

Health Insurance and Medicaid Coverage for Autism Services: A Guide for Individuals and Families

Introduction

Autism is a developmental disability that can affect a wide range of domains, including communication, sensory and motor integration, language development, and emotional regulation. Yet, while many individuals and their families may face a barrage of information on a variety of interventions or treatments designed to build skills or “normalize” autistic behavior, it can be difficult not only to figure out which interventions are best for a specific individual, but also to secure coverage for those interventions.

Without coverage for appropriate, effective, individual needs-based interventions, autistic children and adults may be forced to accept services that are not appropriate, to pay extremely high out-of-pocket fees, or to simply go without needed services. Inappropriate or ineffective services not only may cause delays in developing important skills but also may cause lasting harm of the inappropriate services include painful “aversive” behavioral interventions, interventions that prioritize compliance over meaningful skills, or dangerous and unproven “cures” such as chelation or use of other toxic chemicals.¹

Autistic children and adults may face coverage denials for necessary interventions even when they have health coverage such as private insurance, Medicaid, Medicare, or TRICARE benefits for military families. They may hear one or more of the following reasons for coverage denials:

- The health plan only covers one kind of autism intervention, such as Applied Behavior Analysis (ABA)
- The health plan refuses to cover interventions that aren’t provided by a certain kind of professional, such as a board-certified ABA practitioner
- The health plan rejects a certain kind of autism intervention as “experimental” or “not evidence based,” despite the existence of an adequate evidence base;
- The health plan covers a certain kind of intervention for some other kinds of disabilities but not for autism (for example, the plan covers occupational therapy for brain injury survivors but not autistic individuals, or the plan covers mental health counseling for people with anxiety disorders but not for people with autism diagnoses)
- The health plan refuses to cover an intervention (such as speech therapy or communication supports) because it believes that the intervention is an “educational service” and not “health care”
- The health plan says that it covers the intervention, but not at the level that the person needs (for example, covering only two hours of occupational therapy per month instead of multiple hours per week)
- The health plan covers the intervention, but doesn’t have an adequate number of providers “in network” – which means that people must travel long distances to find a provider, or settle for a provider that does not offer the right kind of service.

¹ For more information on dangerous autism “cures,” see the Food and Drug Administration, “Consumer Update: Beware of False or Misleading Claims for Treating Autism,” available at <http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm394757.htm>.



Advocates have devoted an increasing amount of attention to the problem of inadequate coverage for autism interventions. However, much advocacy to date has been framed largely at improving access to intensive behavioral interventions such as Applied Behavioral Analysis, rather than on improving access to a broader range of quality, evidence-based approaches. As a result, even in states with “autism coverage mandates,” many autistic children and adults still face barriers to coverage for the interventions that are right for them, and lack the support and information they may need to overcome those barriers.

This resource is designed to help autistic people, their families, service providers, and other advocates understand and enforce their rights to health coverage for autism-related services. We hope that this resource also increases awareness of the continued need for policy advocacy across a range of intervention options.

Background

The evidence base

Definition of “evidence-based”

Evidence-based practices in medicine and psychology aim to promote the most effective treatment methods in accordance with careful research, an individual clinician’s preferences, and a patient’s preferences. The movement toward evidence-based practice is rooted in the idea that treatment methods become better when informed by research. There are many possible types of research that can contribute to the body of evidence around a particular treatment. Evidence can include an individual clinician’s overall experience and experience with individual cases, as well as broader types of research involving more people or aggregate data.²

It is important to evaluate the usefulness of evidence-based treatments based on the relevance of their actual measured outcomes in a person’s quality of life. There may be extensive research showing that a particular treatment is very effective in producing a specific outcome. Nevertheless, if that outcome is irrelevant to long-term skills or quality of life as defined by the person receiving the treatment, it is not necessarily an ideal or practical intervention. For example, an intervention that has been proven to teach a child to make eye contact may be called “evidence-based,” but is not necessarily practical or meaningful for long-term outcomes, as opposed to an intervention that successfully teaches a child alternative coping mechanisms to replace aggressive behavior. Although the Department of Education has found the Lovaas model of Applied Behavior Analysis to have a “potentially positive” effect on cognitive development, it found that the intervention had “no discernible effects” on communication and language skills, social and emotional development, or functional abilities.³

