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# AUGMENTING ADVOCACY: GIVING VOICE TO THE MEDICAL-LEGAL PARTNERSHIP MODEL IN MEDICAID PROCEEDINGS AND BEYOND

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MaryBeth Musumeci\*

*The denial of Medicaid coverage for augmentative communication devices, despite an existing legal framework that mandates the opposite result, raises fundamental questions about what independence means for people with disabilities. This situation, compounded by the barriers in the Medicaid administrative appeal process encountered by such beneficiaries, invites new approaches to the delivery of civil legal services, such as medical-legal partnerships (MLPs). MLPs are formalized arrangements that bring lawyers into a healthcare setting to provide specialist consultations when patients experience legal problems that affect health. While there is an emerging scholarship on MLPs, this Article offers the first in-depth analysis of a particular area of the law—Medicaid advocacy for people with disabilities—in the context of the MLP model. Part I explores legal and public policy justifications for Medicaid coverage of services that promote independence for people with disabilities, such as augmentative communication devices. Part II describes the Medicaid administrative hearing process and the barriers it presents to people with disabilities who appeal the denial of a service, including augmentative communication devices. Part III summarizes existing scholarship about MLPs. Part IV applies the MLP model to the problems typically encountered by Medicaid beneficiaries in the appeals process. The Article concludes by recommending some refinements to increase the acceptance of this new legal services delivery model.*

## INTRODUCTION

When her parents requested legal assistance, Sonya was a young adult with cerebral palsy and mental retardation that completely

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foreclosed any natural ability to generate speech.<sup>1</sup> To overcome her communication deficits, Sonya's doctor prescribed an augmentative communication device.<sup>2</sup> This technology would enable her to express basic needs, such as hunger, thirst, and having to use the bathroom; describe physical and medical needs, such as pain and whether something is too hot or too cold; and call for assistance, both in and out of her wheelchair.

Sonya's doctor and speech-language pathologist went through a painstaking process of evaluating the suitability of five different devices for her. She required a device that was large enough to accommodate her somewhat limited motor skills, but also small enough to be portable and durable. A dynamic screen would ensure that her vocabulary would be large and expandable, and would allow her to operate the device independently with a finger touch. An integrated speaker would allow her to adjust the device's volume as appropriate for different environments. Sonya's device also needed to be user-friendly to facilitate vocabulary updates and to ensure that those unfamiliar with the device would find it easy to operate.

The Medicaid managed care organization (MCO)<sup>3</sup> that administered Sonya's healthcare benefits, however, denied authorization for the prescription. Relying on Sonya's home state's definition of "Medicaid medical necessity," the MCO determined that an augmentative communication device was not the least expensive

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1. After she turned eighteen, Sonya's parents were appointed as her legal guardians. Sonya's name and other identifying details have been changed to protect confidentiality. For a general discussion of client consent with respect to publishing stories about cases, see Binny Miller, *Telling Stories About Cases and Clients: The Ethics of Narrative*, 14 GEO. J. LEGAL ETHICS 1 (2000).

2. Augmentative and alternative communication is defined as "an area of clinical practice that attempts to compensate (either temporarily or permanently) for the impairment and disability patterns of individuals with severe expressive communication disorders (i.e., the severe impairments in speech-language, reading and writing)." *Frequently Asked Questions about Augmentative and Alternative Communication*, AM. SPEECH-LANGUAGE-HEARING ASS'N, <http://www.asha.org/NJC/faqs-aac-basics.htm> (last visited Mar. 7, 2011). Some examples of augmentative communication devices include communication boards or books, electrolarynxes, speech amplifiers, and electronic devices that produce speech or written output. *Id.*

3. With limited exceptions for certain beneficiary populations, states may elect to administer their Medicaid program through a managed care system. See 42 U.S.C. § 1396u-2 (2006) (authorization of states to use managed care systems); 42 C.F.R. Part 438 (2009) (regulations covering such systems). While the Medicaid program traditionally uses a fee-for-service model, in which providers are paid for each service performed, the alternative managed care model offers a capitated rate, a fixed sum paid regardless of the amount of services utilized. See Deborah M. Chasan-Sloan, Note, *Managed Care, the Poor, and the Constitution: Are Due Process Rights Ailing under Medicaid Managed Care?*, 8 GEO. J. ON POVERTY L. & POL'Y 283, 286-87 (2001) (describing the rise of Medicaid managed care).

appropriate medical care available for Sonya.<sup>4</sup> Without identifying any other alternative, the MCO also alleged that the device was not the most appropriate option for Sonya and instead was duplicative of other, unspecified, services that the MCO alleged she received.

Sonya's father appealed the MCO's denial, which afforded Sonya an informal hearing at the health plan's office.<sup>5</sup> The hearing panel included an MCO representative who had not been involved in the initial decision, a representative from the state Medicaid agency, and another Medicaid program beneficiary. At the hearing, the MCO nurse case manager who was responsible for Sonya's case defended the denial by asserting that Sonya's natural communication abilities could adequately meet her daily needs without an augmentative communication device. She maintained that because Sonya had the ability to grunt, groan, and bang on things, Sonya could get someone's attention in an emergency if she were in a room alone. Thus, the case manager asserted, Sonya could communicate basic needs without an augmentative communication device, and the Medicaid program did not have to provide her with a more extensive or sophisticated means of communication.<sup>6</sup>

At the hearing, Sonya's father described what having the device would mean for Sonya. He told the panel members that what he most wanted was for Sonya to live like a typical teenager, to the greatest extent possible. He wanted her to have privacy and to be able to spend time in her room without needing someone constantly with her. He also wanted her to be able to experience some of the independence associated with young adulthood. Most of all, he wanted to be able to communicate with his daughter so that he could understand what she was thinking and feeling. The diametrically opposing views about what Sonya's capabilities should be, as expressed by the MCO case manager and her father, were striking. The hearing ended, and the next day, Sonya received a brief letter indicating that the device was approved, over four months after her doctor wrote the prescription. The hearing panel did not share its reasoning for the reversal.

Sonya's case is not unique. The initial response of this particular state's Medicaid program to Sonya's need for an augmentative communication device is representative of how the program often fails in practice to meet the needs of people with disabilities,

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4. The specific regulation has been paraphrased to protect client confidentiality. See Miller, *supra* note 1, at 49, 50.

5. Such a process is required by Federal Medicaid law. See 42 U.S.C. § 1396u-2(b)(4) (2006) (outlining basic grievance procedures for challenging a denial); 42 C.F.R. § 438.406(b)(2) (2009).

6. This information is based on my representation of Sonya at that hearing.

despite an existing legal framework that mandates the opposite result. While Sonya ultimately obtained the device prescribed by her doctor, many others are not so fortunate; they typically wait even longer and often are unable to overcome the barriers described in Part II, *infra*, and thus cannot obtain medically necessary devices.

While Sonya's story involves access to augmentative communication devices, the Medicaid program covers a wide array of medical services, including, *inter alia*, inpatient and outpatient hospitalization, laboratory tests, home health services, and physical therapy and related services.<sup>7</sup> While this Article focuses on Medicaid coverage of augmentative communication devices,<sup>8</sup> its observations about the obstacles faced by Sonya and thousands of other persons with disabilities in accessing such treatment are generally applicable to all types of Medicaid service claims.

These obstacles raise fundamental questions about what independence means for people with disabilities: What does it mean to communicate a basic need?<sup>9</sup> Who determines which needs are basic? What amount of communication is adequate? If technology exists to augment communication, should a person's natural ability to communicate limit her self-expression? Who should have access to this technology, and how should it be funded? Such questions are important for the "approximately two million people [in the United States today] who are able to hear but have little to no usable speech."<sup>10</sup>

Reforming the Medicaid appeals process itself is potentially one way to remedy these problems. However, reconceptualizing the traditional model within which civil legal services are delivered to Medicaid beneficiaries presents another, less obvious alternative that can more effectively address issues arising from the Medicaid

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7. See 42 U.S.C. § 1396d(a) (2006) (defining the "medical assistance" provided under Medicaid).

8. See generally Diane C. Bristow, *Breaking Down the Barriers to Communication through Medicare Reform*, 29 Sw. U. L. REV. 357 (2000) (focusing on Medicare funding of augmentative communication devices); Ellen M. Saideman, *Helping the Mute to Speak: The Availability of Augmentative Communication Devices under Medicaid*, 17 N.Y.U. REV. L. & SOC. CHANGE 741 (1990) (arguing that the Medicaid medical necessity standard entitles recipients to augmentative communication devices that provide unlimited speech).

9. "Communication" is generally defined as "any act by which one person gives to or receives from another person information about that person's needs, desires, perceptions, knowledge, or effective states." *Guidelines for Meeting the Communication Needs of Persons with Severe Disabilities*, AM. SPEECH-LANGUAGE-HEARING ASS'N, <http://www.asha.org/docs/html/GL1992-00201.html> (last visited Mar. 7, 2011) [hereinafter *Guidelines*].

10. *DATI Assistive Technology Facts: Augmentative and Alternative Communication*, DEL. ASSISTIVE TECH. INITIATIVE, <http://www.dati.org/info/acc.html> (last visited Apr. 2, 2011). See also *Guidelines*, *supra* note 9.

appeals process.<sup>11</sup> This Article explores the medical-legal partnership model as one such solution and seeks to add to the developing scholarship in this area.<sup>12</sup> Specifically, establishing, fostering, and formalizing the working relationships between legal advocates and treating physicians on behalf of their common clients and patients in medical-legal partnerships presents an efficient and effective means of overcoming the problems presented in Medicaid service denial appeals. Like Sonya's need for augmentative communication, lawyers for people with disabilities also benefit from augmenting their advocacy through partnering with doctors. While there is an emerging scholarship on medical-legal partnerships, this Article offers the first in-depth analysis of a particular area of the law—Medicaid advocacy for people with disabilities—in the context of the medical-legal partnership model.<sup>13</sup>

This analysis impacts a sizeable population. The Medicaid program insures one in seven Americans—more than 40 million people.<sup>14</sup> While it is typically thought of as a benefit for people with low incomes, Medicaid also is a valuable source of primary or supplemental health insurance coverage for people with disabilities. In fact, "Medicaid is the single largest source of health care financing—public or private"—for low-income people with disabilities.<sup>15</sup> For people with disabilities who cannot work, Medicaid may be the only accessible coverage.

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11. See *infra* Part IV.

12. See, e.g., Pamela Tames et al., *The Lawyer Is In: Why Some Doctors Are Prescribing Legal Remedies for Their Patients, and How the Legal Profession Can Support This Effort*, 12 B.U. PUB. INT. L.J. 505 (2003) (exploring ethical and confidentiality issues arising in multi-disciplinary practice); Barry Zuckerman et al., *Why Pediatricians Need Lawyers to Keep Children Healthy*, 114 PEDIATRICS 224 (2004) (suggesting potential benefits of placing lawyers in pediatric clinics).

13. The views and recommendations expressed in this Article for improving the legal services delivery model are informed by my advocacy in hundreds of Medicaid cases during my tenure at a legal services program.

14. ANDY SCHNEIDER ET AL., KAISER COMM'N ON MEDICAID AND THE UNINSURED, THE MEDICAID RESOURCE BOOK, at \*i (2002), available at <http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=14266>.

15. ANDY SCHNEIDER ET AL., KAISER COMM'N ON MEDICAID AND THE UNINSURED, MEDICAID ELIGIBILITY FOR INDIVIDUALS WITH DISABILITIES I (2000), available at <http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=13323>; SCHNEIDER, *supra* note 14, at 17 (noting that people with disabilities are both more likely to be enrolled in Medicaid and less likely to have private health insurance than members of the general population); see also *Fred C. v. Tex. Health and Human Serv's Comm'n*, 988 F. Supp. 1032, 1034 (W.D. Tex. 1997) (noting that "the majority of adults with severe speech disabilities, [are] dependent on government benefits for access to the modern technology which would allow [them] to speak."); *Hunter v. Chiles*, 944 F. Supp. 914, 916 (S.D. Fla. 1996) ("Plaintiffs, like many people with severe speech disabilities, are dependent on government benefits for access to [augmentative communication devices and services] which would allow them to communicate verbally.").

Medicaid beneficiaries by definition are people with low incomes and/or disabilities, which means that they disproportionately fall into the “justice gap” of unmet civil legal needs.<sup>16</sup> For example, a recent report by the Legal Services Corporation found that “[o]nly a small fraction of the legal problems experienced by low-income people (less than one in five) are addressed with the assistance of either a private attorney (pro bono or paid) or a legal aid lawyer.”<sup>17</sup> Attorneys with the National Center for Medical-Legal Partnership<sup>18</sup> estimate that “every low-income family has an average of three unmet legal needs” and that “publicly funded legal aid agencies turn away three out of every five applicants for assistance.”<sup>19</sup> This justice gap, compounded by the barriers present in the Medicaid administrative appeal process encountered by Sonya and other beneficiaries, invites new approaches to the delivery of civil legal services, such as medical-legal partnerships.

Part I of this Article explores legal and public policy justifications for Medicaid coverage of services that promote independence for people with disabilities, such as augmentative communication devices. Part II describes the Medicaid administrative hearing process and the barriers it presents to people with disabilities who appeal the denial of a service, such as an augmentative communication device. Part III summarizes the existing scholarship about medical-legal partnerships. Part IV applies the medical-legal partnership model to the problems typically encountered by Medicaid beneficiaries in the appeals process. The Article concludes by recommending some refinements to increase the acceptance of this new legal services delivery model.

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16. LEGAL SERVICES CORPORATION, DOCUMENTING THE JUSTICE GAP IN AMERICA: THE CURRENT UNMET CIVIL LEGAL NEEDS OF LOW-INCOME AMERICANS 1 (2009), available at [http://www.lsc.gov/pdfs/documenting\\_the\\_justice\\_gap\\_in\\_america\\_2009.pdf](http://www.lsc.gov/pdfs/documenting_the_justice_gap_in_america_2009.pdf).

