

Building a System of Care for Children With Special Healthcare Needs

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This article describes current efforts to (a) define best practices and desired systems-level outcomes for a system of care for Children with Special Health Care Needs (CSHCN) and their families; (b) describe the interconnections between Part C early intervention programs and those for CSHCN; and (c) develop measuring and monitoring strategies for implementing a state-level system for all CSHCN. The importance of working in partnership with states and family representatives with respect to defining, measuring, and monitoring progress toward a system of care will be illustrated through a description of a federally funded Participatory Action Research project. Results of the project include the development of national indicators for the 6 performance measures to guide states in their efforts to achieve a system of care. **Key words:** *children with special needs, measuring indicators, system of care*

RECENT studies (eg, Newacheck, Hung, Hochstein, & Halfon, 2002; Newacheck et al., 1998; van Dyck et al., 2002) have suggested that as many as 15% of children within the birth-to-5 age range (increasing to about 18% of children birth through 18) meet the new federal definition of children with special healthcare needs (CSHCN). "Children with special healthcare needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 139). This definition, developed through a consensus process led by the federal Maternal and Child Health Bureau's (MCHB) Division of Services for Children with Special Health Care Needs (DSCSHCN),

has been instrumental in spawning significant progress in a number of areas for this population such as research, advocacy, and systems/policy development. This definition focuses on services needed for children rather than the diagnostic characteristics of children. In doing so, it leaps over jurisdictional issues and defines health risk more broadly based on the concept of inclusion rather than exclusion. It recognizes the connectivity among physical conditions, developmental processes, emotional well-being, and behavioral expression of each of these constructs that goes well beyond the traditional medical model of health (McPherson et al.). Young children who meet this definition most typically receive services and supports from multiple facets of a system of care. A system of care as defined by Stroul and Friedman (1986) is a "comprehensive spectrum of . . . health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and their families" (p. 3). For young children with special health needs, examples of the components of a system include families' homes, community medical and mental health

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clinics, pediatric practices, early intervention programs, Early and regular Head Start, regular daycare settings, preschools, and the local public school.

How do we know whether there is an effective system of care for CSHCN in place? Will we know it when we see it in action? What constitutes best practice in such a system and how would it be measured and monitored as part of an ongoing quality-improvement effort? Given the inclusive nature of this broadly defined population, strong partnerships in systems building and monitoring efforts among all the service system components are necessary. This article provides a brief history of the efforts that have led to the definition of a system of care for CSHCN. Next, it highlights the relationship between state Title V CSHCN programs and Part C to illustrate some of the challenges families face in connecting with services in a largely fragmented service system. Finally, it briefly describes a process developed to measure and monitor a system of care for these children and their families.

DEFINING BEST PRACTICE THROUGH PERFORMANCE MEASURES

Over the past 2 decades, the federal DC-SHCN has led a national coalition-building process to develop consensus on the required components of a system of care as well as to begin the process of ensuring that the supports and services families need are available and in place for all eligible children. Taken as a whole, these measures identify the attributes of a system of care for CSHCN and their families (McPherson et al., 1998) and include the following:

1. Families of CSHCN will partner in decision making at all levels and will be satisfied with the services they receive.
2. All CSHCN will receive coordinated ongoing comprehensive care within a medical home.
3. All families of CSHCN will have adequate private and/or public insurance to pay for the services they need.
4. All children will be screened early and continuously for special healthcare needs.
5. Community-based service systems will be organized so that families can use them easily.
6. All youth with special healthcare needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult healthcare, work, and independence.

With the possible exception of measure 6 pertaining to transition to adult life, these measures equally apply to children with special health needs and those being served through the Individuals with Disabilities Education Act's (IDEA) Part C and B (619) programs.

The history leading to the agreement on these 6 performance measures stretches over several decades. Likewise, changes in the healthcare system, IDEA, Welfare Reform, Child Care legislation, Children's Health Insurance Program (CHIP), and Early Head Start have all continued to modify and refine important components of the service system. Although new legislation adds urgency to the task, the most recent efforts to define a system of care go back at least to 1987 with Surgeon General Koop's call to action for a system of care for CSHCN and their families. Hutchins and McPherson (1991) described the necessary components of a system of care and support for young children with special needs and their families that serve as the precursors for the 6 performance measures that define a system of care today. Increasingly since that time, the US Maternal and Child Health Bureau's DCSHCN has focused its resources at the federal level to ensure that such a system is in place by the year 2010.