Evidence base for developmental approaches

There are many types of interventions for autism that can be described as evidence-based. For example, in 2014 a National Institute for Mental Health (NIMH) funded randomized control trial on a Developmental, Individual-differences, and Relationship-based (DIR™) program, the PLAY Project, found significant positive results for this DIR program as compared to usual community services for autistic children.⁴ Also in 2014, another paper found improved communication, daily living, and social skills for autistic children receiving individualized Early Social Interaction (ESI) therapy based on the Social Communication, Emotional Regulation, and Transactional Support (SCERTS™)

2 See “Evidence-Based Practice in Psychology” (2006), p. 274, available at <http://www.apa.org/practice/resources/evidence/evidence-based-statement.pdf>.

3 Institute of Education Sciences, U.S. Department of Education, What Works Clearinghouse Intervention Report: Lovaas Model of Applied Behavior Analysis 2 (August 2010), available at http://ies.ed.gov/ncee/wwc/pdf/intervention_reports/wwc_lovaas_082410.pdf.

4 See Richard Solomon, et al., PLAY Project Home Consultation Intervention Program for Young Children with Autism Spectrum Disorders: A Randomized Controlled Trial, in 35 J. OF DEVELOPMENTAL & BEHAVIORAL PEDIATRICS 475 (2014).

model.⁵ This model aims to integrate social communication skills development into everyday activities and natural environments. The same study found no such gains for children receiving ESI therapy in group settings.⁶

In 2010, research firm Impaq published a comprehensive literature review on interventions and services for autism that had been commissioned by the Centers for Medicare & Medicaid Services (CMS). In the report, the researchers sought to identify evidence-based practices, emerging evidence-based practices, and unestablished practices.⁷ The researchers made this determination based on the overall strength of the scientific backing in available studies for each type of intervention, including whether research had established positive outcomes such as improved sensory issues or adaptive skills. Impaq further categorized behavioral interventions and supports among those targeting different areas of developmental skills and those intended for children, transition-age youth, and adults. Overall, Impaq found that interventions focusing on functional skills from an environmental and developmental perspective tended to be evidence-based or emerging.

A 2005 study on treatment acceptability paradigms among providers of positive behavioral interventions and supports found that many experts no longer consider many consequence-based interventions to be acceptable treatment.⁸ Instead, respondents who had used consequence-based interventions, including forms of ABA, in the past but no longer considered them acceptable now indicated that one of the primary reasons for their paradigm shift was recognizing that alternative developmental interventions result in quicker and more long-lasting positive behavioral changes tailored to the individual's specific needs.

Developmental interventions may be referred to generally as developmental, social, or relationship-based, or they may be referred to by the name of a specific intervention model. One specific kind of developmental intervention is DIR/Floortime, which is a holistic and individualized developmental approach to autism intervention. DIR stands for developmental framework, individual differences, and relationship and affective interactions. This intervention tailors its approach based on both an individual child's profile and unique dynamics of parent-child interaction. Since 2011, four randomized-control trial studies have been published that identified significant skill improvements for autistic children receiving DIR/Floortime, including in cognitive development, language skills, and social interactions.⁹ A study from 2007 of an intervention based on DIR/Floortime similarly found significant improvement in functional developmental levels for autistic children receiving this intervention.¹⁰ In addition, the SCERTS (Social Communication/Emotional Regulation/Transactional Support) model focuses on developmentally grounded goals for social communication and emotional regulation.¹¹ The SCERTS model incorporates a variety of strategies based on available research literature about their effectiveness in reducing challenges and improving specific skills.

5 Amy M. Wetherby, et al., Parent-Implemented Social Intervention for Toddlers With Autism: An RCT, in 136 PEDIATRICS 1084 (2014), available at <http://www.hpcswf.com/wp-content/uploads/2014/11/Wetherby-et-al-Parent-implemented-social-intervention-for-toddlers-with-autism-An-RCT-Pediatrics-20143.pdf>.

6 For more information on the SCERTS model, see Barry M. Prizant, et al., The Scerts Model and Evidence-Based Practice (2010), available at http://www.scerts.com/docs/scerts_ebp%20090810%20v1.pdf.

