

Fred R. Volkmar · Rachel Loftin ·  
Alexander Westphal · Marc Woodbury-Smith  
Editors

# Handbook of Autism Spectrum Disorder and the Law

 Springer

*Editors*

Fred R. Volkmar  
Yale Child Study Center and Autism Center  
of Excellence  
Yale University and Southern Conn. State  
University  
New Haven, USA

Rachel Loftin  
Department of Psychiatry and Behavioral  
Sciences  
Northwestern University Feinberg School  
of Medicine  
Chicago, USA

Alexander Westphal  
Division of Law and Psychiatry  
Yale School of Medicine  
New Haven, USA

Marc Woodbury-Smith  
Biosciences Institute  
Newcastle University  
Newcastle upon Tyne, UK

ISBN 978-3-030-70912-9                      ISBN 978-3-030-70913-6 (eBook)  
<https://doi.org/10.1007/978-3-030-70913-6>

© Springer Nature Switzerland AG 2021

This work is subject to copyright. All rights are reserved by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

The publisher, the authors and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, expressed or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

This Springer imprint is published by the registered company Springer Nature Switzerland AG  
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

# Chapter 20

## Clinicians as Advocacy Allies for People with ASD

Alison Morantz

### Introduction

At each stage of the life cycle—whether the focus is on obtaining medical care or therapy, receiving a free and appropriate public education, attaining a college degree, pursuing a rewarding career, maximizing personal autonomy and financial security, or accessing the community—state and federal laws provide protections and resources that can, in theory, help individuals with Autism Spectrum Disorder (ASD) lead their best lives. Yet translating theory into practice poses formidable challenges. In clinical settings, some individuals with ASD may struggle to communicate their needs and priorities in ways that others will heed and understand, thereby limiting their capacity to shape the treatment decisions that affect their lives. Outside clinical settings, persuading judges or other legal decision-makers that an applicant qualifies for a particular program or benefit, or of the need for a specific service or accommodation, can be difficult if adjudicators lack a nuanced understanding of the challenges the individual faces. In both settings, the ability of individuals with ASD and their families to engage in meaningful *advocacy*—broadly defined here as the capacity to communicate limitations, needs, desires, or priorities to decision-makers in ways that can favorably influence the adjudication of legal entitlements and the delivery of services and supports—often requires considerable knowledge, resources, and a strong circle of support.

For their part, clinicians may feel ill-prepared to help individuals with ASD and their families confront the myriad practical challenges that effective advocacy entails. They may conceptualize their role as limited to either or both of two tasks: providing families with an initial ASD diagnosis; and providing the medical care, therapy, or treatment that was the focus of their clinical education. Lacking training or expertise

---

A. Morantz (✉)  
Stanford University, Stanford, CA, USA  
e-mail: amorantz@law.stanford.edu

in the intricacies of disability law, many clinicians have only a vague and superficial knowledge of the systems that self-advocates, families, and their allies must navigate in their efforts to obtain needed services and supports.

Yet in practice, the success of medical treatments and the success of advocacy efforts are closely intertwined. For example, the inability of an adult with ASD to self-advocate in a clinical setting by conveying her felt experiences and preferences to her nurse or physician may affect her adherence to a particular medical or therapeutic intervention in ways that lessen its benefit. A similarly close relationship between effective advocacy and long-term outcomes exists outside of clinical settings. For example, if the parents of a school-age child with ASD cannot secure funding for home-based Applied Behavior Analysis (ABA), or cannot ensure that an Individualized Education Plan (IEP) includes a robust array of school-based services (such as occupational therapy or speech therapy) to facilitate educational progress, the child is unlikely to thrive even if she attends regular therapy sessions with a skilled psychologist. Likewise, an adult with ASD who cannot secure stable housing, access community supports, or find steady employment may fail to reach his potential even if he is under an expert psychiatrist's care.

Encouraging more effective advocacy by patients and their families may feel daunting to many clinicians, especially those burdened with high patient caseloads. This reluctance is understandable. Yet two factors counsel in favor of clinicians becoming more knowledgeable about—and playing more active roles in—advocacy efforts in clinical and non-clinical domains. First, when it comes to ASD, an ounce of effective advocacy is worth a pound of crisis management. By investing a little more time upfront to overcome barriers to effective service delivery, clinicians can substantially improve their patient outcomes in a holistic fashion, while reducing the frequency of unexpected crises or setbacks that can reverse months or even years of clinical gains. Secondly, although learning to support the advocacy efforts of individuals with ASD and their families requires a significant upfront investment of time, once a clinician learns the “rules of the game” in a particular domain, helping other patients in the same domain becomes far less time-consuming.

This chapter is divided into five sections. The first section presents general principles that can help clinicians think beyond the “medical model” of developmental disabilities, thereby strengthening their therapeutic alliance with their patients and clients with ASD. The second section describes advocacy challenges that can arise in clinical settings and suggests that Supported Decision-Making (SDM) can be used to mitigate these challenges. The third section shifts the focus to adjudicatory hearings and appeals, describing the myriad challenges individuals with ASD and their families face in enforcing their rights under state and federal law. The fourth section contains concrete guidance on how clinicians can become effective “advocacy allies” in these formal legal settings. The fifth and final section lists additional resources upon which clinicians may draw, so they can help individuals with ASD and their families parlay treatment gains into a higher quality of life.

## Thinking Beyond the Medical Model

In the past century, popular and professional understandings of ASD have undergone several cataclysmic shifts. From the 1940s through the 1960s, the dominant theory of autism's pathogenesis—introduced by Leo Kanner (1943) in the early 1940s and popularized in the U.S. by Bruno Bettelheim (1967)—held that a lack of parental (and particularly maternal) warmth during early childhood caused autism, a proposition commonly known as the “refrigerator mother theory.” Bettelheim's recommended solution was to forcibly remove autistic children from their emotionally frigid parents. By the 1970s, in part due to the work of Bernard Rimland (1964), the refrigerator mother theory gave way to a model of autism that emphasized the role of biology, including genetic and environmental factors, in causing the condition (Cohmer, 2018). Yet another critical transformation in thinking came in the 1960s and 1970s with the pioneering work of Ivar Lovaas, who used behavioral principles to develop a comprehensive method of treating children with ASD known as Applied Behavior Analysis (ABA) (Smith & Eikeseth, 2011). The publication of Lovaas's landmark study (1987) demonstrating that almost half of children subjected to intense ABA treatment in early childhood (before age 4) achieved “normal” intellectual and educational functioning by first grade, compared to just 2% of those who did not receive such treatment, raised hopes that autism could be effectively treated and even “cured.” Like Lovaas and the home-based ABA industry that his early research helped to spawn, most autism-focused advocacy organizations around the turn of the twenty-first century prioritized the goal of identifying genetic or environmental biomarkers that could point the way toward effective cures, and perhaps even help to eradicate ASD.

Despite their markedly different assumptions and emphases, all of these medical pioneers shared the belief that the deviation from “normal” brain function that an autism diagnosis implied was pathological and maladaptive, and thus that the focus of treatment should be to change the neurobiology—or, at least, the behavior—of individuals with ASD to align as closely as possible with that of their non-autistic peers. In other words, researchers did not question the medical model that views autism as a complex brain disorder; their goal was rather to amass the knowledge and expertise necessary to prevent or cure it.

