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

Introduction

Autism Spectrum Disorder (ASD) is a developmental disability that can affect a wide range of domains, including communication, sensory and motor integration, language development, and emotional regulation. Interventions for ASD may involve a variety of professionals, including psychiatrists, neurologists, psychologists, occupational therapists, speech therapists, physical therapists, and a range of paraprofessionals and technicians. Appropriate interventions have been linked to improvements in skills, independence, communication, and emotional well-being.

Federal and state laws, such as the Affordable Care Act, ERISA, mental health parity legislation, and state autism coverage mandates, may require plans to offer autism benefits. Ensuring that health plans comply with all of these laws may be a difficult task. Health plan administrators may also struggle to identify reasonable quality controls and medical necessity criteria for services that are mandated to be covered under state or federal laws. Such quality controls are necessary not only in order to ensure cost-effectiveness but also in order to avoid delivery of inappropriate interventions. Such inappropriate interventions may cause either delays in developing important skills or – in the case of painful "aversive" behavioral interventions or dangerous and unproven "cures" such as chelation or use of other toxic chemicals – may cause lasting harm.

This guide is intended to provide guidance to private health plan administrators on developing an effective and compliant autism coverage plan. It includes an overview of effective and emerging interventions, explanation of applicable federal laws governing private health plan coverage, and considerations for developing meaningful coverage standards and quality controls. We hope that this resource also increases awareness of the continued need for policy advocacy across a range of intervention options.

The Evidence Base

What constitutes "evidence-based" practice for autism-related interventions?

Evidence-based practices in medicine and psychology aim to promote the most effective interventions and approaches in accordance with empirical research and sound clinical judgment. 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 health outcomes, 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 (ABA) 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]

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 (last accessed Jan. 9, 2017).

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/Docs/InterventionReports/wwc_lovaas_082410.pdf (last accessed Jan. 9, 2017).

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.[3] 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.

Evidence base for developmental approaches

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.[4] 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.[5] In addition, the SCERTS (Social Communication/Emotional Regulation/Transactional Support) model focuses on developmentally grounded goals for social communication and emotional regulation.[6] The SCERTS model incorporates a variety of strategies based on available research literature about their effectiveness in reducing challenges and improving specific skills.

Although behavioral approaches to autism – such as Applied Behavioral Analysis – frequently dominate discussions of autism coverage, the evidence base for these approaches often is focused on short-term cognitive outcomes – such as eye contact – that are not closely connected with overall health or quality of life. **By contrast, developmental approaches tend to enjoy a more robust evidence base with respect to outcomes such as communication skills and functional skills.**

For example, a National Institute for Mental Health (NIMH)-funded randomized controlled trial of participants in the PLAY Project, a Developmental, Individual-differences, and Relationship-based (DIR™) program, found significant positive results for the approach as compared to usual community services for autistic children.[7] Children showed improvement in engagement, initiation, and functional development.

Another study found similarly promising results for the Early Social Interaction (ESI) therapy based on the Social Communication, Emotional Regulation, and Transactional Support (SCERTS™) model, in areas of communication,

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3 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://journals.sagepub.com/doi/pdf/10.1177/10983007050070020101 (last accessed Jan. 9, 2017).

4 *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 (last accessed Jan. 9, 2017); 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 (last accessed Jan. 9, 2017); 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 (last accessed Jan. 9, 2017).

5 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 (last accessed Jan. 9, 2017).

6 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 (last accessed Jan. 9, 2017).

7 *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).

daily living, and social skills for autistic children.[8] 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.[9]

Further discussion of the research on developmental approaches can be found in a 2010 report on a literature review by the research firm Impaq. The authors of that report, which had been commissioned by the Centers for Medicare & Medicaid Services (CMS), sought to identify evidence-based practices, emerging evidence-based practices, and unestablished practices.[10] They 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 by targeted skill and by target age group (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.

Evidence base for other promising approaches

The 2010 Impaq literature review also identified 15 discrete categories of evidence-based interventions and services for children, of which at least 11 do not include or rely on ABA. Those included:

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

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

8 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 (last accessed Jan. 9, 2017).

9 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 (last accessed Jan. 9, 2017).

10 Julie Young, et al., Impaq International, Autism Spectrum Disorders: Final Report on Environmental Scan (2010), *available at* http://www.impaqint.com/sites/default/files/files/Autism_Spectrum_Disorders.pdf (last accessed Jan. 9, 2017).

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 (verbal, gestural, or physical assistance from adult or peer), and self-management (self-regulation of own behavior) as evidence-based.

Laws Governing Autism-Related Health Coverage

Private health coverage plans must comply with a variety of laws regarding the scope of health benefits. Depending on the type, size, and location of your plan, these laws may include the Affordable Care Act, ERISA, federal or state mental health parity legislation, and state autism insurance mandates. Health plan administrators may also find themselves struggling to determine the scope of coverage for services that also may be provided by schools pursuant to the Individuals with Disabilities Education Act (IDEA).

The Affordable Care Act

The Affordable Care Act of 2010 is a far-reaching law applying to health plans. This guide will only discuss the parts of the Affordable Care Act most likely to come into play when determining coverage for autism interventions.