7 Julie Young, et al., AUTISM SPECTRUM DISORDERS: FINAL REPORT ON ENVIRONMENTAL SCAN (2010), available at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/Autism-Spectrum-Disorders.pdf>.

8 Craig A. Michaels, et al., Personal Paradigm Shifts in PBS Experts: Perceptions of Treatment Acceptability of Decelerative Consequence-Based Behavioral Procedures, in 7 J. OF POSITIVE BEHAVIORAL INTERVENTIONS 93 (2005), available at <http://www.qc.edu/rcautism/publications/PP%20shifts%201.pdf>.

9 See Richard Solomon, et al., PLAY Project Home Consultation Intervention Program for Young Children with Autism Spectrum Disorders: A Randomized Controlled Trial, in 35 J. OF DEVELOPMENTAL & BEHAVIORAL PEDIATRICS 475 (2014); Devin M. Casenhiser, et al., Learning through interaction in children with autism: Preliminary data from a social-communication-based intervention, in 17 AUTISM 220 (2011), available at <http://ossyfirstan.blog.uns.ac.id/files/2014/10/Autism-2013-Casenhiser-220-41.pdf>; Rubina Lal & Rakhee Chhabria, Early Intervention of Autism: A Case for Floor Time Approach, in RECENT ADVANCES IN AUTISM SPECTRUM DISORDERS 691 (2013), available at http://cdn.intechopen.com/pdfs/43407/InTech-Early_intervention_of_autism_a_case_for_floor_time_approach.pdf; Kingkaew Pajareya & Kaewta Nopmaneejumruslers, A pilot randomized controlled trial of DIR/Floortime™ parent training intervention for pre-school children with autistic spectrum disorders, in 15 AUTISM 1 (2011), available at http://www.floortimethailand.com/images/info/Pajareya_PilotRCTDIRFloortime_Thailand_Autism2011.pdf.

10 Richard Solomon, et al., Pilot study of a parent training program for young children with autism: The PLAY Project Home Consultation program, in 11 AUTISM 205 (2007), available at <http://smtp.interactingwithautism.com/pdf/treating/70.pdf>.

11 Barry M. Prizant, et al., The Scerts Model and Evidence-Based Practice (2010), available at http://www.scerts.com/docs/scerts_ebp%20090810%20v1.pdf.

Evidence base for other promising approaches

The Impaq literature review identified 15 discrete categories of evidence-based interventions and services for children, of which at least 11 do not include or rely on ABA. Those included:

- **Antecedent-focused interventions**, which seek to change events in the environment that precede problematic behavior.
- **Cognitive behavioral interventions**, which focus on changing negative thought and behavioral patterns by positively influencing emotions.
- **Joint attention interventions**, which prompt recognition and response to nonverbal interaction.
- **Naturalistic teaching**, which use child-directed interactions to teach functional skills.
- **Peer training**, which teaches children without disabilities to engage with autistic peers to promote play and social interaction.
- **Picture Exchange Communication System (PECS)**, which teaches functional communication skills to children with limited or no speech.
- **Schedules**, which present information about a task or activity in steps.
- **Social communication interventions**, which focus on pragmatic communication skills.
- **Social skills interventions**, which focus on social interaction and range from basic to complex.
- **Story-based interventions**, which use narratives to teach about problematic behavior.
- **Structured teaching (TEACCH)**, which combines predictable schedules, orderly environments, and individualized instruction.

The Impaq report further identified interventions such as Augmentative and Alternative Communication (AAC) devices, behavioral modeling, music therapy, and situational scripting as “emerging” evidence-based practices for children. For adults, the researchers included supported employment, where autistic adults receive training and support to find and keep paid work in an integrated environment.

A more recent literature review conducted in 2014 by the Autism Evidence-Based Practice Review Group at the University of North Carolina identified 27 practices that met criteria for rigorous research backing.¹² In addition to many of the same practices that the Impaq study found to be evidence-based, the 2014 report identified functional behavior assessment (FBA), functional communication training (FCT), pivotal response training (developing response and initiation in learner-centered environment), prompting (scaffolded assistance from adult or peer), and self-management (self-regulation of own behavior) as evidence-based.

¹² Connie Wong, et al., *Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder (2013)*, available at <http://autismpdc.fpg.unc.edu/sites/autismpdc.fpg.unc.edu/files/2014-EBP-Report.pdf>.

