Private Health Coverage for Autism Services: A Guide for Plan Administrators

Introduction

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.

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.

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.

ASAN
AUTISTIC SELF ADVOCACY NETWORK

The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which Autistic people enjoy the same access, rights, and opportunities as all other citizens. We work to empower Autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the Autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!

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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.[1]

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. For example, 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.[2]

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 (DIRTM) program, the PLAY Project, found significant positive results for this DIR program as compared to usual community services for autistic children.[3] 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 (SCERTSTM) model.[4] 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.[5]

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.[6] 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

1 *See* APA Presidential Task Force on Evidence-Based Practice, *Evidence-Based Practice in Psychology*, 61 American Psychologist 271, 274 (2006), *available at* http://www.apa.org/practice/resources/evidence/evidence-based-statement.pdf.

2 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.

3 *See* Richard Solomon, et al., *PLAY Project Home Consultation Intervention Program for Young Children with Autism Spectrum Disorders: A Randomized Controlled Trial*, 35 J. of Developmental & Behavioral Pediatrics 475 (2014).

4 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.

5 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.

6 Julie Young, et al., Impaq International, 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.

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.[7] These are interventions, including forms of ABA, that use incentives such as rewards, withholding of a desired thing or activity, or punishment to shape behavior. Respondents who had used consequence-based interventions 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 model 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.[8] 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.[9] In addition, the SCERTS (Social Communication/Emotional Regulation/Transactional Support) model focuses on developmentally grounded goals for social communication and emotional regulation.[10] The SCERTS model incorporates a variety of strategies based on available research literature about their effectiveness in reducing challenges and improving specific skills.

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.

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

8 *See* Richard Solomon, et al., *PLAY Project Home Consultation Intervention Program for Young Children with Autism Spectrum Disorders: A Randomized Controlled Trial*, 35 J. Developmental & Behavioral Pediatrics 475 (2014); Devin M. Casenhiser, et al., *Learning through interaction in children with autism: Preliminary data from asocial-communication-based intervention*, 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*, 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.

9 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.

10 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.

- **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.[11] 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.

Types of Private Insurance

Different kinds of private insurance plans are covered by different laws. It is important to know which kind of insurance plan you have in order to know what your rights are. Depending on which kind of insurance plan you have, you may have to follow a different process in order to get the coverage you need.

Employer-Sponsored Insurance[12]

Many people have health insurance through their employer, or through a family member's employer. These insurance plans fall into two general categories: **fully insured** or **self-funded.** A **fully insured plan** is one where the employer buys health insurance for its employees from an insurance company. A **self-funded plan**, also sometimes called an **ERISA plan**, is one where the employer puts aside money for its employees' health care into its own special account, and then uses that money to pay for employees' health care costs. In general, very large companies are very likely to have self-funded plans and smaller companies are more likely to have fully insured plans. Depending on which kind of plan you have, you may be covered by very different insurance laws.

It is not easy to tell which kind of plan you have because, even when employees have a "self-funded" plan, they may have an insurance card that looks like it's from a regular insurance company, like Blue Cross Blue Shield or Aetna. This is because many employers who choose "self-funded" plans will hire insurance companies to manage the health plans.

One way to know whether you have a fully insured or self-funded plan is to call your customer service number on your health insurance card, and to ask. Another way to find out is to talk to the employer's human resources department.

If you have trouble navigating telephone systems, there are some shortcuts that may help you find out whether your plan is self-funded. For example, if you got your employer-sponsored insurance through **your state health insurance marketplace**, or through **healthcare.gov**, it is a fully-insured plan, not a self-funded plan. Because many self-funding employers are very large, it is also sometimes possible to find out if your employer self-funds its health coverage plans by searching the internet for the employer's name and the words "self-funded health plan."

11 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.

12 This also includes coverage through a former employer that the employee is continuing to receive through COBRA.

The main difference between fully insured health insurance and self-funded health coverage is that most fully-insured plans are usually covered by **state insurance laws** (including some autism health insurance mandates), whereas all self-funded health plans are exempt from those laws. Self-funded health plans are covered by a special federal law called **ERISA. Both are covered by the Affordable Care Act and federal mental health parity laws**, with some exceptions: self-funded are exempt from certain parts of the Affordable Care Act (see table below), and self-funded state employee health plans can "opt out" of the federal mental health parity law.

What's the Difference?

Fully Insured Plans	Self-Funded (ERISA) Plans
Employer buys insurance from a health insurance company	Employer puts money into a "pot" that it uses to pay for health costs
Can cover both employees and their families	Can cover both employees and their families
Health insurance card looks like it's issued by a typical health insurance company	Health insurance card looks like it's issued by a typical health insurance company
Usually seen in companies with less than 200 employees	Usually seen in companies with more than 200 employees
Covered by state insurance laws, including some states' autism health insurance mandates	Covered by ERISA, and not by state autism health insurance mandates
Covered by Affordable Care Act	Covered by some parts of the Affordable Care Act
Covered by federal mental health parity law	Covered by mental health parity law, with the exception of state employee health plans that opt out of coverage.

Which Type Do I Have?

You can't necessarily tell from your insurance card. Here are some ways to tell:

1. **Think about how you enrolled.** If you went on Healthcare.gov or a state Marketplace site to enroll in your employer health plan, it is Fully Insured.
2. **Check with your HR Department or representative.** If you're at a large company, there is a good chance your plan is self-funded. Your HR representative will be able to find out.
3. **Call the beneficiary information number on the insurance card.**
4. If you want to find out without making a phone call:
    a. **Check online. If you search for your company's name and the terms "self-funded" or "self-insured," you might find this information on the company's web site.**
    b. **Think about how large your employer is.** If it has less than 200 employees, your plan is more likely to be fully insured. If it has less than 200 employees, it is likely to be self-funded. This is especially helpful if your employer is either very small (such a small store or restaurant), or very large (such as a chain restaurant, store, manufacturer, or bank).

If you are covered by a health plan for the military, federal employees, or state employees, you may be covered by some but not all of the above laws. For example, federal employee health plans are exempt from state insurance laws.[13] Some states also treat their state employee health plan differently than other private insurance plans in their state.

13 5 U.S.C. § 8902(m)(1).

State employee health plans may even have more coverage requirements than other insurance plans. On the other hand, state employee health plans can sometimes "opt out" of federal mental health parity requirements.

Individual Insurance

Many people buy insurance for themselves, instead of getting it through an employer. People who buy individual insurance often are self-employed or work for an employer that does not provide health insurance. You can buy individual insurance either on a state health insurance marketplace, through healthcare.gov, through a broker, or directly from the insurance provider.

All individual insurance plans are covered by state insurance laws. Some state insurance laws, such as autism coverage mandates, might apply only to group plans. Individual insurance plans are also covered by parts of the Affordable Care Act of 2010. See below for more details on the Affordable Care Act and state insurance law requirements for individual plans.

