Support for Pediatric Clinicians Conducting Developmental Surveillance, Screening, Referral, and Follow-up

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®

Learn the Signs.
Act Early.

Introduction

The American Academy of Pediatrics (AAP) and pediatricians have long recognized that the medical home extends beyond our office walls. This is especially true for children with developmental delays and disabilities who often have co-occurring conditions and increased complexity of needs. Collaboration among early childhood professionals across systems of care is essential to providing quality services and supports for these children and their families.

The AAP, with support from the Centers for Disease Control and Prevention (CDC), conducted five, one-hour listening sessions in 2022 with Executive Directors and pediatrician leaders from AAP chapters. Chapters with an emphasis on early identification of developmental delays and disabilities within their 2020 chapter annual reports were contacted by AAP staff to participate in the listening sessions. Chapters were asked questions focused on chapter successes and needs related to developmental surveillance, screening, referral, and follow-up. This chapter resource guide is based on the feedback from the listening sessions and input from an AAP *Learn the Signs. Act Early.* work group, comprised of general pediatricians, developmental-behavioral pediatricians, and an early childhood professional.

The guide covers the following topics:
- Assess community assets
- Discover potential community partners
- Collaborate with your state's CDC Act Early Ambassador
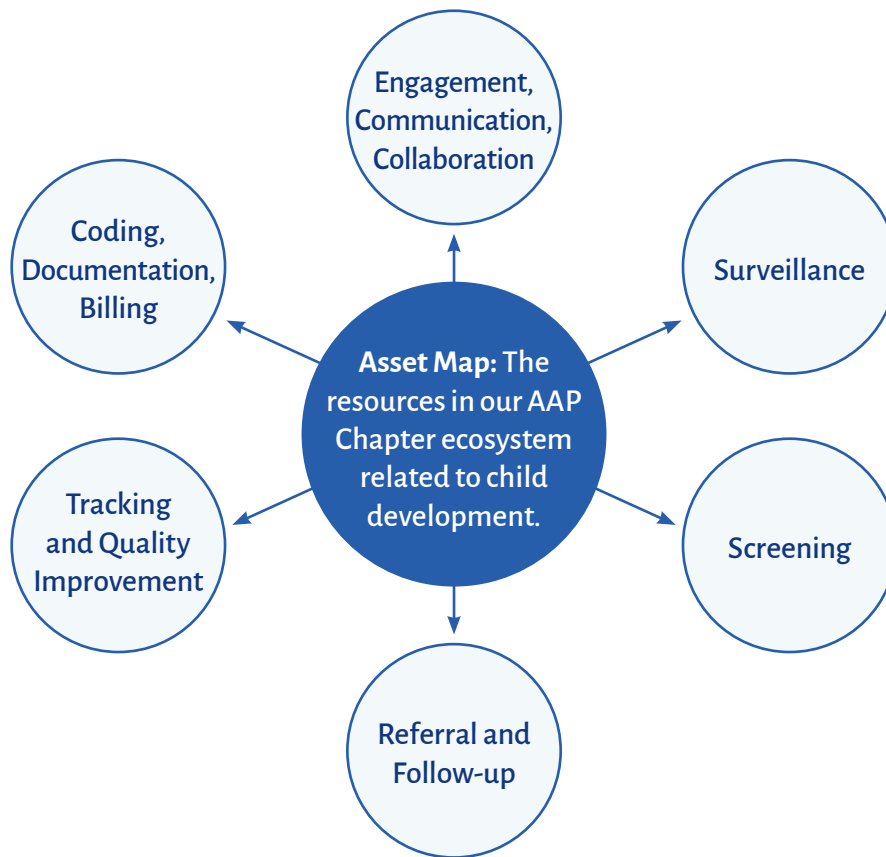- Find resources to facilitate developmental surveillance and screening

Assess Community Assets

As chapters read through the following resource guide, it may be helpful to use or create a community asset map that considers their community's strengths and resources for early identification with information to link to services for children with, or at risk for, developmental delays or disabilities (DD). Note, within a state, there may be differences among communities, and it may be helpful or necessary to consider multiple communities. Some systems will be across a state while other local resources may not be statewide.

A free 1-hour PediaLink course "Innovative Strategies for Improving Developmental Surveillance and Screening" is available to assist chapters and pediatricians in creating asset maps for this work. Additional resources for community asset mapping can be found in the resource section.

