

Introduction

The study topic of the ABCD III (Assuring Better Child Health and Development) project has been screening, referral, receipt of services, and care coordination for children at risk for developmental, behavioral and/or social delays or who have developmental disabilities. The ABCD III project sought to address two primary issues: (1) capitalize on improvements in the spread of structured screening in primary care and build sustainable coordination models; and (2) strengthen the relationship between systems of care and early intervention services, to support medical homes for all children.

For the last ten years, the Commonwealth Fund and the National Academy for State Health Policy (NASHP) have partnered with states to find innovative approaches to improving care for young children at risk for developmental, behavioral and social delays. Through the first two projects, NASHP provided technical supports to a number of states to increase the rates of screening for children at-risk. With ABCD-III, NASHP and the Commonwealth Fund challenged states to find replicable, sustainable, and spreadable ways to strengthen the links among families, doctors, and others involved in early intervention efforts.

Oregon chose to use an innovative strategy that incorporated the ABCD III goals and objectives into an optional Performance Improvement Project (PIP) that Managed Care Organizations (MCO) could implement as part of their External Quality Review (EQR) requirements. Led by Charles Gallia, PhD, the Division of Medical Assistance Programs (DMAP) created a contract for an External Quality Review Organization (EQRO) to develop an ABCD III PIP and to facilitate a Learning Collaborative across the participating MCOs. An innovative component of the development of the PIP was the proposal to use a process of community-level engagement to inform the elements of the PIP. A "Community Café" (based on the WorldCafe) model was proposed.

The Oregon Pediatric Improvement Partnership (OPIP) received the contract to serve as the EQRO-like entity for the ABCD III project. This report summarizes the key activities, learnings and potential implications from the ABCD IIII PIP development and the OPIP-led Learning Collaborative across the eight MCOs that chose to participate. Additionally, MCO-specific summary reports are provided for each of the eight participating MCOs in Appendices A-H. These reports document the activities within the MCO's as of October 2012, when the OPIP-led component of the ABCD III Learning Collaborative efforts ends. The MCO-level work related to the ABCD III PIP will be ongoing, with updates provided to DMAP as part of other EQR-related activities. The eight MCOs that participated in ABCD III serve clients in 20 counties. Table 1 provides a summary of each MCO and the regions in which they provide care.



Table 1: ABCD III MCOs and Communities

ABCD III MCOs AND COMMUNITIES

MCO Participating	Counties Served
in ABCD III PIP	(Communities in Which Community
	Engagement were Held Are in Bold)
Providence Health Assurance	Clackamas, Multnomah, Washington, Yamhill
Tuality Health Alliance	Washington
CareOregon	Clackamas, Clatsop, Columbia, Coos, Douglas, Jackson,
	Klamath, Lincoln, Marion, Morrow, Multnomah, Polk,
	Tillamook, Umatilla, Washington, Yamhill
Marion Polk Community	Clackamas (limited), Linn (limited), Marion, Polk, Benton,
Health Plan (MPCHP)	Yamhill
DCIPA, LLC	Douglas
Lane Individual Practice	Lane, Linn & Benton
Association (Lipa)	
ODS Community Health	Baker, Clatsop, Columbia, Jackson, Malheur, Union, Wallowa,
	Yamhill
Kaiser Permanente Oregon	Clackamas, Marion, Multnomah, Polk, Washington

Oregon Pediatric

As can be seen, the ABCD III PIP pilot was conducted across various-sixed MCOs in varied geographic regions of the state. Therefore, the findings related to this pilot are useful in understanding the PIP and potential implications for continued use of the PIP across the remaining MCOs.

Background Information Used by the OPIP to Frame and Develop the ABCD III PIP

A primary step in OPIP's development of the specific ABCD III PIP components and structure was background literature reviews and examination of state and local data related to screening, referral, receipt of services, and care coordination for children at risk for developmental, behavioral and/or social delays or who have developmental disabilities. This background work was conducted in Early Spring 2011 using the data and information available at the time.

