

Tips for Coordinated Care Organizations (CCOs)

Engaging Community Level Partners to Improve Follow-up to Developmental Screening: Who to Engage and Why

Developed by the Oregon Pediatric Improvement Partnership (OPIP) with support from the Oregon Health Authority Transformation Center

Webinar (October 10, 2018) available here:

<https://www.oregon.gov/oha/HPA/DSI-TC/Pages/Dev-Screen-Tech-Assist.aspx>

Purpose and tips included: This high-level tip sheet is intended for coordinated care organizations (CCOs) and their community-level partners to engage stakeholders in improving pathways from developmental screening to the provision of follow-up services that best address the delays identified. The tip sheet is based on learnings OPIP has gathered in leading work in ten communities in Oregon.

OPIP has learned that for CCOs to improve the follow-up to developmental screening happening in health care, primarily in primary care practices, it is integral to engage stakeholders across the community and various disciplines to understand what follow-up services exist and how children can be referred to these services. These stakeholders, within and outside of health care, represent individuals or systems that either conduct developmental screening and/or provide follow-up services to developmental screening. Not all of these stakeholders will exist in every community.

This tip sheet is organized in four parts:

- **Part 1:** Why it is important to engage stakeholders?.....Pages 1–2
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Part 1: Why is it important to engage across-sector stakeholders around follow-up to developmental screening?

To improve follow-up to developmental screening, a baseline understanding is needed about the current follow-up pathways.

- Input from a diversity of stakeholders is foundational to understanding what pathways currently exist that connect children identified at-risk on developmental screening tools to services.
- The follow-up that is provided and the knowledge, awareness and experience of different stakeholders is often varied, and there is much to be learned through various people’s experiences.
- Interviews with individual stakeholders and group-level meetings of stakeholders can illuminate the following within a community:
 - Existing follow-up pathways, which children are referred to them, and differences between various stakeholders in the follow-up pathways they participate in
 - Experiences with follow-up pathways, including successes, barriers and areas of limited capacity or lack of a follow-up pathway for specific delays identified on screening tools
 - For example, insights gained from an Early Head Start best practice around referral and coordination with Early Intervention (EI) may identify and inform improvement opportunities for primary care practices in referring to EI.

- There are many reasons why children who are identified on screening tools do not make it all the way through a pathway to services. Stakeholder engagement can illuminate specific reasons and improvement opportunities for why children identified at-risk for delays do not receive follow-up services. This can include parent refusal; the referral not making it to the agency being referred to; inability to contact the family to schedule an appointment; a child being determined ineligible for services; lack of communication and coordination and therefore reluctance to refer; and many others. Hearing from various community-level stakeholders is essential to understanding all the reasons why children fall out of existing pathways.
- It is important to understand the perspective and perception of each stakeholder about follow-up pathways and their experiences with specific follow-up resources, as perceptions often drive behaviors. It also can be useful to learn about varied levels of knowledge, awareness and experience among those who conduct developmental screening, including their experiences with providers of follow-up resources.

Local stakeholders will have information about existing resources within the community to address risks identified.

- One important consideration is that existence alone is not sufficient to completely understand whether a resource is adequate to meet the need in the community. As stakeholders are engaged, attention should also be paid to capacity to serve the 0–3 population. A resource that exists but has a long waiting list should be accounted for differently than a resource that exists and has open slots for new children identified.
- Equally important to understanding what exists in a community is understanding what doesn't exist. Stakeholders provide information around critical gaps in community resources for children identified at-risk on screening tools.
- A companion tip sheet to this one is focused on how to use the information gathered through stakeholder engagement to create a community-level asset map of follow-up resources to developmental screening: <https://www.oregon.gov/oha/HPA/DSI-TC/Documents/TipSheet-2B-Dev-Screening-Asset-Map.pdf>

Stakeholder engagement allows you to obtain community input and consensus around priority areas in which to pilot improvements, and buy-in to participate in improvement efforts.

- Any effort to implement and test improvements should be informed and carried out by stakeholders in the community. Getting consensus and buy-in is critical for ensuring that solutions identified are implemented to fidelity, and that they will be sustained after the conclusion of the project.

Part 2: How should stakeholders be engaged?

In OPIP's prior efforts we engaged stakeholders individually first, and then convened group-level meetings including stakeholders across the nine sectors (described on page 4). We have found this mix of individual, in-depth engagement paired with group-level review of the summary findings and discussions about the various perspectives is invaluable. This approach provides a model for galvanizing a collective understanding of the current pathways and opportunities for improvement, and facilitating discussions to obtain consensus around priority areas on which to focus. The following are considerations for how to carry out such an approach.

