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Report on barriers, strategies and effectiveness of practices in the identification of children between the ages of 1-3 with symptoms of autism spectrum disorder

Disability Services Division

November 2020

For more information contact:

Minnesota Department of Human Services
P.O. Box 64967
St. Paul, MN 55164-0967

651-431-4300

651-431-4300 or 866-267-7655

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I. Executive summary

The Minnesota Department of Human Services (DHS) developed this report in response to a legislative mandate (Minn. Stat. §256B.69, subd. 32a), requiring managed care organizations (MCOs) to submit the following information annually. The requirement allows DHS to monitor early screening, diagnosis and treatment services for young children served by the MCOs.

This report identifies barriers to screening, diagnosis and treatment of young children, ages 1-3. It also identifies strategies MCOs and county-based purchasing (CBP) plans are using to address those barriers. It includes recommendations from each MCO about:

- How to measure and report on the effectiveness of the strategies to improve access for young children to periodic developmental and social-emotional screenings (as recommended by the Minnesota Interagency Developmental Screening Task Force)
- Diagnosis.

Treatment recommendations include:

- Training and education for providers on best practices in screening and diagnostic tools
- Training and education for parents and caregivers on typical developmental milestones and the early warning signs of autism spectrum disorder (ASD)
- Culturally meaningful training and education on the early signs of ASD for parents and providers in their preferred language
- Efforts to build provider capacity to reduce wait times and improve timely access to services
- Increased coordination across education, health care, mental and behavioral health resources.

As public program providers, MCOs and county-based purchasing plans have an important role to play in the development of best practices in policies and procedures for screening, diagnosis and treatment of young children in Minnesota. It is also critical to involve other state agencies and multidisciplinary providers who are part of the system of care and supports for children with ASD. This report will provide further analysis and direction for improving timely access to services for young children with developmental concerns.

II. Legislation

The legislative authority requiring that MCOs report barriers to screening, diagnosis and treatment of young children between the ages of 1 and 3 is found in Minn. Stat. 2018, §256B.69, subd. 32a.

Initiatives to improve early screening, diagnosis, and treatment of children with autism spectrum disorder and other developmental conditions.

(a) The commissioner shall require managed care plans and county-based purchasing plans, as a condition of contract, to implement strategies that facilitate access for young children between the ages of one and three years to periodic developmental and social-emotional screenings, as recommended by the Minnesota Interagency Developmental Screening Task Force, and that those children who do not meet milestones are provided access to appropriate evaluation and assessment, including treatment recommendations, expected to improve the child's functioning, with the goal of meeting milestones by age five.

(b) The following information from encounter data provided to the commissioner shall be reported on the department's public Web site for each managed care plan and county-based purchasing plan annually by July 31 of each year beginning in 2014:

> (1) the number of children who received a diagnostic assessment;
>
> (2) the total number of children ages one to six with a diagnosis of autism spectrum disorder who received treatments;
>
> (3) the number of children identified under clause (2) reported by each 12-month age group beginning with age one and ending with age six; and
>
> (4) the types of treatments provided to children identified under clause (2) listed by billing code, including the number of units billed for each child.

(c) The managed care plans and county-based purchasing plans shall also report on any barriers to providing screening, diagnosis, and treatment of young children between the ages of one and three years, any strategies implemented to address those barriers, and make recommendations on how to measure and report on the effectiveness of the strategies implemented to facilitate access for young children to provide developmental and social-emotional screening, diagnosis, and treatment as described in paragraph (a).

III. Introduction

One in 54 children[1] has been identified with ASD, according to estimates from Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring. The CDC defines ASD as "a developmental disability that can cause significant social, communication and behavioral challenges."[2]

ASD usually appears during the first three years of a child's life. Most parents first notice the loss of skills or developmental delays when their children are 15 to 18 months old. Even though researchers cannot point to one specific cause for ASD, research consistently suggests that early diagnosis and intervention offer the best chance for improving function and increasing the child's progress and outcomes.

A recent study from the Minnesota Autism Developmental Disabilities Monitoring network in Hennepin and Ramsey counties found approximately 1 in 44 or 2.3 percent of 8-year-old children were identified with ASD. The average age of diagnosis was 4 years 8 months. ASD might be diagnosed in children as young as 18 to 24 months; however, many children are identified when they enter school or when social demands exceed their skill levels. A delay in proper diagnosis results in a delay in accessing early intervention services.

Despite research indicating early intervention as best practice, for many children ASD is diagnosed several years after the appearance of symptoms (Mandell et al., 2009)[3] and is often misdiagnosed (Mandell, Ittenbach, Levy & Pinto-Martin, 2007)[4]. Late diagnosis and misdiagnosis of ASD disproportionately affects children from culturally and racially diverse communities (Mandel et al., 2009; Mandell, Ittenbach, Levy & Pinto-Martin, 2007). In one study looking at 406 Medicaid-eligible children, researchers found African-American children were found to be 2.6 times less likely than white children to receive an autism diagnosis at their first specialty care visit (the most common misdiagnosis for this population was ADHD) (Mandell, et al.).

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[1] CDC. (2018). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. Accessed from https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm

[2] CDC. (2016). Autism spectrum disorder. Accessed from https://www.cdc.gov/ncbddd/autism/index.html

[3] Mandell, D.S. et al. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. American Journal of Public Health, 99(3), 493-498

[4] Mandell, D.S, Ittenbach, R.F., Levy, S. E. & Pinto-Martin, J.A. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. Journal of Autism and Developmental Disorders, 37(9), 1795-1802

Children who are consistently seeing a primary care doctor are more likely to receive an earlier diagnosis of autism; children who switched pediatricians in their first five years of life had later diagnoses than their peers (Daniels and Mandell, 2014)[5]. Simply seeing more doctors does not always result in earlier diagnosis, however. Some studies have found that seeing a greater number of physicians or other healthcare professionals is associated with a later age at diagnosis (Daniels and Mandell, 2014)[6].

