-508.pdf.

providers, including safety net hospitals,[3] nursing homes,[4] and providers of specialized services.[5]

Medicaid coverage is particularly important for patients with certain conditions.[6] In particular, it is the largest source of payment for mental health services in the country.[7] Among those who benefit most from this coverage are children diagnosed with autism spectrum disorder (ASD), [8] a range of developmental disorders, including autism, that can cause difficulties in social, communication, and behavioral functioning.[9] Those diagnosed with ASD are often referred to as being on the "autism spectrum."[10] Services to treat autism-related conditions can be extremely expensive for families of almost any financial means.[11] In many states, Medicaid covers

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[3] PETER CUNNINGHAM, ROBIN RUDOWITZ, KATHERINE YOUNG, RACHEL GARFIELD & JULIA FOUTZ, UNDERSTANDING MEDICAID HOSPITAL PAYMENTS AND THE IMPACT OF RECENT POLICY CHANGES, KAISER FAM. FOUND. 2 (2016), https://www.kff.org/report-section/understanding-medicaid-hospital-payments-and-the-impact-of-recent-policy-changes-issue-brief/.

[4] *Medicaid Works for Seniors*, CTR. ON BUDGET & POL'Y PRIORITIES (Jan. 19, 2018), https://www.cbpp.org/research/health/medicaid-works-for-seniors.

[5] *See Medicaid Works for People with Disabilities*, CTR. ON BUDGET & POL'Y PRIORITIES (Aug. 29, 2017), https://www.cbpp.org/research/health/medicaid-works-for-people-with-disabilities (discussing providers of specialized services required for disability care).

[6] *See* MARYBETH MUSUMECI & PRIYA CHIDAMBARAM, MEDICAID'S ROLE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS: A LOOK AT ELIGIBILITY, SERVICES, AND SPENDING, KAISER FAM. FOUND. 1 (2019), https://www.kff.org/medicaid/issue-brief/medicaids-role-for-children-with-special-health-care-needs-a-look-at-eligibility-services-and-spending/ (discussing conditions like "intellectual/developmental disabilities, physical disabilities, and/or mental health disabilities").

[7] *Behavioral Health Services*, MEDICAID, https://www.medicaid.gov/medicaid/benefits/behavioral-health-services/index.html (last visited Mar. 27, 2021).

[8] There is debate among autistic individuals, self-advocates, and other stakeholders on the optimal language that should be used to refer to individuals on the autism spectrum. Throughout this article, we use identity-first language as it is the stated preference of many adults in the autism community. We acknowledge that language preferences and practices change over time, and this practice may evolve in the future. *See* Lydia Brown, *Identity-First Language*, AUTISTIC SELF ADVOC. NETWORK, https://autisticadvocacy.org/about-asan/identity-first-language/ (last visited Mar. 27, 2021).

[9] *Autism Services*, MEDICAID, https://www.medicaid.gov/medicaid/benefits/autism-services/index.html (last visited Mar. 27, 2021).

[10] *Id.*

[11] *New Research Finds Annual Cost of Autism Has More than Tripled to $126 Billion in the U.S. and Reached £34 Billion in the U.K.*, AUTISM SPEAKS (Mar. 28, 2012), https://www.autismspeaks.org/press-release/new-research-finds-annual-cost-autism-has-more-tripled-126-billion-us-and-reached.

autism-related developmental services regardless of the family's financial status.[12]

Research suggests that Medicaid is highly effective in covering the special needs of ASD patients.[13] However, for many patients, eligibility and coverage change when they reach age eighteen.[14] Variations in coverage over the lifespan and their effects on access to services is an understudied area. This Article describes Medicaid coverage, gaps in that coverage, especially as patients age into adulthood, and the research that is needed to better understand ways to improve coverage availability.

I. THE MEDICAID PROGRAM

A. *Medicaid History*

Medicaid emerged from an effort in the early 1960s to extend access to health care coverage for many of those who were unable to obtain it through employment. The two groups of people in most direct need of help in this regard were the poor and the elderly. In 1960, Congress took an initial step in enacting the Kerr-Mills Act, which created a state-based program to provide coverage for basic health care expenses for patients who were poor and elderly.[15]

In 1965, Congress took the next step, this one major, when it enacted Medicare to cover the elderly[16] and Medicaid, as an extension of the Kerr-Mills Act, to cover four categories of the

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[12] *See* MUSUMECI & CHIDAMBARAM, *supra* note 6, at 4.

[13] *See* Li Wang & Douglas L. Leslie, *Health Care Expenditures for Children with Autism Spectrum Disorders in Medicaid*, 49 J. AM. ACAD. CHILD & ADOLESCENT PSYCHIATRY 1165, 1165 (2010).

[14] Lindsay L. Shea, Robert Field, Ming Xie, Steven Marcus, Craig Newschaffer & David Madnell, *Transition-Age Medicaid Coverage for Adolescents with Autism and Adolescents with Intellectual Disability*, 124 AM. J. ON INTELL. & DEV'L DISABILITIES 174, 174–75 (2019).

[15] Matthew Gritter, *The Kerr-Mills Act and the Puzzles of Health-Care Reform*, 100 SOC. SCI. Q. 2209, 2216, 2221 (2019).

[16] Nancy-Ann Min DeParle, *Celebrating 35 Years of Medicare and Medicaid*, HEALTH CARE FIN. REV., Fall 2000, at 1, 1.

poor—pregnant women, children and their parents, people with disabilities, and the elderly.[17] Those who are elderly and poor can receive benefits under both programs.[18] Although these programs were enacted at the same time and for similar purposes, they are structured and administered differently, which has had important consequences for eligibility and coverage.[19]

Medicare was structured as a single national program centrally administered by the federal government.[20] At the program's start, the Social Security Administration administered it.[21] In 1977, the Health Care Finance Administration, renamed in 2001 as the Centers for Medicare and Medicaid Services (CMS), took over this responsibility.[22] Initial eligibility applied to those age sixty-five and older, and the criteria were expanded in 1972 to include younger beneficiaries who are totally disabled or have been diagnosed with end-stage renal disease (ESRD).[23] In 2001, coverage was made easier for those disabled from amyotrophic lateral sclerosis (ALS).[24]

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[17] 42 U.S.C. § 1396a(a)(10); NAT'L HEALTH POL'Y F., THE BASICS: MEDICAID ELIGIBILITY & BENEFITS 1–2 (Jan. 5, 2016), https://www.nhpf.org/library/the-basics/Basics_Medicaid_01-05-16.pdf.