Recruitment and engagement of parent advisors

- A key and primary stakeholder group to engage is parents of young children. Parents and families should be central to any improvement effort. It is important to develop strategies that engage parents in each of the communities of focus, and at all project levels. In OPIP's efforts we have paid

parent advisors to provide input and participate in the group-level meetings. Additionally, where possible, parent advisory groups to the early learning hub or within the primary care practices have been engaged for their insight and input.

Individual stakeholder interviews

- These are individual meetings with stakeholders or group-level meetings with stakeholders in a specific setting (e.g. numerous home visiting nurses).
- The purpose is to interview each stakeholder to understand their current experiences, and to understand barriers and opportunities for improvement. In Part 3 we provide examples of specific questions that can be asked of each stakeholder.
- It is important to ensure that stakeholder responses will be kept confidential; all responses should only be summarized generally, and should never be attached to identifying information. It is important to get candid input, which is usually only offered with a degree of anonymity.
 - It should be noted that in many of the communities that OPIP has worked with, there was high value in having a third-party, and external organization like OPIP conduct these interviews. Many stakeholders felt it was of great benefit for the interviewer to not have vested interest in findings or improvement areas identified.
- These interviews are best facilitated using standardized strategic scripts developed for the specific stakeholder being interviewed. Important categories of interview content to consider include: program/organization specific context, important stakeholders to engage, status of developmental screening in the community, status of developmental promotion activities, status of follow-up to developmental screening, experience with organizations that serve children identified at-risk on screening, hopes for the project, and known challenges and barriers that need to be considered.

Group-level stakeholder meetings

- In addition to getting individual insight, OPIP has found it valuable to facilitate group-level meetings of the stakeholders engaged. There are many benefits to group-level meetings. They galvanize the community around the topic, ensure a shared understanding, and allow stakeholders who traditionally don't interact to get to know each other and coalesce around a topic of shared interest. They provide the opportunity to present and discuss comprehensive qualitative and quantitative information collected across sectors to identify and inform improvement opportunities.
- These meetings are most meaningful when each of the identified sectors are represented.

Part 3: Overview of stakeholders to engage by sector, and examples of key questions to ask

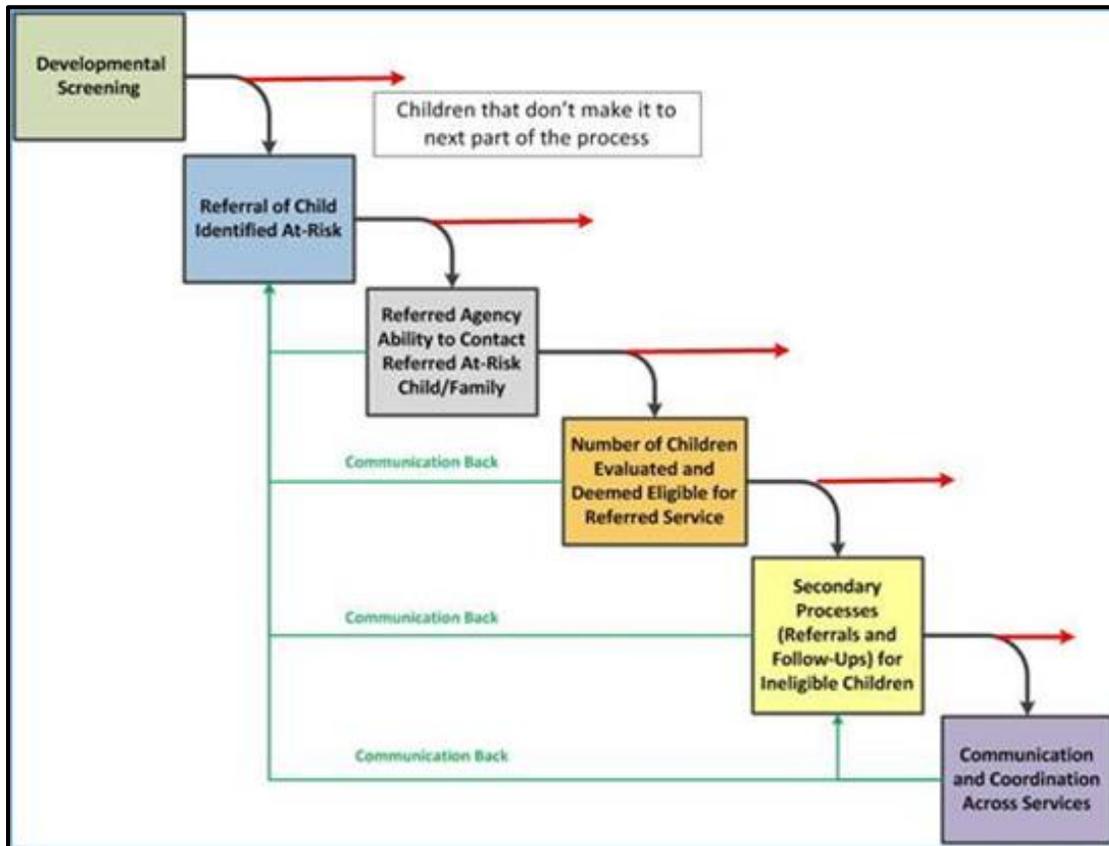
Overall, OPIP has found value in engaging nine different sectors described in the table below. Each of these stakeholders has a unique perspective and a potential role in ensuring young children identified at-risk receive follow-up services.