A strong evidence base shows disparities in the age at which white children and black, indigenous and children of color are diagnosed with autism spectrum disorder (Daniels and Mandell, 2014; Fountain et al., 2011; St. Amant et al., 2018)[5,7,8]. There are a variety of hypotheses as to why this difference exists, all of which are related to social and cultural factors; there is no evidence suggesting that autism prevalence varies by race (Burkett, Morris, Manning-Courtney, Anthony, and Shambley-Ebron, 2015)[9].

During the past several years, DHS and its contractors asked stakeholders about access to intervention services and supports for children with ASD and their families. Wilder Research and the Minnesota Department of Human Services worked together to create the following resources, which could be used by state agencies, providers, or other stakeholders to share information with families of a child with autism:

- Autism Pathways, which has been translated into Hmong, Somali and Spanish
- Overview of Medical Identification and Educational Determination of Autism Spectrum Disorder

Additionally, the following materials could similarly be useful for stakeholders:

- Screening fact sheet for doctors and pediatricians (PDF)
- Centers for Disease Control and Prevention Autism Spectrum Disorder website
- Minnesota Department of Health Recommended Screening Instruments webpage.

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[5] Daniels, A. & Mandell, D. (2014). Explaining differences in age at autism spectrum disorder diagnosis: A critical review. Autism, 18(5), 583-597.

[6] Ibid.

[7] Fountain, C., King, M., & Bearman, P. (2011). Age of diagnosis for autism: Individual and community factors across 10 birth cohorts. Journal of Epidemiology and Community Health, 65(6), 503-510.

[8] St. Amant, H., Schrager, S., Pena-Ricardo, C., Williams, M, & Vanderbilt, D. (2018). Language barriers impact access to services with autism spectrum disorders. Journal of Autism and Developmental Disorders, 2018(48), 333-340.

[9] Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., & Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. Journal of Autism and Developmental Disorders, 2015(45), 3244-3254.

Another result of this engagement process was a report to the Legislature in December 2012 titled A Report on Early Intervention Services for Minnesota's Children with Autism Spectrum Disorders. The report includes a section of stakeholder responses highlighting key characteristics of effective early intervention services broken down into 11 categories. Three of those categories relate to the information MCOs are required to provide under Minn. Stat. §256B.69, subd. 32a. Each of these categories includes comments (identified below by section name) that relate to practices the MCOs have in place or are trying to implement, but have encountered barriers to implementation:

- Early Means Early:
  - Early screening and diagnosis are the keys to effective intervention.
  - Early intervention has been found to be the most effective. It is also often easier for children to access services at a younger age and to receive those services in their home or other natural environments.
  - Providers need a more accessible and systematic process for conducting screening and diagnostic assessment.
- Individualized to unique needs:
  - Providers will show respect for the unique needs, values and perspectives of the person with ASD and his or her family.
  - Providers will design programs around the specific needs of the person with modifications that match their spectrum profile, age and developmental stage. They will use individualized motivational strategies and behavioral and developmental support systems.
  - Providers will deliver services in the home or in a center, depending on the child's needs.
- Data-driven with frequent, ongoing assessment:
  - Providers will identify best practices to track progress toward positive outcomes for each child receiving early intensive intervention services.

DHS has a number of data sources that describe characteristics of children with an ASD. But, it does not have information – beyond claims data – about the screening process used by each MCO, the barriers they encounter and the strategies they use to ensure children have access to appropriate care. The information from MCOs allows DHS, during this reporting cycle, to better understand what is occurring. It also helps to raise awareness for future work, to develop and improve early access to screening, diagnosis and treatment, especially for children who do not meet milestones.

For the seventh year, MCOs met their Families and Children Contract obligation by providing the requested information (see questions 1 to 7) on implementing strategies to reduce barriers to screening, diagnosis and treatment for children, ages 1-3. Below are the MCO responses.

IV. Questions and responses

Question 1: What social-emotional and developmental screening tools are being used by pediatric and family practice clinics for children, ages 1-3?

The Minnesota Interagency Developmental Screening Task Force recommends the following developmental and social-emotional screening instruments for use in Minnesota programs that provide screening for children from birth to 5 years old. The task force approved this list in July 2018 and will update the list as it reviews new or revised developmental screening instruments and in response to statutory, rule or regulatory changes that affect comprehensive screening programs in Minnesota.

- All Instruments at a Glance (PDF) lists all recommended developmental and social-emotional screening instruments by type, age, multiple languages (yes/no), and program.
- Instruments at a Glance for Minnesota Clinics and Providers (PDF) lists a subset of recommended screening instruments that are more practical for use in primary care clinics.

The most commonly used developmental screening tools conducted by parent report, reported by the participating MCOs, were the Ages & Stages Questionnaires: 3rd edition (ASQ-3) and the Parent Evaluation of Developmental Status (PEDS).

The most commonly used developmental screening tools conducted by observation were: the Battelle Developmental Inventory, Second Edition (BDI-2); the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-3); the Brigance Early Childhood Screens (BECS); the Developmental Indicators for Assessment of Learning, Fourth Edition (DIAL-4); and the Early Screening Inventory-Revised (ESI-R). Less commonly used observational screening tools included the Minneapolis Preschool Screening Instrument, Revised (MPSI-R).

The most commonly used social-emotional screening tools were the Ages & Stages Questionnaires: Social-Emotional (ASQ-SE) and the Modified Checklist for Autism in Toddlers (M-CHAT). Less commonly used social-emotional screening tools used were the Brief Infant Toddler Social Emotional Assessment (BITSEA) and the Pediatric Symptom Checklist (PSC).

None of the MCOs reported any use of the following screening tools: Survey of Wellbeing of Young Children (SWYC); Early Screening Profiles (ESP); FirstSTEPS Screening Tool; Infant Development Inventory (IDI); Child Development Review Parent Questionnaire (CDR-PQ); and Denver II. These instruments do not meet the instrument review criteria outlined by MDH. We do not recommend these instruments for use in Minnesota's screening programs and do not approve them for use in Minnesota's Early Childhood Screening program. We recommend programs that use these instruments change to a recommended observational screening tool.

For more information about the screening instruments, see MDH's Developmental and social-emotional screening of young children (0-5 years of age) in Minnesota webpage.

