Health Insurance and Medicaid Coverage for Autism Services: A Guide for Medicaid Providers

Sam Crane, J.D., and Lydia Brown[*]

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. Moreover, federal law requires that Medicaid plans cover the full range of medically necessary diagnostic and intervention services for autistic individuals under age 21, and sets standards for coverage that Medicaid providers must meet for beneficiaries over the age of 21. Nevertheless, it is essential that Medicaid providers maintain active quality controls to avoid funding inappropriate interventions. Such interventions may cause either delays in developing important skills or – in the case of 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 – may cause lasting harm.[1]

This guide is intended to provide guidance to Medicaid plan administrators on developing an effective coverage plan for ASD. It includes an overview of effective and emerging interventions, explanation of applicable federal laws governing Medicaid 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.

Background

The evidence base

Definition of "Evidence-based"

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

---

[*] Sam Crane is the Legal Director and Director of Public Policy at the Autistic Self Advocacy Network. Lydia Brown wrote the section on Evidence Base in this toolkit in her capacity as Policy Associate at the Autistic Self Advocacy Network. For questions or comments on this toolkit, please contact Sam Crane at scrane@autisticadvocacy.org.

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

[2] 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.

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

Evidence base for developmental approaches

There are many types of interventions for autism can be described as evidence-based. For example, in 2014 a National Institute for Mental Health (NIMH) funded randomized control trial on a Developmental, Individual-differences, and Relationship-based (DIR™) program, the PLAY Project, found significant positive results for this DIR program as comparted to usual community services for autistic children.[4] Also in 2014, another paper found improved communication, daily living, and social skills for autistic children receiving individualized Early Social Interaction (ESI) therapy based on the Social Communication, Emotional Regulation, and Transactional Support (SCERTS™) model.[5] This model aims to integrate social communication skills development into everyday activities and natural environments. The same study found no such gains for children receiving ESI therapy in group settings.[6]

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

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

Developmental interventions may be referred to generally as developmental, social, or relationship-based, or they may be referred to by the name of a specific intervention model. One specific 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

---

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

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

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

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

[7] Julie Young, et al., 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.

[8] 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.

interactions.[9] A study from 2007 of an intervention based on DIR/Floortime similarly found significant improvement in functional developmental levels for autistic children receiving this intervention.[10] In addition, the SCERTS (Social Communication/Emotional Regulation/Transactional Support) model focuses on developmentally grounded goals for social communication and emotional regulation.[11] The SCERTS model incorporates a variety of strategies based on available research literature about their effectiveness in reducing challenges and improving specific skills.

Evidence base for other promising approaches

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

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

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

A more recent literature review conducted in 2014 by the Autism Evidence-Based Practice Review Group at the University of North Carolina identified 27 practices that met criteria for rigorous research backing.[12] In addition to many of the same practices

---

[9] 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.

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

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

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

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.

Medicaid Coverage of Autism-Related Health Services

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

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

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

Important state and federal laws

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

Federal Medicaid Law

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

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

The Affordable Care Act

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

---

[13] 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.

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

In addition, these plans must not deny coverage on the basis of disability.[15] The Department of Health and Human Services has recently issued proposed regulations defining disability discrimination in health plans.[16]

Mental Health Parity

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

In April 2015, the federal government proposed a rule that would apply the Mental Health Parity Act to Medicaid managed care plans, Medicaid Alternative Benefit Plans covering people in the Expansion Population, and CHIP plans.[17] The final rule is pending.

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

State autism coverage mandates

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

The Individuals with Disabilities Education Act

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

Creating an Effective Autism Benefit Plan

Medicaid 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;

---

[15] 42 USCS § 18116(a).

[16] Notice of Proposed Rulemaking: Nondiscrimination in Health Programs and Activities, 80 FR 54171 (Sep. 8, 2015), http://federalregister.gov/a/2015-22043.

[17] See Application of Mental Health Parity Requirements to Coverage Offered by Medicaid Managed Care Organizations, the Children's Health Insurance Program (CHIP), and Alternative Benefit Plans, 80 Fed. Reg. 19,417 (proposed Apr. 10, 2015), *available at* http://federalregister.gov/a/2015-08135.

- Maintaining an adequate network of providers and/or developing a mechanism to allow out-of-network services when the local provider network is inadequate; and
- 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);
- 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 Medicaid plan administrators, providers, autistic self-advocates, and Medicaid 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

Advocates have devoted an increasing amount of attention to issues surrounding 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. 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. CMS has made clear that Medicaid plans must offer to EPSDT-eligible individuals the full range of medically necessary services that could be covered under the state plan.[18] These services include, at a minimum:

- Diagnostic testing, including neuropsychological evaluations
- Habilitative services from a doctor or other licensed health care provider, "for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level," whether in a facility, clinic, or home
- Physical therapy
- Home health care services
- At-home personal care services
- Private-duty nursing
- Case management
- Prescription medications
- Eye care
- Any medical care by licensed practitioners within the scope of their practice
- Family planning services for adolescents and young adults[19]

---

[18] 42 U.S.C. § 1396d(a)(6), (a)(13).