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:

- Patients have 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;[12]
- Health plans may not refuse to cover "pre-existing conditions" (health conditions that arose before the beneficiary enrolled in the plan);[13]
- Health plans must provide an opportunity to appeal denials of coverage and request external review of coverage decisions.[14]

These basic protections apply to all private health plans covered by the Affordable Care Act, with some exceptions for certain plans that have been "grandfathered." See page 8 on 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). 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.

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 (last accessed Jan. 9, 2017).

12 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)).

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

14 PPACA, Pub. L. No. 111-148 § 1001 Sec. 2719.

Essential health benefits must include ten basic services:

- Outpatient care (for example, doctors' visits);
- Emergency room visits;
- Inpatient (i.e., hospital) care;
- Maternity care (including health care for people who are pregnant or have just given birth);
- Mental health and substance use services, including behavioral health treatment, counseling, and psychotherapy;
- Prescription medications ;
- Habilitation and Rehabilitation services to build or restore functioning;
- Laboratory testing;
- Preventive health care services that prevent illness, screen for illnesses or disabilities, and help manage long-term conditions; and
- Pediatric services for children, which must include dental and vision care.[15]

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

- **Outpatient care,** such as visits to a neurologist or pediatrician who can diagnose autism and make recommendations for interventions;
- **Mental health and substance abuse services**, including counseling and certain kinds of behavioral health interventions;
- **Prescription medications,** including those intended to treat conditions associated with ASD, such as seizures or anxiety;
- **Habilitative interventions,** such as occupational therapy, speech therapy, physical therapy, and many other interventions (such as Floortime) aimed at building independent living skills; and
- **Preventive health services and pediatric services,** including screening and diagnostic services for ASD and 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.[16]

A note on habilitative services

The definition of **habilitative services** is a 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

15 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. 9, 2017).

16 Easter Seals, State Autism Profiles, *available at* http://www.easterseals.com/explore-resources/living-with-autism/state-autism-profiles.html (last accessed Jan. 9, 2017).

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.

Traditionally, many private health plans have covered rehabilitative services but have offered limited or no habilitative services coverage. Although the Affordable Care Act requires covered plans to begin covering habilitative services in a manner comparable to their coverage of rehabilitative services, many plans have not yet come into compliance with this requirement.[17]

One exception is insurance plans in states that have pre-existing habilitative services mandates. 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.[18]

Minimum Value: an alternative standard

Under the Affordable Care Act, large group[19] and self-funded[20] employer health plans do not have to cover essential health benefits.[21] Neither do certain "grandfathered" health plans.[22] Instead, self-funded, large group, or grandfathered plans must generally provide "minimum value." Although this standard is less comprehensive, in terms of ensuring coverage for a wide range of services, than the "essential health benefits" standard, it nevertheless may be interpreted to include certain kinds of services for people on the autism spectrum.[23] Participants in plans that fail to provide "minimum value" may be eligible for subsidies to enroll in plans through the state marketplace instead.

Self-funded and large group plans are also required to cover preventive health care services that have been rated "A" or "B" by the United States Preventive Services Task Force (USPSTF) and children's preventive services that are recommended by the Health Resources and Services Administration's (HRSA's) Bright Futures Project.[24] 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 2017, there are no autism-related services that have gotten an A or B rating from the USPSTF.[25]

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17 *See* Statewide Associates, Analysis of Rehabilitation and Habilitation Benefits in Qualified Health Plans (2016) (prepared for the American Occupational Therapy Association), available at http://www.aota.org/-/media/corporate/files/advocacy/health-care-reform/essential-benefits/analysis-of-rehabilitation-and-habilitation-benefits-in-qualified-health-plans.pdf (last accessed Jan. 9, 2017).

18 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. 9, 2017).

19 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."

20 Self-funded, or self-insured, plans are benefit packages provided by employers that have committed to directly paying the costs of employees' and their dependents' health care. By contrast, fully-insured plans are health plans purchased from an insurance company by an employer or individual, in which the insurance company pays the direct costs of health care. Often, self-funded plans are administered by a company that also participates in the health insurance market. As a result, employees often may not know whether their plan is self-funded or fully insured. For a resource aimed at individuals and family members attempting to determine which laws cover their health plans, please see http://autisticadvocacy.org/wp-content/uploads/2015/07/Health-Insurance-and-Medicaid-Coverage-for-Autism-Services-A-Guide-for-Individuals-and-Families-7-9-15.pdf.

21 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. 9, 2017).

22 See note on grandfathered plans on page 8.

23 For more information about the minimum value standard, *see* 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. 9, 2017).

24 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. 9, 2017).

25 US Preventative Services Task Force, *available at http://www.uspreventiveservicestaskforce.org/BrowseRec/Search?s=autism* (last accessed Jan. 9, 2017).

Cost limits on Essential Health Benefits

Although self-funded and large group plans are not required to provide the full range of Essential Health Benefits, those Essential Health Benefits that they *do* offer cannot be subjected to certain kinds of cost limits. 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 covers - 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.[26] 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.

Non-Discrimination Based on Disability

Health plans that participate in the statewide marketplace - including individual plans and employer-sponsored small group plans - must obey certain non-discrimination rules, including disability non-discrimination rules.[27] A health plan cannot, for example, refuse to cover any interventions for a certain diagnosis.

