

# Impact Evaluation of the State Implementation Grants for Integrated Community Systems for Children with Special Health Needs



**Classes of 2008, 2009, 2011**



## Introduction

In 1989, HRSA's Maternal and Child Health Bureau (MCHB), together with its partners, defined the service system for children and youth with special health care needs. To achieve optimal health outcomes, the system of care must satisfy six core outcomes:

- Access to coordinated ongoing comprehensive care within a medical home;
- Family/professional partnership at all levels of decision-making;
- Access to adequate financing and private and/or public insurance to pay for needed services;
- Early and continuous screening for special health needs;
- Organization of community services for easy use; and,
- Youth transition to adult health care, work and independence.

Since then, a concerted effort has been made to address deficiencies in the US health system's ability to meet the needs of children and youth with special health care needs (CYSHCN) through changes in policy, allocation of funding, and delivery of care aligned with these six core outcomes. One initiative designed to promote family-centered, community-based, coordinated care is the Special Project of Regional and National Significance (SPRANS) program, State Implementation Grants for Integrated Community Systems for Children with Special Health Needs (SIG). The purpose of the program is for grant recipients, their State Title V Programs, and other state partners to focus on improving the system of care for CYSHCN where the effective system of care must satisfy the six core outcomes.

The Division of Services for Children with Special Health Needs (DSCSHN) began funding states in 2004. Funding was provided for three years during which grantees were expected to provide statewide leadership to promote an understanding of the system of care for CYSHCN, build partnerships, expand workforce capacity, and strengthen quality improvement and performance measurement capabilities.

The program's ten year span provides a unique opportunity to witness and document the evolution of systems integration work of forty-eight states, Navajo Nation and the District of Columbia. Beginning with the first cohort of states, the DSCSHN has documented lessons learned and best practices, informing the approach of subsequent classes as well as targeted technical assistance and training supported by the DSCSHN. With each subsequent class of grantees, increasing emphasis and focus has been placed on requiring grantees to quantify progress in systems integration and, ultimately, on the health outcomes of CYSHCN. In recognition that the experience of the end user of the system of services is the ultimate test of its effectiveness, the DSCSHN looks to families and CYSHCN to assess the degree to which the system of services is meeting their needs through national metrics collected through the CSHCN National Survey. [1]

This report summarizes the first three cohorts of grantees' accomplishments and highlights strategies which catalyze changes that yield the greatest system improvements. Evaluation findings were analyzed alongside a review of the literature confirming trends that were surfacing during analysis. The goals of the evaluation were to identify effective strategies to improve quality of children's health and health care through systems integration; and, disseminate information about what works, why it works, what has the greatest potential for sustainability and replication. Such a significant body of evidence of what it "takes" to work toward and achieve systems integration should inform other areas of public health.

Class	Grant Period	# of Grantees	States Participating
2008	2006–2008	12	AZ, CA, FL, HI, IA, MA, MN, OK, OR, SC, UT, WI
2009	2007–2009	6	ME, NC, NH, NN, NY, RI
2011	2009–2011	12	CT, CO, DC, MD, MI, MO, NE, NV, ND, PA, VT, WV
2012	2010–2012	6	IL, IN, KS, MS, NJ, VA
2014	2012–2014	8	OH, AL, LA, WA, DE, AR, AK, KY
2015	2013–2015	6	MT, SD, TN, GA, TX, NM

## Methodology

The evaluation framework was designed to understand the degree to which each grantee made progress towards achieving an integrated system of care for CYSHCN. At the onset of the evaluation, it was understood that grantees may have changed their original objectives or approach and that the purpose of the evaluation was not to determine whether the grantee did what they said they were going to do. The evaluation had a broader focus, and more strategic, evaluating if the grantee effectively designed, created/implemented, and achieved components of an integrated system and most importantly, whether the grantee evaluated and identified components to be sustained and was able to sustain those components. To address these questions, a methodology was developed consisting of several activities which culminated in this “State of the State Report”. The evaluation consisted of four primary activities: 1. Review of the Literature; 2. Review of Grantee Documents; 3. Grantee Conference Calls; and, 4. Analysis of Performance Measures.

**Review of the Literature.** A literature review was conducted to facilitate the reexamination of the continued applicability of MCHB’s six core outcomes to monitoring the system’s responsiveness and effectiveness. The review also identified strategies for achieving systems integration allowing for a comparison with what the evaluation identified as strategies implemented by grantees. Lastly, the literature review helped to refine the design of the evaluation plan and inform the development of data collection instruments. Public health and health policy, governance and leadership, and system development were the primary disciplines from which articles were reviewed. New literature was continuously identified and reviewed for the duration of the evaluation. A complete bibliography is included as Appendix A.

**Review of Grantee Documents.** Original grant applications, progress reports, final reports and products were reviewed for all grantees from the Classes of 2008, 2009 and 2011. The focus of the review was to understand, document and share key themes, successful strategies, best practices and lessons learned. A summary of each grantee was prepared from submitted materials and is included as Appendix B. Copies of all products produced during the contract period were evaluated using a standardized form which characterized the purpose; audience (e.g., CYSHCN staff, parent/family, community partner, public, etc.); type of product (e.g., webinar, video, fact sheet, manual, survey assessment tool, etc.); core outcome targeted; and rating (e.g., quality, applicability, replicable or adaptable). Over 200 products were reviewed and are included in the CYSHCN Catalog.

**Grantee Conference Calls.** Based on the review of documents, 60-minute follow-up conference calls were conducted with grantees. These calls fulfilled several objectives to: 1. obtain further clarification and implementation details for best practices; 2. assess current status of the initiatives and activities funded by the SIG; 3. identify activities that have been sustained; 4. discuss challenges to sustaining initiatives and activities; and 5. collect performance measures documenting program effectiveness. Findings of each call were included in grantee summary reports (Appendix B).

**Analysis of Performance Measures.** In addition to descriptive information collected from grantees, various national and program datasets were analyzed to evaluate the effectiveness of the system of services for CYSHCN.

- **CSHCN National Survey:** In recognition that the experience of the end user of the system of services is the ultimate test of its effectiveness, the DSCSHN looks to families and CYSHCN to assess the degree to which the system of services is meeting their needs through national metrics collected through the National Survey of Children with Special Health Care Needs (NS-CSHCN). This national survey provides a broad range of information about the health and functional status of children with special health care needs collected in a manner that allows for comparisons between states and at the national level. The survey results are weighted to represent the population of non-institutionalized children with special health care needs 0-17 nationally and in each of the 50 states plus the District of Columbia. The survey has been administered three times (2001, 2005-2006, and 2009-2010). Since the definitions of selected measures have changed since initiation of the survey, data cannot be trended over time. However, the measures do provide a baseline for assessing system status for each of the six core outcomes and comparisons across states.  
<http://www.childhealthdata.org/learn/NS-CSHCN>



- **The Catalyst Center.** The Catalyst Center is a national center dedicated to improving health care coverage and financing for **Children and Youth with Special Health Care Needs (CYSHCN)**. The Online State-at-a-Glance Chartbook on [Coverage](#) and [Financing](#) of Care for **Children and Youth with Special Health Care Needs (CYSHCN)** provides data on carefully selected indicators of health coverage and health care financing for CYSHCN in every state plus DC and Puerto Rico. Using the online Chartbook, data for each state is compared with both national averages and other states' data. <http://data.catalystctr.org>
- **Discretionary Grant Information System (DGIS):** MCHB's Discretionary Grant Information System (DGIS) electronically captures financial, performance measure, program, abstract data, and products and publications about these discretionary grants from the grantees. The data collected are used by MCHB project officers to monitor and assess grantee performance as well as assist in monitoring and evaluating MCHB's programs. MCHB developed 41 national performance measures across many maternal and child public health areas. The measures are either percentage-based or scale-based measures. Percentage-based measures use numerators and denominators to generate the annual indicator, while scale-based measures use data collection forms to generate the annual indicator. MCHB uses the annual indicators to determine if a grantee is meeting their goals.
- **Maternal and Child Health Services Block Grant Program. The Title V Information System (TVIS):** TVIS electronically captures data from the annual Title V Maternal and Child Health Block Grant applications and reports. TVIS is a web-based, searchable database that captures key financial, program and performance/indicator data as reported by the State Title V Maternal and Child Health programs. State-by-State, as well as Regional and National composite data, can be searched, viewed, and printed. Other available information includes each State's and jurisdiction's five-year Needs Assessment, the narrative sections and data forms from each State's and jurisdiction's most recent application and annual report, and the contact information for each State's and jurisdiction's Title V Maternal and Child Health Director and Children with Special Health Care Needs Director. <http://mchb.hrsa.gov/programs/titlevgrants/index.html>



## Effective System of Care for CYSHCN

The six core outcomes that define the effective system of care for CYSHCN were originally developed in the late 1980s after several years of work and expert consensus. A comprehensive review of the literature was conducted to reexamine the continued applicability of these six core outcomes to monitoring the system's responsiveness and effectiveness. **Findings of the international and domestic literature indicate that MCHB's six core outcomes remain on target for defining the system of care for CYSHCN designed to achieve optimal health outcomes.**

In particular, two reports — 2012 World Health Organization report and the Institute of Medicine's 2012 report — validate the six core outcomes. WHO's 2012 *"Monitoring the building blocks of health system: a handbook of indicators and their measurement strategies"* identifies eight key characteristics that would be present in a strong health care system given that service delivery is a "fundamental input to population health status."<sup>3</sup> WHO's key characteristics are very similar to MCHB's six core outcomes and include:

1. *Comprehensiveness*: comprehensive range of health services is provided, appropriate to the needs of the target population.
2. *Accessibility*: Services are directly and permanently accessible with no undue barriers of cost, language, culture, or geography. Health services are close to the people, with a routine point of entry to the service network at primary care level (not at the specialist or hospital level). Services may be provided in the home, the community, the workplace, or health facilities as appropriate.
3. *Coverage*: Service delivery is designed so that all people in a defined target population are covered, i.e. the sick and the healthy, all income groups and all social groups.
4. *Continuity*: Service delivery is organized to provide an individual with continuity of care across the network of services.
5. *Quality*: Health services are of high quality, i.e. they are effective, safe, centered on the patient's needs and given in a timely fashion.
6. *Person-centeredness*: Services organized around the person, not the disease or the financing. Users perceive health services to be responsive and acceptable to them. There is participation from the target population in service delivery design and assessment. People are partners in their own health care.
7. *Coordination*: Local area health service networks are actively coordinated, across types of provider, types of care, levels of service delivery, and for both routine and emergency preparedness. The patient's primary care provider facilitates the route through the needed services, and works in collaboration with other levels and types of provider. Coordination also takes place with other sectors (e.g. social services) and partners (e.g. community organizations).
8. *Accountability and efficiency*: Health services are well managed to achieve the core elements described above with a minimum wastage of resources. Managers are allocated the necessary authority to achieve planned objectives and held accountable for overall performance and results. Assessment includes appropriate mechanisms for the participation of the target population and civil society.

The Institute of Medicine also generated a list similar to WHO's and the six core outcomes.<sup>1</sup> The list describes eight national priority areas for health care quality improvement recommended to guide national healthcare reports. These areas include:

1. *Patient and family engagement*: Engage patients and their families in managing their health and making decisions about their care.
2. *Population health*: Improve the health of the population.
3. *Safety*: Improve the safety and reliability of the U.S. health care system.
4. *Care coordination*: Ensure patients receive well-coordinated care within and across all health care organizations, settings, and levels of care.
5. *Palliative care*: Guarantee appropriate and compassionate care for patients with life-limiting illnesses.



<sup>1</sup> Institute of Medicine of the National Academies. *Future Directions for the National Healthcare Quality and Disparities Reports*. 2010

6. Overuse: Eliminate overuse while ensuring the delivery of appropriate care.
7. Access: Ensure that care is accessible and affordable for all segments of the U.S. population.
8. Health systems infrastructure capabilities: Improve the foundation of health care systems (including infrastructure for data and quality improvement; communication across settings for coordination of care; and workforce capacity and distribution among other elements) to support high-quality care.”

Peer reviewed journal articles provide further confirmation of the MCHB’s framework for systems improvement. One article in particular conducted a systematic literature review to identify a core set of quality measures for pediatric patients with complex health care needs to improve the quality of care for this population. The authors, Chen et al., operated under the premise that quality measures facilitate a very tangible use of evidence-based practices, “provide a standardized evidence-based metric that can be widely implemented in clinical settings” and can help “align payment strategies and motivate improvements in care.”<sup>2</sup> Using patient-centered medical home (accessible, continuous, comprehensive, family-centered, coordinated, compassionate, culturally effective care, has been adopted as a promising care model for all patients; it is a particularly excellent care model for children with complex conditions and special health care needs) as the starting point for the systematic literature review, seventy-four quality measures were identified. The seventy-four measures were then reviewed and narrowed down to thirty-five by an expert panel which were then organized into five domains of care: (1) primary care—general; (2) patient/family-centered care; (3) chronic care; (4) coordination of care; and, (5) transition of care (to adult providers).

In keeping with the identified five domains of care, Chen et al made recommendations which aligned and supported four of the six MCHB core outcomes. These included: importance of family sharing in medical decision making (core outcome 2); CYSHCN receiving coordinated care in the medical home setting (core outcome 2); children receiving early screening (core outcome 4); and transition planning to adult health care (core outcome 6). The remaining 2 core outcomes related to insurance coverage and community-based services were outside the scope of quality of care however were certainly in keeping with WHO and IOM recommendations.

The reexamination of the core measures is in itself a process of quality assurance and improvement—the said gateways to innovation. The World Health Organization commented in a 2010 report that “information is needed to track how health systems respond to increased inputs and improved processes, and the impact they have on improved health indicators. This implies the need to define core indicators of health system performance while developing and implementing appropriate sustainable measurement strategies to generate the required data.”<sup>3</sup> For DSCSHN, the systems integration work spawned increased inputs as new partnerships formed and facilitated improved processes. Understanding the nature of the improvements and their impact is the current task at hand and one that this evaluation is intended to inform.



<sup>2</sup> *Pediatrics* Vol. 129 No. 3 March 1, 2012 pp. 433 -445

<sup>3</sup> World Health Organization. Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies. 2012

## Impact of the Grant Program

This section summarizes findings from the review of the activities of *State Implementation Grants for Integrated Community Systems for Children with Special Health Needs (SIG)* grantees in building an effective system of care. Each section is prefaced by a description of the component or core outcome including its key elements. Examples of promising or best practices employed by grantees in strengthening the system of care are documented and brief case studies used to highlight successes.

### Leadership

Key to the success of grantees in achieving systems improvement is their role in providing leadership to promote the needs of children and youth with special health care needs and to foster systems change through partnership and capacity building.

**Leadership is a function of an articulated strategic direction; broad-based, collaborative partnerships; commitment to quality improvement; and effective use of technologies and systems to support monitoring and program improvement.**

The job of leaders is to inspire collective efforts and devise smart strategies for the future.<sup>4</sup> Experts in the field of leadership and governance note that the information revolution brought with it the need for leaders to create a two-way flow of information. Leadership is critical to ensure that the interests and priorities of leaders and followers are aligned.<sup>5</sup> Systems building, in particular, requires a team approach whereby partners collaborate and cooperate to achieve shared goals. Successful leadership “bridges disciplines, programs, and jurisdictions to reduce fragmentation and foster continuity; clarifies roles and ensures accountability; develops and supports appropriate incentives; and, has the capacity to manage change.”<sup>6</sup> Ideally, these characteristics and the work required is that of multiple leaders, not just a single individual, to provide adequate stability and longevity. This configuration also allows for work at multiple levels of a system so that bridges can be built, horizontally and vertically.

SIG grantees have been uniquely tested as they have implemented complex systems integration initiatives against a national backdrop characterized by economic turmoil and anticipated opportunities and challenges posed by the Patient Protection and Affordable Care Act (PPACA) and the subsequent Reconciliation bill. True leadership was needed to sustain initiatives as states experienced budget cuts and a reduction and/or instability in workforce, eroding capacity and institutional memory while simultaneously responding to the most significant government expansion and regulatory overhaul of the US health care system since the passage of Medicare and Medicaid in 1965.

### Promote Vision and Strategic Direction

Leadership requires vision – an idea of where you are going and what you are trying to accomplish.

In order to provide vision and direction, grantees need to know the “state of the state”, identify gaps and prioritize strategies for addressing gaps. Planning efforts must be forward thinking, assuring sustainability for effective interventions through data informed decision-making. Successful approaches include:

**Conduct Community Needs Assessment:** *Oklahoma (2008)* Sooner SUCCESS (State Unified Children’s Comprehensive Exemplary Services for Special Health Care Needs) is a program with an adaptive systems approach focused at the community and state levels to provide integrated social, emotional/mental, educational and physical services for CYSHCN. Sooner SUCCESS implemented a Community Needs Assessment to help communities identify availability of and access to services for CYSHCN and their families. Conducted every two years, the assessment consists of a survey that solicits feedback from service providers and family members of CYSHCN statewide. The survey (available in both English and



<sup>4</sup> Seaman JT, Jr., Smith GD. Your Company’s History as a Leadership Tool: Take your organization forward by drawing on the past. Harvard Business Review December 2012. [www.HBR.org](http://www.HBR.org)

<sup>5</sup> Kellerman B. Cut Off at the Pass: The Limits of Leadership in the 21st Century. Governance Studies, The Brookings Institution. August 2012. [www.brookings.edu/governance.aspx](http://www.brookings.edu/governance.aspx)

<sup>6</sup> IOM (Institute of Medicine). 2012. Primary Care and Public Health: Exploring Integration to Improve Population Health. Washington, DC: The National Academies Press.