The mandate to develop measuring and monitoring strategies for a system of care for this population of children is derived from several sources. Healthy People 2000 (now 2010) (Gamm, Hutchinson, Dadney, & Dorsey, 2003) serves as the blueprint through which the US health goals and objectives are being described and achieved. Objective

16.23 in Healthy People 2010 states that by the year 2010 we will, “increase the proportion of territories and states that have service systems for children with special needs.” The 6 performance measures are now incorporated into the state data reporting systems for the MCHB Title V block grant report and as indicators for HP 2010 Objective 16.23. In addition, 2 major pieces of legislation passed into law recently by Congress further define the mandate for such a system. The *New Freedom Initiative* amended by President Bush in 2001 describes the current agenda for systems of care and support for “Americans with disabilities by increasing access to assistive technologies, expanding educational opportunities, increasing the ability of Americans with disabilities to integrate into the workforce, and promoting increased access into daily community life” (prologue to the Act). In addition, one part of the education reform package entitled “*No Child Left Behind*” (2001) addresses the educational supports required for children with disabilities and special health needs to be successful in school. Together, these 3 federal initiatives serve as the legislative and administrative mandate for systems development in this arena.

Systems of care for whom?

Ideally, one of the cornerstones of an integrated system of care would be the assurance that families at all economic, educational, and risk levels received the supports needed for young children (eg, Kagan, Goffin, & Pritchard, 1995; Roberts, 1999). A safety net provided for families through a well-integrated system would ensure ade-

quate preventative and proactive safeguards for families in all areas of child health and development. A fully integrated, comprehensive system does not exist currently in the United States, though certain legislative mandates have begun to pave the way for specific age groups and risk conditions. Part C of IDEA is one such example for young children birth to 3 years of age. Although IDEA has been mandated legislatively since 1985, wide variability in Part C exists across the United States with respect to which children qualify and what services or supports are provided under its mandate at the state and local levels. Roberts, Innocenti, and Goetze (1999) developed a continuum that depicted different statewide approaches to the implementation of Part C of IDEA. Was Part C a stand-alone system for a particular population of children; or was it a part of a larger system of care for all children, some of whom had more obvious developmental risk conditions than did others? The same questions can be asked in describing a system of care for CSHCN and their families. The development and description of a system of care for any group has many parallels, not the least of which is the overlapping definitions for these populations of children and families who may be eligible in each of the 2 programs. The concepts described in the continuum below (Fig 1) are equally germane to both populations.

As depicted in the continuum in Figure 1, the left side of the continuum represents the most restrictive conceptualization of a state system—a set of specific services are provided by agencies or private providers with little or no coordination. In the center of

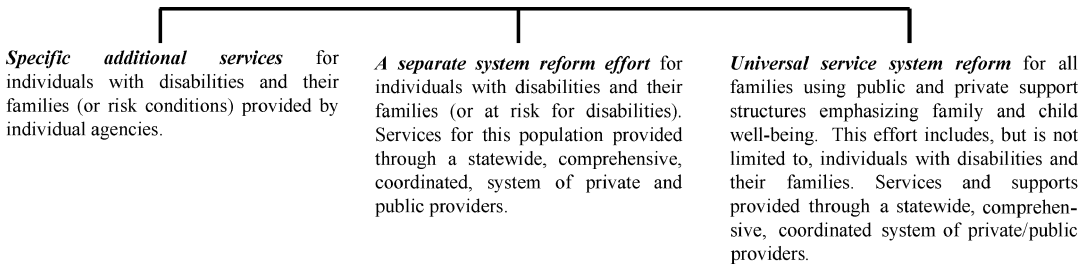


Figure 1. Continuum of services for children and their families in high-risk conditions.