17. *Id.*

18. The National Center for Medical-Legal Partnership conducts research and provides technical assistance to a network of nearly eighty medical-legal partnership sites, serving over 180 hospitals and health centers, throughout the country. See *MLP Network Map*, NAT'L CENTER FOR MED.-LEGAL P'SHIP, <http://www.medical-legalpartnership.org/mlp-network> (last visited Mar. 7, 2011).

19. Ellen Lawton et al., *Disparities in Health, Disparities in Law: The Global Potential of Individual Advocacy*, in HEALTH CAPITAL AND SUSTAINABLE SOCIOECONOMIC DEVELOPMENT 419, 429 (Patricia A. Cholewka & Mitra M. Modlagh eds., 2008).

## I. THE IMPORTANCE OF AUGMENTATIVE COMMUNICATION AND COMMUNITY INTEGRATION

Augmentative communication devices are a cost-effective and efficient way to facilitate independence and integrate people with disabilities into society. Community integration is the goal now espoused by both societal expectations and legal mandates. Effective communication is vital to its realization.

As one federal district court observed, the “inability to speak can be the single most devastating aspect of any handicap.”<sup>20</sup> Communication is conceptualized as “the means by which all other rights are realized and . . . in itself, a basic human right.”<sup>21</sup> The Communication Bill of Rights promulgated by the National Joint Committee for the Communication Needs of Persons with Severe Disabilities<sup>22</sup> underscores the fact that communication is a fundamental human need and asserts that “all individuals have a right to communicate during their daily activities and across the[ir] lifespan.”<sup>23</sup>

A variety of disabilities impact the ability to successfully initiate and sustain communication. Medical conditions that may affect communication abilities include “autism, brain injury, cerebral

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20. *Fred C.*, 988 F. Supp. at 1034; *see also Hunter*, 944 F. Supp. at 920 (noting that the “ability to speak and communicate is vital”).

21. TASH, TASH RESOLUTION ON AUGMENTATIVE AND ALTERNATIVE COMMUNICATION METHODS AND THE RIGHT TO COMMUNICATE I (2000), *available at* <http://tash.org/wp-content/uploads/2011/03/TASH-RESOLUTION-ON-AUGMENTATIVE-AND-ALTERNATIVE-COMMUNICATION-METHODS-AND-THE-RIGHT-TO-COMMUNICATE.doc>.

22. The National Joint Committee for the Communication Needs of Persons with Severe Disabilities provides research, demonstration, and education efforts directed to helping persons with severe disabilities communicate effectively. Its member agencies include the American Speech-Language and Hearing Association, American Association on Mental Retardation, American Occupational Therapy Association, American Physical Therapy Association, Council for Exceptional Children with Communication Disorders, The Association for Persons with Severe Handicaps, and the United States Society for Augmentative and Alternative Communication. *History of the National Joint Committee for the Communication Needs of Persons with Severe Disabilities*, AM. SPEECH-LANGUAGE-HEARING ASS’N, <http://www.asha.org/NJC/history.htm> (last visited Mar. 7, 2011).

23. *Access to Communication Services and Supports: Concerns Regarding the Application of Restrictive “Eligibility” Policies*, AM. SPEECH-LANGUAGE HEARING ASS’N, at \*2–3, <http://www.asha.org/docs/pdf/TR2002-00233.pdf> (last visited Apr. 1, 2011) [hereinafter *Access to Communication Services*]. The National Joint Committee for the Communication Needs of Persons with Severe Disabilities (NJC), an interdisciplinary group that promulgates consensus statements and recommendations in this area, contends that “[i]t is actually difficult to imagine a situation in which communication services, including [augmentative communication supports], are not medically necessary, as most instances of significant communication limitations are associated with diagnosed conditions.” *Frequently Asked Questions about Funding for Service Delivery*, AM. SPEECH-LANGUAGE HEARING ASS’N, <http://www.asha.org/NJC/faqs-funding.htm#15b> (last visited Apr. 2, 2011).



palsy, mental retardation, severe language delay, stroke, and neuromuscular disease such as ALS.”<sup>24</sup> Significantly, research has shown that “with appropriate instruction and support, individuals with severe disabilities can learn to communicate effectively regardless of the nature and/or cause of their underlying impairments.”<sup>25</sup> Often, this is accomplished by using augmentative communication devices.

Augmentative communication devices are “electronic and non-electronic devices that allow individuals to overcome, to the maximum extent possible, communication limitations that interfere with their daily activities.”<sup>26</sup> They “support, enhance, or augment the communication of individuals who are not independent communicators in all situations”<sup>27</sup> and enable such people to “communicate when traditional speaking and writing are not effective.”<sup>28</sup> Rather than inhibiting speech development, “research has shown that communication devices actually encourage natural speech development by reinforcing language through visual, auditory, and motor techniques.”<sup>29</sup>

The Communication Bill of Rights identifies multiple areas in which augmentative communication devices may play an important role, such as the

right to request desired objects, actions, events, and people; refuse undesired objects, actions, or events; express personal preferences and feelings; be offered choices and alternatives; . . . request and receive another person’s attention and interaction; [and] ask for and receive information about changes in routine and environment . . . .<sup>30</sup>

People who have never experienced a disabling condition that impairs communication take such abilities for granted; yet the fundamental nature of these capacities in achieving independence and self-actualization cannot be overstated.

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24. AAC Fact Sheet, DEL. ASSISTIVE TECH. INITIATIVE, <http://www.dati.org/info/acc.html> (last visited Mar. 7, 2011).

25. Access to Communication Services, *supra* note 23, at \*6.

26. William T. v. Taylor, 465 F. Supp. 2d 1267, 1272 (N.D. Ga. 2000) (internal quotations omitted).

27. Del. Med. Equipment Assistance Program, PROVIDER POLICY-MANUAL § 6.4.1, available at <http://www.dmap.state.de.us/downloads/manuals/dme.provider.specific.pdf> (last visited Apr. 2, 2011).

28. AAC Fact Sheet, *supra* note 24.

29. *Id.* See also Access to Communication Services, *supra* note 23, at \*5–6.

30. Communication Bill of Rights, AM. SPEECH-LANGUAGE-HEARING ASS’N, <http://www.asha.org/uploadedFiles/NJC-Communication-Bill-Rights.pdf> (last visited Apr. 2, 2011).

By contrast, the view of people with disabilities espoused by the Medicaid MCO in Sonya's case is closer to that typically associated with the eighteenth and nineteenth centuries rather than to contemporary norms; it does not afford dignity and self-worth to these individuals. Because communication that is effective has been shown to "enhance self-determination, . . . quality of life, and social interactions,"<sup>31</sup> augmentative communication devices are an important means of increased autonomy and independence for persons with disabilities. As one federal district court observed, without augmentative communication devices, people with "severe speech disabilities . . . unable to communicate either verbally or with hand gestures . . . are predestined to depend on others and denied the opportunity to attain [independence] or self-care."<sup>32</sup> This result is precisely what Sonya's father sought to avoid for his daughter, and existing technology provides an easy remedy.

For these reasons, augmentative communication devices are an important aspect of integrating people with disabilities into the community. Services like augmentative communication devices further goals such as individual autonomy that are at the heart of the Medicaid program. The general statutory "purpose of the Federal Medicaid Act is to enable each State 'to furnish . . . rehabilitation and other services to help such families and individuals attain or retain capacity for independence or self-care . . .'"<sup>33</sup> As illustrated by the opening vignette, augmentative communication devices satisfy this goal by supplying an effective, self-directed means of communication for people with disabilities, which contributes to independence and self-care.

However, for many years, people with disabilities frequently were segregated in large residential institutions for all or most of their lives.<sup>34</sup> Reports of deplorable living conditions and patient abuses that became known in the latter half of the twentieth century spurred the movement to deinstitutionalize people with disabilities.<sup>35</sup> The United States Supreme Court's landmark decision in

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31. *Access to Communication Services*, *supra* note 23, at \*3.

32. *Hunter v. Chiles*, 944 F. Supp. 914, 916 (S.D. Fla. 1996).

33. *Id.* at 918 (quoting 42 U.S.C. § 1396(2) (1992)).

34. *See e.g.*, Samantha A. DiPolito, Comment, *Olmstead v. L.C.—Deinstitutionalization and Community Integration: An Awakening of the Nation's Conscience?*, 58 *MERCER L. REV.* 1381, 1384 (2007) ("For over half of the twentieth century, people with mental and developmental disabilities were typically placed in large institutions . . .").

35. *See, e.g.*, Ruth Colker, *Anti-Subordination Above All: A Disability Perspective*, 82 *NOTRE DAME L. REV.* 1415, 1435–36 (2007) (describing investigation of living conditions at Cleveland State Hospital); Arlene S. Kanter, *A Home of One's Own: The Fair Housing Amendments Act of 1988 and Housing Discrimination against People with Mental Disabilities*, 43 *AM. U. L. REV.* 925, 929 (1994) (noting the development of community programs in lieu of institutionalization).

*Olmstead v. L.C.*<sup>36</sup> drew on the “community integration mandate” expressed in Title II of the Americans with Disabilities Act in “[r]ecogni[zing] that unjustified institutional isolation of persons with disabilities is a form of discrimination.”<sup>37</sup> The Court suggested that a state can meet its *Olmstead* obligations if it “were to demonstrate that it had a comprehensive, effectively working plan” for deinstitutionalization of people with disabilities.<sup>38</sup> As of May 2006, lawsuits seeking community placements for people with developmental disabilities had been filed in twenty-five states.<sup>39</sup> Thus, the pressure on states to effectively serve people with disabilities in community settings has intensified. Technology such as augmentative communication devices is an essential means of effectuating states’ *Olmstead* obligations.

In addition to increasing the independence of people with disabilities, providing augmentative communication devices to people with disabilities is also cost-effective. As the *Fred C.* court noted, “[b]ecause the ability to speak and communicate is vital, augmentative communication devices have enabled adult Medicaid recipients with severe speech impairments to live on their own, maintain employment, pay taxes and become productive members of the community rather than wards of the State.”<sup>40</sup> Living in the community requires appropriate supports and services, the provision of which has been shown to result in overall cost savings compared to institutionalized care.<sup>41</sup> The costs of providing health care to people with disabilities are not completely avoidable; they exist whether people live in institutions or in the community. However, the *Fred C.* court credited the increased independence provided by augmentative communication devices and services with “limit[ing] the cost of other medical services, such as nursing expenses, and reduc[ing] or eliminat[ing] the costs of disability and other welfare benefits.”<sup>42</sup>

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for people with developmental and mental disabilities); see also Jefferson D.E. Smith & Steve P. Calandrillo, *Forward to Fundamental Alteration: Addressing ADA Title II Integration Lawsuits after Olmstead v. L.C.*, 24 HARV. J.L. & PUB. POL’Y 695, 703–04 (2001).

36. 527 U.S. 581 (1999).

37. *Id.* at 600.

38. *Id.* at 605. The Court also identified “a waiting list that moved at a reasonable pace” as an additional factor. *Id.* at 606.

39. GARY A. SMITH, HUMAN SERV’S RESEARCH INST., STATUS REPORT: LITIGATION CONCERNING HOME AND COMMUNITY SERVICES FOR PEOPLE WITH DISABILITIES 5 (2006), available at [http://www.napas.org/images/Documents/Issues/Community\\_integration/NDRN\\_hsri\\_docket\\_52906.pdf](http://www.napas.org/images/Documents/Issues/Community_integration/NDRN_hsri_docket_52906.pdf).

40. *Fred C. v. Tex. Health and Human Serv’s Comm’n*, 988 F. Supp. 1032, 1036 (W.D. Tex. 1997) (citing Saideman, *supra* note 8, at 741).

41. Smith & Calandrillo, *supra* note 35, at 704.

42. *Fred C.*, 988 F. Supp. at 1036 (citing Saideman, *supra* note 8, at 741).

Beyond improving cost-effectiveness, the increased independence afforded by augmentative communication also furthers the community integration goal of dispelling harmful stereotypes applied to people with disabilities, encouraging a view of people with disabilities as deserving dignity and full personhood. In support of its decision, the *Olmstead* Court noted that “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.”<sup>43</sup> The Court also acknowledged that “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”<sup>44</sup> All of these activities, of course, are enhanced by the ability to communicate effectively.

The community integration movement reveals the fluid nature of medical conditions that were once perceived to be immutable and permanently disabling. Cases like *Sonya*’s exemplify the nature of disability as a social construct. According to this view, the constraints faced by people with disabilities are a function of the way society is extrinsically ordered rather than resulting from the intrinsic physical or mental limitations imposed by a medical condition.<sup>45</sup> Thus, disability “is not an unavoidable result of injury and chronic disease. Rather, disability results, in part, from choices society makes about health care, working conditions, housing, transportation, and other aspects of the overall environment.”<sup>46</sup> Technology such as augmentative communication devices counters

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43. *Olmstead v. L.C.*, 527 U.S. 581, 600 (1999).

44. *Id.* at 601.

45. See, e.g., PAUL K. LONGMORE, *WHY I BURNED MY BOOK AND OTHER ESSAYS ON DISABILITY*, 238–39 (2003) (observing that disability “is not simply caused by impairments or by physiological features that depart from the typical. Instead, disability is produced through the dynamic interplay of a complicated constellation of factors that includes, not only stigmatized physical and mental limitations and physiological differences, but also physical and architectural environments, social arrangements and cultural values, and the impact of public policies themselves” and that disability “is not an objective condition. It is a set of socially produced, highly mutable, historically evolving social identities and roles”).