Blue Plus

Pediatric & Family Practice Clinics do not use a single uniform screening tool. Acceptable tools can include:

- Developmental screening instruments (Parent report):
  - Ages & Stages Questionnaire, Third Edition (ASQ–3)
  - Parents' Evaluation of Developmental Status (PEDS)
- Developmental screening instruments (Observational):
  - Battelle Developmental Inventory, Second Edition (BDI–2)
  - Bayley Scales of Infant and Toddler Development, Third Edition (Bayley–3)
  - Brigance Early Childhood Screens Three (BECS)
  - Developmental Indicators for Assessment of Learning, Fourth Edition (DIAL–4)
  - Early Screening Inventory, Revised (ESI–R), 2008 Edition
  - Minneapolis Preschool Screening Instrument, Revised (MPSI-R) 2015
- Social-emotional instruments:
  - Ages & Stages Questionnaires: Social-Emotional (ASQ-SE)

HealthPartners

Our contracted providers are required to follow those recommended by Minnesota Interagency Developmental Screening Task Force per DHS provider manual.

- Developmental screening instruments (Parent report):
  - Ages & Stages Questionnaire, Third Edition (ASQ–3)
- Social-emotional instruments:
  - Ages & Stages Questionnaires: Social-Emotional (ASQ-SE)

Hennepin Health

- Developmental Screening instruments (Parent report):
  - Ages & Stages Questionnaire, Third Edition (ASQ–3)
- Social-emotional instruments:
  - Ages & Stages Questionnaires: Social-Emotional (ASQ-SE)
  - Modified Checklist for Autism in Toddlers (M-CHAT)

Itasca Medical Care

In Itasca County the majority of clinics continue to utilize the:

- Developmental Screening Instruments (Parent report):
    - Ages & Stages Questionnaire, Third Edition (ASQ–3)
    - Parents’ Evaluation of Developmental Status (PEDS)
- Social-emotional instruments:
    - Ages & Stages Questionnaires: Social-Emotional (ASQ-SE)
    - Modified Checklist for Autism in Toddlers (M-CHAT)

PrimeWest

PrimeWest Health facilitates the following screenings that are available for children ages 0-3, and requires that providers complete these at every well-child visit or Child and Teen Checkup (C&TC). The screenings are added to members’ electronic medical records (EMRs) as applicable.

- Developmental Screening Instruments (Parent report):
    - Ages & Stages Questionnaire, Third Edition (ASQ–3)
    - Parents’ Evaluation of Developmental Status (PEDS)
- Developmental Screening Instruments (Observational):
    - Battelle Developmental Inventory, Second Edition (BDI–2)
    - Bayley Scales of Infant and Toddler Development, Third Edition (Bayley–III) Screening Test
    - Brigance Early Childhood Screens (0 – 35 months, 3 – 5 years, K & 1)
    - Developmental Indicators for Assessment of Learning, Fourth Edition (DIAL–4)
    - Early Screening Inventory, Revised (ESI–R), 2008 Edition
    - Minneapolis Preschool Screening Instrument, Revised (MPSI–R)
- Social-emotional instruments:
    - Ages & Stages Questionnaires: Social–Emotional (ASQ:SE)
    - Brief Infant Toddler Social Emotional Assessment (BITSEA)
    - Modified Checklist for Autism in Toddlers (M-CHAT)

South Country Health Alliance

South Country Health Alliance does not require providers to use a specific social-emotional and developmental screening tool. We follow the guidance for tools as listed in the DHS Minnesota Healthcare Program (MHCP) manual, which may include the following screening programs: Child & Teen Checkups (C&TC)/ Early Periodic Screening Diagnosis and Treatment (EPSDT) (DHS, MDH), Early Childhood Screening (MDE), Follow Along Program (MDH), and Head Start (MDE).

- Developmental screening instruments (Parent report):
    - Ages & Stages Questionnaire, Third Edition (ASQ–3)
    - Parents' Evaluation of Developmental Status (PEDS)
- Developmental screening instruments (observational):
    - Battelle Developmental Inventory 2nd Edition (BDI-2)
    - Bayley Scales of Infant and Toddler Development, Third edition (Bayley-III)
    - Brigance Early Childhood Screens III
    - Developmental Indicators for Assessment of Learning Fourth Edition (DIAL–4)
- Social-emotional screening instruments:
    - Ages & Stages Questionnaires: Social–Emotional (ASQ:SE)
    - Brief Infant Toddler Social Emotional Assessment (BITEA)
    - Pediatric Symptom Checklist (PSC)

UCare

UCare does not require providers to utilize a specific socio-emotional and developmental screening tool. UCare encourages providers within our network to use one of the screening tools recommended by the Minnesota Interagency Developmental Screening Task Force. Providers have the ability to access screening and recommended instrument information from the MDH website (Developmental and social-emotional screening of young children (0-5 years of age) in Minnesota). Providers are also encouraged to visit the DHS website (Children's Mental Health Screening) for information on early childhood screenings and C&TC.

Question 2: In what settings are social-emotional and developmental screenings conducted for children ages 1-3? In which of these settings are screenings reimbursable as health care services?

The most common settings for social-emotional and developmental screenings are primary care clinics, certified behavioral health clinics or public schools. Many screenings are also conducted in the home in association with family home visits, which are reimbursable. The MCOs reimburse for screenings conducted by eligible licensed health-care professionals.

The MCOs use programs such as Follow Along, Child & Teen Checkups, Help Me Grow, Family Home Visiting, Public Health and Woman and Infant Children (WIC) or other local programs to promote early social-emotional and developmental screenings.

MDH recommends the following programs: Minnesota Early Childhood Screening program is targeted for ages 3 to 4 years and is required before public school entrance. The Follow Along Program is a developmental-screening program targeted at Minnesota children ages birth to 36 months. Child and Teen Checkups (C&TC) is the Minnesota Early and Periodic Screening, Diagnosis and Treatment (EPSDT)

program. For more information, visit [C&TC - Department of Human Services] or [C&TC - Department of Health]. Newborns, children and adolescents through the age of 20 should get routine child and teen checkups. Family home visiting (FHV) is a voluntary, home-based service ideally delivered prenatally through the early years of a child's life. It provides social, emotional, health-related and parenting support and information to families, and links them to appropriate resources.

