DHS-7797-ENG 10-18

DEPARTMENT OF HUMAN SERVICES

# Legislative Report

# 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**

June 2018

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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 to providers on best practices in screening and diagnostic tools
- Culturally meaningful training and education on the early signs of autism spectrum disorder (ASD) to parents and providers in their preferred language
- 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 for requiring that MCOs report on barriers to screening, diagnosis and treatment of young children between the ages of 1 and 3 is found in Minnesota Statutes, section 256B.69, subdivision 32(a).

**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 59 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 42 or 2.4 percent of 8-year-old children were identified with ASD. The average age of diagnosis was 4 years 9 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 the 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 often misdiagnosed (Mandell, Ittenbach, Levy & Pinto-Martin, 2007[4]). Late diagnosis and misdiagnosis of ASD disproportionately affects children from culturally 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.).

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. One 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

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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

tie in to the information MCOs are required to provide under Minn. Stat. §256B.69, Subd. 32a. Each section includes comments (identified below by section name) that link to practices the MCOs have in place or are trying to implement but are encountering barriers as identified in Table 4:

- Early Means Early
    - Early screening and diagnosis as the keys to effective intervention
    - Providers need a more accessible and systematic process for conducting screening and diagnostic assessment
- Individualized to Unique Needs
    - Staff 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 his or her 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

Read a summary in the Autism Spectrum Disorder Task Force Strategic Plan Report (PDF).

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

For the fifth year, the 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. Listed below, are 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 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 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).

Please note that DHS no longer recommends 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 using these instruments to change to a recommended observational screening tool. We also recommend programs still using the first or second edition of the Ages and Stages Questionnaire begin to use the Ages & Stages Questionnaires®: 3rd edition (ASQ-3) as soon as possible. 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.

## Screening Tools

### Blue Plus

- Developmental screening instruments (Parent report):
  - Ages & Stages Questionnaires, Second Edition (ASQ—2)
  - Ages & Stages Questionnaires, Third Edition (ASQ–3)
  - Infant Development Inventory (IDI)
  - 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
  - Developmental Indicators for Assessment of Learning, Fourth Edition (DIAL–4)
  - Early Screening Inventory, Revised (ESI–R), 2008 Edition
  - Early Screening Profiles
  - FirstSTEP Preschool Screening
- 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)
  - Pediatric Symptom Checklist (PSC)

### HealthPartners

- Parent report instruments:
  - Ages & Stages Questionnaire®
- Social / emotional instruments:
  - Modified Checklist for Autism in Toddlers (M-CHAT)
  - Ages & Stages Questionnaires®: Social-Emotional (ASQ-SE)

### Hennepin Health

- Parent report instruments:
  - Ages & Stages Questionnaires, Second Edition (ASQ—2)
  - Ages & Stages Questionnaires, Third Edition (ASQ–3)
- Social / emotional instruments:
  - Ages & Stages Questionnaires®: Social-Emotional (ASQ-SE)
  - Modified Checklist for Autism in Toddlers (M-CHAT)

Notes: Health Care for the Homeless uses these and postpartum mental health assessment. Hennepin County Public Health, a Hennepin Health partner, has Public Health Maternal Child Health prevention program that uses evidence-based home visiting as well as screening and referral.

### Itasca Medical Care

- Parent report instruments:
  - Ages and Stages Questionnaire (ASQ)
  - Parents' Evaluation of Developmental Status (PEDS)
- Social / emotional instruments:
  - Ages & Stages Questionnaires®: Social-Emotional (ASQ-SE)
  - Modified Checklist for Autism in Toddlers (M-CHAT)

Notes: At 24 months, Itasca uses the ASQ/ASQ:SE and repeats the M-CHAT for comparison. One clinic uses the M-CHAT at 9 months and again at 18 months and the PEDS screen at 9 months to assess developmental milestone benchmarks.

### PrimeWest

- Observational instruments:
  - 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)
- Parent report instruments:
  - Ages & Stages Questionnaires, Third Edition (ASQ–3)
  - Parents' Evaluation of Developmental Status (PEDS)
- 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

- A review of medical records retrieved and abstracted for Healthcare Effectiveness Data and Information Set (HEDIS) well-child visits by South Country indicates that several providers and clinics use the MDH C&TC clinic visit forms.
- The most common tools noted are the Ages and Stages Questionnaire and use of the checklist listed under the "Developmental/S-E/Mental Health" section of the form.
- In addition, South Country works collaboratively with our owner-county public health agencies to offer support and serve as a resource when they conduct annual C&TC outreach meetings with our provider clinics. This includes promoting the use of the recommended social-emotional and developmental screening tools, identifying professionals eligible to provide screening components and accurate billing of screening services provided.