Spanish) is distributed by Sooner SUCCESS staff members and state agencies at meetings and gatherings and an online version is available at the Sooner SUCCESS program website. Needs Assessment data are used to evaluate issues within systems, serving as a tool to monitor systems change and measure progress. At a local level assessment data are used to inform county coalition project planning activities. In addition to the needs assessment, Sooner SUCCESS collects all of the referral data that service coordinators obtain, and record it in a database. This data complements the needs assessment results as it provides information about the number of families requesting mental health services, human services, etc. Needs assessment data tends to align with the database, which aggregates all of the referral information collected by the county coordinators. <http://devbehavpeds.ouhsc.edu/ssindex.asp>

- Conduct System Assessment:** Maine's (2009) *Integrated Community Systems for Children and Youth with Special Health Care Needs* systems integration work was facilitated by the use of a modified version of the MCHB CAST-5 Assessment. The CAST-5 helps states and territories understand and optimize their capacity to identify and address key MCH issues, including issues pertaining to CSHCN to bring about desired public health outcomes.<sup>7</sup> The instrument helps programs determine what organizational, programmatic, and management resources must be developed or enhanced to fulfill the program's goals and objectives. For Maine, the modified CAST-5 Assessment highlighted seven of the ten public health essential services and linked them to services with current CSHN Program Strategies. Maine and its project partners (the Maine Support Network, Maine Family Voices, and the Maine Chapter of the American Academy of Pediatrics) held a daylong meeting in which the different indicators were ranked by priority. A SWOT Analysis was also conducted to discern what was and was not possible with direct service health care. Both of these exercises helped Maine create a "Road Map" that charted the state's progress toward creating a sustainable community-based system of care/public health framework including writing a mission and vision; completing the transition from a payor model to a public health model; strengthening care coordination for the broader special needs population; developing a business planning process; ensuring ongoing staff development; and, aligning human and fiscal resources as a component of Maine's Department of Health and Human Services' organizational realignment. For a copy of the CAST-5 go to <http://mchb.hrsa.gov/grants/titlevtechnicalassistance.html>.
- Develop Statewide Plan:** California's *State Implementation Grant for Integrated Community Systems for CSHCN* (2008) continued the work of a statewide plan for CYSHCN that was developed through a project funded by the MCHB Champions for Progress. Development of the statewide plan was led by the State Children's Medical Services Branch (CMS) with the assistance of three project partners: Family Voices of California, the California Medical Home Project, Los Angeles Partnership for Special Needs Children, and the Children's Regional Integrated Service System. This diverse statewide planning group along with others formed the Key Stakeholder Group which served in an advisory and oversight capacity for the SIG initiative. The Key Stakeholder Group identified service delivery strengths, gaps and barriers that would be addressed through a statewide strategic plan to improve the system of care for CYSHCN and their families and address performance shortfalls.

*From 2007–2008, Oklahoma's Sooner SUCCESS distributed 2,758 paper copies of the Community Needs Assessment survey. There were 1,384 respondents statewide, 627 of whom were family members in 53 counties, and 757 providers in 54 counties. Findings from the 20007-2008 showed that learning labs for children with learning disabilities, day care and extended school hours/after school programs were most frequently identified as perceived unmet needs by families in their county of residence; foster homes, family counseling and, as similarly reported by families, day care were the most frequently identified unmet needs by providers statewide. Only 7% of 1,834 total survey respondents indicated they had no unmet needs and in the Sooner SUCCESS counties 54 respondents (6%) of the 856 reported no unmet needs.*

<sup>7</sup> HRSA Maternal and Child Health Bureau. <http://mchb.hrsa.gov/grants/titlevtechnicalassistance.html> . Accessed 7.24.13

## Engage Partners in Decision-Making

A vision and strategic direction provides a framework, but it takes partners and collaborative, integrated, and synergistic implementation of many different interventions, programs and policies carried out by a number of stakeholders, and administered in many different settings<sup>8</sup> to achieve desired objectives. When Title V began transitioning away from direct service to a population based approach, strengthening ties with partners was essential to ensure interventions are implemented consistent with the vision. Grantees use various models to build strong, collaborative partnerships including:

- **Establish Sustainable Infrastructure:** One goal of **Utah's (2008) Integrated Services Project** was to design and implement a sustainable infrastructure to enhance the systematic integration of community-based services and systems for CYSHCN and their families. Utah established a fairly complex infrastructure consisting of an Administrative Team, four subcommittees chaired by Administrative Team members, and thirty-two organizations and programs all of which comprised the Utah Integrated Services Committee (UISC). UISC encompassed two existing and instrumental governing bodies, the Medical Home Advisory Committee (established in 2001) and the Bureau of Maternal and Child Health Advisory Board. This achieved a level of efficiency—streamlining committees that shared similar missions while securing an “institutional memory” that would endure time and change in member composition. The tasks of the UISC were many and diverse including identifying statewide community partners to collaboratively address the six National Performance Outcomes; developing and reviewing a state plan to address state and local service integration for CYSHCN focused on the six National Performance Outcomes; engaging communities and local partners to host summits as an opportunity for partners to have input on the state service integration plan, tailored to local level issues and resources; and identifying gaps in service systems to CYSHCN, especially those from ethnic minority populations. Full committee meetings took place on a quarterly-basis and lasted for approximately two hours at the Department of Health. In total, there were about 40 individuals who participated in these committee meetings.

### Utah Integrated Services Committee

Bureau of MCH Advisory Board		Medical Home Advisory Committee (est. 2001)	
Utah Integrated Services Committee (established May 2005)			
Administrative Team		Subcommittees	32 organizations
Project Director and CSHCN Bureau Director		1. Young Adult	<ul style="list-style-type: none"><li>• 11 federal programs</li><li>• 5 state agencies</li><li>• 10 community organizations</li><li>• 6 family/young adult groups</li></ul>
Project Co-Director and CSHCN Medical Director		Leadership	
U of U Project Co-Director		Council (YAC)	
USU Project Co-Director		2. Early Continuous	
UISP Project Coordinator		Screening	
Utah Family Voices Director and CSHCN Family Advocate		3. Medical Home	
CSHCN Care Coordinator Specialist		4. Transition	
Medicaid Children’s Programs Manager			
CSHCN Program Manager			
Univ. of Utah Dev. Pediatrician			
Utah State Univ. Evaluation Team			
UPIQ Quality Improvement Coordinator			
UISC members include: families; young adults; community groups (ethnic, religious, disability, and parent organizations); private practice physicians; specialty clinic nurses; school nurses; educators; Medicaid; mental health providers; CSHCN staff; Baby Watch/Early Intervention staff; clinical professionals from Primary Children’s Medical Center, Shriners Intermountain West, University of Utah and Utah State University staff.			

- **Convene Stakeholders to Inform Planning, Implementation and Evaluation:** **Maryland (2011)** convened a Community of Care (COC) Consortium, a broad alliance of concerned stakeholders to participate in shared planning, implementation, and evaluation of strategies to achieve all six core outcomes for CYSHCN. The COC Consortium oversees and spreads the use of evidence-based and best practice strategies both at the state and local levels, using mini-grants to support communities, providers, and families as well as through the identification and provision of training. COC members also participated in the development and implementation of the Title V needs assessment survey (*2010 Maryland Parent Survey*). From the consortium evolved a more strategic group called the COC-Leadership Team (COC-LT) that included

<sup>8</sup> Fraser, MR. Bringing it All Together: Effective Maternal and Child Health Practice as a Means to Improve Public Health. *Maternal and Child Health Journal*. 2013. 17:767–775

project staff and partners from Maryland's Title V CSHCN, Maryland Chapter of the AAP and evaluators from Johns Hopkins University. The COC-LT planned and implemented an Invitational Summit to kick off the Maryland Community of Care Consortium for CYSHCN. In preparation for the Summit, the COC-LT drafted implementation briefs on the 6 core components of care for CYSHCN. The COC-LT recruited and supported diverse stakeholder participation for the Summit and the Consortium, and as a result, over 100 stakeholders from across the state of Maryland, including physicians, families, representatives from advocacy, government and professional organizations, public payers, and policy analysts were in attendance to discuss the status of Maryland's current system of care. Summit participants worked in small groups focusing on each of the six core outcomes for CSHCN and their families. Group discussions focused on identifying current objectives in each outcome area, identifying opportunities to improve systems of care, and developing strategies for improving Maryland's performance in each outcome area. The COC Consortium convened quarterly; each meeting averaged 30-40 participants from a wide variety of state and local agencies, providers, advocacy groups, and families of CYSHCN. At quarterly meetings, COC members focused on the priorities identified by participants in the Summit as well as emerging issues.

### *Institutionalize Quality Improvement*

Effective systems development cannot occur when the system remains unchanged over time and no enhancements are made. To generate better results than the ones already created, the effective leader must be prepared to bring change into the system to achieve a new **performance** level. Quality improvement (QI) employs qualitative and quantitative methods to enhance the effectiveness of interventions, programs and policies. Institutionalizing a commitment to quality improvement ensures limited resources are maximized and program objectives are achieved. Furthermore, grantees with effective quality improvement programs are able to make the case for sustainability by quantitatively demonstrating change and impact. Grantees received training, individualized coaching and support to build capacity in QI and to incorporate QI principles in routine business practices. Models for institutionalizing QI that were effective included:

- **Establish a Learning Collaborative:** Using a learning collaborative methodology, the **District of Columbia (2011)** worked with **three** pediatric sites (Children's National Medical Center (the Adolescent Clinic and the Adams Morgan Children's Health Center) and Georgetown's Adolescent Health Clinic), and **two** adult sites (Howard's Family Medicine Clinic and at George Washington's Internal Medicine Clinic) to incorporate into their clinical processes several core elements for transition including transition or privacy/consent policies; a registry to identify youth with special health care needs and monitor transition progress; transition readiness assessments and transition care planning; preparation of medical summaries; and consultation and communication between pediatric and adult practices for transfer of care. At each site a lead physician, care coordinator, and consumer (parent or young adult) received intensive training and coaching support as a part of this quality improvement initiative. Each site measured its progress in implementing the core elements for transition. In addition, each site was asked to spread the use of transition quality improvements in their academic institutions through grand rounds training, residency training programs, and include the core elements of transition as part of their electronic health record systems.
- **Build on Existing State Initiatives:** **Minnesota's (2008)** *Medical Home Initiative* was built on previous work done nationally by the Center for Medical Home Improvement's Building a Medical Home and the national Medical Home Learning Collaborative conducted by the National Initiative for Children's Healthcare Quality (NICHQ), the Center for Medical Home Improvement (CMHI), and the National Center for Medical Home Initiatives at the American Academy of Pediatrics. The *Medical Home Initiative for children with special health care needs* involved a state-coordinated effort to

*Practice teams in Minnesota's **Medical Home Learning Collaborative** focused on quality improvement and implementing Medical Home. Through the Learning Collaborative at least 177 presentations were made by Medical Home team members to other clinicians and an estimated 69 hours of Continuing Medical Education hours to other clinicians related to Medical Home were provided. Each participating clinical practice established criteria for how their clinic defined and identified children with special health care needs. Over the course of the Initiative, clinics reported over 1,200 care plans developed. Overall, participating clinics identified approximately 7,500 children with special health care needs. These numbers ranged from 52 to 1,151 children with special health care needs per clinic. In 2007 Minnesota legislative interest resulted in funding to continue and expand the Medical Home Learning Collaborative and by 2008 the Health Care Home legislation was passed.*

recruit and bring together teams from clinics to share problems, solutions, and strategies for better coordination of care for children with special health care needs. The work of teams involved designing and implementing small incremental changes that could be implemented at the practice. Teams were supported through a series of Learning Collaborative sessions with the first launched in early 2004.