Blue Plus

- The most common settings for these screenings are family practice clinics, primary care clinics and specialty clinics.
- These services are reimbursable as health care services in all of the above settings.

HealthPartners

- Child and teen checkups and well-child visits in a clinic setting – reimbursable
- Early childhood center (Head Start) – reimbursable
- FHV – reimbursable

Hennepin Health

- Screenings are completed in a variety of settings including primary-care, pediatric and family practice, Federally Qualified Health Clinics (FQHCs) and Hennepin County Public Health Clinics, and WIC clinics.
- Screenings provided by primary care, pediatrics, FQHC clinics and public health clinics are reimbursed.
- According to Hennepin County Public Health Department, screens done at the WIC clinic have reimbursement challenges.
- These are not documented in typical systems like electronic health records (EHRs); rather documented in SQL Server Integration Services (SSIS).

Itasca Medical Care

- Itasca County's school districts' early childhood programs, including Head Start and Invest Early, complete the social-emotional and developmental screening for children birth to 7 years of age upon enrollment into the program. This screening is free to anyone and is not billed or reimbursed by any health insurance. The school psychologist can do formal testing, utilizing the Autism Spectrum Rating Scale and Autism Diagnostics Observation Scale (ADOS) with the help of parents and teacher. This can give an educational determination of ASD, a referral must be made for a medical diagnosis.
- Starting at 4 months of age, ASQs are sent in the mail every 4 months and ASQ:SEs are sent every 6 month for parents to complete. This goes up to age 3.

- We make referrals to Help Me Grow (school district birth to three program). Help Me Grow is administered through the local school districts and they complete a special education evaluation.
- Healthy Families Itasca-home visiting program for first time, pregnant moms who qualify for WIC. Evidence-based parenting curriculum, intensive home visiting. This program goes up to the child turning 3 years of age. ASQ and ASQ: SEs are administered in this program as well along with any necessary referral to Help Me Grow. This is a free service offered by the county. If there is a noted concern or delay on either scale, children may be referred to their primary care provider for additional screening or an out of network provider.
- Screenings are reimbursable when completed by a clinic or licensed psychologist (LP).

PrimeWest

Social-emotional and developmental screenings are reimbursed and conducted as health care services in clinical settings, including the following:

- Medical and behavioral health clinics
- Health Care Homes (HCH)
- Public Health outreach, including WIC; FHV; and Public Health nurse visits

South Country Health Alliance

Screenings are conducted in: primary care clinics, pediatric clinics, behavioral health clinics and centers (e.g. mental health or autism), and public health departments.

UCare

- Based on claims data, social-emotional and developmental screenings are conducted in primary clinics, community health clinics, rural health clinics, schools and public health clinics.
- UCare reimburses eligible licensed health care professionals who perform C&TC visits as well as social-emotional and developmental screenings in settings where health care services are provided.

Question 3: What is the protocol for referral and diagnoses if the screening(s) are positive?

All of the MCOs identified some process for formally or informally sending children on to receive an assessment. Each MCO's protocol indicates whether or not a formal referral or prior authorization is required. Generally, a referral or prior authorization is not required to access most services if the screening is positive.

Each plan provides individualized services. The majority of plans indicated that whoever conducts the screening determines where the child should be sent for follow-up. Referrals often include Help Me Grow or a special education evaluation, Follow Along program, speech and language pathology, occupational therapy or physical therapy. If a diagnosis of ASD is suspected, the MCOs will often refer to a medical doctor or mental health professional to complete additional assessments, such as the Comprehensive Multi-Disciplinary Evaluation (CMDE).

Some of the plans have a process for follow-up to ensure the referrals are followed through with. We highly encourage this as there are often barriers to families accessing services and supports.

Blue Plus

- Individual clinics maintain their own internal referral protocols for positive screenings.
- Blue Plus does not require prior authorization, but highly encourages referrals to participating network providers.
- Blue Plus does not require prior authorization for the CMDE for ASD services.
- Blue Plus has clinical guides available to assist with questions or referrals to participating providers.

HealthPartners

- If conducted during a Child and Teen Checkup, the provider indicates that a development and/or social-emotional screen was conducted (96110 and 96127) on the C&TC claim.
- If concerns are identified, a provider would refer a child to additional medical services (such as physical or occupational therapy) and/or Help Me grow. If a referral is made during the C&TC visit, the clinic would add the referral code to the C&TC claim.

Hennepin Health

- Depending upon where the screening was completed and following a parent/guardian discussion, the following referrals occur:
  - Mental health / behavioral health/ school districts/ Help Me Grow/ speech, occupational therapy/ physical therapy/ and EIDBI services
  - If screenings are completed in a clinic setting, a referral to county public health (Front Door Hennepin County) is made.
  - No authorization is required for any of these services.

Itasca Medical Care

- Through the assessment(s), if they determine a need for further evaluation, the clinics make a referral to a pediatric MD who has an interest in ASD and they are also referred to applicable therapies such as speech therapy, occupational therapy and physical therapy.

- Clinics may also refer to Itasca County's early childhood program or Help Me Grow program for additional support and services.
- Referrals are also made to Behavioral Dimensions, which is a business that provides intensive behavioral intervention.
- The Itasca County Disability Resource Group, which was established by mothers, assists parents in accessing area resources. The group has also created a resource book that includes local, state and nationwide resources for parents.
- If problems are identified by the Public Health Follow Along Program, they, too, can make a referral to the Help Me Grow program and notify the child's primary care provider.
- In order to receive the diagnosis for ASD, residents of Itasca County need to go to the metropolitan area or other out-of-network resource.

PrimeWest

- When a child has a positive screening, the primary care provider or public health nurse should refer the child for a comprehensive evaluation with a mental health professional specializing in young children and ASD.
- As soon as an infant/toddler under age 3 is suspected of having a delay or developmental disorder, the child should be referred immediately to Early Childhood Education Services.
- If the child demonstrates language delays, the child should undergo an audio logic evaluation.
- The primary care provider/public health nurse should schedule a follow-up visit within one month of the positive screen.