Not all health plans that you get through the statewide marketplaces are private health plans. For example, in many states, if you try to enroll through the marketplace while earning less than 138% of the federal poverty line, you will be enrolled in a Medicaid plan and not a private plan. Some of these states offer a different Medicaid plan through the statewide marketplace than they offer to many other Medicaid beneficiaries in the state. These are called Alternative Benefit Plans (ABPs). If you are low-income and enrolled through the statewide marketplace, double-check to see whether you are on a Medicaid plan. Keep in mind that some states contract with with private insurance companies to administer their Medicaid plans. If you are covered through Medicaid, check out our resource on autism coverage through Medicaid.[14]

What Are My Rights? Navigating Health Coverage Laws

You may have heard about some of the laws governing health coverage. For example, you may know that the Affordable Care Act (also known as "Obamacare") gives you some rights, like the right to remain on a parent's health plan until age 26 or the right to health coverage for "pre-existing conditions" (health problems that you had before you got the health plan you now have). You may have heard of "autism health coverage" laws in your state.

In practice, there are many laws that may come into play when trying to get coverage for autism interventions. As noted above, some laws only apply to some types of health insurance but not others.

Keep in mind that **nothing in this Guide is a guarantee that you will get coverage for the services you want**. Because it is impossible to anticipate every situation, this Guide can't predict how an insurance company will respond to your claim or whether you can succeed in an insurance appeal or lawsuit. It can only give you a sense of what laws you may be able to use to get coverage for services.

The Affordable Care Act

The Affordable Care Act of 2010 is the most far-reaching law applying to health plans. If you have a private health plan in the United States, it is almost certainly covered by the Affordable Care Act in some way. The Affordable Care Act is a very complex law. It affects nearly every aspect of health plans, from the cost of premiums to the types of services covered. This guide will only discuss the parts of the Affordable Care Act most likely to come into play when trying to get coverage for autism interventions.

14 Samantha Crane, Lydia Brown, *ASAN Resources on Coverage for Autism-Related Services*, Autistic Self Advocacy Network (Dec. 2015), http://autisticadvocacy.org/healthcoverage/.

Basic Protections

The Affordable Care Act includes certain basic protections that apply to almost all private health plans. Some of these protections were phased in until a few years after the Affordable Care Act became law. As of January 2016, these include:

- The right to stay on a parent's health plan until age 26;
- Health plans may not impose annual or lifetime cost limits for services that count as essential health benefits;[15]
- Health plans may not refuse to cover "pre-existing conditions" (health conditions that arose before the beneficiary enrolled in the plan);[16]
- Health plans must provide an opportunity to appeal denials of coverage and request external review of coverage decisions.[17] See page 18 for a guide to appealing denials of coverage under the Affordable Care Act.

These basic protections apply to all private health plans covered by the Affordable Care Act, with the exception of certain plans that have been "grandfathered." See page 12 to learn more about grandfathered plans.

Essential Health Benefits and Other Minimum Coverage Requirements

The Affordable Care Act requires certain kinds of health plans to cover "Essential Health Benefits" (EHB).[18] Plans that must cover EHB include:

- Individual health plans bought on the statewide marketplace; and
- "Small group" plans provided by an employer, but **not** "self-funded" plans.

Essential health benefits must include ten basic services:

1. Outpatient care (for example, doctors' visits)
2. Emergency room visits
3. Inpatient (i.e., hospital) care
4. Maternity care (including health care for people who are pregnant or have just given birth)
5. Mental health and substance use services, including behavioral health treatment, counseling, and psychotherapy
6. Prescription medications
7. Services to build or restore functioning, known as "habilitative" or "rehabilitative" therapies. These may include physical or occupational therapy or speech therapy.
8. Laboratory testing;
9. Preventive health care services that prevent illness, screen for illnesses or disabilities, and help manage long-term conditions;

15 Patient Protection and Affordable Care Act (PPACA), Pub. L. No. 111-148, § 1001 (Codified as amended at 42 U.S.C. §§18071-18122 (2010) (*Amended by* the Health Care and Education Reconciliation Act of 2010, Pub.L. 111–152, at § 10101, § 2301 (2010).

16 PPACA, Pub. L. No. 111-148 § 1201 sec. 2704, 42 U.S.C. § 300gg–3.

17 Center For Medicare and Medicaid Services, "How to appeal an insurance company decision," https://www.healthcare.gov/appeal-insurance-company-decision/ (Last accessed Jan. 2016); PPACA, Pub. L. No. 111-148 § 1001 Sec. 2719.

18 Some individual insurance plans can be bought outside the statewide marketplaces. These plans may not be required to cover all essential health benefits. *See* Louise Norris, Should you look Outside the ACA's Exchanges?: How your individual health care coverage differs—and how it doesn't—when you shop for insurance outside Obamacare's Marketplaces, *Healthinsurance.org* (Oct. 15, 2015), *available at* https://www.healthinsurance.org/obamacare/off-exchange-plans/ (last accessed Jan. 2016).

10. Pediatric services for children, which must include dental and vision care.[19]

In the context of autism-related interventions, the following essential health benefit categories may be particularly important:

- **Outpatient care** can include visits to a neurologist or pediatrician who can diagnose autism and make recommendations for interventions.
- **Mental health and substance abuse services** can include certain interventions for people with ASD diagnoses, such as counseling and certain kinds of behavioral health interventions.
- **Prescription medications** can include medications intended to treat conditions associated with ASD, such as seizures or anxiety.
- **Habilitative interventions** can include occupational therapy, speech therapy, physical therapy, and many other interventions (such as Floortime) aimed at building independent living skills.
- **Preventive health services and pediatric services** can include screening and diagnostic services for ASD. They may also include interventions aimed at preventing secondary health outcomes (for example, nutritionist services for an autistic person with food aversions that result in a very restricted diet).

Each state must issue regulations defining which services are "essential health benefits" in that state. These benefits, at the very least, must be comparable to the standard list of benefits available through most plans. For a comprehensive resource on essential health benefit regulations in each state, see Easter Seals' State Autism Profiles resource.[20]

A note on habilitative services

The definition of **habilitative services** is key issue that is still being resolved. **Habilitative services** are services to build a skill that the beneficiary never had before, whereas **rehabilitative services** are services to restore a person's functional abilities after an illness or injury. Often, the same service can be classified differently based on the underlying diagnosis. For example, a person who experienced a brain injury and lost the ability to speak fluently, and an autistic person who has never been able to speak fluently, may both need occupational or speech therapy in order to learn to communicate with an assistive communication device. This service would be considered a rehabilitative service for the person who experienced a brain injury, but would be considered a habilitative service for the autistic person.

Before the Affordable Care Act, many health plans covered rehabilitative services but not habilitative services. That means that, when states define habilitative services, they cannot simply look at the list of habilitative services that major health plans already covered. Instead, many states are looking to definitions set by insurance industry groups or by federal Medicaid laws.[21]

Other states have definitions of habilitative services that they have been using since before the Affordable Care Act. Maryland, for example, passed a law requiring coverage of habilitative services for children in 2000. In Maryland, habilitative services include physical therapy, occupational therapy, speech therapy, psychologist services, and behavioral health treatment. Insurers must cover up to 25 hours per week for children between 18 months and six years old, and must cover up to 10 hours per week for a person between the ages of six and 19 years old.[22]

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19 42 U.S.C. §§ 18021(a)(1)(B), 18022(b)(1); *see also* HealthCare.gov Blog, 10 health care benefits covered in the Health Insurance Marketplace, *Healthcare.gov* (Aug. 22, 2013), *available at* http://www.healthcare.gov/blog/10-health-care-benefits-covered-in-the-health-insurance-marketplace/ (last accessed Jan. 2016).