Background Data Used to Inform the ABCD III PIP Development in Oregon

There is growing evidence of the effectiveness of early screening for developmental disabilities within primary care practices caring for young children. Interest in the early identification and referral of these children is increasing across health and education sectors; early detection and treatment helps to prevent poor academic and social outcomes of unrecognized developmental challenges. According to the American Academy of Pediatrics statement on the Role of the Medical Home in Family-Centered Early Intervention Services, "the early childhood years present a singular opportunity to influence lifelong development and prevent or minimize developmental problems in children with disabilities or those who are at risk of developing disabilities." (1)

Despite this interest in early recognition and referral, children with developmental challenges remain under-recognized. Recent studies have shown that the prevalence rates of developmental challenges may be much higher than previously thought. In a study examining the Early Childhood Longitudinal Study Birth Cohort (ECLS-B) it was found that about 13% of the children in the sample had developmental delays that would make them eligible for Part C Early Intervention; however at 24 months of age, only 10% of children with delays were receiving appropriate services.(2) Research has demonstrated that early detection and referral of children suspected of developmental disabilities allows for therapies that can alter that child's developmental trajectory and allow for improvements in later school functioning.(1, 2)

Currently, standardized screening within primary care is inadequate; and dependence on clinical observation in the detection of developmental disabilities remains despite the lack of validity of this clinical interpretation. In the National Survey of Children's Health it was found that only 19.5% of children aged 10 months to 5 years had been evaluated using a standardized developmental screen; in Oregon, only 13.5% of children had been screened.(3) Without the use of standardized screening tools, clinicians correctly identify only 30% of children with developmental delays; using standardized tools increases this rate to 70-80%.(4) Furthermore, Hix-Small, et al., found that using screening tools not only improves recognition but allows for earlier identification. Implementing standardized developmental screening tools increased EI referral rates by 224%; referrals to Early Intervention that were based on a failed screening tool coupled with clinician judgment showed 92% agreement with EI intake testing.(5)



For providers, multiple barriers exist in the implementation of appropriate developmental screening, including time to conduct screening, knowledge of appropriate tools and materials, familiarity with coding and billing for standardized tools, and knowledge of referral resources. Further attitudinal barriers include provider failure to trust screening results, a reliance on observation, and the use of non-standardized tools in developmental assessments.(6) Given these facts, the American Academy of Pediatrics published a policy statement guiding the use of standardized developmental screening tools in 2006, stating:

"The authors recommend that developmental surveillance be incorporated at every well-child preventive care visit. Any concerns raised during surveillance should be promptly addressed with standardized developmental screening tests. In addition, screening tests should be administered regularly at the 9-, 18-, and 30-month visits. (Because the 30-month visit is not yet a part of the preventive care system and is often not reimbursable by third-party payers at this time, developmental screening can be performed at 24 months of age)." (7)

Screening and referral are the first steps in the care of children with developmental challenges, but the provider and health system practicing within a highly functioning medical home that involves coordinating care received in the community is needed for these children. The medical home concept includes several relevant principles: providing comprehensive care, assisting in care coordination, long-term or chronic care management, and attending to family concerns (family centered care). (8) The current state of well child care does not adequately address care coordination or family centered care. It is estimated that two of five parents have concerns about their infant or toddler's social, behavioral, or cognitive development; only one of five said their child receives the full range of preventative and developmental services recommended by experts in pediatric care. (9) Furthermore, studies show that over half of parents report they weren't asked about their child's learning, development or behavior, and over 90% of parents report leaving their child's appointment with important unmet needs. (10)

Care coordination for children at risk for developmental, behavioral and social delays or with developmental disabilities within the medical home encompasses several key functions. First, the provider should be "knowledgeable about the referral process to early intervention programs in his or her community and knowledgeable about the parents' right for multidisciplinary team evaluation by the school- or state-designated agency if a disabling condition may be present." (11) Second, a plan of care (jointly developed by the physician, patient, and family) should be shared with other agencies involved with the care of the patient. The health plan could play an integral role in coordinating and ensuring these processes and information are in place. Third, the provider and health system should ensure that periodic measures of patient progress are made, allowing for continuity of care over time. In a highly functioning medical home, "all pediatricians should offer to be available by written communication or participate by conference call or other means to offer input to and receive feedback from the [Early Intervention] assessment team. Ideally, the pediatrician should be a member of the team and attend the IEP/IFSP meeting."(11)