### *Invest in Technologies and Data Systems to Support System Monitoring and Improvement*

To support priority setting and quality improvement, grantees need access to timely information. To ensure that partners are aligned with strategic priorities, this information must be shared with stakeholders. New technologies provide unique and effective ways of informing partners and disseminating information for decision-making. Grantees have successfully developed integrated data systems and methods for disseminating information to partners including:

- **Using Electronic Medical Records: West Virginia (2011)** is instituting an electronic medical records system that will include a “My Chart” component. This piece of the medical record will provide access to information by patients, parents and caregivers. Documents in “My Chart” will include disease specific action plans, transition documents, and health education action plans. By being placed in “My Chart”, patients, families and caregivers will have access to these and will be able to share them with other members of the medical home including school nurses and the primary care physician. The electronic medical records program will have online trainings for families as well as a handout explaining “My Chart”. Specific trainings for families will be conducted to provide families an opportunity to see the “My Chart” feature.
- **Integrated Data Systems: South Carolina’s (2008) State Data Warehouse (SDW)** is one of the most developed data warehouses of any state in the nation - providing advanced capability for data compilation and analysis. The State Data Warehouse (SDW) is a repository for almost all South Carolina state agencies and hospitals as well as state employee insurance plan data. This collaborative system links files by connecting individuals’ multiple data files through unique identifiers. Through use of claims data, this integrated system links data about children served by state agencies. The Data Warehouse also offers the potential to create after-the-fact analyses of children with various disability types, as well as analyses of Medicaid costs and utilization and type of Medicaid services provided. Through the SDW, children can be tracked across systems of care from birth; for example, a child’s diagnosis can be linked with educational achievement, cost of services, and family demographics.
- **Provide Reports to Partners: Rhode Island (2009)** maintains a data system that generates practice reports and surveys to support continuous program monitoring and improvement. Monthly and quarterly reports with data collected by Parent Consultants were provided to the Family Voices Leadership Team (FVLT) and pediatric primary and specialty care sites to identify system gaps and barriers in the special health care needs service delivery system. These gaps and barriers were monitored to assess services and access to medical homes; developmental screening; evaluation/diagnosis; adolescent transition; and, health insurance. Reports also provided information regarding the number of patients and families served; issues and concerns addressed; and outcomes. Another data source to identify barriers and best practices as well as assess impact was the Pediatric Practice Enhancement Project (PPEP) quarterly surveys. These surveys were tracked by Parent Consultants to ensure that surveys were completed and returned. This efficient and effective strategy allowed for an adequate response rate, a challenge often faced by other states when administering surveys. As the PPEP model spreads, new practices continue to use the data system which is housed at Rhode Island Parent Information Network. The goal is to have the data incorporated into the patient record at the practice level for case management.
- **Engage Partners in Interpretation of Data: Utah (2008)** established the Participatory Action Research (PAR) model to assist those who are committed to systems change to use data and information to drive their actions in achieving project goals. Utah used this approach in project development, implementation and evaluation by engaging evaluators, administrators, families and providers participating in the Utah Integrated Services Committee, the Administration Team, the Young Adult Leadership Committee, and the Medical Home Learning Collaborative. Regular meetings of these groups provided a forum for interpreting data and inviting members to give meaning to the data with respect to their progress toward the agreed upon goals.

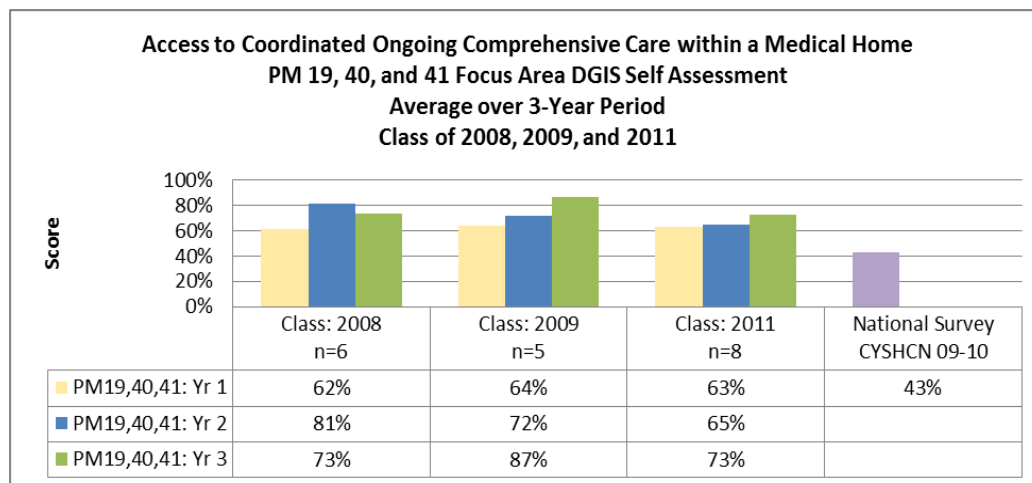
## Access to Coordinate Ongoing Comprehensive Care within a Medical Home



The first of six core outcomes is access to a medical home that provides for a usual source of care, access to specialists, coordinated care, and family centered care. The history of medical home is rooted in the innovative thinking of maternal and child health professionals' commitment to improve health status and outcomes of children and youth with special health care needs. As with most innovative ideas that evidence success early on, the medical home model, recognized for its relevance to the broader population, is quickly being adopted as a best practice. "A medical home is an approach in which the care provided is accessible, continuous, comprehensive, compassionate, and culturally effective.<sup>9</sup> It is provided by doctors or nurses who provide primary care and help to manage and facilitate essentially all aspects of pediatric care, including specialty care."<sup>9</sup> And, central to a medical home approach is patient- and family-centered care coordination. Care coordination is recognized as having the following defining characteristics: 1. patient- and family-centered; 2. proactive, planned, and comprehensive; 3. promotes self-care skills and independence; and, 4. emphasizes cross-organizational relationships.<sup>10</sup> Its effectiveness is said to be measured by the experiences of the families that receive the services requiring them to be proactively engaged in the design of systems and policies that will support the development of care coordination as an integral part of the health care system.<sup>10</sup>

For the SIG grantees, medical home is by far the greatest facilitator to system integration efforts. It provides a concrete mechanism that can be demonstrated and then spread. By nature of its multidisciplinary approach, the medical home model allows grantees to address several related outcomes such as transition, the organization of community services and family partnership in decision making. Figure 1 shows the experience of the Classes of 2008, 2009 and 2011 who targeted medical home for improvement through their three-year SIG grant. Grantees report annual improvement in performance as a result of their focused efforts. A fully functioning system would receive a score of 100%; by the third year of the grant, grantees report performance between 73–87%. It is noted, however, that the results of the 2010 CSHCN National Survey which reports the experience of the end user of the system of services—children with special health care needs and their families—rated access to a medical home at 43% out of 100%.

Figure 1.



\* Note: PM changed – PM19 was replaced with PM40 and PM41 in 2010.

Successful strategies for promoting the medical home model include:

### Advance Policies to Support Medical Home Development

- Legislative Support for Medical Home: Minnesota (2008)** passed legislation in 2008 to support the Health Care Home. The legislation includes recommendations of the Governor's Transformation Task Force and the Legislature's Health Care Access Commission to create a comprehensive health care package making significant advances for Minnesotans in several areas including promoting the use of "health care homes" to coordinate care for people with complex or chronic conditions. Minnesota Departments of Human Services and health were charged to: develop and implement standards of

<sup>9</sup> McPherson M, Weissman G, Strickland B, van Dyck PC. Implementing Community-Based Systems of Services for Children and Youths With Special Health Care Needs: How Well Are We Doing? *Pediatrics* 2004;113;1538

<sup>10</sup> Antonelli, RC, McAllister, JW, Popp, J. Making Care Coordination A Critical Component of the Pediatric Health System: A Multidisciplinary Framework. The Commonwealth Foundation. May 2009

certification for health care homes by July 1, 2009; establish standards for state certification of health care homes and evaluating outcomes; and, ensure that health care homes receive care coordination payments from public and private health care purchasers. Today, there are currently 257 health homes in Minnesota.

