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Please see attached response to RFI.

Thank you!

Best,

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**RESPONSE TO RFI  
STATE OF FLORIDA  
AGENCY FOR HEALTH CARE ADMINISTRATION  
REQUEST FOR INFORMATION**

June 3, 2022

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**Early Child Development and Long-term Population Health**

This response to the SMMC RFI for innovative ideas and best practices focuses on the following domains:

- Enhance specialty health plans services to improve outcomes for recipients. Increase the number of plans to address target populations with specific health conditions or needs
- Improve mental health outcomes (e.g., developmental, behavioral, etc.) for children and adolescents.
- Consider innovative delivery methods, including care bundling, that empower recipients in making more informed health care decisions.
- Increase timely access to providers and services.
- Improve recipients' experience with the SMMC Program.
- Improve providers' experience with the SMMC Program.

**Key Ideas**

- **The health and well-being of children, including those with neurodevelopmental disorders (e.g., autism spectrum disorder, ADHD) is critical to our state.**
- **Medicaid is one of the largest investments in children in the state budget, and with the next SMMC procurement there is an opportunity to address barriers to diagnosis and access to services for children with neurodevelopmental disorders to improve outcomes for such children.**

**Background**

Autism Spectrum Disorder (ASD) is a neurodevelopmental disability involving deficits in social communication and social interaction, as well as restricted, repetitive behaviors (American Psychiatric Association, 2013). Current prevalence estimates indicate that 1 in 44 children in the U.S. are diagnosed with autism spectrum disorder (Maenner et al., 2021). ASDs are generally considered lifelong developmental disabilities (Croen et al., 2015; Roux et al., 2014), with a high level of diagnostic stability over time (Giseman-Kiss & Carter, 2020; Hyman et al., 2020; Lord et al., 2006; Turner et al., 2006; Zwaigenbaum et al., 2016).

Despite evidence that ASD can be accurately diagnosed by age 2 (Gordon-Lipkin et al., 2016; Turner et al., 2006; Zwaigenbaum et al., 2016) or even younger (Zwaigenbaum et al., 2009; Zwaigenbaum et al., 2013; cited in Zwaigenbaum et al., 2015a), diagnosis is often not made until closer to 3 to 4 years of age (Fountain et al., 2011; cited in Zwaigenbaum et al., 2015b; also Daniels & Mandell, 2014; Maenner et al., 2021). Significant disparities exist in the diagnosis of ASD, with children from racial and ethnic minority groups as well as lower socioeconomic backgrounds being diagnosed later (Benevides et al., 2021; Constantino et al., 2020; Hyman et al., 2020; Keehn et al., 2021; Mandell et al., 2010).

Research highlights that there are significant barriers to diagnosis which impact access to treatment for families of children with ASD. These include long wait times for specialized evaluations once concerns are identified through screening (Wiggins, Baio, & Rice, 2006; cited in Zwaigenbaum et al., 2016) or failure to refer for follow-up diagnostic testing due to the way that early intervention systems are structured (Williams et al., 2021). Other barriers include the time and cost related to conducting diagnostic evaluations, provider shortages and comfort level with making a diagnosis (Gordon-Lipkin et al., 2016).

Additionally, Keehn and colleagues (2021) highlight the “critical role that insurers play in limiting intervention access” by requiring the use of “specific assessment tools(s) instead of allowing qualified clinicians to use a flexible evidence-informed evaluation process” (p. 599). To this end, many insurers specifically require the Autism Diagnostic Observation Schedule-Second Edition (ADOS) as part of the comprehensive diagnostic evaluation (CDE) in order to authorize interventions for ASD and have limitations on the use of telehealth evaluations for this purpose (Keehn et al., 2021); these practices increase wait times for evaluation, delaying diagnosis and access to services (Gordon-Lipkin et al., 2016; Keehn et al., 2021). However, while the ADOS is considered to be a ‘gold standard’ diagnostic tool (Gordon-Lipkin et al., 2016), no single diagnostic tool is appropriate or sufficient for all cases (Keehn et al., 2021; Hyman et al., 2020).

Given that the “ultimate goal of early detection and screening is to ensure that children with autism spectrum disorder (ASD) can access evidence-based interventions to provide the best opportunity for optimal development and outcomes” (Zwaigenbaum et al., 2009; cited in Zwaigenbaum et al., 2015c, p. S61), delays in acquiring a diagnosis will certainly impact prognosis. Further, as with diagnosis, there is evidence for disparities in access to treatment; there is a greater likelihood of “unmet service needs” among families who are “generally underrepresented in service systems on the basis of race, ethnicity, and income level” (Smith et al., 2020; cited in Hyman & Iadarola, 2020, p. 2). Hyman and Iadarola further note that these “disparities are exacerbated by Medicaid restrictions for insurance mandates, which may disproportionately affect populations that are already underserved” (p. 2).

