

Implementing Community-Based Systems of Services for Children and Youths With Special Health Care Needs: How Well Are We Doing?

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ABSTRACT. *Objective.* To provide a baseline measure of the proportion of US children who meet the Maternal and Child Health Bureau's core outcomes for children with special health care needs (CSHCN). Those core outcomes include the following: 1) families of CSHCN will partner in decision making and will be satisfied with the services that they receive; 2) CSHCN will receive coordinated, ongoing comprehensive care within a medical home; 3) families of CSHCN will have adequate private and/or public insurance to pay for the services that they need; 4) children will be screened early and continuously for special health care needs; 5) community-based service systems will be organized so that families can use them easily; and 6) youths with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.

Methods. A national household survey was conducted using telephone interviews. We analyzed data on 38 866 CSHCN included in the 2001 National Survey of CSHCN and 13 579 children included in the 2001 National Health Interview Survey. We assessed the proportion of US children who met each of the 6 core outcomes for CSHCN using data from 2 surveys.

Results. Success rates ranged from 6% (the core outcome on successful transition to adulthood) to 74% (the core outcome on organization of the service system). For 5 of the 6 core outcomes, success rates exceeded 50%.

Conclusion. Our results indicate that, for the most part, the United States is well positioned to meet the 6 core outcomes. However, much more work lies ahead before success can be claimed. This is especially true for the core outcome on transition to adulthood, for which only 6% of children in the target population are now meeting this goal. *Pediatrics* 2004;113:1538–1544; children with special health care needs, children, chronic illness, access, insurance, medical home.

ABBREVIATIONS. CSHCN, children with special health care needs; DHHS, Department of Health and Human Services; MCHB, Maternal and Child Health Bureau; National Survey of CSHCN, National Survey of Children With Special Health Care Needs; NSCH, National Survey of Children's Health; NHIS, Na-

tional Health Interview Survey; SLAITS, State and Local Area Integrated Telephone Survey; NIS, National Immunization Survey.

The release of findings from the first National Survey of Children With Special Health Care Needs marks an important milestone in our ability to measure, at the national and state levels, the implementation of community-based systems of services for children with special health care needs (CSHCN).¹ The conceptualization and development of those systems has a long history, spanning almost 3 decades.^{2,3} Thirty years ago, the term "children with special health care needs" was not even part of our vocabulary. Instead, states had "crippled children's" programs, and the children whom they served were seen for diagnosis and correction of defects. By the late 1970s, however, there was growing recognition of the need to change the way we cared for many of our nation's most vulnerable children. For some families, particularly those whose children had serious or complex medical, emotional, or behavioral conditions, the only care available or covered by insurance was hospital-based or institutional. This meant that many children could not live at home with their families and in their communities. Even families with less severely affected children struggled to find the services that they needed. Caregivers and policy makers overlooked that families often knew the most about caring for their children.

To bring national attention to these issues, in 1982, the US Department of Health and Human Services (DHHS) convened a Workshop on Children With Handicaps and Their Families. The Surgeon General spoke of "our continuing interest in assisting the family as the prime source of nurture, support, protection, and guidance to the growing child."⁴ The workshop developed a number of major recommendations for action, which policy makers at the federal and state levels, families, service providers, and professional organizations began to address during the next several years. Many state crippled children's services programs that originally served mainly children with orthopedic impairments broadened their focus to include children with other physical disabilities, sensory impairment, developmental disabilities, and chronic physical illnesses. The focus of care also shifted, from care for the defect to care for the child and, finally, to care for the family. There was growing recognition that care was best delivered

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through a comprehensive, coordinated, multidisciplinary, and multiagency approach centered on the child, family, and community.²

In June 1987, the Surgeon General issued another report, titled *Campaign '87—Commitment to Family-Centered, Coordinated Care for Children With Special Health Care Needs*, which he characterized as a “call to action.”⁵ In response to this call to action, parents and other family members; health professionals; financing experts; partners in school and social service agencies; and local, state, and federal governments came together to develop a national agenda for CSHCN. The agenda delineated the elements of an ideal services system. It charged communities with major responsibility for planning, designing, and implementing these systems and state governments with the responsibility for assisting them to do so.⁶ Families and >70 professional organizations signed on to this agenda, which was formally unveiled at a second Surgeon General’s conference, Campaign ‘88. Campaign ‘88 focused on defining ways to organize community systems of services around the principles of family-centered, comprehensive, coordinated, and culturally competent care.²

In 1989, a major step forward occurred as the national agenda was incorporated into federal legislation. Under the Omnibus Budget Reconciliation Act of 1989, new language for Title V of the Social Security Act directed the states to “provide and . . . promote family-centered, community-based, coordinated care . . . for children with special health care needs and . . . facilitate the development of community-based systems of services for such children and their families.” In 1990, the federal government put forward *Healthy People 2000*, which called for all states to put these comprehensive systems in place by the year 2000.⁷