20 Easter Seals, State Autism Profiles, *available at* http://www.easterseals.com/explore-resources/living-with-autism/state-autism-profiles.html (last accessed Jan. 2016).

21 Patient Protection and Affordable Care Act; Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation, 78 Fed. Reg. 12834, 12844 (Feb. 25, 2013) (responses to public comments) (final regulations codified at 45 C.F.R. parts 147, 155, 156).

22 Pathfinders for Autism, Understanding Insurance: Autism Insurance in Maryland, *available at* http://www.pathfindersforautism.org/resources/understanding-insurance/autism-insurance-in-maryland (last accessed Jan. 2016).

Minimum Value: an alternative standard

Under the Affordable Care Act, "large group"[23] and self-funded employer health plans do not have to cover essential health benefits.[24] Neither do certain "grandfathered" health plans.[25] Instead, self-funded, large group, or grandfathered plans must generally provide "minimum value." This standard is less comprehensive, in terms of ensuring coverage for a wide range of services, than the "essential health benefits" standard. If a plan fails to provide "minimum value," you may be able to get a subsidy to help you enroll in a plan through the state marketplace instead.

Self-funded and "large group" plans are also required to cover some services, such as preventive health care services that have been rated "A" or "B" by the United States Preventive Services Task Force (USPSTF) or children's preventive services that are recommended by the Health Resources and Services Administration's (HRSA's) Bright Futures Project.[26] The Bright Futures Project recommendations include autism screening for children ages 18 to 24 months, developmental screenings for children up to age 3, and behavioral assessments for children up to 17 years old. As of January 1, 2016, there are no autism-related services that have gotten an A or B rating from the USPSTF.[27]

Cost limits on Essential Health Benefits

Even self-funded plans are not allowed to place certain kinds of limits on services that would count as "essential health benefits." For example, while the Affordable Care Act does not require a self-funded plan to cover habilitative services, if the plan does cover habilitative services it cannot place a maximum dollar limit on the habilitative services it does covey–either per year or over the course of a person's lifetime. Even "grandfathered" plans cannot impose dollar limits on essential health benefits.

Non-Discrimination Against Providers

Health plans covered by the Affordable Care Act—including self-funded plans, fully insured employer-sponsored plans, and individual insurance plans—are not allowed to discriminate against health care providers who are acting within the scope of their expertise and licensure.[28] For example, if a licensed clinical social worker is allowed by the state to provide certain kinds of behavioral health and counseling services, and has expertise in providing these services to autistic people, the health plan cannot refuse to cover those services simply because it would prefer that someone with a different kind of license provide those services.

This provision can be important. Some plans, for example, might insist that behavioral health treatment be provided only by board-certified behavior analysts (BCBAs) who are trained in Applied Behavioral Analysis (ABA)–even if the intervention to be provided is not ABA. This would not be allowed under the Affordable Care Act. Depending on the state's licensing requirements and the expertise of the person providing the intervention, some behavioral health interventions could instead be provided by a licensed psychologist, a licensed clinical social worker, an occupational therapist, a physical therapist, or a speech-language pathologist.

The non-discrimination requirement does not prevent health plans from covering only services by in-network providers. It also does not prevent health plans from paying providers differently based on their level of performance or quality of services provided.

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23 Large group plans are plans for employers with more than 50 "full-time equivalent" workers. An employer with 51 full-time employees would count as a "large group." An employer with 41 full-time employees and 20 employees who work 20 hours a week would also count as a "large group."

24 Internal Revenue Service, Group Health Plans that Fail to Cover In-Patient Hospitalization Services, Notice 2014-69 1, at 2 (2014), *available at* https://www.irs.gov/pub/irs-drop/n-14-69.pdf (last accessed Jan. 2016); Minimum Value of Eligible Employer Sponsored Plans and Other Rules Regarding the Health Insurance Premium Tax Credit, 78 Fed. Reg. 25909, 25910 (May 3, 2013) (codified at 26 C.F.R. pt.1), available at https://www.gpo.gov/fdsys/pkg/FR-2013-05-03/pdf/2013-10463.pdf (last accessed Jan. 2016).

25 See note on grandfathered plans on page 12.

26 Henry J. Kaiser Family Foundation, Preventative Services Covered by Private Health Plans Under the Affordable Care Act, *available at* http://benelect.com/http://kff.org/health-reform/fact-sheet/preventive-services-covered-by-private-health-plans/ (Last accessed Jan. 2016).

27 US Preventative Services Task Force, *available at* *http://www.uspreventiveservicestaskforce.org/BrowseRec/Search?s=autism* (last accessed Jan. 2016)

28 PPACA, Pub. L. No. 111-148, §§ 1201, 2706 (Codified as amended at 42 U.S.C. §§18071-18122 (2010).

Non-Discrimination Based on Disability

If you got your health plan through the statewide marketplace—either an individual plan or an employer-sponsored health plan that was brokered through the statewide marketplace—then you are also entitled to certain protections from discrimination based on disability.[29] Your health plan cannot, for example, refuse to cover any interventions for a certain diagnosis.

You are also protected from disability discrimination in health plans that are supported by federal funding in some way. For example, if your employer-based health plan is sponsored by a hospital, you are protected from disability discrimination in that plan because hospitals receive federal funding.

This does not mean, however, that the plan has to cover the same interventions for everyone regardless of their diagnosis. There are some cases where a health plan will decide, based on available research, that a particular intervention is evidence-based for some diagnoses but not others. They may also decide that certain interventions that are generally evidence-based, might be dangerous if provided to someone who has another complicating health condition.

The non-discrimination rule also protects against discrimination based on race, color, national origin, sex, and age. That means that if a plan covers some services for children and not adults, it must prove that this distinction is based on actual age-based differences in an intervention's risks or effectiveness.

Which Parts of the ACA Apply?

	Insurance through employer (not through the statewide Marketplaces)	Insurance through a statewide Marketplace (either individual or small-business)	Self-funded coverage through an employer
Right to stay on a parent's health plan until age 26	Yes (except grandfathered plans)	Yes	Yes (except grandfathered plans)
Coverage for pre-existing conditions	Yes (except grandfathered plans)	Yes	Yes (except grandfathered plans)
Process to appeal denials	Yes (except grandfathered plans)	Yes	Yes (except grandfathered plans)
Essential Health Benefits	Only if it is a "small group" plan. Large group plans must provide "minimum value" (see page 10)	Yes	No, but they must provide "minimum value" (see page 10)
No annual or lifetime cost limits for services that count as essential health benefits	Yes (except grandfathered plans)	Yes	Yes (except grandfathered plans)
Non-discrimination against providers	Yes	Yes	Yes
Non-discrimination based on disability	Only if the plan is supported by federal funding. Some discrimination based on disability by an employer-sponsored plan may violate the ADA.	Yes	Only if the plan is supported by federal funding. Some discrimination based on disability by a self-funded plan may violate the ADA.

29 42 U.S.C. § 18116(a).

Note on "grandfathered" plans

Some health plans that would otherwise be covered by the Affordable Care Act have been "grandfathered." This means that if they had terms that did not meet the Affordable Care Act requirements before the law was passed, they can keep *some* of those requirements for a certain number of years. Your health plan is required to notify you if it plans on using "grandfathered" terms.

