INHERENT CHALLENGES FACED BY HEALTH PLAN CARE MANAGEMENT OF ABA SERVICES FOR THE TREATMENT Of AUTISM SPECTRUM DISORDER

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Executive Summary

Health plan insurers and managed behavioral health care organizations face three major challenges in providing effective care management services for their members diagnosed with autism spectrum disorder ("ASD").

- A provider community with a high percentage of relatively new providers that lack professional adoption of basic standards such as medical record documentation, dosage of treatment, and agreement on significant clinical progress, and are not trained to consider diagnostic dilemmas for members with complex co-morbid diagnostic profiles,
- A care management and utilization management system not designed to track member response to treatment over the years of time with multiple providers and complex conditions, and most importantly,
- A care management system that is inadequate to meet the needs of members who often have comorbid medical and behavior issues, significant intellectual disabilities, social determinant of health complications, and overwhelmed family members over the long periods of time typically involved in an episode of treatment.

This document reviews the scope of the of issue by examining research pertinent to ASD as a condition and the use of Applied Behavior Analysis (ABA) to treat ASD. This review includes the history of the treatment and research supporting the efficacy of ABA, the prevalence and diversity of the ASD condition, and the use of standardized assessments to measure treatment effectiveness.

Each of the identified components in the system, (the provider community, the management systems, and the member in their environment), are then examined in detail to highlight the inherent challenges faced by third-party payors in managing ASD impacted members and their families.

In conclusion, the document provides a template of best practices health plans can adopt to promote the triple aim of health care which includes improving patient experience, reducing per capita costs, and promoting population management for members diagnosed with ASD and families.

Scope of the Issue

The history of behavioral treatment dates back over 100 years with psychology behaviorists such as John Watson and B.F. Skinner. The field of Applied Behavior Analysis (ABA) began to take off with research

conducted in the 1960's as noted by such theorists as I.O. Lovaas, initiation of the Juniper Gardens Children Project and Twin Oaks, and the creation of the Journal of Applied Behavior Analysis. In 1987, Lovaas published his famous study, 'Behavioral treatment and normal educational and intellectual functioning in young autistic children', which has been cited as proof that Early Intensive Behavior Interventions (EIBI) can create significant improvement in symptoms and severity of ASD in young children (Gilmore, 2019).

Mandates for coverage of ABA treatment for ASD began in Indiana in 2001, and by 2019, all 50 states had some type of mandate in place requiring coverage of ABA services. With all 50 states having a mandate, advocates for coverage of ABA services for the treatment of ASD are now focusing on changing mandates or health insurance policies that limit treatment by number of hours, age, or length of treatment (Bernhard, 2019; National Conference of State Legislators, 2021).

The prevalence of individuals diagnosed with ASD has grown significantly over the past two decades. In 2000, the CDC reported 1 in 150 children were diagnosed with ASD. This number has increased to 1 in 44 children by 2018. This is an increase of 6.7 children per 1000 to 23 children per 1000, or more than a 3-times increase in the number of individuals identified with ASD (CDC, 2021).

The average medical cost difference for those individuals with ASD as compared to those without ASD ranges from $4,110 - $6,200 per year. In addition to medical costs, Intensive behavior interventions such as Applied Behavior Analysis treatment cost an additional $40,000 to $60,000 per child per year with an average length of treatment of 2 to 3 years (National Conference of State Legislators, 2021).

ASD is associated with approximately 3.6 million dollars in lifetime social costs per individual. Total lifetime social costs to date are about 7 trillion dollars. If prevalence remains the same, the cost will be 11.5 trillion dollars by 2029 (Cakir, J., Frye, R. E., & Walker, S. J. 2020).