- If the clinic is an EIDBI provider, it uses Comprehensive Multi-Disciplinary Evaluation (CMDE) as the screening tool.

### UCare

- UCare does not require providers to use a specific social-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.
- UCare also encourages providers to visit DHS's Children's mental health identifying mental health concerns webpage for information about 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 Public Health 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, Public Health and Woman and Infant Children (WIC) 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.

### Blue Plus

- 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 – these screenings are now required at certain ages for a complete C&TC – reimbursable
- Early childhood center (Head Start) – reimbursable
- Early childhood center (Head Start) – reimbursable

### Hennepin Health

- Screenings are completed in a variety of settings including primary-care, behavioral-health or mental-health clinics, specialty-care and public-health clinics. In most of the Hennepin Health primary-care clinics, screening is mandatory for ages 9 months, 18 months and 30 months.
- Health Care for the Homeless is another primary-care clinic that is unique in the population it serves.
- Screens are reimbursable when they are completed in clinics.

### Itasca Medical Care

- Itasca County school districts' early childhood programs, including Head Start and Invest Early, complete the social-emotional and developmental screening for children birth to 7 years old upon enrollment into the program. This screening is free to anyone and is not billed or reimbursed by any health insurance.
- The school psychologist may do formal testing, using the ASD Rating Scale and ASD Diagnostics Observation Scale with the help of parents and teacher. He or she may give an educational diagnosis of ASD; a referral must be made for a medical diagnosis.
- From the time a child reaches 4 months until age 3, providers send ASQs in the mail every four months and ASQ:SEs every six months for parents to complete.
- IMCare makes a referral to Help Me Grow (school district birth-to-age-3 program)
- Healthy Families Itasca is a home-visiting program for first-time pregnant moms who qualify for WIC. It is an evidence-based parenting curriculum, with intensive home visiting. This program continues until the child turns 3 years old. Providers administer ASQs and ASQ: SEs in this program, along with any necessary referral to Help Me Grow. This is a free service offered by the county.
- If the provider notes a concern or delay on either scale, he or she completes the ASD screening and might refer children to their primary-care providers for additional screening or to an out-of-network provider.
- Screenings are reimbursable when completed by a clinic or licensed psychologist.

### PrimeWest

- Medical and behavioral health clinics
- Health care homes
- Public health outreach, including women, infants and children (WIC)
- Family home visits
- Public health nurse visits

### South Country Health Alliance

- Follow Along Program offered by our owner-county Public Health departments (home visits in person or over the phone) using the ASQ.
- Home-visiting programs offered by owner-county Public Health departments.
- At age 3: Early childhood screenings offered by local school districts (ECFE) or at Head Start conducted by a trained professional.

- Provider (primary care) clinic settings by a trained professional.
- Certified behavioral health clinic
- CMDE (in-person or via telemedicine) at a mental health or autism center reimbursable setting
- All Minnesota Health Care Plan services are reimbursed when provided by eligible MHCP-enrolled providers, including nurse practitioners, physicians, physician assistants and public health nurses approved by MDH who have completed the C&TC screening component training and C&TC developmental screening workshop and who are under the supervision of a physician.

### UCare

- Based on claims data, social-emotional and developmental screenings are conducted in:
    - Primary clinics
    - Community health clinics
    - Rural health clinics
    - Schools
    - Public health clinics
- UCare reimburses eligible licensed health-care professionals who perform child 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 would determine where the child should be sent for follow-up. Referrals often include Help Me Grow or special education services, 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 CMDE.

Some of the plans have a process for follow up to ensure the referrals are followed through with. This is highly encouraged 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 Cross does not require prior authorization, but highly encourages referrals to participating network providers.
- Blue Plus does not require prior authorization for the CMDE for autism services.
- Blue Plus has clinical guides available to assist with questions or referrals to participating providers.