The term “neurodiversity,” which gained currency around the turn of the millennium and is closely associated with the autism rights movement, challenged the supremacy of the medical model. Rather than conceptualizing autism as a “disease” to be cured or eradicated, the neurodiversity paradigm views it as a distinct neurological profile that confers strengths as well as weaknesses, and as such, should be valued and supported (Armstrong, 2015; Silberman, 2015). This perspective is typically grounded in the broader “social model” of disability, which emphasizes the critical role that societal norms, attitudes, and institutions play in turning “impairments,” nonstandard physical or neurological characteristics, into disabilities. From this perspective, the disability itself is in large part “caused by a contemporary social organization that takes little or no account of people who have impairments and

thus excludes them from participation in the mainstream of social activities” (Oliver, 1996: 22). From a neurodiversity standpoint, the goal of therapy should be to help people with ASD obtain the skills, opportunities, services, and supports that maximize their quality of life, regardless of how closely their behavior resembles that of their non-autistic peers (Sinclair, 1993). Noting that autistic people historically have had little influence over the decisions that affect their lives, many activists have additionally emphasized the importance of giving self-advocates a greater voice in their own treatment and in broader policymaking on ASD-related issues, versus a status quo in which (non-autistic) professionals typically make decisions on their behalf (Dawson, 2003, 2004). This perspective is sometimes encapsulated by the slogan “Nothing about us without us” (Autistic Self Advocacy Network [ASAN], 2020a).

Applicable to a wide range of disabilities, the idea of “person-centered thinking” usefully captures many of the principles associated with the neurodiversity/autism rights perspectives. Described as a “philosophy behind service provision that supports positive control and self-direction of people’s own lives,” person-centered thinking emphasizes:

- The importance of being listened to and the effects of having no positive control.
- The role of daily rituals and routines.
- How to discover what is important to people.
- How to respectfully address significant issues of health or safety while supporting choice.
- How to develop goals that help people get more of what is important to them while addressing issues of health and safety (D.C. Dept. on Disability Services, n.d.).

Yet in many real-world settings, individuals with ASD and their families struggle to communicate their needs and desires in ways that are persuasive to decision-makers, limiting the extent to which person-centered thinking can be put into practice. In light of this reality, the remainder of this chapter identifies barriers to effective advocacy and suggests how clinicians can help to overcome them.

## **Supporting Advocacy Efforts in Clinical Settings**

Because the autism spectrum encompasses individuals with a wide range of impairments and support needs, it is difficult to generalize about the difficulties individuals can face in ensuring that their needs and priorities are taken into account. Some patients may rely on augmentative and alternative communication technology to convey their thoughts and desires; others may not use any conventional language system. Some may have difficulty in grasping the nature of the alternatives presented, including their attendant risks and benefits, in real time. Still others may struggle to make choices, or to communicate their preferences clearly, in the physical settings

where clinical consults or care team meetings are typically held. Given these realities, it can be very difficult for individuals with ASD to contribute meaningfully to decisions that affect their treatment.

In recent years, the concept of Supported Decision-Making (SDM) has gained increasing prominence as a method to mitigate barriers to effective self-advocacy in a wide range of settings. In recognition of the fact that “good communication is essential for accurate diagnosis, for negotiating treatment plans and for adherence ... [and] is key to patient safety” (Kripke, 2016: 445), the essential aim of SDM in clinical settings is to “enable people with intellectual or developmental disabilities to name a trusted person [or persons] to communicate with doctors, understand health care information, make informed decisions about health care, and/or carry out daily health-related activities” (ASAN, 2020b). Importantly, even if some individuals with I/DD cannot fully grasp the nature or consequences of the available alternatives in certain domains, they may still be able to convey preferences regarding which individual(s) are permitted to provide them with decision-making support. For individuals with communication challenges, SDM practitioners also stress the importance of using individualized communication supports and attending to nonverbal forms of communication, such as body language and facial expressions (National Council on Disability, 2019: 76).

As of this writing, SDM has not yet become a standard part of clinical training and practice, and some implementation problems have yet to be resolved. Among the unsettled questions are the extent to which the technique can, and ethically should, be used with individuals who lack legal capacity to make decisions on their own behalf. For example, adults with ASD sometimes are stripped of legal capacity through the creation of guardianship or power of attorney arrangements. Moreover, until recently, minors were often categorically presumed to lack the capacity to make medical decisions on their own behalf (Lang & Paquette, 2018). Thus the use of SDM with individuals under guardianship, or among minors with I/DD, raises special complexities. Another potential consideration is the fact that trusted supporters, especially if they are parents or caregivers, may not always be available when needed, may not monitor symptoms proactively, and may not relay information accurately (Kripke, 2016).

In response to widespread inconsistencies and perceived injustices in medical professionals’ treatment of patients with ASD, the Autistic Self Advocacy Network and the Quality Trust for Individuals with Disabilities have developed model legislation, “An Act Relating to the Recognition of a Supported Health Care Decision-Making Agreement for Adults with Disabilities,” in an effort to place SDM on firmer statutory footing in health care settings. The model law seeks to address a number of important nuances in the implementation of Supported Health Care Decision-Making Agreements, such as the conditions under which supporters can be disqualified because of conflicts of interest; the rights and responsibilities of supporters; and the ability of health care providers to withhold treatment if they believe that the patient’s consent was coerced or based on misinformation (ASAN, 2014a, 2014b).

In short, although the use of SDM in clinical treatment settings is still at a relatively early stage and some details have yet to be fully worked out, the technique holds

considerable promise as a tool to promote effective self-advocacy among individuals with ASD.

## **Legal Advocacy Challenges in Adjudicatory Hearings and Appeals**

The civil rights of individuals with ASD are protected by an extensive array of federal and state laws. For example, several major federal statutes—including the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), and Section 504 of the Rehabilitation Act of 1973 (Section 504)—help facilitate equal access to public education, higher education, and competitive integrated employment. Meanwhile, broad federal entitlement programs overseen by federal agencies and administered at the state level—such as Medicaid, SSI, SSDI, and Vocational Rehabilitation—provide health insurance, cash benefits, and a variety of services and supports that can improve standard of living. Individuals with ASD also can benefit from discrete state and federal laws that address specific problems, such as the inadequacy of behavioral health care benefits available from private insurers, or the difficulty of accumulating savings without losing eligibility for federal entitlement programs.

Yet navigating this dense legal thicket is often bewildering for individuals with ASD and their families. First of all, given the highly fragmented nature of the system—which encompasses dozens of different laws and programs administered or enforced by a range of public and private entities—it is difficult for families even to identify the full range of resources that are available.