The practice of ABA treatment is often divided into two categories. The first, Comprehensive treatment or Early Intensive Behavior Interventions ("EIBI"), is typically provided for young children under 7 years of age, is delivered at an intensity of 25-40 hours per week over 2-3 years and addresses six primary domains of early development. These domains include expressive language, receptive language, pragmatic communication, adaptive skills, maladaptive behaviors, and parent/ caregiver training. The second, Focused treatment, is typically provided to older children, is delivered at an intensity of 10 – 25 hours per week for a limited duration and focuses on the acquisition of specific skills or the reduction of specific behaviors (BACB, 2014; Eldevick, et. al., 2006 as cited by Davis, 2018)

Peer reviewed research on the effectiveness of ABA has focused on younger children receiving EIBI interventions. Less peer reviewed research is available on the effects of Focused ABA treatment and the treatment of older children. The effectiveness of EIBI in peer reviewed research such as the Lovaas study indicate that nearly 50% of children in the experimental group made significant progress as indicated by measured increases in intellectual functioning and school placement (Lovaas, 1987). Unfortunately, the ramification of this study also indicates that some children do not make significant gains as a result of EIBI treatments.

Further complicating the effectiveness of EIBI is the wide range of deficits observed in individuals with ASD. The diagnosis of ASD requires deficits in social communication and social interaction across multiple contexts and restrictive and/or repetitive behaviors which manifest in the early years of childhood development and cause significant impairment in activities of daily life. The symptom severity can range from minor deficits such a difficulty making friends, organizing, and/or planning to non-verbal, unable to understand social interactions, and/or with severe behaviors that can cause injury to self or others (DSM-V, 2013).

In addition to a wide potential array of symptom severity, individuals with ASD are also at higher risk for confounding comorbid conditions that limit potential treatment gains such as intellectual deficits, mental health conditions, and/ or medical disorders that interfere with progress.

70% of individuals with ASD have a comorbid mental disorder such as stereotypic movement disorders, attention deficit/ hyperactivity disorder, anxiety disorder, and depressive disorder (DSM-V, 2013) and 70% of individuals with ASD have some level of intellectual disorder (Srivastava & Schwartz, 2014); a full 31% have a diagnosed intellectual disability, defined as having lower than a 70 IQ (Elfein, 2020).

50% to 80% of individuals with ASD have sleep disorders, while up to 25% of individuals with ASD have a cooccurring seizures (Richdale & Schreck, 2009, cited by Davis,2018). Other frequently co-occurring medical disorders include immune dysregulation disorders, allergies, gastrointestinal problems, eating/ feeding problems, and metabolic abnormalities (Treating Autism and Autism Trust 2013, cited by Davis, 2018).

Differential diagnosis concerns are also prevalent as evidenced by medical conditions such as Rett syndrome, lead poisoning, deafness, or genetic disorders such as Fragile X, Williams syndrome, Angelman syndrome, Prader-Willi syndrome, and others (Autism Research Institute, DSM 2013).

In summary, the prevalence of individuals diagnosed with ASD continues to increase and include a wide range of presenting symptom severity. All 50 states now recognize some form of EIBI as an effective treatment of ASD and have some mandate requiring coverage of EIBI or ABA as a treatment for ASD.

Similar disorders that have autism-like symptoms create the potential for misdiagnosis and thus problematic treatment planning. Confounding comorbid behavioral health, medical, and intellectual disabilities make understanding progress and barriers to progress a challenge.

While standardized measures for determining progress in intellectual functioning have been used to support state mandates, the profession as a whole recognizes outcomes as meaningful and significant even without a corresponding increase in intellectual functioning as measured with standardized assessments. Significant outcomes are also demonstrated showing increase in client independence, self-efficacy, and ability to participate in family as shown with reduction in behavior symptoms and acquisition of functional skills.

The ABA Treatment Provider Community: State of the Profession

High comparative percentage of newly credentialled providers

The ABA treatment community, in comparison to other medical and behavioral health professionals, have a high number of newly credentialled providers and report inconsistent initial training in new jobs.

The autism behavioral treatment community is largely made up of Behavior Analysts, most of which are certified by the Behavior Analyst Certification Board (BACB) either because their state has no licensure requirements, or their state licensure requires the professional to be a Board Certified Behavior Analyst (BCBA) as the major component of licensing. Currently, only 33 states require licensure to provide ABA services to individuals with ASD. Of those 33 states, nearly 1/3 have only been licensing during the last five years, and some are so recent the states have yet to implement application systems (BACB, 2022).