This does not mean, however, that the plan must cover the same interventions for everyone regardless of diagnosis. Health plans may 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.

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

27 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." If a grandfathered plan had terms that did not meet the Affordable Care Act requirements before the law was passed, it can keep *some* of those requirements for a certain number of years.

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	Employer-sponsored 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 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 without co-pays • Let enrollees appeal coverage denials	• Cover essential health benefits • Cover preventative care without co-pays • End yearly dollar limits on coverage • Cover pre-existing health conditions • Let enrollees 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 plan 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 that requires plans to cover specific services related to autism spectrum disorder. These services may include 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.[28]

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 must 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.

28 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 that some insurers interpret to exclude many 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."[29] Services other than "behavioral health treatment" may still be mandated as essential health benefits under the ACA or by federal and state mental health parity rules.

California's insurance mandate specifically lists Applied Behavioral Analysis (ABA) as a covered intervention, while failing to name any other specific intervention.[30] As a result, insurance companies may attempt to challenge interventions other than ABA as not "evidence-based" and therefore not mandated by the law. Nevertheless, as discussed earlier in this guide, there are a variety of evidence-based interventions for autistic individuals. An intervention other than ABA will be covered by California's insurance mandate if it is evidence-based, and:

- 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 provided 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."[31]

As noted in further detail below, insurers may benefit from a proactive approach to covering evidence-based services other than ABA. These services may be more cost-effective and clinically effective for a specific targeted goal (such as language development) than ABA. For more information on analyzing whether an intervention is evidence-based, see page 1.

California's mental health parity law may also 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 compliance with mental health parity laws, see page 11 below.

Example: Maryland

Some states, like Maryland, have mandates that cover not only autistic individuals but also people 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.[32]

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

30 *Id.* § 10144.51(c)(1).

31 *Id.*

32 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. 9, 2017).

Like California, Maryland law specifically prohibits health insurers from declaring ABA to be "experimental or investigational."[33] Nevertheless, insurers in Maryland must also cover other evidence-based interventions. These other services may be more cost-effective and clinically effective for a specific targeted goal (such as language development) than ABA. For more information on analyzing whether an intervention is evidence-based, see page 1.

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[34]
- American Speech Hearing Association, States with Specific Autism Mandates[35]
- 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.[36] 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, some beneficiaries 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.

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.[37] 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.[38]

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.

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

34 Easter Seals, State Autism Profiles, *available at* http://www.easterseals.com/explore-resources/living-with-autism/state-autism-profiles.html (last accessed Jan. 9, 2017).

35 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. 9, 2017).

36 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).

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

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

	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 enrollees may 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

Self-funded employer health plan are not 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.

Nevertheless, self-funded health plans must provide the opportunity to appeal denials of coverage. They are also required to operate in a way that obeys the terms of the health plan and is not "arbitrary and capricious."[39] For example, a self-funded health plan cannot classify an intervention as "experimental" if there is actually compelling evidence that the intervention is effective. For more information on determining whether an intervention is experimental or evidence-based, see page 1.

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 a health 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. The question of whether an intervention is medically necessary is independent of whether it may be available through other sources. Only when a service is actually duplicative of another service that the beneficiary is receiving, such that provision of an

39 *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).

additional service will render no additional medical benefit, should a health plan refuse coverage of a service based on the fact that it is also delivered in school. For more information on determining whether a service is duplicative, see page 20.

Creating an Effective Autism Benefit Plan

Plan administrators face several challenges when developing a benefit structure for ASD. These challenges include:

- Determining which types of interventions should be included in the benefit, including intensive interventions such as Floortime or Applied Behavior Analysis (ABA);
- Setting appropriate licensing and supervision requirements for each intervention;
- Maintaining an adequate network of providers and/or developing a mechanism to allow out-of-network services when the local provider network is inadequate;
- Determining when a particular benefit is "medically necessary" and the level of care (LOC) appropriate in a particular case;
- Avoiding duplication of services provided through other sources, such as services provided pursuant to the IDEA, state DD programs, or Vocational Rehabilitation (VR); and
- Implementing meaningful quality controls

ASAN developed its Model Plan Language, attached as Appendix A of this toolkit, to address these challenges. We created this language through extensive interviews and collaboration with plan administrators, providers, autistic self-advocates, and regulators, as well as a review of applicable laws and regulations.

Our Model Plan Language is intended as just one example of a good plan. We determined, however, that any effective plan must include the elements listed below.

Adequate Range of Intervention Options

State legislatures, regulators, and advocates have devoted an increasing amount of attention to issues surrounding coverage for autism interventions. However, much this attention is focused on coverage of intensive behavioral interventions such as Applied Behavioral Analysis, rather than of other high-quality, evidence-based approaches. As a result, many plans have made amendments to the scope of coverage for ABA but have not made similar changes to the scope of coverage for other interventions, such as occupational therapy, speech-language services, or social-communication interventions.

This may result in poor matching of policyholders with the services that are right for them. Mismatching of services to service needs may negatively affect health outcomes. It may also lead to overuse of services, as policyholders must receive a higher number of hours of a poorly-matched service in order to achieve the same results that could be realized through fewer hours of another more appropriate service. A broader approach to coverage would not only improve patient care, but also increase legal compliance and – most likely – lead to decreased cost.