[18] NAT. HEALTH POL'Y F., *supra* note 17, at 2–3; Diane Rowland & Barbara Lyons, *Medicare, Medicaid, and the Elderly Poor*, HEALTH CARE FIN. REV., Winter 1996, at 61, 66.

[19] Judith D. Moore & David G. Smith, *Legislating Medicaid: Considering Medicaid and Its Origins*, HEALTH CARE FIN. REV., Winter 2005–2006, at 45, 47.

[20] *See* Nancy De Lew, George Greenberg & Kraig Kinchen, *A Layman's Guide to the U.S. Health Care System*, HEALTH CARE FIN. REV., Fall 1992, at 151, 152.

[21] DEP'T OF HEALTH & HUM. SERVS. & CTR. FOR MEDICARE & MEDICAID SERVS., MEDICARE & MEDICAID MILESTONES 1937–2015 3, 7 (2015), https://www.cms.gov/About-CMS/Agency-Information/History/Downloads/Medicare-and-Medicaid-Milestones-1937-2015.pdf.

[22] *Id.* at 2–3.

[23] *Key Milestones in Medicare and Medicaid History, Selected Years: 1965–2003*, HEALTH CARE FIN. REV., Winter 2005–2006, at 1, 1.

[24] Steve Anderson, *A Brief History of Medicare in America*, MEDICARERESOURCES.ORG (Sept. 1, 2019), https://www.medicareresources.org/basic-medicare-information/brief-history-of-medicare; Louise Norris, *Medicare Eligibility for ALS and ESRD Patients*, MEDICARERESOURCES.ORG (Jan. 10, 2019), https://www.medicareresources.org/medicare-eligibility-and-enrollment/medicare-eligibility-for-als-and-esrd-patients/ ("In 2001, Congress passed landmark legislation to add ALS as a qualifying condition for automatic Medicare coverage.").

Medicaid, structured as a federal-state partnership, functions as a series of state-administered programs that operate within federal parameters and with substantial federal financial support.[25] Federal oversight and funding are administered by CMS. The program's authorizing legislation, which is contained in the Social Security Act, specifies some benefits, including inpatient hospital care and physician services, that must be covered for all beneficiaries whose income falls below thresholds set by each state.[26] These thresholds vary widely, and states can opt to cover a broader array of benefits for those with slightly higher incomes.[27] The federal government matches the amount that states spend according to a formula based on the state's average per capita income.[28] For 2021, the matching share varies from 50% for the wealthiest states to 77% for the poorest.[29] Although participation in the program is voluntary, all states have opted in.[30]

The eligibility of poorer families for coverage and the range of covered benefits has expanded substantially since the program's creation.[31] In terms of eligibility, in 1997 Congress enacted a companion program for children in families with

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[25] PENNY THOMPSON, KAISER FAM. FOUND., MEDICAID'S FEDERAL-STATE PARTNERSHIP: ALTERNATIVES FOR IMPROVING FINANCIAL INTEGRITY 2–3 (2004), https://www.kff.org/wp-content/uploads/2013/01/medicaid-s-federal-state-partnership-alternatives-for-improving-financial-integrity.pdf.

[26] Moore & Smith, *supra* note 19, at 50.

[27] *See Medicaid Income Eligibility Limits for Adults as a Percent of the Federal Poverty Level*, KAISER FAM. FOUND. (Jan. 1, 2020), https://www.kff.org/health-reform/state-indicator/medicaid-income-eligibility-limits-for-adults-as-a-percent-of-the-federal-poverty-level.

[28] Social Security Act, 42 U.S.C. § 1397a; *see also* ROBIN RUDOWITZ, KENDAL ORGERA & ELIZABETH HINTON, MEDICAID FINANCING: THE BASICS 1 (2019), http://files.kff.org/attachment/Issue-Brief-Medicaid-Financing-The-Basics.

[29] Federal Financial Participation in State Assistance Expenditures; Federal Matching Shares for Medicaid, the Children's Health Insurance Program, and Aid to Needy Aged, Blind, or Disabled Persons for October 1, 2020 Through September 30, 2021, 84 Fed. Reg. 66,204, 66,205–06 (Dec. 3, 2019).

[30] The last state to participate was Arizona in 1982. *See, e.g.*, CTR. FOR HEALTH CARE STRATEGIES, INC., MEDICAID: A BRIEF HISTORY OF PUBLICLY FINANCIAL HEALTH CARE 2 (2019), https://www.chcs.org/media/Medicaid-Timeline-Fact-Sheet_01.14.20v2.pdf.

[31] GARY SMITH, CILLE KENNEDY, SARAH KNIPPER, JOHN O'BRIEN, USING MEDICAID TO SUPPORT WORKING AGE ADULTS WITH SERIOUS MENTAL ILLNESSES IN THE COMMUNITY: A HANDBOOK 31–35 (2005), https://aspe.hhs.gov/system/files/pdf/74111/handbook.pdf.

incomes slightly higher than the Medicaid limit,[32] known as the Children's Health Insurance Program (CHIP).[33] As of July 2020, that program covered almost seven million children.[34] In 2010, Congress enacted the Patient Protection and Affordable Care Act (ACA), which offers a financial inducement to states[35] to extend eligibility to everyone with an income below 138% of the federal poverty level without regard to category.[36] As of March 2021, thirty-eight states and the District of Columbia had chosen to accept the expansion.[37] Benefits have also grown through a mechanism known as waivers, through which states request that CMS waive federal rules to permit expanded or innovative benefit arrangements.[38] These are the primary bases for Medicaid coverage of services for ASD in the home and the community.[39]

B. *Medicaid Waivers*

The Social Security Act contains two provisions that authorize CMS to approve waiver requests. First, Section 1115

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[32] *Program History*, MEDICAID, https://www.medicaid.gov/about-us/program-history/index.html (last visited Mar. 27, 2021). CHIP programs now cover children in families with incomes up to at least 200% of the federal poverty level in all states. *Id*.

[33] 42 U.S.C. §§ 1397aa–mm.

[34] MEDICAID AND CHIP LEARNING COLLABORATIVE, *supra* note 1, at figure 1.

[35] The Act committed the federal government to paying 90% of the cost of coverage for a larger population of beneficiaries. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (codified as amended 42 U.S.C. § 18022(d)(1)(D)).

[36] 42 U.S.C. § 18051(e)(1)(B); *Medicaid Expansion & What It Means For You*, HEALTHCARE.GOV, https://www.healthcare.gov/medicaid-chip/medicaid-expansion-and-you/ (last visited Mar. 7, 2021) (noting that although the Act expands coverage to households below 133% of the poverty line, "[b]ecause of the way this is calculated, it turns out to be 138% of the federal poverty level.").