Table 1. Sectors, Roles and Organizations to Engage Around Follow-up to Developmental Screening

1. Coordinated Care Organization	2. Primary Care and Specialty Care	3. Early Learning Hub	4. Early Intervention and Education	5. Home Visiting and Head Start/Early Head Start	6. Childcare and Parenting Supports	7. Mental Health	8. Other Stakeholders	9. Parents and Families
<p>Medical director</p> <p>Mental health director</p> <p>Staff who oversee children's services</p> <p>Staff who work on incentive metrics</p> <p>Practice support staff</p> <p>Liaison to early learning hub</p> <p>OHA innovator agent</p>	<p>Primary Care: Practices Conducting Developmental Screening <i>Include the following staff in interviews:</i></p> <ul style="list-style-type: none"> Practice managers Providers Care coordinators Referral coordinators RNs and MAs Behavioral health staff Data staff <p>Specialty services that provide care for children 0-3: <i>Systems and clinics providing:</i></p> <ul style="list-style-type: none"> OT/PT/speech therapy Developmental behavioral pediatrician Neuropsychology 	<p>Director</p> <p>Community engagement staff</p> <p>Staff working on developmental screening</p> <p>Hub parent advisory groups and parent advisors</p>	<p>ESD superintendent</p> <p>Early childhood director</p> <p>Service center coordinators</p> <p>EI referral intake staff</p> <p>EI evaluation and services staff</p> <p>School district representatives</p>	<p>CaCoon</p> <p>Babies First!</p> <p>Early Head Start providers</p> <p>Head Start providers</p> <p>Other community services that provide services to 0-3 age group</p>	<p>Childcare Resource and Referral</p> <p>Childcare Centers that are screening</p> <p>Oregon Parenting Education Collaboratives</p> <p>Family Support Network</p> <p>Relief nurseries</p> <p>Other community services providing parent supports</p>	<p>Mental health clinic directors from clinics serving 0-3 age group</p> <p>County mental health providers serving 0-3 age group</p> <p>Private mental health providers serving 0-3 age group</p> <p>Other community services providing mental/behavioral health supports to children 0-3</p>	<p>DHS</p> <p>Oregon Accountable Health Communities</p> <p>211</p> <p>ASQ Oregon</p> <p>Tribal communities</p> <p>Interdisciplinary teams serving 0-3 age group (Community Connections, Service Integration, etc.)</p> <p>Other community organizations and programs whose work coincides with potential pathways</p>	<p>Parent advisors</p> <p>Parent groups in the community</p> <p>Parent committees for health systems and practices</p>

What follows is a high-level overview of why OPIP has found each of these nine stakeholders important to engage, examples of specific roles to engage, and key areas of input that should be obtained from each specific stakeholder. In OPIP's previous projects conducting these interviews, we developed customized and individualized scripts for each interview and each stakeholder.

Figure 1 illustrates the general focus of the stakeholder engagement in understanding the current pathways for follow-up to developmental screening in a community, levels of care coordination, and specific reasons why children may fall out of a pathway and not receive a follow-up service addressing the child's delay identified on the developmental screening tool.



