Measuring Care Coordination for Children at Risk of Developmental Delay:
Challenges and Opportunities

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November 2010
Acknowledgements

The authors wish to thank the Commonwealth Fund for its support of NCQA’s ongoing efforts to develop measures of child health quality and coordination of care. We particularly wish to thank Dr. Ed Schor for his guidance and expertise in the projects and in developing this paper. We also thank the ABCD III states, who generously shared their experience and insights with us, and we thank NCQA’s Child Care Coordination Expert Advisory Panel for lending their expertise and perspectives to this effort. We thank NASHP, and in particular, Neva Kaye and Jill Rosenthal, for their assistance and with this effort and the many people who reviewed and commented on drafts of this report.

Supported by The Commonwealth Fund, a national, private foundation based in New York City that supports independent research on health care issues and makes grants to improve health care practice and policy. The views presented here are those of the author and not necessarily those of The Commonwealth Fund, its directors, officers or staff.
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Abstract
The use of evidence-based tools is increasing for screening infants and young children for potential developmental delays, and more children with delays are being identified early, when intervention is most effective. But there are significant challenges to following up on screening results, and many children do not receive the services they need. Measures are needed to assess care coordination structures, processes and outcomes and that incorporate the perspectives of the patient and family, of the primary care provider (PCP), of early intervention or other non-medical providers and of the state. These perspectives reflect distinct interests and accountabilities. Health information technology (IT) has the potential to significantly improve coordination of care and its measurement, but underlying differences in professional culture, fragmented financing, conflicting privacy protections and inadequate infrastructure for measurement must be resolved if before substantial gains can be made. This paper specifically addresses measurement of care coordination for children at risk of developmental delays, but we believe there is significant application to other populations, such as other children with special health care needs, persons with severe disabilities and persons with chronic conditions.

Project background
Developmental delays affect 12 percent–18 percent of children in the United States.\(^1\)\(^2\) When left untreated, they can result in challenges throughout life, including behavioral problems, school failure and social or emotional problems.\(^3\) Early detection and intervention are key to ensuring a child’s healthy developmental trajectory.\(^3\)\(^4\) Indeed, this period of development is so critical that in 1984 Congress established a program for infants and toddlers with disabilities (Part C of the Individuals with Disabilities Education Act). This federal grant program helps states operate comprehensive early intervention services for infants and toddlers with disabilities, ages birth to 3.

The use of evidence-based tools is increasing for screening infants and young children for potential developmental delays, and more children with delays are being identified early, when intervention is most effective. There are significant challenges to following up on screening results, however. Numerous barriers to timely developmental services have been documented: fragmentation of services; eligibility gaps among different programs and delivery systems; lack of knowledge about Part C Early Intervention (Text Box 1) and other referral resources among pediatric primary care providers; lack of funding for services to children at risk (without a diagnosis); limited capacity to support resources from pediatric primary care to other providers; and shortages of providers, particularly for social-emotional or mental health services.\(^5\)\(^6\)
Additionally, there are concerns that lack of care coordination can lead to too much care and care inefficiency, such as duplicate testing and redundant care coordinators and poor quality, such as medication interaction. Several reports point to improved care coordination as part of a solution. There is widespread agreement that coordination of care is a key domain of health care quality, but it is challenging to identify feasible, reliable, valid measures for its evaluation.

While most patients could benefit from enhanced coordination of care, it is particularly important for vulnerable populations, such as children with developmental problems or special health care needs, the frail elderly and patients with severe mental illness. Ongoing work on measurement focuses on specific transitions in the health care system (e.g., hospital to home-based care) rather than on coordinating the multiple sectors that serve these vulnerable populations. We need a robust, flexible and affordable approach for measuring care coordination, embedded in feasible implementation strategies that support service delivery and quality. This issue brief describes potential measures of care coordination for children at risk of developmental delays; identifies barriers to coordination of care and its measurement for this population; and recommends approaches to addressing these barriers.

Methods

Using the literature, building on NCQA’s previous work on coordination of care between adult primary care providers and specialists and drawing on input from leaders in care coordination, we mapped the process of care coordination for children at risk of developmental delays. We identified potential opportunities for measurement of care coordination for different levels of the health care system, which reflect different accountabilities:

- Primary Care Practice (PCP) (See Text Box 1)
- Early Intervention Provider
- Community Level
- State.