Awareness of the outcome of a referral to community agencies and/or developmental screening and services provided by community agencies is critical to appropriate care coordination within the medical home. In order for the provider to refer, baseline knowledge of available community agencies for referral is needed. Providers must be aware of barriers to appropriate communication between the health care and education sectors, including relevant referral procedures and confidentiality laws. Lack of a communication loop between these sectors can lead to fewer referrals to community agencies. Additionally, a lack of knowledge of recourse for those children that do not qualify for services may inhibit future referrals. (11) And, vice versa, coordination and communication by community agencies is also needed in order to effectively coordinate services. (12-14)

Local Efforts Related to Screening and Referral

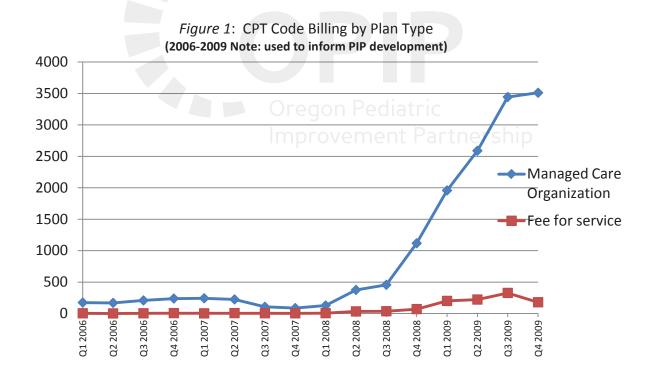
Several projects within the state of Oregon have centered on increasing rates of standardized screening tool use amongst primary care providers. The Screening Tools and Referral Training (START) program is an example of a provider-led screening initiative that not only trained primary care providers in using standardized screening tools, but also helped to establish connections between primary care providers and community resources that care for children at risk for developmental disabilities and autism. This program began in the third quarter of 2008 in the Portland Metropolitan area. To date, the START program has conducted dozens of trainings that have reached over 900 participants, including over 300 providers. During the course of this project, many providers were also given a referral and release form to use to enable communication between primary care and the community sector. This form was intended to address information exchange barriers by obtaining parent consent for release of information under HIPPA and FERPA laws, to explain the reason for referral (including medical conditions, developmental domains of concern, and failed screening tests), and to indicate which pieces of the evaluation the provider was most interested in receiving from Early Intervention.

The Oregon ABCD Screening Academy is another example of a local effort focused on policy and practice-level efforts to increase the identification and referral of children at risk for developmental, behavioral and social delays. The goal was to increase surveillance and standardized developmental and social-emotional screening for children ages birth through five. The practice-level efforts focused on demonstrating the feasibility and meaningfulness of developmental screening in practices, and were conducted in the pediatric clinic of Kaiser Permanente Northwest. Additionally, a number of policy-level clarifications were made in the Medicaid Provider handbook about screening recommended, applicable tools, and appropriate claims that should be used. These two projects resulted in an increase in the number of billings of the CPT code 96110 for children birth to five over the years preceding the initiation of this project (Table 2):



Table 2: CPT Code 96110 Billing in Oregon (2006-2009)			
Delivery System	Oct 2006-Sep 2007	Oct 2007-Sep 2008	Oct 2008-Sep 2009
Managed Care Organizations	814	1046	8984
Fee-for-Service	22	81	823
Total	836	1127	9807

When examined by quarter (see Figure 1), the data show an increase in the number of billings after the implementation of these two programs; however, it is unclear how many providers are still not screening, or if billing is in fact correctly associated with the administration of a standardized screening tool.