46. Marilyn J. Field & Alan M. Jette, *Dealing with Disability*, *ISSUES IN SCI. & TECH.*, Winter 2008, at \*1, available at <http://www.issues.org/24.2/field.html>; see also Richard K. Scotch, *Models of Disability and the Americans with Disabilities Act*, 21 *BERKELEY J. EMP. & LAB. L.* 213, 214 (2000) (noting that “[i]n the socio-political model, disability is viewed not as a physical or mental impairment, but as a social construction shaped by environmental factors, including physical characteristics built into the environment, cultural attitudes and social behaviors, and the institutionalized rules, procedures, and practices of private entities and public organizations.”); Deborah Kaplan, *The Definition of Disability: Perspective of the Disability Community*, 3 *J. HEALTH CARE L. & POL’Y* 352, 356 (2000) (emphasizing that disability is a social construct).

the intrinsic effects of medical conditions, making them less disabling.

Many of the problems faced by people with disabilities stem from societal discrimination and stereotypes that promote the erroneous equation of disability with dependence and incapacity.<sup>47</sup> In this vein, society's perceptions about people with disabilities' potential to contribute meaningfully to the community influence the actual limitations experienced by this population.<sup>48</sup> In Sonya's case, the Medicaid managed care organization's views about the type and extent of communication that was adequate for a person with Sonya's disabilities—getting attention through primitive means such as groaning and banging on objects—influenced its determination that an augmentative communication device was not “necessary.” Recognizing the extent to which the restrictions associated with disability are socially constructed allows people with disabilities to be viewed in a different light. This is particularly true when technology, such as augmentative communication devices, helps to counter the effects of socially constructed disability.

The arguments in support of Medicaid coverage for augmentative communication devices and services also serve the important interest of adjudicatory economy. Society has an interest in maximizing the effectiveness and efficiency of the legal system. Similarly, individual Medicaid beneficiaries have an interest in avoiding the delays associated with coverage denials that are not legally justified. Particularly where, as here, the governing law strongly supports Medicaid coverage,<sup>49</sup> people like Sonya should not have to forgo the developmental opportunities presented by augmentative communication while waiting for an appeal to be resolved, nor should they need to navigate an adjudicatory process that is stacked against them.

Ensuring access to technology such as augmentative communication devices is increasingly important because people with disabilities are living longer. People with medical conditions who formerly did not survive beyond birth or childhood are now living

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47. See Scotch, *supra* note 46, at 215–16 (“People with disabilities are victimized by negative stereotypes that associate physical or mental impairment with assumed dependence on others and a general incapacity to perform social and economic activities.”); see also Kaplan, *supra* note 46, at 355 (“The disability model recognizes social discrimination as the most significant problem experienced by persons with disabilities and as the cause of many of the problems that are regarded as intrinsic to the disability under other models.”).

48. See Scotch, *supra* note 46, at 215 (“Thus, the consequences of physical and mental impairments for social participation are shaped by the expectations and attitudes of the larger society.”).

49. See discussion *infra* Part II.

well into adulthood.<sup>50</sup> Thus, there is increasing demand for technology like augmentative communication devices to improve the quality of life and promote independence for people with disabilities. Medical advances are not only prolonging life but also are creating increasingly effective and sophisticated ways of augmenting natural abilities and assisting people with disabilities. For these advances to be meaningful, people with disabilities must have access to new devices that are appropriate for their needs.

Despite the significant potential for augmentative communication devices to alter both negative societal perceptions of people with disabilities and the real barriers they encounter in daily life, the path to accessing such technology is rife with obstacles.

## II. BARRIERS ENCOUNTERED BY MEDICAID BENEFICIARIES SEEKING COVERAGE OF AUGMENTATIVE COMMUNICATION DEVICES

Given the benefits of augmentative communication devices, barriers to Medicaid coverage must be minimized. Receiving a prescription for a medical device or service from a doctor often is not the endpoint in a Medicaid beneficiary's search for effective treatment. Rather, the Medicaid program's denial of coverage marks the beginning of an appeals process that many beneficiaries find confusing, tedious, and adversarial. While Sonya's story ended well, this result did not come about without a contentious fight that lasted several months and required both legal and medical expertise. In fact, most Medicaid appellants' stories really begin not with a doctor's prescription, but with the denial of payment for a necessary service.<sup>51</sup>

Once a Medicaid beneficiary is denied coverage of a prescribed service, she faces daunting obstacles to an appeal. First, coupled

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50. See, e.g., CLAIRE H. LIACHOWITZ, *DISABILITY AS A SOCIAL CONSTRUCT: LEGISLATIVE ROOTS* 87 (1988) (observing that in colonial America, the "inability to prevent or combat infections suggests that many children with physical infirmities would not have survived for more than days or weeks"); COMM. ON DISABILITY IN AM., *THE FUTURE OF DISABILITY IN AMERICA* 98 (Marilyn J. Field & Alan M. Jette eds., 2007) ("For children with cystic fibrosis, congenital heart disease, spina bifida, and other conditions that once were often or always fatal in infancy or childhood, what might earlier have seemed a fantasy of the future—planning for college and work life—is now a reality for many families.").

51. There is a lack of easily accessible data surrounding the Medicaid benefits process. For example, I am unable to locate statistics about the number of Medicaid service denials in a given period of time, the number of appeals arising from those denials, or the outcomes of those appeals. The National Health Law Program, the national backup center for legal services attorneys working in this area, also is unfamiliar with the compilation of such data. This suggests a fruitful area of future research to quantify the problem, while my years of experience working in this field suggest that the problem is not a small one.

with the scarcity of lawyers available to Medicaid beneficiaries is the fact that interpretation of the federal Medicaid Act<sup>52</sup> in the process of making coverage determinations is an arduous challenge for both judges and lawyers. Writing for the United States Supreme Court, Justice Powell observed that the statute's "Byzantine construction" makes it "almost unintelligible to the uninitiated."<sup>53</sup> Other judges have characterized the Medicaid Act as an "aggravated assault on the English language"<sup>54</sup> and a "virtually impenetrable 'Serbonian bog' "<sup>55</sup> For Medicaid recipients, the appeals process is an onerous task, with access to crucial medical services hanging in the balance.<sup>56</sup>

The Medicaid appeals process offers two options for beneficiaries facing service denials. A Medicaid beneficiary may request an informal hearing with the MCO, as Sonya did. In addition, she also may request an administrative "fair hearing" with an independent branch of the state agency that administers Medicaid benefits.<sup>57</sup> However, each route presents several barriers to the effective resolution of these cases. These barriers can be divided into three general groups: disincentives to initiate the appeal; inequities in the administrative hearing process itself; and misinformation or incomplete information underlying decisions in the prior authorization<sup>58</sup> and appeals context. For these reasons, it is not surprising that "[w]ithout trained advocates, eligible recipients might forfeit their right to essential benefits."<sup>59</sup>

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52. 42 U.S.C. §§ 1396–1396(w)(5) (West 2011).

53. *Schweiker v. Gray Panthers*, 453 U.S. 34, 43 (1981).

54. *Friedman v. Berger*, 409 F. Supp. 1225, 1226 (S.D.N.Y. 1976).

55. *Ross v. Giardi*, 680 A.2d 113, 116 (Conn. 1996).

56. See Lisa Brodoff, *Lifting Burdens: Proof, Social Justice, and Public Assistance Administrative Hearings*, 32 N.Y.U. REV. L. & SOC. CHANGE 131, 142 (2008) (describing the "devastating" effects of the denial or termination of Medicaid medical services).

57. See 42 U.S.C. § 1396a(a)(3) (2006) (establishing the hearing option); 42 C.F.R. § 431.205 (2007) (fleshing out rules for the hearing process). Such a hearing is the type endorsed by the U.S. Supreme Court in *Goldberg v. Kelly*, 397 U.S. 254 (1970).

58. Prior authorization is the process by which a Medicaid beneficiary specifically requests MCO coverage of a prescribed service, before the service is provided. See, e.g., Chasan-Sloan, *supra* note 3, at 290 (asserting that effective appeal procedures take on greater importance in the managed care context because "[u]nder the original fee-for-service Medicaid system, beneficiaries' disputes generally concerned reimbursement by the Medicaid program for services already rendered" while "disputes in Medicaid managed care . . . are more likely to involve the outright denial or delay of services").

59. David I. Schulman et al., *Public Health Legal Services: A New Vision*, 15 GEO. J. ON POVERTY L. & POL'Y 729, 776 (2008).

*A. (Dis)incentives to Initiate an Appeal*

The circumstances in which a Medicaid beneficiary and her family find themselves prior to initiating an appeal are often significant determinants in the decision to appeal. For example, in addition to seeking Medicaid approval of prescribed services, recipients and their families are frequently dealing with a private health insurer,<sup>60</sup> with its own coverage standards, requiring the navigation of multiple and at times contradictory systems.<sup>61</sup>

Furthermore, the health care system is only one arena in which conflicts arise. Families also must advocate with their child's school district for appropriate educational programming and related services.<sup>62</sup> They must find a way to go to work when the private duty nurse or home health aide who will care for a child in the parent's absence is unable to cover her shift. They must adhere to a regular schedule of doctor's appointments, visits with specialists, medical testing, and various therapy sessions one or more times a week—physical, occupational, or speech, or sometimes all three.

Additionally, children with significant disabilities often require a dizzying array of medication, equipment, and supplies, each of which must be obtained, administered, and maintained each day. All of these demands intensify when a child, sometimes unpredictably, experiences a medical emergency or another exacerbation of her illness. Against this backdrop (without even addressing the parents' own needs and the needs of other children in the family), it is not difficult to see why the decision to appeal a Medicaid service denial, even if the prescription is in fact medically necessary, is

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60. Children with significant disabilities can qualify for Medicaid regardless of household income through a state option under the Tax Equity Fiscal Responsibility Act of 1982 (TEFRA), informally known as the "Katie Beckett" Medicaid option. Pub. L. No. 97-248, § 134, 96 Stat. 324, 375 (1982) (codified as amended at 42 U.S.C. § 1396a(e)(3) (2006)).

61. Because Medicaid is the payor of last resort, any private insurance coverage that a child has must deny a service request to trigger Medicaid coverage. See 42 U.S.C. §§ 1396a(a)(25), b(o) (establishing that Medicaid applies only to fill in gaps not covered by private insurance). The Medicaid benefits package for children offers a comprehensive array of services, and its focus on "correct[ing] or ameliorat[ing]" all physical and mental health conditions and their effects provides a favorable standard for children with disabilities. 42 U.S.C. § 1396d. By contrast, private health insurance policies typically are designed to cover generally healthy people with relatively short-term treatment needs. For example, private health insurance policies may cover physical therapy for a limited period of time, such as sixty days, which may allow rehabilitation for someone injured in an accident but is insufficient for the years of therapy needed by children with cerebral palsy, muscular dystrophy, and other congenital conditions.

62. See generally Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400–1409 (2006) (providing special education and related services for qualifying children with disabilities); 29 U.S.C. § 794 (2006) (requiring school districts to reasonably accommodate children with disabilities).



not one to be taken lightly: families of children with significant disabilities must carefully choose the battles to which they devote their limited time and energy.<sup>63</sup> Such extrinsic factors cannot be directly remedied by reforms to the Medicaid appeals process.

### B. (Un)fair Hearings

Despite an administrative process that is designed to be less formal than court,<sup>64</sup> families frequently find that Medicaid appeals are complex and adversarial battlegrounds. This is due to several factors, both procedural and substantive.

First, the appeals process is multi-layered and not intuitive for a layperson to navigate. If Medicaid benefits are administered by a managed care organization (MCO), a beneficiary must be afforded an in-person informal hearing at the MCO.<sup>65</sup> Because the MCO retains a great deal of control over the informal hearing process, this option may or may not present a realistic opportunity to have an initial denial reversed. For example, the decision maker at an MCO hearing can range from a sole MCO employee to a panel that also includes representatives from the state Medicaid agency and the health plan members.<sup>66</sup> The MCO hearing can thus involve a careful second look at the merits of the prescription or a mere rubber stamp of the original denial.

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63. Cf. Brodoff, *supra* note 56, at 152 (noting that public assistance recipients often are disadvantaged in the appeals process by the barriers of “poverty, disability, age, education, [and] language”).

64. The alternative to the fair hearing process, challenging Medicaid denials in federal court as a violation of § 1983 of the Civil Rights Act, is beyond the scope of this Article.

65. 42 U.S.C. § 1396u-2(b)(4) (2006); 42 C.F.R. § 438.406(b)(2) (2009). Despite the federal requirement that the MCO offer the beneficiary the chance to appear in person, the MCOs’ adherence to this requirement was variable in my experience. See, e.g., N.D., DPCI #0001337430, at \*22, Steinberg, H.O. (Del. Dep’t of Health & Soc. Serv’s, Div. of Medicaid and Medical Assistance May 21, 2007) (noting “Appellant[’s] conten[tion] that she was not provided with an opportunity to participate in an in-person hearing during the internal appeals with [the MCO]” and that “the agency is also aware of continuing concerns about the availability of in-person appearances for members”).

66. In my experience, including diverse perspectives on the hearing panel helps to make the process exhibit more of the characteristics of a critical review of the underlying determination rather than a rubber stamp on the MCO’s denial. The manner in which the MCO conducts an informal health plan hearing, such as Sonya’s, can also limit the advocacy opportunities. For example, when I first began practicing in these fora, the Medicaid beneficiary and her representative were not allowed in the hearing room during the MCO’s presentation to the panel. After I appealed to the state Medicaid director, the beneficiary and her representative won the right to be in the room, but still were forbidden from questioning the MCO’s witnesses, which detracts from the full presentation of both sides of the case.

After or instead of an internal MCO hearing, Medicaid beneficiaries always have the right to an administrative “fair hearing.”<sup>67</sup> In the tradition of *Goldberg v. Kelly*, this forum is intended to provide recipients with the opportunity to be heard, as required by the Due Process Clause of the Fourteenth Amendment to the United States Constitution.<sup>68</sup> A beneficiary’s rights at a Medicaid fair hearing include the ability to present witnesses, evidence, and arguments and to cross-examine adverse witnesses.<sup>69</sup> This hearing offers the promise of a deliberately neutral review, if the beneficiary is able to navigate the process.

