

First STEPS—Change Package Toolkit for Developmental Delays and Autism Spectrum Disorder (ASD)

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Improving Health Outcomes for Children (IHOC) is a collaborative effort in Maine and Vermont supported by a federal grant to improve child health by producing standard pediatric quality measures, improving information technology for sharing pediatric data, and supporting practice improvement efforts. First STEPS is the practice improvement effort of the IHOC Program, and is a two year Learning Collaborative based on the AAP Bright Futures Curriculum that aims to increase the rate of EPSDT (Early, Periodic, Screening, Diagnosis, and Treatment) services for children receiving MaineCare benefits, building upon the principles of the Patient Centered Medical Home (PCMH) model to promote practice improvement.

Partnering Organizations: Maine Quality Counts, Maine DHHS, MaineCare, Maine CDC, Maine Office of Information Technology, Muskie School of Public Service, USM, Vermont Child Health Improvement Program, Maine Chapter of the American Academy of Pediatrics, Maine Academy of Family Physicians, Maine Primary Care Association MaineHealth, Eastern Maine Health Systems, Central Maine Medical Group, MaineGeneral Health, Martin’s Point Health Care State Agencies Interdepartmental Early Learning and Development Team (Development Systems Integration Project (DSI/SAIEL))

A. First STEPS Developmental Screening and ASD System Index

Practice Name: _____ Date: _____

Person(s) Completing: _____

Please circle your answer:

1. **Yes or No.** Have you identified a physician champion and an office manager or nurse champion to improve developmental screening rates?
Comments: _____
2. **Yes or No.** Are staff clear on the difference between surveillance and screening?
Comments: _____
3. **Yes or No.** Have clinicians in your practice agreed upon, documented, and posted a standard schedule for developmental and autism screening?
Comments: _____
4. **Yes or No.** Are staff knowledgeable about developmental milestones?
Comments: _____
5. **Yes or No.** Does your practice provide information to families around developmental milestones (e.g., Bright Futures)?
Comments: _____
6. **Yes or No.** Do you use Bright Futures or some other tool (e.g., Tufts) for purposes of surveillance?
Comments: _____
7. **Yes or No.** Do you currently perform routine evidence-based screening for developmental delays and ASD in your practice using a standard tool (e.g., ASQ, MCHAT 1/2 or MCHAT R/F)?
Comments: _____
8. **Yes or No.** Does the practice have a standard process in place for next steps when a concern is noted during the development screening process?
Comments: _____
9. **Yes or No.** Do you have a standard process in place for when a child needs a referral to child developmental services or to a developmental pediatrician?
Comments: _____
10. **Yes or No.** Are referrals for children identified at risk for or with developmental and timely—they are able to get the follow up they need in a timely fashion?
Comments: _____
11. **Yes or No.** Do you have a tracking system in place to track children at risk for or with a positive developmental or autism screening result?
Comments: _____

- 12. Yes or No.** Do you have a care coordinator that assists families through the referral and treatment process for developmental delay and autism?
Comments: _____
- 13. Yes or No.** Do you involve parents or patients in improving your office’s care for children with developmental delay or autism?
Comments: _____
- 14. Yes or No.** Does your practice integrate quality improvement efforts in your office procedures to monitor the effectiveness of surveillance and screening tools (e.g., assessment, work flows, etc.)?
Comments: _____
- 15. Yes or No.** Does your practice provide ongoing training and orientation to staff on how to conduct developmental surveillance, diagnostic screening and on how to communicate concerns and screening results?
Comments: _____
- 16. Yes or No.** Have you made changes/improvements in your office space to design the optimal experience for children with ASD and developmental delays?
Comments: _____
- 17. Yes or No.** Is your practice billing and coding properly for screening for developmental delays and ASD (e.g., familiarity with MaineCare codes)?
Comments: _____
- 18. Yes or No.** Is your practice reliably collecting and reviewing data on the number of children getting developmental screenings (e.g., via claims based through utilization reports, registry reports)?
Comments: _____
- 19. Yes or No.** Do you have systems in place to connect patients and parents with community resources and supports?
Comments: _____
- 20. Yes or No.** Does your practice direct families to resources around care and treatment for children with developmental delays and/or ASD?
Comments: _____