A second barrier to effective advocacy is the fact that individuals with ASD and their families are often required to enforce their legal rights at the same time they are experiencing considerable anxiety, uncertainty, and upheaval. In the aftermath of an ASD diagnosis,

[Parents are] force[d] to rearrange their schedules and often to quit their jobs or restructure their time ... [they] are often not able to take time to focus on how to process the news of the diagnosis. They are immediately caught up in whirlwind of therapists and intensive interventions and are reminded over and over again of the critical window of opportunity for helping their children. (de Wolfe, 2014: 78)

In these stressful and tumultuous circumstances, it may be difficult for parents to muster the resources and emotional energy necessary to challenge, let alone reverse, unfavorable eligibility determinations or denials of services. Later in the life cycle, individuals with ASD and/or their family members may similarly be required to engage in vigorous advocacy in the midst of major life transitions or crises, such as immediately upon leaving the public school system, or in the wake of catastrophic disruptions in service delivery. For these reasons, having to locate an attorney and



mount an appeal can feel overwhelming to those most directly affected by a discriminatory practice or an adverse decision by an insurer, provider, or administrative agency.

Yet another barrier to effective advocacy is that the process for challenging adverse determinations is often cumbersome and opaque; the procedural requirements of different laws often vary widely, and even a single law's provisions can change across state lines. A brief procedural overview of six preeminent federal laws affecting the civil rights and entitlements of individuals with ASD—Medicaid, SSI, SSDI, the IDEA, the ADA, and Section 504 of the Rehabilitation Act—helps to illustrate this point.

In most cases pertaining to the IDEA, SSI, and SSDI, consumers initially must challenge adverse official determinations through administrative hearings (Rothstein & Johnson, 2014: 251; Ryther & Samuels, 2019; Yell, 2019: 63). Only after exhausting these remedies may the complainant seek judicial review of the adverse determination in a state or federal court (Rothstein & Johnson, 2014: 251; U.S. Social Security Administration [SSA], 2019).

The requirements for exhaustion of administrative remedies and the provision of judicial review are more variable in the Medicaid context, as states have considerable discretion over the design of the program. Complainants are generally required to challenge adverse decisions through the administrative hearing process before proceeding to state court (McCormick, 2019), but the specific procedural requirements depend on the case law and administrative law of each state.<sup>1</sup> Federal law does not guarantee Medicaid complainants the right to any judicial review (Medicaid and CHIP Payment and Access Commission [MACPAC], 2018), and in some jurisdictions, the only explicit form of administrative review may be an appeal to the director of the Medicaid Agency (MACPAC, 2018; Oklahoma Department of Human Services, 2015).

Section 504 of the Rehabilitation Act, which helps to protect the rights of students (among others) with ASD—particularly in postsecondary educational settings, to which the IDEA does not apply—provides a different configuration of procedural mechanisms to enable claimants to enforce their rights. As with the IDEA, the right to file Section 504 claims in court is generally guaranteed (Rothstein & Johnson, 2014: 305; Yell, 2019: 115). Yet the exhaustion requirement is somewhat more complex. Under federal law, exhaustion of administrative remedies is uniformly required if the subject matter of the complaint is covered by the IDEA (*Fry v. Napoleon Comm. Schools*, 2017), but not if the subject matter falls outside the IDEA's scope (Rothstein, 2019). Additionally, the procedural requirements for administrative hearings under Section 504 are less extensive and robust, and contain fewer explicit procedural safeguards than those provided under the IDEA (Council for Exceptional Children, 2002; Howey, 2019; U.S. Department of Education, n.d.; U.S. Department of Education, Office of Civil Rights, 2020).

---

<sup>1</sup> This requirement is generally waived for complainants who sue the state in federal court (McCormick, 2019).

The IDEA and Section 504 also differ in other ways that can affect families' capacity to advocate effectively on behalf of school-age children with ASD. For example, only the IDEA gives parents the right to obtain an Independent Educational Evaluation (IEE) at the district's expense if they disagree with the results of a school district's evaluation, although a district can circumvent this obligation by successfully challenging the IEE's necessity during an administrative hearing (Yell, 2019: 62).

The ADA, which is often used to protect the rights of individuals with ASD in the workforce and in higher education, sets forth yet another array of enforcement procedures. In the employment setting (Title I), plaintiffs have the right to file a claim in court as long as this right has not been waived by a contractual provision requiring disputes to be resolved through mandatory arbitration. However, they must first exhaust administrative remedies by filing a charge with the Equal Employment Opportunity Commission (EEOC) (U.S. Department of Justice, Civil Rights Division [DOJCRD], 2013; Yell, 2019: 129). The portions of the ADA that apply to public educational institutions (Title II) do not require plaintiffs to exhaust administrative remedies before filing claims in court (Yell, 2019: 130); however, the case law is unsettled as to whether complainants filing court actions against private educational institutions (through Title III) must first exhaust administrative remedies (Joseph et al., 2019). Moreover, in each of these contexts, complainants have the option of filing complaints with one or more federal agencies (DOJCRD, 2017; Yell, 2019: 130–132).

One particularly important source of variation among these federal laws is the availability (or lack thereof) of “cost-shifting” provisions that enable prevailing plaintiffs to recover attorney's fees. Both the IDEA and Section 504 allow courts to award attorney's fees to prevailing claimants in administrative or judicial proceedings (Osborne & Russo, 2014: 241–243; Weber, 2012: 645), although only Section 504 has been interpreted as allowing such awards to include expert witness fees (Council of Parent Attorneys & Advocates, 2013; Weber, 2012: 642, 646). The ADA likewise includes a cost-shifting provision that encompasses both judicial and administrative proceedings (42 U.S.C. § 12205). On the other hand, the federal regulations governing Medicaid administrative hearings contain no cost-shifting requirements (42 C.F.R. §§ 431.200–431.250), and the extent to which prevailing consumers can recover attorney's fees in administrative and/or judicial proceedings varies by state (Mo. Rev. Stat. § 536.087; Cal. Welf. & Inst. Code § 10962). For example, in several states' Medicaid hearings, the benefits at issue were categorized in such a way that prevailing claimants were deemed ineligible to recover attorney's fees (*Braddock v. Mo. Dep't of Mental Health*, 2006; *Good v. Iowa Dep't of Human Servs.*, 2019). Claimants who successfully challenge a denial of SSI or SSDI benefits by the Social Security Administration (SSA) likewise cannot typically recover attorney's fees at the administrative hearing stage (SSA, 2017). However, if a claimant successfully appeals an adverse decision to federal court, they may recover attorney's fees under the provisions of the Equal Access to Justice Act (28 U.S.C. § 2412).

## How Clinicians Can Support Advocacy in Adjudicatory Hearings and Appeals

As discussed in the prior section, the barriers to effective advocacy facing individuals with ASD and their families in formal adjudicatory proceedings are formidable and multifaceted. Even in the best of circumstances, the civil rights enforcement and service delivery systems that in theory are available to provide assistance are highly fragmented, making it difficult for (self-)advocates even to identify which legal channels to pursue. These practical difficulties can become particularly acute during times of crisis or transition. The six federal laws discussed above—the IDEA, the ADA, Medicaid, Section 504 of the Rehabilitation Act, SSI, and SSDI—differ markedly in the scope, forum(s), sequence, and financial accessibility of their respective enforcement procedures; even the same federal law can vary significantly across state lines. In light of these complexities, there is no straightforward or uniform answer to the question of how clinicians can best assist families in adjudicatory hearings and appeals. The precise tasks that clinicians are expected to complete, and the manner in which they must carry them out, are highly contextual and case-specific.