the continuum, a separate, comprehensive, statewide, coordinated system of care and support is provided for CSHCN and their families through a system of private and public providers. On the right, a more universal system is envisioned in which all children, including CSHCN, receive services through a statewide comprehensive coordinated system of private and public providers. A CSHCN system defined through the 6 performance measures falls between the middle and the right-hand side of this continuum. That is, some measures reflect aspects of systems of care and support for all children, while others are directed specifically to those with special healthcare needs. Interestingly, it is not the content of each performance measure that defines the need for it to be limited to a particular population of children and families. Rather, the parameters defining the population along the continuum are more a matter of legislative authority than family and child need. For example, the need for adequate insurance and ongoing, coordinated, pediatric care within the context of a medical home concerns all children as well as those with special healthcare needs. At present, 13.5% of all children in the United States are without health insurance. This does not address the adequacy of coverage but only if it is present to some degree. (Newacheck et al., 1998)

This systems-building continuum and the questions it poses for systems development can be applied to almost every national service program for children and families in the United States (Roberts & Magrab, 1999). Although the specific populations of interest may differ, the issues in systems building do not. Historically, this situation exists because the United States has built its social safety net one advocacy group at a time, in many cases limiting the role of government to payer and insurer of last resort (Farrow, 1994). Historically, the one exception has been education because all children, independent of condition or circumstance, have the same right to a free and appropriate public education. In all other areas of support, services are not an entitlement in the same way

that education is a right. For instance, children have no right to ongoing healthcare, adequate housing, and safe neighborhoods. Much has been written about how the lack of a unified system for families has resulted in a set of fragmented services and supports provided through a patchwork of programs, policies, funding streams, and eligibility requirements that vary from state to state and community to community (cf., Kagan et al., 1995; Roberts & Magrab, 1999; Roberts, Rule, & Innocenti, 1998). Direct implications, both for systems building and measurement efforts in achieving a more universal, integrated, family-centered and user-friendly child/family support system, can be measured in cost, family hassle factors, and the achievement of outcomes concerned with family and child well-being. Roberts et al. have described the consequences of this model of social, health, and educational support to families representing the differences between the US system and more universal models through the following diagram (Fig 2). Over time in the United States, the base of services and supports for families with young children has increased (eg, SCHIP, TANF, Early Head Start, Child Care subsidies). As a consequence, the 2 models depicted in Figure 2 have moved closer together as the US federally supported base of services has grown. A recent article appearing in the *Journal of the American Medical Association* (Physicians' Working Group, 2003) advocates for a common 1-payer insurance system across the United States for all Americans. Such an initiative would be a major step toward a more integrated system, as funding is such a huge component of eligibility requirements for entitlement programs.

How does the administrative relationship between Part C and CSHCN programs affect state systems of care?

Two systems that have a direct impact on outcomes for infants and young children with developmental and health challenges are the state Title V CSHCN programs and Part C of IDEA, commonly known as *early intervention*. The issues discussed above affect both the Part C and CSHCN programs in all states

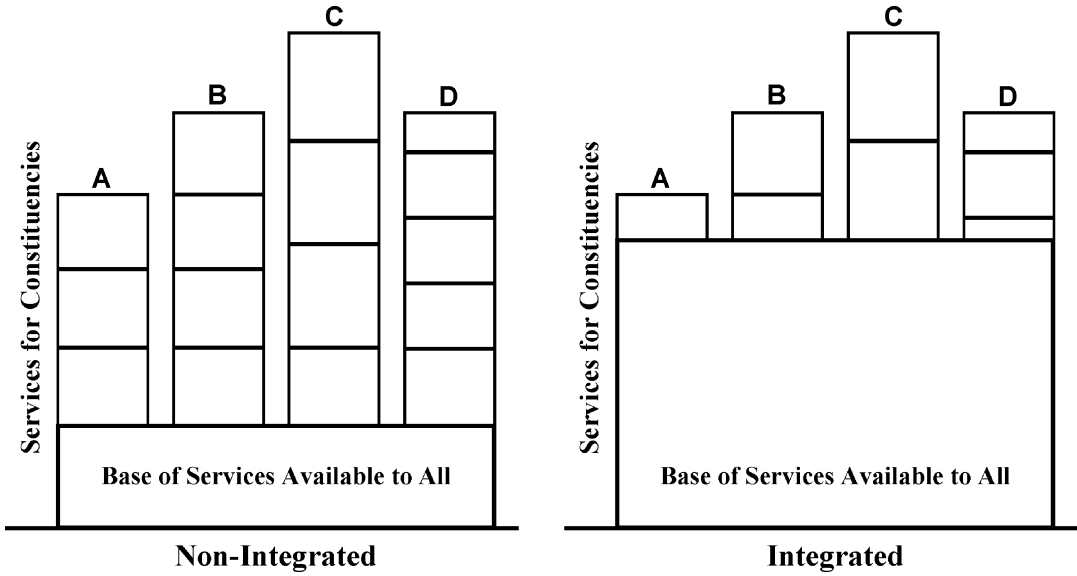


Figure 2. Integrated vs nonintegrated models of service delivery.