For Questions 1-20, Total “Yes” Responses _____ Total “No” Responses _____

B. First STEPS—

Developmental Delays & ASD “Quick Picks” (Based on System Index)

PRIMARY CHANGE CATEGORY	SECONDARY CHANGE CATEGORY
Leaders as champions for change	<ul style="list-style-type: none"> <input type="checkbox"/> Identify a practice team including, at least, a physician, nurse, and office manager that champions the project and meets at least once a month to review data/quality metrics on developmental screening and care. <input type="checkbox"/> Assure all staff understand the differences between systems for surveillance and systems for screening. <input type="checkbox"/> Agree upon, document and post standard schedules for developmental and autism screening.
Early identification of developmental delays and/or autism spectrum disorder (ASD)	<ul style="list-style-type: none"> <input type="checkbox"/> Assure all staff are knowledgeable about developmental milestones. <input type="checkbox"/> Assure families receive information about and understand developmental milestones. <input type="checkbox"/> Conduct routine surveillance for developmental delays and/or ASD. <input type="checkbox"/> Conduct routine evidence-based screening for developmental delays and/or ASD.
Diagnosis of developmental delays and/or autism spectrum disorder (ASD)	<ul style="list-style-type: none"> <input type="checkbox"/> Routinely train staff in diagnostic evaluation. <input type="checkbox"/> Standardize processes related to follow up and referral to developmental specialists. <input type="checkbox"/> Develop reliable systems for tracking children at risk. <input type="checkbox"/> Routinely train staff in communicating concerns and screening results to patients, parent partners and care givers. <input type="checkbox"/> Develop reliable referral systems ensuring timely referrals for children identified as at-risk or with developmental delays and/or ASD.
Management of developmental delays and/or autism spectrum disorder (ASD)	<ul style="list-style-type: none"> <input type="checkbox"/> Involve patients and families in quality improvement work related to care and treatment for children with developmental delays and/or ASD. <input type="checkbox"/> Redesign office environment to optimize the experience for children with developmental delays and/or ASD. <input type="checkbox"/> Integrate quality improvement into office practice. <input type="checkbox"/> Assure staff knowledgeable about care and treatment for children with developmental delays and/or ASD. <input type="checkbox"/> Assure families have information necessary to effectively help manage care. <input type="checkbox"/> Create highly reliable care coordination processes such as a care coordinator to assist families through the referral, treatment and management process. <input type="checkbox"/> Assure staff regularly collecting and reviewing data on the number of children getting developmental screenings for purposes of improvement (e.g., via claims based through utilization reports, registry reports). <input type="checkbox"/> Assure practices is billing and coding properly for screening for developmental delays and ASD (e.g., familiarity with MaineCare codes).
Linkages to and/or maintenance of community connections to optimize care	<ul style="list-style-type: none"> <input type="checkbox"/> Identify community partners with whom partnering will optimize care for children with developmental delays and/or ASD. <input type="checkbox"/> Develop reliable systems for communication with community partners.

C. First STEPS System Index Action Planning Template

Primary Change Category	Secondary Change Category	Action Steps for Practice: Change/Person(s) Responsible for Completing/Notes & Comments
Leaders as champions for change	<input type="checkbox"/> Identify a practice team including, at least, a physician champion, nurse, and office manager that champions the project and meets at least once a month to review data/quality metrics on developmental screening and care.	
	<input type="checkbox"/> Assure all staff understand the differences between systems for surveillance and systems for screening.	
Early identification of developmental delays and/or autism spectrum disorder (ASD)	<input type="checkbox"/> Assure all staff are knowledgeable about developmental milestones.	
	<input type="checkbox"/> Assure families receive information about and understand developmental milestones..	
	<input type="checkbox"/> Conduct routine surveillance for developmental delays and/or ASD.	
	<input type="checkbox"/> Conduct routine evidence-based screening for developmental delays and ASD.	
Diagnosis of developmental delays and/or autism spectrum disorder (ASD)	<input type="checkbox"/> Routinely train staff in diagnostic evaluation.	
	<input type="checkbox"/> Standardize processes related to follow up and referral to developmental specialists.	
	<input type="checkbox"/> Develop reliable systems for tracking children at risk.	
	<input type="checkbox"/> Routinely train staff in communicating concerns and screening results to patients, parent partners and care givers.	
	<input type="checkbox"/> Develop reliable referral systems ensuring timely referrals for children identified as at-risk or with developmental delays and/or ASD.	