Nevertheless, a few generalizations can be made. First, clinicians are typically asked to render a professional opinion on one of two questions: whether a claimant's ASD diagnosis brings him/her within the scope of a particular law; and whether a claimant's functional impairments justify the level of services, supports, or accommodations that an agency or employer is being asked to provide. Second, clinicians are usually called upon to render these opinions in writing in the form of checklists, questionnaires, or letters of support, and sometimes may be asked to attend a proceeding by phone or in person. Third, clinicians usually, but not always, perform these tasks at the request of attorneys or other professionals representing individuals with ASD or family members. Fourth, patients and family members often have little if any familiarity with the advocacy challenges they are about to confront, let alone the clinician's role in helping to achieve a favorable result.

Finally, it is safe to assume that in most contexts, clinicians play an essential role in persuading (or dissuading) the decision-maker of the merit of the individual's claim. Moreover, a well-substantiated diagnosis and thoughtful treatment plan help to align resources with expectations, providing a roadmap that the individual with I/DD, his/her family members, and other allies can use to obtain the supports necessary for a high quality of life. As the Social Security Administration notes in its guidance to medical professionals:

[M]edical evidence is the cornerstone for the determination of disability .... SSA regulations place special emphasis on evidence from treating sources because they are likely to be the medical professionals most able to provide a detailed longitudinal picture of the claimant's impairments and they may bring a unique perspective to the medical evidence that cannot be obtained from the medical findings alone .... [T]imely, accurate, and adequate medical reports from treating sources accelerate the processing of the claim because they can greatly reduce or eliminate the need for additional medical evidence to complete the claim. (SSA, n.d.-a.)

The same observation holds true for most, if not all, civil domains in which clinicians are frequently called upon to render professional opinions.

The following four practices can help clinicians effectively support advocacy efforts across a wide range of adjudicatory settings.

***Sympathetically Acknowledge the Magnitude of the Advocacy Challenge Facing the Patient/Client and Their Family, Express a Desire to Help, and Set Clear Expectations Upfront***

Although the “refrigerator mother theory” of ASD’s etiology described earlier was largely discredited by the 1980s, individuals with ASD and their families may nonetheless come away from interactions with medical professionals feeling intimidated, shamed, or blamed. For children or adults with ASD, the medical model’s implicit assumption that autistic traits constitute a “disorder” that needs to be “fixed” can trigger feelings of inadequacy and low self-esteem. Meanwhile, parents may fear that medical professionals are judging them (or may even judge themselves) for failing to deliver enough services to cure or alleviate their child’s condition, even if they do not blame themselves for causing it. These negative feelings not only constitute barriers to effective treatment, but also can interfere with the sense of trust and empowerment that successful advocacy demands.

To overcome these psychological barriers, clinicians can begin by familiarizing themselves with the concept of neurodiversity and the social model of disability. Not only are these perspectives far less stigmatizing than the conventional medical model, but in viewing ASD in a more holistic and accepting fashion that acknowledges societal barriers to inclusion, they draw attention to the accommodations, services, and supports that can help individuals with ASD lead full and rewarding lives.

More specifically, clinicians should aim to accomplish three goals when discussing the enforcement of legal rights with patients with ASD and their parents: (1) *conveying empathy* for the enormous time and effort that ongoing advocacy requires of patients with ASD and their families; (2) *communicating a willingness to help* by fulfilling a designated role within a particular adjudicatory proceeding; and (3) *setting clear boundaries and expectations* about the scope, timing, and cost of the task(s) the clinician is willing to perform.

The last point is particularly important, especially for medical professionals with large caseloads who may be unable to devote significant time to any individual patient. Knowing at the outset how much time a clinician can devote to an advocacy-related task enables the individual with ASD, together with his/her attorney and/or allies, to make informed choices about how best to prepare for an upcoming adjudication. For example, if a clinician can only devote twenty minutes to completing a checklist, and is not willing to draft a letter of support or attend a hearing in person or telephonically, conveying this information upfront gives the advocacy team an opportunity

to approach other clinicians or rethink their litigation strategy. Discussing the clinician's expected role and his/her time constraints upfront also can create opportunities for creative problem-solving. For example, even if a clinician does not have enough time to draft a complete letter of support, he or she may be willing to review, edit, and cosign a letter drafted by another care provider.

Finally, clinicians should be sensitive to the fact that in most adjudicatory settings, the preeminence of the medical model is taken for granted, and eligibility determinations are focused narrowly on patients' deficits and limitations, not their strengths. Alerting patients and families to this reality upfront can help them prepare emotionally for what lies ahead, and lessen the risk that they feel stigmatized or shamed by the adjudicatory process itself.

### ***Refer the Patient/Client and Their Family to Local Advocacy Resources***

Although it is not always formally required, legal representation is crucial in most judicial or administrative adjudications. Yet as discussed earlier, some important federal laws (such as those governing Medicaid, SSI, and SSDI) do not guarantee plaintiffs who prevail in administrative proceedings the right to recover litigation fees and costs. Even if attorneys' fees are technically recoverable in the wake of a successful appeal to state or federal court, finding an attorney who is willing to accept a contingency fee arrangement (in which the attorney is entitled to fees only if the appeal is successful) may prove difficult. Many families, especially those who cannot afford to pay an upfront retainer or to pay an attorney on an hourly basis, may fail to secure any legal representation. Moreover, individuals with ASD or family members who opt to represent themselves (or are forced to do so because they cannot find an attorney) may struggle to learn enough about the applicable legal standards to advocate effectively on their own behalf.

Clinicians can play a critical role in referring patients with ASD and their families to local and online resources that can help them secure legal representation, or alternatively, to gain at least the basic knowledge necessary to advocate on their own behalf. The final section of this chapter lists a few helpful websites and national organizations, which can be augmented to include experienced attorneys, agencies, and legal clinics in the surrounding area. Providing patients and families with a list of advocacy-focused organizations and resources, ideally as a routine part of the intake process, can help them better understand and anticipate the advocacy challenges that await them.

## *Understand the “Clinical-Legal” Mindset*

In most adjudicatory contexts, as noted above, clinicians are asked to opine on one of two questions: (1) whether the patient’s disability qualifies him/her for legal protection or support; or (2) the nature and extent of the services, supports, or accommodations to which the patient is entitled. When called upon to opine on the first question,

Many providers erroneously assume that simply confirming medical diagnoses is sufficient to document disabilities. ‘Disability’ is an administrative/legal determination made by an agency [or court,] not a medical diagnosis . . . . The role of clinicians and others is to provide documentation, or evidence, of disability. In other words, medical professionals are asked to provide the facts—diagnoses and functional limitations—that are necessary to determine disability. That is why a simple statement such as “my patient is disabled” is not sufficient. (O’Connell et al., 2007: 6)

This excerpt succinctly captures the essence of the “clinical-legal” mindset. Establishing that a patient meets the criteria for an ASD diagnosis under the DSM is rarely, if ever, adequate to establish his/her eligibility for legal accommodation or support. Rather, the adjudicator (typically a hearing officer, judge, or arbitrator) evaluates the scope, quality, and credibility of evidence presented by qualified clinician(s) to determine whether the claimant meets the eligibility criteria laid out in the pertinent statute.