We tested the concepts with key informants from The Assuring Better Child Health and Development (ABCD) III initiative (Text Box 2) in which five states are collaborating to improve links in care delivered to young children. We presented our initial thoughts to representatives from these five states and to the National Academy for State Health Policy (NASHP), and used the feedback to refine the measure concepts. We next conducted site visits to four states to obtain input from a broad range of stakeholders, including personnel from the State Medicaid Agency, state personnel responsible for early intervention evaluation and services, primary care clinicians, early intervention providers and data experts.

We convened a panel of experts in early child health and development to review results and recommend priorities in measuring care coordination, both for children at risk of developmental delay and more broadly. We presented our work to date and discussed the reactions and concerns we heard on our state visits.

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**Text Box 1: Definition of Terms**

**Developmental Service Provider:** Provides a broad range of programs and services for children suspected of having developmental and behavioral disorders. Includes pediatricians, psychologists, social workers and educational consultants; services include diagnostic assessment, care planning, follow-up care coordination, referrals and community outreach.

**Early Intervention:** Programs administered by states under the Federal Individuals with Disabilities Education Act (IDEA)–Part C, to provide physical, occupational and speech therapy services, among others, to children under age three with disabilities or developmental delays and who meet state eligibility requirements.

**FERPA:** Family Educational Rights and Privacy Act. A federal law that protects the privacy of student records in all schools receiving funds under an applicable program of the U.S. Department of Education.

**HIPAA:** Health Insurance Portability and Accountability Act. A federal law that provides for the proper use and disclosure (and protection) of individuals’ health information by health plans, providers and health care clearinghouses.

**IFSP:** Individualized Family Service Plan: A written plan required under IDEA, developed by early intervention service providers and the child’s family, to guide the provision of early intervention and other (non-Part C) services.

**Primary Care Practice/Primary Care Provider:** A patient’s first point of entry into the health care system and the continuing focal point for all needed health care services. Primary care practices give patients ready access to their own physician or to an established “back-up” physician when the primary physician is not available.

Primary care practices provide health promotion, disease prevention, health maintenance, counseling, patient education, diagnosis and treatment of acute and chronic illnesses in a variety of health care settings.
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FINDINGS
Measure concepts

Measures concepts (Table 1) address structure, process and outcomes of care coordination at the individual provider level (both medical and early intervention) and at the community and state levels. In this paper, “community level” means the constellation of medical, early intervention and other service providers who serve a common set of children in a geographic area (e.g., a county).

Structural measures articulate the roles of different providers and entities providing coordination of care, and specify conditions or resources necessary for systematic coordination. These could include policies and procedures; physical or information system infrastructure; or access to specific types of information or services. Structural measures at the clinical practice or early intervention level include defined roles for care team members, standardized referral forms and a tracking system for open referrals. Community-level structural measures include a system for the maintenance of a community resource list or a registry of patients with developmental delay. State-level structural measures include systems for promoting care coordination and for measuring performance.

Such measures have significant utility in assessing the presence of conditions necessary for systematic and effective care coordination, but these systems and conditions do not generally exist today except in the context of small pilot projects and demonstrations. Definitions of the medical home model (e.g., NCQA’s Physician Practice Connections—Patient Centered Medical Home14) or state-sponsored programs (e.g., Minnesota’s Health Care Homes15) include provider-level, structural requirements like those described, but implementation varies. Stakeholders acknowledge structural measures as a feasible starting point, but are not enthusiastic about them because they reflect necessary—but not sufficient—structural conditions before there can be coordination of care, and because in some cases there is no evidence of links to outcomes.

Process measures are useful for identifying the specific aspects of care coordination most likely to fail, and which have potential for improvement. Examples of process measures are monitoring the use of a standardized referral form; the presence/absence of essential information in a referral from a primary care provider (PCP) to early intervention, or in a report from Early Intervention back to the PCP; documenting receipt and review of key elements of the Individualized Family Services Plan (IFSP); Text Box 1) in the child’s medical record; documenting key medical information reflected in the IFSP; and a current care plan created and maintained in the primary care setting. By their nature, these measures describe the activities of care coordination.

Text Box 2: ABCD III

Five states joined this learning collaborative under the leadership of National Academy of State Health Policy (NASHP), to improve care coordination for young children. Each state has taken a different approach to improving links, but all have engaged stakeholder groups to improve coordination of care for children at risk of developmental delay.