Medicaid Coverage of Autism-Related Health Services

Many autistic people are covered by Medicaid, either as children or as adults. Autistic children and adults are generally eligible for Medicaid if they are:

- Children whose families earn under a certain amount (which may vary by state);
- Children or adults with disabilities who qualify for Supplemental Security Income (SSI);
- If they earn too much to receive SSI, but pay for Medicaid through a “Buy-In” program; or
- In many states, if they are adults earning less than 138% of the federal poverty level (FPL). This population is called the “Medicaid Expansion Population” because they are eligible for Medicaid as a result of the Affordable Care Act’s expansion of Medicaid eligibility in 2010. People eligible through this program may receive a separate set of benefits, known as an Alternate Benefit Program (ABP) instead of regular Medicaid.

There are other sources of eligibility for Medicaid coverage as well. In addition, many children who are not eligible for Medicaid may be eligible for insurance through the Children’s Health Insurance Program (CHIP). The CHIP program is covered by some laws that govern Medicaid but not by others.

Important state and federal laws

Medicaid is funded through the federal government, but each state has its own Medicaid program. As a result, Medicaid benefits are covered by both state and federal laws that govern the types of benefits that Medicaid needs to provide.

Federal Medicaid law

All people under the age of 21 who have Medicaid coverage are entitled to a wide range of services, known as Early Periodic Screening, Diagnosis, and Treatment (EPSDT), regardless of whether those services are listed in the State Plan. CMS recently issued [guidance on EPSDT rights of autistic children and young adults](#)¹³ who are covered by Medicaid. As CMS noted, states *must* cover all medically necessary autism-related interventions that count as “medical assistance” under federal Medicaid law. Children who are covered by CHIP do not have to receive EPSDT services. Some additional services, such as family respite services, may also be available under Medicaid waivers for autistic children.

In addition, federal law requires that state Medicaid programs – including Medicaid managed care plans – ensure adequate access to timely care, including by keeping an adequate network of providers and allowing people to go outside of the network when no in-network providers are available.

The Affordable Care Act

The Affordable Care Act of 2010 (“ACA”), also popularly known as “Obamacare,” requires many kinds of health care plans – including the Medicaid Alternate Benefit Programs and CHIP programs – to cover “Essential Health Benefits.” The Department of Health and Human Services is required to issue regulations explaining in more detail what these benefits must include, but has not done so yet. What we do know is that they must include mental health benefits, rehabilitative and habilitative services (such as occupational therapy or speech therapy), and prescription medications, among other things.¹⁴ In addition, these plans must not deny coverage on the basis of disability.¹⁵

Mental Health Parity

The Mental Health Parity and Addiction Equity Act of 2008 (“Mental Health Parity Act”) requires that health plans treat their coverage of mental health conditions the same as their coverage of physical health conditions. This means that they cannot require people to pay higher co-pays for services and cannot impose caps on mental health care that are

13 Cindy Mann, et al., CLARIFICATION OF MEDICAID COVERAGE OF SERVICES TO CHILDREN WITH AUTISM (2014), available at <http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf>.

14 42 U.S.C. §§ 18021(a)(1)(B), 18022(b)(1).

15 42 USCS § 18116(a).

more restrictive than caps on physical health care. They cannot impose a separate deductible for mental health care and cannot impose more restrictive medical necessity or in-network care requirements for mental or behavioral health care than they do for medical or surgical care.

Recently, the federal government proposed a [rule](#) that would apply the Mental Health Parity Act to Medicaid managed care plans, Medicaid Alternative Benefit Plans covering people in the Expansion Population, and CHIP plans.

Mental Health Parity rules can become relevant to coverage for autism when plans will offer some types of benefits – like occupational therapy or physical therapy – to people with physical or brain injuries but not to people whose primary diagnosis is autism spectrum disorder. They may also become relevant when health plans try to impose more restrictions on out-of-network care for behavioral health interventions than they would impose for medical interventions, or deny interventions as “not medically necessary” without explanation.