Similar logic applies to adjudications regarding what type of accommodation(s), service(s), or support(s) an employer, agency, or other entity is required to provide. Here again, a clinician’s mere assertion that the patient’s ASD diagnosis and/or symptoms give rise to particular needs is legally insufficient. If the clinician cannot document and substantiate the particular way(s) in which ASD manifests in the particular individual and the functional impairments to which it gives rise, and then clearly link these facts to the necessity for a particular form of accommodation or relief, advocacy is unlikely to achieve its intended result.

Although exceptions are plentiful, the focus of the administrative or judicial proceeding often varies depending on whether the law at issue affects a patient’s civil rights, or his/her entitlement to an accommodation or public benefit. For civil rights laws such as the ADA, IDEA, and Section 504, demonstrating that an individual with ASD is entitled to legal protection is frequently straightforward; often, the more formidable challenge lies in persuading the adjudicator to grant the requested accommodations or services. This is not the case for public benefit programs—such as Medicaid, SSI, and SSDI—in which demonstrating the patient’s threshold eligibility for services often poses the most significant evidentiary hurdles. In adjudications involving Medicaid-funded programs, *both* of these questions (threshold eligibility and entitlement to services) are frequently in dispute.

## ***Ground All Supporting Documentation or Testimony in Clinical-Legal Reasoning***

Regardless of whether the issue being adjudicated is the patient's threshold eligibility for support or the nature and scope of that support, providing effective documentation or testimony to support the patient's advocacy team typically includes the following steps:

- Identifying the specific clinical-legal issue(s) to be resolved. In most contexts, as noted above, the primary advocacy challenge is either demonstrating threshold eligibility, or proving the patient's entitlement to particular services, supports, or accommodations. In some contexts, however, an adjudicator may be asked to resolve both of these questions in a single proceeding.
- Understanding the legal standard(s) to be applied. To provide effective support to the advocacy team, a clinician must understand the standards the adjudicator will apply to resolve the clinical-legal issue, and ensure that any documentation produced is sufficiently detailed and comprehensive to meet those standards. Yet in so doing, the clinician must bear in mind that the applicable standards can vary widely between different state and federal laws.

For example, to qualify as "disabled" under SSI or SSDI, an individual with ASD not only must meet the basic diagnostic criteria ("Medical documentation of ... [q]ualitative deficits in verbal communication, nonverbal communication, and social interaction; and [s]ignificantly restricted, repetitive patterns of behavior, interests, or activities"), but also must exhibit "extreme limitation" in one or "marked limitation" in four respective areas of mental functioning: "[u]nderstand[ing], remember[ing], or apply[ing] information"; "[i]nteract[ing] with others"; "[c]oncentrat[ing], persist[ing], or maintain[ing] pace"; or "manag[ing] oneself" (SSA, n.d.-b). Medicaid, in contrast, allows states considerable discretion to specify the diagnostic tools, the relative importance of adaptive functioning measures, and definition of "institutional" level of care that are used to make eligibility determinations (Zaharia & Moseley, 2008). Under the IDEA, a child not only must have a "developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three," such as ASD, but the disability must be shown to "adversely affect[] [the] child's educational performance" (34 C.F.R. § 300.8(c)(1)). Title I of the ADA takes yet another approach: the job applicant or employee not only must prove that (s)he has a "physical or mental impairment that substantially limits one or more major life activities" (or alternatively, has a record of or is regarded as having such an impairment); but also that (s)he is qualified to perform the "essential functions" of the job "with or without reasonable accommodation" (42 C.F.R. §§ 12102(1), 12111(8)).

The same logic applies to determinations regarding an eligible individual's claim to a particular mixture of services, supports, or accommodations. Because different federal laws use different criteria to assess the merits of the claim and

- the array of benefits or accommodations to which the claimant is entitled, clinical documentation must be carefully drafted to meet the relevant legal standards.
- Compiling a checklist of criteria necessary to meet the applicable legal standard. Once the clinician understands the precise question(s) to be resolved and the legal standard(s) to be applied, the next step is to compile a checklist of the criteria that must be met for the claimant to prevail. For example, in the case of Social Security eligibility described above, the Listing of Impairments and associated documentation (available online) enumerates the specific criteria that a claimant with ASD must meet to qualify as “disabled” for purposes of SSI or SSDI (SSA, n.d.-b). The contents of the required “checklist” can vary widely depending on the law or regulation at issue and the specific issue being resolved. Importantly, clinicians must address *all* of the relevant criteria in their documentation (or testimony) to persuade an adjudicator of the patient’s threshold eligibility and/or right to requested services.
  - Substantiating each item on the checklist with supporting facts and documentation. Unlike a “doctor’s note,” which often simply asserts that an individual has a particular medical condition that necessitates a particular type of accommodation, clinical assertions carry no weight in adjudicatory settings unless they are backed up with supporting facts. For example, a clinician seeking to persuade a hearing officer in an SSI hearing that a patient with ASD has an extreme limitation in his/her capacity to “interact with others” must substantiate that claim by describing in some detail the patient’s history of interaction with family members, coworkers, and care providers; and explaining how specific aspects of his/her disability—such as disruptive behaviors, unusual responses to sensory stimuli, cognitive rigidities, deficits in theory of mind, a diminished capacity to read social cues, restricted interests or activities, and/or verbal and nonverbal communication skills—have severely impeded his/her functional capacity to interact with others in a broad range of settings, including the workplace.
  - Getting the right signatures. In most adjudicatory proceedings, different clinicians’ opinions are accorded different evidentiary weights. To support a disability claim before the SSA, for example, federal regulations specify that documentation of a medical impairment must come from an “acceptable medical source,” a category that is limited to physicians, licensed or certified psychologists, and qualified speech and language pathologists (O’Connell et al., 2007: 18). Moreover, “[b]y law, the statement of a treating [acceptable medical] source carries more weight than any other evidence, including the report of an outside examiner” (O’Connell et al., 2007: 18).

Although the SSA’s clinician credentialing requirements are unusually explicit and detailed, similar principles apply in other adjudicatory settings. Rightly or wrongly, opinions and testimony submitted by certain clinicians (usually licensed physicians and psychologists) are granted more deference than others; and the opinions of treating clinicians who know their patients well and can describe their history in detail are generally accorded more weight than those of consulting clinicians. For this reason, if a document is drafted by a clinician who does not provide ongoing



care, or who lacks an advanced clinical degree, it may be helpful for the document to be edited and cosigned by a treating medical provider and/or one with the “best” formal credentials.