### HealthPartners

- If conducted during a C&TC, the provider indicates that a development and/or social-emotional screen was conducted (96110 and 96127) on the C&TC claim.
- If a provider identifies concerns, he or she would refer a child to additional medical services (such as physical or occupational therapy) and/or Help Me Grow. If the provider makes a referral during the C&TC visit, the clinic would add the referral code to the C&TC claim.

### Hennepin Health

- Hennepin Health does not require prior authorization for the diagnostic assessment or referrals to services. When screenings are positive, referrals are made to Help Me Grow, the statewide resource for early childhood development.
- Also, referrals are made to special education, behavioral health, in-home services and appropriate community resources.
- For sites that include a behavioral health area, referrals may be forwarded to the in-house mental health professionals. Clinicians follow up with referrals to ensure that the family did not miss the appointment.
- Referrals are also made to specialty care, such as speech therapy, occupational therapy, physical therapy and to the child's school district.

### Itasca Medical Care

- If the assessment(s) determine a need for further evaluation, the clinics make a referral to a pediatric MD who has an interest in ASD. They also refer patients 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.
- Clinics also make referrals to Behavioral Dimensions, which is a business that provides intensive behavioral intervention.
- The Itasca County Disability Resource Group, established by mothers, helps parents to access local resources. The group has also created a resource book that includes local, state and national resources for parents.
- If problems are identified by the Public Health Follow Along program, it, too, can make a referral to the Help Me Grow program and notify the child's primary care provider.
- In order to receive the ASD diagnosis, 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 or 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 audiological evaluation.
- The primary care provider or public health nurse should schedule a followup visit within one month of the positive screen.

### South Country Health Alliance

- Generally, a referral or prior authorization is not required to access most services if the screening is positive.
- Referrals may be needed to access a mental health professional for an extended diagnostic assessment, other specialty provider, school-based evaluations or to the county for behavioral-health services.
- We will connect the member with a care coordinator when possible or his or her community care connector to help the member with making the referral.
- 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.
- South Country recommends and supports provider use of the two-character CTC HIPAA-compliant referral code (see above) for claims billing that indicates the provider completed a referral to a recommended provider(s) for follow-up services.
- South Country has a referral code priority chart in its provider manual on the South Country website.

### 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 his or her 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 health-care 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 families struggling to identify the early warning signs of ASD. It is a common misconception that an educational diagnosis 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 also struggle to cover the cost of purchasing and training providers on ASD-specific screening and diagnostic assessment tools. Providers also struggle to complete a thorough assessment during a typical well-child visit. 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 diagnosis 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 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 also 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 not receiving 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 currently implementing; namely, to ensure that clients receive C&TC checkups. In addition, the proposed strategies to address these barriers should be addressed across state agencies, counties and MCOs.

### Blue Plus

- Largest barrier is how to educate parents and caregivers to increase awareness and knowledge about ASD screenings
- Providers also struggle with the time it takes to incorporate these screenings into their visits.

### HealthPartners

- Duplication of services – Screenings are 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).
- 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 discuss fully the results of a developmental or social-emotional screen.
- Access to follow-up services – There is a lack of EIDBI providers in Minnesota. Getting timely access to services is a barrier to treatment.

### Hennepin Health

- Lack of infant and early childhood mental health service providers. As a result, waits to start services can be long.
- Referrals are often sent to external resources, which can cause further delays.
- Volume of screenings that need to be completed.

### Itasca Medical Care

- The primary barrier identified by providers is a parent or caregiver's reluctance to accept that his or her child is experiencing significant delays in 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. Local mental health providers do not provide diagnostic services for ASD. Itasca County has one provider that uses applied behavioral analysis (ABA); however, that provider has limitations on how many cases it can take. Additional local providers are needed to better serve this population.
- Another barrier for screening is parents' lack of knowledge that screening are 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 because families 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.

### PrimeWest

- Primary care providers indicate a lack of time during visits to conduct thorough screening when combined with all other expectations for a well-child visit
- Rural areas lack specialty early childhood mental health providers
- The distance to specialty providers can cause transportation challenges for the authorized guardian
- Long wait times for specialty providers, including rural areas

### South Country Health Alliance

- Providers indicate overall concerns with the number of screening components involved in doing a complete C&TC screening and the amount of time involved, obtaining cooperation from the child/parent and on occasion, parent refusal for a recommended referral for additional testing.
- Additional potential barriers include lack of parental understanding of the significance of and rationale for screening or treatment and access to additional services for followup because of distance and/or location. An observation from completing the medical record review process for HEDIS well-child visit

measures: Parents of children with reoccurring illnesses such as ear infections, strep or congestion/bronchitis tend to skip recommended C&TC (well-child) exams, which in turn increases the risk for an already at-risk population.