Table on Grandfathered Plans

Plan Type	Job-based grandfathered plans (both fully-insured and self-funded)	Individual grandfathered plans	Ordinary, non-grandfathered health care plans
Plan Explanation	Health care plan created by your employer before March 23, 2010	Health care plan created as an individual rather than group plan before March 23, 2010	Health care plans created after March 23, 2010
Plan Enrollment	New people can still be enrolled in a job-based plan without it losing its "grandfathered" status Plan can stay "grandfathered" if it: **(1)** has covered at least one person since March 23rd, 2010, **(2)** notifies plan holders that they have a grandfathered plan, and **(3)** hasn't been changed in ways that substantially cut benefits or increase costs for plan holders	If new people are enrolled in an individual plan after March 23, 2010, the plan loses its "grandfathered" status. However, the plan can still cover people who were enrolled before that date. An insurance company can decide to stop offering the plan. If it does, people enrolled in the plan would need to get a new, non-grandfathered plan."	Includes anyone enrolled in the plan. Even if you enrolled before March 23, 2010, if your plan is not "grandfathered" you have ACA protections.
Plan Does Not Have to...	• Cover essential health benefits • Cover preventative care for free • Let you appeal coverage denials	• Cover essential health benefits • Cover preventative care for free • End yearly dollar limits on coverage • Cover pre-existing health conditions • Let you appeal coverage denials	No exemptions
Plan Still Must....	• End lifetime dollar limits on coverage • Cover adult children up to age 26 • End arbitrary cancellations of health care coverage • Provide a Summary of Benefits and Coverage	• End lifetime dollar limits on coverage • Cover adult children up to age 26 • End arbitrary cancellations of health care coverage • Provide a Summary of Benefits and Coverage	Must cover all things covered by ACA for the type of plan (see table comparing fully-insured plans and self-funded plans on page 11).

State Insurance Laws

If your health insurance is not a self-funded or federal employee health plan, it may be covered by state insurance laws. In many states, certain private health plans have an "autism insurance mandate," which means that they are legally required to cover specific services related to autism spectrum disorder such as diagnosis, counseling, speech therapy, occupational therapy, physical therapy, behavioral interventions, and other services.

These laws vary from state to state. Each state may have different standards for:

- Which health plans are covered, such as:
  - Small group employer-sponsored plans,
  - Large group employer-sponsored plans,
  - Individual plans, and/or
  - State employee health plans
- Which services are covered by the mandate, such as:
  - Screening;
  - Diagnosis;
  - Occupational, physical, and/or speech-language therapy;
  - Applied Behavioral Analysis (ABA);
  - "Behavioral Health Treatment" services other than ABA, such as developmental/relationship-based interventions, social communication interventions, parent training, etc.; and/or
  - Assistive or augmentative communication services, including AAC devices.

Example: Massachusetts

Massachusetts has a very robust autism insurance mandate. It covers all "treatment of autism spectrum disorders," which includes:

- Any services provided by licensed psychologists or psychiatrists;
- services provided by licensed or certified speech therapists, occupational therapists, physical therapists or social workers;
- "professional, counseling and guidance services and treatment programs . . . that are necessary to develop, maintain and restore, to the maximum extent practicable, the functioning of an individual"–this includes but is not limited to ABA; and
- prescribed medications, to the same extent that medication is covered for other diagnoses.[30]

These services cannot be subjected to annual or lifetime dollar limits. Health plans covered by this law also cannot impose absolute limits on the number of visits or sessions that will be covered.

To be covered by the mandate, services have to be prescribed or ordered by a licensed psychologist or doctor who thinks the services are medically necessary. Services that are provided through a student's school under an individualized education plan (IEP) do not have to be covered by a health plan.

30 Mass. Ann. Laws tit. XXII ch. 175 § 47AA (traditional individual and group insurance plans); tit. XXII ch. 176A §8DD (individual or group hospital service plans); tit. XXII ch. 176B § 4DD (individual or group medical service agreements); tit. XXII ch. 176G § 4V(HMOs); tit. IV ch. 32A § 25 (state employee health plans) (2010 Mass. Acts, Chap. 207; H.B. 4935 of 2010).

Example: California's Autism Treatment Law

California has an autism health insurance mandate that is intended to be comprehensive but includes some roadblocks to those seeking interventions other than ABA. California's autism coverage mandate covers only "behavioral health treatment," which must "utilize evidence-based practices, with demonstrated clinical efficacy in treating pervasive developmental disorder or autism."[31]

As discussed earlier in this guide, there are a variety of evidence-based interventions for autistic individuals. However, California's insurance mandate specifically lists Applied Behavioral Analysis (ABA) as a covered intervention, while failing to name any other specific intervention.[32] As a result, insurance companies may attempt to challenge interventions other than ABA as not "evidence-based" and therefore not mandated by the law.

Californians who are seeking coverage for autism-related interventions other than ABA must also be ready to show that the intervention:

- Is intended to "develop or restore" a person's functional abilities;
- Is prescribed by a doctor or part of a treatment plan created by a licensed psychologist;
- Is provide by a "qualified autism service provider," which could be a doctor, physical therapist, occupational therapist, psychologist, family therapist, counselor, speech-language pathologist, audiologist, or a licensed professional with certification from a board that focuses on autism interventions;
- Is delivered by a qualified "autism service provider," "autism service professional," or "autism service paraprofessional," which may include people who do not have a professional license or board certification but have received relevant training and are supervised by a licensed professional;
- Is delivered according to a detailed treatment plan that, among other things, "has measurable goals over a specific timeline that is developed and approved by the qualified autism service provider for the specific patient being treated."[33]

California also has a mental health parity law that may cover some services that do not count as "behavioral health treatment." The mental health parity law requires all insurance companies in California to cover "mental health" treatment, which includes treatment related to autism spectrum disorder, to the same extent that they cover treatment for physical conditions. This means, for example, that an insurance company that covers occupational therapy for people with physical injuries must also cover occupational therapy for autistic individuals. For more information on mental health parity laws, see page 15.

The mental health parity law has limits. For example, if an insurance company only covers an hour per week of occupational therapy for people with injuries, it only has to cover an hour per week of occupational therapy for an autistic beneficiary. This can mean a significantly lower level of care than required for therapies that are covered by California's autism coverage mandate. As a result, wherever possible, it is a good idea to try to show that the intervention is a "behavioral health treatment" as defined by the autism coverage law.

Example: Maryland

Some states, like Maryland, have mandates that cover not only autistic children but also children with other kinds of developmental disabilities such as Down Syndrome. Maryland's mandate covers a wide range of habilitative services, which can include not only behavioral health treatment but also occupational therapy, physical therapy, and speech-language interventions. Insurers must cover up to 25 hours per week for children between 18 months and six years old, and must cover up to 10 hours per week for a person between the ages of six and 19 years old.[34]

31 Cal. Insurance Code § 10144.51(c)(1)(C)(iii) (2011 Cal. Stats., Chap. 650).

32 *Id.* § 10144.51(c)(1).

33 *Id.*

34 Pathfinders for Autism, Understanding Insurance: Autism Insurance in Maryland, *available at* http://www.pathfindersforautism.org/resources/understanding-insurance/autism-insurance-in-maryland (last accessed Jan. 2016).

