

National Landscape: Program and Initiatives to Promote Developmental and Autism Screening

In 2014-2015, AMCHP's State Public Health Autism Resource Center (SPHARC) developed several resources related to developmental and autism screening activities. This included an environmental scan of the wide range of state screening activities. Building upon that scan, and in alignment with efforts of federal and national partners, AMCHP developed this resource of national and federal programs, initiatives and efforts to improve developmental screening. This is not an exhaustive list of all programs but focuses on those with: 1) a national or multi-state/jurisdictional reach and 2) that have specific objectives and/or measures related to developmental and/or autism screening. This guide is expected to grow and will be updated as new initiatives are identified and/or implemented.

If you have questions or would like to suggest a resource, contact Kate Taft at ктаft@amchp.org.

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FEDERAL PROGRAMS

ADMINISTRATION OF CHILDREN AND FAMILIES (ACF)

HEAD START/EARLY HEAD START

Head Start promotes the school readiness of young children from low-income families through agencies in their local community. Head Start and Early Head Start programs support the mental, social, and emotional development of children from birth to age 5. In addition to education services, programs provide children and their families with health, nutrition, social, and other services. Head Start services are responsive to each child and family's ethnic, cultural, and linguistic heritage.

Related Measures: The Head Start Act requires all children to receive a developmental, sensory, and behavioral screening within 45 days of entering the program, in order to determine if further evaluation is needed. Annually, HS/EHS grantees are required to report on:

- Number of all newly enrolled children who completed required screenings within 45 days for developmental, sensory, and behavioral concerns
 - Of these, the number identified as needing follow-up assessment or formal evaluation to determine if the child has a disability
- The instrument(s) used by the program for developmental screening

Reach: National - *Head Start has served over 30 million children and their families in urban and rural areas in all 50 states, the District of Columbia, Puerto Rico and the U.S. territories.*

Website: <http://www.acf.hhs.gov/programs/ohs>

BIRTH TO FIVE: WATCH ME THRIVE!

Birth to 5: Watch Me Thrive! is a coordinated federal effort to encourage healthy child development, universal developmental and behavioral screening for children, and support for the families and providers who care for them. This initiative will help families and providers: celebrate milestones; promote universal screening; identify possible delays and concerns early; and enhance developmental supports.

The federal partners contributing to this initiative include: Administration for Children and Families, Administration for Community Living, Centers for Disease Control and Prevention, Centers for Medicare & Medicaid Services, Health Resources and Services Administration, Eunice Kennedy Shriver National Institute of Child Health and Human Development, Substance Abuse and Mental Health Services Administration, Office of Special Education Programs at the Department of Education.

Related Measures: *Birth to 5* partners developed a [Compendium of Screening Measures for Young Children](#), which is a collection of research-based screening tools for children under the age of 5.

Reach: National initiative

Website: <http://www.acf.hhs.gov/programs/ecd/child-health-development/watch-me-thrive>

CENTERS FOR DISEASE CONTROL AND PREVENTION

AUTISM AND DEVELOPMENTAL DISABILITIES MONITORING (ADDM) NETWORK

The ADDM Network is a group of programs funded by CDC to estimate the number of children with autism spectrum disorder (ASD) and other developmental disabilities living in different areas of the United States. The ADDM Network sites all collect data using the same methods, which are modeled after CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP).

Related Measures: ADDM uses a record review methodology to measure the prevalence of ASD in 8-year old children. Data tracked also includes: characteristics/demographics of children identified with ASD; Children more likely to be identified with ASD; intellectual ability of children identified with ASD; when children were first evaluated for developmental concerns; number of children diagnosed and when diagnosed with ASD; # of children that had an eligibility for ASD special education services at school; etc.

Reach: Currently 10 sites are funded - AZ, AR, CO, MD, MN, MO, NJ, NC, TN, WI; and GA (CDC) (16 sites have been funded since 2000)

Website: <http://www.cdc.gov/ncbddd/autism/addm.html>

LEARN THE SIGNS. ACT EARLY. PROGRAM

CDC's "Learn the Signs. Act Early." program aims to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need. The program is made up of three components:

1. **Health education campaign** promotes awareness of healthy developmental milestones in early childhood the importance of tracking each child's development the importance of acting early if there are concerns
2. **Act Early Initiative** works with state, territorial, and national partners to improve early childhood systems by enhancing collaborative efforts to improve screening and referral to early intervention services supporting the work of Act Early Ambassadors to promote "Learn the Signs. Act Early." messages and tools and improve early identification efforts in their state
3. **Research and evaluation** improves campaign materials and implementation activities and increases our understanding of the factors that influence early identification and referral

Related measures: Ambassador and state systems grantees report at least annual on measures developed to measure progress towards their goals, including to improve screening /early identification and referral to services.