as they continue to refine issues such as the population served, services provided, funding mechanisms to pay for needed services, and monitoring continuous quality improvement (CQI) processes. Even though the majority of children who qualify for Part C services also meet the broader definition of CSHCN, the 2 programs operate independently in most states.

State and federal programs are challenged with the complexity of defining the system, specifying systems-level outcomes, developing monitoring strategies/appropriate data sources, and tracing funding streams. As many CSHCN/Part C children and their families receive services from multiple agencies, the complexity of these challenges to the states continues to grow. For example, at the federal level, the Part C program receives its legislative mandate, funding, regulations, and monitoring through the US Department of Education; while state Title V CSHCN programs' federal authority comes through the US Maternal and Child Health Bureau, Centers for Disease Control, and Center for Medicare and Medicaid Services. Nearly 50% of states house the Part C program within the State Department of Health (DOH)—often within the Title V CSHCN program. In other states, the

legislative authority, funding streams, and administrative structure may lie within other state departments where neither education nor health may be responsible for one or more of these programs (eg, mental health). Even so, the state and local community-level inter-agency coordinating councils for the Part C program are composed of representatives of multiple private and public programs as well as families of children being served. These councils address many policies, such as care coordination, insurance, family involvement in decision making, and access to a medical home, which affect both CSHCN and Part C-eligible children.

These multiagency administrative structures demonstrate why it is no small endeavor to develop and maintain a system of care for CSHCN, including Part C-eligible children, which assures access to appropriate services across programs for those who meet the eligibility requirements. These programs cover a sizeable number of children and involve multiple providers, funding models, and constituencies in the public and private sectors. Policymakers, program staff, and families need a road map to understand the dual systems and ensure that children and their families receive the services and supports most

appropriate for the child's needs. A road map of an integrated system of care would define the available resources and support for families using these services. To be useful at the planning, implementation, and monitoring levels, such a road map would also need a way to measure current status of programs toward specified outcomes as well as ways to monitor progress over time. Interagency attempts to coordinate outcomes to be achieved across federal agencies are still very much in their infancy. The complexity of this challenge was recently illustrated by a report commissioned by the Federal Interagency Coordinating Council (FICC). The Government Performance and Results Act (GPRA; 1993) requires each federal program to specify outcomes to be achieved and benchmarks to assess progress toward that end. Outcomes for each of the FICC partner agencies were compared to determine the degree of overlap and coordination (Roberts & Hunt, 2001). Little collaboration or coordination was evident within the GPRA outcomes to support the desired integrated system of care described earlier in this article.

Although all states serve some young children with special needs under the age of 3 through state-operated Part C and CSHCN programs (eg, specialty services through state-operated specialty clinics), data clearly suggest that many more children qualify for either program than are currently being served through the state-sponsored programs alone (cf., Newacheck et al., 1998).

As both Part C and CSHCN programs continue their systems-building efforts, the need for these activities to be coordinated is paramount in order for a more integrated system to emerge. Nowhere is this more important than for families who are trying to access the services their children need. At the present time, families gaining proficiency in learning the system in one state find that it is a skill not transportable across state lines—the state-specific nuances require families to begin their learning process all over again. In a recent study of the Part C program in Utah, fully 7% of families moved out of state during the time their children were enrolled in Part

C (Roberts et al., 1999). The emerging field of infant mental health services is another example of the need for Part C and CSHCN programs to collaborate so that new programs in this area are designed in ways that allow for easy access by families regardless of the agency with which they may be working.

What principles underlie successful systems-building efforts?