[37] *Status of State Medicaid Expansion Decisions: Interactive Map*, KAISER FAM. FOUND. (Mar. 5, 2021), https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/. The ACA, as drafted, mandated that states lose all federal Medicaid matching funds if they did not accept the law's expansion. However, in 2012, the Supreme Court ruled that states that reject the expansion may only lose funding for the expansion. *See* NFIB v. Sebelius, 567 U.S. 519, 587 (2012).

[38] 42 U.S.C. § 18052.

[39] *See* M. Beth Merryman, Nancy A. Miller, Emily Shockley, Karen Goldrich Eskow & Gregory S. Chasson, *State Adoption of Medicaid 1915(c) Waivers for Children and Youth with Autism Spectrum Disorder*, 8 DISABILITY & HEALTH J. 443, 444 (2015).

covers demonstration programs.[40] These programs may be used for experiments in payment reform for providers, use of managed care for administration of benefits, and expanded access to care at home or in the community for beneficiaries who are at risk of institutionalization.[41] Second, Congress added Section 1915 in 1981 to expand CMS's waiver authority.[42] It permits states to vary their Medicaid programs in a number of ways on an ongoing basis. An example of the use of waiver authority in program administration is to permit payment of providers through managed care arrangements operated by private companies, rather than through fee-for-service payments directly from the state.[43]

Of particular importance for autistic individuals, subsection (c) of section 1915 permits CMS to approve broader coverage for home and community-based services (HCBS) for those with developmental disabilities, which are often available regardless of family income.[44] These services may include assistive technology, behavioral support, communication support, family and caregiver training and support, shift nursing, transportation, and physical, occupational, and speech therapy.[45] HCBS coverage may also be available for children through Medicaid's Early Periodic Screening, Diagnostic, and Treatment (EPSDT) program.[46] Benefits under this program are more extensive than those available for autistic adults, as they

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[40] 42 U.S.C. § 1315.

[41] ELIZABETH HINTON, ROBIN RUDOWITZ & MARYBETH MUSUMECI, KAISER FAM. FOUND., 3 KEY QUESTIONS: SECTION 1115 MEDICAID DEMONSTRATION WAIVERS 4 (2017).

[42] *See* 42 U.S.C. §1396n; *Using Medicaid to Support Working Age Adults With Serious Mental Illnesses in the Community: A Handbook. Section 1915(c) Waiver Authority*, ASPE (Jan. 24, 2005), https://aspe.hhs.gov/report/using-medicaid-support-working-age-adults-serious-mental-illnesses-community-handbook/section-1915c-waiver-authority.

[43] 42 U.S.C. §1396n(a)(1)(A).

[44] *See* 42 U.S.C. §1396n(c)(1).

[45] *See Adult Autism Waiver*, PA DEP'T OF HUM. SERVS., https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Adult%20Autism%20Waiver.aspx (last visited Mar. 27, 2021).

[46] 42 U.S.C. § 1396d(r).

include early detection and preventive care in addition to medically necessary services.[47]

Forty-four states have waiver programs under section 1915(c) for people with developmental disabilities.[48] Twenty-nine of them have programs that specifically target autistic children, although their terms vary considerably.[49] Without these programs, many specialized services would only be eligible for Medicaid reimbursement in institutional settings.[50] Thus, waivers enable thousands of children to receive care at home, including many children of families whose income is otherwise too high to qualify for Medicaid.[51] Research has found waivers to be highly effective in meeting unmet needs for care.[52] They also enable many parents of ASD children to work outside the home.[53] However, coverage under many waiver programs for ASD services extends only to age eighteen (twenty-one under EPSDT),[54] forcing many adult patients to seek other sources of coverage for services in their homes or communities.[55]

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[47] *See* Cindy Mann, Director, Ctr. for Medicaid & Chip Servs., CMCS Informational Bulletin, Clarification of Medicaid Coverage of Services to Children with Autism, at 5 (July 7, 2014), https://www.medicaid.gov/federal-policy-guidance/downloads/cib-07-07-14.pdf.

[48] *Disability Services & Waivers*, MEDICAIDWAIVER.ORG, http://www.medicaidwaiver.org/ (last visited Mar. 27, 2021).

[49] Diana L. Velott, Edeanya Agbese, David Mandell, Bradley D. Stein, Andrew W. Dick, Hao Yu & Douglas L. Leslie, *Medicaid 1915(c) Home- and Community Based Services Waivers for Children with Autism Spectrum Disorder*, 20 AUTISM 473, 475 (2016).

[50] *See id.*

[51] *See* Rafael M. Semansky, Ming Xie & David S. Mandell, *Medicaid's Increasing Role in Treating Youths with Autism Spectrum Disorders*, 62 PSYCHIATRIC SERVS. 588, 588 (2011).

[52] Douglas L. Leslie, Khaled Iskandarani, Andrew W. Dick, David S. Mandell, Hao Yu, Diana Velott, Edeanya Agbese & Bradley D. Stein, *The Effects of Medicaid Home and Community-Based Services Waivers on Unmet Needs Among Children with Autism Spectrum Disorder*, 55 MED. CARE 57, 63 (2017).

[53] *See* Douglas L. Leslie, Khaled Iskandarani, Diana L. Velott, Bradley D. Stein, David S. Mandell, Edeanya Agbese & Andrew W. Dick, *Medicaid Waivers Targeting Children with Autism Spectrum Disorder Reduce the Need for Parents to Stop Working*, 36 HEALTH AFFS. 282, 287 (2017).

[54] Shea et al., *supra* note 14, at 175.

[55] Whitney Schott, Kate Verstreate, Sha Tao & Lindsay Shea, *Autism Grows Up: Medicaid's Role in Serving Adults on the Spectrum*, PSYCHIATRIC SERVS. (published online ahead of print Sept. 29, 2020), https://ps.psychiatryonline.org/doi/10.1176/appi.ps.202000144.