Reach: National campaign.

- Act Early Systems Grants: 7 states have a current grant - MN, MT, NJ, NM, NC, OK, WI
- Act Early Ambassador Program: Currently 29 state ambassadors & 1 organizational partner

Website: <http://www.cdc.gov/ncbddd/actearly/index.html>

CENTERS FOR MEDICARE AND MEDICAID SERVICES

CHIPRA/CHILD CORE SET MEASURES

Implementation of a standardized Child Core Set is helping the Centers for Medicare & Medicaid Services (CMS) and states move toward a national system for quality measurement, reporting, and improvement.

The data collected from these measures helps CMS to better understand the quality of health care children receive through Medicaid and CHIP programs.

Related Measure: DEV-CH: The percentage of children screened for risk of developmental, behavioral, and social delays using a standardized screening tool in the 12 months preceding their first, second, or third birthday (*Data source: Claims Data or Medical Chart Review Data / NQF Measure #1448*)

Reach: National (*20 states reported the developmental screening measure in FFY 2013*)

Website: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Quality-of-Care/CHIPRA-Initial-Core-Set-of-Childrens-Health-Care-Quality-Measures.html>

EARLY AND PERIODIC SCREENING, DIAGNOSTIC AND TREATMENT (EPSDT)

The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. Periodic developmental and behavioral health screenings are required for all children enrolled in Medicaid, through the EPSDT benefit, and they are also covered for children enrolled in the Children's Health Insurance Program (CHIP). Federal matching funds are available for states that provide additional reimbursement to providers who perform developmental and behavioral screenings during a well-child visit.

Related Measures: See Child Core Set above. States must also provide CMS with annual performance information (via Form CMS-416). Screening related reporting items include:

- Number of children provided child health screening services
- Number of children referred for corrective treatment

Website: <http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html>

DEPARTMENT OF EDUCATION

CHILD FIND PROGRAM (IDEA)

Child Find requires all school districts to identify, locate and evaluate all children with disabilities (birth - 22), regardless of the severity of their disabilities. The Individuals with Disabilities Education Act (IDEA) requires all States to develop and implement a practical method of determining which children with disabilities are receiving special education and related services and which children are not. Child Find applies to all children who reside within a State, including children who attend private schools and public schools, highly mobile children, migrant children, homeless children, and children who are wards of the state.

Related Measures:

- **Part B Indicator 11:** Percent of children who were evaluated within 60 days of receiving parental consent for initial evaluation or, if the state establishes a timeframe within which the evaluation must be conducted, within that timeframe.
- **Part C Indicator 1:** Percent of infants and toddlers with IFSPs who receive the early intervention services on their IFSPs in a timely manner.
- **Part C Indicator 5:** Percent of infants and toddlers birth to one with an Individualized Family Service Plan (IFSPs) compared to national data.
- **Part C Indicator 6:** Percent of infants and toddlers birth to three with IFSPs compared to national data.
- **Part C Indicator 7:** Percentage of eligible infants and toddlers with IFSPs for whom an evaluation and assessment and an initial IFSP meeting were conducted within Part C's 45-day timeline

Reach: National

Website: <http://idea.ed.gov/>

RACE TO THE TOP-EARLY LEARNING CHALLENGE

The Race to the Top–Early Learning Challenge (RTT-ELC) discretionary grant program supports states in building statewide systems that raise the quality of Early Learning and Development Programs and increase access to high-quality programs for children with high needs, so that all children enter kindergarten ready to succeed.

Related measures: RTT-ELC grantees submit annual performance reports on performance metrics. One of the focused investment areas states can select is identifying and addressing the health, behavioral, and developmental needs of children with high needs. Progress in this area is reported in six areas: standards, screening and referral, promoting child development, training educators, healthy children, and leveraging resources. Screening and referral performance measures are:

- Number of Children with High Needs screened
- Number of Children with High Needs referred for services who received follow-up/treatment

Reach: 20 states - 5 reported on the identifying and addressing the health, behavioral, and developmental needs focused investment area in the recent progress report (Dec 2014) CA, DE, MD, NC, and OR

Website: <http://www2.ed.gov/programs/racetothetop-earlylearningchallenge/index.html>

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

TITLE V MCH BLOCK GRANT

Enacted in 1935, the Title V Maternal and Child Health Block Grant Program is the Nation's oldest federal-state partnership. For over 75 years, the Federal Title V Maternal and Child Health program has provided a foundation for ensuring the health of the Nation's mothers, women, children and youth, including children and youth with special health care needs, and their families. Some goals of the program include: ensuring access to quality care; increasing the number of children receiving health assessments and follow-up diagnostic and treatment services; providing and ensuring access to preventive and child care services and rehabilitative services for certain children; and implementing family-centered, community-based systems of coordinated care for children with special health care needs.