State autism coverage mandates

A growing number of states have laws requiring that insurance companies (and, sometimes, the state Medicaid plan) cover certain kinds of autism-related interventions. Although these are often referred to as “autism health care mandates,” it is important to look carefully at the law in each state to determine exactly which kind of autism-related health care must be covered and which kinds of health plans are subject to the laws. Many of these laws apply only to children under a certain age or allow insurance companies to impose annual cost caps on autism interventions. In addition, although most of these laws supposedly require health plans to cover a range of behavioral health interventions for autistic individuals, in some statutes the only specific intervention modality mentioned by name is Applied Behavioral Analysis (ABA). As a result, some insurance companies have misinterpreted these laws as requiring only that health plans cover ABA and not other types of services.

The Individuals with Disabilities Education Act

Children and young adults under the age of 21 may also be eligible for services under the Individuals with Disabilities Education Act (IDEA). The IDEA covers services that are necessary in order to ensure a child receives a free, appropriate public education. This may include services that are also available through your health coverage plan, such as occupational therapy or speech therapy. Nevertheless, health insurance plans (including CHIP and Medicaid) should not refuse to cover a medically necessary health intervention based solely on the fact that it might also be provided by the child’s school.

Overcoming Coverage Challenges

The first step toward getting coverage for behavioral health treatment through Medicaid is checking the terms of your Medicaid plan. Important questions to ask include:

- Does my Medicaid plan generally cover this service?
- Do the terms of the plan require me to get the service from an in-network provider? If so, is there an in-network provider with availability that you feel comfortable using?
- Do the terms of the plan require the service to be provided by people with certain licensure requirements? Are these requirements a barrier for the type of service in question?
 - For example, some plans will tell beneficiaries that all behavioral health interventions for autistic children be provided by licensed, board-certified behavior analysts. For non-ABA interventions, this requirement may be a barrier.
- Do beneficiaries need to get pre-authorization from your coverage provider in order to get coverage for this service?
- Does the coverage provider impose caps on the number of hours or visits that are covered?
- How much, if anything, will you have to contribute as a co-pay?

Often, this information is available online. You can also look at information [online¹⁶](#) about specific programs that your state Medicaid plan may have to provide care for autistic people, including State Plan Amendments (SPAs), Demonstrations, and Waiver programs.

If you are having trouble finding the answer to your question, try contacting either the state agency or, if your state has one, a [Consumer Assistance Program¹⁷](#) with questions about what your Medicaid plan covers.

If your plan says that it will not cover a service that you need, or imposes requirements that make it difficult for you to get the service (such as caps on number of hours or unreasonable limits on who can provide the service), you may still have a right to appeal or challenge this decision. The following guide addresses various challenges that beneficiaries and providers have faced when seeking Medicaid coverage for necessary health services and interventions and discusses potentially effective approaches to overcoming them. Here are a few examples.

My health plan denied coverage because the service I wanted was “experimental” or “not medically necessary.”

Sometimes, Medicaid plans may say that they cover “medically necessary” interventions like occupational therapy, speech therapy, or psychologist services, but will refuse to cover the specific service you want because it is considered “experimental” or “not medically necessary.” Sometimes, health plans will decide that an intervention that helps build skills or manage behavior is actually an “educational” service and not a “health care” service, and deny coverage on those grounds.

You have a right to appeal a determination that an intervention isn’t “medically necessary.” The Medicaid appeals process can be complicated, but the Kaiser Family Foundation has a very good [guide to the Medicaid appeals process](#).¹⁸ Pay careful attention to the deadlines for appealing Medicaid claim denials in your state. If you have a Medicaid managed care plan, appeals may have to go through the managed care organization’s process for appeals, which may have its own separate set of deadlines.

In your appeal, you should include as much documentation as you can showing that the intervention is actually medically necessary and evidence-based. If possible, include a letter from one of your treating health care providers (such as a family doctor, psychiatrist, or psychologist) and/or from the provider who is offering the services you’d like to be covered, explaining why the intervention is appropriate, medically necessary, and evidence-based. If you know of research that is relevant, you can include that as well - the chapter on Evidence Base in this Guide can help you here.