South Country Health Alliance

- Typically, a referral or prior authorization is not needed for most services.
- If the screening is positive, referrals could be made to a mental health professional for an extended diagnostic assessment, pediatric Physician, EIDBI Provider, Early Childhood Education Services or Help Me Grow programs.
- On a C&TC claim, the provider must indicate the referral codes (AV - patient refused referrals, ST - Referral to another provider for diagnostic or corrective treatment or scheduled for another appointment with screening provider for diagnostic or corrective treatment) for at least one health problem identified during an initial or periodic screening service, S2 - patient is currently under treatment for referred diagnostic or corrective health problems, NU – no referral made

UCare

- The majority of developmental problems for children age 1-3 years old are identified during primary care or pediatrician visits.

- If a pediatrician or primary care physician requests an evaluation by a mental health professional or other specialist, no referral from UCare is required.
- The member or guardian may also self-refer and has the ability to go directly to the provider of their choice.
- If requested, UCare can assist the member or family with finding a provider. This assistance can be provided to the member or the member's healthcare practitioner.

Question 4: What barriers has the MCO identified to providing screening, diagnosis and treatment to children, ages 1-3?

The MCOs have listed several barriers to providing screenings, diagnosis and treatment to children ages 1 to 3. One of the most commonly reported barriers is that families struggle to identify the early signs of ASD. It is a common misconception that an educational determination is sufficient to access services and supports. Providers also report that families are reluctant to follow up on referrals or accept that their children are experiencing developmental delays. English-language learner families may be additionally affected by screening tools that are not adapted to reflect their language, cultural values and customs.

Providers struggle to cover the cost of purchasing and training staff on ASD-specific screening and diagnostic assessment tools. Providers also struggle to complete a thorough assessment during a typical well-child checkup. A formal medical diagnosis from a mental health professional or a medical doctor who specializes in diagnosing ASD is required to access many services. Although it is recommended that a child receive a formal diagnosis, families should be encouraged to receive the educational evaluation that has no cost to them. Children are often able to access supports through their local school district within 30 to 45 days.

Lack of coordination between service providers and all payment plans often leaves families to coordinate services on their own. There are also barriers to exchanging and sharing information between mental health professionals and the primary care providers.

There is a shortage of qualified providers in the state who are specially trained to provide ASD screenings, diagnosis and treatment to meet the high demand for services. The shortage of providers means long waiting lists or the child does not receive services at the intensity that is recommended. The shortage of qualified providers disproportionately affects rural Minnesota where families are often forced to move or travel a great distance to access services and supports.

These barriers make it especially important to work on one of the strategies that the health plans are implementing; namely, to ensure that clients receive child and teen checkups (C&TC) and are aware that this service is provided to them at no cost. In addition, the proposed strategies to address these barriers should be targeted across state agencies, counties and MCOs.

Blue Plus

- Educating families on where and how to get screenings.
- Providers also struggle with the time it takes to incorporate these screenings into their visit.
- Access to mental health providers that specialize in early childhood treatment can also be a barrier for timely services.

HealthPartners

- Duplication of services conducted in various settings including the clinic, school districts, home visits and early childhood facilities.
- Expense to providers of purchasing the screening tools (ASQ and ASQ-SE) especially for electronic or online versions.
- Clinic workflow - clinics must adjust their workflows for certain ages to do screening as well as account for timing of collecting and evaluating the results from the parent-reported tools.
- Visit time – some providers feel there is not enough time in a standard well-child/C&TC visit to fully discuss the results of a developmental or social-emotional screen.
- Access to follow-up services – Shortage of children’s mental health providers throughout state makes it difficult for children to receive services even after a referral, especially in more rural communities.

Hennepin Health

- Lack of understanding of importance of C&TC screening.
- Time to follow up, information sharing and potential for duplication.
- Lack of knowledge of billing and reimbursement coding by public health and providers.
- Cultural barriers related to the social-emotional screening. Some families are reluctant to accept referrals for follow up of social-emotional delays.

Itasca Medical Care

- The primary barrier identified by providers is parent/caregiver's reluctance to accept that their child is experiencing significant delays in their social-emotional functioning and/or overall developmental delays.
- Providers also indicate that parents have a misconception of the early signs of ASD.
- In addition, Itasca County does not have local access to diagnostic specialists. Many of the primary care providers are not comfortable making a diagnosis of ASD and local mental health providers do not provide diagnostic services for ASD. Currently Itasca County has one provider that utilizes Applied Behavioral Analysis (ABA); however, they have limitations as to how many cases they can take. Additional local providers are needed to better serve this population.

- Another barrier for screening is parents' lack of knowledge that screening is available at no cost through the school district's early childhood education program. Anyone can make a referral to the program so there is no barrier associated with that.
- The primary barrier is that it takes a lot of time before a medical diagnosis is made as they have to go to the metropolitan area. However, in the meantime they would have an educational diagnosis, which does allow the parent/ child(ren) to receive services.
- Lack of EIDBI providers in the plan area.

PrimeWest

- Identified barriers to screening include primary care providers indicating a lack of time during visits to conduct a thorough screening when combined with all other expectations of a well-child visit.
- In addition, rural areas are lacking in specialty early childhood mental health providers. The distance to specialty providers can potentially cause transportation challenges for the authorized guardian(s), and wait times to see providers can be long (this includes rural providers).

South Country Health Alliance

Barriers include:

- Members electing to not bring their children in for well-child checks and other screening opportunities (e.g. early childhood screening) as recommended
- Improper coding by providers
- Rural areas lack specialty including early childhood mental health providers and EIDBI services
- Parents may have a difficult time distinguishing between what is normal development for their child and what may be impaired development which would trigger then to ask for help.

UCare

There are numerous barriers for children to receive socio-emotional and developmental screenings, diagnosis and treatment. UCare has identified the following barriers that may affect our members:

- Fragmentation: the service system from primary care to mental health professionals is fragmented. Often, families are left to coordinate services on their own while trying to deal with the personal and financial stress of the child's condition. Additionally, there is reluctance to exchange information between mental health professionals and primary care.