Independent of where a particular system falls along the continuum (see Fig 1) and which of the 6 performance measures is being addressed, we and others have found that systems best meet the needs of their intended audience to the degree that they share a common set of underlying principles that define *how* they will do *what* they do (eg, Roberts & Magrab, 1999; Roberts, Behl, & Akers, 2003). The 6 principles are the following:

Families are better able to achieve optimal outcomes when there is a system of supports available to them that is at the same time

1. responsive to family challenges, priorities, and strengths;
2. developed in partnership with constituents;
3. reflective and respectful of the cultural norms and practices of the families participating;
4. accessible to everyone;
5. affordable to those who need assistance; and
6. organized and coordinated through collaboration so that resources are equitably distributed in an efficient and effective manner.

These principles share many common themes with the 6 performance measures elaborated for CSHCN and from the organizing framework for guiding the applied research in measuring and monitoring strategies described below.

Principles in action in the measuring and monitoring process

As we have described throughout this article, CSHCN are served through a number of different private and public agencies. Each of

these agencies develops its own requirements governing how and what client-level data are collected for monitoring and/or quality improvement purposes. Each agency, office, or program knows some things about a given child but usually there is no central agency that has the complete picture. Data warehousing activities are still relatively rare in which all of the data collected across programs for each child using some form of common identifier is housed in a single location (Roberts et al., 2003). The questions asked earlier (how would we know if a system was working? and, what changes are needed to improve it?) become increasingly more complex as multiple agencies are involved in reporting services and outcomes for this population. Measuring and Monitoring Community-Based Systems of Care for Children with Special Health Needs (M&M), a project funded by DSCHSN and awarded to the Early Intervention Research Institute, addressed these 2 questions in a very systematic manner using many of the principles listed above to guide this research.

Over the course of a 5-year period, M&M collaborated with up to 10 states to (a) develop operational definitions (or indicators) of the CSHCN goals; (b) identify current measurement strategies and data sources available within national, state, and local systems to measure progress; and (c) create new mea-

surement strategies for reporting on the status of the broader population of CSHCN. The 6 original states collaborated on at least steps a and b while 4 new states have worked specifically on step c alone.

The M&M Project used a participatory action research (PAR) methodology to engage state CSHCN programs and their partners in developing the indicators through which the 6 performance measures (see page 5 for listing) could be operationalized in such a manner that they might be measured using state data systems to gauge progress (see Table 1 for examples of indicators). PAR is a specific form of action research defined as a “participatory democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes” (Reason & Bradbury, 2001, p. 1). PAR is related to community action research, which “rests on a basic pattern of interdependency, the continuing cycle linking research, capacity building and practice: the ongoing creation of new theory, tools and practical know how” (Senge & Scharmer, 2001, p. 248). The purpose of using a PAR methodology is to foster “relationships and collaboration among diverse organizations and among the consultants and researchers working with them; creating settings for collective reflection that enable people from diverse organizations to see themselves in one another; and leveraging

Table 1. Example of state-level indicators used to measure progress on CSHCN performance measures

<p>Performance measure #2: All children with special healthcare needs will receive coordinated ongoing comprehensive care within a medical home</p> <ol style="list-style-type: none"> 1. % of CSHCN with a regular source of primary medical care through a primary care provider 2. % of CSHCN whose regular source of care communicates in a way that is clear and understandable to the family 3. % of parents whose regular source of primary medical care identifies, discusses, and addresses the comprehensive needs of their child and family 4. % of CSHCN whose regular source of primary medical care ensure age-appropriate well-child check, including vision, hearing, developmental, behavioral/mental health, oral health, newborn screening, immunizations 5. % of parents of CSHCN who receive referrals and assistance from their regular source of primary medical care in accessing needed/desired services
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progress in individual organizations through cross-institutional links so as to sustain transformative changes that otherwise would die out" (Senge & Scharmer, p. 238). As such, PAR is particularly well suited to the task of developing a measuring and monitoring system for states because of its democratic principles in which each voice at the table counts.

How did PAR work in the M&M states with respect to the 6 principles of care?

In each state, the CSHCN program assumed a leadership role and agreed to work closely with the M&M staff in implementing the project locally. A team of people representing 3 distinct constituent groups was organized consisting of parents, private and public service providers, and state program leadership/data management staff—particularly early intervention. At a minimum, state and local representation from the following agencies was requested: Health, Education, Vocational Rehabilitation, Disability, and Medicaid and Family Advocacy groups. By using this model, PAR teams represented the constituencies that needed to be involved in the planning and program development effort. At the same time, it fostered the development of new partnerships among constituents, while being responsive to family priorities, strengths, and challenges. M&M encouraged parent participation by soliciting nominations for parents from a wide variety of parent groups in each state and ensuring that parent out-of-pocket expenses and mileage were reimbursed for their participation. Family members played an active role in developing the indicators for the performance measures as well as in developing measurement strategies.