[19] 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.

The recent guidance from CMS makes it clear that states must cover a full range of medically necessary services for autistic children and young adults under age 21 – not just one kind of service, such as Applied Behavioral Analysis.[20] Nevertheless, some state Medicaid programs have continued to take the position that they only need to cover certain kinds of services, such as Applied Behavioral Analysis, or that they cover only services to those provided by licensed ABA practitioners and not other competent professionals such as psychologists or occupational therapists.

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

This does not mean that providers will have to provide any service, on demand, to any covered individual. Medicaid plan administrators still have the right and the duty to engage in appropriate quality control and oversight to ensure that individuals receive the *"the right care to the right child at the right time in the right setting."*[21]

Finally, some states have laws requiring that health plans cover services related to autism diagnoses. Many of these states' laws only cover private health plans, not Medicaid plans. But in some states, Medicaid managed care plans or other Medicaid-funded plans may also be included. Check the CMS State of the States on Services and Supports for People with ASD[22] to see whether your state has a law that applies to your plan. Often, these insurance mandates also include limits on the caps or co-pay requirements that insurance providers can impose.

Better Patient Care

As the American Psychiatric Association acknowledged in its most recent revision of the diagnostic criteria for ASD,[23] 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, Medicaid plans can better accommodate variations in individual need.

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 intensive interventions, such as Floortime, typically call for a less intensive level of care and are therefore less costly. Moreover, these interventions usually are provided in the place of, not in addition to, more intensive interventions such as Applied Behavioral Analysis. 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.

---

[20] 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. 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.

[21] 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

[22] L&M Policy Research, Autism Spectrum Disorders (ASD): State of the States of Services for People with ASD (Jan. 24, 2014), *available at* http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/ASD-State-of-the-States-Report.pdf.

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

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 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. Potential

- Developmental interventions such as DIR/Floortime;
- Social communication interventions;
- Occupational, physical, or speech therapy; or
- Behavioral interventions such as Applied Behavioral Analysis (ABA).
- Speech therapy to teach a covered individual how to talk or understand spoken information;
- Communication 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; and
- Social communication or developmental interventions to assist with emotional or behavioral regulation.
- 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
Rapid Prompting Method (RPM)[24]	Augmentative and Alternative Communication Device
Applied Behavioral Analysis (ABA)	Behavior-based intervention
SCERTS	Social communication intervention

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

---

[24] RPM is a strategy for teaching autistic individuals to communicate by pointing to letters on a letter-board. Other strategies for teaching individuals to use letter-boards or other spelling-based forms of communication also exist.

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; 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.[25] 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.

A note on billing codes

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

Outreach to Beneficiaries

Once the Medicaid 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.

Licensing Requirements

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.

In the past, plan administrators have attempted to use restrictive licensing requirements for autism-related services, such as requiring a BCBA certification for all providers of intensive developmental or behavioral services, or even requiring that service providers hold a license to practice medicine. This approach has exposed states to litigation over provider network adequacy and maintenance of "arbitrary and capricious" licensing requirements.

Example 1.

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).

---

[25] 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.

Example 2.

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

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

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

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 3.

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 because the BCaBA does not have 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.

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.
- 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."[26]

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.

---

[26] 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).

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.

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 that is inconsistent with the integration mandate of the Americans with Disabilities Act. As state programs, Medicaid plans must comply with this integration mandate. Moreover, skills learned in clinic-based settings may be more difficult to generalize across other environments. 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 case workers 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 nonduplicative, the caseworker continues to request records from the school on a periodic basis.

Even when services are non-duplicative, coordination between school-based and Medicaid-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 Medicaid-funder 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, Medicaid plans should enable providers to be reimbursed for time spent coordinating with school-based providers, such as time spent meeting with other 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 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.

ASAN recommends use of pre-authorization and continuing utilization reviews to 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.

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.

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.

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. These reviews may be necessary in order to ensure that the plan continues to be medically necessary.

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

New proposed regulations would extend the Mental Health Parity Act to CHIP plans, Medicaid Alternate Benefit Programs, and Medicaid managed care plans. Although it applies only to plans that cover mental health services, nearly all Medicaid plans covered by this law do cover mental health care. The Affordable Care Act also has a Mental Health Parity provision. Many states also have their own mental health parity laws.

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

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

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

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 Medicaid 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 but also is a necessary element of compliance with federal Medicaid law, the Affordable Care Act, and Mental Health Parity law. ASAN is committed to ensuring that state Medicaid programs provide access to the full range of services that may be medically necessary for autistic children and adults.