Like California, Maryland law in some ways treats ABA preferentially to other evidence-based behavioral interventions. Maryland regulations specifically prohibit health insurers from declaring ABA to be "experimental or investigational."[35] However, the law does not specifically prohibit insurers from declaring other interventions, like Floortime, to be experimental and denying coverage on those grounds. This means that beneficiaries may have to go through a lengthy process to establish that Floortime should be covered.

More About State Laws

For information about autism coverage laws in your specific state, check out the following state-by-state guides:

- Easter Seals, State Autism Profiles[36]
- American Speech Hearing Association, States with Specific Autism Mandates[37]
- Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD

Federal and State Mental Health Parity Laws

The Mental Health Parity and Addiction Equity Act of 2008 requires that most individual and group health plans, including self-funded plans, treat their coverage of mental health conditions the same as their coverage of physical health conditions.[38] They cannot require people to pay higher co-pays for services and cannot impose caps on mental health care that are 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. 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 autism-related coverage 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.

Mental health parity laws can be limited insofar as they only require coverage on the same terms as coverage for comparable treatments for medical conditions. As a result, if an insurer places limits on number of speech therapy visits per week for a person recovering from a brain injury, the mental health parity law does not prevent the insurer from placing similar limits on the number of speech therapy for autistic people. Other minimum coverage mandates, like the Essential Health Benefits (EHB) requirement or state autism coverage mandates, may require a higher level of care than the minimum required by mental health parity laws.

For example, in *Micheletti v. State Health Benefits Commission*, the New Jersey Superior Court found that New Jersey's State Health Benefits Commission could not deny coverage for speech and occupational therapy when those services were medically necessary for the treatment of autism spectrum disorder.[39]

35 MD. Code Regs. 31.10.39.03(G) (2016).

36 Easter Seals, State Autism Profiles, *available at* http://www.easterseals.com/explore-resources/living-with-autism/state-autism-profiles.html (Last accessed Jan. 2016)

37 American Speech-Language Hearing Association, State Insurance Mandates for Autism Spectrum Disorder: States with Specific Autism Mandates, *available at* http://www.asha.org/Advocacy/state/States-Specific-Autism-Mandates/ (Last accessed Jan. 2016)

38 Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008, Pub. L. No. 110-343 Div. C, Subtit. B, §§ 511-512 (2008), codified at 29 U.S.C. § 1185a (self-funded plans) and 42 U.S.C. § 300gg–5 (fully insured and individual plans) 26 U.S.C. § 9812; *see also* PPACA, Pub. L. No. 111-148 § 1311(j) (applying Mental Health Parity Act to qualified health plans offered on statewide exchanges).

39 *Micheletti v. State Health Benefits Comm'n*, 913 A. 2d 842 (N.J. Super. Ct. 2007).

In *Markiewicz v. State Health Benefits Commission*, the court reached a similar conclusion with respect to a child who had pervasive developmental disorder-not otherwise specified (PDD-NOS), a developmental disability that is part of the autism spectrum.[40]

Although the Mental Health Parity and Addiction Equity Act only applies to plans that offer mental health benefits, this will be true of the majority of plans because the Affordable Care Act requires that most health plans include mental health coverage.

	State insurance mandates	Affordable Care Act Essential Health Benefits (EHB) Requirement	Federal Mental Health Parity Law
Individual plans bought through statewide marketplaces	Often apply (depending on the state law)	Always applies	Always applies
Small group/ employer plans bought through statewide marketplaces	Often apply (depending on the state law)	Always applies	Doesn't apply, but you should be able to get the same protections through the EHB requirement
Large group employer plans	Often apply (depending on the state law)	Doesn't apply	Always applies
Self-funded employer plans	Don't apply	Doesn't apply	Usually applies (except for some state or local governmental health plans that opt out of coverage; these plans may be covered by state mental health parity laws)

ERISA

If you have a "self-funded" health plan, it will not be covered by state laws (such as state autism coverage mandates or state mental health parity laws). Instead, it is covered by a federal law called ERISA. It is also covered by parts of the Affordable Care Act and the federal Mental Health Parity law.

As noted above, it can be difficult to tell whether the insurance you get from your employer is "self-funded." Many employers who "self-fund" their insurance benefits hire another company—often a large insurance provider like Blue Cross Blue Shield or Aetna—to administer the plan. As a result, employees may have an insurance card with the name of a common insurance company on it, but their insurance is still not regulated by state insurance laws. If you work for a very large employer that provides health insurance, there is a good possibility that your employer self-funds your health coverage. The best way to know for sure is to call the customer service number on your insurance card and ask, or to contact your company's human resources department.

Even if your self-funded plan is not covered by state insurance mandate laws, you still have the right to appeal denials of coverage. "Self-funded" health plans are required to operate in a way that obeys the terms of the health plan and is

40 *Markiewicz v. State Health Benefits Com'n*, 915 A.2d 553 (N.J. Super. Ct. 2007).

not "arbitrary and capricious."[41] For example, the health plan cannot classify an intervention as "experimental" if there is actually compelling evidence that the intervention is effective.

Self-funded health plans also are required to process claims and appeals in a timely manner. If they decide that an intervention is not covered, they must provide a written explanation of the denial. This explanation should include a reference to the part of the plan contract that they think justifies the denial of coverage, as well as any facts about the beneficiary's health care that are relevant to the denial.

To challenge a health plan's decision under ERISA, you must follow a specific internal appeal procedure. If you do not succeed in your internal appeal, you may have the right to go to court to challenge the denial. For more information, see page 19.

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 private insurance 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.

Getting Coverage for the Right Interventions: Step by Step

The first step toward getting coverage for autism-related interventions is checking the terms of your health coverage plan and speaking with a plan representative. If the provider that you want to use takes your insurance, they may already be familiar with what is covered. If not, you may either check your plan documents or call the patient information line listed on the back of your insurance card. Many health plans also have text-based options such as live chat or web-based question submission forms.

Important questions to ask include:

- Does your plan generally cover this service?
- Does your health plan require you to use an in-network provider? If so, is there an in-network provider with availability that you feel comfortable using?
- Does the plan require pre-authorization for this service? What kinds of documentation do you need to submit in order to get pre-authorization?
- How many hours or visits per week does the plan cover? Is there a process to get approval to exceed those hours?
- *Note*: plans covered by the Affordable Care Act can't impose annual *cost* limits on most covered services. They can, however, sometimes limit the number of hours or visits they will cover.[42]
- Does the plan only cover the service when it is provided by people with a certain kind of license or certification? Does the provider you want to use have the required certification?
- 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?

41 *Potter v. Blue Cross Blue Shield*, 2013 U.S. Dist. LEXIS 119391 *1, 15 (E.D. Mich. Mar. 30, 2013); *Firestone Tire & Rubber Co. v. Bruch*, 489 U.S. 101 (1989).

42 Department of Health and Human Services, Lifetime and Annual Limits, *available at* http://www.hhs.gov/healthcare/about-the-law/benefit-limits/index.html (Last accessed Jan. 2016)

If you get an answer that is disheartening—for example, that the health plan does not cover the service or does not have the right kind of provider in-network—don't give up. You may have a right to appeal a coverage decision. You may also have rights under the Affordable Care Act, Mental Health Parity laws, state mandates, or ERISA. Which rights you have, and what process to use when enforcing those rights, may depend on what sort of health plan you have.

First Steps

No matter what kind of health plan you have, there are some basic steps that you should take if you plan to appeal a denial of coverage or limitation on coverage.