II. AUTISM RESEARCH

A. *Examining Autism-Specific Experiences and Outcomes in the Medicaid System*

Medicaid is a valuable system in which to study the enrollment and service use experiences of autistic individuals because administrative claims data contain clinical information and details on services provided (e.g., date, type of service, service location).[56] Research using this rich data source can observe if and how autistic individuals gain, and remain enrolled for, services and, among those who are enrolled, the services that they use. A search of peer-reviewed research articles in PubMed, the primary search engine for biomedical literature, reveals that the number of research articles focused on autism and Medicaid has grown from one per year in 2001 and 2002 to nineteen per year in 2019 and 2020.[57] This total remains a small proportion of the several hundred articles on autism overall published in PubMed (579 in 2001) and the several thousand articles published in PubMed in 2020 (6,469 in 2020).[58] This suggests that Medicaid data are underutilized as a source of information about coverage and access to services in the autistic population.

Because Medicaid serves as a primary insurer for many autistic individuals, it is likely that legal professionals who represent them or their families, service providers, or other care delivery sites (such as school districts) should be aware of the existing evidence base and where research focused on understanding outcomes of autistic individuals in this system

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[56] *See* Beth Virnig, *Strengths and Limitations of CMS Administrative Data in Research*, RSCH. DATA ASSISTANCE CTR. (Jan. 10, 2018), https://www.resdac.org/articles/strengths-and-limitations-cms-administrative-data-research.

[57] PUBMED.GOV, https://pubmed.ncbi.nlm.nih.gov (type "medicaid autism" in the search bar, then click the arrows to expand the timeline) (last visited Mar. 27, 2021).

[58] *Id.* (type "autism" in the search bar, then click the arrows to expand the timeline) (last visited Mar. 27, 2021).

is lacking.[59] For example, legal background on the lack of research on how the Medicaid system sustains enrollment as autistic youth age into adulthood provides a critical baseline for legal cases that may be based on access to care and inclusive settings. The existing research centered on younger children is an asset in interpreting if or how a family may have experienced unequal quality of care or important differences in treatment planning.

B. *Equity Issues*

In particular, building on opportunities to examine the experience of the autistic population within the Medicaid system could be a promising avenue to tackle a fundamental shortcoming of autism-focused research: inadequate attention to individuals from minority groups and individuals from low socioeconomic status backgrounds.[60] Emerging research that compares participants in autism research to the demographic characteristics of the broader United States population indicates that research participants are significantly less likely to be Black or Latinx and less likely to be from low socioeconomic status backgrounds.[61] This research echoes findings from treatment-specific research studies documenting that caregivers of non-white children on the autism spectrum experience racial bias and disproportionate impact of denial, shame, and stigma

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[59] *See* Schott et al., *supra* note 55.

[60] *See* Elizabeth A. West, Jason C. Travers, Talya D. Kemper, Lisa M. Liberty, Debra L. Cote, Meaghan M. McCollow & L. Lynn Stansberry Brusnahan, *Racial and Ethnic Diversity of Participants in Research Supporting Evidence-Based Practices for Learners with Autism Spectrum Disorder*, 50 J. SPECIAL EDUC. 151, 153 (2016); Claudia L. Hilton, Robert T. Fitzgerald, Kelley M. Jackson, Rolanda A. Maxim, Christopher C. Bosworth, Paul T. Shattuck, Daniel H. Geschwind & John N. Constantino, *Under-Representation of African Americans in Autism Genetic Research: A Rationale for Inclusion of Subjects Representing Diverse Family Structures*, 40 J. AUTISM & DEV'L DISORDERS 633, 633–34 (2010).

[61] Katherine Pickard, Nuri Reyes & Judy Reaven, *Examining the Inclusion of Diverse Participants in Cognitive Behavior Therapy Research for Youth with Autism Spectrum Disorder and Anxiety,* 23 AUTISM 1057, 1059 (2018).

related to ASD.[62] The popular press and media have also issued calls to action for autism research to actively incorporate a focus on engaging minority groups.[63] Furthermore, legal professionals need this type of research to more effectively identify differential access to treatment planning or services among autistic individuals and their families or caregivers.

Characteristics of Medicaid make it a prime safety net system within which to study individuals who may be from minority groups or from low socioeconomic backgrounds, given its historical focus on individuals who are living in poverty or unemployed.[64] Because of the entrenched racial wealth gap in the United States, Medicaid disproportionately serves individuals from minority groups,[65] including those who have been impacted by structural racism and other factors that increase the likelihood of poverty and suboptimal health and economic outcomes. Because Medicaid disproportionately serves individuals at risk of those conditions, research on conditions that occur at higher rates in minority groups, such as systemic lupus erythematosus and lupus nephritis,[66] has focused on using data from Medicaid claims and encounters. Examining experiences of individuals who are from minority

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[62] Sarah Dababnah, Wendy E. Shaia, Karen Campion & Helen M. Nichols, *"We Had to Keep Pushing": Caregivers' Perspectives on Autism Screening and Referral Practices of Black Children in Primary Care*, 56 INTELL. & DEV'L DISABILITIES 321, 329–30 (2018).

[63] *See* Katherine K.M. Stavropoulos, *Increasing Diversity in Neuroscience and Autism Research*, PSYCH. TODAY (Feb. 16, 2020), https://www.psychologytoday.com/us/blog/neuroscience-in-translation/202002/increasing-diversity-in-neuroscience-and-autism-research; Emily Mullin, *Autism Research Lacks Cultural and Ethnic Diversity*, FORBES (Mar. 30, 2016, 9:30 AM), https://www.forbes.com/sites/emilymullin/2016/03/30/autism-research-lacks-cultural-ethnic-diversity/?sh=2880928e5a01.

[64] *See* NAT'L HEALTH POL'Y F., *supra* note 17, at 1–3; *What Is Medicaid's Value?*, COMMONWEALTH FUND, (Dec. 13, 2019), https://www.commonwealthfund.org/publications/explainer/2019/dec/medicaids-value.

[65] *See Medicaid & CHIP*, KAISER FAM. FOUND. (2013), https://www.kff.org/state-category/medicaid-chip/medicaid-beneficiaries/ (select "Medicaid Enrollment by Race/Ethnicity") (last visited Mar. 27, 2021) (finding that African Americans and Hispanics make up roughly 50% of Medicaid beneficiaries).

[66] Candace H. Feldman, Linda T. Hiraki, Jun Liu, Michael A. Fischer, Daniel H. Solomon, Graciela S. Alarcón, Wolfgang C. Winkelmayer & Karen H. Costenbader, *Epidemiology and Sociodemographics of Systemic Lupus Erythematosus and Lupus Nephritis Among U.S. Adults with Medicaid Coverage, 2000-2004*, 65 ARTHRITIS & RHEUMATISM 753, 755 (2013).

groups or low socioeconomic background groups within Medicaid also provides a unique window into their health care needs and presents new opportunities for service system design to improve outcomes. Understanding these gaps also provides necessary evidence for policymakers to identify key targets in forming policy solutions, whether they add to existing infrastructure or substantively reform safety net programs in the United States.