IFSPs (Individualized Family Service Plans) are tracked by the Oregon Department of Education (ODE) and reported annually in IDEA (Individuals with Disabilities Act) "Report Cards." State targets are set for each county based on the estimated number of children eligible for EI in the birth to 1-year (IFSP 1) and birth to 3-year (IFSP 3) age groups. (15) IFSP 1 and IFSP 3 targets are



determined using the most recent adjusted census data and annual Special Education Child Count (SECC). Analysis of number of children and families receiving IFSPs in the five-county region targeted by this initiative shows there is work to be done to reach the targets set by ODE. The ABCD II Screening Academy and START projects may have slightly impacted the number of families receiving services beginning in the year 2006-2007; however, only one county, Lane (where the ASQ was developed and extensively tested), met or exceeded the IFSP targets for the year 2008-2009. Multnomah showed slight increases in the percentage of IFSP 1 and IFSP 3 completed in this same year (Figure 2), yet remained below target; and three counties (Clackamas, Douglas, and Washington) had downward trends in the percentage of IFSPs in both age groups during 2008-2009 (Figures 2-5). (16)



Figure 2: Multnomah County IFSP 1 & IFSP 3 (2005-2009 Note: used to inform PIP development)



Figure 3: Clackamas County IFSP 1 & IFSP 3 (2005-2009 Note: used to inform PIP development)

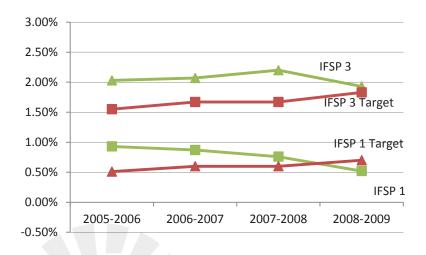


Figure 4: Douglas County IFSP 1 & IFSP 3 (2005-2009 Note: used to inform PIP development)

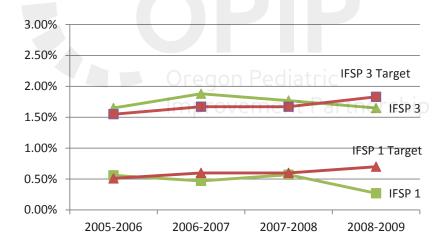
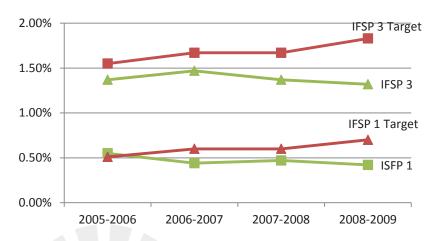




Figure 5: Washington County IFSP 1 & IFSP 3 (2005-2009 Note: used to inform PIP development)



Community Engagement to Inform the ABCD III PIP Development

As noted earlier, the DMAP contract included an expectation that the PIP would be informed by meetings with "participating MCOs, their providers, community health and social service providers, and the families with children who are at risk of developmental delays in each of the participating areas through Community Cafés and regular meetings to become familiar with communities and service providers." In December '10-January '11 the ABCD III Core Team (including OPIP) received training on the "Community Café'" approach by members of the National Alliance of Children Trust & Prevention Funds. Following these individual trainings, three group-level trainings were conducted in three specific geographic regions (Metropolitan Portland, Eugene, and Roseburg). Key stakeholders in the region were invited to these trainings, including the representatives from the MCO, primary care providers, community based providers, Early Intervention, parents of young children and others. The group-level trainings were meant to provide the community with context about the café's, provide examples of café techniques and to identify parent leaders in the community.

Originally, the contract stated that OPIP would then help to facilitate a community café meant to inform the ABCD III PIP development. The parent leaders identified in the trainings would serve as the leader for the café's. However, key learnings were gathered from the trainings about the community participants' current knowledge of the topics relative to ABCD III, their relative engagement, and potential issues that may limit the level and type of information gathered in the Café's to inform the PIP.

Therefore, building off the learnings from the café' trainings and based on OPIP's past experience with engaging stakeholders on quality improvement, OPIP instead proposed the use



of a three-staged process of Community Engagement. OPIP also proposed that this three-staged process be conducted in each of the three geographic regions to ensure that community-level variations were addressed and that the key stakeholders within each of the communities were engaged so that they could serve as potential partners in the improvement efforts. This process was meant to ensure that the ABCD III interventions were designed using an approach that is direct and local, rather than one-model-fits-all.