ABA services are most often directed by behavior analysts (BCBAs) who develop and modify the client's master treatment plan and who supervise behavior technicians, who typically implement the ABA treatment plan, and assistant behavior analysts (Board Certified Assistant Behavior Analysts, "BCaBAs"), who often help develop and/or modify treatment protocols. The BCaBA is an undergraduate certification that can perform the same tasks as the BCBA but must do so under the supervision of a BCBA.

In states with no licensure, health plans must determine which types of national certification they will accept as eligible providers for reimbursement of ABA services. Even in states with licensure, many do not require specific training or certification for the behavior technicians who do the bulk of the hands-on work with the patients, instead depending on the BCBAs oversight of their training. While the BACB does have a registration process for behavior technicians and a code of ethics outlining the BCBAs responsibilities, little operational oversight is provided (BACB, 2020).

The BACB has been certifying behavior analysts for just over 20 years, and the industry has blossomed as a result of state mandates requiring commercial health care coverage for ABA services. Just under 14,000 BCBA candidates were certified in 2014 from inception of certification in 1999 by the BACB (Deochand, N. & Fuqua R. W., 2016). By the end of 2021, a total of 54,223 BCBAs had earned their behavior analyst certification, with 10,460 of those new in 2021 (BACB, 2022). This means that nearly 20% of the workforce is in their first year of practice treating this vulnerable population of often very young children with complex needs.

Given the high influx of new BCBAs, mentorship and oversight by experienced practitioners is a critical component to ensuring quality patient treatment as well as helping new professionals to manage the teams of non-licensed support staff who do the bulk of the direct care. In states where any requirement exists, behavior technicians are only required to have 40 hours of didactic training and very little on the job training.

According to surveys, BCBAs often do not receive adequate mentoring before practicing independently and are often financially incented to carry higher caseloads of clients. Only slightly more than 50% of new BCBAs received pre-service training before working independently. Orientation methods ranged

from verbal instruction, to written instruction, to role play, and to practice with actual clients. Of the group surveyed that received pre-service training, 63% of those indicated "initial orientation prepared them to complete their job responsibilities successfully." A majority were not required to meet a mastery criterion (DiGennaro-Reed, F. D., & Henley, A. J., 2015). With such an inexperienced workforce, it is not uncommon for quality-of-care issues to be reported and even published, though little research has been done to quantify the prevalence.

Professional training on 3rd party reimbursement

Compounding the issue, the educational course work required to become a behavior analyst or to apply for the BCBA certification does not require or provide any specialized training about how to manage the differing types of 3rd party reimbursement for ABA services. Commercial insurers, school systems, and Medicaid funding all play a part in the overall reimbursement of ABA services, and all have very specific requirements for what the member's benefit does and does not cover.

In addition to the lack of educational requirements, there is little guidance from professional associations differentiating ABA services designed for multiple purposes. These differing purposes include:

- ABA treatment of ASD for diagnosed patients as covered by a member's health benefit;
- ABA services for students designed to improve academic performance and that should be covered through the Individuals with Disabilities Education Act (1990) and specified through public education Individualized Education Plans (IEPs); and,
- ABA services designed for respite care required by individuals with such severe deficits that long term support and maintenance is required.

These issues can be especially challenging for ABA therapists of older children who may be receiving health plan coverage for the treatment of ASD at the same time the educational system is funding services to improve academic achievement.

The issue can be further muddled and is often seen in the growing market of private schools with specialized services for individuals diagnosed with ASD. Private school settings by and large do not have access to government funding to educate students diagnosed with a disability but often heavily rely on behavior technicians to provide para-professional services designed to support academic achievement.