1. Gather Health Documentation.

Get copies of all medical records and other documents that you think may help your claim. These should include the results of psychological or neurological testing, treatment records, or educational records explaining the nature of your or your family member's disability. They should also include a prescription from a doctor or a letter from a licensed psychologist describing the intervention that you are seeking and explaining why you or your family member would benefit from it.

If you are seeking coverage for the testing necessary to get a diagnosis in the first place, try to gather documentation explaining why testing is necessary. For example, you may gather school records or a note from a doctor explaining why you or your family member needs to be tested for ASD.

You generally have a right to your medical and educational records. You also have a right to access records of someone other than you if you are that person's legal guardian (for example, your child, foster child, or other person for whom you are authorized to make medical decisions), or if there is a valid legal document naming you as their health care decisionmaker.[43]

2. Request Pre-Authorization or Reimbursement

If your health plan requires you to get pre-authorization for the service, or requires you to get a referral from your primary care provider, then you should follow this process first. You may also want to get pre-authorization for any service that you know you cannot afford to pay for if it is not covered. Otherwise, you may have to pay for the whole cost of the service while you appeal a denial of coverage from the insurance company. You also will have no guarantee that your appeal will be successful, even if it seems obvious that it should be.

You need a denial of coverage in writing in order to file an appeal. This means that, even if your health plan has told you over the phone or otherwise that it will not give you pre-authorization, it is very important to submit a written pre-authorization request anyway and get the denial **in writing**. Otherwise, you may not be able to file an appeal.

When submitting the pre-authorization request, you should include any documentation that could support your request–including the results of diagnostic tests, a doctor's prescription for the intervention, or a note from a psychologist explaining why the intervention is necessary and expected to be effective.

If you can afford to pay for the services yourself and can accept the risk that you will not be paid back by the insurance company, *and* if your insurance company doesn't require pre-authorization for the service, you can simply start getting the service and request reimbursement by the coverage provider afterwards. Many service providers will give you bills with clear instructions on how to submit them for reimbursement. If you pay for services out of pocket, you must submit a claim for reimbursement and be denied before you can file an appeal. It is not enough to simply be told over the phone that the coverage provider will not pay the claim.

43 For more information, *see* http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/consumer_rights.pdf.

Denial Notifications

If your health plan denies your claim or request for coverage *and* is covered by the ACA or is a grandfathered self-insured plan, it must tell you about the denial within a certain amount of time. That amount of time depends on what kind of claim you're filing and for what reason. It must notify you:

- Within **15 days** if you're seeking pre-authorization or payment for a service before it has been delivered.
- Within **30 days** if you've already received a service and you're looking to get your health plan to pay for it.
- Within **72 hours** for urgent cases in which you might get hurt, sick, or lose your ability to function normally if you do not receive the service immediately. Depending on your needs, the health plan may have to make a decision even faster.

Internal and External Appeals

If coverage provider denies your claim or request for pre-authorizaton, it has to explain the reasons for its decision within a certain amount of time in a written **notification**.

You can then file an "internal" appeal, which requires the health insurance company to re-examine its decision to deny your claim. Health plans that are covered by the Affordable Care Act—including self-funded employer-sponsored plans—are required to provide you with an opportunity to appeal coverage decisions unless they are "grandfathered" (see page 12). Even if the plan is "grandfathered," you may still be entitled to some appeal rights either under your state's insurance laws or—if the plan is a self-funded employer plan—through ERISA.

You may be required to go through the internal appeals process before you can file a lawsuit against the health plan. For example, if you have a self-funded plan, you have to go through the internal appeals process before going to court. You do not, however, also have to file an external appeal before going to court.[44]

If your plan is covered by the Affordable Care Act and not "grandfathered," you also have the right to file for an external review of a claims decision. This allows you to get a claims decision reviewed by someone other than the health plan itself. You can ask for an external review **within 60 days** of any final decision made by the insurance company (like the end of the internal appeal period). This is where you get an independent third party to review the claim, and the insurance company then can't decide for itself whether it wants to pay you or not. The independent third party's decision becomes the final decision in the case.

What kinds of denials and issues can you appeal?

You can appeal a wide variety of different types of denials of coverage, including cases where the health plan claims that:

- The benefit isn't offered under your health plan, or is an "educational" service and not a health service;
- The benefit is generally covered, but your health plan believes the requested service or treatment is "not medically necessary";
- If the insurer believes that the service or treatment is an "experimental" or "investigative" treatment rather than one backed up by clinical evidence.

Internal Appeals

All plans covered by the ACA, as well as "grandfathered" self-funded employer plans, must allow you to file internal appeals of claims denials. Once you have a denial notification, you must file your appeal **within 180 days** (around six months) of receiving any notice that your claim was denied (even if you did not receive a full explanation of why until later). Some health plans may allow a longer time for appeals.

44 *Potter v. Blue Cross Blue Shield*, 2013 U.S. Dist. LEXIS 119391 *1, 15 (E.D. Mich. Mar. 30, 2013).

To file the appeal, you have to fill out the forms that your health plan provides for the purposes of filing that appeal. *(Note: the health plan might just have these forms listed online rather than actually send them to you. You might have to go looking for them on the health plan's website.)* You may be able to attach a letter to more clearly describe why you think the service should be covered.

If your health plan doesn't require any forms like this, write your health plan a letter with your name, claim number, and the ID number on your coverage card. The letter must describe the decision you're asking them to reconsider and explains why you think the service should be covered. An example of what one of these letters would look like can be found on page 26.

You might also have to send in any extra documentation (such as a letter from your doctor) that goes with the appeal or that you want the insurance agency to consider. Sometimes, you can get the Consumer Assistance Program[45] in your state to file an appeal for you.

Keep a copy of any form, letter, or documentation that you send your insurer, including the date it was sent. Sometimes it can help to send your appeal through certified mail or some other service that gives you proof of when you mailed it.

Your health plan must resolve your internal appeal within a certain amount of time. Here are the deadlines for completion of an appeal:

- It must decide your internal appeal within **30 days** if your appeal is for a service you haven't received yet.
- It must decide your internal appeal within **60 days** if your appeal is for a service you've already received.
- If your appeal is for urgently needed services, the plan must decide your appeal appeal within **72 hours**, or less if necessary.

At the end of the internal appeals process, your health plan must provide you with a written decision. If the plan is covered by the ACA, it must tell you how to ask for an external review.

External Review

If your internal review is not successful, and your health plan is covered by the ACA, you can file for an external review anytime within 60 days of the final decision in the internal appeals process, unless the plan specifically gives you a later deadline.

Emergency Situations

In most situations, you have to file an internal appeal before you can file an external appeal. But if the situation is urgent—that is, the length of the normal appeals process could seriously jeopardize your functioning or health—you can also file an external appeal while you are still waiting for a decision on your internal appeal. In urgent situations, the external reviewer must make a final decision as quickly as your medical condition requires, but no later than four business days after your request is received. This final decision can be delivered verbally, but must be followed by a written notice **within 48 hours.**

The External Review Process

The process for external review depends on what state you live in. Some states have a specific external review process that they use for reviewing Affordable Care Act claim denials. In other states, the federal Department of Health Care and Human Services (HHS) reviews appeals. Some health plans contract with an independent external review agency in places of the state or federal process.