The structure and content of the interviews should be designed so key information about each of the steps in the above illustrated pathway is understood. In general, each interview should include questions about:

- Current follow-up processes and/or knowledge and awareness of follow-up resources in the community
- Perceptions about strengths and barriers to follow-up to developmental screening
- Review of which stakeholders are engaged and their input on who else they would recommend be engaged
- Input on resources that don't exist that would be beneficial
- Important opportunities related to follow-up to developmental screening efforts
- Concerns about efforts focused on follow-up to developmental screening

On the following pages is a high-level summary, by the nine sectors, of specific questions to ask each of these stakeholders.

1) Coordinated care organizations (CCOs)

- **Why are CCOs important to engage?** In addition to their role as payers for health care services, CCOs play important roles as conveners, facilitators, and sources of support for all kinds of activities occurring in communities across the state. CCO leadership and staff have critical insight related to developmental screening and the status of pathways for follow-up to developmental screening. Secondly, several follow-up services or access to follow-up services reside within the CCO service lines or could be impacted by the CCO. These follow-up services include:
 - an evaluation by a developmental and behavioral pediatrician,
 - medical therapy services such as speech therapy or occupational and physical therapy services, and
 - behavioral health services.

CCOs can also potentially support transportation to follow-up services recommended by health care providers that reside outside of health care (for example, Early Intervention).
- **Persons to engage within the CCO:**
 - Medical director
 - Mental/behavioral health director
 - Quality improvement staff or staff who work on incentive metrics, specifically on the developmental screening metric, and who have had experience working with practices and at the community level to improve screening
 - Practice and provider support staff who have worked with practices and understand their screening and follow-up processes
 - Liaison to early learning hubs
 - OHA innovator agent for the CCO
 - Staff who oversee non-emergent medical transportation and address barriers to families not being able to access transportation to referred follow-up services such as Early Intervention.
- **Examples of specific questions to include for CCOs:**
 - What have you learned from efforts related to developmental screening, and were there any issues identified related to follow-up? What services are used now? What barriers have been identified?
 - What work has been done on this topic (follow-up to developmental screening)?
 - What assets and services exist to provide follow-up in your community?
 - Specifically ask about the level of services available for children 0–3 years old identified at-risk on developmental screening. Hone in on the availability of services for children 0–3 that provide: a) an evaluation by a developmental and behavioral pediatrician, b) medical therapy services such as speech therapy or occupational therapy and physical therapy services, and c) behavioral health services. These behavioral health services can be within a primary care setting or within specialized infant and early childhood mental health (for example, parent child interaction therapy or child and parent psychotherapy).
 - What do you know about capacity of follow-up resources in the community?
 - With whom, and what is the best way to share lessons learned around capacity of systems to serve children who need follow-up?
 - What role does your CCO play in supporting electronic health record (EHR) functionality in the region and what opportunities might there be to improve EHR templates related to follow-up?
 - Has your CCO addressed non-emergent medical transportation for children to access community-based services such as Early Intervention or specialty services that reside outside your area, such as in Portland? In this work, have you addressed unique barriers parents of young children may experience such as wanting both parents to be present, needing to bring siblings, or other issues that impact their ability to travel?

2) Primary care providers who are conducting developmental screening, and specialty care providers who are providing follow-up services

Primary care

- **Why are primary care providers who are conducting developmental screening important to engage?** At a population level, in most communities the highest number of children are screened in primary care. Therefore, primary care plays a central and critical role in providing or connecting to follow-up services. The follow-up that primary care provides can be:
 - Internal to the practice, such as providing anticipatory guidance and education, monitoring the child, or providing behavior health services within the primary care settings
 - Referring the child to resources outside the practice and ensuring care coordination
- **Persons to engage in the primary care practice:** OPIP has found it invaluable to engage a multidisciplinary team from practices that conduct developmental screening. This often includes the following roles:
 - Office managers
 - Providers
 - Nurses and medical assistants
 - Internal behavioral health staff
 - Care coordinators
 - Referral coordinators
 - Practice data staff
- **Key types of questions to ask primary care include:**
 - What developmental screening tools do you use, and at what periodicity?
 - What is the process for follow-up in your practice for children identified at-risk? Which children do you provide follow-up to and where? Is there variation between providers? How do you decide which children identified at-risk should receive a referral?
 - Does your EHR have templates related to developmental screening, particularly follow-up to developmental screening?
 - How do you generate referrals for each of the follow-ups identified? Do any of the referrals use a specific form? (Ask this question for each referral service noted.)
 - What kinds of follow-up services do you provide internal to your practice?
 - What kinds of parent education and anticipatory guidance do you provide for children identified at-risk for delays that are specific to the delays identified on the screening tool?
 - Which children do you rescreen? How soon afterward do you set up an appointment to rescreen the child?
 - If applicable: Which children do you refer to the behavioral health services within your practice?
 - From your perspective, what assets and services exist in your community to provide follow-up to developmental screening? (Be sure to be specific about follow-up for children 0–3 identified as at-risk on developmental screening tools.)
 - What is your perspective about the capacity of the resources in the community?
 - What has been your experience referring to and coordinating with these entities?