- Lack of resources: The demand exceeds the available resources and many providers do not have adequate equipment. Professionals skilled in the screening, diagnosis and treatment of children below the age of 3 are primarily located in the metro area, Duluth and Rochester. This results in barriers to accessibility of services for families seeking screening, diagnosis and treatment for the affected child.
- Inadequate data: Although there is data on members who receive a socio-emotional and developmental screening, this data does not include screenings by providers who do not submit data claims to MCOs. There is also inadequate data regarding the number of members evaluated by a mental health professional as a result of a positive socio-emotional and developmental screening.
- Language/cultural barriers: Families who do not read or speak English as their primary language may have difficulties understanding information on screenings and developmental disorders. Some screening tools may not be adapted to reflect cultural differences and norms of such families and children. These families may also struggle with understanding how to access health care.
- Stigma: Families may be reluctant to discuss and seek help for developmental issues due to stigma surrounding developmental disorders and mental health. Families may have a fear of telling health care professionals about the challenges in caring for children with developmental disorders in the home.

Question 5: What strategies has the MCO implemented or will it be implementing to facilitate access to periodic developmental and social-emotional screening(s), diagnosis and treatment for young children, ages 1-3?

The majority of MCOs use the C&TC as the main strategy for reducing barriers to screening, diagnosis and treatment. MCOs support the C&TC efforts by:

- Educating providers and members about screening tools and treatment options
- Providing incentives to providers for administering complete screenings
- Providing incentives to the member for completing the assessment.

Clinics are also working to implement strategies to expedite the screening process.

DHS encourages the MCOs to continue to use services such as C&TC coordinators to help families follow up on referrals and locate providers in their area. We recommend MCOs contact the family's county or regional human services, social services or family services office to get in touch with the local C&TC coordinator. The coordinator will also help arrange interpreter services and/or transportation.

There are C&TC coordinators in each county and tribal nation. Periodic examinations or screenings are delivered according to the C&TC Schedule of Age-Related Screening Standards (PDF), also known as the Periodicity Schedule. The C&TC program has brochures and information for families and providers that the MCOs may request and distribute to their members.

C&TC also provides training to primary care providers and clinic staff, local public health, Head Start, schools and other people who provide screening for children, adolescents and young adults in Minnesota. These trainings are offered in various locations throughout the state. To locate an upcoming in-person training opportunity or to request a training, see the Child and Teen Checkups In-person Training registration & requests page. MDH, MDE and DHS periodically offer trainings for programs and staff that provide developmental and social-emotional screening services for Minnesota children. For more information, see the Training Toolkit for developmental and social-emotional screening and referral. This is a training curriculum resource for Minnesota's public screening programs to provide staff training on early childhood developmental and social-emotional screening, referral and linkage to services.

Minnesota recently redesigned and expanded the Help Me Grow website. The updated website continues to connect children ages 0-5 to Early Childhood Special Education evaluations at local school districts.

The updated Help Me Grow website also provides families with additional resources and information. DHS, MDH and MDE will continue to educate MCOs and members on the features of the expanded Help Me Grow website.

Blue Plus

- Blue Plus feels our strongest vehicle for insuring and managing early screening of young children with autism or a potential autism diagnosis is our commitment to Child and Teen Checkups. We support this screening effort by educating providers and incenting them for administering complete screenings.
- Members are also provided educational materials and incentives for completing Child and Teen Checkups. We attend Regional County Child and Teen Checkup meetings to stay informed and utilize the information received from the counties regarding child and teen check-ups to align resources for our members.
- Our aim is to increase engagement so the members seek and receive care in the right place at the right time—including identifying the need for early intervention services for children at risk.
- Blue Plus has a pilot partnering with community health workers to provide education, connect resources and supports to members in diverse communities.
- By helping members to understand the importance of early screening, it will also facilitate access, referrals and follow-up treatment for young children.

HealthPartners

- Child and Teen Checkup clinic trainings – participate in MDH and county C&TC trainings with clinics to promote the use of screening tools.
- Share learnings from the experience of adding the ASQ and ASQ-SE into our HPMG and Park Nicollet Clinics to assist clinics with implementation.
- Children's Health Initiative - HealthPartners is engaged in an enterprise-wide initiative to improve the health of children from prenatal to age 5. The three main areas of focus are to promote early brain development, provider family-centered care and to strengthen communities. One of the 10 priorities is Early Childhood Experience: screen every child for exposure to harmful events that might impact a child's development. This includes developmental and social-emotional screenings.
- Little Moments Count - HealthPartners launched a statewide initiative to improve early brain development through promoting reading, singing and talking to babies and young children. The initiative is in partnership with local public health agencies, community organizations and pediatric health care systems.
- Help Me Grow - HealthPartners employees and clinicians have been involved in the Help Me Grow work groups

Hennepin Health

- Parent/family incentives for completing screening visits.
- Follow-up and sharing information with clinics.
- Quarterly meetings held with Hennepin County Public Health include topics like child and teen check-ups.
- Removal of barriers (i.e. authorization requirements) for any therapy services, including EIDBI.

Itasca Medical Care

- IMCare utilizes the member and provider newsletters to educate members and providers about available screening options through public health's Help Me Grow program.
- IMCare's disease management coordinator partners with local educational groups such as Communities for Health and the regional C&TC to evaluate ways to further educate the community about available resources.
- IMCare has attempted to assist DHS in recruiting EIDBI providers by sharing information with providers who may meet criteria to become an enrolled provider through email and provider newsletters.

PrimeWest

- PrimeWest offered a $50 voucher for completion of Child and teen check-up along with a reminder phone call to members/authorized representatives.
- PrimeWest partners with provider network, local county partners, and members under age 21 and their authorized representatives with the Bright Futures program which promotes and facilitates care coordination of infants and children who are medically fragile, technology-dependent, and who have high social risk factors while minimizing re-hospitalizations.
- PrimeWest Health is working with providers to extend appointment times to allow time for adequate screening.