C. *Sources of Medicaid Data*

Researchers can access Medicaid data in multiple ways to examine experiences of individuals on the autism spectrum. National data or data from a subset of states, known as Medicaid Analytic eXtract files or MAX data, can be purchased from the Research Data Assistance Center, based at the University of Minnesota School of Public Health.[67] Researchers can also form partnerships at the state level to gain access to Medicaid data through state Medicaid agencies.[68] For example, several states have partnerships with state universities or colleges to use their state Medicaid data to perform analyses to improve state Medicaid operations.[69] These agreements may serve as a platform for researchers to engage with state Medicaid partners to then publish their results for a research audience. Understanding the structure of these agreements is key for legal professionals based at universities and state

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[67] *Medicaid Analytics eXtract Data: Identification of Medicaid Managed Care Beneficiaries*, RSCH. DATA ASSISTANCE CTR. (Jan. 26, 2018), https://www.resdac.org/articles/medicaid-analytic-extract-data-identification-medicaid-managed-care-beneficiaries.

[68] *See* Jay Himmelstein & Andrew B. Bindman, *Advancing the University Mission Through Partnerships with State Medicaid Programs*, 88 ACAD. MED. 1606, 1607 (2013).

[69] *Id.*; *see also* ANDREW F. COBURN, PAUL SAUCIER, VERNON K. SMITH, EILEEN ELLIS & CHARLES MILLIGAN, IMPROVING MEDICAID POLICY THROUGH STATE/UNIVERSITY RESEARCH PARTNERSHIPS 5 (2007) (surveying six state/university health policy research partnerships); *About*, PUB. UNIV. MEDICAID P'SHIPS, https://www.universitypartnerships.org/content/about (last visited Mar. 27, 2021) (joint partnership between Ohio's and Massachusetts's medical schools); *CHC Evaluation*, UNIV. OF PITT. HEALTH POL'Y. INST. MEDICAID RSCH. CTR., http://www.healthpolicyinstitute.pitt.edu/medicare-medicaid/chc-evaluation (last visited Mar. 27, 2021) (partnership between University of Pittsburgh and the Commonwealth of Pennsylvania).

agencies, since the regulatory requirement for data access and reporting require an intricate understanding of HIPAA and FERPA regulations.

Medicaid data are structured differently based on the nature of the state or program in which a person is enrolled. Generally, individuals enrolled in traditional fee-for-service programs, including those covered under many types of Medicaid waivers, can be observed in claims data.[70] Because fee-for-service claims are generally billed and adjudicated on a rolling basis, i.e., as services are utilized and paid, data from these claims are available more quickly than claims data under other program types.[71] Individuals who are enrolled in Medicaid managed care programs are observed through "encounter" data, which can take longer to accrue because it is gathered from contractual partners who are executing the managed care programs.[72] The contractual structure of managed care operations can be a key element of the amount and type of data that contractual partners are required to provide. Legal professionals employed by state Medicaid agencies and provider entities will require a robust understanding of these requirements for enforcement, monitoring, and compliance with state and federal laws.

D. *Children on the Autism Spectrum and Medicaid*

Children on the autism spectrum have multiple pathways for enrollment in Medicaid. Understanding these pathways and how they provide access to needed care for these children is important for legal professionals because it is an essential element of navigating individual and family claims of unequal access to important, needed services. Since children may

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[70] *See* Zuleyha Cidav, Lindsay Lawer, Steven C. Marcus & David S. Mandell, *Age-Related Variation in Health Service Use and Associated Expenditures Among Children with Autism*, 43 J. AUTISM & DEV'L DISORDERS 924, 925 (2013).

[71] *See id.* The contractual nature of managed care data can make the content of the care delivered proprietary and not available for use in research at the same level of detail that fee-for-service data can provide.

[72] *Id.*

qualify on their own by virtue of their own disability or through their parents or familial status (e.g., family income thresholds),[73] examinations of how children rely on Medicaid has the potential to generate information that can inform their immediate care and longer-term outcomes as they age. For example, research demonstrates that among children on the autism spectrum, early access to services yields improved outcomes later in life,[74] further reinforcing the importance of understanding how Medicaid supports children on the autism spectrum in gaining access to and using the services aligned with their needs. Research that has compared spending on services among children on the autism spectrum enrolled in Medicaid with those enrolled in private insurance has found that Medicaid spends more overall and more per child on services than private insurance,[75] further emphasizing the critical role Medicaid plays in covering these children.

Some research has utilized Medicaid data to examine outcomes among children who are at risk of adverse outcomes, such as those involved in foster care. States rely on Medicaid as a primary mechanism for providing health insurance to children who are in foster care,[76] making it an especially promising system in which to study outcomes in these youth. A study using national Medicaid data from 2001 to 2007 found that children on the autism spectrum were at increased risk for foster care involvement when compared with their counterparts with intellectual disability and that the number of children on the autism spectrum within the foster care system

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[73] *See supra* Section I.A.

[74] *See* Rebecca J. Landa, Efficacy of Early Interventions for Infants and Young Children with, and at Risk for, Autism Spectrum Disorders (July 6, 2018) (manuscript at 12–14) (published in 30 INT'L REV. PSYCHIATRY 25–39 (2018)).

[75] *See* Li Wang, David S. Mandell, Lindsay Lawer, Zuleyha Cidav & Douglas L. Leslie, *Healthcare Service Use and Costs for Autism Spectrum Disorder: A Comparison Between Medicaid and Private Insurance*, 43 J. AUTISM & DEV'L DISORDERS 1057, 1062 (2013).

[76] KAMALA D. ALLEN & TAYLOR HENDRICKS, SPARC, MEDICAID AND CHILDREN IN FOSTER CARE 4 (2013), http://childwelfaresparc.org/wp-content/uploads/2013/03/medicaid-and-children-in-foster-care.pdf.

increased substantially during the study period.[77] Research from 2013, using Medicaid data from Illinois, found that the median length of stay in the foster care system among children on the autism spectrum was 1.6 times longer than for other children.[78] Results from these studies have pointed to the need for further exploration of factors driving these differences.[79] For example, the characteristics of both the child and the family may be important contributors to increased risk for foster care system involvement. There may also be a need for more or different access to community-based services and supports for both children on the autism spectrum and their caregivers to prevent or limit involvement in the foster care system.