- Another ongoing issue is children disenrolling from South Country then enrolling with a different PMI number.
- One issue specific to ASD services is the limited number of providers in greater Minnesota certified by DHS and MDH to provide EIDBI services.

### UCare

- 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. There is also 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 younger than 3 are primarily located in the metro area, Duluth and Rochester. This results in barriers in 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 social-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 about the number of members evaluated by a mental health professional as a result of a positive social-emotional and developmental screening.
- Language/cultural barriers: Families who do not read or speak English as their primary language might have difficulties understanding information about screenings and developmental disorders. Some screening tools might not be adapted to reflect cultural differences and norms of such families and children. These families might also struggle with understanding how to access health care.
- Stigma: Families might be reluctant to discuss and seek help for developmental issues because of the stigma surrounding developmental disorders and mental health. Families might fear 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.

We encourage the MCOs to continue to use services such as the C&TC coordinators (PDF) to help families follow up on referrals and locate providers in their area. The coordinator will also help to arrange for interpreter services or transportation. There are C&TC coordinators in each county and tribal area. 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.

### Blue Plus

- Blue Plus feels our strongest vehicle for insuring and managing early screening of young children with ASD or a potential ASD diagnosis is our commitment to C&TCs. We support this screening effort by educating providers, communicating with members and providing incentives to providers for administering complete screenings.
- We also use the information received from the counties about C&TC to align resources for our members. Our aim is to increase engagement so that 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.

### HealthPartners

- Child and teen checkup clinic trainings: participate in MDH and county C&TC trainings with clinics to promote the use of screening tools.
- 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 affect a child's development. This includes developmental and social-emotional screenings.
- HealthPartners provides an open-access behavioral health network to ensure access to services for our members.

### Hennepin Health

- Public health nurses complete screenings at WIC clinics and at the Health Care for the Homeless clinic.
- Hennepin Healthcare (formerly HCMC) has added screenings to all of its clinics. Other Hennepin Health clinics have developed processes that expedite the screening.
- At NorthPoint Health and Wellness Center, developmental screenings are completed and prepared by a medical assistant then reviewed by the provider, expediting the process.
- Human Services has expanded the pool of mobile diagnostic assessment providers available to conduct diagnostic assessments and psychological testing for children and youth needing to access services.

### Itasca Medical Care

- IMCare uses its 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 educate the community further about available resources.

### PrimeWest

- PrimeWest Health is working with providers to extend appointments to allow time for adequate screening.
- PrimeWest Health is committed to ensuring all members have access to high-quality and timely medical care that improves health outcomes at the individual and population levels while reducing health-care spending. We achieve this is by emphasizing person-centered care, working to engage members and their families to improve their health, and providing and promoting preventive health care.
- PrimeWest Health encourages and supports relationships between members and primary care providers that begin at birth. Establishing relationships between members and providers who can screen for developmental and social-emotional status is critical to ensuring screenings occur regularly.
- As part of this emphasis on relationships, PrimeWest Health encourages members to select a primary-care clinic. Having a primary-care clinic is important because members who select and use one tend to stay healthier and have fewer urgent care and emergency room visits. Members with a primary-care clinic also maintain medical histories and related information in a single location.
- Bright Futures program: The Bright Futures program is a collaborative endeavor that includes PrimeWest Health, its provider network, local county partners and members under age 21 and their authorized representatives. This collaborative effort is integral to ensuring positive outcomes for children who may have special medical needs. Bright Futures 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. The program also strives to ensure that parents and other caregivers receive appropriate training and skills to feel confident in providing care in a nurturing environment.
- Integration with county agencies: PrimeWest Health is organizationally integrated with county agencies, including county public health and social/human/family services. Public health is a provider of C&TCs, a visit during which a developmental and social-emotional screening is conducted. Both public health and social/human/family services conduct complex case management for PrimeWest Health Families and Children (formerly called the Prepaid Medical Assistance Program) members. If a member has an elevated screening score, he or she can be referred to complex case management by a public health nurse. County case managers help parents to navigate the mental health system to access appropriate services.
- Voucher program: In 2017, as part of PrimeWest Health's recognition of the importance of C&TCs and related screenings and to improve our HEDIS® / Star Ratings, PrimeWest Health offered members and authorized representatives the opportunity to receive a pre-paid MasterCard Reward Card for receiving the following services:
    - $50 for an annual C&TC for members ages 12 to 21
    - $50 for two doses of the HPV vaccine