Additionally, as a reflection of the emerging market of ABA services, health plan carriers and MBHO's often have differing and varied requirements to demonstrate the medical necessity of treatment, leaving ABA service providers to cope with often very different requirements for each child on their case load. Compounding the issue is inconsistency with application of CPT codes by health plans and the adoption of Healthcare Common Procedure Common System (HCPCS) codes to cover supervision of the behavior technician, a service that is already covered as part of description of service components found under the current category I CPT coding (AMA CPT, 2021). An example of this is the use of H0032 to cover supervision of behavior technicians that is included as part of the service provided under the 97153 code (Adaptive behavior treatment by protocol) and the 97151 code (Adaptive behavior treatment with protocol modification).

For health plans and MBHOs, this often means working with providers who have little knowledge of how third-party funding mechanisms work and who may have little experience as they begin their professional careers. These factors require a very knowledgeable care management workforce who:

- understand the premise of how ABA therapy should work;
- understand the differences in ABA interventions as they may apply to different funding streams; and,
- are savvy enough to spot problematic quality of care issues based on medical record submissions that may negatively impact their members.

No standard record of documentation

While professional organizations such as the Association for Behavior Analysts International (ABAI), the Behavior Health Center of Excellence (BHCOE) and the Council of Autism Service Providers (CASP) are working towards standardization, the profession as a whole does not have a consensus on such basic building blocks as the contents of a standard medical record or the definition of measurable meaningful progress.

With little consistency from provider group to provider group on the necessary components included in a medical record, health plan organizations are left to interpret each medical record as unique, limiting the ability to aggregate data on member progress based on symptom severity and recorded progress as a result of ABA treatment.

This becomes especially problematic as members frequently change service providers over the course of treatment even within the same agency. While an argument can be made for changing BCBA therapists during an episode of care to promote client generalization of acquired skills, the lack of consistency in the documenting the effects of treatment can make it difficult to understand the true extent of progress over time.

Agreement on measures of meaningful progress

Treatment for individuals with ASD is not rehabilitative in nature as it is with the majority of medical and behavioral health commercially covered health benefits. The goal of rehabilitation is to return an individual to their previous baseline functioning or as close to it as possible through medical and behavioral interventions. EIBI is instead habilitative with the goal of improving the clients functioning from a baseline to their highest potential. When successful, individuals with ASD who require substantial support often gain significant independence. Measuring the practical effect of highest possible potential, especially for young children, has become a quagmire of differing opinions.

Many of the state mandates requiring coverage of ABA services for the treatment of ASD use, as proof to support the treatment efficacy of EIBI, research by Lovaas and point to gains measured by standardized testing as proof points (Lovaas, O. I., 1987). Despite this, the industry, as a whole, argues against using standardized intellectual measures as a determining factor for measuring significant progress.

Even under Lovaas's research, only 50% of the children treated made significant progress as a result of treatment as measured by increases in standardized intelligence measures and/or less restrictive placement in educational settings.

Research demonstrating the effectiveness of EIBI has also cited improvements in standardized development measures. As a result, commercial and public payers alike have required the use of periodically administered standardized evaluations to help track progress over time. These instruments include such standardized tools as the Adaptive Behavior Assessment Scale (ABAS), Behavior Assessment System for Children (BASC), the Pervasive Developmental Disorder Behavior Inventory (PDDBI), and the Vineland Adaptive Behavior Assessment (Vineland). Even so, the ABA professional industry have cautioned that such measures often do not reflect significant and meaningful progress as should be determined during a medical necessity review for reimbursement of ABA services (DOD Comprehensive Autism Care Demonstration Annual Report, 2021).

As part of the Tricare ABA Demonstration project, when looking at standardized measures such as the PDDBI, fewer than 50% of children being treated make any gains from treatment, and of those, only 20% show significant improvement based on the measure.

Given a lack of agreement on significant progress, health plans and MBHO's are forced to create medical criteria without peer supported research to determine which members are making significant progress. For health plans, significant progress is often defined as creating an observable change that impacts day to day functioning and provides for a meaningful improvement in individual self-efficacy, independence, and better functioning within the family.

Agreement on length and intensity of care

In addition to difficulties in determining meaningful significant progress during the course of ABA care, there is also little consensus on the intensity and length of care. Several sources point to Comprehensive care lasting between 2 and 3 years; however, it is not uncommon for ABA providers to request ongoing Comprehensive care beyond five or more years, especially for children with comorbid intellectual disabilities (Linstead, et.al 2016, Peters, et,al 2011).