Specialty care

- **Why is specialty care important to engage?** Medical and therapy services are an important follow-up pathway for children identified at-risk for delays. It is important to understand what services they provide to these children, the capacity they have to serve them, and context around how they receive referrals and coordinate with local primary care providers.

- **Persons to engage from specialty care:**
 - Occupational therapy, speech therapy and physical therapy representatives
 - Developmental behavioral pediatricians
 - Neuropsychologists serving the 0–3 population
- **Key types of questions to ask specialty care include:** In conducting interviews, it is imperative to be clear that you are specifically asking about services for children 0–3 years old identified at-risk on developmental screening tools, and whether they provide services in specific languages. A significant barrier we have found is that some of these services are not available in languages other than English.
 - Do you serve children 0–3? What insurance types are accepted?
 - For each service you provide for children 0–3, can you provide that direct service in languages other than English?
 - What is the process for scheduling these services in languages other than English?
 - Do you get referrals for children identified at-risk on screening tools? What specific referral forms to you use?
 - What is your process for receiving referrals?
 - What tools or strategies do you use to communicate and coordinate with primary care or the person who referred the child to you?
 - From your perspective, what assets and services exist to provide follow-up to developmental screening in your community? (Be sure to be specific about follow-up for children identified on developmental screening tools who are 0–3 years old.)
 - What is your perspective about the capacity of the resources in the community?

3) Early learning hubs

- **Why are early learning hubs important to engage?** The purview of early learning hubs is to bridge early childhood resources and facilitate a cohesive system that prepares children for kindergarten. In communities we have worked with, the hubs have had cross-sector context and have had an important convener and facilitator role.
- **Persons to engage from the early learning hub:**
 - Director or executive director
 - Community engagement staff
 - Staff working on efforts related to developmental screening
 - Parent advisors
 - Parent advisory committee
- **Key types of questions to ask hub representatives include:**
 - What is your perception of follow-up to developmental screening in the community?
 - Have you focused on follow-up to developmental screening in this region before? What was learned?
 - What assets and services exist to provide follow-up (for children age 0–3) in your community?
 - What do you know about capacity of assets in the community?
 - With whom, and what is the best way to share lessons learned around capacity of systems to serve children who need follow-up?
 - Are there resources that don't exist that would be beneficial?
 - Who are other key partners to engage?
 - What challenges or barriers exist around follow-up to developmental screening?

4) Early Intervention (EI) and education stakeholders

- **Why is Early Intervention important to engage?** Early Intervention is another primary follow-up pathway for children identified at-risk for delays. It is important to understand what services EI provides to these children, the capacity EI has to serve them, and context around how EI receives referrals and coordinates with local primary care providers. It is also important to understand key context from education stakeholders from the education service districts and individual school districts, specifically related to how they interact with EI. This can be different within regions and across school districts.
- **Numerous stakeholders from within the education service district should be engaged:**
 - Education service district superintendent
 - Early childhood director
 - EI regional leadership and staff (if applicable)
 - EI service center coordinators
 - EI referral intake staff
 - EI evaluation staff
- **As noted, It is also important to engage local school district staff, which may include:**
 - School district superintendents
 - School principals
 - Special education staff
- **Key types of questions to ask EI include:**
 - Have you done work in supporting follow-up to developmental screenings conducted in health care? If yes, what was covered and what was learned?
 - What is your process for receiving and documenting referrals?
 - Have you ever focused on children who were referred, but who you are not able to contact? What do you do when this happens?
 - How do you coordinate with entities that refer to you? How do you communicate about evaluation results and services provided? How has that gone?
 - Do you refer children not eligible for EI to other entities? If so, which entities and how?
 - Have you shared EI data with CCOs or the early learning hub? What was your experience with this?
 - From your perspective, what assets and services exist to provide follow-up to developmental screening in your community? (Be sure to be specific about follow-up for children 0–3 identified at-risk on developmental screening tools).
 - What is your perspective about the capacity of the resources in the community?
- **Key types of questions to ask school district representatives include:**
 - Have you done work in trying to provide services for young children with developmental delays before they get into school? What was learned?
 - What kids are you seeing in school who were not identified and not served who are not ready to learn?
 - Please describe the relationship between the school district and EI. How are evaluations administered?
 - What opportunities do you see for community-level improvements in getting young children ready for kindergarten?
 - From your perspective, what assets and services exist to provide follow-up to developmental screening in your community? (Be sure to be specific about follow-up for children 0–3 identified at-risk on developmental screening tools.)