With respect to intervention, there is sizable empirical support for behavior analytic (e.g., ABA) interventions as efficacious and evidence-based practices (Reichow et al., 2018; cited in Hyman & Iadarola, 2020; Smith & Iadarola, 2015 and Spreckley & Boyd, 2009; cited in Gordon-Lipkin et al., 2016; Steinbrenner et al., 2020). However, it is important that intervention approaches be individualized to meet child and family needs, values and preferences as there is “insufficient evidence to assume a single approach is effective for all individuals with ASD” (Hyman & Iadarola, 2020, p. 2).

As with diagnostic tools, there should not be a ‘one size fits all’ approach to intervention. In this respect, there is an increasing evidence base for interventions that are not usually “covered by insurance mandates” (Hyman & Iadarola, 2020, p. 1). These include naturalistic developmental behavioral interventions (NDBIs; Schreibman et al., 2015; Steinbrenner et al., 2020; Williams et al., 2020) and other intervention approaches including augmentative and alternative communication, peer-based instruction and interventions, cognitive-behavioral instructional strategies, and social skills training (Steinbrenner et al., 2020). Recently, there has been an emphasis on parent-implemented/parent-mediated interventions as an evidence-based and empirically supported treatment approach for children with ASD (Steinbrenner et al., 2020; also see Hyman et al., 2020 for a review). Interventions which incorporate parent-implemented components along with clinician-delivered strategies, have been found to improve outcomes (Landa et al., 2018; cited in Williams et al., 2020). Some empirically supported parent-implemented approaches include Parent-Child Interaction Therapy (PCIT; Allen et al., 2022), Improving Parents as Communication Teachers (Project ImPACT; Ingersoll & Dvortcsak, 2019; Stadnick et al., 2015) and the RUBI Autism Network (Bearss et al., 2015a; Bearss et al., 2015b, Bearss et al., 2018) among many others (Steinbrenner et al., 2020).

Further, there is increasing empirical support for the use of telehealth procedures for diagnosis (Stainbrook et al., 2019; Juárez et al., 2018; cited in Keehn et al., 2021), an area which grew significantly in response to the additional barriers created by the COVID-19 pandemic. Such procedures are needed, since the ADOS cannot be adequately administered via telehealth and its scoring is not valid when administered in-person with PPE (Dattaro, 2021; see also Berger et al., 2021 and Jang et al., 2021; cited in Keehn et al., 2021). Some novel measures with empirical support include the TELE-ASD-PEDS (Wagner et al., 2021) and the Brief Observation of Symptoms of Autism (BOSA; Dow et al., 2021). The Childhood Autism Rating Scale, Second Edition (CARS-2) is another diagnostic tool which has been empirically validated and which has good diagnostic agreement with the ADOS (Dawkins et al., 2016; Chlebowski et al., 2010; Reszka et al., 2014; cited in Hyman et al., 2020). A benefit of the CARS-2 is that it can be rated by clinicians based on observation conducted via telehealth. There has also been an emergence of research supporting the efficacy of telehealth-based interventions (see Hyman et al., 2020), which has the potential to improve access to care by being more cost-effective, reducing wait times for services, and reducing barriers for families who may have difficulty traveling to clinics for services (Gordon-Lipkin et al., 2016; Keehn et al., 2021).

## Recommendations

Based on the above considerations, we recommend that AHCA consider the following:

### Diagnosis:

- Identification of children at risk for ASD should first include screening by a medical provider (e.g., neurologist, pediatrician), a birth-3 intervention program, or mental health professional, and should include the administration of an **ASD-specific screening measures** (e.g., MCHAT-R, STAT, CSBS, SCQ; Lipkin & Macias, 2020; Norris & Lecavalier, 2010). They would identify those children at most risk for ASD and refer for a comprehensive assessment.
- ASD diagnoses should be made on the basis of a **comprehensive assessment**, which includes careful review of the child's behavioral and developmental history **and** direct observation of symptoms (e.g., ADOS-2, CARS2, BOSA, TELE-ASD-PEDS; Hyman et al., 2020).
  - The history of symptoms of ASD can be supported by questionnaires such as the Social Communication Questionnaire (SCQ), Social Responsiveness Scale (SRS) and/or the Autism Spectrum Rating Scale (ASRS). None of these questionnaires is sufficient alone to make a diagnosis of ASD, but all provide a structured approach to elicit symptoms of ASD.
  - Observation of ASD symptoms should include the administration of an observational (and play-based for young children) ASD-diagnostic tool such as the ADOS-2, CARS2, BOSA, or TELE-ASD-PEDS, **through telehealth, in-person, and/or hybrid models**.
    - Anyone with a master's degree (MA, MS, MSW, CAGS) in psychology, school counseling, occupational therapy, speech-language pathology, social work, education, special education, or a related field can administer the ADOS-2 (or similar measure) if properly trained.
    - Short clinical visits may not be sufficient, even for experienced clinicians, to accurately recognize symptoms of ASD (Gabrielsen, et al., 2015).
  - A comprehensive evaluation should also include formal assessment of language, cognitive or developmental skills, and/or adaptive abilities.