Legal Compliance Concerns

As noted above in this brief's discussion of the evidence base, there are a variety of effective approaches that may be appropriate for different individuals. Plans may be required to offer a range of approaches either as part of the Essential Health Benefits package or as required by mental health parity rules or autism coverage mandates.

The Essential Health Benefits package, for example, must include not only behavioral health treatment but also habilitative and rehabilitative services, such as occupational therapy or speech therapy.[40] Although there is not yet any official list of all the types of autism-related services that must be covered as Essential Health Benefits, these benefits at the very least need to be comparable to the standard list of benefits available through most plans.

The Centers for Medicare and Medicaid Services, in guidance interpreting Medicaid plans' obligation to cover the full range of medically necessary services to individuals under age 21,[41] has clarified that these medically necessary services may include a variety of autism-related interventions – not just one kind of service, such as Applied Behavioral Analysis.[42] Although this guidance refers to Medicaid plans, it gives some insight into how federal regulators may interpret requirements that private health plans cover medically necessary autism-related services.

This does not mean that providers will have to provide any service, on demand, to any covered individual. Plan administrators still have the right and the duty to provide the *right care to the right child at the right time in the right setting*."[43]

Many state autism coverage mandates also require coverage of occupational therapy, speech-language therapy, and evidence-based behavioral health interventions. Plans that are covered by such mandates cannot come into compliance merely by covering one or two types of intervention. Often, these insurance mandates also include limits on the caps or co-pay requirements that insurance providers can impose. The CMS State of the States on Services and Supports for People with ASD[44] and the Easter Seals State Autism Profiles[45] contain useful state-by-state information on the scope of each state's laws.

Better Patient Care and Beneficiary Satisfaction

As the American Psychiatric Association acknowledged in its most recent revision of the diagnostic criteria for ASD,[46] autistic individuals may have a range of different service needs. Even individuals with very similar traits may respond to interventions very differently. Moreover, an individual's needs and response to interventions may vary dramatically over time. By covering a broad potential range of services, health plans can better accommodate variations in individual need and in policyholder preference.

Reduced Cost

Some autism interventions can be highly intensive, leading some plan administrators to express concerns about cost. Expanding the range of potentially covered interventions may, at first, give rise to concerns that such an expansion would result in even greater costs. In reality, however, increasing consumer choice can actually reduce costs.

One reason that expansion of choice can reduce cost is the fact that the most commonly mandated intervention – Applied Behavioral Analysis – is extremely intensive, often involving upwards of 30 hours per week. Other interventions, such as Floortime, typically call for a less intensive level of care. Moreover, these interventions usually are provided in the place of, not in addition to, more intensive interventions such as Applied Behavioral Analysis.

40 *See, e.g.*, 42 U.S.C. §§ 18021-18022.

41 42 U.S.C. § 1396d(a)(6), (a)(13).

42 The Department of Education has issued similar guidance with respect to coverage of autism interventions under the Individuals with Disabilities Educations Act, http://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/dclspeechlanguageautism0706153q2015.pdf (last accessed Jan. 9, 2017). Although the Individuals with Disabilities Education Act uses a standard that is different from EPSDT's medical necessity standard, some interventions – such as assistance learning skills of independent living that are essential for both integration into the community and receipt of a free appropriate public education – may be covered under both standards.

43 Centers for Medicare and Medicaid Services, Centers for Medicaid and CHIP Services Informational Bulletin, Clarification of Medicaid Coverage of Services to Children with Autism (July 7, 2014), *available at* http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf (last accessed Jan. 9, 2017).

44 L&M Policy Research, Autism Spectrum Disorders (ASD): State of the States of Services for People with ASD (Jan. 24, 2014), *available at* https://www.medicaid.gov/medicaid/ltss/downloads/asd-state-of-the-states-report.pdf (last accessed Jan. 9, 2017) http://www.medicaid.gov/Medicaid- CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf (last accessed Jan. 9, 2017).

45 Easter Seals, State Autism Profiles, *available* at http://www.easterseals.com/explore-resources/living-with-autism/state-autism-profiles.html (last accessed Jan. 9, 2017).

46 American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, 5th ed. ("DSM-V") (2013).

By offering the option of selecting a less intensive intervention, plan administrators not only increase choice and quality of care but also can see reduced costs.

Another reason that expansion of choice can reduce cost is better efficiency through matching people with the most effective interventions for their particular needs. Individuals who respond better to developmental or social communication interventions may see results from these interventions much faster when given the choice to use the intervention that works best for them. Once the beneficiary reaches his or her goals, he or she may elect to reduce the intervention to a "maintenance" level of intensity, to discontinue the intervention, or to choose another goal that will promote the beneficiary's long-term health and well-being.

Finally, we have found that individuals who have limited choice of services may seek greater control by advocating increasing the level of care, whereas individuals who are presented with more choices may spend that same energy on finding the most efficient intervention to meet their own individual goals.