The BACB and behavior analyst professional organizations agree that treatment for children with ASD is delivered in two primary types. Comprehensive treatment, which is most often used with very young children to address all seven domains of functioning, and Focused treatment, which, as the name suggests, focuses on specific domains such as interpersonal social skills or problematic behavior reduction. Comprehensive treatment has a recommended intensity of 25- 40 hours per week, and Focused ABA treatment has a recommended intensity of 10-24 hours per week (BACB, 2014; Davis, 2018).

While up to 40 hours of treatment is often recommended, in practice and in research, under 30 hours of treatment is often associated with client progress. Research also indicates that a greater number of hours delivered to children with similar profiles does not necessarily equate to higher treatment gains when measured using standardized developmental measures (DOD annual report, 2021).

There is also little agreement in the industry on specific guidelines that indicate when patients should be transitioned from Comprehensive ABA treatment to Focused ABA treatment. It is not rare for care managers to be advised by both ABA treatment professionals and/or parents alike that Comprehensive ABA treatment should be continued for as long as the member is still a child and therefore developing.

Dosing of both Comprehensive ABA treatment and Focused ABA treatment becomes a very individualized recommendation that varies across providers, even for individuals with similar symptom presentations, and is often influenced by the availability of the patient. This practice is most evident as providers request additional treatment hours based on their client's availability. With little standardized agreement on objective measurable standards for both dosing of ABA treatment over time and for agreement on maximum potential benefit, health plan care managers often struggle to balance determinations that meet the triple aim of health care excellence (Care, Health, and Cost: Berwick, D. M., and Noland, T. W., 2008).

Identifying comorbid and SDOH issues

As a profession, behavior analysts are not trained to diagnose behavioral health or medical conditions nor understand the complexities around differential diagnosis that are associated with evidence-based clinical best practices. Behavior analysts are also not professionally trained to provide case management assessment services. This includes identifying and addressing social determinant of health issues that are often linked to a poor prognosis for patient treatment across the health industry as a whole. A behavior analysist's repertoire of interventions, unlike many other medical and behavioral professions, is limited to a single grouping of techniques under the category of applied behavior analysis.

As such, behavior analysts must heavily depend on other behavioral health and medical professionals to help understand the comorbid conditions and recommended treatments for their patients. While the BACB and professional organizations such as BHCOE, ABAI, and CASP often stress the importance of coordination of care with other treating professionals, in practice this does not always occur. It is not uncommon to find treatment plans addressing issues of anxiety, attention deficit disorder, feeding disorders, gross movement impairments, and speech disorders without consultation and/or coordination with other health care professionals despite the research supporting evidence-based care for these conditions by specialists.

Summary: State of the Profession

In summary, health plans and MBHO care managers have little support from the ABA professional industry for using standardized intellectual or developmental measures to make medical necessary care determinations, and care managers must grapple with:

- understanding the effects of treatment over time using provider submitted medical records that may not match well from one authorization period to the next,
- making determinations on appropriate dosing based on a membership with a wide range of symptom severity and with little guidance on the most efficient number of hours for treatment or the length of treatment,
- making determinations on which aspects of a provider treatment plan are medically necessary under the member's health plan benefit while denying coverage for treatment plan elements

that support academic achievement or are respite in nature, or that are targeted by other professionals such as occupational therapy, speech and language therapy, physical therapy, and behavioral counseling,
- teasing out how comorbid medical and other behavioral health conditions, including intellectual disabilities, may impact the progress of treatment, and,
- ensuring that members receive Comprehensive evaluations that differentially diagnose comorbid disorders and recommend specialist care for these conditions.

Care Management Systems

Health plan and MBHO Care management systems are primarily rehabilitative by design to provide short term care management support for 30 to 90 days following a member's substantial decline in functioning due to medical illness, disease, or accidents, with the goal of helping the member regain lost functioning and return to baseline functioning.