Formal administrative hearing officers, however, need not be lawyers. They are intended to be neutral decision-makers, but they nonetheless are employed by the state, albeit in a different arm of the agency than the entity that determines initial eligibility and directly administers benefits. There is no guarantee that the hearing officer will truly be “neutral,” however; “in almost half of all state hearing systems, the [hearing officer] is directly employed by the very agency whose decision is being challenged.”<sup>70</sup> Elsewhere, the “administrative hearing office is . . . often funded by the very agencies whose decisions they are overseeing.”<sup>71</sup>

The reality that the adverse party has a greater degree of familiarity with the administrative hearing process also influences the Medicaid beneficiary’s experience. Denials are defended by either the state Medicaid agency or a private MCO that contracts with the state agency to administer benefits. In either scenario, the adverse party is a repeat player in the hearing process, unlike most Medicaid beneficiaries and their families who are unfamiliar with administrative hearings.<sup>72</sup>

Further skewing the balance against the beneficiary is the fact that the adverse party always has access to legal counsel, either through the state Attorney General’s office or through a private

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67. 42 U.S.C. § 1396a(a)(3) (2006).

68. *Goldberg v. Kelly*, 397 U.S. 254, 266 (1970) (“[T]he stakes are simply too high for the welfare recipient, and the possibility for honest error or irritable misjudgment too great, to allow termination of aid without giving the recipient a chance, if he so desires, to be fully informed of the case against him so that he may contest its basis and produce evidence in rebuttal.” (quoting *Kelly v. Wyman*, 294 F. Supp. 893, 904–905 (S.D.N.Y. 1968))); see also 42 C.F.R. § 431.205(d) (2007) (requiring state Medicaid programs to establish hearing procedures that meet the *Goldberg v. Kelly* requirements).

69. 42 C.F.R. § 431.242 (2009).

70. Brodoff, *supra* note 56, at 157–58 (internal citations omitted) (analogizing such an arrangement to “having the fox guard the henhouse”) *Id.* at 158).

71. *Id.* at 159.

72. See *id.* at 152–53 ((noting that public assistance recipients “are disadvantaged by the fact that the state is always represented by an experienced advocate in the hearing”) *Id.* at 152).

law firm retained by the MCO.<sup>73</sup> By contrast, most beneficiaries proceed *pro se* in their appeals and must navigate a legal realm that is far from intuitive.<sup>74</sup>

Although formal administrative hearings do not require all of the official procedures of a trial, they often involve technicalities that laypersons may not be able to master, such as hearsay objections.<sup>75</sup> And, because any further appeal in the state court system is on the record,<sup>76</sup> the administrative hearing is the only opportunity to present witness testimony and other evidence. For these reasons, having a legal representative at the formal administrative hearing is vital to ensure that a Medicaid beneficiary has the best possible opportunity to overturn a service denial.<sup>77</sup>

The support of a doctor is just as important as that of a lawyer for beneficiaries in Medicaid appeals. Perhaps most significantly, the doctors and nurses who will testify in support of the denial are employees of the adverse party.<sup>78</sup> This means that participating in administrative hearings is part of their job, and consequently, they

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73. Query whether the use of Medicaid program funds to retain private lawyers is, in the words of one state Medicaid medical necessity definition, the “least costly, appropriate . . . alternative” and an “effective and appropriate use of program funds,” particularly when the cost of litigating a case may exceed the cost of actually providing the services at issue in the appeal. 2 Del. Reg. Regs. 1250 (Jan. 1, 1999). To cite just one example, I represented a teenager who required surgery to correct gynecomastia. The Medicaid program denied coverage, but we obtained a commitment from a hospital to donate the medical providers’ time to perform the procedure. The only costs would be the necessary supplies. Acknowledging that the MCO would spend significantly more in legal fees going to hearing, the case was nonetheless litigated. In the end, the MCO’s decision was reversed, and it was ordered to pay for the procedure in full.

74. See, e.g., Brodoff, *supra* note 56, at 148 (noting that the “vast majority of public assistance appellants appear at their hearings *pro se*”).

75. See Brodoff, *supra* note 56, at 149 (describing fair hearings as “a scary, intimidating, and complex process that involves court-like procedures, public speaking, motion practice, entry of exhibits, objections to evidence, and an understanding of complicated laws and procedures”).

76. See, e.g., DEL. CODE ANN. tit. 31, § 520 (2009) (“Any applicant for or recipient of public assistance benefits . . . may appeal [a] decision . . . . The appeal shall be on the record without a trial *de novo*.”)

77. The administrative hearing process is effectively the only means of appeal in this context. See Brodoff, *supra* note 56, at 143, 146–47 (noting that “very few public assistance cases are appealed into the court system” and explaining that to succeed on appeal, a “public assistance appellant must not only be savvy enough to have put on all the testimony and exhibits necessary for the [administrative law judge] to make favorable factual findings, she must also have spotted and raised all the legal arguments and defenses she could have at the hearing” as well as overcome “the deference courts give to an agency’s permissible construction of its governing statutes”).

78. See *id.* at 153–54 (“Welfare agencies can and do call their own doctors, dentists, nurses, and program managers, to testify as paid experts . . . . Finding and hiring expert witnesses who can testify [on behalf of the appellant] . . . is difficult at best for low-income appellants in the hearing process. Yet this expert testimony can be the decisive evidence in a benefits eligibility case.”).

are willing and available to do so. By contrast, the Medicaid beneficiary's prescribing physician and other treatment providers must take time out of their busy schedules and agree to testify. In many states, the administrative hearing officer lacks subpoena power to compel witnesses' attendance.

While some doctors generously take the time to advocate for their patients, there are many reasons why doctors will not voluntarily participate in these hearings. Sometimes the treating provider is employed by the same health system that contains the Medicaid MCO, in which case the provider's employer may refuse to give permission for the provider to participate. Even without such a direct conflict, there are economic disincentives: providers' time is valuable, and they are paid to see patients, not to participate in administrative hearings. Sometimes, doctors tell patients that they will not testify unless the patient pays a sizeable hourly rate.

In other situations, a hospital's general counsel's office may not allow its employees to testify, despite the fact that the proceedings are closed and do not involve allegations of wrongdoing on behalf of the treating doctor. Still other doctors are reluctant of their own accord to become involved with any enterprise that involves lawyers.<sup>79</sup> Lawyers' reputations precede them in the medical field, and doctors generally see lawyers as adversaries, not allies.<sup>80</sup> Even willing doctors proceed with trepidation, as they are likely unfamiliar with the hearing process and wary of cross-examination.

If the treating provider will not participate, it may be possible, although not without significant extra effort, to locate another supportive physician who is willing to review the case and provide a professional opinion *pro bono*. Testimony at the administrative hearing may be required, but many times, a well-written letter of medical necessity with supporting medical records and the knowledge that a treating provider is willing to participate in a hearing can be enough for the MCO to change its mind. To be most effective, this type of collaboration needs to occur early in the prior authorization process. Regardless, it is extremely difficult to

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79. In one case that I handled, in which a prescribing physician was reluctant to testify in support of a prescription he wrote for a patient, the general counsel for the hospital agreed that he had no legal obligation to do so, but pointed out that he did have a moral one.

80. See, e.g., Elizabeth Tobin Tyler, *Allies Not Adversaries: Teaching Collaboration to the Next Generation of Doctors and Lawyers to Address Social Inequality*, 11 J. HEALTH CARE L. & POL'Y 249, 249-50 (2008) (describing the sometimes antagonistic relationship between the two professions).

prevail in Medicaid service denial cases without some expert medical opinion to counter that of the MCO's medical director.

Finally, substantive Medicaid law is a complex collection of federal and state statutes, regulations, and sub-regulatory material. Consider the legal analysis required to obtain Medicaid coverage for an augmentative communication device. A prescribed service must satisfy two tests before it is approved: it must fit into one of the enumerated federal statutory categories, and it must be determined "medically necessary."

Augmentative communication devices can qualify under four statutory categories. The first is equipment or appliances suitable for use in the home, a component of the mandatory home health services category, which must be included in every state's Medicaid program.<sup>81</sup> In addition, there are three optional categories of Medicaid covered services into which augmentative communication devices may fall: "physical therapy and related services," which expressly includes "services for individuals with speech, hearing, and language disorders . . . includ[ing] any necessary supplies and equipment,"<sup>82</sup> prosthetic devices, which are prescribed, *inter alia*, to "[p]revent or correct physical deformity or malfunction,"<sup>83</sup> and

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81. See 42 U.S.C. § 1396d(a)(7) (2006) (listing "home health care services" as a medical service); 42 C.F.R. § 440.70 (2009) (further defining "home health services"); 42 C.F.R. § 441.15 (2009) (fleshing out the definition in § 440.70). Some twenty-four states currently classify augmentative communication devices in this category. See *William T. v. Taylor*, 465 F. Supp. 2d 1267, 1285 n.21 (N.D. Ga. 2000) (citing Pls.' Br. in Supp. of Mot. for Summ. J. at 23); see also *Fred C. v. Tex. Health and Human Servs' Comm'n*, 988 F. Supp. 1032, 1036 (W.D. Tex. 1997) (holding that augmentative communication devices are "durable medical equipment and covered as a Texas Medicaid benefit"); *Hunter v. Chiles*, 944 F. Supp. 914, 920 (S.D. Fla. 1996) (holding that augmentative communication devices and services are "durable medical equipment and covered as a Florida Medicaid benefit under the home health care provision"). But see *Wolan v. Thomas*, No. CV 970404219, 1998 WL 165107, at \*1, \*3 (Conn. Super. Ct. Mar. 30, 1998) (endorsing as "reasonable" the conclusion that augmentative communication device is not medical equipment because it does not "diagnose, treat or prevent . . . the recurring esophageal stenosis condition" that made plaintiff's speech "very difficult to understand").

82. See 42 U.S.C. § 1396d(a)(11) (defining Medicaid "medical assistance" to include "physical therapy and related services"); 42 C.F.R. § 440.110 (further defining "physical therapy"); *William T.*, 465 F. Supp. 2d at 1287 & n.24 (noting that three states classify augmentative communication devices in this category and finding that augmentative communication devices "are properly considered [speech-language pathology] equipment"); see also *Meyers v. Reagan*, 776 F.2d 241, 243-44 (8th Cir. 1985) (holding that "Iowa cannot arbitrarily exclude electronic speech devices from coverage under its Medicaid program" which included "physical therapy and related services"). But see *Wolan*, 1998 WL 165107, at \*3-4 (rejecting claim for Medicaid coverage premised upon classification of augmentative communication device as a speech pathology service, because device did not "[p]revent or correct physical deformity or malfunction . . . [or] diagnose, screen for or prevent the plaintiff's cerebral palsy or speech dysarthria . . . [or] correct his conditions").

83. See 42 U.S.C. § 1396d(a)(12) (defining Medicaid "medical assistance" to include "prosthetic devices"); 42 C.F.R. § 440.120(c) (further defining "prosthetic devices"); *William*

“other . . . rehabilitative service including any medical or remedial services (provided in a facility, a home, or other setting) recommended by a physician . . . for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level.”<sup>84</sup>

A related point is that state Medicaid programs must offer the potential for coverage of augmentative communication devices somewhere in their benefits packages. Coverage must be more than an illusory promise; to be legally sufficient, beneficiaries must have a realistic chance to actually obtain coverage. Thus, states may not unconditionally omit augmentative communication devices from all categories of Medicaid covered services. One federal district court noted that in eighteen cases, no court had permitted a state Medicaid program to exclude these devices from coverage either generally or for a specific sub-population of beneficiaries.<sup>85</sup> Moreover, states must offer payment rates for augmentative communication devices that enable beneficiaries to actually obtain the devices that are authorized.<sup>86</sup> Furthermore, states cannot limit Medicaid service categories to only some groups of beneficiaries. Rather, if a state elects an optional category of Medicaid services, it must provide those services to all eligible beneficiaries.<sup>87</sup>

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*T.*, 465 F. Supp. 2d at 1286 & n.23 (noting that 15 states classify augmentative communication devices as prosthetic devices for Medicaid coverage purposes and holding that augmentative communication devices “correct physical malfunction by replacing the functions of the brain, nerve pathways, and organs of speech, which when unimpaired, yield intelligible speech” (citing and quoting Pls.’ Br. in Supp. of Mot. for Summ. J. at 28 n. 79)); *Fred. C.*, 988 F. Supp. at 1037 (rejecting argument that augmentative communication is not a prosthetic device because it does not replace missing vocal cords). *But see Wolan*, 1998 WL 165107, at \*3 (finding that augmentative communication device did not meet definition of prosthesis because “plaintiff is not missing his vocal cords, they are damaged [and h]is vocal cords are not corrected, replaced or supported by” the prescribed augmentative communication device).

84. See 42 U.S.C. § 1396d(a)(13) (defining Medicaid “medical assistance” to include “rehabilitative services”). Medicaid “[r]ehabilitative services . . . includes any medical or remedial services recommended by a physician . . . for maximum reduction of physical or mental disability and restoration of a recipient to his best possible functional level.” 42 C.F.R. § 440.130(d).

85. See *William T.*, 465 F. Supp. 2d at 1285 (citing Pls.’ Br. in Supp. of Mot. for Summ. J. at 21).

86. See Case Reports: Health—California Agrees to Reimbursement Rates Sufficient to Give Medicaid Recipients Access to Speech-Generating Devices, 39 CLEARINGHOUSE REV. 107, 107 (2005) (summarizing the case of *Joseph Q. v. Shewry [Bonta]*, a challenge to California’s 20% payment rate reduction, which plaintiffs alleged made the Medicaid payment rate for augmentative communication devices substantially below that paid by other funding sources); see also Brief for Plaintiff, *Joseph Q. v. Bonta*, No. CIV. S-04-1008, (E.D. Cal. case settled Oct. 25, 2004), available at <http://www.povertylaw.org/poverty-law-library/case/55800/55870/55870a.pdf>.