## Conclusion

Engaging in successful advocacy—that is, communicating an individual’s limitations, needs, desires, or priorities to decision-makers in ways that can favorably influence the distribution of legal entitlements or the delivery of services and supports—is a vitally important, yet often very difficult, challenge for individuals with ASD and their families. Yet even clinicians who want to assist their patients or clients with this daunting task may not have the training or experience to do so effectively. This chapter outlines two distinct ways in which clinicians can become skilled advocacy allies. First, they can strengthen their therapeutic alliance with their patients or clients by understanding the concept of neurodiversity and the limitations of the medical model, and learn how SDM principles can be used to give people with ASD a greater “voice” in their own health care. In formal adjudicatory settings, clinicians likewise can play crucial supporting roles if they master the “clinical-legal” mindset, and understand how decision-makers in each case will evaluate the documentation or testimony they are asked to provide. Although becoming a proficient advocacy ally may require an upfront investment of time—especially among clinicians with little relevant training—it becomes far more manageable with increasing experience, and is an essential tool in improving the health, economic security, and long-term welfare of individuals with ASD.

## Additional Resources

### *Perspectives on Neurodiversity/Autism Rights Movement*

- *Don’t Mourn for Us by Jim Sinclair*: Though primarily directed toward parents, this essay reflects many of the tenets of the autism rights movement and can help inform clinicians’ interactions with individuals with ASD and their families (Sinclair, 1993).
- *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity by Steve Silberman*: This book traces the history of ASD diagnosis and treatment before outlining the concept of neurodiversity (Silberman, 2015).
- *What Can Physicians Learn from the Neurodiversity Movement? by Dr. Christina Nicolaidis*: This article explains the clinical and non-clinical relevance of the neurodiversity movement and encourages physicians to incorporate a social understanding of disability, explained above, into their practice (Nicolaidis, 2012).

- *The Myth of the Normal Brain: Embracing Neurodiversity by Dr. Thomas Armstrong*: This article frames disability as a condition that carries with it both strengths and weaknesses, and encourages physicians to think beyond the medical model of “curing disease” (Armstrong, 2015).

### ***Resources on the Use of Supported Decision-Making (SDM) in Health Care Settings***

- *National Resource Center for Supported Decision-Making*: The Center’s online website, found at <https://www.supporteddecisionmaking.org/>, provides informational and planning resources related to SDM, as well as descriptions of every state’s guardianship and SDM laws (National Resource Center for Supported Decision-Making, n.d.).
- *University of California Davis, Center for Excellence in Developmental Disabilities (CEDD)*: CEDD offers an extensive online list of resources explaining SDM, its implementation, and its relationship to other decision-making arrangements for people with ASD. These resources can be found at <https://health.ucdavis.edu/mindinstitute/centers/cedd/sdm.html> (University of California Davis, Center for Excellence in Developmental Disabilities, 2020).
- *Autistic Self Advocacy Network (ASAN) Model Legislation*: As discussed above, ASAN has drafted model legislation providing guidance on the implementation of SDM in health care settings (ASAN, 2014a, 2014b).
- *Supported Decision-Making Teams: Setting the Wheels in Motion by Suzanne Francisco and Jonathan Martinis*: This resource provides planning materials and additional information related to SDM, financial planning, and other services for people with ASD (Francisco & Martinis, 2017).
- *WITH Foundation*: The WITH Foundation provides grants to organization developing programs to encourage the use of SDM in clinical settings and elsewhere. For example, they have supported advocacy projects and training related to SDM, including those listed here: <https://withfoundation.org/previous-grant-recipients/> (WITH Foundation, 2020).

### ***Resources for Medical Providers on Documenting Disability for Patients with ASD***

- *Documenting Disability: Simple Strategies for Medical Providers by James O’Connell et al.*: This report offers tips to medical providers on how best to document disability for the purposes of obtaining SSI and SSDI (O’Connell et al., 2007).
- *Documenting Disabilities for Medical Providers by the National Health Care for the Homeless Council*: A collection of online informational modules and videos

for providers about how to document patients' disabilities, mostly in the context of SSI/SSDI claims. These resources can be found at <https://nhchc.org/online-courses/documenting-disability/> (National Health Care for the Homeless Council, 2019).

### ***Legal Representation and Resources for Individuals with ASD, Family Members, and Allies***

- ***Protection and Advocacy Systems (P&As)***: Each state is required to have its own protection and advocacy organization to provide legal support, training, and support to people with disabilities, including ASD. A comprehensive list of the state organizations can be found on the U.S. Administration for Community Living's website, <https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems> (U.S. Administration for Community Living, 2019).
- ***LawHelp.org***: LawHelp provides legal assistance for people of low and moderate incomes, connecting individuals with free legal aid in their communities and providing state-specific legal information as well as necessary forms for services related to many areas, including disability (LawHelp.org, 2020).
- ***Legal aid organizations***: Many organizations across the country provide free legal services to low-income families on issues related to public benefits, housing, and other matters of direct service. A list of legal aid organizations by state can be found on the Legal Services Corporation's website, <https://www.lsc.gov/grants-grantee-resources/our-grantees> (Legal Services Corporation, n.d.).
- ***Law school clinics***: In these clinics, law students provide free legal aid to low-income individuals and/or other disadvantaged groups, oftentimes including individuals with disabilities. A complete list of clinics can be found on the American Bar Association's website, [https://www.americanbar.org/groups/center-pro-bono/resources/directory\\_of\\_law\\_school\\_public\\_interest\\_pro\\_bono\\_programs/definitions/pi\\_pi\\_clinics/](https://www.americanbar.org/groups/center-pro-bono/resources/directory_of_law_school_public_interest_pro_bono_programs/definitions/pi_pi_clinics/) (American Bar Association, 2020).

### ***Self-Advocacy Organizations Run by and for Individuals with ASD***

- ***Autistic Self Advocacy Network (ASAN)***: ASAN, whose motto is "Nothing about us without us," engages in legal and political advocacy to protect the rights of people with ASD. ASAN's website can be found at <https://www.autisticadvocacy.org/> (ASAN, 2020a).
- ***Self Advocates Becoming Empowered (SABE)***: SABE is a nonprofit organization whose voting membership is made up of individuals with disabilities. Its mission is to ensure that people with disabilities receive equal treatment and

are given the same rights, responsibilities, and opportunities to empower themselves as everyone else. See <https://www.sabeusa.org/> (Self Advocates Becoming Empowered, 2020).

- *Autistic Women & Nonbinary Network (AWN)*: AWN is a nonprofit advocacy organization that provides “community, support, and resources for Autistic women, girls, transfeminine and transmasculine nonbinary and genderqueer people, trans people of all genders, Two Spirit people, and all others of marginalized genders.” Founded in 2006, the organization seeks to encourage broader discourse on the intersection of gender and disability. AWN’s website can be found at <https://www.awnnetwork.org/> (Autistic Women & Nonbinary Network, 2020).