Sometimes the coverage provider will argue that an intervention is *never* medically necessary, such as when it decides that it’s “experimental” or “educational.” Other times, the coverage provider will instead say that the intervention is not “medically necessary” for the specific beneficiary – either because the beneficiary is not “disabled enough” and doesn’t need it, or because the company has decided that the beneficiary is “too disabled” to make any progress. If your coverage provider is arguing that the intervention is unlikely to work for the specific beneficiary, you may need to ask treatment providers, educators, or other people who have experience with the beneficiary to send in documentation such as progress notes and evaluations to support their opinion that the intervention is or would be helpful.

If your appeal is still denied, you may have legal options available to you, including a lawsuit to enforce your rights under Medicaid. If you have questions about where to go for help, feel free to contact ASAN at info@autisticadvocacy.org. ASAN is looking into this issue and may be able to refer you to a lawyer in your area willing to give you advice. You can also contact your state’s Protection and Advocacy organization, which may either be able to provide direct representation or refer you to someone who can. State Protection and Advocacy organizations are federally funded groups to protect the rights of people with disabilities. You can find your state’s Protection and Advocacy organization by visiting <http://www.ndrn.org/en/ndrn-member-agencies.html>.

16 <http://www.medicaid.gov/medicaid-chip-program-information/by-state/by-state.html>

17 <https://www.cms.gov/CCIIO/Resources/Consumer-Assistance-Grants/>

18 <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8287.pdf>

My health plan says that this type of service isn't covered

Under Medicaid law, plans are required to cover a wide range of medically necessary services for autistic children. There are also laws requiring Medicaid plans to cover a smaller range of medically necessary services for autistic adults.

Children and Young Adults Under 21, Enrolled in Medicaid

Medicaid plans are required to offer certain “Early Periodic Screening, Diagnosis, and Treatment” services to all beneficiaries under age 21, *even if those services aren't usually included in the state's regular Medicaid plan.*¹⁹ CMS recently issued [guidance on EPSDT rights of autistic children and young adults](#)²⁰ who are covered by Medicaid. As CMS noted, states *must* cover all medically necessary autism-related interventions that count as “medical assistance” under federal Medicaid law.

EPSDT services include the full range of medical services that, under federal Medicaid law, are allowed to be included in a Medicaid plan. These include not only regular vaccinations, doctor's visits, dental services, hospitalizations, surgical care, and lab tests, but also services that are particularly useful for autistic children and adults, such as:

- Diagnostic testing, including neuropsychological evaluations
- Habilitative services from a doctor or other licensed health care provider, “for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level,” whether in a facility, clinic, or home
- Physical therapy
- Home health care services
- At-home personal care services
- Private-duty nursing
- Case management
- Prescription medications
- Eye care
- Any medical care by licensed practitioners within the scope of their practice
- Family planning services for adolescents and young adults

The recent guidance from CMS makes it clear that states must cover a full range of medically necessary services for autistic children and young adults under age 21 – not just one kind of service, such as Applied Behavioral Analysis. Nevertheless, some state Medicaid programs have continued to take the position that they only need to cover certain kinds of services, such as Applied Behavioral Analysis, or that they cover only services to those provided by licensed ABA practitioners and not other competent professionals such as psychologists or occupational therapists.

If your state Medicaid plan refuses to cover medically necessary services for autistic children or adults under age 21, you can appeal this denial. For a good overview of the appeals process, see the Kaiser Family Foundation's [guide to the Medicaid appeals process](#).²¹ Your appeal should specifically state that the service should be covered through the EPSDT benefit, and should include documentation that the service is “medically necessary” (see our previous section on medically necessary coverage requirements). It is important to include information on why the service you want is not medically equivalent to ABA.

19 Note that participants in the CHIP program may not be entitled to this full range of services.

20 <http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf>

21 <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8287.pdf>

Keep in mind that other laws discussed in our section on adults over age 21, directly below this one, may also apply to you. In general, EPSDT is a much richer source of rights to health care access than the Affordable Care Act, Mental Health Parity laws, or state autism insurance mandates. But you can still also refer to these in your appeal. For example, if your state has a law requiring private health insurance companies to cover the type of service you are seeking, it will be harder for the state to argue that these services aren't "medically necessary" and therefore required to be covered under EPSDT.

If your appeal is still denied, please contact ASAN at info@autisticadvocacy.org. We may be able to refer you to someone who can help, which may either be able to provide direct representation or refer you to someone who can. State Protection and Advocacy organizations are federally funded groups to protect the rights of people with disabilities. You can find your state's Protection and Advocacy organization by visiting <http://www.ndrn.org/en/ndrn-member-agencies.html>.