87. See *Lankford v. Sherman*, 451 F.3d 496, 501–02, 511 (8th Cir. 2006) (“While a state has discretion to determine the optional services in its Medicaid plan, a state’s failure to

Once a service is determined to be part of a statutory category, the second part of the legal test requires that it then satisfy the state's definition of Medicaid medical necessity.<sup>88</sup> While the legal analysis for adults turns to each state's individual criteria at this point, the federal Medicaid Act applies another set of requirements to children. Medicaid's mandatory Early and Periodic Screening Diagnosis and Treatment (EPSDT) provisions,<sup>89</sup> with their own definition of medical necessity,<sup>90</sup> govern determinations for Medicaid beneficiaries age twenty-one and younger.<sup>91</sup> Under EPSDT, medical services must be covered for Medicaid beneficiaries under age twenty-one if the services are "necessary . . . to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services,"<sup>92</sup> whether or not such services are covered under the State plan.<sup>93</sup> Congress also has directed that all of the categories of covered services listed in the Medicaid Act must be made available to EPSDT beneficiaries, regardless of whether the state has elected to include any optional service categories in its Medicaid benefits package for adults.<sup>94</sup> This

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provide Medicaid coverage for non-experimental, medically-necessary services within a covered Medicaid category is both per se unreasonable and inconsistent with the stated goals of Medicaid.").

88. See, e.g., *Lagowski v. Whalen*, 706 N.Y.S.2d 283, 284 (N.Y. App. Div. 2000).

89. See 42 U.S.C. § 1396a(a)(43) (2006) (mandating that a State plan for medical assistance provide for "informing all [eligible] persons in the State who are under the age of 21 . . . of the availability of early and periodic screening, diagnostic, and treatment services"); 42 U.S.C. § 1396d(r)(5) (defining "early and periodic screening, diagnostic, and treatment services"); 42 C.F.R. § 440.40(b) (fleshing out the definition of EPSDT); see also S.D. *ex rel. Dickson v. Hood*, 391 F.3d 581, 589 (5th Cir. 2004) ("The medical assistance made available to EPSDT children must be for health care described in the list of twenty-seven categories set forth in § 1396d(a)—modified by the requirement that it must be necessary for corrective or ameliorative EPSDT purposes—further modified by the statutory mandate that it must be provided whether or not it is covered under the state plan.").

90. See, e.g., S.D., 391 F.3d at 589–93; *Dep't of Cmty. Health v. Freels*, 576 S.E.2d 2, 6 (Ga. Ct. App. 2002) (affirming that "[i]nstead of requiring proof that [a medical service] . . . meets the definition of medical necessity reserved for adult Medicaid recipients, the [Department] should have focused its inquiry on whether [the service] was necessary to correct or ameliorate [the EPSDT child's] physical condition'" (quoting *Freels v. Comm'r*, No. 01-CV-2932-10, 2001 WL 1809412, at \*4 (Ga. Super. Ct. 2001))).

91. 42 U.S.C. § 1396a(a)(43); 42 U.S.C. § 1396d(a)(4)(B); 42 U.S.C. § 1396d(r)(5).

92. EPSDT screening services include doctor's appointments "at such other intervals, indicated as medically necessary, to determine the existence of certain physical or mental illnesses or conditions." 42 U.S.C. § 1396d(r)(1)(A)(ii).

93. 42 U.S.C. § 1396d(r)(5). Courts have looked to the dictionary definition of ameliorate—"to make better or more tolerable"—to guide their analysis of medical necessity under EPSDT. *Collins ex rel. Collins v. Hamilton*, 231 F. Supp. 2d 840, 849 (S.D. Ind. 2002) (citing WEBSTER'S NEW COLLEGIATE DICTIONARY (7th ed. 1963)).

94. 42 U.S.C. § 1396d(r)(5); see also *Rosie D. v. Romney*, 410 F. Supp. 2d 18, 26 (D. Mass. 2006) ("The breadth of EPSDT requirements is underscored by the statute's definition of 'medical services.' Section 1396d(a)(13) defines as covered medical services any 'diagnostic, screening, preventative, and rehabilitative services, including any medical or

means that all four of the above statutory categories are available for children to access augmentative communication device coverage, even if only the sole mandatory category (home health services) is available to adults in the state.

The EPSDT medical necessity standard also means that, for Medicaid beneficiaries age twenty-one and younger, states may not incorporate other criteria, such as appropriateness,<sup>95</sup> standard of care,<sup>96</sup> cost, or other elements into the medical necessity determination.<sup>97</sup> By articulating a definition of medical necessity

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remedial services . . . for the *maximum reduction of physical or mental disability* and restoration of an individual to the *best possible functional level.*” (quoting 42 U.S.C. § 1396d(a)(13)); *Eklhoff v. Rogers*, 443 F. Supp. 2d 1173, 1179–80 (D. Ariz. 2006) (observing that “[e]very Circuit which has examined the scope of the EPSDT program has recognized that states must cover every type of health care or service necessary for EPSDT corrective or ameliorative purposes that is allowable under § 1396d(a)” and that “from reading the legislative history and the Congressional Record, it appears that there is a very strong inference to be inclusive rather than exclusive”).

95. For an example of the court interpreting this standard, see *Jackson v. Millstone*, 801 A.2d 1034, 1048–49 (Md. Ct. App. 2002) (“The federal program makes no mention of utilizing an ‘appropriateness’ analysis in determining whether a [M]edicaid-eligible child should receive medically necessary treatments provided through EPSDT services. Nevertheless, the Maryland [M]edicaid provision regarding preauthorization of services . . . requires that medically necessary treatment for a [M]edicaid-eligible child must also be ‘appropriate,’ which is beyond the dictates of federal law. The federal guidelines allow states no discretion to use an ‘appropriateness’ test in deciding whether a person under 21 can receive medically necessary treatment. Therefore, because the provision imposes additional criteria upon qualified recipients, which illegally denies services to those who would normally receive medically necessary treatment, we agree with the plaintiffs that [the Maryland regulation] is partially invalid under federal law.”).

96. [T]he Department applied the wrong legal standard by focusing on whether [the therapy at issue] was an accepted treatment that was medically necessary . . . . [T]he proper inquiry was whether [the therapy] was necessary “to correct or ameliorate a physical or mental defect or condition” regardless of whether it is an accepted medical practice . . . / . . . / . . . [T]he federal statute does not require that a treatment also be “an acceptable standard of medical practice” . . . . “[I]nstead of requiring proof that [a service] is the accepted standard medical practice, or that it meets the definition of medical necessity reserved for adult Medicaid recipients, the [Department] should have focused its inquiry on whether [the therapy] was necessary to correct or ameliorate [Freels’] physical condition.”

Dep’t of Cmty. Health v. Freels, 576 S.E.2d 2, 5–6 (Ga. Ct. App. 2002) (internal citations omitted).

97. See, e.g., *S.D. ex rel. Dickson v. Hood*, 391 F.3d 581, 585, 592 (5th Cir. 2004) (observing, in a case in which the “state administrative law judge ruled in favor of [the state Medicaid program] without referring to the Medicaid EPSDT provisions,” that “the plain words of the statute and the legislative history make evident that Congress intended that the health care, services, treatment and other measures that must be provided under the EPSDT program be determined by reference to federal law, not state preferences”); *Collins v. Hamilton*, 349 F.3d 371, 375–76 (7th Cir. 2003) (rejecting state Medicaid program’s attempt to read an additional criterion (a durational limit) into the EPSDT medical necessity standard); *C.F. v. Dep’t of Children & Families*, 934 So. 2d 1, 5–6 (Fla. Dist. Ct. App. 2005) (“The hearing officer erred in applying [a] definition[] of ‘medical necessity’ . . . that [is] too restrictive and violate[s] federal Medicaid law . . . . Because C.F. is a minor entitled to EPSDT benefits, his need for . . . services must be evaluated under the more expansive federal definition.”).



specifically for children who receive Medicaid, in addition to placing an emphasis on preventive healthcare,<sup>98</sup> and mandating that states cover children for all services that are considered optional under federal law for adults,<sup>99</sup> Congress demonstrated its intention that Medicaid coverage of children's benefits be expansive. Consequently, children's requests for medically necessary augmentative communication devices should not often be denied.

At best different, and at times competing, definitions of medical necessary for children and adults further complicate the legal analysis in this area. To the extent that a state's own Medicaid medical necessity definition differs from the EPSDT statutory definition, arguments for generous coverage of augmentative communication devices for children could unwittingly undercut arguments for coverage of the same services for adults. However, courts that have considered the issue have reached the opposite conclusion and instead used a state's coverage of augmentative communication devices for children to require similar coverage for adult Medicaid beneficiaries.<sup>100</sup> For example, in a case involving a forty-eight year old man with brain damage from a head injury sustained when he was twelve, the federal district court ordered Texas to provide an augmentative communication device under its Medicaid program.<sup>101</sup> The district court, later affirmed by the Fifth Circuit Court of Appeals, concluded that Texas's classification of augmentative communication devices as home health services and prosthetic devices for EPSDT beneficiaries but not for adults was patently unreasonable: "[t]his Court cannot divine a rational basis

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98. See, e.g., 42 U.S.C. § 1396d(r) (1) (2006) (mandating periodic screening services); H.R. REP. NO. 101-247, at 399 (1989), reprinted in 1989 U.S.C.C.A.N. 1906, 2125 (describing "preventative thrust of the EPSDT benefit").

99. See 42 U.S.C. § 1396d(r)(5) (stating that necessary services must be provided under EPSDT "whether or not such services are covered under the State plan"). Under Medicaid, states may choose (from a list of optional services) which services they will offer for adults in their state Medicaid plans. This section of the statute makes clear, however, that all services on the list must be covered for children, regardless of which options the state has selected for adults.

100. See *Fred C. v. Tex. Health and Human Serv's Comm'n*, 988 F. Supp. 1032, 1036 (W.D. Tex. 1997) (holding that "Texas Medicaid's selection of age as the sole criterion for denying benefits is wholly unrelated to the medical decision at hand and cannot meet the fundamental legal concept of reasonableness" where state Medicaid program considered augmentative communication devices to be durable medical equipment for EPSDT beneficiaries (children) but not for adult recipients of home health services); *Hunter v. Chiles*, 944 F. Supp. 914, 920 (S.D. Fla. 1996) (finding that Medicaid funding for augmentative communication devices "cannot be denied on the basis of age"); see also *William T. v. Taylor*, 465 F. Supp. 2d 1267, 1288 (N.D. Ga. 2000) (supporting, in dicta, plaintiffs' objection to draft criteria limiting augmentative communication coverage to beneficiaries under 21 as violative of Medicaid Act's "reasonable standards provision" and "amount, duration, and scope" requirements).

101. *Fred C.*, 988 F. Supp. at 1036.

to make available the blessings of speech to one who is twenty years three hundred sixty-four days old and deny the same blessing to one who is two days older.”<sup>102</sup> Thus, state coverage of augmentative communication devices for EPSDT beneficiaries can buttress comparable claims for adult Medicaid beneficiaries. Both children and adults, however, fare better in Medicaid appeals with the support of lawyers and doctors.

### C. (Mis)information Underlying Decisions to Deny

A final group of barriers to coverage of augmentative communication devices is the information, or lack thereof, that is considered by decision-makers in the Medicaid appeals context. This problem has multiple dimensions. First, the MCOs tend not to seek input from the prescribing physician when making coverage determinations. Information that the MCOs do collect when making coverage decisions is typically limited to medical and, sometimes, school records. The creators of those records, however, are typically not familiar with the criteria used in Medicaid coverage determinations and therefore may not address those issues.

One reason why MCOs may not seek relevant information from prescribers may be that the MCO system provides incentives for the MCO not to spend money. Unlike the traditional fee-for-service system, MCOs are paid a capitated rate for each beneficiary, regardless of the amount of services that the beneficiary actually uses. While the MCO may receive a higher rate for children with significant disabilities than for healthy children, medical care for children with chronic health conditions is exponentially more costly. Thus, the system encourages MCOs to conserve resources, whether when making coverage determinations or when affirmatively gathering information that might support decisions to provide coverage.<sup>103</sup>

Information from treating physicians is especially helpful when evaluating these cases, however. MCO medical directors tend to have general practice backgrounds or backgrounds in medical specialties that are not particularly relevant to children with disabilities, such as emergency room care. They often are unfamiliar with the relatively rare medical conditions,<sup>104</sup> with which

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102. *Id.*

103. *See, e.g.*, Chasan-Sloan, *supra* note 3, at 284.

104. An example of a rare condition is cri-du-chat syndrome, a “chromosomal condition . . . characterized by intellectual disability and delayed development, small head size (microcephaly), low birth weight, and weak muscle tone (hypotonia) in infancy.” *Cri-du-chat*

children with disabilities can present, and therefore are not familiar with the resultant care and treatment needs. Because of their lack of specialty qualifications, MCO medical providers sometimes misinterpret medical and school reports.<sup>105</sup>

Another information problem with administrative hearings can arise when MCOs fail to adequately explain their decisions. The constitutionally-required notice that the MCO must provide when denying services is intended to avoid this problem. As part of the *Goldberg v. Kelly* procedural due process requirement, this notice must state the agency's action, the reason(s) for the action, the legal citation that supports the determination, and the right to request a hearing.<sup>106</sup> One district court has described the "minimum" that agencies must do to meet due process requirements as including an "explan[ation], in terms comprehensible to the claimant . . . [as to] why the agency is taking this action."<sup>107</sup>

However, some or all of the required elements, particularly the legal citation and the explanation, are frequently missing from the notices. Sometimes "reasons" are based on inaccurate accounts of the facts. In one representative case, for example, a notice denied an augmentative communication device to a teenager with mental retardation who wandered away from her yard and was unable to provide her address or phone number to passersby. The MCO's notice stated only that she "is able to express basic skills presently and is able to express her needs verbally," without any supporting reasons or further explanation as to why the MCO reached this decision.<sup>108</sup> It is hard to imagine how the ability to communicate one's address and phone number qualifies as anything other than a basic communication skill.