Primary Change Category	Secondary Change Category	Action Steps for Practice: Change/Person(s) Responsible for Completing/Notes & Comments
Management of developmental delays and/or autism spectrum disorder (ASD)	<input type="checkbox"/> Involve patients and families in quality improvement work related to care and treatment for children with developmental delays and/or ASD.	
	<input type="checkbox"/> Redesign office environment to optimize the experience for children with developmental delays and/or ASD.	
	<input type="checkbox"/> Integrate quality improvement into office practice.	
	<input type="checkbox"/> Assure staff knowledgeable about care and treatment for children with developmental delays and/or ASD.	
	<input type="checkbox"/> Assure families have information necessary to effectively help manage care.	
	<input type="checkbox"/> Create highly reliable care coordination processes such as a care coordinator to assist families through the referral, treatment and management process.	
	<input type="checkbox"/> Assure staff regularly collecting and reviewing data on the number of children getting developmental screenings for purposes of improvement (e.g., via claims based through utilization reports, registry reports).	
	<input type="checkbox"/> Assure practice is billing and coding properly for screening for developmental delays and ASD (e.g., familiarity with MaineCare codes).	
Linkages to and/or maintenance of community connects to optimize care	<input type="checkbox"/> Identify community partners with whom partnering will optimize care for children with developmental delays and/or ASD.	
	<input type="checkbox"/> Develop reliable systems for communication with community partners.	

D. First STEPS Change Package Checklist

Developmental Delays and Autism Spectrum Disorder (ASD)

Developmental Delay and ASD Change Package Check Sheet

Leaders as Champions for Change

- **Identify a practice team including, at least, a physician, nurse, and office manager that champions the project and meets at least once a month to review developmental delay and ASD screening data/quality metrics.**
 - Identify a leader within the practice who can assure that resources will be allotted; mitigate challenges, and who will take responsibility for the success of the improvement initiative.
 - Establish characteristics for the champions (provider, clinical support and administrative champions)—one of each per project received. Ensure champion agrees to coordinate and support all developmental and ASD screening activities and keep staff up to date on current practices and new information
 - Champion writes (in conjunction with team) and communicates improvement vision to the entire practice and take on responsibility for engaging other providers in support of the vision.
 - Write job descriptions for all staff that clearly delineate roles, responsibilities, and interdependencies related to evidence-based surveillance and screening; defined enough so that staff can hold themselves and others accountable but flexible enough to change as standard processes evolve.
 - *Agree upon, document and post standard schedules for developmental and autism screening.*

- **Assure all staff understand the differences between systems for surveillance and systems for screening.**
 - Provide staff training and opportunities to practice with both surveillance and screening tools.
 - Provide staff with tools to support both important processes.

Developmental Delay and ASD Change Package Check Sheet

Early identification of developmental delays and/or autism spectrum disorder (ASD)