Figure 6: Three-Staged Community Engagement Process

Three - Staged Community Engagement Process

1. Community Café's (CC) with Parents

"Harvest" from café of potential solutions, current perceptions of process and barriers, anchored to principles of ABCD III

2. Strategic Interviews and Engagement with Community Providers*

Participants include Early Intervention and other community providers (including home visit nurses and mental health agencies), front-line PCPs and health plans AND the parent leader from the community café.

- -- Feedback to parents who participated in the community café's (cc)
- 3. Engagement/Group Meeting of Community Providers

Participants are those who participate in Tier 2.
Blended model of community café/Infrastructure meeting

-- Feedback to parents who participated in the community café's (cc)

Improvement Partnership

Guided by parents as leaders, OPIP facilitated community engagement activities in each MCO-based community to discuss experiences from a variety of perspectives and suggest improvements to the ABCD III teams. The participants in the engagement process included the breadth of stakeholders that have a role in providing and improving care in this shared system (the identification, referral, receipt of services, and care coordination for children at risk for developmental delays). Specifically, this process incorporated parents of young children who receive early intervention, MCO leadership and quality improvement staff, primary care providers and clinical staff, early intervention specialists, public health providers, and Early Intervention leadership and providers.

A full report of the methods and findings from the ABCD III Community-Level Engagement has already been provided to DMAP. Overall, the process revealed a wealth of information about each of the communities of focus and provided participants the opportunity to be involved in a process that they wouldn't usually have the occasion to influence.



The information from all three stages of the community engagement and from all participating stakeholders were agreed upon and summarized in Table 3. Throughout the ABCD III Learning Collaborative OPIP explicitly referenced the Community-Engagement findings and asked plans to address how the needs of the community were being addressed.

Table 3: ABCD III Areas of Opportunity

Identifying Resources

"Central Resource List" – for parents, PCPs, EI, MCOs, etc. Specific to needs- Age, region, specialty/service type

Navigating "The System"

- For Families
 - Understanding the roles of different service providers
 - Someone to talk to about navigating the system and processes
 - Knowing what questions to ask providers
 - Knowing how best to communicate with their plan, and understanding what is covered and by who
- For Service Providers
 - Knowing how to effectively and efficiently refer to different providers
 - Understanding questions around coverage
 - Knowing who to ask about parts of the processes that are unclear

Communication and Coordination

- For Families
 - Understanding what care coordination means
 - Understanding parents role in care coordination
 - Knowing who to talk to about aspects of their child's care
- For Service Providers
 - Knowing how best to get information about their patients
 - Knowing how best to provide pertinent information about their patients
 - Understanding constraints and barriers experienced among entities
 - Understanding mechanisms for coordination, including available incentives



The participating MCOs were regularly reminded of the findings of the community engagement process and were encouraged to consider this information as they carried out their projects. This was at times a challenge, as while this information is extremely valuable, it was hard for plans to interpret as immediately actionable. Overall, the experience proved valuable, and MCOs regularly repeated certain key input from parents especially as important considerations as they planned and executed strategies.

ABCD III Performance Improvement Project (PIP) Framework

Therefore, based on the background review, baseline assessment, and the community engagement processes it was determined that while local efforts had demonstrated improvements at the practice-level and in overall number of claims submitted, the overall rates of children screened using standardized tools remains low and larger; system-level efforts are needed. Referral to Early Intervention combined with IFSP rates for most of the counties being studied remain lower than expected, particularly in the birth to one year age range.

Using this local and community-based information OPIP created the framework for the ABCD III PIP. This framework is described in Table 4 on following page. Overall, the ABCD III PIP is comprised of four specific goals:

ABCD III PIP GOAL # 1.	Early Identification of Children At-Risk for Developmental,
	Behavioral or Social Delays
ABCD III PIP GOAL # 2.	Children Identified at Risk for Developmental, Behavioral or Social
	Delays and/or with Developmental Disability are Referred to Early
	Intervention Improvement Partnership
ABCD III PIP GOAL # 3.	Children At-Risk or with Developmental Disabilities Receive Early
	Intervention or Other Community-Based Services
ABCD III PIP GOAL # 4.	Care Coordination Between the Primary Care Provider and the

For each goal, OPIP outlined specific evidence-based strategies found in the literature, from the ABCD efforts at-large, and from local, successful efforts. Specific strategies that could be used by the Managed Care Organizations were further noted. Lastly, the indicators that would be used to gauge the ABCD III efforts are noted.