<http://www.health.state.mn.us/divs/opa/08reformssummary.html>

- **Track Medical Home Implementation: New York State (2009)** leads the nation in the number of National Committee for Quality Assurance (NCQA)-identified Patient Centered Medical Homes (PCMH) pilots currently under way and in the number of providers and practices that have pursued and achieved NCQA recognition.<sup>11</sup> One contributing factor to the high number of currently operating pilots is the financial benefits that accompany receiving NCQA recognition. On July 1, 2010 New York State's Medicaid program implemented a payment system that rewards providers who receive NCQA recognition. Another factor is the consistent recruitment of practice champions that advocate to their peers regarding the benefits of the PCMH model, thereby building a network that encourages other providers to receive NCQA recognition. Medical home tracking is also another factor that influences the growing number of NCQA-identified PCMH pilots. New York State developed a strong partnership with the Office of Health Insurance, which allows for the health department to track medical home visits and care through insurance payment records. This efficient use of an already established tracking infrastructure was the result of a partnership that was cultivated through D70 grant activities.
- **Engage Providers in Medical Home Learning Collaborative: Nebraska (2011)** enrolled primary care practices in the Medical Home Learning Collaborative (MHLC). The MHLC learning sessions were convened to establish a common understanding of a Medical Home; introduce the Medical Home tool kit; allow participating clinic teams to assess the "Medical Home-ness" of their individual clinics; and develop priority areas for practice improvement. All of the participating practices moved forward in their acquisition of medical home certification as recognized by the NCQA, and some practices were able to receive certification during the project.
- **Promote Medical Home Certification: Pennsylvania (2011)** worked to engage Federally Qualified Health Centers (FQHC), FQHC look-alikes and Rural Health Centers (RHC) in the medical home model by disseminating information at a professional conference and meetings with the state's primary care association to increase awareness of medical home.



*Colorado Department of Public Health and Environment had a vision for Colorado to become a "medical home state". In 2007 Legislation was passed (SB-07-130 and SB-07-211) to provide medical homes for children and to require measurement of medical home as a quality standard for pediatric health. To achieve this vision, Colorado provided assistance to local communities to build systems for medical home implementation. To ensure the system of care met patient needs, youth and families were involved in planning.*

- **Practice transformation facilitation: New Jersey (2011)** provided technical assistance, resources and support to primary care providers through a learning collaborative model. Technical assistance was provided to medical home quality improvement teams by the Medical Home Resource Team consisting of New Jersey's Statewide Parent Advocacy Network (SPAN), American Academy of Pediatrics-NJ, and Title V, individually on site through medical home visits and on monthly Medical Home Leadership Action Group calls. Technical assistance on working more effectively with families of CYSHCN was also provided to practices by county Family Resource Specialists and trained Parent Partners. The goals of the learning collaborative were to build teamwork within practices, help practices develop and implement protocol improvements, provide resources and enhance cultural competence.

<sup>11</sup> [http://www.medicalhomeinfo.org/state\\_pages/new\\_york.aspx](http://www.medicalhomeinfo.org/state_pages/new_york.aspx)

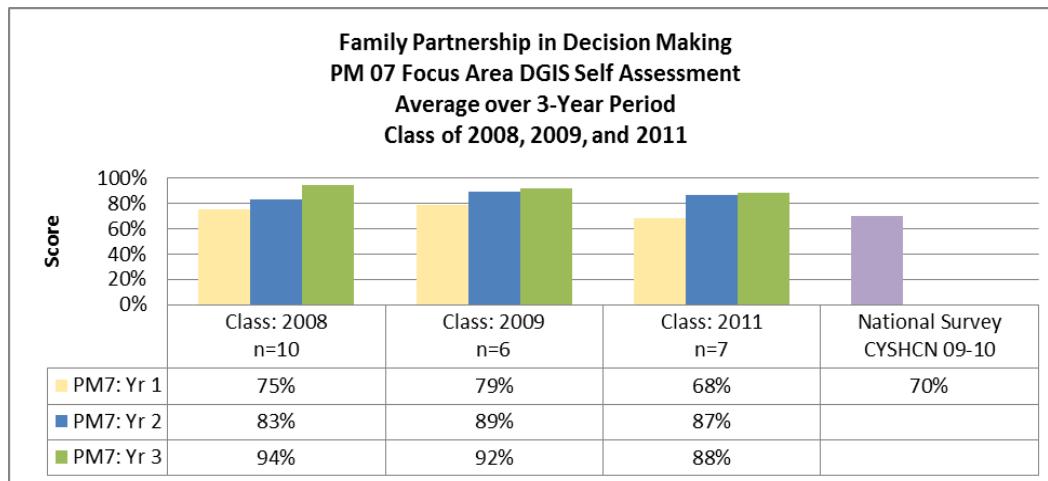
## Family Partnership in Decision-Making



The second of six core outcomes is partnering with families and youth in decision-making at all levels. The effective system of services must meet the needs of children and youth with special health care needs and their families. If the system is to be successful, the end users of the system must be involved in its design and ongoing evaluation.

Figure 2 shows the experience of the Classes of 2008, 2009 and 2011 who targeted family partnership in decision making for improvement through their three-year SIG grant. Grantees report annual improvement in performance as a result of their focused efforts. A fully functioning system would receive a score of 100%; by the third year of the grant, grantees report performance between 88-94%. It is noted, however, that the results of the 2010 CSHCN National Survey which reports the experience of the end user of the system of services – children with special health care needs and their families - rated family partnership in decision making at 70% out of 100%.

**Figure 2.**



\* Please Note: PM changed - PM 7 expanded from 6 to 8 questions. Effective 2010.

States engaged families and youth as partners and leaders in a number of ways including:

### Engage Families and Youth in Policy and System Development

- **Serve on Statewide and Regional Planning/Advisory Bodies:** **Massachusetts' (2008)** Family-Professional Partners Institute was the primary facilitator for establishing and enhancing family-professional partnerships. The purpose of the Institute was to facilitate and broker partnerships between families and organizations, and provide training and mentoring to the partnerships. Partnerships were created in four areas: clinical settings, academic/research settings, health plans and community-based organizations. An orientation and training session attended by families and organizational partners was conducted to introduce the family and organizational partners to each other; educate all partners about the history and development of family involvement; present the basic principles and goals underlying family-professional partnerships; provide needed tools, resources and understanding for engaging in a partnership and working with an organization; and, establish a starting point for the actual work of the family-professional partnership. An *Institute Manual, Structure & Spark!: Brokering Family-Professional Partnerships to Improve Care for Children with Special Health Needs* was developed for promoting family-professional partnerships. The manual provided information and tools to help organizations in other states to develop the Institute model. [www.neserve.org/neserve/pub\\_structure.htm](http://www.neserve.org/neserve/pub_structure.htm)
- **Advocate for CYSHCN:** **Colorado (2011)** felt strongly that the absence of the youth/young adult voice in community systems was a significant oversight. Therefore, the state established a youth leadership council; mentored a small group of youth/young adults with complex health care needs in the development of their voice and role in state medical home systems planning; and provided opportunities for them to educate other youth, students, adult and pediatric providers, and state officials in the benefit of having youth/young adults involved in medical home efforts.
- **Train Families as Leaders:** **Navajo Nation (Class of 2009)** empowered teams of parents of CYSHN to become leaders. The project was structured to rapidly teach families basic skills in leadership, meeting facilitation, communication and recruitment strategies. This capacity building was directed at the teams of parent leaders in four communities. Teams

followed a community development process established during a seed grant from the Champions for Progress initiative and subsequently received training in family advocacy, leadership skills, Community Based Participatory Research (CBPR), local and national networking, and resource identification and mapping. Team members were responsible for outreach to other communities to share their experiences with the project, explain the process and activities in order to spread the initiative by establishing more Family Teams. The outcome of these trainings was a cohesive group of parents who practiced leadership skills by developing agendas and chairing meetings as well as identifying and visiting with potential partners including Chapter leadership, school and health administration, and legislative delegates to provide information on the project. Parents were also instrumental in educational and training events. Parent Leaders hosted a Navajo Nation-wide project summit with approximately 130 attendees. Parent Leaders facilitated the entire summit, taking the leadership role in planning for the Summit and conducting and/or participating in the breakout sessions.

- **Reimburse Families for Involvement: Hawaii (Class of 2008)** engaged families and youth as partners and leaders through its project named Hilopa'a meaning "to braid firmly". Hawaii's goal was to establish a tie between its Title V programs, its families and the professionals who served them, "binding together the strength of individual partners to make strong the connection to put forth the 2010 objectives." To better understand how, and in what capacity to engage families, the Hilopa'a project administered a family and youth survey to identify areas of interest and participation, providing direction to areas where families might be engaged. Recognizing that lack of compensation hindered family participation Hawaii developed, implemented and shared guidelines on compensation for family participation (<http://health.hawaii.gov/cshcn/files/2013/05/hilopaafamilyparticipationguidelines.pdf>). Flexibility is a key ingredient in the successful implementation of family compensation guidelines. Currently, Hawaii's parent partners who are engaged for leadership and serve as official consultants are paid for their contributions, including travel and childcare. For family participation in training events, Hilopa'a provides childcare on-site or provides compensation for in-home contributions as necessary.