Research has also focused on the nature of care that children on the autism spectrum receive when they are enrolled in Medicaid. Using national Medicaid claims between 2002 and 2004, one study found that the national average age of diagnosis is significantly older than the recommended optimal age to improve long-term outcomes.[80] Substantial differences in the age of diagnosis have also been identified among children from different racial and ethnic groups, including delayed age of diagnoses among Black children.[81] This research has provided important groundwork for research on the age of diagnosis internationally,[82] and subsequent studies have used other data

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[77] Zuleyha Cidav, Ming Xie & David S. Mandell, *Foster Care Involvement Among Medicaid-Enrolled Children with Autism*, 48 J. AUTISM & DEV'L DISORDERS 176, 176 (2018).

[78] Lucy A. Bilaver & Judy Havlicek, *Foster Children with Autism Spectrum Disorder: Prevalence, Length of Stay, and Placement Patterns*, 7 J. PUB. CHILD WELFARE 496, 496 (2013).

[79] *See id.* at 514; *see also* Cidav et al., *supra* note 70, at 924.

[80] *See* David S. Mandell, Knashawn H. Morales, Ming Xie, Lindsay J. Lawer, Aubyn C. Stahmer & Steven C. Marcus, *Age of Diagnosis Among Medicaid-Enrolled Children with Autism, 2001-2004*, 61 PSYCHIATRIC SERVS. 822, 822, 827 (2010).

[81] David S. Mandell, John Listerud, Susan E. Levy & Jennifer A. Pinto-Martin, *Race Differences in the Age at Diagnosis Among Medicaid-Eligible Children with Autism*, 41 J. AM. ACAD. CHILD & ADOLESCENT PSYCHIATRY 1447, 1449 (2002).

[82] *See e.g.*, Loretta Thomaidis, Nikoletta Mavroeidi, Clive Richardson, Antigoni Choleva, George Damianos, Konstantinos Bolias & Maria Tsolia, *Autism Spectrum Disorders in Greece: Nationwide Prevalence in 10–11 Year Old Children and Regional Disparities*, J. CLINICAL MED., art. no. 2163, July 2020, at 1, 3.

sources to home in on the reasons for these variations in the age of diagnosis.[83]

Medicaid data have also enabled observation of clinical outcomes that inform the development of intervention programming and community-based service needs among children on the autism spectrum. National Medicaid data from 2001 were used in one study to identify trends in the prescription of psychotropic medication to young children on the autism spectrum.[84] The study findings led to a call to action to examine prescribing patterns, particularly among very young children, and to consider opportunities for community-based, behavioral services and supports instead of pharmacologic interventions.[85] Research that has followed up on these findings using data from five health systems found that prescriptions for psychotropic medication were much more frequent among children on the autism spectrum compared to their counterparts, even after adjustment for other clinical factors, including psychiatric diagnoses.[86] Research based in the United Kingdom has also yielded important findings about psychotropic medication prescription patterns for children with co-occurring ASD and attention deficit hyperactivity disorder,[87] further emphasizing the utility of Medicaid data to spur new

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[83] *See* Colby Chlebowski, Eliana Hurwich-Reiss, Blanche Wright & Lauren Brookman-Frazee, *Using Stakeholder Perspectives to Guide Systematic Adaptation of an Autism Mental Health Intervention for Latinx Families: A Qualitative Study*, 48 J. CMTY. PSYCH. 1194, 1197 (2020); *see also* Patricia Garcia Primo, Christoph Weber, Manuel Posada de la Paz, Johannes Fellinger, Anna Dirmhirn & Daniel Holzinger, *Explaining Age at Autism Spectrum Diagnosis in Children with Migrant and Non-Migrant Background in Austria*, BRAIN SCIS., art. no. 448, July 2020, at 1, 3.

[84] *See* David S. Mandell, Knashawn H. Morales, Steven C. Marcus, Aubyn C. Stahmer, Jalpa Doshi & Daniel E. Polsky, *Psychotropic Medication Use Among Medicaid-Enrolled Children with Autism Spectrum Disorders*, 121 PEDIATRICS e441, e441 (2008).

[85] Jeanne M. Madden, Matthew D. Lakoma, Frances L. Lynch, Donna Rusinak, Ashli A. Owen-Smith, Karen J. Coleman, Virginia P. Quinn, Vincent M. Yau, Yinge X. Qian & Lisa A. Croen, *Psychotropic Medication Use Among Insured Children with Autism Spectrum Disorder*, 47 J. AUTISM & DEV'L DISORDERS 144, 145 (2008).

[86] *Id.* at 144.

[87] Richard Houghton, Chuang Liu & Federico Bolognani, *Psychiatric Comorbidities and Psychotropic Medication Use in Autism: A Matched Cohort Study with ADHD and General Population Comparator Groups in the United Kingdom*, 11 AUTISM RSCH. 1690, 1690 (2018).

lines of research to understand the experiences of children on the autism spectrum.

E. *Medicaid-Covered Services Impacting Families and Caregivers*

Medicaid data and data from other sources, such as national surveys, that inquire about child and caregiver or family experiences within the Medicaid system can also serve as rich opportunities to observe how families are, or are not, supported by Medicaid coverage programs. Understanding this evidence base provides legal professionals a comparison between access and quality of care within the Medicaid system and care delivered through other mechanisms, such as private health insurance. These differences are especially key to monitoring the implementation and enforcement of mental health parity laws, although states differentially define mental health so that it may or may not include ASD. Research that has utilized data from a survey of Medicaid enrollees (the National Survey of Children with Special Health Care Needs, or NS-CSHCN) has found that within states where new Medicaid programs have been implemented to provide services and supports to children on the autism spectrum, family members (primarily parents) are less likely to have experienced a workforce participation impact than families living in states without these programs.[88] This research indicates that when children on the autism spectrum have access to programs to support their care needs, there can be important and valuable improvements for family members in their quality of life.[89] Other research used focus groups composed of families and providers to identify programmatic solutions to engaging families in Medicaid to

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[88] Douglas L. Leslie, Khaled Iskandarani, Diana L. Velott, Bradley D. Stein, David S. Mandell, Edeanya Agbese & Andrew W. Dick, *Medicaid Waivers Targeting Children with Autism Spectrum Disorder Reduce the Need for Parents to Stop Working*, 36 HEALTH AFFS. 282, 282–88 (2017).

[89] *See id.* at 286.

sustain and maintain eligibility.[90] Results from this work highlighted flexible program delivery, demystifying written materials for a lay non-Medicaid audience, affirming parent and interventionist relationships, involving extended family members, and engaging families in intervention implementation in everyday practices.[91] These findings suggest promising ways in which states can modify Medicaid programs to engage families.