## References

- 28 U.S.C. § 2412. (2018). <https://www.govinfo.gov/app/details/USCODE-2018-title28/USCODE-2018-title28-partVI-chap161-sec2412>. Accessed 7 July 2020.
- 34 C.F.R. § 300.8. (2020). [https://www.ecfr.gov/cgi-bin/text-idx?SID=f2af09c10e0e612c119166b3ab6928df&mc=true&node=se34.2.300\\_18&rgn=div8](https://www.ecfr.gov/cgi-bin/text-idx?SID=f2af09c10e0e612c119166b3ab6928df&mc=true&node=se34.2.300_18&rgn=div8). Accessed 7 July 2020.
- 42 C.F.R. §§ 431.200–431.250. (2020). <https://www.ecfr.gov/cgi-bin/text-idx?node=pt42.4.431&rgn=div5#sp42.4.431.e>. Accessed 7 July 2020.
- 42 U.S.C. § 12102(1). (2010). <https://www.govinfo.gov/app/details/USCODE-2010-title42/USCODE-2010-title42-chap126-sec12102>. Accessed 7 July 2020.
- 42 U.S.C. § 12111(8). (2010). <https://www.govinfo.gov/app/details/USCODE-2010-title42/USCODE-2010-title42-chap126-subchapI-sec12111>. Accessed 7 July 2020.
- 42 U.S.C. § 12205. (2018). <https://www.govinfo.gov/app/details/USCODE-2018-title42/USCODE-2018-title42-chap126-subchapIV>. Accessed 7 July 2020.
- American Bar Association. (2020). *Public interest clinics*. [https://www.americanbar.org/groups/center-pro-bono/resources/directory\\_of\\_law\\_school\\_public\\_interest\\_pro\\_bono\\_programs/definitions/pi\\_pi\\_clinics/](https://www.americanbar.org/groups/center-pro-bono/resources/directory_of_law_school_public_interest_pro_bono_programs/definitions/pi_pi_clinics/). Accessed 7 July 2020.
- Armstrong, T. (2015). The myth of the normal brain: Embracing neurodiversity. *AMA Journal of Ethics*, 17(4), 348–352. <https://doi.org/10.1001/journalofethics.2015.17.4.msoc1-1504>.
- Autistic Self Advocacy Network. (2014a). *Model legislation: An Act relating to the recognition of a Supported Health Care Decision-Making Agreement for adults with disabilities*. <https://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-Supported-Decisionmaking-Model-Legislature.pdf>. Accessed 7 July 2020.
- Autistic Self Advocacy Network. (2014b). *Questions and answers on the model Supported Health Care Decision-Making Agreement Act*. <https://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-Q-and-A-on-model-legislature.pdf>. Accessed 7 July 2020.
- Autistic Self Advocacy Network. (2020a). *Nothing about us without us*. <https://autisticadvocacy.org/>. Accessed 7 July 2020.
- Autistic Self Advocacy Network. (2020b). *Healthcare transition toolkit*. <https://autisticadvocacy.org/policy/toolkits/healthtransition/>. Accessed 7 July 2020.
- Autistic Women & Nonbinary Network. (2020). *Neurodiversity is for everyone*. <https://awnnetwork.org/>. Accessed 7 July 2020.
- Bettleheim, B. (1967). *The empty fortress: Infantile autism and the birth of the self* (p. 1967). Free Press.
- Braddock v. Mo. Dep’t of Mental Health, 200 S.W.3d 78. (Mo. Ct. App. 2006). <https://casetext.com/case/braddock-v-missouri-dept-of-mental-hlt>. Accessed 7 July 2020.

- Cal. Welf. & Inst. Code § 10962. (2019). [https://leginfo.legislature.ca.gov/faces/codes\\_displaySection.xhtml?sectionNum=10962&lawCode=WIC](https://leginfo.legislature.ca.gov/faces/codes_displaySection.xhtml?sectionNum=10962&lawCode=WIC). Accessed 7 July 2020.
- Cohmer, S. (2018). Infantile autism: The syndrome and its implications for a neural theory of behavior (1964), by Bernard Rimland. *The embryo project encyclopedia*. <https://embryo.asu.edu/pages/infantile-autism-syndrome-and-its-implications-neural-theory-behavior-1964-bernard-rimland>. Accessed 7 July 2020.
- Council for Exceptional Children. (2002). *Understanding the differences between IDEA and Section 504*. LD OnLine. <https://www.ldonline.org/article/6086/>. Accessed 7 July 2020.
- Council of Parent Attorneys and Advocates. (2013). *Reinstate prevailing parents' right to expert witness fees*. <https://www.copaa.org/page/ExpertWitness>. Accessed 7 July 2020.
- Dawson, M. (2003). *No autistics allowed: Autism Society Canada speaks for itself—An open letter*. [https://www.sentex.ca/~nexus23/naa\\_js.html](https://www.sentex.ca/~nexus23/naa_js.html). Accessed 7 July 2020.
- Dawson, M. (2004). *No autistics allowed one year later: Autism Society Canada builds a Ghetto*. [https://www.sentex.ca/~nexus23/naa\\_one.html](https://www.sentex.ca/~nexus23/naa_one.html). Accessed 7 July 2020.
- D.C. Department on Disability Services. (n.d.). *Person-centered thinking philosophy*. <https://dds.dc.gov/page/person-centered-thinking-philosophy>. Accessed 7 July 2020.
- de Wolfe, J. (2014). *Parents of children with autism: An ethnography*. Palgrave Macmillan.
- Francisco, S. M., & Martinis, J. G. (2017). *Supported decision-making teams: Setting the wheels in motion*. National Resource Center for Supported Decision-Making. <https://www.supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>. Accessed 7 July 2020.
- Fry v. Napoleon Community Schools, 580 U.S. \_\_ (2017). <https://www.oyez.org/cases/2016/15-497>. Accessed 7 July 2020.
- Good v. Iowa Dep't of Human Services, 924 N.W.2d 853. (Iowa 2019). <https://casetext.com/case/good-v-iowa-dept-of-human-servs>. Accessed 7 July 2020.
- Howey, P. (2019). *Key differences between Section 504 and IDEA*. Wrightslaw. <https://www.wrightslaw.com/howey/504.idea.htm>. Accessed 7 July 2020.
- Joseph, B., Magrisso, J., & Schuster, S. (2019). Private rights of action—Remedy for existing violation of Title III. In *Public accommodations under the Americans with Disabilities Act: Compliance and litigation manual*. Thomson Reuters Westlaw. Available via Westlaw Edge. Accessed 7 July 2020.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217–250.
- Kripke, C. (2016). Supported health care decision-making for people with intellectual and cognitive disabilities. *Family Practice*, 33(5), 445–446. <https://doi.org/10.1093/fampra/cmw060>.
- Lang, A., & Paquette, E. T. (2018). Involving minors in medical decision making: Understanding ethical issues in assent and refusal of care by minors. *Seminars in Neurology*, 38(5), 533–538. <https://doi.org/10.1055/s-0038-1668078>.
- LawHelp.org. (2020). *Helping people find solutions to their legal problems*. <https://www.lawhelp.org/>. Accessed 7 July 2020.
- Legal Services Corporation. (n.d.). *Our Grantees*. <https://www.lsc.gov/grants-grantee-resources/our-grantees>. Accessed 6 May 2021.
- Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55(1), 3–9.
- McCormick, H. (2019). Exhausting administrative remedies—Generally. In *Medicare and Medicaid claims and procedures*. Thomson Reuters Westlaw. Available via Westlaw Edge. Accessed 7 July 2020.
- Medicaid and CHIP Payment and Access Commission. (2018). *Elements of the Medicaid appeals process under fee for service, by state*. <https://www.macpac.gov/publication/elements-of-the-medicaid-appeals-process-under-fee-for-service-by-state/>. Accessed 7 July 2020.
- Mo. Rev. Stat. § 536.087. (2019). <https://law.justia.com/codes/missouri/2019/title-xxxvi/chapter-536/section-536-087/>. Accessed 7 July 2020.