As such, utilization management and care management systems are often not designed for the specific need of managing members with very intense treatment needs who often make slow progress over a long period of time.

To compound the matter, BCBAs and licensed behavior analysts are not eligible to become certified care managers as the behavior analyst educational curriculum does not prepare them for this service. While BCBAs may be the best at understanding the treatment being provided and the language used by treating professionals to describe member progress and efficacy of treatment results, care manager expertise in assessing whole member and whole family functioning, identifying and addressing SDOH issues and comorbid conditions, improving health literacy, and activities such as supporting medication reconciliation may be missed.

A second confounding issue is that the language of ABA treatment is not understood by the general behavioral health community provider professionals, who often are the ones making utilization management determinations and providing care management for the members.

This can create significant barriers to having clinical conversations between ABA providers and health plan care managers. Common problems faced by care managers include:

- Understanding the difference between treatment goals designed to treat the symptoms of autism versus those that focus on academic achievement or provide paraprofessional services to support academic achievement. For example, the ability to correctly identify the difference between adjectives and adverbs in a sentence.
- Understanding nuances in generalization of treatment. This is often seen in changing goals that indicate a member can learn a specific behavior, but then cannot translate that behavior into action across different settings and/or caregivers. For example, the ability to perform and action in a clinical treatment setting without the ability to generalize to the home or community.
- Spotting incremental goals that have the appearance of making progress but taken as a whole, do not support meaningful progress towards self-efficacy or independence.
- Identifying insufficient treatment dosage for members who could benefit from recommended treatment but that for a variety of reasons are unable to participate in treatment.

- Understanding appropriate clinical rationale from treating professionals who request more than the 10% to 20% of direct services for the purpose of medically necessary protocol modification. Not understanding this difference can lead to authorization for a higher paying CPT code when a lower paying CPT code is adequate and more appropriate.
- Understanding appropriate clinical rationale for higher-than-normal requests for initial and re-occurring treatment evaluations and planning hours.
- Duplication of services between ABA treatment and other specialized services such as speech and language therapy, occupational therapy, physical therapy, and behavior therapy for comorbid behavior health conditions.

Confusion between the health plan care manager and the treating professionals is further complicated by ABA professional organizations advocating for ABA services to treat other medical and DSM-5 disorders including other developmental delays, Down Syndrome, dementia, attention deficit disorder, conduct and oppositional defiant disorders, separation anxiety disorders, selective mutism, pyromania, kleptomania, other eating disorders, tic disorders, enuresis, encopresis, rumination disorder, insomnia, neurocognitive disorders, and traumatic brain injury, to name a handful (Model Coverage Policy, 2020).

In addition to potentially being outside the member's coverage policy for reimbursable ABA treatment, it can also lead to treatment that does not follow established evidenced based medical practice such as consideration of psychiatric medication for the treatment of attention deficit disorder.

Summary: Care Management Systems

Health plans are struggling to manage ABA services due to several factors including:

- care management data systems not designed to collect and track progress over multiple treatment years,
- barriers in technical jargon communication between behavior analysists and other behavior health professionals including psychologists, social workers, professional counselors, nurses, and psychiatrists, and
- agreement on the efficacy for ABA in treating comorbid medical or behavioral health services.

These limitations degrade the ability of the health plan to ensure adherence to all three points of excellent health care services as defined by the triple aim (care, health, and cost). As implied, these limitations can create problematic medical policies or denials that limit the potential growth of children who might benefit from ABA care and can also increase the cost of overall health care by covering ongoing ABA services that do not significantly improve the patient's day to day level of functioning.

Member and Caregiver Needs

Comorbid Disorders

As noted above, individuals with ASD often have comorbid medical and behavior health diagnoses that complicate treatment of their overall health. Teenagers with ASD are more likely to have comorbid behavioral health disorders including anxiety disorder and attention deficit disorder but are less likely to be receiving treatment for these disorders (Patrick, et al., 2021).