5) Home visiting programs and Early Head Start/Head Start providers

Home visiting programs

- **Why are home visiting programs important to engage?** Often various home visiting programs can exist in a community that are critical to engage for two reasons: 1) They conduct developmental screening and therefore play a role in follow-up pathways to developmental screening, and 2) depending on their program eligibility and capacity, they may be a follow-up resource for children identified with delays on developmental screening tools.
- **Home visiting programs that may exist in your community and should be engaged:**
The table on the next page summarizes the two primary home visiting models in Oregon that could be an option for follow-up to developmental screening that occurs in primary care at the recommended periodicity. Some communities have invested additional resources to provide expanded home visiting services, so your community may have other programs, including culturally specific home visiting programs.
- **Key types of questions to ask include:**
 - **Questions related to the home visiting program's screening and follow-up services:**
 - What populations do you serve? How are children eligible to receive your services?
 - What is your process for follow-up when a child is found at-risk on a developmental screening? Which children do you conduct follow-up for and what resources do you use?
 - What entities do you refer to? What is your experience with these entities?
 - Are there resources that don't exist that would be beneficial?
 - **Questions related to whether the home visiting program receives referrals from primary care practices for follow-up to developmental screening:**
 - Most primary care practices conduct developmental screening according to Bright Futures recommendations at the 9-month, 18-month, and 24/30-month visit. If a child is identified at-risk at those ages, can they be referred to your program?
 - In addition to a delay identified on the developmental screening tool, what other child or family factors are important for the primary care provider to consider before referring to you?
 - What is the current capacity of your program? Who provides these services and what days are they available?
 - Do you accept children/families with all insurance types? Do you prioritize patients with OHP?
 - Is there currently an age priority for our county? If so, what is it?
 - Are there social risk factors that make a child/family more likely to be eligible for your services?
 - What is the process for referring to your agency? Is there a standard referral form?
 - What communication and coordination happens with the referring entity once a referral is made?
 - How is the communication and coordination done?

Table 2. Home Visiting Programs That Can Be A Follow-Up to Developmental Screening Conducted in Primary Care Offices at the Bright Futures Recommended Periodicity: Overview

	Website	Program Overview	Ages Served	Eligibility for Services
CaCoon	https://www.ohsu.edu/xd/outreach/occyshn/projects/cacoon.cfm	Triage home visiting services that prioritize the most vulnerable children and families. In referring to this agency it is best to include as much information that aligns with their eligibility criteria as possible.	Ages 0 to 21; some regions prioritize specific ages	Families with a child with a disability or chronic health condition. The “B Codes” of the Oregon Child Health Information Data System outline diagnostic eligibility: https://www.oregon.gov/oha/PH/HEALTHYPEOPLEFAMILIES/DATAREPORTS/ORCHIDS/Documents/RiskCodes_BabiesFirst_CaCoon.pdf
Babies First!	https://www.oregon.gov/oha/PH/HEALTHYPEOPLEFAMILIES/BABIES/HEALTHSCREENING/BABIESFIRST/Pages/Program-Information.aspx	Eligibility criteria are aligned with social risk factors that may be affecting a child’s development.	Serves women prenatally and children ages 0 to 5	Recently expanded to include pregnant women. The “A Codes” of the Oregon Child Health Information Data System outline diagnosis eligibility for children: https://www.oregon.gov/oha/PH/HEALTHYPEOPLEFAMILIES/DATAREPORTS/ORCHIDS/Documents/RiskCodes_BabiesFirst_CaCoon.pdf

Some home visiting programs are **not listed** in Table 2, as they are often not a follow-up to developmental screening because their age-based eligibility criteria are targeted for prenatal care or within the first few months of life. These include:

1. **Healthy Families:** Serves women prenatally and children up to 90 days old <https://oregonearlylearning.com/healthy-families-oregon>
2. **Early Head Start Home-Based Services:** Serves children who are enrolled in Early Head Start. Early Head Start is listed as pathway on the following page. <https://oregonearlylearning.com/early-head-start>
3. **Nurse-Family Partnership:** Mothers enrolled by 28 weeks of pregnancy; services through child’s second birthday. <http://www.nursefamilypartnership.org/>