- National Council on Disability. (2019). *Turning rights into reality: How guardianship and alternatives impact the autonomy of people with intellectual and developmental disabilities*. [https://ncd.gov/sites/default/files/NCD\\_Turning-Rights-into-Reality\\_508\\_0.pdf](https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf). Accessed 7 July 2020.
- National Health Care for the Homeless Council. (2019). *Documenting disability for medical providers*. <https://nhchc.org/online-courses/documenting-disability/>. Accessed 7 July 2020.
- National Resource Center for Supported Decision-Making. (n.d.). *Everyone has the right to make choices*. <https://supporteddecisionmaking.org/>. Accessed 7 July 2020.
- Nicolaidis, C. (2012). What can physicians learn from the neurodiversity movement? *AMA Journal of Ethics*, 14(6), 503–510.
- O’Connell, J. J., Zevin, B. D., Quick, P. D., Anderson, S. F., Perret, Y. M., Dalton, M., & Post, P. A. (Ed). (2007). *Documenting disability: Simple strategies for medical providers*. Health Care for the Homeless Clinicians’ Network, National Health Care for the Homeless Council. <https://nhchc.org/wp-content/uploads/2019/08/DocumentingDisability2007.pdf>. Accessed 7 July 2020.
- Oklahoma Department of Human Services. (2015). *Requesting a fair hearing, procedures and appeals from hearing decisions*. <https://www.okdhs.org/aboutus/ogc/Pages/hearappeals.aspx>. Accessed 7 July 2020.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. Palgrave Macmillan.
- Osborne, A. G., & Russo, C. J. (2014). *Special education and the law: A guide for practitioners* (3rd edn.). Corwin.
- Rimland, B. (1964). *Infantile autism: The syndrome and its implications for a neural theory of behavior*. Appleton-Century-Crofts.
- Rothstein, L. (2019). Section 504 and the ADA—Procedural issues. In *Disabilities and the law*. Thompson Reuters Westlaw. Available via Westlaw Edge. Accessed 7 July 2020.
- Rothstein, L., & Johnson, S. F. (2014). *Special education law* (5th edn.). Sage.
- Ryther, P., & Samuels, B. (2019). Exhaustion of administrative remedies. In *Social Security disability claims: Practice and procedure*. Thompson Reuters Westlaw. Available via Westlaw Edge. Accessed 7 July 2020.
- Self Advocates Becoming Empowered. (2020). *Self advocates becoming empowered*. <https://www.sabeusa.org/>. Accessed 26 June 2020.
- Silberman, S. (2015). *Neurotribes: The legacy of autism and the future of neurodiversity*. Penguin Random House.
- Sinclair, J. (1993). Don’t mourn for us. *Our Voice*, 1(3). [https://www.autreat.com/dont\\_mourn.html](https://www.autreat.com/dont_mourn.html). Accessed 7 July 2020.
- Smith, T., & Eikeseth, S. (2011). O. Ivar Lovaas: Pioneer of applied behavior analysis and intervention for children with autism. *Journal of Autism and Developmental Disorders*, 41, 375–378. <https://doi.org/10.1007/s10803-010-1162-0>.
- University of California Davis, Center for Excellence in Developmental Disabilities. (2020). *Supported Decision Making (SDM)*. <https://health.ucdavis.edu/mindinstitute/centers/cedd/sdm.html>. Accessed 7 July 2020.
- U.S. Administration for Community Living. (2019). *State protection & advocacy systems*. <https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>. Accessed 7 July 2020.
- U.S. Department of Education. (n.d.). *About IDEA*. <https://sites.ed.gov/idea/about-idea/>. Accessed 7 July 2020.
- U.S. Department of Education Office of Civil Rights. (2020). *Frequently asked questions about Section 504 and the education of children with disabilities*. <https://www2.ed.gov/about/offices/list/ocr/504faq.html>. Accessed 7 July 2020.
- U.S. Department of Justice Civil Rights Division. (2013). *Filing a complaint with the equal employment opportunity commission*. [https://www.ada.gov/filing\\_eeoc\\_complaint.htm](https://www.ada.gov/filing_eeoc_complaint.htm). Accessed 7 July 2020.
- U.S. Department of Justice Civil Rights Division. (2017). *ADA designated investigative services*. <https://www.ada.gov/investag.htm>. Accessed 7 July 2020.

- U.S. Social Security Administration. (2017). *Your right to representation*. <https://www.ssa.gov/pubs/EN-05-10075.pdf>. Accessed 7 July 2020.
- U.S. Social Security Administration. (2019). *Federal court review process*. [https://www.ssa.gov/appeals/court\\_process.html](https://www.ssa.gov/appeals/court_process.html). Accessed 7 July 2020.
- U.S. Social Security Administration. (n.d.-a). *Consultative examinations: A guide for health professionals*. <https://www.ssa.gov/disability/professionals/greenbook/ce-evidence.htm>. Accessed 7 July 2020.
- U.S. Social Security Administration. (n.d.-b). *Appendix 1 to subpart P of Part 404—Listing of impairments*. [https://www.ssa.gov/OP\\_Home/cfr20/404/404-app-p01.htm](https://www.ssa.gov/OP_Home/cfr20/404/404-app-p01.htm). Accessed 7 July 2020.
- Weber, M. C. (2012). Procedures and remedies under Section 504 and the ADA for public school children with disabilities. *Journal of the National Association of Administration Law Judiciary*, 32(2), 610–647.
- WITH Foundation. (2020). *Previous grant recipients*. <https://withfoundation.org/previous-grant-recipients/>. Accessed 7 July 2020.
- Yell, M. L. (2019). *The law and special education* (5th edn.). Pearson.
- Zaharia, R., & Moseley, C. (2008). *State strategies for determining eligibility and level of care for ICF/MR and Waiver program participants*. Rutgers Center for State Health Policy. <https://www.nasddd.org/uploads/documents/NASDDDS-EligibilityReportFinal.pdf>. Accessed 7 July 2020.

**Alison Morantz** is the James and Nancy Kelso Professor of Law at Stanford University; the Director of the Stanford Intellectual and Developmental Disabilities Law and Policy Project; and a Senior Fellow of the Stanford Institute for Economic Policy Research. Her research focuses on the rights and welfare of individuals with I/DD, and the law and economics of protective labor regulation. A former anti-discrimination advocate, she has been the principal investigator of research projects funded by the National Science Foundation, the Department of Labor, and the National Institute of Occupational Safety and Health.