50% to 80% of individuals with ASD have sleep disorders, while up to 25% of individuals with ASD have a co-occurring seizure (Volkmar et al, 2014 cited by Davis 2018). Other frequently co-occurring medical disorders include immune dysregulation disorders, allergies, gastrointestinal problems, eating/ feeding problems, and metabolic abnormalities (Treating Autism and Autism Treatment Trust 2013 as cited by Davis, 2018). Differential diagnosis concerns are also prevalent, as evidenced by medical conditions such as Rett syndrome, lead poisoning, deafness, or genetic disorders such as Fragile X, Williams syndrome, Angelman syndrome, Prader-Willi syndrome, and others (Autism Research Institute, DSM 2013).

In young children with ASD, families report sleep behavior concerns specifically related to sleep anxiety, bedtime resistance, and night awakenings, whereas Goldman et al., reports that older children and young adults are more likely to have parent reported difficulties in falling asleep, daytime sleepiness, and consistency in the amount of sleep the individual receives each night (Goldman, Richdale, Clemons & Malow, 2012, as cited by Davis, 2018).

The rates of hospitalization have been researched as being higher for individuals with ASD with a rate of 65.6/100000 admissions. Rates of hospitalization were highest with males between the ages 10 -20. Individuals with ASD also had longer lengths of stay than individuals without ASD (Lokhandwala, T., Khanna, R., West-Strum, D., 2012).

Other examples of preventative healthcare include treatment of pica (or, the consumption of non-edibles), food refusal and food selectivity (Kodak & Piazza, 2008 as cited by Davis, 2018). Between this and the common use of medications with adverse side effects, the risk of obesity is greatly higher in children diagnosed with ASD than that of the general population (Hill, Zuckerman & Fombonne, 2015, as cited by Davis, 2018).

Impact on Family and Social Determinants of Health

In addition to the member's health, the family is often under a very high level of strain in dealing with the burden of caring for an individual with developmental disabilities. As the severity of ASD symptoms increases and/or additional medical and/or behavior comorbid conditions complicate the member's overall health, the higher their caregiver's strain. For many individuals with ASD, life-long respite care will be required even after a full course of ABA treatment.

In the CDC published Autism and Developmental Disability Monitoring report (ADDM), a study was completed for 8-year-old children identified with ASD that indicated approximately one-third (35.2%) also had an intellectual disability. A high percentage of these children, despite best medical and behavioral treatment efforts, will not be able to be fully independent once reaching adulthood and will need ongoing support from family and state Intellectual Developmental Disability wavers (Center for Disease Control and Prevention, 2021).

While many families adjust very well to having a family member with a developmental disability and report an overall positive impact, having a sibling with ASD does alter normative life cycle events. In families with less support, this may become a significant negative impact (Ferraioli, S. J. & Harris, S. L. 2010). More than 50% of parents with children with disabilities require more help managing stress as

compared to families without children with disabilities. Parents of children with disabilities lose, on average, 5 hours per week or 250 hours per year managing children with disabilities. Taken from the National Business Group on Health (Pyrillis, 2015).

The negative impact can include financial stress, family conflict, and psychological and health stress. In one survey, 88% of parents reported experiencing psychological strain and many parents reported at least one chronic physical aliment that they directly attributed to the long-term effects of caregiving. Differential time and attention provided to age-appropriate developing sibling children in the family have also been associated with adjustment problems (Dumke, M. 2015).

Literature suggests siblings of children with ASD have been shown to do more poorly on a number of measures, including "higher levels of internalizing and externalizing disorders, social and behavioral adjustment problems, hassles with sibling behavior, and distressing emotions such as guilt" (Green, 2013). "The conditions that emerge in childhood — autism, ADHD, intellectual disability, learning disorders, tic disorders, conduct disorders and emotional disorders — are 2.5 times more common, overall, among siblings of children with ASD than among siblings of controls" (Jokiranta-Olkoniemi, E., et.al. 2016 as cited by Griswold, 2016).

A review of literature indicated that children with a sibling diagnosed with ASD and growing up under ideal social conditions did as well as siblings in similar social conditions without a sibling with ASD. This finding points to social determinants of health as the complicating factor. Of the participants showing high levels of objective and subjective caregiver strain, most were receiving inadequate support (Kenny & McGilloway, 2007).