Early Head Start and Head Start

- **Why are Head Start providers important to engage?** Early Head Start and Head Start providers administer developmental screening, and often they have close working relationships with other resources in the community who provide follow-up services. Additionally, they may be a key follow-up service for a child identified at-risk. However, it should be noted that in the context of improving follow-up to developmental screening in the first three years of life, those children are too young to be eligible for Head Start services.
- **Key types of questions to ask include:**
 - What populations do you serve? How are children eligible to receive your services?
 - What is your developmental screening process?
 - What follow-up to developmental screening do you provide? Which children do you conduct follow-up for and what resources do you use?
 - What entities do you refer to? What is your experience with these entities?
 - Are there resources that don’t exist that would be beneficial?
 - What is the current capacity of your program?

- From your perspective, what assets and services exist to provide follow-up to developmental screening in your community? (Be sure to be specific about follow-up for children 0–3 identified at-risk on developmental screening tools.)
 - What is your perspective about the capacity of those resources?
- Are there resources that don't exist that would be beneficial?

6) Childcare and parenting supports

- **Why are childcare and parenting supports important to engage?** Some childcare providers administer developmental screening tools and can provide key context around screening and follow-up in their setting. Lessons learned can be valuable in identifying opportunities and best practices for improvement. Additionally, other childcare and parenting supports in the community may be identified as an additional support for families in need of follow-up to developmental screening.
- **Entities and programs that support parents or provide childcare should be engaged, including:**
 - Childcare Resource and Referral coordinators
 - Childcare centers that are conducting developmental screening
 - Parenting hubs and local representatives of the Oregon Parenting Education Collaborative
 - Family Support Network
 - Relief nurseries
- **Key types of questions to ask include:**
 - What populations do you serve? Do you serve children age 0–3? Do you specifically target and serve children with delays in development?
 - What context can you provide about follow-up to developmental screening in your organization and community? Do you consider yourself a follow-up resource?
 - What capacity do you have to serve young children screened in health care that are identified with delays?
 - From your perspective, what assets and services exist to provide follow-up to developmental screening in your community? (Be sure to be specific about follow-up for children 0–3 identified at-risk on developmental screening tools.)
 - What is your perspective about the capacity of the resources in the community?

7) Mental health providers

- **Why are mental health providers important to engage?** Based on the ASQ domain identifying the child as at-risk, and other family risk factors that may be present, the best match follow-up service for some children may be a mental health provider. This is especially true for children identified in the problem solving and social emotional domains. Follow-up services provided by specialty infant and early childhood mental health include child and parent psychotherapy and parent child interaction therapy.
- **Persons to engage from mental health include:**
 - Mental health clinic directors from clinics serving children age 0–3
 - County mental health providers serving ages 0–3
 - Private mental health providers serving ages 0–3
 - Other community services providing mental/behavioral health supports to children age 0–3
- **Key types of questions to ask include:**
 - What populations do you serve? Do you serve children age 0–3?
 - Do you get referrals for children identified at-risk on screening tools?
 - What capacity do you have to serve this population?
 - What is your process for receiving referrals?

- Describe your assessment and eligibility process.
- How do you coordinate with entities that refer to you? How has that gone?
- What is your perspective about the capacity of the resources in the community for children age 0–3?

8) Other stakeholders to engage

- Numerous other stakeholders in any given community have a function, role or viewpoint that warrants engagement around this topic.
- **These stakeholders could include:**
 - Local or regional Department of Health and Human Services staff
 - Oregon Accountable Health Communities project staff
 - 211 representatives
 - Ages and Stages Questionnaire (ASQ) Online
 - Tribal communities
 - Interdisciplinary teams serving the 0–3 age group, such as Community Connection Network and Service Integration Teams
- **Key types of questions to ask:** Specific questions to ask depends on the stakeholder, but the general flow should map to the categories outlined above, including screening, follow-up to screening, assets and resources, pathways to assets and resources, and identifying opportunities for improvement.