Here is an example of a community asset map regarding early identification and intervention for developmental delays and disabilities.

Community Asset Map: Early Identification for Developmental Delays and Disabilities

Asset Map: The resources in our AAP Chapter ecosystem related to child development.

- Engagement, Communication, Collaboration
- Surveillance
- Screening
- Referral and Follow-up
- Tracking and Quality Improvement
- Coding, Documentation, Billing

What and who are the resources available in a community to help inform and uncover solutions?

Get Started: Begin by thinking of the assets available in these major categories of the early childhood development ecosystem.

A Guiding Principle: During the process of developing your Asset Map, it is critical that you build in a method for meaningful representation of the voices of the patient, family, and community served. They are the most important stakeholders in the process and their input should be central to your plan.
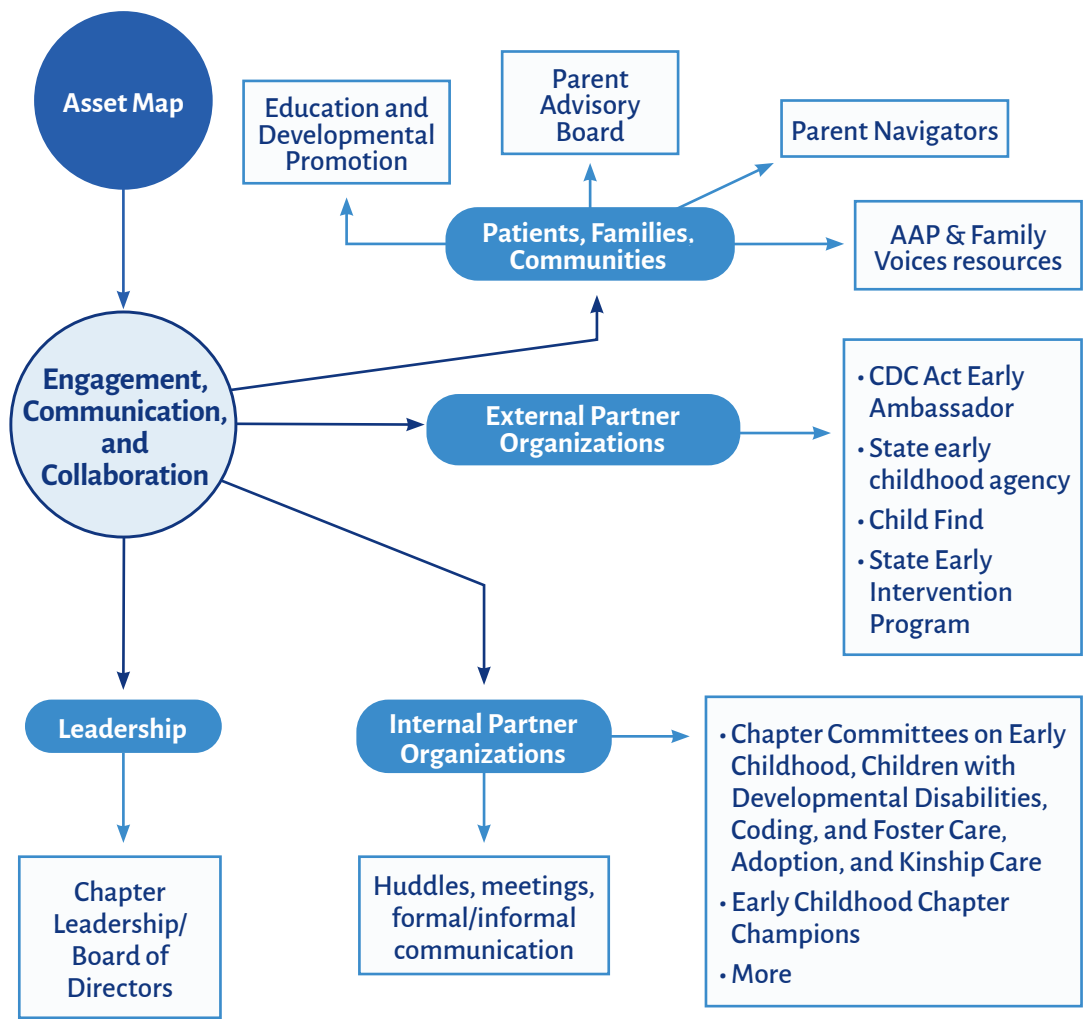
When reading through this resource guide, chapters can further break down sections of their asset map to determine their community's current partners and resources while also identifying areas they may want to expand and seek collaborations.