- The integration of historical information **and** objective observation by a clinician trained to diagnose autism and related conditions to inform the DSM-5 diagnostic criteria is the critical element to diagnostic evaluation.
- Although most children will need to see a specialist (such as a child psychologist, developmental-behavioral or neurodevelopmental pediatrician, neurologist, or psychiatrist) for a diagnostic evaluation, general pediatricians **using the diagnostic clinical best practices outlined above** can make an initial clinical diagnosis (Hyman et al., 2020).
- Medicaid should cover the cost of a comprehensive assessment when such assessment is warranted based on identification of risk for ASD by a medical professional, early intervention birth-3 provider or mental health professional using ASD-specific screening measures (e.g., MCHAT-R, STAT, CSBS, SCQ)
- Since ASD is a lifelong neurodevelopmental disorder with high stability over time (Giseman-Kiss & Carter, 2020; Hyman et al., 2020; Lord et al., 2006; Turner et al., 2006; Zwaigenbaum et al., 2016), Medicaid should not continue to require periodic re-evaluations [i.e., comprehensive diagnostic evaluations (CDEs)] once a diagnosis has been established in order to maintain authorization for services. This creates a burden for families, is not cost-effective, and adds to the long wait times for specialized evaluations for children seeking initial diagnoses.
  - Instead, determining whether services should continue to be re-authorized should be based on continued need for services, such as continued functional impairment, maladaptive behaviors and/or adaptive functioning. These could be completed by the current ABA or other services provider.

### Intervention

- ABA should be covered for children with behavioral concerns associated with other diagnostic groups, other than ASD (e.g., ADHD)
- Coverage should be expanded to include evidence-based approaches that have been highlighted in the National Clearing House on Autism Evidence & Practice (Steinbrenner et al., 2020), a report based on a systematic review of intervention research studies published between 1990 and 2017.
  - These include many approaches that have not traditionally been covered by insurance mandates (Hyman & Iadorola, 2020) but for which significant evidence exists for their efficacy, including (but not limited to):
    - Naturalistic Developmental Behavioral Interventions (NDBIs; Schreibman et al., 2015). Some examples include:
      - Pivotal Response Treatment (PRT; Koegel et al. 1987; Hardan et al., 2015; Suhrheinrich et al., 2018)
      - Joint Attention Symbolic Play and Emotion Regulation (JASPER; Kasari et al., 2006; Kasari et al., 2021)
      - Early Start Denver Model (Fuller et al., 2020; Howard & Dawson, 2020; Rogers & Dawson, 2009)
      - Social Communication/Emotional Regulation/Transactional Support (SCERTS; Prizant et al. 2003)
    - Parent-mediated treatment or parent management training. These are evidence-based approaches appropriate for young children with ASD and/or developmental concerns and/or co-occurring conditions (e.g., maladaptive behaviors; Hyman et al., 2020). Some examples include:
      - Parent-Child Interaction Therapy (Allen, et al., 2022)
      - Improving Parents as Communication Teachers (Project ImPACT; Ingersoll & Dvortcsak, 2019; Stadnick et al., 2015)
      - RUBI Autism Network (Bearss et al., 2015a; Bearss et al., 2015b, Bearss et al., 2018)

Medicaid financing is one of the most powerful mechanisms that state and federal governments have to improve child health and well-being, especially among children who face challenges due to neurodevelopmental disorders. As healthcare systems transition to value-based arrangements, health-policy leaders at AHCA have the opportunity to improve outcomes for children with the potential for long-term impact. The next SMMC procurement is an opportunity to explore how align best practices in the diagnosis and intervention of autism spectrum disorders with innovative approaches to decrease barriers, increase cost-effectiveness, and improve access to care, and ultimately, child outcomes.

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