Arkansas. Building on previous work to increase the use of standardized developmental screening tools, Arkansas is working to improve linkages among pediatric primary care providers and other community providers serving children by increasing primary care provider knowledge about community resources, addressing the multiple conduits for referrals, improving referral and follow-up processes and increasing care coordination capacity.

Illinois. Illinois is focusing on two major areas; 1) identify the best, sustainable practices for ensuring effective referrals and linkages are made across screening, referral and treatment/prevention programs, including sharing of minimal data sets needed to support care management, and 2) ensure that all children are linked to the services that best fit their unique needs, including children in need of services, but who are not eligible for early intervention.

Minnesota. Minnesota is piloting efforts in four communities to continue to more systematically screen, refer and track services for children at risk of developmental and mental health delays, increase the number and timeliness of referrals, create communication and feedback loops between clinics and early intervention staff, and improve families’ experience of coordination.

Oklahoma. Oklahoma is working to and improve care coordination between primary care providers and community providers focusing on four issues: 1) infrastructure to ensure follow-up for referrals, linkage of subsystems and monitoring of performance; 2) consistent single point of contact or consistent service infrastructure across communities; 3) process to assure that families are connected with appropriate services; and 4) resources and visibility in rural areas.

Oregon. Through its Medicaid quality improvement processes, Oregon is increasing the spread of developmental screening using standardized tools in primary care and assuring sustainable, patient-centered coordination systems -- strengthening the relationship between systems of care. The efforts will contribute to a better understanding of effective pediatric medical homes.
Process measures are particularly useful in quality improvement, but data that support measurement are difficult to extract from existing data systems and records because they are not recorded, or if they are, they are recorded in a nonstandard format or in documents that are not part of the usual health care record. For process measures to be useful, data must be a byproduct of the care coordination process. Currently, data for such measures are hidden in paper medical records, telephone logs or other manual systems—if they exist at all. Our stakeholders highlighted the need for process measures that address coordination of care for children who were referred to early intervention from primary care, children who enter early intervention without a PCP referral and children who need developmental services but do not qualify for early intervention. Stakeholders also made it clear that the pathways through which children receive services display unique perspectives and require information from different sources, reflecting different accountabilities.
Table 1. Measure Concepts for Care Coordination: Children at Risk of Developmental Delay

<table>
<thead>
<tr>
<th>Accountability</th>
<th>Structure</th>
<th>Measure Type</th>
<th>Process</th>
<th>Outcome</th>
<th>Child/Family Experience</th>
<th>Societal:</th>
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<tbody>
<tr>
<td><strong>Clinical Practice</strong></td>
<td></td>
<td>1. Communication Between PCP and Early Intervention</td>
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<td></td>
<td>● Defines roles</td>
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<td>● PCP provides key information to early intervention with referral request</td>
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<td>● Receives timely services</td>
<td>● Increases appropriate utilization (planned care, prevention)</td>
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<td></td>
<td>● Uses standard format for care plan</td>
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<td>● PCP provides key information to family about referral</td>
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<td>● Is invited to participate in shared decision making</td>
<td>● Decreases or avoids inappropriate utilization (duplicate testing, avoidable ED visits, rehospitalization)</td>
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<td></td>
<td>● Uses standard referral form, including information/form for parents</td>
<td></td>
<td>● Early intervention communicates evaluation result to family</td>
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<td>● Experiences coordinated care</td>
<td>● Decreases costs of care</td>
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<td></td>
<td>● Tracks referrals to early intervention</td>
<td></td>
<td>● Early intervention communicates evaluation result to referring PCP</td>
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<td>● Knows whom/how to access central point of contact when issues arise</td>
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<td></td>
<td>● Accesses current information about available resources</td>
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<td>● Gets help from central point of contact to understand what is going on, gets advice</td>
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<td>● Obtains parent/consumer input through formal mechanism</td>
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<td>● Has access to written or electronic information summarizing child’s care and history, and an action plan for the family</td>
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<td><strong>Early Intervention or other social service agency</strong></td>
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<td>2. Individualized Family Services Plan (IFSP)</td>
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<td></td>
<td>● Defines roles</td>
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<td>● Early intervention develops IFSP with patient/family and PCP input</td>
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<td>● Understands diagnosis</td>
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<td></td>
<td>● Has system for supporting Individualized Family Service Plan (IFSP)</td>
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<td>● Early intervention provides IFSP or IFSP summary to PCP</td>
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<td>● Receives support for managing child’s condition</td>
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<td></td>
<td>● Uses standard format for IFSP</td>
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<td>● Maintains intact family</td>
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<td></td>
<td>● Uses standard referral form, including information/form for parents</td>
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<tr>
<td></td>
<td>● Tracks referrals from PCP/others</td>
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<td></td>
<td>● Obtains parent/consumer input through formal mechanism</td>
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<td><strong>Community</strong></td>
<td>● Maintains community resource list systematically</td>
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<td></td>
<td>● Systematically updates and maintains patient list/registry</td>
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<td>● Supports relationship building among child-serving providers through a consistent process</td>
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<tr>
<td></td>
<td>● Obtains parent/consumer input through formal mechanism</td>
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<td><strong>State/Population</strong></td>
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<td>3. Updated Care Plan</td>
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<td>● Incentivizes the use of standardized tools and reporting systems</td>
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<tr>
<td></td>
<td>● Maintains infrastructure to measure and track performance</td>
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Outcome measures are seen by some as preferable to structural and process measures, given the limited evidence connecting the structures and processes of care coordination with outcomes. Outcome measures are useful for determining the overall success of care coordination, but they face challenges. Clinical outcomes can occur relatively infrequently, they require risk adjustment and they can be difficult to attribute to particular actions or players. Outcome measures that reflect patient/family perspectives show promise, providing a unique approach to measuring outcomes and specific processes. The expert panel recommended that measures include family reports on timeliness of services; shared decision making; patient/family experience with coordinated care; having a contact when issues arise; understanding the diagnosis; and receiving enough support to keep the family intact.