Identifying Resources and Partners to Expand on Your Community Asset Map

Next focus on one category:

Begin listing assets related to that category, whether currently accessible to your chapter or on a wish list of future resources you might develop a plan to access. These can also be created for a practice, in addition to a chapter.

Engagement, Communication, and Collaboration

- Pediatricians and Practice Managers
- Patients, Families, Community
- External Partner Organizations
- Internal Partner Organizations
- Leadership

Asset Map

Education and Developmental Promotion

Parent Advisory Board

Parent Navigators

Patients, Families, Communities

AAP & Family Voices resources

Engagement, Communication, and Collaboration

External Partner Organizations

- CDC Act Early Ambassador
- State early childhood agency
- Child Find
- State Early Intervention Program

Leadership

Chapter Leadership/ Board of Directors

Internal Partner Organizations

Huddles, meetings, formal/informal communication

- Chapter Committees on Early Childhood, Children with Developmental Disabilities, Coding, and Foster Care, Adoption, and Kinship Care
- Early Childhood Chapter Champions
- More

Discover Potential Community Partners

Many chapters are successfully partnering with external organizations. These partnerships are considered a success within the chapters. Many partnerships require a champion or leader to maintain these relationships over time. Networking or connecting with other chapters or practices to inquire about their partnerships is a good way to start the process. Listed below are examples of chapter/external organization partnerships.

Government Partnerships

- State Health Departments https://www.usa.gov/state-health
- Federally Qualified Health Centers (FQHC) https://data.hrsa.gov/data/reports/datagrid?gridName=FQHCs
- The National Association of State Directors of Developmental Disabilities Services. Search by state https://www.nasddds.org/state-agencies/
- State Council on Developmental Disabilities https://acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities
- Women, Infants and Children (WIC). Search by state https://www.fns.usda.gov/program-contacts/wic
- Act Early Ambassadors http://www.cdc.gov/ActEarly/Ambassadors
- Child Care Development Fund state agency https://www.acf.hhs.gov/occ/contact-information/state-and-territory-child-care-and-development-fund-administrators
- Home Visiting Programs https://nhvrc.org/
- Head Start https://eclkc.ohs.acf.hhs.gov/state-collaboration/article/head-start-collaboration-offices
- Title V Program https://mchb.hrsa.gov/programs-impact/title-v-maternal-child-health-mch-block-grant
- Early Intervention Contact Information by State https://www.cdc.gov/ncbddd/actearly/parents/state-text.html
- Part C (Children B-3) State Systems and Coordinators https://ectacenter.org/contact/ptccoord.asp
- Part B, Section 619 State Programs and Coordinators https://ectacenter.org/contact/619coord.asp

Health Partnerships

- Family Voices Information Center/ Family to Family (F2F) https://familyvoices.org/
- Association of Infant Mental Health (search by state or region)
- Help Me Grow https://helpmegrownational.org/

Other

- Early Childhood Chapter Champions https://www.aap.org/en/pages/chapter-early-childhood-champions/
- Reach Out and Read https://reachoutandread.org/
- Library systems (search by community area)

Collaborate with Your State's CDC Act Early Ambassador

CDC's *Learn the Signs. Act Early.* (LTSAE) program aims to improve early identification of children with autism and other developmental disabilities (DDs) so children and families can access services and support as early as possible. Act Early Ambassadors, funded by the program, have worked to expand the reach of the program, and support their respective state/territory's work toward improving early identification.

Since 2011, professionals with medical, child development, developmental disability, special education, and early intervention expertise have been selected to:

- Serve as state or territorial points-of-contact for the national *Learn the Signs. Act Early.* program.
- Support the work of Act Early Teams and other state/territorial or national initiatives to improve early identification of developmental delay and disability.
- Promote the adoption and integration of *Learn the Signs. Act Early.* resources into systems that serve young children and their families.

- Find your Act Early Ambassador
- Example of integrating LTSAE materials into pediatric practice

How Can Act Early Ambassadors Help Our Chapter and Pediatric Community?

Act Early Ambassadors are eager to improve the early identification of developmental delays/disabilities in young children, and to partner with pediatric clinicians to do so.