The complexity of services available has duplicated efforts in some aspects of care, while leaving critical gaps in services in other aspects (Nolan, Orlando & Leptik, 2007 as cited by Davis, 2018). Given the pervasive deficits and comorbid disorders and large population of individuals with ASD who will not make significant gains with behavioral treatment, care managers are often responsible to help care givers successfully interface with educational systems and navigate complex government programs supporting Individuals with Developmental Disabilities. Often these programs have years long wait lists for services and the support needed to successfully care for these individuals throughout their lives.

With treatment lasting for years, social determinant of health factors not present during the initiation of treatment can and do occur during the treatment episode. Divorce, re-marriage, emerging medical conditions for the member or family, loss of job, change in schools, transportation issues, natural disasters, pandemics, as well as navigating complex educational or government funding systems can occur at any point during the members course of treatment.

As such, Health plan care managers must assess and reassess members and their caregivers periodically over the course of years in an attempt to stay in front of potential social determinant of health issues that may become a barrier to the member's progress in treatment.

Conclusion

Managing ABA benefits for members with ASD is a significant challenge to Health Plan and MBHO's alike. The ABA industry is comparatively new and growing, with a significant proportion of newly credentialled or licensed providers of whom a high percentage report not receiving adequate training in care delivery and managing behavior technician staff. Complicating the issue are factors such as:

- the industry advocating for the expansion of the types of disorders that are eligible for treatment with ABA under health plan policies, without peer review research supporting the treatment as evidenced based medicine,
- the limited ability of behavior analysts to address differentiating diagnostic dilemmas,
- lack of coordination of care, and,
- lack of education in third party billing requirements.

The care management systems used by health plans and MBHOs as well as the professionals traditionally employed for utilization management review are often not prepared for the specifics of managing ABA care. Difficulties arise from systems that are not able to track progress over time, difficulty interpreting medical records without standard components on the data to be included, and a general lack of agreement in the industry on what constitutes meaningful progress.

The professionals traditionally employed to manage utilization for behavior health are often not versed or trained in ABA techniques or jargon and, as such, struggle to have meaningful conversations about member treatment and member progress. Those professionals who are trained in the application of ABA are not qualified to become certified care managers without meeting significant additional requirements such as having dual licensure with other behavioral health degrees.

Because of the plethora of comorbid medical and behavior complications affecting many individuals with ASD and the associated potential negative impact to families, ongoing care management becomes a critical support necessary to ensure members have the greatest possible potential for a positive impact from ABA treatment.

To ensure the triple aim of excellence in health care are met, health plan and MBHO's require:

- a system of management that can adequately measure and track progress over time, including:
    - differentiating member severity of symptoms and length and intensity of treatment to support agreement on adequate dosing, type of treatment provided (Comprehensive versus Focused), and appropriate length of ABA treatment;
    - identification of potential member, caregiver, or provider treatment barriers limiting the efficacy of treatment and smooth transition of care; and,
    - identification of quality of care and/or missed evidenced based best clinical practice interventions likely to produce significant improvement.
- a multi-disciplinary team of professionals who can:
    - interpret medical record submissions,
    - have meaningful clinical conversations with ABA professionals,
    - assess and provide for care management of members and their families that include assessment for SDOH issues, comorbid medical and behavioral issues, as well as support navigation of public and educational third-party payer systems; and,

- provide education and direction as necessary on third party payment requirements to both providers and caregivers.

Ideally, the utilization management and care management staff would have access to a single integrated member treatment assessment platform capable of:

- interpreting provider medical record submissions in a standardized format for review by a multi-disciplinary team,
- tracking member progress over time using standardized assessment tool results and meaningful progress as evidenced by improved member and family functioning,
- identifying potential medical necessity concerns that promote member focused collaborative clinical conversations between providers and utilization management staff,
- identifying and stratifying care management opportunities that may emerge at different times over the course of years, and,
- providing guidance on the appropriate type of treatment and dosing based on overall member functioning, length of treatment, member response to treatment, and symptom severity.

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