Measures of patient/family experience speak directly to the needs and expectations of patients. Their primary drawback is that while experiences of care are arguably “outcomes,” they may relate to other outcomes of interest (cost, morbidity, functional status) only tangentially and they require special data collection. Creating and administering valid and relatable surveys can also be expensive.

Population measures are equally important outcomes. Changes in patterns of utilization from frequent acute care (including ED visits) to more planned and preventive care, reduction of duplicate or unnecessary services and the resulting reduced costs are significant outcomes. Although the panel endorsed the importance of population measures, like other outcome measures they are difficult to attribute to specific actions or entities. In addition, severity-based risk adjustment may be needed and confounding variables beyond care coordination might affect outcomes (e.g., the availability of certain providers or specialized equipment in a community).

Certain outcomes, such as school readiness or achievement of developmental progress, engendered much debate. Stakeholders agreed that the goal of care is to enable children to reach their full potential, not merely to experience good care coordination; however, outcomes such as school readiness reflect not only the success of care coordination but also other important factors, such as quality and availability of services and the potential of an individual child.

Barriers to care coordination

Although there was consensus about measurement concepts in general, we found limited capacity to implement or measure care coordination, and there was no agreement on the specifics (e.g., roles and responsibilities of care coordination, information that should accompany PCP referrals, information that should be reported from early intervention to PCPs). Furthermore, we found several common barriers when we asked about state efforts to improve coordination of care:

- Varying beliefs about the role of PCPs and early intervention in supporting children’s development
- Financing streams that direct or limit services
- Lack of infrastructure and measurement accountability.

Beliefs and culture

During our state site visits and meetings with PCPs and early intervention service providers, we heard different views about children’s developmental needs and expected roles for different providers. PCPs generally follow a medical model and place themselves at the hub of the medical home. When they believe evaluation or treatment beyond their expertise is warranted, they refer their patient to a specialist for evaluation but continue to manage the patient’s care. In certain cases, the PCP deliberately transfers responsibility for the patient to the specialist. In other cases, the PCP and the specialist might co-manage a problem. But even in the shared culture of the medical environment there can be confusion about responsibility for a patient, and requests for consultation may not be explicit. Most families who seek early intervention services for their children either self-refer or are referred by sources other than the child’s PCP, and early intervention providers place themselves, with the child’s family, at the hub of the developmental services system. We heard from both PCPs and early intervention providers that there
is confusion about, and dissatisfaction with, the other provider’s expectations for evaluation and treatment of, and communication about, a patient’s developmental progress. Some physicians may take a “wait and see” approach to developmental delays rather than moving aggressively to arrange for early intervention services.