A feature of the M&M Project's PAR process included a set of agreed-upon rules that facilitated the development of this good will in what had the potential for being a divisive rather than a unifying experience. The primary rule in every PAR discussion in the individual and combined state meetings stated, "Everyone in the room is right from his or her own perspective." Group discussions produced a melding of these perspectives into

a greater understanding of the issues among the participants so that the final set of indicators reflected the common experience and the greater understanding of all.

This model allowed each member to be heard. In doing so, it challenged the group to understand why any given issue was so important to any one or set of individuals. M&M staff, as the facilitators of the group discussions, modeled this behavior and ensured that it became the group norm over time.

It was in this venue that the strength created through the diversity of the teams became apparent. Parents needed to hear the perspectives of providers and state employees, understanding the fiscal constraints that can tie the hands of providers. Likewise, providers needed to listen carefully to the passionate perspectives of family members on the good and bad experiences they have had with the service system. Everyone heard and had the opportunity to respond to the perspectives of the measurement experts with respect to the question, "How can we formulate indicators in ways that are measurable and comprehensive?" The participation of representatives of each of the stakeholder groups ensured that the resulting set of indicators had high face, content, and ecological validity. The indicators were created in the cauldron of the discussions of all of the constituent groups and tested by the fire of the participant process.

The M&M indicators were developed through a consensus process, which, by its very nature, was a political one. The positive side of this process was that the indicators had high face validity with the target groups. That is, family members, service providers, and representatives of various state governmental agencies were part of the developmental process. On the other hand, each constituent group had a particular perspective with respect to components of the indicators that were particularly important to them. For example, early intervention representatives were especially committed to ensuring children were screened early (performance measure #4) and continuously as well as

supporting coordination so services can be used easily (performance measure #5). The end result was a compromise capturing those nonnegotiable components of the indicator for each of these groups. The point of the process was to start with the premise that it was important to define the attributes of each goal. How would a state, a pediatric practice, or a family know if they had a medical home? How would states monitor their progress to ensure that services and supports were organized in ways that families can use them easily? Thus the indicators gave flesh to the skeleton of the performance measures themselves and helped to define the construct that was represented in each of the 6 performance measures. After these constructs had been agreed upon by the M&M states, the next task was to discover the degree to which data existed to develop a baseline in monitoring progress for each indicator (Roberts et al., 2003).

State PAR teams encountered the difficulties inherent in describing, measuring, and monitoring a system of care for a population of children and families who interact daily with multiple public and private care providers. Multiple agencies provide a prescribed set of services or supports as well as data with respect to child progress and system efficacy. States have multiple examples of how they are approaching data collection from data warehousing models to inter-agency data teams. The requirements of ensuring compliance with HIPPA have added an additional level of complexity to the issue of data sharing for the purpose of systems monitoring. At the federal level, state CSHCN programs are now required to organize their state

plans and report on progress in systems development in their state Title V Block grant applications through the use of the 6 performance measures. The framework for this process and the results obtained thus far are contained in other work (Roberts et al., 2003).

It has only been very recently (January 2003) that states have had access to state-level data gathered and summarized through the National Survey of CSHCN families (Newacheck et al., 2002). Given the variables that drove the National Survey (including cost), the number of questions addressing any 1 of the 6 performance measures was limited. Although availability of national data is a major accomplishment that now enables states to have comparable data at the state and national levels, it does not replace the rich information already potentially available at the state level housed in the various agency silos. The lack of a comprehensive, integrated systems of care for children with special health needs highlights the problems faced by states in their mandates to measure and monitor child quality-of-life indicators in each domain. Children do not live in silos or domains. The challenges, adventures, and milestones that they and their families face are rarely agency or discipline specific. The federal DCSHN, through the M&M project, has taken important steps in beginning to define the scope of the issues involved in using data as part of an ongoing system change effort in all 59 states and territories. To paraphrase the astronauts on the Eagle as it landed on the moon, *one small step for measuring, one big paradigm change in creating a system of care for children with special needs and their families.*

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