Case Study

Child has insurance through MediCal. Parents want their child to receive a developmental intervention provided by a licensed clinical psychologist with a doctoral level degree. The psychologist specializes in treating autistic children using this approach. However, the private contractor administering MediCal's mental health program says that they will only approve licensed Board-Certified Behavioral Analysts (BCBAs) to bill for behavioral services provided to autistic children. BCBA licensure requires less coursework and training than a doctoral-level psychology degree, and the training for BCBA licensure focuses on Applied Behavior Analysis (ABA), not developmental based interventions like the one the family is seeking. When the parents point out that Medicaid law requires coverage of a range of behavioral health treatment and not just ABA, the agency responds that it is willing to cover a range of interventions, but only when they are provide by a BCBA or a person working with an ABA-focused agency.

Medicaid law requires that all medically necessary health services for children be covered. Even though MediCal's mental health program is being administered by a private company, that company is still covered by EPSDT.

The parents could potentially prove that they are legally entitled to coverage by showing that (1) developmental-based interventions are medically necessary for their child, and (2) refusing to cover care provided by anyone other than licensed BCBAs unreasonably restricts their ability to access developmental-based interventions.

Adults over Age 21 and Children Covered Through CHIP

Even if you are not longer covered by EPSDT, you can appeal denials of coverage using other laws that may apply to your plan: the Affordable Care Act and the Mental Health Parity Act. For a good overview of the appeals process, see the Kaiser Family Foundation's [guide to the Medicaid appeals process](#).²²

The **Affordable Care Act** requires that many publicly-funded plans – including CHIP and Alternate Benefit Programs for people who are enrolled in Medicaid through the Medicaid Expansion – to cover a set of Essential Health Benefits. These include mental health benefits, rehabilitative and habilitative services (such as occupational therapy or speech therapy), and prescription medications, among other things. Although there is not yet any official list of all the types of autism-related services that must be covered as Essential Health Benefits, these benefits at the very least need to be comparable to the standard list of benefits available through most plans.

In addition, new proposed regulations would extend the **Mental Health Parity Act** to CHIP plans, Medicaid Alternate Benefit Programs, and Medicaid managed care plans. Although it applies only to plans that cover mental health services, nearly all Medicaid plans covered by this law do cover mental health care.

The Mental Health Parity Act, as explained above, requires that health plans treat mental health care – including autism-related care – similarly to care for physical conditions. They cannot refuse to provide care for an ASD diagnosis that would be covered for other diagnoses, or place stricter limits on care for ASD diagnoses than they do for other diagnoses. They cannot require people to pay higher co-pays for services and cannot impose caps on mental health care (including care for ASD diagnoses) that are more restrictive than caps on physical health care. They also cannot impose a separate deductible for “mental health” care and cannot impose more restrictive medical necessity or in-network care requirements for mental or behavioral health care than they do for medical or surgical care. Many states also have their own mental health parity laws.

Although many people do not see autism-related interventions as “mental health” care, insurance companies often classify many autism-related services – especially ones like counseling, diagnosis, psychotherapy, and developmental or behavioral interventions – as part of their “mental health” benefit. As a result, many people have enforced their rights to ASD-related coverage under Mental Health Parity laws.

Mental Health Parity rules can become relevant to coverage for autism when plans will offer some types of benefits – like occupational therapy or physical therapy – to people with physical or brain injuries but not to people whose primary diagnosis is autism spectrum disorder. They may also become relevant when health plans try to impose more restrictions on out-of-network care for behavioral health interventions than they would impose for medical interventions, or deny interventions as “not medically necessary” without explanation.

In addition, some states have **laws requiring that health plans cover services related to autism diagnoses**. Many of these states’ laws only cover private health plans, not Medicaid plans. But in some states, Medicaid managed care plans or other Medicaid-funded plans may also be included. Check the [CMS State of the States on Services and Supports for People with ASD²³](#) to see whether your state has a law that applies to your plan. Often, these insurance mandates also include limits on the caps or co-pay requirements that insurance providers can impose. We discuss these later in this Guide.