Services to Include

ASAN proposes that plan administrators permit coverage of a wide range of interventions for individuals with a primary diagnosis of ASD, and rely primarily on medical necessity, level-of-care, pre-authorization, quality control, and continuing review requirements (rather than on coverage exclusions) in order to avoid excessive or unnecessary care. These interventions may include:

- Developmental interventions such as DIR/Floortime;
- Social communication interventions;
- Occupational, physical, or speech therapy;
- Mental health services; or
- Consequence-focused behavioral interventions such as Applied Behavioral Analysis (ABA), where required by law.

The interventions should "matched" to the individual's goal. Examples of "matched" goals and interventions include:

- Speech therapy to teach a covered individual how to talk or understand spoken information;
- Communication interventions, including pivotal response training or joint attention interventions, designed to teach a covered individual how to communicate through some means other than speech, such as through typing, signing, pointing, or using a picture board;
- Physical therapy to teach a covered individual how to roll over, sit, walk, or acquire other motor skills;
- Occupational therapy to teach a covered individual how to perform activities of daily living; balance while standing, sitting or walking; or assist with ability to meet behavioral or performance demands in educational or work settings;
- Social communication or developmental interventions to assist with emotional or behavioral regulation; and
- Typical mental health services, such as counseling, family therapy (including training for families on interacting with an autistic family member), and mental health crisis interventions.

Covered interventions should not be defined by "brand" (such as Applied Behavioral Analysis, Floortime, or SCERTS) but rather the type and characteristics of an intervention. This approach avoids arbitrariness in coverage determinations and potential network inadequacy. It also avoids the need for repeated revisions of the coverage list in response to emerging brands. Finally, it enables plan administrators to match interventions with supporting research, which may apply broadly to certain categories of interventions rather than to specific brands. Examples are listed below.

Brand Name	Category Description
Floortime	Developmental Relationship-based Treatment
Dynavox[47]	Augmentative and Alternative Communication Device
Applied Behavioral Analysis (ABA)	Consequence-based behavioral intervention
SCERTS	Social communication intervention

It should be noted that evidence-based practices - such as social communication or joint attention interventions - may be used in several different "branded" interventions, including "branded" interventions that typically focus on another intervention modality. Different practitioners within a "brand" may vary considerably in their fidelity to the specific techniques most commonly associated with those brands.

For more information, see our discussion below with respect to medical necessity determinations and appropriate quality control measures.

A note on billing codes

Avoiding "brand"-based categories is also important when developing billing codes. Clustering multiple unrelated intervention types into a single billing code makes it difficult for plan administrators to track cost, effectiveness, and utilization of different interventions.

Unsafe or Dangerous Services

Some services that claim to "alleviate" or "cure" ASD are unproven or dangerous. These include:

- Biomedical interventions inconsistent with accepted clinical practice, such as chelation, "mineral" therapies, or hyperbaric oxygen therapy;[48] and
- Interventions that use aversive or unpleasant stimuli to modify behavior. These may include skin shocks, unpleasant odors, deprivation of food, or seclusion and restraint.

These services should not be included in the plan.

In addition, some services that may technically be included in the plan – such as intensive behavior-based intervention – may include use of aversives to modify behavior.[49] It may be necessary to implement quality controls to ensure that covered interventions do not include use of aversives or other excluded interventions. Quality control measures are discussed in more detail below.

47 Dynavox is a particular brand of speech-generating device.

48 *Hyperbaric Oxygen Therapy: Don't Be Misled,* U.S. Food and Drug Administration, http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm364687.htm (last accessed Jan. 9, 2017)

49 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://journals.sagepub.com/doi/pdf/10.1177/10983007050070020101 (last accessed Jan. 9, 2017).

Licensing Requirements

The Affordable Care Act prohibits discrimination against providers operating within the scope of their license and expertise. While this does not mean that health plans must allow every provider to join their network, it does prohibit plans from restricting coverage to providers with a certain license. For example, a plan administrator cannot require a BCBA certification for all providers of intensive developmental or behavioral services.

Unnecessarily restrictive licensing requirements may also expose plans to litigation over provider network adequacy or maintenance of "arbitrary and capricious" licensing requirements, which are prohibited by ERISA. Similar litigation has also occurred in the context of Medicaid plans.

As a result, when developing a list of covered services, it is important to also craft licensing requirements for each service that are aimed at ensuring that service providers are qualified and adequately licensed while maintaining broad enough criteria to ensure an adequate provider network.

Example:

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

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

To avoid this outcome, ASAN recommends that licensed or certified professionals be permitted to bill for a service as long as (1) provision of the service by that professional is consistent with state licensing laws; (2) the service is within that professional's scope of practice; and (3) other professionals are either supervising or providing consultation support where necessary to ensure that the service remains medically necessary, safe, and consistent with accepted standard clinical practices.

For example, a clinical psychologist, clinical social worker, or psychiatrist with expertise in developmental disability should be eligible to offer services like developmental or behavioral interventions, counseling, or family coaching. Occupational therapists, physical therapists, or speech-language pathologists should also be eligible to provide developmental interventions within the scope of their expertise, without needing an additional certification or license such as a BCBA certification.