Early intervention typically includes services for both the child and the family, teaching and empowering the family to support the child’s development. Early intervention providers view referrals from physicians as a transfer of responsibility. Once it has been determined that a child requires services and is eligible for them under federal and state funding rules, the early intervention provider assumes full responsibility for coordinating and managing the child’s developmental services. The provider may report to the PCP about the results of the evaluation or the plan for services, or may not.

There appear to be both role and power conflicts between primary care and early intervention. Even when both parties have the child’s best interests at heart, differences in approach and expectations can inhibit effective communication and collaboration. Our expert panel corroborated this finding and extended it, describing a controversy about who should serve as the central point of contact for the child with developmental delays. In addition, the federal law establishing Early Intervention requires the development of an IFSP by an interdisciplinary team of Early Intervention providers and therapists, within 45 days of evaluation. The time pressure of this requirement, and the usual approach to developing the IFSP (in a meeting of an interdisciplinary team), make it difficult to involve the PCP in the development of the IFSP.

Eligibility for Entitlement Services

Different financing streams and their associated eligibility and service requirements exacerbate professional culture differences that impede coordination of care. The federal government dictates certain mandatory eligibility requirements, but it offers states significant latitude in determining eligibility for early intervention. States define developmental delay differently, use different instruments and methods for determining and quantifying such delays, add to the federal list of diagnoses and conditions for which eligibility is presumed, and sometimes cover children at risk of developmental delay. All states limit the provision of early intervention services to children with certain levels of delay, expressed as a percentage of delays in a specified number of areas or as a number of standard deviations below the mean. Medicaid, which provides primary care for a significant number of children with developmental delay, maintains its own eligibility requirements with which PCPs are generally familiar. Early intervention eligibility limitations intensify conflicts between PCPs and early intervention providers. Many children who are ineligible for early intervention under a state’s rules could in fact benefit from early intervention services. PCPs seeking developmental assistance for their young patients may not be familiar with early intervention eligibility requirements or alternative developmental resources for children who do not qualify for early intervention. Consequently, they are frustrated in their efforts to meet their patients’ developmental needs.

Lack of infrastructure for care coordination and measurement

There is significant lack of data infrastructure to link early intervention services with medical care. While some children enter early intervention at the suggestion of their PCP, most come through other entry points, including self-referral, daycare and hospital (for newborns). Early intervention providers often have no direct contact with the PCP, and information does not flow easily at the provider level or at the state level. This barrier is exacerbated by the Federal Educational Rights and Privacy Act’s (FERPA) (Text Box 3) requirement of the child/family’s prior approval for the release of personally identifiable, education-related information to anyone outside the education system. Strict interpretation of these rules impedes communication with the PCP, although considering the role of the PCP and of early intervention with the family, and the potential for the state to mediate, it should be possible to secure release of this information. Although there is currently no accountability mechanism
to support this type of care coordination or measurement, the potential exists to use lessons from Health Insurance Portability and Accountability Act (HIPAA) (Text Box 3) implementation.

Table 2 provides examples of various challenges affecting measurement opportunities (e.g., provider attitudes, program cultures, a long history of provider separation, low accountability for coordination of services). The panel confirmed our finding that differences in professional culture, funding fragmentation and conflicting privacy rules were the most significant barriers to progress, and it offered suggestions for policy actions and priorities for focus that could advance measurement and improve care coordination.

Our expert panel believes that measurement is an essential component of a multifaceted strategy to improve care coordination for young children. The barriers we identified are not new—they have been described in previous literature and in ABCD reports. Their continued presence raises questions about where leverage for change and integration will come from. Can measurement shed light on barriers to care coordination? Can it focus attention on accountability? Can measurement of care coordination’s progress and of its failures provide information essential to its improvement? Can it lead to more family-centered (less turf-driven) service systems? Can it galvanize interest in accepting the challenge of improving care coordination for vulnerable children?

**Text Box 3**

**HIPAA:** Protects individually identifiable health information (including demographic data):
- The individual’s past, present or future physical or mental health or condition
- The provision of health care to the individual, or
- Past, present or future payment for the provision of health care to the individual
- Any information that identifies the individual or for which there is reasonable basis to believe it can be used to identify the individual.