To find out what process your plan uses and how it works, you should check the Explanation of Benefits (EoB) or the final denial of coverage by your health plan. Both of these documents must explain how to file for an external review (including any required deadlines), or at least how you can contact the organization that will file your claim for you.

45 Center for Medicare and Medicaid Services, Consumer Assistance Program, *available at* https://www.cms.gov/CCIIO/Resources/Consumer-Assistance-Grants/ (last accessed Jan. 2016)

Do this as soon as possible after getting notice that your appeal was denied, in order to make sure you do not miss the deadline for external review.

You have some special rights during an external review of an ACA claim denial. Whether it's the state, the federal government, or an independent reviewer receiving your request for external review, you are entitled to certain consumer protections and standards. Reviewers must follow standards that, at a minimum, match or are substantially similar to the ones outlined in the Uniform Health Carrier External Review Model Act. This is not a law in and of itself, but a set of standards was developed by the National Association of Insurance Commissioners (NAIC).[46] These standards are very detailed and include specific criteria for deciding whether different services should be covered. Some states or external reviewers may follow standards that go beyond the NAIC standards.

How long does it take the reviewer to get a final decision back to you?

It differs depending on what state you're in, but they *must* get back to you no later than 60 days after you filed a request.

Filing Different Types of Appeals

Whether you're filing an internal appeal or for external review, the documentation you should send in may depend on the reason that your health plan gave for denying your claim. Here are a few examples.

My health plan says it covers services related to an ASD diagnosis, but denied coverage because the service I wanted was "experimental," "educational," or "not medically necessary."

Many health plans will 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 can appeal this type of decision either through an internal appeal or an external appeal. In your appeal, you should include as much documentation as you can showing that the intervention is actually medically necessary and evidence-based. If at all possible, this should include:

- A letter from your 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; and
- Medical records, such as the results of diagnostic testing and treatment or progress notes, that show the need for the services, what those services involve, and the impact the services can have on your life.

You may also attach guidance from the Centers for Medicare and Medicaid Services (CMS), which explains that a variety of autism-related interventions can be "medically necessary" and evidence-based. That guidance is available here.[47]

Information to add when the health plan says the intervention is evidence-based:

Refer to our "Evidence Base" section on page 3 for resources on proving your intervention is evidence-based. Your provider also might be able to point to research that supports the intervention. You may also want to attach copies of studies showing the evidence base for the intervention.

You should also try and get information about how your insurer decided that the intervention is not "evidence-based." Is the insurer basing this determination on non-arbitrary, clear standards that it lays out in its descriptions of what services it covers? Or is it simply using a list of "evidence-based" interventions created by some other group?

46 Uniform Health Carrier External Review Model Act (Nat'l Ass'n of Ins. Comm'rs 2010).

47 CMS Informational Bulletin, "Clarification of Medicaid Coverage of Services to Children with Autism," (July 7, 2014) *available at:* https://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf

If you feel that the plan is using arbitrary criteria to decide what is "evidence-based," may may want to explain why in your appeal or external review request.

If you refer to studies in your appeal, you should include what is called a "citation" for each study when possible. The citation includes the names of the authors, the name of the study, the journal where the study was published, and the year it was published. Often, it helps to use the following format:

> Solomon R, Van Egeren LA, Mahoney G, Quon Huber MS, Zimmerman P. PLAY Project Home Consultation Intervention Program for Young Children With Autism Spectrum Disorders: A Randomized Controlled Trial. Journal of Developmental and Behavioral Pediatrics. 2014;35(8):475-485. doi:10.1097/DBP.0000000000000096.

Information to add when the plan says the intervention is not medically necessary and appropriate for the beneficiary:

Sometimes a health plan will agree that an intervention is evidence-based for some people, but will argue that it is not medically necessary or evidence-based for the particular beneficiary. The health plan might argue that the beneficiary is not "disabled enough" and doesn't need the intervention, or 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. It can also help to have a letter from the provider that explicitly ties the beneficiary's needs to evidence that the intervention is effective for those needs.

Information to add when the plan said the intervention is "educational" and not "medical":

Some health plans will argue that certain kinds of services, such as behavioral health, occupational therapy, or speech therapy services, are not covered because they are available through the school system. You can argue that these services are not solely "educational" by explaining why they are also medically necessary. For example, you may show that you are seeking occupational therapy to improve daily living skills that are used outside of school.

If the beneficiary has an Individualized Education Plan (IEP), you may want to include a copy of it in your appeal. You should specifically explain that the services provided through the IEP are different from the services for which you want coverage. For example, a student may receive occupational therapy services in school that are focused entirely on writing skills. It also helps to ask the pediatrician and/or developmental psychologist who recommended the services you're seeking to write a note saying that they have reviewed the student's IEP and explaining how the services they are recommending are different from the ones provided through the IEP.

My health plan says that this category of service isn't covered by the plan.

Some health plans will argue that certain kinds of services aren't covered by the plan regardless of whether they are "evidence-based" or medically necessary. For example, the plan may say that it simply does not cover occupational therapy except for people recovering from injuries or illnesses. Or it may say that the only autism-related service it covers it Applied Behavioral Analysis.

In these situations, you may be able to appeal that decision based on **(1)** a state insurance mandate that applies to your plan, **(2)** the Essential Health Benefits requirements of the Affordable Care Act (if they apply to your plan), or **(3)** federal mental health parity laws. To see which laws cover which plans, see the table on page 16.

Plans covered by state "autism health insurance" mandates

In many states, most private health insurance companies (except self-funded plans) are required to cover medically necessary services related to an autism spectrum diagnosis, including diagnosis, counseling, speech therapy, occupational therapy, physical therapy, behavioral interventions, and other services. To see if a state mandate covers your plan, see "More about state laws" on page 15. To learn more about state mandates, see our section on State Insurance Laws on page 13.

We have heard from people and providers in some states who have been told by their health plan that the "autism mandate" only requires coverage for 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 insurer.

If your plan is covered by a mandate and you think the service you want is covered by that mandate, you can raise that concern in your internal or external appeal. If your appeals process is unsuccessful, you might even have some other options–such as filing a lawsuit.

Plans covered by the EHB requirement

If your plan is covered by the Essential Health Benefits requirement, you may be able to argue that the type of service you want must be covered. Many behavioral health services can qualify either as "mental health services" or "habilitation services." Screening services can qualify as preventive health or pediatric services. See page 10 for more details. If you think that the service you're requesting should be covered as an essential health benefit, you can raise that issue in your appeal.

Plans covered by mental health parity law

If your plan is covered by mental health parity laws, check to see if the service you want is the same, or similar, to a service that the health plan already offers for people with physical health concerns. For example, if you know that your health plan covers occupational therapy for people who have been injured, then you may be able to argue that it should cover occupational therapy for people with ASD. Be sure to make a note in your appeal of any comparable services that are covered by your plan for people with physical disabilities, injuries or illnesses, but are not covered for people with ASD diagnoses.

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

Health plans covered by the Affordable Care Act—including self-funded plans, fully insured employer-sponsored plans, and individual insurance plans—are not allowed to discriminate against health care providers who are acting within the scope of their expertise and licensure.[48] See page 10. This means, for example, that a health plan covered by the ACA is not allowed to cover behavioral health treatment provided by BCBAs, but not behavioral health treatment provided by licensed psychologists who are trained or otherwise qualified to provide that treatment.