Here are some examples of how chapters can partner with Act Early Ambassadors:

- Give Grand Rounds for hospital systems on early identification of developmental disabilities and LTSAE resources.
- Give presentations and demonstrations at AAP chapter meetings.
- Provide a low cost or free table/booth for free resources at chapter meetings/conferences.
- Ask ambassadors to play a role in "connecting" pediatricians to early intervention and preschool special education systems to establish and improve referral and follow up across systems of care.
- Collaborate with state partners and AAP chapter by serving on early childhood committees and work groups.
- Provide information on how to obtain and use Act Early resources.
- Depending on your Ambassador's expertise, other assistance may be available!

Examples of Chapters Working to Improve Surveillance and Screening in Collaboration with State Partners and their State's Act Early Ambassador

Act Early Collaboration Example, by Lisa Heidi Shulman, MD, FAAP

Rose F. Kennedy Children's Evaluation and Rehabilitation Center (RFK CERC) has a 5-year grant with New York State called the Early Childhood Comprehensive Systems: Health Integration Prenatal-to-Three program under Maternal and Child Health. Now on its second year, the goal is to provide quarterly seminars/ lectures/ grand rounds to promote developmental screening and LTSAE. The priority audience(s) are primary care pediatricians/providers in New York city and surrounding areas. Oscar Purugganan, MD, FAAP (an RFK CERC Developmental-Behavioral Pediatrician) works with Liz Isakson, MD, FAAP, a pediatrician, Act Early Ambassador, and executive director for a non-profit Docs for Tots. Together they collaborate on giving talks discussing developmental surveillance/ screening/ evaluation. Grand Rounds have been given along with presentations to pediatric residents, Early Intervention providers, and pediatric practices.

Act Early Collaboration Example, by Toni Whitaker, MD, FAAP

The Tennessee Chapter of the American Academy of Pediatrics offers a "Screening Tools and Referral Training" (START) program throughout the state to educate primary pediatric health care providers and staff to incorporate developmental surveillance and screening into their practices. START aims to increase early identification and referral of children with developmental delays or behavioral concerns through training on:

- surveillance strategies and use of validated screening tools,
- promotion of referral resources in the community, and
- education on documentation, coding, and payment that supports sustainability.

START is funded by a collaboration with the Tennessee Early Intervention System (TEIS), a statewide program sponsored by the Tennessee Department of Intellectual and Developmental Disabilities as outlined under the Individuals with Disabilities Education Act (IDEA), Part C, to provide early identification and intervention services to eligible children. START training is free to clinicians and their office staff, who are encouraged to attend a START training together at the practice location to emphasize the value of working together to optimize workflow and responsibility for various surveillance and screening components. Nearly 1000 participants are trained each year. Medical practices are offered a free developmental screening kit for participating. Free American Board of Pediatrics Maintenance of Certification Part 4 credit is available for clinicians who extend their involvement to complete an office-based quality improvement project, also supported by the chapter. START training is also offered in alternate formats appropriate for pediatric trainees (residents in pediatrics and family medicine, nurse practitioners, physician assistants), early childhood educators, and early childhood and home visiting program staff.

The START training is divided into three parts. Part I provides education on developmental/behavioral screening using standardized screening tools and emphasizes how developmental and behavioral screening enhances parent-engaged developmental monitoring (surveillance). Part II examines standardized developmental and behavioral screening tools that can easily be incorporated into the child health visit. Participants get hands-on experience scoring and interpreting developmental and behavioral tools, as well as a tool for detecting autism spectrum disorder, through case studies. Part III provides strategies for implementing screening procedures during the child health visits and information and strategies practices can use to access appropriate referral resources in their community. Trainers are pediatricians and developmental pediatricians who are trained to facilitate the session. START also partners with a similar program to expand behavioral screening and assessment. The Behavioral Healthcare in Pediatrics (BeHiP) training program helps address additional behavioral concerns.

Find Resources to Facilitate Developmental Surveillance and Screening

Resources for Families

CDC's *Learn the Signs. Act Early.* Milestone Checklists for Developmental Surveillance
https://www.cdc.gov/ncbddd/actearly/freematerials.html
Interactive checklists with photo and video examples of developmental milestones help you know what to look for in your child.