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- PrimeWest Health staff and public health C&TC coordinators made phone calls to remind members/authorized representatives that the member was due for a C&TC and was eligible to participate in the voucher program. During these calls, PrimeWest Health staff and county C&TC coordinators offered assistance to address transportation and appointment scheduling. PrimeWest Health's Women & Children Care coordinator also reviewed the importance of a C&TC with members and authorized guardians during member calls. In addition, members who were identified as being eligible to redeem vouchers were sent a letter that stressed the importance of a C&TC. The letter also outlined the process for redeeming the voucher: During the service, the health-care provider confirmed its completion by signing the voucher. The member or authorized representative then mailed the voucher to PrimeWest Health to receive a pre-paid MasterCard Reward Card.
- PrimeWest Health has the screens listed in Question 1 available for children from birth to age 3 and requires that the provider complete these at every well-child visit/C&TC. These screenings are provided as part of the Integrated/Shared Care program and have been added to members' electronic medical records as applicable.
- To encourage and support developmental and social-emotional screenings by primary-care providers and physical health screening by case managers/care coordinators, PrimeWest Health provides the following:
    - DHS standards and approved screening tools and assessments
    - Education about the application and use of the tools
    - Concurrent review with appropriate followup if indicated
    - Chart auditing
    - PrimeWest Health Integrated/Shared Care program

### South Country Health Alliance

- South Country actively promotes parents and legal representatives of eligible members scheduling complete C&TC exams with health-care providers in the educational information we provide to them as well as to their health-care providers. Our Take Charge! Be Rewarded! health promotions program offers gift card rewards to eligible infants completing at least six C&TC visits before age 15 months as well as for children ages 3-6 for completing an annual CTC visit.
- South Country covers the entire registration fee (scholarship) for ECFE participation. The scholarship applies to ECFE classes or events that include a parent-child component within the classroom setting during each session, and targets newborn to kindergarten-age children. This provides an opportunity for early detection of social, emotional and/or developmental concerns and referral for screening and followup services.
- South Country has developed C&TC program guidelines to help our owner-county C&TC coordinators with scheduling annual C&TC clinic outreach meetings with providers in their respective counties. This has proved to be very successful and promotes a collaborative approach in determining attendees, topics of discussion and agendas. County C&TC coordinators facilitate meeting logistics. Providers, county public health and South Country representatives are invited to attend. Collaborative meetings in which a C&TC representative from MDH is present to provide information and helpful

suggestions/directives to providers on the recommended screening instruments and successful strategies to engage members/parents have been very well received.
- Regarding EIDBI, South Country continues to engage potential providers.

### UCare

- Handing out C&TC periodicity schedules to members at health resource and screening fairs.
- Having UCare staff call members to remind them about getting their C&TC visit and helping them to schedule when needed.
- UCare offers incentives to encourage members to receive preventive health visits/screening. Providers may 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) with articles that provide continuing education on C&TC, how to bill for services and the additional reimbursement available for screenings.
- UCare is 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 2014 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 and early intervention services provided the Early Intensive Developmental and Behavioral Intervention (EIDBI) Benefit.

### Blue Plus

- Children with Blue Plus might be referred for additional assessments when they are not meeting developmental milestones.
- Children with symptoms of ASD or related conditions might be referred for a CMDE to determine best fit and intensity of needed services.
- Additional referrals might 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 to receive a CMDE for assessment of additional services.
- Referral to Help Me Grow

### Hennepin Health

Referrals are made to:

- Help Me Grow and to educational resources in the child's school district
- Behavioral health and other psycho-social services. The behavioral health staff at Hennepin Health are active on a Human Services panel of children's mental health professionals. We are in the process of identifying ways to work better together and streamline processes for children who need services.