- **Assure all staff are knowledgeable about developmental milestones.**
 - Inventory staff and physicians regarding education, training, and competencies.
 - Write plan for and systematically train all appropriate staff on ion developmental milestones..
 - Educate staff on an ongoing basis about appropriate milestones for various ages as to be able to ID early warning signs
 - Use system of prompts and reminders for various developmental milestones such as the milestone checklists by age group
 - Educate staff and role play on ongoing basis how to appropriately counsel families
- **Assure families receive information about and understand developmental milestones.**
 - At visits, create a safe environment and engage family in conversations about developmental milestones.
 - Develop mechanisms to alert parents and family members to early warning signs of developmental delay and/or ASD as to expedite early evaluation
 - Use anticipatory guidance sheets to help inform parents and caregivers of what to expect at each visit.
- **Conduct routine surveillance for developmental delays and/or ASD.**
 - Monitor for developmental delays at every well child visit using a tool such as the American Academy of Pediatrics' Bright Futures or the Tufts tool
- **Conduct routine evidence-based screening for developmental delays and/or ASD.**
 - Screen for developmental delays and ASD during regular well-child visits at 9, 18 and 24 (or 30) months per the American Academy of Pediatrics recommendation (ASD screenings should take place at 18 and 24 (or 30) months.
 - Select and reliably administer a developmental screening tool such as Ages and Stages Questionnaire (ASQ-3) or the Parents' Evaluation of Developmental Status (PEDS)
 - Select and reliably administer screening tool such as Modified Checklist for Autism in Toddlers (MCHAT 1/2 or MCHAT R/F) when concern indicated during developmental screening process.
 - Integrate systems for screening into office flow including updating office billing/coding system to capture MaineCare codes and modifiers for developmental screening (ASQ-3/PEDS): 96110 and autism screening (MCHAT 1 or MCHAT R): 96110 HI and autism screening follow-up (M-CHAT2 or MCHAT-F): 96111 HK .

Diagnosis of developmental delays and/or autism spectrum disorder (ASD)

- ***Routinely train staff in diagnostic evaluation***
 - Train staff how to perform comprehensive evaluation for developmental delays and ASD—orientation and re-orientation programs.
- ***Standardize processes related to follow-up and referral to developmental specialists.***
 - Identify resources available to provide additional evaluation and early intervention when necessary.
 - Develop reliable systems for tracking children at risk.
 - Develop reliable referral process to specialist for additional diagnostics as necessary .
 - Develop reliable tracking process for children referred to specialists.
- ***Routinely train staff in communicating concerns and screening results to patients, parent partners and care givers.***
 - When discussing concerns with family, provide specific examples, acknowledge their concerns, and explain importance of further evaluation.
 - Ask open ended questions for better understanding (provider and parents) .
 - Address language barriers and make certain educational materials appropriate for all.
 - Collaborate with others to support families and link families to support systems (e.g., Family Voices).
 - Use mechanism for parent/child feedback about developmental assessment and diagnosis.

Management of developmental delays and/or autism spectrum disorder (ASD)

- ***Involve patients and families in quality improvement work related to care and treatment for children with developmental delays and/or ASD.***
 - Host/facilitate meetings with families and caregivers in appointments to investigate how their child's condition affects the family and to inform things that the practice may do differently or resources that could be organized.
 - At visits, create a safe environment for parents and care givers to offer their points of view in response to evidence based recommendations.
 - Consider forming a parent partner group to work with and advise practice on improvement opportunities when providing care to children and families of children diagnosed with developmental delays or ASD.
- ***Ensure effective communication systems in place***
 - Support families by providing referrals to appropriate therapies and community resources.
 - Providers trained in anticipatory guidance.
- ***Redesign office environment to optimize the experience for children with developmental delays and/or ASD.***
 - Design space with optimal experience for children with ASD in mind with attention to waiting areas, exam rooms, fluorescent lights, noise, smells, and child's sensitivity to pokes/prods/touch.
- ***Assure staff knowledgeable about care and treatment for children with developmental delays and/or ASD.***
 - Identify management approaches and strategies for children diagnosed w/ developmental delays & ASD .
 - Assure families have information necessary to effectively help manage care to assist families through the referral, treatment and management.
 - Staff trained in how cultural norms may influence caregivers decision making regarding care mgmt.
 - Staff trained in facilitating difficult conversations.
- ***Create highly reliable care coordination processes***
 - Identify a care coordinator to assist families through the referral, treatment and management process.
 - Integrate quality improvement into office practice including regular collection and review of data on numbers of children receiving screenings at recommended visits in addition to other important measures related to sharing results with families/care givers, that appropriate follow up is completed and that action plans are developed.
 - Guide parents and families on community resources.
 - Identify and develop relationships with community resources and providers of alternative therapies.
 - Engage parents in care planning and follow up.