A covered entity may not use or disclose protected health information, except either: as the Privacy Rule permits or requires; or as the individual who is the subject of the information (or the individual’s personal representative) authorizes in writing.

**FERPA:** Protects educational records (i.e., records that directly relate to a student and that are maintained by an educational agency or institution or by a party acting for the agency or institution), including:
- Written documents (including student advising folders)
- Computer media
- Microfilm and microfiche
- Video or audio tapes or CDs
- Film
- Photographs.

Any record that contains personally identifiable information directly related to the student is an educational record under FERPA. This information can also include records kept by the school in the form of student files; student system databases kept in storage devices such as servers; or recordings or broadcasts which may include student projects. Non-directory information must not be released to anyone, including parents of the student, without the student’s prior written consent.
Table 2. Measurement Challenges for Care Coordination for Children at Risk of Developmental Delay

<table>
<thead>
<tr>
<th>Type of measure</th>
<th>Measurement Challenges</th>
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| **Structure**   | • Location of early intervention within state Department of Education in some states and strict interpretation of (FERPA) impedes communication between early intervention and PCP and limits Medicaid’s access to patient-specific early intervention information.  
• Agency-specific data systems operating in silos and lack of state support impede timely and effective communication between PCPs and early intervention and other child-serving agencies. |
| **Process: “Opening the Loop”**  
Referral from PCP to Early Intervention | • Lack of standards for when a child should be referred to early intervention, and for content of referral documentation.  
• Informal referrals (e.g., instruct parents to call early intervention or PCP phone call to early intervention) cannot be tracked as follow-up; data cannot be stratified by referral source.  
• Written referrals require intensive labor to pull for tracking and review for evaluation (of content).  
• Difficult to ascertain referral information provided to family.  
• No mechanism for direct communication between early intervention and PCP when children arrive in early intervention from sources other than PCP (the majority of cases). |
| **Assessment and Care Planning** | • Lack of standardized IFSP format makes it difficult for PCPs to review or integrate IFSP into the child’s medical care plan and makes it difficult to extract specific data elements.  
• Wide variation among states in early intervention’s ability to conduct assessment and initiate services without PCP approval impedes standardized measurement of coordination of the assessment and care planning process.  
• Federal rules requiring completion of the IFSP within 45 days of referral make it difficult to involve the PCP in planning. |
| **“Closing the Loop:”**  
Results of Services Communicated to PCP | • It may be possible to evaluate the presence of the IFSP in the PCP’s records, but it is more difficult to measure the PCP’s use of the information contained in the IFSP.  
• Early intervention may or may not share the IFSP and its annual updates with PCPs; there are no standards or requirements for such communication. Furthermore, PCPs typically prefer summary information and find it difficult to use the full IFSP. There is no standard definition of “essential information” or format for communication, making it challenging to measure transmission of information. |

Discussion

The presence of barriers to care coordination and its measurement raises several critical questions.

*Which solutions should be local, and which should be implemented nationally?* Working within existing federal funding streams and rules for health and education services will require states to find local solutions to overcoming barriers associated with the fragmentation of federal programs. Because eligibility for Medicaid and early intervention services—as well as the organization of health care delivery and early childhood development services—varies among states, many solutions will have to be local. Other solutions can be applied nationally: selection of specific measures for state-to-state comparison or for a health-information exchange infrastructure that is interoperable across state lines.

*How can measurement identify and expose failures and opportunities for care coordination?* There may be a “chicken vs. egg” challenge with respect to care coordination and its measurement. Many structures and processes essential to coordination of care do not exist, exist only in small pockets or are not well developed. For example, there are few standardized tools or formats for referrals or IFSP documentation and there is a lack of communication, registries and referral tracking systems. Communication between early intervention and primary care is frequently inadequate. Sometimes measurement can help expose such deficits and focus attention and resources on correcting them, but there must be basic structures and processes in place before there can be measurement. Consideration must be given to timing and staging of efforts to implement these structures and processes, and to measuring their presence and effectiveness.

*What aspects of care coordination are universal and do not depend on who has primary responsibility for a child’s care?* Like other children with special health care needs, children at risk of...
developmental delays may receive care from a variety of providers (e.g., PCP, early intervention, medical specialist), depending on their condition. For example, children who have a developmental delay but are otherwise healthy may depend primarily on early intervention or other developmental service providers for care. Children with medical and developmental conditions are likely to depend on their PCP for most of their care, and for coordination of that care. Children with special health care needs might depend heavily on a specialist for care.