South Country Health Alliance

- South Country Health Alliance educates and encourages members to stay on track with well child visits.
- South Country has member education and incentive programs to encourage utilization of services.
- South Country is working to educate county partners and providers on EIDBI provider enrollment process and service benefits and how to obtain a CMDE.
- South Country attends public health C&TC meetings to review C&TC guidelines and best practices. C&TC visits include developmental and social-emotional screenings.
- Member online resource “Embracing Life” encourages and educates on C&TC which includes gift card incentive upon completion of 6 well-care visits before 15 months of age.
- Provider newsletter provides periodic updates and information/education on C&TC
- South Country partners with our county Public Health and Human Service departments for their great programs for early screening
- Explore the use of telehealth/e-visits for communication between parents and their primary provider.

UCare

- UCare implements a number of strategies and interventions to facilitate access to periodic development and social-emotional screening(s), diagnosis, and treatment for young children age 1-3 years. In 2019, some of those activities included:
- Handing out C&TC periodicity schedules to members at health resource and screening fairs.
- Providing telephonic outreach by internal UCare staff to members to remind them about getting their C&TC visit and assisting them with scheduling when needed.
- UCare offers member incentives to encourage members to receive preventive health visits/screening and providers can participate in our Pay for Performance program to receive incentives for improving preventive health visit rates.

- UCare has a dedicated C&TC chapter in our Provider Manual where we encourage Child and Teen Checkups and link to a variety of resources for C&TC including the Dakota County C&TC billing grid and DHS and MDH C&TC websites.
- UCare publishes a provider newsletter (health lines) in which articles about C&TC screenings have been included to provide continuing education on C&TC, instructions on how to bill for services provided and the additional reimbursement available for screenings.
- UCare is currently working with a large pediatric health network to close health care gaps on Well Child visits by identifying screenings and immunization action lists for overdue patients.

Question 6: Pursuant to section 6.1.23 (C) (2) of the 2018 Families and Children Contract, what evaluation and assessment, including treatment recommendations, are provided to children who do not meet milestones?

The majority of MCOs report making referrals to medical or mental health professionals for additional assessments. Treatment recommendations often include physical therapy, educational services, occupational therapy, speech and language pathology, children's therapeutic services and supports (CTSS) and early intervention services provided the Early Intensive Developmental and Behavioral Intervention (EIDBI) benefit.

Blue Plus

- Children with Blue Plus may be referred for additional assessments when developmental milestones are not being met.
- Children presenting with Autism symptoms or related conditions may be referred for a Comprehensive Multi-Disciplinary Evaluation to determine best fit and intensity of needed services.
- Additional referrals may be made for physical therapy, occupational therapy and speech therapy as needed.

HealthPartners

- Referral to a specialty provider for a more in-depth assessment.
- Referrals to developmental pediatrics, child psychiatry, child psychology, speech therapy, occupational therapy and other rehabilitative services.
- Referral to EIDBI services and receive a CMDE for assessment of additional services.
- Referral to Help Me Grow

Hennepin Health

- Potential treatment options are provided through school districts and public health clinics if accepted by parents/guardians.
- Treatment recommendations focused on developmental milestones, such as behavior and communication approaches, occupational therapy, speech therapy, sensory integration, dietary approaches, and medications, complementary and alternative medicine.

Itasca Medical Care

- When a child is not meeting critical developmental or social-emotional milestones, providers are referring the child directly to the early childhood program or the Help Me Grow program.
- Once they are in the early childhood system, treatment may include speech therapy, physical therapy, occupational therapy and/or behavioral therapy.
- Home-based mental health services are also available for children who meet criteria. If the child meets criteria and enters into the program, ongoing assessments are conducted by the treatment team.
- An IMCare mental health provider, Children's Mental Health Services, is also located within the school and provides mental health support to individuals and in a group setting for those children who qualify.

PrimeWest

For children who do not meet milestones to have access to appropriate evaluation and assessment, including treatment recommendations to improve a child’s functioning with the goal of meeting milestones by age 5, the following are possible treatment recommendations:

- DC 0-3R assessments (diagnostic assessments for additional mental health evaluation of infants and toddlers)
- Behavior and communication approaches
- Occupational therapy
- Sensory integration therapy
- Speech therapy
- Dietary approaches
- Medication
- Complementary and alternative medicine
- EIDBI services

South Country Health Alliance

For children who do not meet milestones, referrals may be made to:

- A provider for diagnostic or corrective treatment
- Early Childhood Education for evaluation
- Assessment for PT, OT and/or speech
- Mental health professionals
- A qualified mental health professional for a CMDE for possible eligibility for EIDBI
- A dietician for nutritional support.

Referrals are not required to access these services. Members may also be referred back to the county for assistance with obtaining other necessary community-based services or resources. South Country ensures access to services and works with in- and out-of-network providers to meet member need in the area of early screening, diagnosis and treatment of autism and other developmental conditions.

UCare

- When children do not meet developmental milestones, the treatment recommendations would be determined by the screening tool and treatment guidelines. UCare supports the use of best clinical practices (ICSI best practices and UCare provider resource).
- As an integral part of UCare's medical management of members, the UCare Special Health Care Needs (SHCN) program identifies persons with special health care needs. The SHCN program assists identified members with access to care and monitors their treatment plan. Children ages 1-3 years old with a developmental disorder and in need of case management or assistance with finding a practitioner, and coordinating treatment are eligible to participate in the SHCN program.

Question 7: What are the recommendations of the MCO on how to measure and report on the effectiveness of the strategies implemented or to be implemented on facilitating access to developmental and social-emotional screening, diagnosis and treatment to children, ages 1-3?

The MCOs provided many recommendations to help address the identified barriers. Increasing awareness and education, both to providers and families, on the importance of regular screenings and checkups is one of the key recommendations. Additional data evaluation could be conducted to determine which areas of the state require more education to increase the rates of completing screening and assessments.

Many people are simply unaware of the benefits available to them through their health plans. The MCOs also recommended the use of multiple communication strategies to reach providers and members. In particular, they recommended communicating to families the early signs of ASD, where to access screening and diagnostic assessments, as well as the full range of treatment services and supports that are available to them. Finding effective ways to engage and communicate with English-language learner families is also critical.

The MCOs also recommend increasing coordination across agencies to ensure that the DHS, MDH and MDE are working together to ensure communication across service providers and coordinated services.