Related Measures: In 2015, the Title V block grant guidance was revised and includes a new national performance measure on developmental screening:

- NPM6: Percent of children, ages 9–71 months, receiving a developmental screening using a parent-completed screening tool

Reach: National - 59 states and jurisdictions receive Title V MCH Block Grant funding.

Website: <http://mchb.hrsa.gov/programs/titlevgrants/index.html>

STATE AUTISM PLANNING AND IMPLEMENTATION GRANTS

As part of its implementation of the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act, HRSA/MCHB provides funding to state or nonprofit agencies for State Planning

and Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities. Grantees implement existing state plans to improve services for these young people by: 1) developing a system of service that includes screening children early for possible ASD/DD; 2. conducting early, interdisciplinary, evaluations to confirm or rule out ASD/DD; and 3) providing evidence-based, early interventions when a diagnosis is confirmed.

Related Measures: Grantees provide progress reports and evaluation data annually.

Reach: National - 12 current state grantees (*30 states have/have had a planning or implementation grant*)

Website: <http://mchb.hrsa.gov/programs/autism/>

STATE IMPLEMENTATION GRANTS FOR ENHANCING THE SYSTEM OF SERVICES FOR CYSHCN (D70)

Initiated in 2004, the State Implementation Grants for Systems of Services for CYSHCN program provide assistance to states to facilitate implementation of a well-functioning system of services for CYSHCN and their families using MCHB's six core outcomes framework (which includes early and continuous screening for special health needs). The current grant program aims to increase the proportion of CYSHCN who receive integrated care through a patient/family-centered medical/health home approach by 20% over 2009/2010 levels by 2017. Through a national technical assistance center and a cross-state learning community, states will increase their capacity to coordinate policy, program development/analysis, and collaborative partnerships across agencies, organizations and programs at the state and local levels.

Related Measures: Aims and measures are currently under development and will vary by grantee. Some may focus on measures related to better integrating/linking screening and referral.

Reach: National – *48 states have/had a D70 grant. Twelve states received funding in the recent cycle (AK, CO, IN, IA, MA, MN, OR, RI, UT, VT, WA, WI)*

Website: <http://www.mchb.hrsa.gov/programs/stateimplementation/index.html>

EARLY CHILDHOOD COMPREHENSIVE SYSTEMS (ECCS)

ECCS brings together primary care providers, teachers, families, and caregivers to develop seamless systems of care for a children in the critical formative years from birth to age 3. Working with health care providers, social services and child care and early childhood education programs, ECCS help children grow up healthy and ready to learn by addressing their physical, emotional and social health in a broad-based and coordinated way. Grantees focus on one of the following strategies to improve and integrate services for children from birth to age 3: 1) Mitigate toxic stress and trauma in infancy and early childhood; 2) Coordinate the expansion of developmental screening activities in early care and education settings; and 3) Improve state infant and toddler child care quality improvement efforts.

Related Measures: ECCS grant recipients are required to report on statewide data that aligns with the six MIECHV benchmarks. Screening related benchmarks include:

- % of children who received developmental screening and did not need follow up or referral. (Benchmark area 3). *Suggested Data Sources: State surveys; State records, Head Start, EPSDT; Potential Data Sources: National Survey of Children's Health, HRSA/MCHB and CDC/NCHS*
- Measured coordination with documented referrals between child care programs, medical homes and early intervention service providers. (Benchmark area 6) *Suggested Data Sources: Program documents. referral records and/or documentation of a statewide central intake system*

Reach: National - *ECCS grantees work in every U.S. State (except Georgia, Maine and Mississippi), Washington, DC, Guam, Northern Mariana Islands, Puerto Rico, Republic of Palau and the U.S. Virgin Islands. Nineteen (19) grantees focus on the developmental screening strategy.*

Website: <http://mchb.hrsa.gov/programs/earlychildhood/comprehensivesystems/>

FAMILY TO FAMILY HEALTH INFORMATION CENTERS

Family-to-Family Health Information Centers (F2F HICs) are family-staffed organizations that assist families of children and youth with special health care needs (CYSHCN) and the professionals who serve them. F2F HICs provide support, information, resources, and training around health issues. The F2F HIC Program also assists in assuring that families of CSHCN will partner in decision making at all levels (i.e. individual, peer, community, or systems).