Some aspects of care coordination rest with a specific type of provider. For example, early intervention providers are responsible for developing the IFSP, while medical consultants are responsible for communicating their findings and recommendations to the referring provider. Other aspects of care coordination, such as referral tracking, must be accomplished regardless of which providers are primarily responsible for care. Different providers might link with schools, social services or other community services. When developing measures for coordination of care, it will be important to clarify the processes to measure and identify the relevant providers and their roles in those processes. There should be a mechanism for shared understanding of accountability.

Implementation opportunities

This project focused specifically on coordination of care for children with, or at risk of, developmental delay. Improvements for this population could theoretically reduce or eliminate inefficiency in care, including duplication of services and the downstream costs of unidentified problems. Measure concepts apply to a host of other populations and conditions that require coordinated care, including children with complex needs. To achieve the best outcomes, newborns diagnosed with a heritable disorder, children with special health care needs, adults with severe disabilities and patients of all ages with multiple chronic conditions all need care coordination, including coordination between the medical and nonmedical sectors. We believe the measurement approach outlined here, as well as many of the challenges, are likely to apply to these populations and conditions. While additional research is needed to test this theory and to identify both common and unique measurement concerns, we should also move ahead with vigor to build measures, feedback and accountability for what can be accomplished within our current knowledge and data systems.

State and federal activities underway because of health care reform and other initiatives offer promising opportunities for improving coordination between primary care and early intervention. Given the fragmentation of federal programs under which health care and early intervention operate, additional support will be needed to integrate these programs within states and to realize their promise. Recommendations for such support are detailed elsewhere. Additional important opportunities result from efforts to expand the use of health IT and the increased investment in measurement of child health quality mandated in the Children’s Health Insurance Program Reauthorization Act (CHIPRA).

With incentives for the adoption and meaningful use of health IT, it is possible to imagine information and clinical decision support tools and systems that could prompt PCPs to issue referrals when triggered by specific screening results. Such systems could also standardize the referral format, prompting PCPs for appropriate content and documenting the referral in detail for the PCP, early intervention provider and the family; and facilitate referral tracking and follow-up. Adoption and meaningful use of health IT could further facilitate communication and approvals needed between early intervention and the PCP, creating documentation of communication as a byproduct.

Robust health information exchange could facilitate referrals (and tracking) by creating data links and enabling exchange of relevant clinical information and follow-up communication between PCPs and early intervention. Health information exchanges could potentially make tracking accessible by county or state care coordinators or by others outside the primary care or early intervention practice. To achieve the aims of health information exchange, data sharing agreements will be needed to facilitate data sharing within HIPAA and FERPA rules.
CHIPRA’s support for quality measurement and investment in research and demonstration projects creates new incentives for states to participate in quality measurement and reporting, along with new mechanisms to improve access to integrated data sets for quality measurement and improvement. Several state demonstrations funded through CHIPRA will address improvement and measurement of care coordination. In addition, CHIPRA authorizes a pediatric quality measure program to improve existing quality measures and to develop additional measures for children; specifically, children with special health care needs. This could substantially improve multiple aspects of measurement, including data recording, data collection and acceptance of accountability for improvement.

Recommendations for Additional Federal Action

Because so many challenges to coordination of care arise from fragmented federal programs, funding, eligibility and service rules, states are limited in their ability to improve coordination for children with developmental delays. Federal programs that serve children should collaborate across agencies to align and integrate efforts, and should incorporate coordination requirements at the state level as programs are implemented. The most significant potential for improvement depends on integration of, and coordination among, federal programs.

Demonstration projects aimed at implementation of accountable care organizations and medical homes for children, called for in health care reform, are ideal environments in which to establish and set incentives for specific care coordination requirements. These projects could extend beyond the usual medical care environment to include coordination of care with early intervention and community resources and education programs.

Federal legislation is needed to harmonize the privacy protections afforded under HIPAA and FERPA, so that providers of early childhood services—early intervention, educational or medical—can communicate with each other for the benefit of the children they jointly serve.

In implementing the Pediatric Quality Measures Program established under CHIPRA, the Department of Health and Human Services (HHS) should focus on developing and implementing measures of care coordination and on implementing accountability through pay-for-performance, public reporting and other programs. When applied, such measures and levers have the potential to improve the efficiency and effectiveness of care for a high-need, high-cost population.