Community-Based Services.

Early identification of children behavioral or social delays. at-risk for developmental, GOAL #1:

Primary Care Providers (PCP) at Evidence-Based Strategies: Standardized screening by

the 9, 18 and 24/30 month well--- Routine, longitudinal

developmental surveillance by the screening of children identified at various domains of development,

Strategies MCO Can Use to Promote Evidence Based

-- Provide the proprietary Strategies*:

-- Sponsor trainings on screening screening tools for PCPs to use. Pay for screening (claim: 96110) for commercial and (e.g. START)

component of the applicable well--- Require screening to be a publicly insured children

screened in the community and coordinate with PCP (e.g in Head -- Obtain info, about children Start). If no PCP, get one

Indicator Tracking Progress towards GOAL:

years of life (CHIPRA core screened in the first three -- Proportion of children measure)

Data Source: Claims, Medical Chart

and/or with developmental disabilities developmental, behavioral delays Children identified at-risk for

Intervention Services or other

disabilities receiving Early

Children at-risk or with

community-based services. Evidence-Based Strategies:

referred to Early Intervention Evidence-Based Strategies:

 PCP referral when child fails standardized screening tools &/or referral of a child with developmental delays/dis. - Use of standardized referral forms that contain the following:

A) Results from screening tool

B) Clarification about what information from the provider the PCP wants (e.g. PCP referral when child fails

can provide information back to the PCP eligibility, summary of services, IFSP) C) FERPA agreement signed so that El about referral

Strategies MCO Can Use to Promote Evidence Based Strategies*:

what should be included in referral and -- Provide information to PCP about examples of referral forms. Provide information about communitylist of resources and provide easy ways based services to which providers can refer. Continually update and maintain for primary care providers to access these services.

-- Connect with community-based efforts to create a list of community resources and connections (e.g. 211, Help Me

Indicator Tracking Progress towards GOAL:

 Proportion of children identified at risk or with delays in the first three years of life who were referred to Early intervention.

It is important to note that each MCO may identify additional strategies that are not listed above that achieve the goals of ABCD III Data Source: Medical Chart, Early Intervention Data: Referral rates

Identify Strategies to Achieve this Goal

Community Cafés & Engagement =

Primary Focus of

primary care sector and community between the primary care provider/ Care Coordination GOAL #4:

based-services

Provider (PCP) in a way that is relevant and community services and the Primary Care meaningful to the PCP. (A key component Ensure information about services provided is shared between EI and other from community provider -Within Goal 2) of this is PCP use of a referral form that explicitly states that they want feedback -- Where appropriate, PCP develops an Ensure information about services Evidence-Based Strategies: individualized care plan for the child, incorporating the community based

eligible for services, are referred to other community-based services.

Children referred to Early Intervention, but not identified as

Ensure children referred go to

the referred services.

Strategies MCO Can Use to Promote Evidence Based Strategies*:

Strategies MCO Can Use to

Promote Evidence Based

Strategies*:

services received

community-based services (claim:99366, Pay for PCP coordination with

about community-based systems child is -- Develop systems to gather information

99367, 99368)

children access referred services

info. needed to ensure referred

-- Work with PCP on strategies/

Intervention, enrolled in the plan,

children who accessed Early

Obtain information about

who were not eligible for Early

Intervention Services and for

 Assist in data integration between El and accessing and receiving

other community-based services and the

-- Support development of individualized care plans and cross-system planning in collaboration with PCP

whom community based services

should be identified. coordinate with PCP

-- Develop referral systems and

El, community based services that have not Develop flags for children receiving nonbeen screened by PCP for the PCP. If no PCP, coordinate assign. of one for child

Indicator Tracking Progress towards

whose PCP received information about -- Proportion of children accessing El El services accessed and/or received GOAL:

Data Source: Medical Chart, Early (ABCD III core measure) Intervention

three years of life who received El. Data Source: Early Intervention

Proportion of children identified

at risk or with delays in the first

Indicator Tracking Progress

towards GOAL:



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