Related measures: F2F HICs are required by their grant guidance to track data on the people whom they serve, including follow-up questions on the impact of the help provided. Annually, each F2F HIC aggregates the data they have collected:

- Data includes F2Fs self-reports of their impact in specific policy areas in their communities, including promoting continuous screening,

Reach: National - *F2F HICs are funded in all states and the District of Columbia*

Website: <http://mchb.hrsa.gov/programs/familytofamily/> | <http://www.fv-ncfpp.org/>

HEALTHY START

Healthy Start works to prevent infant mortality in 87 communities with infant mortality rates at least 1.5 times the national average and high rates of low birthweight, preterm birth, maternal mortality and maternal morbidity (serious medical conditions resulting from or aggravated by pregnancy and delivery). Healthy Start grants to health and social service organizations in communities with high rates of infant mortality have helped reduce racial and ethnic disparities and improve health outcomes for mothers and children for 22 years.

Related Measures: The program focuses on the contributing factors which research shows influence the perinatal trends in high-risk communities. Annually, grantees of the MCHB Healthy Start Program provide information on their program. This includes related risk reduction/prevention services for program participants:

- (Infants 0-23 mo) Participants that Receive Risk Prevention Counseling and/or Risk Reduction Counseling for Developmental Delays

Reach: National - *105 Healthy Start projects located in 39 U.S. states, DC and Puerto Rico*

Website: <http://mchb.hrsa.gov/programs/healthystart/index.html> | <http://nationalhealthystart.org/>

MATERNAL, INFANT, AND EARLY CHILDHOOD HOME VISITING (MIECHV)

The MIECHV facilitates collaboration and partnership at the federal, state, and community levels to improve health and developmental outcomes for at-risk children through evidence-based home visiting programs. The program provides grants to support programs to improve maternal and newborn health, promote school readiness and achievement, prevent family violence and child injury, and develop family economic self-sufficiency. Additionally, MCHB launched a Home Visiting Collaborative Improvement and Innovation Network (HV CoIIN) to achieve breakthrough improvements in select process and outcome measures, including benchmark areas legislatively mandated for the MIECHV program, while reducing or maintaining program costs. One of the topics for improvement is early detection and service provision for developmental delays.

Related Measures: Related MIECHV benchmark areas:

- **Benchmark 3:** % of children who received developmental screening and did not need follow up or referral. *Suggested Data Sources: State surveys; State records, Head Start, EPSDT; Potential Data Sources: National Survey of Children's Health, HRSA/MCHB and CDC/NCHS*
- **Benchmark 6:** Measured coordination with documented referrals between child care programs, medical homes and early intervention service providers. *Suggested Data Sources: Program documents, referral records and/or documentation of a statewide central intake system*

Related HV CoIIN measures:

- **Aim:** Increase by 25% from baseline the percent of children with developmental or behavioral concerns receiving intervention in a timely manner.
Screening related process measures:
 - Increase to 95% the percent of visits during which parents are asked if they have any concerns regarding their child's development, behavior, or learning.
 - Increase to 75% the percent of children screened with an appropriate instrument at appropriate intervals.
 - 75% of all children with a parental concern and/or positive screening, and where a home visitor judges need, will be referred to community resource(s) for assessment or intervention services, including EI services.

Reach: National - HRSA supports Home Visiting Programs in every U.S. State, DC and five territories
HV CoIIN - 8 grantee states are focusing on developmental screening in the HV CoIIN

Website: <http://mchb.hrsa.gov/programs/homevisiting> and <http://hv-coiin.edc.org/>

MCH TRAINING PROGRAMS: LEND AND DBP

MCHB/HRSA's Division of MCH Workforce Development provides national leadership and direction in educating and training the nation's future leaders in maternal and child health. This includes the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) and Developmental-Behavioral Pediatrics (DBP) Program. LEND programs provide interdisciplinary training to enhance the clinical expertise and leadership skills of professionals dedicated to caring for children with neurodevelopmental and other related disabilities including autism. The intent of the DBP Program is to train the next generation of leaders in developmental-behavioral pediatrics and to provide pediatric practitioners, residents, and medical students with essential biopsychosocial knowledge and clinical expertise.

Related Measures: LEND and DBP report annual data to HRSA. Screening related items include:

- Number of trainees who completed coursework covering one of more of the following topics: early signs of ASD/DD; screening, diagnosis, and/or evidence-based interventions for ASD/DD.
- Number of trainees who participated in clinical activities or field work that included one or more of the following topics: early signs of ASD/DD; screening; diagnosis; and/or evidence-based interventions for ASD/DD.
- Total number of CE events that addressed one or more the following topics: valid, reliable screening tools; valid diagnostic tools, and/or evidence-based interventions for ASD/DD.
- Number of training events (excluding CE) offered through the LEND/DBP program relating to one or more the following topics: valid, reliable screening tools; valid diagnostic tools, and/or evidence-based interventions for ASD/DD.
- Number of faculty and trainees who participated in the conduct of ASD/DD related research (for example, research on valid and reliable screening or diagnostic tools, evidence-based interventions and supports, service delivery models, or other related topics).