The checklists are available in a variety of formats, including:
- *Milestone Tracker* app
- Printable milestone checklists 2 months – 5 years of age (available in multiple languages)
- Online milestone checklists 2 months – 5 years of age (available in English and Spanish)
- *Milestone Moments* Booklets

Family Friendly Referral Guide
English: https://downloads.aap.org/AAP/PDF/LTSAE_FamilyFriendlyGuide_English.pdf

Spanish: https://downloads.aap.org/AAP/PDF/LTSAE_FamilyFriendlyGuide_Spanish.pdf
The free Family Friendly Referral Guide (in English and Spanish) focuses on supporting families and caregivers whose child has a developmental concern identified during an office visit. Practices can customize this guide with information about local referral resources, and then use the guide to support families/caregivers in understanding next steps and the importance of following through with developmental referrals.

Milestones Matter - Don't Underestimate Developmental Surveillance (Expires 01/06/2024)

https://shop.aap.org/milestones-matter-dont-underestimate-developmental-surveillance/

AAP offers a free online PediaLink course that highlights fundamental steps for performing developmental surveillance for pediatricians. Users completing course are eligible for *AMA PRA Category 1 Credit™* and Maintenance of Certification (MOC) Part 2 points.

Innovative Strategies for Improving Developmental Surveillance and Screening (Expires 12/14/2024)

https://shop.aap.org/innovative-strategies-for-improving-developmental-surveillance-and-screening/

Pediatric clinicians can learn new and innovative strategies for improving developmental surveillance, screening, referral, and follow-up within their current models of care to ensure that children are receiving these essential services. Pediatric clinicians will identify and assess new strategies to identify resources (community asset mapping) to support early identification. Users completing course are eligible for *AMA PRA Category 1 Credit™* and Maintenance of Certification (MOC) Part 2 points.

Complementary Practice Pearls to Support Developmental Surveillance and Screening

https://downloads.aap.org/AAP/PDF/Emerging%20Practice%20Pearls_proof3.pdf

Practice Pearls complement PediaLink courses and the emerging practice repository (below). This document highlights lessons learned and details innovative strategies for incorporating developmental surveillance, screening, referral, and follow-up in light of a public health emergency, such as the COVID-19 pandemic.

Resources for Pediatricians

Additional resources available on the AAP.org patient care page for developmental surveillance and screening

https://www.aap.org/en/patient-care/developmental-surveillance-and-screening-patient-care/developmental-surveillance-resources-for-pediatricians/

- Developmental Surveillance Facilitated Mini Training
- Recorded developmental surveillance coffee talk with case studies
- Webinar on developmental surveillance
- Many, many more!

Screening and Testing Coding Fact Sheet

https://downloads.aap.org/AAP/PDF/coding_factsheet_developmentalscreeningtestingandEmotionalBehvioraassessment.pdf

Developmental screening is conducted using age-appropriate instruments, which vary in length. This coding fact sheet provides guidance on how pediatricians can appropriately report those instruments which are standardized developmental screening and testing services.

Getting Started: Implementing a Screening Process

https://www.aap.org/en/patient-care/screening-technical-assistance-and-resource-center/getting-started-implementing-a-screening-process/

Tools and resources to get you started on developing a process for screening, counseling, and referring, including assessing your office environment, creating a family-centered screening process, and understanding your community resources.

Asset Maps

https://www.ruralhealthinfo.org/toolkits/rural-toolkit/1/asset-identification

Overview of developing an asset map.

Repository of Practices Describing Innovations in Developmental Surveillance and Screening

https://www.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/emerging-practices-strategies-to-continue-health-screening-and-follow-up-during-the-covid-19-pandemic/

Pediatricians were interviewed to identify challenges and successes to implementing developmental surveillance, screening, and referral during the COVID-19 pandemic. This resource guide is available for chapters and practices to review innovative strategies applied by small and large practices in rural, urban, and suburban settings.

Identifying Strengths, Risks, and Protective Factors: Resource Guide for Pediatric Clinicians

https://downloads.aap.org/AAP/PDF/LTSAE_PediatriciansResourceGuide.pdf

Pediatricians reported challenges identifying strengths, risks and protective factors, a key component of developmental surveillance as outlined in the AAP clinical report, *Promoting Optimal Developmental: Identifying Infants and Young Children with Developmental Disorders Through Developmental Surveillance and Screening*. This resource is designed to assist pediatricians with this component of surveillance.

> **Please reach out to Krysta Gerndt, kgerndt@aap.org, at the AAP with any additional questions or requests for resources.**

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