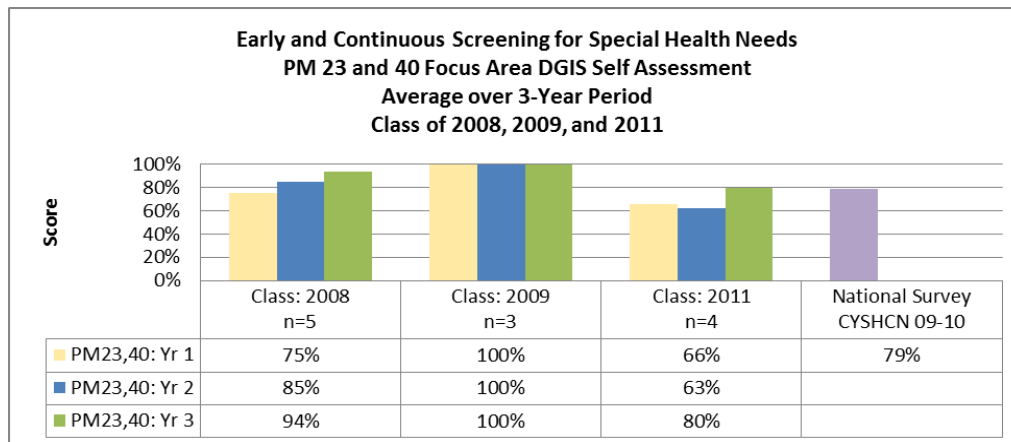


## Early and Continuous Screening



The third of six core outcomes is providing children and youth age-appropriate medical, dental, and behavioral health screenings and early intervention. This core outcome requires that all children and youth receive early and continuous screening to identify conditions that may result in special health care needs.<sup>9</sup> SIG grantees' initiatives to address early and continuous screening looked to achieve universal and consistent standards. Figure 3 shows the experience of the Classes of 2008, 2009 and 2011 who targeted early and continuous screening for improvement through their three-year SIG grant. Grantees report annual improvement in performance as a result of their focused efforts. A fully functioning system would receive a score of 100%; by the third year of the grant, grantees report performance between 80-100%. It is noted, however, that the results of the 2010 CSHCN National Survey which reports the experience of the end user of the system of services – children with special health care needs and their families - rated access to early and continuous screening at 79% out of 100%.

Figure 3.



\* Please Note: PM changed - PM 23 was replaced with portions of PM40 in 2010.

Successful strategies for promoting early and continuous screening include:

### *Advance Policies to Comply with Recommended Screenings and Interventions*

- **Develop Guidance: New York (2009)** developed public health guidance for local health departments (LHDs) about the provision of primary and preventive services for all children under the age of 21, including CSHCN. This guidance outlines the public health activities that are eligible for state aid reimbursement to localities. Previous guidance was substantially expanded and strengthened to include strategies that relate to insurance, medical homes, information and referral, service provision, and quality improvement. In December 2007, draft guidance was presented to and discussed with leadership from the New York State Association of County Health Officials (NYSACHO). In April 2009, the guidelines were adopted and are now utilized by 57 localities and one municipality as the public health framework for primary and preventive services for children. This document is a cornerstone systems piece for public health services for children including CYSHCN.

### *Implement Tracking Systems to Monitor Adherence*

- **Use Standardized Screening Tool: New York (2009)** convened a Child Development Learning Collaborative (CDLC) to enhance practice capacity in screening. In preparation for the CDLC, recruited practices were asked to review current screening and surveillance practices. The review was based on the medical records of the last ten children seen for the 18-month and 24-month well child visits, respectively. Practices reported the number of children screened (and who received "surveillance", or neither screening nor surveillance) for general development at 18 months and for autism at 24 months; the number of children identified with concerns by each method; and follow-up including referral. In addition, practices were asked to develop a standardized method to make referrals. Involvement of parents was encouraged to improve overall performance of their practice's efforts to meet the developmental and other medical needs in the context of the "medical home". Prior to the Learning Collaborative, none of the five practices were regularly using a standardized developmental screening tool to identify children birth to thirty-five months at risk for developmental delay or problems. At the end of the Learning Collaborative, three of the five practices reported regular use of a standardized screening tool for developmental monitoring and surveillance; and, two practices integrated the Ages and Stages Questionnaire (ASQ) into well child visits (<http://agesandstages.com/>).

- **Target Screening for Improvement: Utah's (2008)**

Pediatrics Partnership for Health (UPIQ) Learning Collaborative targeted newborn, vision and hearing screening for improvement. Practices in the learning collaborative were required to pull five charts each month to evaluate compliance with recommended screenings. The chart reviews not only tracked whether screenings were completed, but also tracked screening system methods and processes, including the location of the screening (provider office, home, or school), what tool was used, how the score was recorded, who collected and provided the test information, and follow-up (i.e. if normal and abnormal result procedures were correctly implemented and if screenings were re-administered, etc.). Site visits were conducted quarterly to conduct interviews and collect qualitative data which were shared with other practices in the collaborative regarding systems changes to support screening. Although integrating screening tools into routine care proved difficult, the learning collaborative provided an opportunity for teams to build off one another's successful ideas through PDSA cycles and shared learning. Due to the importance of timely follow-up, diagnosis and treatment in screening

programs, the chart review approach through the learning collaborative was particularly helpful in improving the number of children who received appropriate and early intervention screenings and allowed practices to adopt each other's effective strategies. Findings of the collaborative were shared in learning sessions. The first session provided a forum for teams to present on their progress with these screenings and speakers presented on topics including: the family's perspective on medical home screening, newborn metabolic screening, hearing screening, and vision screening. Additionally, community resources and case examples were discussed. A second learning session focused on developmental, social emotional and depression screening. Experts provided information on developmental screening, referrals for subspecialty consultation, depression in CYSHCN and their families, and selected age groups/conditions.

<http://www.medicalhomeportal.org/clinical-practice/building-a-medical-home/medical-home-training-and-resources>

***Iowa's 1st Five Healthy Mental Development Initiative builds partnerships between physician practices and public service providers to enhance high quality well-child care. 1st Five promotes the use of developmental tools that support healthy mental development for young children during the first five years. By using a tool for all children that includes social-emotional development and family risk factors, providers are able to identify children at risk for developmental concerns that, if left untreated, would play out later in life. Iowa's evaluation findings showed that the average number of referrals made during 2008 to the 1st Five care coordinators by the 51 total participating PCPs was 20.7 per PCP. 1st Five care coordinators then connected families to needed community-based services, including the Part C early intervention program. The average number of connections to community services and resources for each child served by 1st Five was nearly 3.5 (3,688 referrals made for 1,057 children), though the average number of connections per child varied across sites from 1.1 at the Polk Co. sites to 6.5 at the Dubuque sites.***

<http://www.idph.state.ia.us/1stfive/overview.asp>

### ***Inform Providers on Recommended Screenings and Interventions***

- **Inform Private Providers of Community-Based Care Coordination Resources: Iowa's (2008)** Assuring Better Child Health and Development (ABCDII) project (supported by the Commonwealth Fund) encouraged partnerships to promote early childhood developmental screening to assure healthy mental development. Child Health Specialty Clinics and Iowa Medical Home Initiative supported early childhood screening as an important component of the medical home and further emphasized this component through maintaining and growing public-private partnerships. One proposed avenue was to support Iowa's homegrown follow-up to the ABCDII project, called 1st Five, where private PCPs were introduced to public community-based care coordination resources. During Iowa's SIG, the 1st Five program worked with primary care providers (PCPs) in three major geographical areas of the state to enhance early childhood developmental screening and follow-up. The follow-up component relied largely on building connections between PCPs and other community-based service providers to assure that necessary early intervention services are accessible and coordinated. The 1st Five sites developed strategies to: 1. promote the spread of recommended screening standards within pediatric and family medicine practices while also facilitating referrals to recommended interventions for children and families identified in need of services and support; 2.) promote the knowledge of children's healthy mental development, including the impacts of maternal depression, and recommended interventions through training and outreach to local service providers; and, 3.) collaborate with local service providers and support systems, including Iowa Empowerment (local programs benefiting 0–5 year olds) and the Part C early intervention programs.

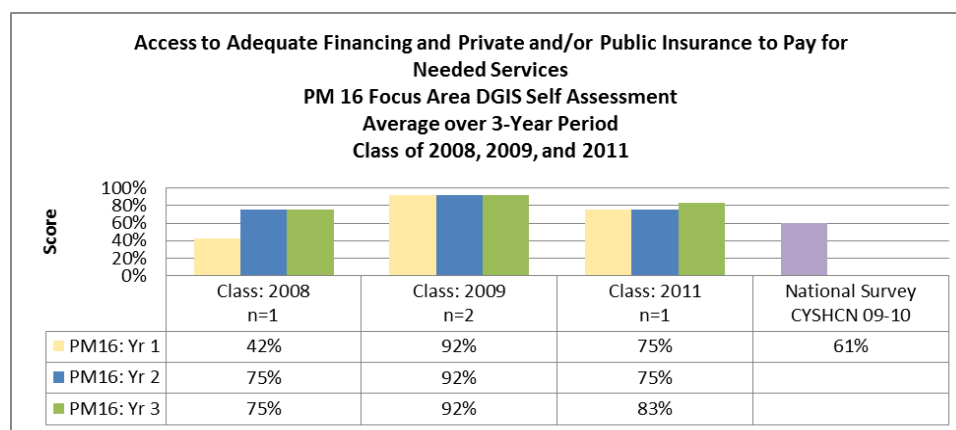
## Adequate Financing for Needed Services



The fourth of six core outcomes is continuous and adequate health insurance and other financing to pay for needed services. Optimal health outcomes cannot be achieved if CYSHCN cannot afford needed services. About one third of CYSHCN and their families experience underinsurance; they have either private or public coverage, but the benefits do not cover important health care expenditures such as durable medical equipment (DME), medical supplies, rehabilitation therapies, mental health services or dental care.<sup>12</sup> For some privately insured families the co-payments for visits and deductibles for other services are exorbitant. Given that health insurance plays a key role when trying to access needed care and services, the MCHB's goal is that all CSHCN have insurance and that insurance should be adequate to meet the child's service needs.<sup>9</sup>

Figure 4 shows the experience of the Classes of 2008, 2009 and 2011 who targeted adequate financing for needed services for improvement through their three-year SIG grant. Grantees report annual improvement in performance as a result of their focused efforts. A fully functioning system would receive a score of 100%; by the third year of the grant, grantees report performance between 75-92%. It is noted, however, that the results of the 2010 CSHCN National Survey which reports the experience of the end user of the system of services – children with special health care needs and their families – rated adequacy of financing at 61% out of 100%.