Reach: National - MCHB currently funds 43 LEND programs at universities and children's hospitals; DBP – Currently 10 programs are funded: (3 sites), CO, MA, OK, PA, RI, SC

Website: LEND - <http://www.mchb.hrsa.gov/training/projects.asp?program=9> | DBP - <http://www.mchb.hrsa.gov/training/projects.asp?program=6>

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

PROJECT LAUNCH

The purpose of Project LAUNCH (Linking Actions for Unmet Needs in Children's Health) is to promote the wellness of young children ages birth to 8 by addressing the physical, social, emotional, cognitive, and behavioral aspects of their development. The long-term goal of Project LAUNCH is to ensure that all children enter school ready to learn and able to succeed. Project LAUNCH seeks to improve coordination across child-serving systems, build infrastructure, and increase access to high-quality prevention and wellness promotion services for children and their families. Grantees implement five core prevention and promotion strategies, one of which is: screening and assessment in a variety of child-serving settings.

Related Measures: Related program objectives:

- Increase access to screening, assessment, and referral to appropriate services for young children and their families

Reach: National - *Since 2008, Project LAUNCH communities have been funded in 38 states and territories and 11 tribal grantees.*

Website: <http://www.healthysafechildren.org/grantee/project-launch>

NATIONAL PROGRAMS & INITIATIVES

AMERICAN ACADEMY OF PEDIATRICS (AAP)

BRIGHT FUTURES

Bright Futures is a national health promotion and prevention initiative, led by the American Academy of Pediatrics and supported by the Maternal and Child Health Bureau, Health Resources and Services Administration. The *Bright Futures Guidelines* provide theory-based and evidence-driven guidance for all preventive care screenings and well-child visits. Bright Futures content can be incorporated into many public health programs such as home visiting, child care, school-based health clinics, and many others. The AAP recommends that children be screened for developmental delays or disabilities during the nine-month, 18-month, and 24- or 30-month well-child visits and specifically for ASD at 24 and 30 months.

Related Measures: Bright Futures provides a [set of materials and measures](#) to track and document preventive care activities and services. Related measures include:

- Perform developmental screening and follow-up
- Perform autism-specific screening and follow-up

Reach: National - Public Domain

Website: <https://brightfutures.aap.org>

ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS (AMCHP)

AMCHP has several resources and efforts related to developmental screening produced through [the State Public Health Autism Resource Center \(SPHARC\)](#), including the suite of environmental scan resources. Other related programs include:

NATIONAL STANDARDS FOR IMPROVING QUALITY SYSTEMS OF CARE FOR CYSHCN

The standards address the core components of the structure and process of an effective system of care for children and youth with special health care needs (CYSHCN). They were derived from a comprehensive review of the literature, early project guidance from more than 30 key informants, case studies of standards currently in use within selected sites, and input and guidance from a national work group comprised of national and state leaders representing state Title V CYSHCN programs, state Medicaid agencies, pediatric providers, health plans, children's hospitals, families/consumers, health services researchers, and others. They are intended for use or adaptation by a wide range of stakeholders at the national, state and local levels.

Related Measures: One of the core domains is "Screening, Assessment and Referral." Within that domain, developmental and ASD/DD screening related standards are (abbreviated):

- **SA5:** All children receive periodic, developmentally appropriate, and recommended comprehensive screenings, in accordance with Bright Futures Guidelines.
- **SA6:** Screening efforts, results and referrals for further assessment are documented, relayed to the child's medical home and family, and coordinated among all screening entities.
- **RF1:** Following a screening and assessment, the CYSHCN and their family are referred to needed services, and follow-up is provided to ensure such referrals are completed.
- **RF2:** Regardless of the entity conducting a screening and referral, protocols and documentation methods are in place for the primary care provider, medical home, etc. to follow-up with the child and family.

Reach: Public domain - available for use nationally

Website: <http://www.amchp.org/programsandtopics/CYSHCN/Pages/default.aspx>

ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES (AUCD)

SIX BY FIFTEEN CAMPAIGN

This campaign celebrates 25 years of the Americans with Disabilities Act (ADA) and 40 years of the Individuals with Disabilities Education Act (IDEA). The campaign developed six goals which we hope to achieve by the end of 2015 to directly improve the lives of people with disabilities across the country

Related Measures: Early childhood goals include:

- At least six states increase by 15 percent the proportion of children ages 0-3 who receive recommended developmental screening.
- At least six states commit to improving cross-system information exchange that supports access to services for children identified by screening.