Example:

A seven-year-old beneficiary is unable to speak. The extent to which the beneficiary is able to understand or produce words in English is unknown. The family requests coverage for interventions aimed at developing the ability to communicate using augmentative communication (AAC) devices. The plan may reimburse a speech-language pathologist (SLP) or licensed psychologist to develop a plan to instruct the individual on AAC use, provided that assisting with language acquisition is within the scope of that professional's practice. However, the plan may reject a request to reimburse an associate behavioral analyst (BCaBA) to provide this service, unless the BCaBA holds another relevant certification, because training for BCaBAs does not include adequate training on language acquisition.

During the course of the intervention, it becomes apparent that motor control issues are a barrier to the individual's ability to use the device. The plan may reimburse an occupational therapist (OT) to develop a plan for modification and placement of the AAC device. The OT may also create a plan for helping the individual develop the motor skills necessary to use the device.

Outreach to Beneficiaries

Once the health plan has been amended to include a broad range of autism services, it will be necessary to conduct outreach to beneficiaries to ensure that they are aware of the range of services available to them. You may wish to include materials from your provider network describing the services that your network providers offer.

Medical Necessity and Level of Care Determinations

Unlike many medical conditions, ASD has no known "cure." It is a developmental disability that can be expected to last for the lifetime of an individual. As a result, medical necessity determinations should be based not on prevention or cure of autism, but rather on habilitative interventions designed to enable the individual to live independently and achieve better overall health outcomes.

Habilitative Services

Habilitative services are interventions designed to improve an individual's ability to acquire or retain skills necessary for activities of daily living (ADLs). ADLs include speaking, walking, communicating, feeding or dressing oneself, maintaining hygiene, and learning in school.

For example, a Plan may cover:

- Training in the use of an AAC device in order to communicate. Improved communication ability can, in turn, improve an individual's ability to communicate health-related information, increase emotional well-being, and help an individual stay safe and manage behavior.
- Assistance in developing independent living skills such as dressing, toileting, and hygiene.
- Interventions to promote an individual's ability to regulate behavior at home and in public.
- Assistance in developing strategies to manage sensory challenges that make it difficult to participate in community life, such as intolerance of loud noises or crowds.

Managing Secondary Conditions

Sometimes, traits associated with ASD may result in "secondary" medical conditions. For example, an autistic person who repeatedly "bangs" his or her head may experience head trauma or damage to eyes or ears. An autistic person who has difficulty maintaining a dental care regimen may experience gum disease or tooth decay, and an autistic person who cannot tolerate a range of food options may experience malnutrition.

Services to prevent, diagnose, correct, cure, alleviate, or preclude deterioration of secondary medical conditions can be medically necessary. For example, a plan may cover:

- Interventions to reduce self-injurious behaviors by identifying environmental triggers and replacement behaviors, including communication supports.
- Occupational therapy to assist an individual in maintaining a dental care regimen that accommodates motor control challenges and sensory needs.

Consistency with Individual Need

No covered intervention will be appropriate for *all* individuals diagnosed with ASD. As a result, medically necessity criteria should include a requirement that the intervention is based on an individualized assessment of an individual's skills, situation, goals, and characteristics. For example, an individual who does not experience difficulties with ADLs will not need habilitative services aimed at developing skills of independent living. However, individual needs vary over time: an individual who at age three did not have difficulties with ADLs as compared to other three-year-olds may nevertheless, at age nine, encounter challenges acquiring the more complex skills expected of the average nine-year-old.

When determining whether an intervention is necessary to achieve an individual's goals, coverage providers should pay particular attention toward ensuring that the goals are not primarily for the convenience of the recipient, caretaker, or provider or elimination of the appearance of disability. For example, an intervention aimed at increasing eye contact or reducing repetitive movements (such as hand-flapping) would typically not be considered medically necessary unless they can be tied to the individual's safety and ability to perform activities of daily living, or prevention or management of secondary health conditions. It should be noted that while eye contact and reduction of repetitive movements are often characterized as "social skills" goals, studies have shown that peer and family training is more effective at improving social relationships than attempts to reduce behaviors perceived as "odd."[50]

Finally, coverage providers should ensure that an intervention is not inconsistent with an individual's other health goals. For example, a behavioral plan that uses sugar-containing candy as a reinforcement may not be appropriate for a child who also has diabetes.

Level of Care

Level-of-Care determinations should be determined in light of (1) the anticipated time frame for the relevant goal; (2) standard clinical practice recommendations; and (3) ensuring that the level of care is not inconsistent with other important needs, such as community integration, ability to participate in school, managing fatigue levels, and ensuring adequate resting time during a regular day.

Some goals must be met on accelerated time frames. For example, if a goal is necessary for the safety of an individual or in order to prevent an immediate secondary health outcome and more intensive interventions have been shown to help achieve faster outcomes, a higher level of care may be necessary. Similarly, some interventions are only proven to work if delivered at a particular intensity level.

These considerations must be balanced against other individual needs. For example, a child who attends school during the day may, due to fatigue, be unable to benefit from three hours of intensive behavioral interventions delivered after the end of a school day. In fact, such intensive interventions may result in significant additional fatigue and result in poorer behavior or ability to learn the next day. Coverage providers may elect to limit the number of hours of intervention covered during school days in order to avoid this sort of diminishing return.