Defective notices are problematic because they do not allow Medicaid recipients to make an informed decision about whether

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*syndrome*, GENETICS HOME REFERENCE, <http://ghr.nlm.nih.gov/condition=cr duchatsyndrome> (last visited Apr. 2, 2010).

105. For example, in one case I handled, the medical director testified that a prescription medication used to help control a child with spina bifida's neurogenic bladder was for Attention Deficit Hyperactivity Disorder (a diagnosis that the child did not actually have). In another case, a nurse case manager testified that a notation of "HOH" in a physical therapy report meant that the child engaged in tasks while holding his hands in the air over his head, instead of understanding that the therapist was indicating that the child required "hand over hand assistance" to complete tasks. See generally, J.R., DCIS No. 5005010054, at \*15, Higgins, H.O. (Del. Dep't of Health and Soc. Serv's, Div. of Medicaid and Medical Assistance Aug. 21, 2006).

106. 42 C.F.R. §§ 431.205(d), 210 (2009).

107. *Ortiz v. Eichler*, 616 F. Supp. 1046, 1061 (D. Del. 1985), *aff'd*, 794 F.2d 889 (3d Cir. 1986).

108. Medicaid Service Denial Notice (on file with the University of Michigan Journal of Law Reform).

an appeal is meritorious, nor do they enable recipients to adequately prepare for the arguments to be raised at the hearing.<sup>109</sup> The information deficit in the administrative hearing context is exacerbated because little to no formal discovery is permitted. The Medicaid beneficiary has the right to request a copy of her MCO file as well as any regulatory or policy material cited in the notice.<sup>110</sup> However, if the defective notice fails to cite any authority, this right is of little use. Further, there is no standard definition as to what constitutes a Medicaid beneficiary's file. One MCO will produce an exhaustive record of all service requests and denials throughout the beneficiary's enrollment. Another MCO will turn over information related only to the denial at issue, and even then, that information will not include documents purportedly relied upon in support of the determination.<sup>111</sup>

Some states require the MCO to prepare a "fair hearing summary," which includes a synopsis of the MCO's position, the supporting reasons, and a list of witnesses.<sup>112</sup> However, while filings can provide some insightful information, they often include the same deficiencies as the original denial notice. Otherwise, there is usually no opportunity to take depositions or issue interrogatories, make requests for admission, or make requests for production of other documents. Such tools would be useful for gathering additional information, narrowing the issues, and, particularly where doctors' schedules may conflict with hearings, memorializing testimony.

Another aspect of the information problem in these appeals stems from the documentation typically maintained by the prescribing physicians. First, doctors write in medical terms, which often do not track the legal language of the applicable medical necessity standard. Failing to speak in terms consistent with the statutory or regulatory standard can be fatal to an appeal. Second, submitting letters of medical necessity into evidence at a hearing in the absence of a live witness can present hearsay problems.<sup>113</sup>

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109. *Ortiz*, 616 F. Supp. at 1062 ("This detailed information is needed to enable claimants to understand what the agency has decided, so that they may assess the correctness of the agency's decision, make an informed decision as to whether to appeal, and be prepared for the issues to be addressed at the hearing.").

110. See 42 C.F.R. § 438.406(b)(3) (2009) (providing beneficiary the right "to examine the enrollee's case file, including medical records, and any other documents and records considered during the appeals process").

111. Often this information consists of webpage printouts, the dates on which, in my experience, frequently and problematically post-date the decision to deny.

112. See, e.g., 16 DEL. ADMIN. CODE § 5312 (2009).

113. See, e.g., 16 DEL. ADMIN. CODE § 5600 (stating that hearsay evidence is not admissible unless it meets one of the exceptions provided in the same section); § 5601 ("Findings of

Finally, the appeals process does not afford doctors the opportunity to formally respond to the reasons raised in the denial notice. MCOs often argue that any information generated after the denial date is irrelevant because it is "new." They take the position that the hearing is a determination about whether the MCO's denial was reasonable based upon the information it had at the time, instead of whether the service is in fact medically necessary for the beneficiary, based on all available information.<sup>114</sup> For all of these reasons, the Medicaid administrative hearing process presents multiple barriers to beneficiaries who want to challenge service denials.

### III. THE MEDICAL-LEGAL PARTNERSHIP MODEL FOR THE DELIVERY OF CIVIL LEGAL SERVICES

Under the traditional civil legal services delivery model, a Medicaid recipient typically finds a lawyer independent from her relationship with the prescribing doctor. Most such lawyers work for civil legal aid or legal services programs. Medicaid denial notices often contain contact information for the local legal services program, and some clients initiate a call to request legal assistance.<sup>115</sup> Other clients are referred by a social worker or other service provider who is familiar with the legal services office.

The lawyer is then charged with contacting the prescribing doctor to obtain medical records and, ideally, a brief interview to determine the merits of the case. Thus, collaborations between the medical and legal fields often arise on an ad hoc basis, necessitated by the demands of a particular service denial, as in Sonya's case. However, during the last seventeen years, some lawyers and doctors are consciously working together to establish formal medical-legal

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fact must be supported by at least some evidence which is admissible in a court of law."). For an example of a possible solution to the hearsay problem, see DEL. UNIF. R. EVID. 807 (providing an exception to the hearsay rule).

114. Contrast this with the Supplemental Security Income and the Social Security Disability Insurance appellate processes wherein the administrative records remain open until the time of the administrative hearing. *See also* *Juras v. Dep't of Pub. Welfare*, 457 A.2d 1020, 1022 (Pa. Commw. Ct. 1983) (concluding that fairness required that petitioner's failure to introduce evidence at an earlier hearing did not constitute a waiver of right to introduce evidence at a later stage of the proceedings); *Gilliard v. Dep't of Pub. Welfare*, 477 A.2d 614, 616 (Pa. Commw. Ct. 1984) (holding that beneficiary must be allowed to fully present his case for continued eligibility for public assistance benefits even though he failed to introduce evidence he had in his possession at an earlier stage of the proceedings).

115. This is not to suggest that most people who are denied Medicaid services obtain legal representation or appeal the denial.

partnerships as a new means of delivering services to people who are disadvantaged by poverty and/or disability.

*A. History and Development of Medical-Legal Partnerships*

The delivery of legal services in a medical-legal partnership model has its roots in work that began in Boston, Massachusetts. In the late 1980s, Gary Bellow, one of the pioneers in the contemporary legal services movement and founder of Harvard Law School's first clinical program, initiated a project involving "legal check-ups"<sup>116</sup> at the Brigham and Women's Hospital ambulatory care waiting room.<sup>117</sup> Just as doctors systematically review each body system during a routine physical, lawyers assess the client's profile for potential eligibility for various public benefits. The Brigham and Women's project work was interdisciplinary, with doctors, lawyers, non-lawyer advocates, and law, medical, and social work students participating.<sup>118</sup>

Gary's work, along with that of his wife and colleague Jeanne Charn,<sup>119</sup> arose in response to several problems that they observed: many clients received medical care but not the public benefits to which they were legally entitled; legal advocates faced hurdles in securing medical records and opinion letters from treating physicians as evidence in public benefits cases; and lawyers alone were unable to meet the great need for advocacy on behalf of clients in the public benefits system.<sup>120</sup> The strategy was twofold: "legal check-ups" were performed in the hospital waiting room to screen patients for public benefits eligibility, and doctors and other medical staff were trained in how to more effectively advocate on behalf of their patients—for example, by contacting the welfare office or a utility company to remedy problems.<sup>121</sup> Thus, a transformation in the delivery of legal services—to a model that is proactive and collaborative, rather than reactionary and adversarial—began.

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116. See Jeffrey Selbin & Mark Del Monte, *A Waiting Room of Their Own: The Family Care Network as a Model for Providing Gender-Specific Legal Services to Women with HIV*, 5 DUKE J. GENDER L. & POL'Y 103, 124 (1998) (describing the use of the "legal check-up" model in a medical-legal partnership, in which lawyers ask "explicit questions about the client's potential legal needs.").

117. I was fortunate enough to have been a student of Gary's and to have worked with him as a clinical student at the Community Law Center in Jamaica Plain, Massachusetts.

118. See Gary Bellow & Jeanne Charn, *Paths Not Yet Taken: Some Comments on Feldman's Critique of Legal Services Practice*, 83 GEO. L.J. 1633, 1659 (1995).

119. I have also had the privilege of working with Jeanne Charn at the Community Law Center, where I completed an independent clinical project under her supervision.

120. Bellow & Charn, *supra* note 118, at 1659.

121. *Id.* at 1659–60.

Medical-legal partnerships in their current form have their genesis in the work of Dr. Barry Zuckerman. Dr. Zuckerman, a physician at Boston Medical Center, experienced the frustration of prescribing appropriate medical treatment in the hospital for a child's asthma exacerbation, only to have the improvement be short-lived after the child returned home to a moldy apartment that triggered yet another episode. In 1993, he took the unprecedented step of hiring a lawyer to remedy those substandard housing conditions, resulting in a subsequent improvement in the child's health.<sup>122</sup> Thus the predecessor to what is now the National Center for Medical-Legal Partnership was born. Today, nine lawyers and four paralegals work as part of the medical teams at Boston Medical Center,<sup>123</sup> and a "national network [that] now includes over eighty partnerships serving over 180 health care sites in thirty-six states . . . serv[ing] over 10,000 clients in 2008."<sup>124</sup>

The medical-legal partnership model "integrate[s] lawyers directly into the healthcare system and make[s] attorneys part of the medical team . . . so that when a doctor, nurse, or social worker sees a patient whose basic needs are not being met, that medical provider can simply send the child's family to the lawyer working next door."<sup>125</sup> The model recognizes the value of specialist consultations and understands that health can be improved by non-medical solutions. Just as a doctor would refer a patient to a cardiologist for a heart problem, the patient is referred to a lawyer when the doctor encounters an issue appropriate for legal expertise. In this setting, lawyers "train and back up front-line clinicians to develop their triage instincts for the social determinants of health, and dispense small 'doses' of legal information and consultation to a broad population of front-line staff."<sup>126</sup>

This paradigm utilizes a "three-pronged strategy," including training and education of healthcare staff, direct legal assistance to

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122. Schulman et al., *supra* note 59, at 758; *see also* Jane R. Wettach, *The Law School Clinic as a Partner in a Medical-Legal Partnership*, 75 TENN. L. REV. 305, 306-07 (2008) (describing another case where an attorney was successfully involved in the work of the partnership); Zuckerman et al., *supra* note 12 (discussing how lawyers can contribute to the work of pediatricians).

123. Staff, MED-LEGAL PARTNERSHIP BOSTON, <http://www.mlpboston.org/about-us/staff> (last visited Apr. 2, 2011).

124. Schulman et al., *supra* note 59, at 763; *see also* Selbin & Del Monte, *supra* note 116, at 120-23 (describing Berkeley Community Law Center's HIV/AIDS Law Project, which provides legal services to patients at three primary health care provider sites).

125. Lawton et al., *supra* note 19, at 431.

126. Schulman et al., *supra* note 59, at 772.

patients, and systemic advocacy.<sup>127</sup> The medical-legal partnership model differs from the traditional delivery of civil legal services, in which lawyers are less prepared to act proactively because clients' problems are too far advanced by the time they obtain a lawyer. In a medical-legal partnership, lawyers engage in "preventive legal care"<sup>128</sup> by "offering services to persons who are not yet in crisis, who may not yet have critical or emergent legal needs, with the express aim of educating them about their rights and encouraging them to pursue [legal] treatment."<sup>129</sup> For Sonya, this may have meant the difference between submitting a well-documented letter of medical necessity along with her doctor's original prescription and litigating the case months later at an adversarial hearing.

Thus, sites in the National Center for MLP network view clients holistically by seeking to diagnose and treat the social determinants of health. Simply put, "many health conditions [can be traced] to social factors that are potentially remediable by fair enforcement of existing laws and regulations."<sup>130</sup> For low-income patients,<sup>131</sup> key areas of basic need include housing, utilities, and homelessness, hunger and nutrition, employment and income, health insurance, immigrant status, childcare and parenting support, disability, education, and domestic or community violence, all of which can affect health and well-being.<sup>132</sup>

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127. Lawton et al., *supra* note 19, at 431; see also Wettach, *supra* note 122, at 308–09 (demonstrating, through a real-life example, the multiple ways a medical-legal partnership can assist persons with disabilities).

128. See Schulman et al., *supra* note 59, at 759 ("As it turns out, legal advocacy is the best medicine for the social determinants of health. For lawyers, it presented an opportunity to change the way legal services are typically delivered, away from crisis-generated litigation toward *preventive law*." (internal citation omitted)); Selbin & Del Monte, *supra* note 116, at 125–26 (describing the "early intervention" model of service provision, "in which clients' legal needs are identified "irrespective of whether a formal legal proceeding is underway" with the result that "many incipient legal problems [are prevented] from becoming more difficult, time-consuming, and stressful for the client and the [medical-legal services provider] to resolve").

129. Schulman et al., *supra* note 59, at 776.

130. Lawton et al., *supra* note 19, at 426–27.

131. While the client profiles in this Article are drawn from work on behalf of people with disabilities, the target population of the National Center for Medical-Legal Partnership has generally been people with low incomes. In reality, the two groups overlap significantly. See, e.g., *Office on Disability—Prevalence and Impact Fact Sheet*, U.S. DEP'T OF HEALTH & HUM. SERVS., [http://www.hhs.gov/od/about/fact\\_sheets/prevalenceandimpact.html](http://www.hhs.gov/od/about/fact_sheets/prevalenceandimpact.html) (last visited Apr. 2, 2011) ("According to a 1997 U.S. Bureau of the Census report—The poverty rate among the population 25-to-64 years old with no disability was 8 percent, compared with 10 percent for people with a nonsevere disability and 28 percent for people with a severe disability.").