Reach: National campaign

Website: <http://sixbyfifteen.org/>

ASSURING BETTER CHILD HEALTH AND DEVELOPMENT (ABCD) PROGRAM

The ABCD Program was funded by the Commonwealth Fund, and administered by the National Academy for State Health Policy (NASHP). It was designed to assist states in improving the delivery of early child

development services for low-income children and their families by strengthening primary health care services and systems that support the healthy development of young children, ages 0-3. The program focused particularly on preventive care of children whose health care is covered by state health care programs, especially Medicaid. From 2000-2014, the program convened three learning collaboratives and a Screening Academy.

Related measures: Measures vary by state and phase. See:

http://nashp.org/sites/default/files/screening_academy_results.pdf?q=files/screening_academy_results.pdf

Reach: 27 states (AL, AK, AR, CA, CO, CT, DE, DC, IL, IA, KS, MD, MI, MN, MT, NJ, NM, NC, OH, OK, OR, PR, UT, VT, VA, WA, WI)

Website: <http://www.nashp.org/abcd-welcome>

HELP ME GROW

Help Me Grow (HMG) provides a comprehensive, statewide, coordinated system for early identification and referral of children at risk for developmental and behavioral problems. States affiliated with the Help Me Grow National Center use the HMG system to implement effective, universal, early surveillance and screening for all children, and then link them to existing quality programs. The HMG model is designed to:

1. Support child health care providers as well as early care and education providers, human service providers, and families in effective developmental surveillance and screening to promote early detection
2. Provide a centralized call center with the care coordination capacity, our listening and learning approach, to assist families and professionals in connecting children to appropriate programs and services
3. Develop a system that facilitates greater access to and collaboration among professionals (i.e., child health care, early child care, and human service providers), nonprofit organizations, and government agencies committed to promoting optimal child development

Related Measures: The HMG National Center is developing a comprehensive HMG data system to support HMG affiliates with data collection, tracking and utilization. Related common indicators include:

- **Developmental screenings conducted within the HMG system :**
 - Total Number of Children Who Participated in Developmental Screening Programs Per Year;
 - Total Number of Developmental Screenings with Low Scores
 - Total Number of Children Referred for Services Based on Developmental Screening Results

Reach: 23 Affiliate States & growing (AL, CA, CO, CT, DE, DC, FL, IA, KY, LA, MA, MI, MN, NJ, NY, OR, PR, SC, UT, VT, WA, WV, WY)

Website: <http://helpmegrownational.org/index.php>

NATIONAL ASSOCIATION FOR THE EDUCATION OF YOUNG CHILDREN - ACCREDITATION

Since 1985, NAEYC has offered a national, voluntary accreditation system to set professional standards for early childhood education programs, and to help families identify high-quality programs.

Related Criteria:

- **4.A.03:** The program's written assessment plan includes the multiple purposes and uses of assessment, including arranging for developmental screening and referral for diagnostic assessment when indicated...(etc.)

- **4.C.01:** All children receive developmental screening that includes:
 - a. the timely screening of all children within three months of program entry;
 - b. screening instruments that meet professional standards for standardization, reliability, and validity;
 - c. screening instruments that have normative scores available on a population relevant for the child being screened;
 - d. screening of children's health status and their sensory, language, cognitive, gross-motor, fine-motor, and social-emotional development;
 - e. a plan for evaluating the effectiveness of the screening program
 - f. using the results to make referrals to appropriate professionals, when needed, and ensuring that the referrals are followed.

Reach: Nationwide - over 6,500 child care programs, preschools, early learning centers, and other center- or school-based early childhood education programs are currently NAEYC-Accredited.

Website: <http://www.naeyc.org/academy/>

NATIONAL IMPROVEMENT PARTNERSHIPS

The National Improvement Partnership Network (NIPN) is a network of over 20 states that have developed Improvement Partnerships to advance quality and transform healthcare for children and their families. An Improvement Partnership is a durable state or regional collaboration of public and private partners that uses the science of quality improvement and a systems approach to change healthcare infrastructure and practice. Improvement Partnerships in the following states have focused on developmental and autism screening:

- Developmental Screening: 10 states - AL, AZ, IN, ME, NH, NJ, NM, OR, SC, VT
- Autism Screening: 5 states - IN, MD, ME, UT, VT

Related measures: Each project has defined measures and targeted over-arching goals, involves PDSA cycles, and longitudinal data collection.