50 *See* Kasari et al., *Making the Connection: Randomized controlled trial of social skills at school for children with autism spectrum disorders.* 53 J. Child Psychology & Psychiatry 431-439 (2011).

In addition, if an intensive intervention is delivered in a clinic-based setting, rather than integrated into a child's day, it may result in isolation from the community and failure to generalize newly learned skills or behaviors. Additional commuting time to the clinic - as opposed to receiving services at home or in another community-based setting where the individual already spends time - may also result in long-term fatigue that may impair behavior and ability to learn. These considerations may be relevant when setting level of care as well as when determining which setting is appropriate for particular services.

Coordination with Other Service Systems

One common challenge faced by coverage providers is determining when to cover a service that may also be provided by another payer, such as a school district or vocational rehabilitation services provider.

Although coordination is critical in order to ensure non-duplication of services, coverage determination processes should make initial medical necessity determinations without regard to whether a service may be provided by another payer. Only after a service has been determined medically necessary should caseworkers determine whether the service is already being provided through another source. Moreover, when determining whether a service is provided through another source, careful attention should be paid to the nature and goals of that service, not only to the billing code.

School districts, for example, are required by the Individuals with Disabilities Education Act to provide students with disabilities auxiliary aids and services that may be necessary in order for the students to receive a free appropriate public education (FAPE). These services may include occupational therapy, physical therapy, speech-language pathology services, or counseling. These services are typically limited to goals that are relevant to educational goals. For example:

- Occupational therapy may be limited to enabling a student to develop skills necessary for learning, such as holding a pencil, writing, and staying seated at a desk.
- Counseling services may be limited to enabling a student to manage emotions and behavior during the course of the school day – not outside of it.
- Nursing services may be available during the school day to students with complex medical needs who need these services in order to attend school. They will not be provided by the school outside of school hours.

As a result, an individual who needs services in order to develop independent living skills may receive some but not all needed services in school.

Case example:

A case manager receives a pre-authorization for five hours per week of occupational therapy. The beneficiary is a school-aged autistic child who needs this therapy in order to develop independent living skills, including using the bathroom, tying shoes, dressing, brushing teeth, using an AAC device, and typing.

The case manager determines that all of these goals are appropriate and within the scope of practice of an occupational therapist. Nevertheless, because the beneficiary is school-aged, the case manager requests a copy of the child's school-based Individualized Education Plan (IEP) and other records of services provided pursuant to the IEP. The parent signs an authorization to release records so that the school can provide them directly to the case manager.

When reviewing the records, the case manager sees that the beneficiary receives three hours a week of occupational therapy at school. Occupational therapy is focused on holding a pencil, behaving appropriately in class, and identifying strategies for managing sensory sensitivities in the school setting. These skills are not listed as goals in the pre-authorization request. As a result, the case manager does not consider these services to be duplicative of the services requested through the pre-authorization process. As a result, the services are authorized. To ensure that the services remain non-duplicative, the caseworker continues to request records from the school on a periodic basis.

Even when services are non-duplicative, coordination between school-based and insurance-funded service providers can be critical to delivering high-quality care. For example, an occupational therapist in the school may identify strategies for managing sensory sensitivities in school situations that can be translated easily into out-of-school contexts. Maintaining consistent strategies across school and home settings helps the student remember to use them and helps the health plan avoid wasting time trying out other strategies before finding one that works. Moreover, active care coordination can take the burden of coordination off of beneficiaries and their families, who otherwise often are required to fulfill this role.

One major barrier to care coordination is provider buy-in. Providers may resist participating in care coordination activities due to insufficient reimbursement options for time spent on care coordination. As a result, health plans should reimburse its providers and case managers for time spent coordinating with school-based providers. This may include time spent meeting with the school-based providers, reviewing records, or attending IEP development meetings. Because coordination helps to avoid duplicative services and enables providers to build on each other's work, allowing providers to bill for such coordination time is likely to result in overall cost savings.

Implementing Meaningful Quality Controls

As plan administrators broaden access to a variety of interventions and providers, they should also implement meaningful quality oversight to ensure that these services remain consistent with medical necessity criteria and clinical best practices.

Pre-authorization and continuing utilization reviews may help ensure quality of care, especially with respect to intensive ongoing services. Pre-authorization and continuing utilization reviews should include review of:

- Underlying diagnostic documentation;
- The specific patient needs and goals;
- How the intervention plans to achieve the specific goals;
- Proposed level of care and justification for the level of care;
- Qualifications of proposed providers, including experience with autism and experience providing the proposed intervention; and
- Where an intervention targets behavior that may be caused or complicated by an underlying medical condition, documentation that medical causes or complicating factors have been ruled out.

Note that some state autism coverage mandates include specific requirements for pre-authorization and continuing review teams for certain kinds of services. These requirements may include minimum or maximum periods between reviews.

Composition of Review Teams

The pre-authorization and continuing review teams should include individuals who are familiar with the full range of covered interventions, including at least one developmental psychologist. The teams should also include other types of professionals who provide services to autistic individuals, including occupational therapists and speech-language pathologists. Team members should be familiar not only with behavioral interventions but also with other common challenges associated with ASD, such as speech development, motor coordination skills, and development of self-regulation skills.