Figure 4.



\* Please Note: PM changed - PM 16 expanded from 4 to 8 questions. Effective 2010.

Successful strategies for promoting adequate financing for needed services include:

### Advance Policies to Address Gaps in Financing

- Medicaid Reimbursement for Needed Services: Pennsylvania (2011)** implemented a Transition Learning Collaborative that engaged 32 public and private professionals, youth and parents to improve transition from high school to adulthood. The Learning Collaborative created four workgroups that addressed resource identification and dissemination; integration of disciplines for transition; medical provider issues; and, youth wellness and self-advocacy. The Medical Provider work group had the most significant impact. The Learning Collaborative successfully worked with the Pennsylvania Department of Public Welfare Office of Medical Assistance Programs to develop and issue an operations memo that provides a bridge from pediatric to adult care for families. The Medicaid Managed Care Operations Memo (MC OPS) allows adult physicians to be paid for three visits as a medical consultant while the youth is still capitated to the pediatric practice. The three paid medical visits helps families make sure the match with the physician is satisfactory and to exchange medical information or a medical visit with three separate adult practices to determine which practice meets their needs.
- Demonstrate Cost-Benefit to Secure Funding: Rhode Island Department of Health (Class of 2009)** met with Rhode Island's Health Insurance Commissioner and the Rhode Island State Legislature regarding the cost savings and efficiency of the Pediatric Practice Enhancement Project (PPEP) model as well as disseminated information on project activities and findings to key constituents. This dissemination strategy of project activities and the results of a cost benefit analysis enabled the state to secure funding for the PPEP. Through collaboration with consumer advisory committees, and state and community stakeholders, Rhode Island Department of Health worked to ensure that a benefits package would be consistent with medical home best practices for CYSHN.

<sup>12</sup>Catalyst Center. <http://hdwg.org/catalyst>. Accessed 7.19.13

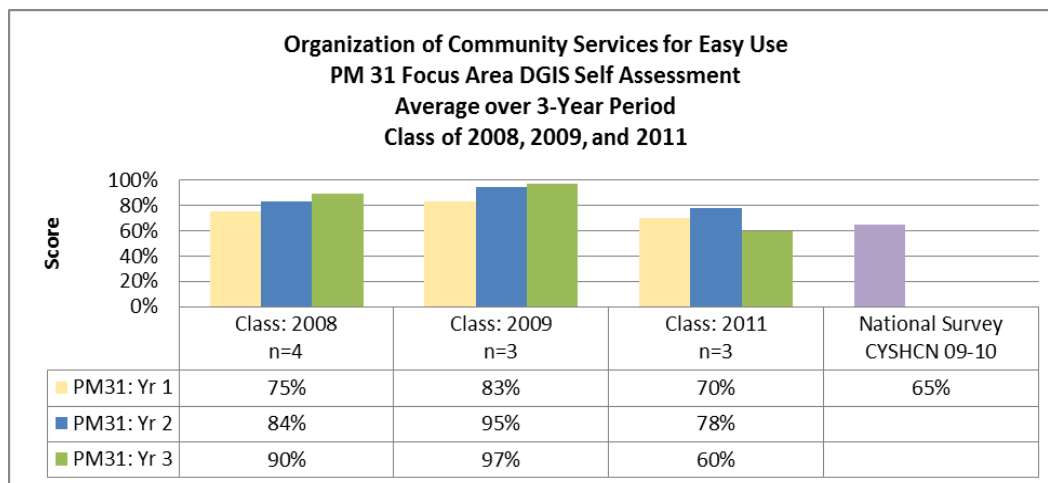
## Services Organized for Easy Use



The fifth of six core outcomes is easy access to a family-centered network of community based services (e.g., health, development, education, vocation, therapies, recreation and transition to adulthood) designed to promote the healthy development and well-being of children and their families. The difficulty of navigating the health care system to access needed services is frequently compounded by service fragmentation due to funding mechanisms for various programs with their own respective eligibility criteria.<sup>9</sup> Grantees addressed this challenge primarily through work with medical homes and partnership building.

Figure 5 shows the experience of the Classes of 2008, 2009 and 2011 who targeted improvement in the organization of community services for easy use through their three-year SIG grant. Two of the three classes report annual improvement in performance as a result of their focused efforts. A fully functioning system would receive a score of 100%; by the third year of the grant, grantees report performance between 60-97%. It is noted, however, that the results of the 2010 CSHCN National Survey which reports the experience of the end user of the system of services – children with special health care needs and their families – rated organization of community services at 65% out of 100%.

**Figure 5.**



\* Please Note: PM changed - PM 31 expanded from 4 to 8 questions. Effective 2010.

Successful strategies for promoting services organized for easy use include:

### *Promote Coordination of Care*

- Place Parent Consultants in Practices: Rhode Island's (Class of 2009)** Pediatric Practice Enhancement Project (PPEP) (2009) provides a coordinated system of care for CYSHCN and their families by placing and supporting trained Parent Consultants (peers) in pediatric primary and specialty care practices to assist families in accessing community resources and specialty services, and to identify barriers to coordinated care. The Department of Health subcontracts with the Rhode Island Parent Information Network for overall model implementation (including training of the Parent Consultants) and with Family Voices Leadership Team (FVLT) for project oversight. The latter, acting as the project's Steering Committee, provided a system for quality improvement to address barriers to the provision of an integrated community system of care for CYSHCN and their families. Practices implementing the PPEP model have the option of hiring the Parent Consultant or pay Rhode Island Parent Information Network (RIPN) to hire a Consultant. While Rhode Island has not yet been successful at getting a billing code for the Parent Consultant to work individually with patients, pediatricians can extend the visit code to a 30, 45 or 60 minute visit that assumes an umbrella over the Parent Consultant's work. Since implementation in 2004, the model has demonstrated that PPEP participants experience fewer healthcare encounters and a decrease in inpatient utilization. PPEP was accepted as a Promising Practice in the field of Maternal and Child Health by the Association of Maternal and Child Health Programs and written up as a case study by the Robert Wood Johnson Foundation.

- Partnering Pediatric Practice and Insurance Case Management: New Hampshire (Class of 2009)**  
 developed and implemented a new model of care coordination, Partners in Chronic Care (PCC). Partners in Chronic Care was originally developed by The Hood Center for Children and Families (an organization at Dartmouth Medical School that promotes research, best practices, resource development, community partnerships, and public policies for the well-being of families of children with special health care need) and evolved into a public and private partnership among Anthem BCBS in New Hampshire, New Hampshire Special Medical Services, New Hampshire Medicaid, Cigna in New Hampshire pediatric practices, and families of CSHCN. The PCC model promoted the medical home concept of the pediatric practice as the hub of communication for the family and the multiple systems with which they interact. A partnership between the pediatric practice, and the insurance case management staff created a collaborative structure for increased creative problem solving, lessening the burden of care management for the family. A Care Coordination Assistance Team (CCAT) made up of New Hampshire Title V case managers, Hood Center staff, a nurse consultant, Anthem BCBS pediatric case managers and Family Voices staff provided tools and support to practices including: 1) a mechanism for identifying the CSHCN within a practice; 2) tools and support for determining what level of services specific children need through the use of complexity measures; and 3) piloting a consultation model that offered customized care coordination to families. The basic framework of the PCC model includes four components: 1) an initial home visit for assessment of current status and needs of the child and family; 2) a team meeting at the primary care pediatric office which generates a care plan with specified tasks, and responsibilities for follow-through; 3) implementation of care plan and related activities; and 4) monitoring progress and changes in needs with family by phone.

*Rhode Island's **Pediatric Practice Enhancement Project (PPEP)** ensures a coordinated system of care for CYSHCN and their families by placing trained Parent Consultants in pediatric primary and specialty care practices to assist families in accessing community resources, to assist physicians and families in accessing specialty services, and to identify barriers to coordinated care. A Cost Benefit Comparative Evaluation of PPEP revealed that when care was coordinated through the PPEP model CYSHN had fewer health care encounters than before care coordination occurred. Additional findings indicated that inpatient utilization was 24% lower for PPEP participants compared to pre-PPEP, and 34% lower compared to CYSHN in standard care; and, annual healthcare costs were 39% lower for PPEP participants compared to pre-PPEP, and 27% lower compared to CYSHN in standard care. Findings resulted in funding for practice reimbursement (enhanced rate) for the PPEP participating sites and supported the PPEP post grant funding. <http://www.health.ri.gov>*

- Educate Providers about Role of Parents as Care Coordinators: Nebraska (2011) Integrating Systems of Care (NISOC) for CYSHCN**  
 worked with several experts to improve care coordination and delivery by engaging ten practices in a Medical Home Learning Collaborative (MHLC). NISOC worked with a Family Voices representative to the American Academy of Pediatrics (AAP) National Center of Medical Home Implementation Project Advisory Committee and Director of the Hali Project, to conduct a learning session on the role of parents as care coordinators in primary care practices. Upon request, additional training was provided to three of the MHLC practices for their parent partners.