Efforts are being undertaken to help address the shortage of providers in Minnesota. For more information or to increase participation from the MCOs to help address the provider shortage, see the Building EIDBI provider capacity webpage.

Blue Plus

- Strategies should include the continued education of enrollees regarding the importance of these screenings for early diagnosis and treatment.
- Provider adoption/screenings completed data could also be obtained through encounter data. The data could be used to identify possible areas for provider education as well as to identify how many children who receive these screens get connected to additional treatment services.

HealthPartners

- Evaluate access to screenings - Evaluate use of billing codes through encounter data for early childhood screenings - CPT Code 96127 and the CPT Code 96110 are for developmental screenings.
- Measure access to services - Use encounter data to review the number of children accessing EIDBI and other treatment services.
- Monitor the number of EIDBI and other child developmental specialist providers.

Hennepin Health

- Evaluation of claims information with the appropriate modifiers before intervention of strategies and after. Evaluating changes in services utilized for children diagnosed from 1-3.
- Hennepin County Public Health worked with Assuring Better Child Health and Development (ABCD) to close the loop. ABCD is a proven, universal approach to screening young children in health care settings. ABCD works to increase health and developmental screening and referral rates for all young children by integrating routine screenings into well-child visits. This has been especially effective for children in the Minneapolis Public Schools (MPS). This allows the school district and the clinic to coordinate and make sure that the results of the ECSE assessment is

shared with the medial provider. In addition, it allows for sharing information regarding referrals and the completion of further treatment. The MPS also keeps excellent records of referrals made and what intervention the child is receiving.

Itasca Medical Care

- IMCare would recommend working with the MDE on this issue as the early childhood program works with children who have a diagnosis of ASD throughout their school life, but can start as early as birth. These educational programs submit data to the MDE.
- Another consideration is that once children are diagnosed with ASD, they typically obtain disability status and are no longer on a managed care program.
- As a second option, collaboration with Public Health to monitor progress for those enrolled in the “Follow Along” Program, a comparison of ASQs to determine the improvement they've made in comparison to age-appropriate ratings.

PrimeWest

As we work to ensure members ages 0-3 have access to developmental and social-emotional screening, diagnosis and treatment, the PrimeWest Health chief senior medical director and local providers offered the following goals and recommendations:

- Decrease number of emergency room (ER) visits for behavioral and/or psychiatric diagnosis
- Decrease number of hospitalizations for behavioral and/or psychiatric diagnosis
- Decrease number of readmissions within 30, 60 or 90 days for behavioral and/or psychiatric diagnosis
- Increase length of time between hospitalizations
- Increase prescription/medication fill percentage
- Increase medication refill percentage
- Reduce appointment wait times for members who were triaged to an adult or child psychiatrist
- Improve or maintain screening scores
- Improve quality-of-life determination survey
- Increase provider satisfaction survey responses
- Increase percentage of members accessing mental health treatment post positive screen date
- Increase percentage of members demonstrating continuous access to mental health services one year post diagnosis of mental health disorder (visits occur minimum of once every three months)

South Country Health Alliance

- Measure the number of emergency room visits for age 1-3 for behavioral diagnosis.
- Measure member adherence to the recommended C&TC checkups.

- Survey providers regarding barriers to accessing screening and treatment for this population.
- Measure member diagnosis of Autism within member population and age group.

UCare

UCare's Child and Adolescent workgroup uses the Plan-Do-Study-Act (PDSA) methodology with each intervention planned. The workgroup places a high emphasis on measurement in order to study if the intervention is achieving the intended results and to improve interventions for the following year. We also monitor Healthcare Effectiveness Data and Information Set (HEDIS) rates for increases and to identify opportunities for improving C&TC.

VI. Conclusion

The MCOs are implementing or have plans to implement strategies for overcoming barriers to screening, diagnosis and treatment (as required under Minn. Stat. § 256B.69, subd, 32a). Families, however, are still struggling to access appropriate services. This report identifies barriers and provides recommendations to address barriers to accessing early screening, diagnosis and treatment of ASD and related conditions. The recommendations include:

- Improve public awareness and education, including ASD early signs and symptoms through a variety of communication and outreach strategies targeting providers and others interacting with families
- Increase awareness and education to parents, caregivers and providers about the importance of early screening, effective screening tools, proper diagnosis and treatment
- Increase awareness and education to parents and caregivers about the services available through their current health plans
- Increase awareness of the C&TC trainings available, as well as the training toolkit and increase funding for effective screening tools to all providers
- Increase incentives for providers to implement recommended screening tools consistently and for families to follow through on screening appointments
- Identify best practices in screening and diagnostic tools used to identify children early in order to develop consistent practices across primary physicians and health-care providers
- Develop the workforce and increase access to providers who are trained to implement screening, diagnosis and treatment of ASD across a variety of settings.
- Improve communication, collaboration, coordination across educational, medical and human service providers and agencies
- Streamline the process for referrals and ensure that referrals are followed up on
- Increase awareness of the Follow Along, Child & Teen Checkups, Public Health and Woman and Infant Children programs to promote early social-emotional and developmental screenings
- Place a special focus on outreach and awareness of the expanded Help Me Grow system once it is launched
- Expand education to multicultural and linguistic communities about the importance of early screening and understanding of typical and atypical child development and resources available for treatment
- Ensure that current screening tools are adapted to the language, culture, values and customs of all families
- Eliminate barriers for all families, including but not limited to race, ethnicity, socio-economic status, geographic location, etc.
- Ensure that everyone in need of services has access to services.

As public program providers, MCOs and county-based purchasing plans have an important role to play in the development of best practices in policies and procedures for screening, diagnosis and treatment of young children in Minnesota. It is also critical to involve other state agencies and multidisciplinary providers who are part of the system of care and supports for children with ASD as identified in Options for Coverage of Treatment for Autism Spectrum Disorders in Minnesota (PDF) submitted by the Minnesota Department of Commerce to the Minnesota Legislature in September 2013.

Addressing the barriers that families and providers face requires a multifaceted, multiagency approach, including health, education, social services and public and private health coverage. The recommendations listed in this report should be the collaborative focus of all state agencies, providers, MCOs, counties and tribal nations.