Reach: National - currently a partnership of over 20 states (*12 have had a developmental and/or autism screening focus*)

Website: <http://www.nipn.org/>

NATIONAL QUALITY FORUM

The National Quality Forum (NQF) aims to improve the quality of American health care by endorsing standardized and validated measures. By endorsing measures they hope to promote the widespread use of quality measurement in clinics, insurance plans, Medicaid/Medicare and population-based health. Below are NQF endorsed measures related to developmental screening:

- #1385: Developmental screening using a parent completed screening tool (Parent report, Children 0-5)
The items are age-specific and anchored to parent-completed tools. The age-specific items assess whether children 10-71 months are screened.
- #1448: Developmental Screening in the First Three Years of Life
Includes 3 age-specific indicators assessing if a child is screened for risk of developmental, behavioral or social delays using a standardized screening tool at 12, 24 and 36 months of age.

As noted above, the Promoting Healthy Development Survey (PHDS) Consumer Assessment of Healthcare Providers and Systems Clinician & Group Survey (CG-CAHPS) are NQF-endorsed.

Reach: National

Website: <http://www.qualityforum.org/>

NATIONAL SURVEYS AND MEASURES

CONSUMER ASSESSMENT OF HEALTHCARE PROVIDERS AND SYSTEMS (CAHPS) CLINICIAN & GROUP SURVEY

The Agency for Healthcare Research and Quality (AHRQ) Consumer Assessment of Healthcare Providers and Systems Clinician & Group Survey (CG-CAHPS) is a standardized survey instrument that asks patients to report on their experiences with primary or specialty care received from providers and their staff in ambulatory care settings over the preceding 12 months. The survey includes standardized questionnaires for adults and children. All questionnaires can be used in both primary care and specialty care settings. Survey results can be used to: Improve care provided by individual providers, sites of care, medical groups, or provider networks; and Equip consumers with information they can use to choose physicians and other health care providers, physician practices, or medical groups.

Related Measures: Related Items from Provider's Attention to Your Child's Growth and Development:

- Respondent and provider talked about child's learning ability
- Respondent and provider talked about age-appropriate behaviors

Reach: Public domain (national use)

Website: <https://cahps.ahrq.gov/surveys-guidance/cg/index.html>

HEALTHY PEOPLE 2020

Healthy People provides science-based, 10-year national objectives for improving the health of all Americans. For three decades, Healthy People has established benchmarks and monitored progress over time in order to: encourage collaborations across communities and sectors; empower individuals toward making informed health decisions; and measure the impact of prevention activities. The overall goals of Healthy People include to: promote quality of life, healthy development, and healthy behaviors across all life stages, and create social and physical environments that promote good health for all.

Related Measures: MICH-29: Increase the proportion of young children with autism spectrum disorder (ASD) and other developmental delays who are screened, evaluated, and enrolled in special services in a timely manner

- **MICH 29.1:** Increase the proportion of children (aged 10-35 months) who have been screened for an ASD/DD
- **MICH 29.2:** Increase the proportion of children with ASD having a first evaluation by 36 months of age
- **MICH 29.3:** Increase the proportion of children with ASD enrolled in special services by 48 months of age
- **MICH 29.4:** (Developmental) Increase the proportion of children with a developmental delay with a first evaluation by 36 months of age
- **MICH 29.5:** (Developmental) Increase the proportion of children with a developmental delay enrolled in special services by 48 months of age

Website: <http://www.healthypeople.gov/>

PROMOTING HEALTHY DEVELOPMENT SURVEY

The Promoting Healthy Development Survey (PHDS) is a parent-completed survey that assesses whether young children (under 4 years) are receiving nationally recommended preventive and developmental services, based on the Bright Futures Guidelines. PHDS is endorsed by The National Quality Forum as a valid measure for system, plan, practice and provider-level assessment. Components of the PHDS are also in the National Survey of Children’s Health. The PHDS was designed to measure the communication-dependent aspects of care – what providers and parents discuss at the visit. The PHDS not only assesses whether recommended care is provided, but also the degree to which parents have their informational needs met and whether the care provided is family-centered.

Related Measures:

- Developmental surveillance – assesses whether the provider asked about and addressed parents’ concerns about their child’s learning, development and/or behavior.
- Developmental screening – determines whether standardized screening tools for developmental and behavioral delays were used.
- Follow up for children at risk – measures whether children at risk were referred and/or received follow-up services.

Reach: Available nationally

Website: <http://www.cahmi.org/projects/phds/about-phds/>

NATIONAL SURVEY FOR CHILDREN'S HEALTH (REDESIGN)

The National Survey of Children’s Health (NSCH) touches on multiple, intersecting aspects of children’s lives. The survey includes physical and mental health status, access to quality health care, as well as information on the child’s family, neighborhood and social context. The redesigned NSCH will be fielded in 2016, yielding both national and state-level estimates in late spring 2017. National estimates will be produced annually with new state-level estimates produced annually as two-three year rolling estimates beginning in 2018 or 2019.