132. Lawton et al., *supra* note 19, at 424, Figure 21.3.



### B. Existing Medical-Legal Partnership Scholarship

Existing scholarship about medical-legal partnerships centers around two areas. First, partnership sites are collecting data to learn more about their work. This takes the form of legal needs assessments, which demonstrate the extent of unmet legal needs among patients, as well as outcome measures that strive to document the impact that access to legal services has on patient health. Second, scholars from partnership sites are writing about how the model is changing and informing the work of legal services lawyers.<sup>133</sup> These articles examine issues surrounding interdisciplinary work and help to reframe the provision of legal services from a reactive to a preventive medicine model.

#### 1. Unmet Legal Needs and Impact on Patient Health

Studies of partnership patients consistently reveal that a medical setting is a prime area to identify people with unmet legal needs and, importantly, to link those people with lawyers. For example, data from the National Center for MLP's 2007 study "to assess the legal needs of a hospital-based population" demonstrate that "[o]ver 94% of families reported facing or experiencing at least one concern within the last month; 67% reported experiencing concerns related to at least five of the 12 basic needs" surveyed.<sup>134</sup> Gary Bellow's Medical-Legal Services Project found in its first eighteen months of operation that over 90% of patients had "legal problems;" that is, problems potentially resolvable or improvable with the intervention of a person trained in the law.<sup>135</sup>

Similarly, a needs assessment of patients conducted by Widener University School of Law students, in conjunction with a local legal services provider in a fledgling MLP, discovered unmet legal needs.<sup>136</sup> The survey was conducted at Westside Health, a federally qualified health center in Wilmington, Delaware.<sup>137</sup> Of the sixty-two patients surveyed, twenty-six reported problems with public benefits, especially Medicaid and Medicare, and twenty-one reported

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133. See, e.g., Lawton et al., *supra* note 19; Schulman et al., *supra* note 59.

134. Schulman et al., *supra* note 59, at 765-66.

135. Bellow & Charn, *supra* note 118, at 1660.

136. See COMMUNITY LEGAL AID SOCIETY, INC., MEDICAL LEGAL FAMILY ADVOCACY PROGRAM NEEDS ASSESSMENT: 2007 SURVEY RESULTS 5 (2007) (on file with the University of Michigan Journal of Law Reform) ("[A] gap exists between the need for legal assistance . . . and the availability of affordable legal assistance for these participants and their families.").

137. *Id.* at 1.

problems with housing.<sup>138</sup> Significantly, only two of these patients reported consulting an attorney about their legal problems, an illustration of the “justice gap.”<sup>139</sup> Westside patients also reported experiencing problems with abuse and disability-related discrimination and access to services.<sup>140</sup> None of the surveyed patients consulted with an attorney in these areas.<sup>141</sup> The survey concluded that a disconnect exists between Westside Health patients’ need for legal assistance and the availability of affordable legal assistance.<sup>142</sup>

The medical-legal partnership model seeks to bridge this gap and is grounded in the belief that addressing patients’ legal needs improves patient health: “there is more involved in maintaining good health than what a doctor alone is able to provide, and a check-up or a chronic care visit has to include making sure patients’ basic needs are met.”<sup>143</sup> This emerging area of research for medical-legal partnerships involves documenting the linkage between addressing patients’ unmet legal needs and improving patient health. The National Center for MLP posits:

The inability to access legal services for guidance with regard to healthcare coverage or benefits, and for basic needs such as habitable housing and adequate nutrition, can prevent vulnerable individuals from effectively managing their illnesses. This can lead to lack of compliance with their course of treatment, which negatively affects their quality of life.<sup>144</sup>

The ability to document and confirm this hypothesis presents an important source of support for the maintenance and expansion of the partnerships.

Early on, Gary Bellow’s Medical-Legal Services Project found that while “[d]ocumenting the health effects of the project remains problematic . . . some surprising outcomes have already emerged.”<sup>145</sup> These included a “statistically significant” drop in hypertension and “dramatic” health improvements in asthma patients whose substandard housing conditions were remedied and in patients whose stress levels were reduced after obtaining disability benefits to meet their basic needs.<sup>146</sup> While there are “many

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138. *Id.* at 3–4.

139. *Id.*

140. *Id.* at 4.

141. *Id.*

142. *Id.* at 5.

143. Schulman et al., *supra* note 59, at 763.

144. *Id.* at 767.

145. Bellow & Charn, *supra* note 118, at 1663.

146. *Id.*

explanations for these outcomes . . . they do suggest potentially important ‘secondary’ results from projects of this nature.”<sup>147</sup>

Some recent efforts illustrate the continuation of this type of research. For example, a study evaluating the effectiveness of medical-legal partnerships in New York City found that 78% of cancer patients surveyed stated that their health condition brought about legal problems.<sup>148</sup> Another New York City study concluded that “patients who received legal intervention had significant improvements in asthma severity, cortico-steroid usage courses, and reduced emergency room visits as compared to the group of patients who did not receive legal intervention.”<sup>149</sup> A recent study in California demonstrated that MLPs “increase[d] access to legal and social services and decrease[d] barriers to health care . . . [including] increased access to food and income supports.”<sup>150</sup> Significantly, two-thirds of families surveyed reported improved child health and well-being as a result of medical-legal partnership services.<sup>151</sup> This service delivery model thus has the demonstrated potential to improve both legal and medical outcomes.

## 2. Transforming Legal Services to an Interdisciplinary Preventive Care Model

Medical-legal partnerships represent a new lens through which to view the advocacy required for clients like Sonya. The National Center for MLP model for the delivery of legal services draws on the healthcare field’s emphasis on preventive care and carries this analogy over into the legal services realm. Under this new model:

Doctors, because of their position of trust, are well-positioned to screen patients through regular contact . . . . Lawyers are able to bring a new type of expertise to the healthcare setting, so patients will be treated more holistically than in a typical medical exam room and they will be seen earlier than in a traditional legal services office.<sup>152</sup>

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147. *Id.*

148. Schulman et al., *supra* note 59, at 768.

149. *Id.* at 769.

150. Dana Weintraub et al., *Pilot Study of Medical-Legal Partnership to Address Social and Legal Needs of Patients*, 21 J. HEALTH CARE FOR POOR & UNDERSERVED 157, 165 (2010).

151. *Id.* at 164.

152. Schulman et al., *supra* note 59, at 759–60.

The National Center for MLP approach critiques the traditional “battlefield triage model,”<sup>153</sup> where lawyers for poor people are reactive and move from crisis to crisis, and “posits that greater investment in preventive [legal] care today, even at the cost of abandoning some crisis intervention today, is warranted by the long-term benefits achieved by the prevention efforts.”<sup>154</sup>

The need for lawyers to work in an interdisciplinary context that is proactive and collaborative is increasing, particularly at the intersection of law and medicine.<sup>155</sup> In the words of Ed Sparer, “[t]he law . . . cannot be understood without grasping the way legal and social institutions in these areas interact with life.”<sup>156</sup> Legal education’s tendency to divide “the theoretical and practical, and the cognitive and affective consciousness, is one reason why law schools do not come close to adequate scrutiny of our complex institutions.”<sup>157</sup> At the same time, “[l]awyers and physicians often have tense relationships. Members of the 2 [sic] professions frequently disagree about the definition of appropriate evidence, the value of adversarial proceedings, and the social utility of due process.”<sup>158</sup> The MLP model not only offers a means of remedying these disconnects but also helps each profession better accomplish its goals.

Cases like Sonya’s enable lawyers and doctors to work together on a more cooperative and collaborative venture. While Sonya’s lawyer and doctor were able to work together informally, taking the next step of “[a]nchoring” legal services in the medical context enables doctors to see lawyers as part of a helping profession, working to improve patient health, rather than being “overly focused” on limiting liability and preventing malpractice.<sup>159</sup> Thus, medical-legal partnerships present the opportunity to harness the benefits

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153. *Id.* at 744.

154. *Id.* at 778; see also Selbin and Del Monte, *supra* note 116, at 118 (“Women with HIV often need services before a problem they are experiencing has progressed to the point where an attorney will recognize it as a ‘legal’ one.”).

155. See, e.g., Wettach, *supra* note 122, at 310 (“Exposure to a law practice that is intentionally interdisciplinary [such as a medical-legal partnership focused on education issues] gives students an opportunity to work directly with other [non-legal] professionals, which they likely will need to do frequently during their legal careers.”).

156. David F. Chavkin, *Training the Ed Sparers of Tomorrow: Integrating Health Law Theory and Practice*, 60 BROOK. L. REV. 303, 319 (1994) (quoting Edward V. Sparer, *The Responsibility of Law Teachers*, 53 N.Y.U. L. REV. 602, 604 (1978), and emphasizing the limitations inherent in teaching subjects such as health care law solely in the classroom without an experiential learning component) (internal quotations omitted).

157. *Id.*

158. Schulman et al., *supra* note 59, at 733 n.9 (quoting Daniel M. Fox, *The Professions of Public Health*, 91 AM. J. PUB. HEALTH 1362, 1363 (2001)) (internal quotations omitted).

159. Lawton et al., *supra* note 19, at 431.

of interdisciplinary work on behalf of common clients/patients by fostering collaboration.

An interdisciplinary approach also benefits the medical partners. “[P]ediatricians and other health care providers often find themselves in the difficult situation of recognizing the effect of social factors on the health of their vulnerable young patients, while feeling helpless to address them.”<sup>160</sup> Just as a family practice doctor would consult with an orthopedist to treat Sonya’s cerebral palsy, there is a role for a legal advocate as a member of her medical care team. In the medical-legal partnership model, the legal specialist is available to consult on possible solutions to the problems identified by medical staff.

As Sonya’s case demonstrates, “[l]awyers can provide specialized treatment for rights violations and can take the appropriate legal steps to hold agencies, landlords, schools, and others accountable on behalf of families.”<sup>161</sup> Such an approach reflects the real-world experiences of clients/patients: “The practices of medicine and law, particularly for low-income families, cannot exist separate from one another. We must recognize the correlations between hunger, housing and health as well as the negative impact that a delay in access to the legal system can have on a patient’s well-being.”<sup>162</sup>

For the insights from an interdisciplinary approach to be effective, practitioners in other disciplines must act as advocates, in addition to acting as fact witnesses. The medical-legal partnership model recognizes that healthcare providers are especially well positioned to serve in this role.

When evaluating and treating patients, health care professionals frequently identify how inadequate food, housing, and community and individual safety; poor access to basic medications such as vaccines; or other unmet basic needs contribute solely or in part to preventable medical illness and poor health. Physicians are thus in a unique position to set in motion advocacy that ensures that the laws and policies protecting health are effectively implemented.<sup>163</sup>

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160. Schulman et al., *supra* note 59, at 759.

161. Lawton et al., *supra* note 19, at 432.

162. Schulman et al., *supra* note 59, at 763; *see also* Lawton et al., *supra* note 19, at 428 (“[W]hen doctors and lawyers work together, they leverage the combined expertise of both professions to most effectively disrupt the links between child poverty and its adverse health outcomes.”).

163. Schulman et al., *supra* note 59, at 771.

Medical-legal partnerships provide the support and expertise necessary to foster successful legal and non-legal advocacy to the benefit of clients and patients.

#### IV. MEDICAID AUGMENTATIVE COMMUNICATION DEVICE APPEALS IN THE CONTEXT OF THE MEDICAL-LEGAL PARTNERSHIP MODEL

Situating cases like the opening vignette in a medical-legal partnership model overcomes the barriers posed by disincentives to appeal, inequities in the hearing process, and misinformation.

##### *A. Disincentives to Appeal*

Several aspects of the medical-legal partnership model present the potential to alleviate the appeal disincentives commonly experienced by Medicaid beneficiaries and their families. First, the partnership model is built around a team approach. It is not just the Medicaid beneficiary against the adversary, or even the Medicaid beneficiary and her lawyer. Instead, the patient and lawyer are supported by the entire medical team who can bring to bear medical evidence and information to champion the case. Having such backing encourages families to enter into the often-complicated Medicaid appeals process, in the midst of the many other demands on their time and energy associated with parenting a child with a significant disability. Despite the merits of their service request, Medicaid beneficiaries are less likely to pursue an appeal and less likely to succeed if they are navigating the system alone.

Moreover, the model's "preventive law" approach allows issues to be referred for legal assistance before the crisis stage is reached, potentially reducing family stress. As noted above, in cases like Sonya's, a well-written and documented letter of medical necessity that directly responds to the applicable legal standard can lead to an initial approval instead of a denial notice.

Medical-legal partnerships also can teach clients about potential legal solutions to the problems they face. In spite of the array of social and income supports available, bureaucratic or arbitrary program administration "too often results in illegal denials or lack of access to benefits and services, which leads to preventable poor health outcomes."<sup>164</sup> Moreover, many patients do not identify the

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164. Lawton et al., *supra* note 19, at 427 (internal citations omitted).

problems they are experiencing as legal problems<sup>165</sup> and do not realize that they have important rights that they can seek to enforce.

Along these lines, medical-legal partnerships present a valuable opportunity to reach clients who otherwise might not access a lawyer. For example, in the Medicaid context, clients may feel too overwhelmed, unsophisticated, or intimidated to access the appeal system on their own. One patient's mother, for example, had cognitive disabilities that made it difficult for her to advocate for her son by herself. The speech-language pathologist involved in the case had firsthand knowledge of the denial and was able to identify the problem as one meriting legal assistance. An existing medical-legal partnership would serve to facilitate and formalize this process, rather than relying on the vagrancies of *ad hoc* connections.