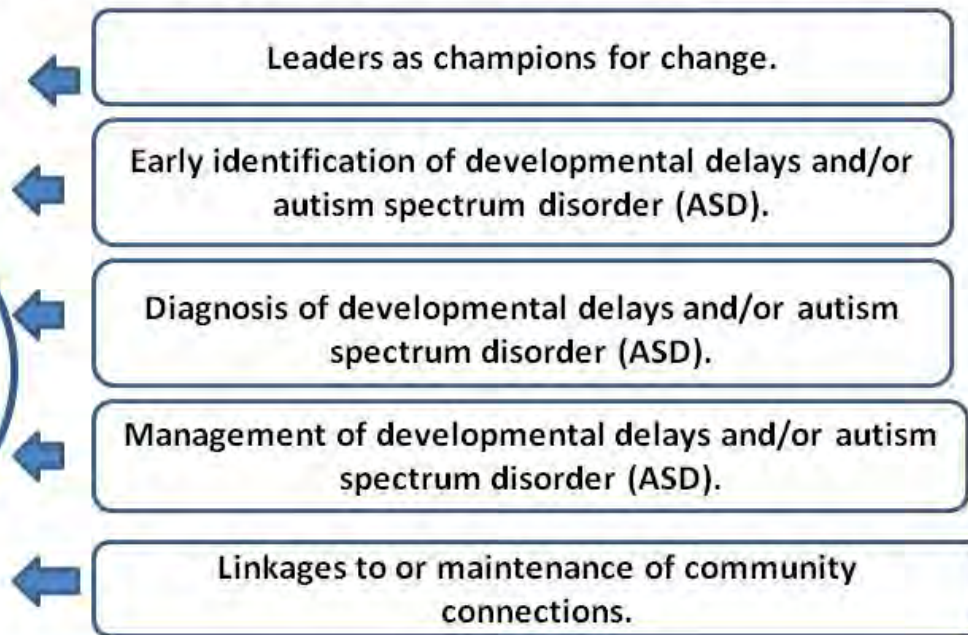
Linkages to and/or maintenance of community connections to optimize care

- **Identify community partners with whom partnering will optimize care for children with developmental delays and/or ASD**
 - ID local community resources and compile and/or update resource list to make available to staff and to patients.
- **Develop reliable systems for communication with community partners**
 - Ensure system in place for feedback loop/communication between primary care and specialist or community partner.
- **Timely referral for children identified as at-risk for or with developmental and social emotional delay**
 - Standardize referral forms and referral tracking systems .
 - Design the referral process into office flow as to create highly reliable processes for care coordination .

Resources & References

Please go to the Quality Counts for Kids webpage on the Maine Quality Counts website at <http://www.mainequalitycounts.org/page/2-971/provider-resources-web-links> for a list of resources and references for Developmental Screening, Developmental Surveillance, and Autism Screening. The site includes references and links to many things including tool kits, forms, terminology, and further reading to name a few.

Improving Care for Children w/ Developmental Delays and/or Autism Spectrum Disorder



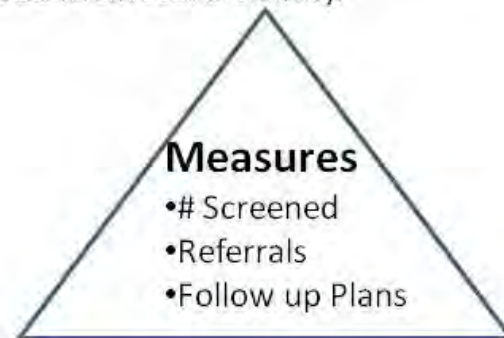
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Specific Aims

From August 2013 to August 2016, we will increase the number of children enrolled in MaineCare receiving general developmental screening by primary care providers by 3 percentage points a year using MaineCare claims data as the source.

By 2016: MaineCare claims data will show 11.1% of children by age 1 (from 2.1%)

12.4% of children by age 2 (from 3.4%), and 9.5% of children by age 3 (from 0.5%) received a general developmental screening. (Baseline data is from 2011 MaineCare claims).



(DRAFT Updated 11.4.13) ¹