We have heard from people and providers in these states who have been told by their insurance company that the company is only required to cover Applied Behavioral Analysis, or services provided by a licensed Board-Certified Behavioral Analyst. *Often, this is not actually true.* It is important to read your state’s autism insurance law, if one exists, and be prepared to refer to it when talking to your plan.

My health plan refuses to cover services from someone with a certain kind of professional license

This kind of coverage denial may be subject to some of the same laws that apply to denials of coverage for certain types of services. In our Medi-Cal example above, for example, the provider refused to cover behavioral services for autistic children unless they were provided by a Board-Certified Behavior Analyst – even if the service provider had another license with more stringent qualification requirements (such as a Ph.D. or Psy.D.). Because BCBAAs are trained specifically in Applied Behavior Analysis, this coverage limitation makes it more difficult to access other types of intervention modalities.

Medicaid law allows states to cover “preventive, and rehabilitative services, including any medical or remedial services” or “any other type of remedial care recognized under State law,” as long as it is recommended or provided by licensed professionals “within the scope of their practice under State law.”²⁴ These state laws include licensing laws defining the types of services that different kinds of professionals can provide. Licensed Occupational Therapists, Physical Therapists, Psychiatrists, Psychologists, and related licensed technicians who routinely care for autistic patients would all count as licensed professionals acting “within the scope” of their practice.

²³ <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf>

²⁴ 42 U.S.C. § 1396d(a)(6), (a)(13).

This means that anyone covered by EPSDT (see above, *Children and Young Adults Under 21, Enrolled in Medicaid*) should have access to medically necessary services from any professional who is licensed to provide that type of service. As a result, a clinical psychologist, clinical social worker, or psychiatrist with expertise in developmental disability should be eligible to offer services like developmental or behavioral interventions, counseling, or family coaching. Occupational therapists, physical therapists, or speech-language pathologists should also be eligible to provide developmental interventions within the scope of their expertise, without needing an additional certification or license such as a BCBA certification.

The process for your appeal will be much like the process for other kinds of appeals, discussed above. As discussed in our section above on services for children and young adults under 21 covered through Medicaid, make it clear whether or not you are covered by EPSDT, and include information – such as a doctor’s note and/or research studies – explaining why the service you want is medically necessary. Then, explain why the state’s restrictions on the type of provider who can provide these services makes it overly difficult to get the specific service you need. For a good overview of the appeals process, see the Kaiser Family Foundation’s [guide to the Medicaid appeals process](#).²⁵

For those not covered by EPSDT, an appeal may be more difficult. If you run into this problem, contact ASAN at info@autisticadvocacy.org or your state’s Protection and Advocacy organization by visiting <http://www.ndrn.org/en/ndrn-member-agencies.html>.

Example

A set of parents sued the state of Louisiana for refusing to approve psychologists as providers of services under Medicaid. As a result, the parents could not use their Medicaid coverage to access behavioral and mental health services delivered by licensed psychologists. Instead, the state told the parents that they should get these services through its Mental Health Rehabilitation program, community mental health clinics, public schools, or psychologists who worked in doctors’ offices. The court found that services from licensed psychologists were medically necessary for many autistic children, and therefore covered under EPSDT. It also found that the state’s restrictions on where parents could get services made it effectively impossible for parents to access services for their children. For example, the state’s mental health clinics would not treat anyone who was diagnosed with autism but not with any mental illness.

—*Chisholm v. Hood*, 133 F. Supp. 2d 894 (E.D. La. 2001).

Conclusion

Autism is a complex disability that affects sensory processing, communication, cognition, and many other domains in addition to behavior. When autistic individuals and their families are offered exclusively behavior-focused interventions, these other needs go unmet. Lack of access to the right services for a given individual can be tantamount to lack of access to any services at all.

It is vital that autistic individuals and their families are both aware of their right to a range of services and able to enforce that right. People who are enrolled in Medicaid are especially unlikely to be able to pay out-of-pocket for services that their Medicaid plans refuse to cover. At the same time, access to the right services can have lasting impact on individuals’ quality of life and ability to exercise greater independence and autonomy. ASAN is committed to ensuring that state Medicaid programs provide access to the full range of services that may be medically necessary for autistic children and adults.

25 <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8287.pdf>