This only works for people who are offering services within the "scope" of their license and their practice. For example:

- Most states allow mental health therapy services to be provided by a licensed psychologist, a psychiatrist with a license to practice medicine, or a licensed clinical social worker.
- A dermatologist cannot provide mental health therapy, even though both dermatologists and psychiatrists are both licensed to practice medicine. This is because mental health therapy is not within the dermatologist's scope of practice.
- A licensed massage therapist also cannot provide mental health therapy, because mental health services are not within the "scope" of a massage therapy license.
- A health plan may not cover mental health services for children unless they are provided by a person who normally treats children (or both children and adults). Treating children may be within the scope of the person's license, but not within the scope of that person's practice.

48 Patient Protection and Affordable Care Act (PPACA), Pub. L. No. 111-148, § 1201 (2010).

If your claim or request for pre-authorization was denied because the provider you want had the "wrong" kind of license, you can raise this issue in your internal or external appeal. If you do this, you should specifically refer to the "provider non-discrimination" portions of the Affordable Care Act. You should also include information explaining:

- What type of license or certification your chosen provider has;
- What kinds of services your provider typically offers, and for what groups of people;
- How the services services you are requesting fit within the scope of the provider's license or certification; and
- Whether the provider has any other experience or training that is relevant to the service you want (e.g., whether the provider specializes in providing services to people with ASD diagnoses, or has special certifications for specific kinds of interventions).

I want to use an out-of-network provider.

Some health plans have a special process for approving services from an out-of-network provider. Laws may also require the plan to let you go out-of-network in some situations, even if there are providers available in-network that you could use. For example, the Mental Health Parity Act requires that health plans offer the same opportunities to go out-of-network for mental health or developmental disability services as they offer for physical health services. See page 15 above. If your health plan covers out-of-network providers for physical health services, it must cover out-of-network providers for behavioral health services in the same situations.

The Affordable Care Act and certain state laws may also give you the right to use an out-of-network provider in situations where there are no qualified in-network providers who are taking new patients. The Affordable Care Act requires that all "Qualified Health Plans"—including individual plans purchased through the Exchange and small-group employer plans—to include an "adequate network of primary care providers, specialists, and other ancillary health care providers." Some states also have their own network adequacy requirements.

If you want to challenge a claim that was denied because your provider was not in network, you can raise this issue in your internal or external appeal. If you want to argue that the out-of-network provider should have been covered under the terms of plan or mental health parity laws, you should include a description of your health plan's terms–both for the service you want and for similar physical health services. If you want to argue that there are no qualified in-network providers available to you, you should include:

- The list of in-network providers that your health plan gave you; and
- An explanation as to why each provider in that list was unavailable or not qualified. This explanation can include:
    - A description of the in-network providers' expertise or qualifications, showing that they lacked the expertise to provide the service;
    - A description of the providers' locations, showing that they were very far away;
    - A description of your attempts to contact the providers, showing that they are either out of business, unresponsive, unwilling to provide the service you need, or not accepting new patients; and/or
    - An explanation of other access needs that you have (e.g., a physically accessible office, Spanish/ASL interpreter, or other need), and evidence that the in-network providers could not meet those needs.

After the Appeal

If your appeal is denied, you may have legal options available to you. For example,

- If you have a private health insurance plan that is covered by state law (i.e., coverage through your employer that is not a self-funded employer plan, or coverage through the statewide health insurance exchanges), you may be able to file an administrative complaint with the state agency that regulates insurance.
- If you have health insurance through Medicaid, you may be able to file an administrative appeal with the state Medicaid agency or even with the Centers for Medicare and Medicaid Services.
- If you've exhausted your appeal rights within your plan, you may be able to file a lawsuit in court asking the health plan to cover your claim. Some lawyers offer free services to low-income clients. Others may offer to only send you a bill after you've gotten a good resolution for your claim.

> ***Example:***
>
> In California, a group of families filed a lawsuit in California court, challenging the Kaiser Health Plan's refusal to cover behavioral health services and speech therapy for autistic children. Kaiser had told families that these interventions were "behavioral" and not medical, and should be provided through state-run regional centers for developmental disabilities instead of through health insurance. The California Court of Appeals found that the families had potentially valid claims under the terms of the health insurance contract and under California's Mental Health Parity Act. Kaiser eventually settled the lawsuit, agreeing to pay many of its policyholders who had been denied speech therapy or behavioral interventions and to stop categorically denying these sorts of claims in the future.

If you have questions about where to go for help, feel free to contact ASAN and/or your local Protection and Advocacy organization, which you can find the contact information for here. ASAN is looking into this issue and may be able to refer you to a lawyer in your area willing to give you advice.

Sample Appeal Letter

Here is a basic outline of the type of letter you would use to request an internal appeal, if your insurer has no specific paperwork that you must file for an internal appeal. Be as specific and concise as possible. Wherever you can, include references to documents and studies, and attach those documents to the end of your letter.

Use write short, factual sentences. Do not include emotional language, threats, or personal attacks:

Good example	Bad example
I need occupational therapy in order to stay independent. My occupational therapists help me to find ways to perform essential activities of daily living, such as bathing and cooking, without becoming overwhelmed. Without an occupational therapist, I have gone for weeks without cooking a meal by myself. It was affecting my health. My occupational therapy is absolutely medically necessary.	How could you refuse to cover my occupational therapy??? Do you want me to starve? If you don't cover my occupational therapy I WILL SUE! I have no idea how you can sleep at night knowing that you are getting rich by denying people the services they need! If I die because you denied this claim I will haunt you. >:(

[Your Name]
[Your Address]

[Date]

[Address of the Health Plan's Appeal Department]

Re: **[Name of Beneficiary]**, Member # **[Member ID Number]**
Group # **[Group Number]**
Claim # **[Claim Number]**

To Whom It May Concern:

I am writing to request a review of your denial of my claim for **[service]** by **[name of provider].** I received your denial letter on **[date].** The reason for denial was listed as **[reason listed for denial]**.

I have reviewed my policy and believe that **[name of health care plan]** is required to cover this service**. [Service]** is an evidence-based intervention for people with autism spectrum disorder. It is medically necessary in order to **[describe the benefit to be provided, such as improving functioning or preventing injury or illness].**

[Beneficiary]'s **[type of treatment provider]**, **[name],** has determined that this intervention is necessary due to **[describe specific needs of the beneficiary that will be addressed by the service].** The intervention will address these needs by **[describe what is involved in the intervention].**

[Add more detailed information about the situation. See pages 20-23 above for examples of information to include in different situations. Be thorough. If you are including documents, include a list of what you are sending here.]

If you need additional information, I can be reached at **[telephone number and/or e-mail address.]** I look forward to receiving your response as soon as possible.

Sincerely,

[Signature]
[Typed Name]

Conclusion

Getting coverage for the services you need can be a difficult process, but it can help to know your rights and be persistent. All autistic people should have access to high-quality coverage that meets their individual needs.

If you believe your legal rights have been violated, please consider getting advice from a lawyer. This resource alone is not meant to give you advice on whether to file a lawsuit or whether you would win a lawsuit. If you need help finding a lawyer in your area, contact your state Protection and Advocacy organization (http://www.ndrn.org/en/ndrn-member-agencies.html) or email Samantha Crane at scrane@autisticadvocacy.org.