Medicaid also helps families of children on the autism spectrum by covering genetic testing. Several studies have identified a genetic component in autism occurrence.[92] Genetic testing and follow-up genetic counseling are services covered by Medicaid that can aid families in understanding an ASD diagnosis and support treatment planning.[93] National Medicaid claims have been used to identify an increase in the rate of genetic testing and counseling provided to children on the autism spectrum and genetic counseling delivered to their caregivers.[94] Interestingly, the same research has identified preliminary and substantial differences in genetic testing and counseling service delivery by race and ethnicity, in addition to differences across clinical presentation among children on the autism spectrum.[95] This research indicates that there is more work to be done in understanding these patterns of care and ways in which they may inform future service delivery and interactions between providers and families. National Medicaid

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[90] Katherine E. Pickard, Amanda N. Kilgore & Brooke R. Ingersoll, *Using Community Partnerships to Better Understand the Barriers to Using an Evidence-Based, Parent-Mediated Intervention for Autism Spectrum Disorder in a Medicaid System*, 57 AM. J. CMTY. PSYCH. 391, 391–93 (2016).

[91] *Id.* at 391.

[92] Chris Plauché Johnson & Scott M. Myers, *Identification and Evaluation of Children with Autism Spectrum Disorders*, 120 PEDIATRICS 1183, 1183–86 (2007).

[93] Lei Xu, Linda C. Mitchell, Alice R. Richman & Kaitlyn Clawson, *What Do Parents Think About Chromosomal Microarray Testing? A Qualitative Report from Parents of Children with Autism Spectrum Disorders*, AUTISM RSCH. & TREATMENT, June 2016, at 1, 2, 6.

[94] Lindsay Shea, Craig J. Newschaffer, Xie Ming, Scott M. Myers & David S. Mandell, *Genetic Testing and Genetic Counseling Among Medicaid-Enrolled Children with Autism Spectrum Disorder in 2001 and 2007*, 133 HUM. GENETICS 111, 116 (2014).

[95] *Id.* at 115.

data can continue to serve as important scaffolding for this work, given the diverse range of individuals enrolled in the program and large sample size needed to stratify subjects in research studies according to demographic characteristics.

F. *Life Course and Lifespan Approaches to Autism in Medicaid*

Emerging and rapidly-growing approaches to understanding the needs of autistic individuals include the life course approach. The life course approach moves beyond a medical model to seek to identify and address the holistic needs of individuals and families.[96] This approach acknowledges that ASD is a lifelong disorder and that long-term planning for needs must begin early in life and include key stakeholders and caregivers who can support an autistic individual in working toward goals.[97] Examining ASD through these perspectives supports legal professionals in being prepared to understand the goals of individuals and families as they navigate and advocate within and across complex, siloed systems.

Two studies have utilized national Medicaid data to identify trends in enrollment patterns among individuals on the autism spectrum.[98] Both found that the number of children on the autism spectrum enrolled in Medicaid had increased[99] and that adults on the autism spectrum are among the fastest growing age groups to rely upon Medicaid for services and supports.[100] Using Medicaid data from Wisconsin, one study observed a trend of autistic individuals enrolled in Medicaid decreasingly present with co-occurring intellectual disability.[101] This pattern has two possible conflicting implications: It may indicate that individuals are able to remain enrolled in Medicaid without

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[96] *See* Schott et al., *supra* note 55.

[97] *See* Eric Rubenstein & Lauren Bishop, *Is the Autism Boom Headed for Medicaid? Patterns in the Enrollment of Autistic Adults in Wisconsin Medicaid, 2008–2018*, 12 AUTISM RSCH. 1541, 1548 (2019).

[98] *See* Schott et al., *supra* note 55; Rubenstein & Bishop, *supra* note 97, at 1542–43.

[99] Schott et al., *supra* note 55; Rubenstein & Bishop, *supra* note 97, at 1550.

[100] Schott et al., *supra* note 55.

[101] Rubenstein & Bishop, *supra* note 97, at 1547.

needing a co-occurring intellectual disability diagnosis to qualify, or it may be a red flag that more autism-specific programs (that do not require a co-occurring intellectual disability) are needed to ensure continuity in eligibility.

In fact, studies that have examined trends in Medicaid enrollment indicate that transition-age youth and young adults on the autism spectrum (i.e., those who are moving from pediatric care to adult care) are likely at increased risk of disenrollment from Medicaid, with many losing access as they age into adolescence and adulthood.[102] Risk of disenrollment is only one kind of suboptimal outcome observed in this group. Research using national Medicaid claims has identified worrisome drops in the utilization of key types of services (e.g., community-based support services) among transition-age youth on the autism spectrum as they age into adulthood,[103] and these findings have been echoed in other statewide surveys.[104] Further research is needed to determine whether the observed decreases in the use of important services by autistic individuals are due to a lack of access to services, or whether the programs include limits or other barriers to accessing services even when they are technically available through Medicaid.

To date, studies that have sought to catalog state Medicaid programs available to individuals on the autism spectrum have predominantly focused on children.[105] A thorough examination of 1915(c) waivers that explicitly included children on the autism spectrum documented the emergence of multiple Medicaid programs that are only available for children and

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[102] Shea et al., *supra* note 14, at 181.

[103] Lindsay L. Shea, Ming Xie, Paul Torcotte, Steven Marcus, Robert Field, Craig Newschaffer & David Mandell, *Service Use and Associated Expenditures Among Adolescents with Autism Spectrum Disorder Transitioning to Adulthood*, 48 J. AUTISM & DEV'L DISORDERS 3223, 3226 (2018).

[104] *See* Paul Turcotte, Mary Mathew, Lindsey L. Shea, Eugene Brusilovskiy & Stacy L. Nonnemacher, *Service Needs Across the Lifespan for Individuals with Autism*, 46 J. AUTISM & DEV'L DISORDERS 2480, 2487 (2016).