9) Parents and families

- **Why are parents and families important to engage?** Engaging parents and families is foundational to any effort to address follow-up to developmental screening. They are the primary end user trying to navigate the web of sectors, systems and services that serve children. If improvements are to be made to the pathways from screening to services, parents and families should be at the table to help understand the current status, and to identify quality family-centered opportunities for improvement. If possible, it is important to engage parents and families of children who experienced being identified with a potential delay, and subsequently navigated pathways to services.
- **Ways parents can be engaged:**
 - Paid parent partners who participate in any organized effort to address follow-up to developmental screening
 - Parent focus groups convened around specific efforts or topics
 - Existing parent groups among stakeholder organizations or community agencies
 - Existing parent advisory committees among health systems and practices
 - Specific parents identified by stakeholders as having a valuable perspective to understand
- **Key types of questions to ask include:**
 - Tell us about your experiences with navigating pathways to services for potential delays identified.
 - Was your child identified in primary care? Describe your experience.
 - Describe the referral process to each follow-up service you were referred to.
 - What went well? What was difficult?
 - For services that require an assessment or process for eligibility:
 - What went well? What was difficult?
 - What improvements or supports would have been helpful in getting from screening to services?
 - What is your perspective about the capacity of the resources in the community for children age 0–3?

- What other organizations or individuals were helpful to you along the way?
- Are there resources that don't exist in the community that would be beneficial?

Part 4: Example key findings to summarize from the stakeholder engagement

Once stakeholders have been engaged and interviewed, it is important to strategically summarize the information so it can be used effectively to facilitate important community-level conversations. Processing and using all of this information can be incredibly onerous, so it is important to be strategic about how you document and summarize what you are learning as you go. OPIP has found the following components critical to effectively summarizing the information collected during stakeholder engagement activities.

Experiences and processes related to follow-up to developmental screening

Information collected about experiences and processes related to follow-up to developmental screening are critical to document and summarize.

Appendix A includes a template of summary tables that OPIP has used to distill and succinctly summarize the community-level engagement.

Types of summary information to feedback to the community-level stakeholders, and to use to identify priority areas of improvement include:

- Which children receive follow-up?
- What developmental promotion is happening?
- What referrals are commonly provided in the community?
- What are experiences with referrals to primary referral sources? Include summaries specific to Early Intervention, developmental behavioral pediatricians, mental health providers, home visiting programs, etc.
- What are experiences with medical and therapy services?
- What are ways data from across settings have been used for community-wide improvement efforts? What are the best ways we can use data to inform efforts related to follow-up to developmental screening?

Experiences and processes related to communication and coordination across settings

Information collected about experiences and processes related to communication and coordination across settings is also important to summarize.

- What do referrals look like for various entities across the community?
- What communication is happening when entities aren't able to reach families that are referred?
- What communication is happening when entities aren't able to evaluate or assess children referred?
- What communication is happening around results of assessments and evaluations?
- What communication and coordination is occurring around services being provided across settings?
- What communication and coordination is occurring around the end of service provision across settings?

Known barriers to follow-up to developmental screening, including capacity concerns

Summarizing known barriers to this work in a given community is critical. One such barrier that will be present in all communities is a lack of capacity to serve children 0–3 who have been identified as at-risk for delay. Summarizing this information is an important early step for identifying what can be done to make improvements. Examples of things to summarize include:

- What are known barriers to work on follow-up to developmental screening?
- What resources in the community are at capacity, or don't have enough capacity to catch children identified?
- What resources don't exist in the community that you wish did?

Appendix A: Stakeholder Engagement Summary Table

The following table can be used to summarize information collected as part of stakeholder engagement activities. Organizing the information in this way helps to facilitate effective community-level conversations and work toward the identification of improvement opportunities.

Experiences and Processes Related to Follow-up to Developmental Screening	
Which children receive follow-up in different settings?	
What developmental promotion is provided in different settings?	
What referrals are commonly provided?	
<i>Experiences referring to EI</i>	
<i>Experiences referring to developmental behavioral pediatricians</i>	
<i>Experiences referring to home visiting</i>	
<i>Experiences referring to mental health</i>	
<i>Experiences referring to parenting classes or supports</i>	
Experiences with medical and therapy services	
<i>Occupational therapy/physical therapy/speech therapy</i>	
Other information	
Experiences and Processes Related to Communication and Coordination Across Settings	
What does the referral process look like across entities engaged?	
What communication is occurring across settings when entities aren't able to reach families that have been referred?	
What communication is occurring across settings when entities aren't able to evaluate or assess referred children?	
What communication is occurring across settings around results of assessments and evaluations?	
What communication and coordination is occurring across settings about services being provided?	
What communication is occurring across settings about the end of service provision?	
Known Barriers to Follow-Up to Developmental Screening, Capacity Concerns, Resources That Don't Exist	
What are known barriers to work on follow-up to developmental screening?	
What resources in the community are at capacity, or don't have enough capacity to catch children identified?	
What resources don't exist in the community that you wish did?	