### *Provide Families with Resources to Facilitate Access to Care*

- Resource Directory: Hawai'i's (2008) Rainbow Book** is a resource directory developed in collaboration with families for families and the service provider community. The *Rainbow Book* provides a landscape of all core programs and services for CYSHCN and their families in Hawai'i along the continuum from birth to adulthood. It includes promotional materials and referral forms and is indexed for easy reference. The first iteration of the *Rainbow Book* was developed under SIG funding, and has become the go-to resource for the state. It continues to be updated and enhanced with resources on access to a range of services. The family guidelines can be accessed through multiple venues- in both provider and family networks, and it has evolved from its first iteration that focused primarily on care coordination and transition work. In order to obtain a copy, family participants must attend an in-depth 1-day training on the manual. Trainings are now available via webinar in order to improve access. Participation in the training serves a dual-purpose as attendees are not only briefed on the valuable resources of the *Rainbow Book*, but it also serves as an opportunity to build relationships as the audience is typically mixed. The trainings are free of charge, childcare is provided, and all participants receive a hard copy until completion of the brief course.

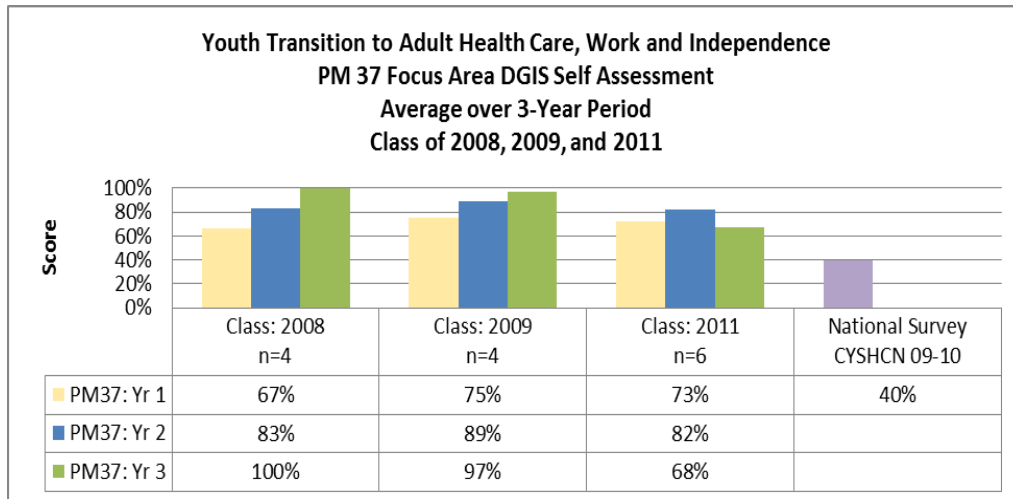
## Transition to Adult Health Care



The last of six core outcomes is that youth receive the services necessary to make appropriate transitions to adult health care, work, and independence. The transition to adulthood presents many challenges for CYSHCN, especially those with significant impairments. Effective transition addresses the changing medical needs that accompany the transition to adulthood and the receipt of vocational or career training needed for employment as an adult.

Figure 6 shows the experience of the Classes of 2008, 2009 and 2011 who targeted youth transition to adult health care, work and independence through their three-year SIG grant. Two of the three classes report annual improvement in performance as a result of their focused efforts. A fully functioning system would receive a score of 100%; by the third year of the grant, grantees report performance between 68-100%. It is noted, however, that the results of the 2010 CSHCN National Survey which reports the experience of the end user of the system of services – children with special health care needs and their families - rated transition services at 40% out of 100%.

**Figure 6.**



\* Please Note: PM changed - PM 37 expanded from 3 to 13 questions. Effective 2010.

Successful strategies for promoting transition services include:

### *Advance Transition Services through Policies and Programs*

- Train Medical Providers in Transition Care: District of Columbia (2011)** through The National Alliance to Advance Adolescent Health, worked with five academic medical institutions' departments of pediatrics (3), internal medicine (2), and family medicine (1) to incorporate into their pediatric and adult clinical processes the "Six Core Elements of Health Care Transition," developed by Got Transition. These include 1) a transition policy, 2) a registry to identify youth with special health care needs and monitor transition progress, 3) a transition readiness assessment to review self-care skills, 4) transition plan of care, which address transition needs and gaps and includes a portable medical summary and emergency care plan, if needed, 5) transfer of care, which involves communication between pediatric and adult practices and preparation of the transfer package, and 6) transition completion, which confirms completed transfer and, if needed, available pediatric consultation. At each site a lead physician, care coordinator, and consumer (parent or young adult) received intensive training and coaching support as a part of this quality improvement initiative. Each site measured its progress in implementing the core elements for transition using Got Transition's Health Care Transition Indices. In addition, each site was actively involved in spreading transition quality improvements in their academic institutions through grand rounds training, residency training, and including the core elements of transition as part of their electronic health record systems. The experience and sample tools from DC's Transition Learning Collaborative were shared on the Got Transition website and at state and national meetings.

- **Reimburse Transition Services: Pennsylvania (2011)** successfully worked with the Pennsylvania Department of Public Welfare Office of Medical Assistance Programs to develop and issue an operations memo that provides a bridge from pediatric to adult care for families. The Medicaid Managed Care Operations Memo (MC OPS) allows adult physicians to be paid for three visits as a medical consultant while the youth is still capitated to the pediatric practice. The three paid medical visits helps families make sure the match with the physician is satisfactory and to exchange medical information or a medical visit with three separate adult practices to determine which practice meets their needs.

### *Prepare Families and Youth for Youth Transition to Independence*

- **Involve Stakeholders in Transition Planning: Pennsylvania (2011)** established a Transition Learning Collaborative (TLC) comprised of 32 public and professionals, youth and parents involved in transition planning. The TLC hosted forums where families, CYSCHN and providers engaged in discussion towards improving the process of transitioning from high school to adulthood for families, and infusing health care issues into the annual statewide Transition Conference. To address these goals, TLC established four work groups: Resource Identification; Integration of Disciplines from Transition; Medical Provider Issues; and Youth Wellness and Self-advocacy. The TLC produced a number of resources including a *Welcome to Transition* primer for families and a resource list for youth, parents and health care providers on transition information and services. <http://www.pealcenter.org/leadershipdevelopment/youth.html>
- **Engage Youth in Promoting Independence: Utah (2008)** engaged youth adults in speaking out about their experiences as they took responsibility for their health care in terms of scheduling appointments and asking their provider questions. A video was made with the youths' comments and is available on YouTube: <http://www.youtube.com/watch?v=RJVgU7aGUZw> . In follow-up, Utah developed a Youth Leadership Toolkit which includes videos of young adults sharing their hints and tips for other youth and young adults on a range of topics. [http://blt.cpd.usu.edu/Leadership\\_Toolkit.html](http://blt.cpd.usu.edu/Leadership_Toolkit.html).



## Lessons Learned

How states managed data, information and in turn the increased understanding and knowledge of systems improvement and integration positioned them for sustainability. Those that exercised knowledge management—shared and communicated data and information systematically with diverse stakeholders including families, made data informed decisions, and monitored processes—were more likely to utilize the *State Implementation Grants for Integrated Community Systems for Children with Special Health Needs (SIG)* as a catalyst for securing future funding; a lever for capitalizing on opportunities; and a diffuser for spreading innovation. For public health, knowledge management can provide an effective and efficient way of organizing what is known and then applying this in a variety of capacities to improve public health services.<sup>13</sup>

**Catalyst:** Based on evaluation findings, results of quality improvement initiatives or the garnering of stakeholder support, several grantees were able to use the SIG as a springboard to secure additional funding that enabled them to further their work.

**Lever:** Since the first graduating class of 2008, it was immediately recognized that establishing a partnership with Title V, the local chapter of the American Academy of Pediatrics (AAP), state Medicaid and families was critical to the continued progress and success of project activities. And, the potential of this partnership improves exponentially if it is broadened to include other key stakeholders such as education and provider champions. Grantees noted during follow-up conference calls that it is of the utmost importance to include all organizations at the same table for collaboration at the time of grant funding, and beyond. SIG provided an opportunity for state CYSHCN programs to establish a presence amongst key stakeholders. The SIG program can help build long-term credibility related to improving the systems of services for CYSHCN which can be vital in receiving ongoing supplemental funding and involvement in relevant work.

**Diffuser:** Data (qualitative and quantitative) helped demonstrate impact and identify promising strategies for systems change. States were effective when they shared data informing policy and practice. Data were also used to document and communicate the experiences of families, who are significant contributors to systems change.

Through SIG, grantees who have sustained or grown their work have done so through knowledge partnerships—“associations and networks of individuals or organizations that share a purpose or goal and whose members contribute knowledge, experience, resources, and connections, and participate in two-way communications. These partnerships thrive when there is a strategic, structural, and cultural fit, and when members embrace a collaborative process, behave as a coherent entity, and engage in joint decision making and action.”<sup>14</sup> And central to these entities is the ability to utilize and share data, opening up opportunities for organizations to gain knowledge and leverage strengths.



<sup>13</sup> Association of State and Territorial Health Officials. Knowledge Management for Public Health Professionals, January 2005 [www.StatePublicHealth.org](http://www.StatePublicHealth.org)

<sup>14</sup> Asian Development Bank. Guidelines for knowledge partnerships. Mandaluyong City, Philippines: Asian Development Bank, 2011 <http://www.adb.org/sites/default/files/pub/2011/guidelines-knowledge-partnerships.pdf>

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