Because teams should include professionals with expertise in occupational therapy, physical therapy, and speech-language pathology – all typically classified as "medical" interventions – it will not usually be practical to use typical "behavioral health" teams to coordinate services for autistic beneficiaries. Rather, the teams should include a

combination of professionals typically classified as focused on "behavioral health" – such as psychologists – and professionals typically classified as "medical."

In addition, it is best to have at least one team member or consulting individual who is capable of identifying situations in which behaviors or other traits may be attributable to medical or psychiatric concerns, so that appropriate specialist referrals can be requested.

Continuing Utilization Reviews

Continuing utilization reviews can be used as part of a quality control program. Intervention plans that initially met medical necessity requirements may stop meeting these requirements as the initial goals are achieved and new ones are developed. In addition, it is important to ensure that intervention plans are revisited and adjusted when they fail to result in meaningful progress toward the listed goals despite intensive services.

In states that do not impose legal minimum or maximum intervals between utilization reviews, ASAN recommends conducting more frequent reviews of interventions that are delivered primarily by para-professionals without a master's or doctorate-level degree – at least one review every six months. These interventions may be particularly vulnerable to "mission creep" as goals are met and new ones are developed, and may benefit most from oversight. Interventions delivered primarily with master's- or doctorate-level professionals should be reviewed at least once per year. It may be necessary to conduct more frequent reviews for very young children, whose abilities and skills may change rapidly, or in cases where an individual exhibits sudden changes in behavior or medical needs. To avoid loss of progress, services should continue during these reviews unless there is a reason for concern about abuse.

These continuing reviews should include a review of progress notes and measurements, the most recent version of the intervention plan, and a description of the individual's continuing needs. If it appears to the case management team that an intervention has not produced meaningful and measurable results in the time period anticipated, the case management team may recommend, as a condition of continued coverage, a re-assessment of the plan. The re-assessment may include proposals for alternative interventions, progress measurement methods, or goals. Alternatively, the re-assessment may lead to a referral for further evaluation, such as an evaluation to rule out potential medical barriers to achievement of the goal.

Reviews should also include an assessment to ensure that the plan remains in compliance with best practices, is sufficiently integrated into the community, and does not involve harmful practices such as seclusion or restraint. With behavioral plans, particular attention should be paid to descriptions of the consequences applied to behaviors to ensure that those consequences (1) are not aversive, and (2) are not inconsistent with individual well-being (such as making meals, rest time, or social interaction contingent on behavior).

In addition, ASAN recommends that reviews be required whenever a plan is significantly altered, including addition of a new goal that is significantly different from previous goals. These reviews may be necessary in order to ensure that the plan continues to be medically necessary and that the new goal is consistent with the evidence base for the intervention approach.

Finally, the review team may request a continuing utilization review when necessary in light of other developments in an individual's health or plan of care, such as a new diagnosis or commencement of an intervention or treatment program that may affect the individual's participation in the existing plan.

If the review team identifies significant concerns with regard to one beneficiary's plan of care – such as use of seclusion or restraint, failure to appropriately address potential medical causes of behavior, or inappropriate matching of goals to provider expertise – the review team may also elect to conduct a review of all beneficiaries served by that provider and, where there appears to be a systemic quality or safety concern, terminate that provider's authorization to serve plan beneficiaries.

Mental Health Parity Concerns

As noted on page 11, most private health plans are covered by some mental health parity legislation, such as the Affordable Care Act, Mental Health Parity and Addiction Equity Act of 2008, and/or state mental health parity regulations. Courts have interpreted parity laws to require coverage of certain ASD-related services. Beneficiaries have been particularly successful in using mental health parity laws to secure access to coverage when they were requesting a particular category of service – such as occupational therapy or speech-language services – that the plan covered for individuals recovering from injuries or experiencing a physical health problem but categorically excluded those services for an underlying diagnosis of ASD.

When developing plan language, administrators should therefore carefully evaluate whether the plan covers certain services as part of their physical healthcare package that may also be medically necessary for individuals with a primary diagnosis of ASD. These services include but are not limited to:

- Speech-language therapy
- Physical therapy
- Occupational therapy
- Nutritionist services
- Counseling
- Case management
- Telehealth services
- Assistive technology

If these services are part of the plan's physical healthcare package, they must also be provided when medically necessary for individuals with ASD.

Plan administrators should also ensure that:

- The plan does not require higher co-pays or caps for these services, when provided to individuals with ASD, that are more restrictive than the caps or co-pays that apply to the same services in physical healthcare contexts.
- The plan does not impose more restrictive medical necessity requirements or in-network care requirements for these services, when provided to individuals with ASD, than it imposes for the same services in physical healthcare contexts.
- Beneficiaries are not required to pay a separate deductible for ASD-related services than they pay for physical health services.

Conclusion

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

It is vital that health plans not only provide a range of services, but educate beneficiaries and their families in order to ensure that they are matched to the right services for them. Offering a range of services not only improves beneficiary health outcomes and cost-efficiency but also is a necessary element of compliance with federal laws, such as the Affordable Care Act and Mental Health Parity and Addiction Equity Act, as well as state-level mandates. Careful case management and coordination can help to ensure that services are used appropriately and efficiently and can help beneficiaries determine which services are right for them.