[105] Schott et al., *supra* note 55.

adolescents, but not adults.[106] These programs represent important advancements in supporting the needs of children on the autism spectrum. However, there may be meaningful variations in how states define eligibility for services through them. One case study described crucial differences in how states base eligibility on specific features of autism and how this impacts children, especially transition-age youth.[107] Research on autism insurance mandates, legislative insurance coverage requirements that have been enacted in most states, has also mostly focused on children.[108] Although several autism insurance mandates require coverage both through Medicaid and private insurance, almost all of these initiatives focus on children younger than age twelve and do not extend through the transition to adulthood.[109]

A few studies have sought to characterize the health care needs of autistic adults,[110] with most focusing on their experience in the Medicaid system. Because many states employ cost control measures that include waiting lists for Medicaid home and community-based services programs, half a million people with disabilities, including individuals on the autism spectrum, are currently on waiting lists for them.[111] A

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[106] *See* Velott et al., *supra* note 49, at 475 ("All children's ASD waivers included personal care services, caregiver support and training, and evidence-based treatments. All but three . . . offered respite care and half offered direction of services . . . .").

[107] *See generally* Marian E. Williams, Barbara Y. Wheeler, Lisa Linder & Robert A. Jacobs, *Evolving Definitions of Autism and Impact on Eligibility for Developmental Disability Services: California Case Example*, 55 INTELL. & DEV'L DISABILITIES 192 (2017).

[108] *See, e.g.*, *id.*; Bradley D. Stein, Mark J. Sorbero, Upasna Goswami, James Schuster & Douglas L. Leslie, *Impact of a Private Health Insurance Mandate on Public Sector Autism Service Use in Pennsylvania*, 51 J. AM. ACAD. CHILD & ADOLESCENT PSYCHIATRY 771, 774–75 (2012).

[109] *See* Stein et al., *supra* note 108, at 773–74.

[110] *See* Paul T. Shattuck, Tamara Garfield, Anne M. Roux, Jessica E. Rast, Kristy Anderson, Elizabeth McGhee Hassrick & Alice Kuo, *Services for Adults with Autism Spectrum Disorder: A Systems Perspective*, CURRENT PSYCHIATRY REPS., Feb. 2020, at 1, 6–7.

[111] *Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers*, KAISER FAM. FOUND., https://www.kff.org/state-category/medicaid-chip/home-and-community-based-services/ (last visited Mar. 27, 2021); (click "Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers"); *see also* Whitney Schott, Stacy Nonnemacher & Lindsay Shea, *Service Use and Unmet Needs Among Adults with Autism Awaiting Home- and Community-Based Medicaid Services*, 51 J. AUTISM & DEV'L DISORDERS 1188, 1189 (2021) [hereinafter Schott et al., *Service Use*].

recent study from Pennsylvania of adults on a waiting list and their caregivers found that they have significant needs, with more than half reporting needs for functional skill services, employment services, and mental or behavioral health services.[112] Individuals least likely to be receiving services, or who were receiving the fewest services, while waiting to participate in Medicaid HBCS programs, include those who were Black, Hispanic, over twenty-one years of age, and had completed college.[113] These results indicate that state Medicaid waiting lists include groups that have traditionally been underserved, but they also reflect the complex nature of the autism spectrum, which includes adults with high educational achievement.[114]

G. *Future Research Directions*

Among important areas for further research is the longitudinal experiences of children on the autism spectrum as they age through adulthood. The lifespan approach has begun to tackle this research need but substantial gaps persist.[115] Legal professionals are likely to be at the forefront of this issue as individuals and families experience declines in access and quality of care and supports as they age. A baseline for understanding the experiences of children on the autism spectrum as they become adolescents, adults, and seniors can be established through research into whether Medicaid serves as an effective coverage mechanism starting in childhood.[116] One study that used multiple waves of data from the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs yielded promising

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[112] *See* Schott et al., *Service Use*, *supra* note 111, at 1197–99.

[113] *See id*. at 1198.

[114] *See id.* ("Underserved populations were receiving fewer services, specifically African-Americans and Hispanics, suggesting that disparities that are well known in terms of ASD diagnosis as well as service use in general also apply to minority populations on the waiting list for Medicaid-funded HCBS." (citations omitted)).

[115] *See supra* Section II.F.

[116] *See supra* Sections II.D–E.

findings that Medicaid waivers help address disparities in unmet needs among children on the autism spectrum across racial and ethnic groups.[117] Although there are fewer adult ASD Medicaid programs to examine, replicating this work among adults on the autism spectrum could provide pathways to designing and implementing better programs for autistic adults.

Research that has utilized national Medicaid claims data to examine the service experiences of transition-age youth on the autism spectrum has found increasing rates of emergency-based care, medication use, and respite care, but decreasing rates in the use of core services, such as speech therapy, that address ASD symptoms and challenges.[118] This research begs the question of what happens as these youth continue to age: Do these patterns of declining use of key services persist and the use of emergency care and medication usage increase? Research that uses data from Medicaid to examine these service patterns is optimally positioned to identify programs that yield positive outcomes that could be models for further program development.

Another study that used Medicaid data from three states from 2000 to 2008 found elevated rates of co-occurring medical and mental health diagnoses among adults on the autism spectrum (ages 22–64).[119] Autistic adults also had higher annual mean spending for outpatient care and prescription drugs.[120] National studies are needed to determine whether these are widespread trends and to understand how to translate them into recommendations for service composition and availability.

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[117] Michelle LaClair, Davis S. Mandell, Andrew W. Dick, Khaled Iskandarani, Bradley D. Stein & Douglas L. Leslie, *The Effect of Medicaid Waivers on Ameliorating Racial/Ethnic Disparities Among Children with Autism*, HEALTH SERVS. RSCH. 912, 917 (2019).

[118] Cidav et al., *supra* note 70, at 928.

[119] Rini Vohra, Suresh Madhavan & Usha Sambamoorthi, *Comorbidity Prevalence, Healthcare Utilization, and Expenditures of Medicaid Enrolled Adults with Autism Spectrum Disorder*, 21 AUTISM 995, 995 (2017).

[120] *Id.* at 1006.

CONCLUSION

Medicaid-funded services are crucial for individuals on the autism spectrum, particularly children. State waivers and the EPSDT program have been especially important in enabling them to access services in their homes and communities rather than in institutions. Recent increases in the number and variety of waiver programs have been especially important as they have occurred as the prevalence of ASD diagnoses has increased dramatically. These advances are important and should be celebrated. However, much work remains to understand outcomes across Medicaid and other health care insurers and providers. Legal professionals are key allies in navigating these systems, advocating for individual rights, and working to advance options to ensure autistic individuals have access to the necessary services and supports as they age and their needs change. Further research into the effectiveness of Medicaid in meeting the needs of patients on the autism spectrum, especially as they age through adulthood, will be important in designing future programs to better address their needs. Such programs will also be important in addressing the needs of their families and caregivers, providers of services for them, and other professionals who assist them, including legal professionals.