Related Measures: The [new NSCH will have developmental screening items](#) related to:

- Percent of children, ages 10 through 71 months, receiving a developmental screening using a parent-completed screening tool (*the screening must include questions regarding child's language and social development*)
 - Changes reflected in the redesigned survey for this measure include that data will now be collected for children aged 9-71 months to be consistent with AAP guidelines.

Reach: National

Website: <http://www.childhealthdata.org/learn/NSCH>

OTHER RELATED PROGRAMS/RESOURCES

There are many other programs and initiatives related to screening, especially in connecting early intervention, referrals, care coordination and early childhood outcomes. Some of these include:

ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (AIDD)/ ADMINISTRATION FOR COMMUNITY LIVING

STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

State Councils on Developmental Disabilities are federally funded, self-governing organizations charged with identifying the most pressing needs of people with developmental disabilities in their state or territory. Councils are committed to advancing public policy and systems change that help these individuals gain more control over their lives. Key activities include conducting outreach, providing training and technical assistance, removing barriers, developing coalitions, encouraging citizen participation, and keeping policymakers informed about disability issues.

Reach: National – *56 councils across the U.S. states and territories*

Website: <http://www.acl.gov/Programs/AIDD/Programs/DDC/index.aspx>

UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE (UCEDD)

Since 1963, UCEDDs have been working to accomplish a shared vision that foresees a nation in which all Americans, including Americans with disabilities, participate fully in their communities. Independence, productivity, and community inclusion are key components of this vision. Currently, 68 UCEDDs in every state and territory are located in a university setting. UCEDDs are key partners in the Center for Disease Control's [Learn the Signs. Act Early](#) campaign, which also aims to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need. Several UCEDD staff are [Act Early Ambassadors](#) working to expand the reach of the "Learn the Signs. Act Early." program and support their respective state's work toward improving early identification. Many UCEDDs across the nation provide early childhood assessment services for individuals.

Reach: National - *at least 1 in every U.S. state and territory*

Website: <http://www.acl.gov/Programs/AIDD/Index.aspx> | <http://www.aucd.org/template/page.cfm?id=24>

DEPARTMENT OF EDUCATION

PRESCHOOL DEVELOPMENT GRANTS

The Preschool Development Grants competition supports States to (1) build or enhance a preschool program infrastructure that would enable the delivery of high-quality preschool services to children, and (2) expand high-quality preschool programs in targeted communities that would serve as models for expanding preschool to all 4-year-olds from low- and moderate-income families. These grants would lay the groundwork to ensure that more States are ready to participate in the Preschool for All formula grant initiative proposed by the Administration. Over 18,000 additional children will be served in high-quality preschool programs in Year 1 of the program. For more information, visit: <http://www2.ed.gov/programs/preschooldevelopmentgrants/index.html>

PARENT TO PARENT TRAINING AND INFORMATION CENTERS

Parent to Parent Training and Information Centers (PTIs) serve families of children and young adults from birth to age 22 with all disabilities: physical, cognitive, emotional, and learning. They help families obtain appropriate education and services for their children with disabilities; work to improve education results for all children; train and inform parents and professionals on a variety of topics; resolve problems

between families and schools or other agencies; and connect children with disabilities to community resources that address their needs. For more information, visit: <http://www.parentcenterhub.org/>

AUTISM SPEAKS: EARLY ACCESS TO CARE

The Autism Speaks "Early Access to Care" (EAC) initiative aims to lower the average age at diagnosis and increase access to early intervention services for all children. In particular, the initiative focuses on reducing socioeconomic as well as racial/ethnic disparities in access to screening, diagnosis and treatment for autism in the United States. These goals, as well as the associated objectives and activities of EAC, are directly aligned with the work of the "Learn the Signs. Act Early." campaign and associated Act Early Ambassador Program. For more information, visit: <https://www.autismspeaks.org/early-access-care>

EASTER SEALS

Easter Seals programs across the country provide a wide variety of interventions that help individuals of all abilities, including those with autism. Easter Seals currently has a combination of services specifically targeting individuals with the diagnosis of ASD as well as other services that include individuals with ASD among their service recipients. Easter Seals compiles state autism profiles, which are posted to their website. Through "Make the First Five Count," Easter Seals offers a free, comprehensive and confidential online screening tool (ASQ-3) to help parents track of their child's growth and development during the first five years. For more information, visit: <http://www.easterseals.com/our-programs/autism-services/>