### Itasca Medical Care

- When a child is not meeting critical developmental or social-emotional milestones, providers refer the child directly to the early childhood program or the Help Me Grow program. Once the child is in the early childhood system, treatment might 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 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 people 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
- Early Intensive Developmental and Behavioral Intervention (EIDBI) services.

### South Country Health Alliance

- For children who do not meet milestones, providers make recommendations to parents and legal representatives for referral and follow up based on the outcome of the evaluation/assessment. Services might include speech/language, physical therapy, occupational therapy, community-based programs such as Head Start, ECFE or early childhood special education, referral for additional hearing, vision and/or behavioral screening and referral for additional specialty consultation.
- Referrals might be made to a provider for diagnostic or corrective treatment.
- A referral could be made to school-based centers or to mental health professionals depending on what milestones were not met. One example of a referral may be to a qualified mental health professional for a CMDE for possible eligibility for EIDBI. Referrals are not required to access these services.
- Members might also be referred back to the county for help 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 people with special health-care needs. The SHCN program helps identified members with access to care and monitors their treatment plan. Children ages 1-3 with a developmental disorder and who need 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 barriers they identified. Increasing awareness and education, both to providers and families, on the importance of regular screenings and checkups is one of the major 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 warning signs of ASD, where to access screening and

diagnosistic 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 Department of Education (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 EIDBI – Building Provider Capacity webpage.

### Blue Plus

- Strategies should include the continued education of enrollees about 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 is 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

- Integrating mental health services into programs that target families with young children who are county-involved is one recommendation.
- Many people aren't aware of the benefits available to them through their health plans. Multiple communication strategies would be advisable, particularly targeted strategies to the caregivers of newly diagnosed young children.

### Itasca Medical Care

- IMCare would recommend working with 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 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

- Decrease number of emergency room 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 after a positive screen
- Increase percentage of members demonstrating continuous access to mental health services one year after a diagnosis of mental health disorder (visits occur minimum of once every three months).

### South Country Health Alliance

- One of the challenges or barriers in providing recommendations is that the Medicaid population has a tendency to be transient as observed when conducting medical record reviews for HEDIS well-child visit measures. However, South Country continues to work with our owner counties and health care providers to review provider-specific HEDIS well-child rates, which include the physical developmental assessment and mental developmental assessment components.
- Through claims data, we are also able to assess/analyze whether or not the well-child visits were billed as a complete C&TC using the S0302 code. In essence, we believe that increasing performance outcomes for overall C&TC screening participation and/or HEDIS well-child visit participation rates is our most effective means of measuring member access to screening and referral for additional services.
- Continue to engage in intervention strategies such as member education and incentive rewards for completing preventive-care services
- Continue to cover the costs of ECFE classes for eligible members
- Continue to participate in annual C&TC collaborative clinic outreach meetings facilitated by county Public Health C&TC coordinators, in conjunction with South Country and providers (to promote recommended screening components at the specified ages, conducting complete C&TC exams and accurate billing of services). This is the most realistic and consistent means for assessing whether or not we can effectively affect performance outcomes of HEDIS well-child visit measures and CTC performance participation, which include screening and referral for additional services.

### UCare

- UCare's Child and Adolescent workgroup uses the Plan-Do-Study-Act (PDSA) methodology with each intervention planned. The workgroup emphasizes measurement to study if the intervention is achieving the intended results and to improve interventions for the following year.
- We also monitor HEDIS rates for increases and to identify opportunities for improving C&TC.

# V. Conclusion

The MCOs are implementing or have plans to implement strategies for overcoming barriers for 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 in access and provides recommendations to address barriers in access to early screening, diagnosis and treatment of ASD and related conditions. The recommendations include:

- Improve public awareness and education, including ASD early warning signs and symptoms through a variety of communication and outreach strategies
- 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
- Educate clinics, health plans, clinicians and other providers about the currently recommended screening tools and phase out those screening tools that are no longer recommended
- Increase funding and training 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 provider enrollment
- Improve communication and collaboration across educational, medical and human service providers and agencies
- Improve coordination of services and providers
- Streamline the process for referalls and ensure that referrals are followed up on
- Increase awareness of the Follow Along, Child & Teen Checkups, Help Me Grow, Public Health and Woman and Infant Children programs to promote early social / emotional and developmental screenings
- 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 clients in greater Minnesota have access to the same services as metro families.

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 and counties.