Further, medical-legal partnerships foster a culture of advocacy among the patients who are served. A study at Boston Medical Center found that "MLP Boston patient-families felt more empowered to access the services they needed than patient-families at other health centers. Overall, MLP Boston patient-families were better, more skilled advocates."<sup>166</sup> Specifically, "MLP Boston patient-families were more likely to get what they needed with less work. [They] employed more effective strategies to solve legal problems than patient-families seen at other health centers, such as calling Boston's housing code enforcement agency services versus using Raid to handle a cockroach infestation."<sup>167</sup> Thus, there is some evidence that medical-legal partnerships not only make a difference in the context of the particular case that gives rise to a legal referral, but also that the experience of working with a seasoned advocate helps to foster clients' own advocacy skills for the future.

### B. Unfair Hearings

Many of the inequities Medicaid beneficiaries experience in the appeals process can be remedied by access to a lawyer. A lawyer is uniquely positioned to analyze the complex law that applies to a service request. A lawyer also assists the Medicaid beneficiary in navigating the complex appeals process.

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165. See, e.g., Selbin & Del Monte, *supra* note 116, at 117–18 (noting that HIV-infected women often do not identify their needs, such as insufficient income, substandard housing, inadequate access to health care, and uncertain financial and family planning as "at least partly 'legal' in nature").

166. Schulman et al., *supra* note 59, at 765.

167. *Id.*

In addition to improving patient access to legal aid lawyers, some medical-legal partnerships also have worked to increase the overall supply of lawyers available to advocate on behalf of poor and/or disabled clients. Medical-legal partnerships are involved with private law firms' *pro bono* efforts, as firms "adopt" health centers and their patients.<sup>168</sup> Medical-legal partnerships located in law school clinics enable student attorneys to represent patients and, while doing so, "hope to inculcate some sense of social responsibility in future lawyers to [continue to] represent the underrepresented."<sup>169</sup>

The other major source of inequity in the appeals process is Medicaid beneficiaries' lack of access to doctors to participate as witnesses in hearings. This is particularly troubling given the law's deference to a treating physician's professional opinion. In the augmentative communication context, a federal district court has endorsed the proposition that the "'determination of medical necessity must rest with the individual recipient's physician and not with clerical personnel or governmental officials.'"<sup>170</sup> *Hunter v. Chiles* involved the claims of both an adult and a pediatric Medicaid beneficiary for augmentative communication device coverage. The plaintiffs were "unable to communicate either verbally or with hand gestures."<sup>171</sup> The court endorsed plaintiffs' treating professionals' recommendation that augmentative communication devices were "the only speech-language pathology treatment methodology that will allow the Plaintiffs to have effective expressive communication . . . . [This determination was] based, in part, on the lack of success prior speech language pathology services have had in allowing the plaintiffs to produce speech organically."<sup>172</sup> Not surprisingly, the medical testimony in support of the plaintiffs was crucial to their success.

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168. See "Adopt-a-Health-Center" Proposal Letter from Medical-Legal Partnership to Unnamed Law Firm (2008) (on file with the University of Michigan Journal of Law Reform) (describing National Center for MLP's partnership with private law firms which have adopted community health centers to conduct intake and handle cases on behalf of patients).

169. Chavkin, *supra* note 156, at 304.

170. *Hunter v. Chiles*, 944 F. Supp. 914, 922 (S.D. Fla. 1996) (quoting *Pinneke v. Preisser*, 623 F.2d 546, 550 (8th Cir. 1980)). Deference to the treating provider in Medicaid medical necessity determinations is not limited to the augmentative communication device context. See S. REP. NO. 89-404 (1965), *reprinted in* 1965 U.S.C.C.A.N. 1943, 1986 ("[T]he physician is to be the key figure in determining utilization of health services . . . it is a physician who is to decide upon admission to a hospital, order tests, drugs and treatments . . . ."); see also *Collins v. Hamilton*, 349 F.3d 371, 376 n.8 (7th Cir. 2003) ("[A] state's discretion to exclude services deemed 'medically necessary' by an EPSDT provider has been circumscribed by the express mandate of the statute.").

171. *Hunter*, 944 F. Supp. at 916.

172. *Id.* at 922 (internal citations omitted).



A common institutional barrier to advocacy arises when doctors, who already face overburdened schedules, do not prioritize making time for the “non-medical” work that advocacy in the legal realm entails. Integrating lawyers into the healthcare team can save time in the long run because patients can access legal consultations before problems become crises. Identifying legal issues in a doctor’s office instead of a lawyer’s office creates efficiencies in securing the records and supporting opinions that the lawyers need to prove the case and that the doctors are uniquely suited and otherwise may be hesitant to provide, without an up-close understanding of the lawyer’s work.<sup>173</sup> Effective advocacy is enhanced because the “partnership gives the [legal advocate] much easier access to the doctor, who can elaborate as needed on the condition, administer required tests, or make important notations in the chart.”<sup>174</sup> For example, Gary Bellow’s Medical-Legal Services Project found that in the first eighteen months of the project, “[a]ccess to [medical] records [has] improved. Doctors’ letters to the social security administration are longer, better written, and more cognizant of the appropriate legal standard.”<sup>175</sup>

Medical providers’ desire and skill to advocate on behalf of patients may not be enough if there are institutional impediments, actual or perceived, to such advocacy. The establishment of a formal medical-legal partnership at a healthcare center demonstrates that the medical partner institution recognizes that legal advocacy can benefit patients’ health and values such work. One such institutional barrier is the warning bells that often sound whenever there is talk of lawyers being involved in a case, as doctors (and their lawyers) worry about malpractice liability. As stated above, medical-legal partnerships create opportunities for doctors and lawyers to interact as collaborators rather than adversaries. The assent of the healthcare center’s general counsel is a key step in establishing a formal partnership and sends the message that this type of legal advocacy on behalf of patients is permitted and valued. Inviting lawyers into medical centers sends a message that can counter popular perceptions about lawyers, with good results for patients. Further, a medical-legal partnership that involves a law school clinic “provides an opportunity for the law school to show the community—particularly the medical community—that it is training its students to be compassionate and caring professionals

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173. See Schulman et al., *supra* note 59, at 771–72 (elaborating on how the partnership might work).

174. Wettach, *supra* note 122, at 310.

175. Bellow & Charn, *supra* note 118, at 1662.

(not just malpractice attorneys!).”<sup>176</sup> All these efforts have incremental positive effects in improving service delivery to clients.

### C. Misinformation

One of the most obvious benefits offered by medical-legal partnerships is the infusion of viewpoints from non-legal disciplines that can shape and strengthen a case. In the augmentative communication context, the work of physicians and speech-language pathologists helps lawyers to better understand and give meaning to the entitlements and standards contained in the Medicaid statute and regulations.<sup>177</sup> While advocating on behalf of clients is intrinsic to a lawyer’s work,<sup>178</sup> this role may not be comfortable or familiar for medical professionals. Gary Bellow’s Medical-Legal Services Project found that “[s]uccessful intervention [on behalf of patients] requires advocacy (not simply advice or assistance) most effectively provided by staff trained on-the-job for some significant period of time.”<sup>179</sup>

The medical-legal partnership model bridges this gap by enabling the lawyer and the doctor to understand what work is necessary to achieve the client’s goals and how to best accomplish this end in light of the tools and information available in each discipline. For example, the legal advocate in a medical-legal partnership “can help the doctor understand what specific findings, test results, or other conclusions must be in the records to meet the legal standards.”<sup>180</sup>

Cases can be won or lost depending upon the effectiveness of advocacy efforts by non-lawyers. For example, in the augmentative communication context, affidavits from a Medicaid beneficiary’s treating physician and speech pathologist were crucial to establishing that an “electronic speech device [was] a necessary and

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176. Wettach, *supra* note 122, at 313.

177. See Selbin & Del Monte, *supra* note 116, at 127 (describing advantages of multidisciplinary service integration model in legal claims for Medicaid, Supplemental Security Income disability benefits, and standby guardianship cases).

178. Effective advocacy may not come naturally to law students, either, and medical-legal partnerships housed in law school clinics can be an effective means of achieving this pedagogical goal. See Chavkin, *supra* note 156, at 326–27 (noting that experiential learning enables “students [to] personally feel the injustices experienced by the client and develop the special sense of urgency in addressing the client’s problem that goes far beyond the minimum levels of ethical diligent representation”); see generally Wettach, *supra* note 122 (outlining reasons for law school clinics to participate in medical-legal partnerships).

179. Bellow & Charn, *supra* note 118, at 1661.

180. Wettach, *supra* note 122, at 311.

reasonable form of treatment.”<sup>181</sup> During the course of the litigation in *Meyers v. Reagan*, the state reversed its initial denial and offered to provide the original augmentative communication device in question.<sup>182</sup> However, after the complaint was filed, a more expensive device with additional features came on the market, and Meyers amended her complaint to seek that device.<sup>183</sup> After determining that Meyers was eligible for augmentative communication under the Medicaid program, the Court remanded for a hearing about which device was more appropriate for her needs.<sup>184</sup> Thus, effective participation by Meyers’ medical professionals was essential to both satisfying the legal standard to enforce her legal right to Medicaid coverage of augmentative communication in general and to ultimately realizing that right by obtaining the specific device most appropriate for her needs.

Along the same lines, the court in *Lagowski v. Whalen*<sup>185</sup> focused on the testimony of the healthcare providers in that case. Essential to the reversal of the state’s denial of Medicaid coverage of augmentative communication was the uncontroverted testimony of a speech-language pathologist who explained that the recommended device would enable the recipient to directly select vocabulary using only one hand or finger and was otherwise more appropriate for his needs than less costly alternatives asserted by the state.<sup>186</sup> The recipient also presented the testimony of a representative from his residential facility who opined that the augmentative communication device would “enhance [his] overall quality of life and would enable the staff ‘to more efficiently meet [petitioner’s] needs as it would give [petitioner] the ability to express himself.’”<sup>187</sup>

It is important to recognize that often the emergence of such evidence in the record is not a matter of happenstance. Two contributing factors are essential: the lawyer must understand both the legal elements that must be established in the case and the non-legal proof of those elements, and the doctor must be comfortable acting in an advocacy role by testifying, providing medical records, and/or writing a letter of medical necessity. Because the medical-legal partnership model calls for lawyers to be integrated

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181. *Meyers v. Reagan*, 776 F.2d 241, 243 (8th Cir. 1985).

182. *Id.*

183. *Id.*

184. *Id.* at 244.

185. 706 N.Y.S.2d 283 (N.Y. App. Div. 2000).

186. *See Lagowski*, 706 N.Y.S.2d at 284. A second speech-language pathologist also testified that a less costly alternative with manual overlays would not meet the client’s needs. *Id.*

187. *Id.*

into the patient's healthcare team and often on-site at the healthcare center, both the lawyer's and the doctor's jobs become easier in a sense. Each has access to the other and can draw on his or her respective expertise while at the same time appreciating more fully how the parameters of another discipline bear on the case. Such collaboration is valuable to fostering proactive advocacy efforts as well as in providing interdisciplinary support in crises.

### CONCLUSION

Despite the tremendous potential for enhanced autonomy that augmentative communication devices present for people with disabilities, and the strong legal basis for obtaining funding through the Medicaid program, securing approval for augmentative communication devices often requires legal advocacy. That advocacy is strengthened when the perspectives of treating medical professionals are integrated. While such collaboration can arise on an *ad hoc* basis, the establishment of formal medical-legal partnerships offers several benefits for realizing the right to medically necessary services under the Medicaid program.

Cases involving access to augmentative communication devices under the Medicaid Act illustrate the enormous potential presented by lawyers, doctors, and other medical professionals working together on behalf of their mutual clients/patients. While augmentative communication cases are used as examples, the analysis in this Article is more generally applicable to all Medicaid medical necessity appeals as well as a wider array of cases in which a lawyer must acquire specialized or technical knowledge in a non-legal area and work with medical or other professionals to fit the facts, including the reality of the client's situation and the insights and observations of another discipline, into the language of the applicable legal standard to achieve the client's goals. These partnerships offer an innovative way to address a range of problems that affect health, including Medicaid, other public benefits, housing, immigration, domestic violence, child support, special education, disability discrimination, and other areas. Integration of the different training, skills, and perspectives offered by lawyers and doctors can be a powerful means of obtaining results to which clients are legally entitled and that improve patient health and quality of life.

Some modest refinements may further enhance the adoption of the medical-legal partnership model for the delivery of civil legal services. First, while emerging scholarship about medical-legal

partnerships advocates for a transformation from the traditional delivery of legal services to a new model of public health legal services,<sup>188</sup> the benefits of medical-legal partnerships can be realized even without a wholesale transformation to the preventive care model. Overburdened legal services agencies may be more willing to adopt the model if they can see that much of the work they already are doing falls into the medical-legal paradigm. Informal working partnerships among lawyers and doctors frequently emerge out of necessity on a case-by-case basis. Formalizing these relationships results in better case outcomes from both a medical and legal perspective as well as efficiencies in the use of limited time and resources. Problems can be identified earlier and doctors will know what information should be supplied in the first place, thereby alleviating the cost and time associated with denials. Medicaid beneficiaries and their families can have access to a team of professionals to support their needs.

Second, at a time of both increasing demand and shrinking funding for legal services work, the medical-legal partnership model presents valuable opportunities for increasing both the overall supply of lawyers and legal services funding. Research that confirms the beneficial impact of MLP work can be used to support grant applications from funding sources that may not have traditionally supported legal work. Finally, in addition to improving patient health, medical-legal partnerships have been shown to improve the medical providers' bottom lines. One recent study demonstrated that hospitals receive sixteen dollars in revenue for every dollar invested in the collaboration.<sup>189</sup> Consequently, medical-legal partnerships are an investment that makes sense, both financially and as a tool to augment the advocacy of legal services lawyers.

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188. See Schulman et al., *supra* note 59, at 778 ("The empirical investigation needed to sustain that argument remains to be completed.").

189. See JIMMY BOYLE & ADA CHIU, LEGALHEALTH, FINANCIAL IMPACT STUDY OF LEGALHEALTH SERVICES TO NEW YORK CITY HOSPITALS 2 (2007) (on file with the University of Michigan Journal of Law Reform).