Recommendations for State Policy Actions

To exploit the opportunities afforded by federal investment in health IT and child quality measurement, states must strategize their use of these resources. State efforts to integrate data and develop health information exchange should address the unique developmental needs of young children. Many state-administered programs serve a common group of children and all would benefit through sharing of child-level data (although not all services or data are strictly “health” data). States should ensure that data-exchange efforts (e.g., developing data-sharing agreements, finding practical approaches to bridging the information gaps created by HIPAA and FERPA rules) include relevant, nonmedical data from education, early intervention and other providers. Some states have already addressed this issue. One approach could be to develop common privacy/release of information forms that meet both HIPAA and FERPA requirements.

Standard information templates and exchange periods offer the opportunity to facilitate referrals to early intervention, communication of early intervention evaluation results and development and communication of IFSP and IFSP updates. Such efforts should be designed to improve efficiency and reduce time wasted pursuing missing information, for both early intervention providers and for PCPs.

States should revisit Medicaid and CHIP payment policies to provide incentives for effective coordination of care. Such policies might include pay-for–performance for meeting specific care coordination goals; or bonus payments for practices that implement structural measures, such as referral tracking systems or standardized referral forms; or for practices that meet other medical home or

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coordination requirements. States should establish and enforce requirements for documenting communication and coordination at critical junctures. For example, as a condition of payment for preventive care claims, the state could require PCP review of early intervention evaluation, or could make payment to early intervention conditioned on review of clinical information in developing the IFSP. States should also consider how to facilitate communication with PCPs about children that enter early intervention from other sources—which in most states constitutes the majority of early intervention cases. With appropriate Medicaid policies and information infrastructure, states could promote better communication between early intervention providers and PCPs.

**Recommendations for Workforce Development**

All health care professionals (from students to established practitioners) serving children could benefit from education and training on the variety of providers and disciplines that serve young children and their families. Training could discuss the use of standardized instruments for developmental screening (which was well underway in the states we visited); introduce local programs and resources available to support young children and their families; and discuss financing for services and local approaches to coordination of care. It could help bridge the professional and cultural gaps that impede effective communication between individual providers and across child-serving agencies.

**Recommendations for Practices**

Medical practices that serve children need technical assistance and appropriate financial support to promote their participation in medical home demonstration programs and qualification efforts. Participation builds coordination of care capabilities and infrastructure support and identifies high-performing practices to purchasers and consumers. In making a commitment for formal evaluation as a medical home, a practice enhances its capabilities and, in many circumstances, becomes eligible for enhanced compensation. Even practices that are not involved in medical homes should devote specific resources to coordination of care, but resources must be provided through appropriate reimbursement mechanisms. For example, primary care practices could designate a staff person as a care coordinator, establish relationships with community resources that provide coordination services or ensure that the health IT they have adopted works for children. State Medicaid agencies could pay for coordination services or provide a per-patient fee to practices that are organized to provide coordination of care.

**Conclusion**

Opportunities to improve and to measure care coordination and the flow of information exist under recently enacted federal legislation. Health IT incentives and health information exchange development have the potential to enable the useful exchange of information, and CHIPRA demonstration grants and pediatric quality measure development will create and test new methods for measuring and improving quality and care coordination. The federal government can—and should—do more to ensure progress in this area: harmonize medical and educational privacy protections; support ACO and medical home demonstration projects; and include measures of care coordination in pediatric measure development efforts. States have the opportunity to provide leadership and vision that span professional disciplines and federal funding streams.

Collaboration across state agencies will be critical to success. Resources developed through ABCD collaboratives and CHIPRA demonstration grants can provide useful models for states to adopt or adapt. Additional research and demonstrations are needed to answer questions about solutions that may be most effective at the state or community level or that would be most effective at the national level. Experimentation will be important to support providers and care coordinators in real time, to facilitate quality improvement in medical homes and accountable care organizations and to identify specific measures that can be used for public reporting and accountability.

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Notes


2 [www.cdc.gov/ncbddd/child/devtool.htm](http://www.cdc.gov/ncbddd/child/devtool.htm) (July 1, 2010)


8 Bodenheimer, T, Coordinating Care – A Perilous Journey through the Health Care System, New England Journal of Medicine, March 6, 2008; 358: 1064-1071.


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