During the intervening years, work on the national agenda has moved forward on a number of fronts. A new definition of the population was developed and disseminated by the DHHS’s Maternal and Child Health Bureau (MCHB).⁸ This definition includes children with chronic physical, developmental, behavioral, and emotional conditions that result in an increased need or use of health and related services. Moreover, every state has embarked on the implementation of community-based systems of care for their CSHCN. *Healthy People 2010* charged the states and territories with putting in place service systems for all CSHCN by 2010.⁹

To catalyze further the growth of community-based systems of services, MCHB articulated the following 6 core outcomes for measuring progress in putting these systems in place and is using these outcomes as performance measures for all state Title V programs.^{9–11}

1. Families of CSHCN will partner in decision making and will be satisfied with the services that they receive.
2. CSHCN will receive coordinated, ongoing, comprehensive care within a medical home.

3. Families of CSHCN will have adequate private and/or public insurance to pay for the services that they need.
4. Children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized so that families can use them easily.
6. Youths with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.

To measure progress in achieving the 6 core outcomes, the MCHB has developed a monitoring strategy that uses 2 new national surveys of children’s health: the National Survey of Children With Special Health Care Needs (National Survey of CSHCN) and the National Survey of Children’s Health (NSCH). The National Survey of CSHCN is designed to assess the prevalence and characteristics, including health care experiences, of noninstitutionalized CSHCN. The NSCH is designed to assess the health and health care experiences of the general noninstitutionalized child population. The National Survey of CSHCN is being used to measure 5 of the core outcomes; the NSCH will be used to measure 1 of the core outcomes.

The monitoring strategy is intended to provide a current or baseline assessment of each core outcome, a midpoint assessment, and a final assessment in 2010. The baseline assessment conducted in 2001 indicates how far the nation must go to reach 100% success in achieving each core outcome. The midpoint assessment, to be conducted in 2005 or 2006, will provide information on the degree of progress made on each core outcome, as well as an indication of where barriers may be occurring if progress is not robust. The final assessment will indicate the degree of overall success, as well as whether additional follow-up efforts are needed beyond 2010. The monitoring strategy presented here is unique in that it is based entirely on the experiences and perceptions of affected families and their children. Hence, it represents a family-centered approach to monitoring important public health goals. It assumes that families are in the best position to judge how well the health care system is working for their children.

This article reviews the development of the monitoring strategy and describes the analytic approach and the data sources used for evaluating success. Baseline results for the 6 core outcomes are also presented. Finally, the public health implications of the baseline results are discussed.

METHODS

Analytic Approach

The monitoring strategy establishes measurable criteria for judging success in attaining each core outcome and then applies those criteria to data from 1 of the national surveys as a means of assessing the percentage of children who meet that core outcome. With planned repetition of these surveys over the coming decade, there will be a basis for monitoring progress between now and 2010.

The measurement process involved 3 steps. First, each core outcome was disaggregated into its essential elements or under-

lying concepts. For example, the core outcome stating that “all children with special health care needs will receive coordinated ongoing comprehensive care within a medical home” was disaggregated into 5 essential elements or underlying concepts: 1) having a usual source of care, 2) having a personal doctor or nurse (ie, a health professional who knows well the child and his or her health history), 3) receiving all needed referrals for specialty care, 4) receiving help as needed in coordinating care within the health care system and outside the health care system (eg, in special education), and 5) receiving family-centered care.

Second, these essential elements or underlying concepts were translated into measurable criteria using items contained in either the National Survey of CSHCN or NSCH questionnaires. For example, the concept of family-centered care described previously was measured using 5 questionnaire items from the National Survey of CSHCN: 1) the family reports that the child’s doctors spend enough time with the child, 2) the doctors listen carefully to family concerns, 3) the child’s doctors are sensitive to family values and customs, 4) the child’s doctors provide needed information, and 5) the child’s doctors make the family feel like a partner in the child’s care. A similar process was used to operationalize each of the remaining essential elements or underlying concepts for the medical home objective. In total, 5 sets of criteria corresponding to the 5 essential elements or underlying concepts were developed for the medical home core outcome. To qualify as successfully achieving this core outcome, a child must meet all 5 criteria.

The third step involved creating estimates of the proportion of CSHCN who met each core outcome by applying the criteria to the national survey data. In the case of the medical home core outcome, the National Survey of CSHCN was used to estimate the proportion of CSHCN nationally who met the 5 sets of criteria, individually and collectively. The basic approach was to assume that all children in the sample met the medical home core outcome. Next, each child who did not meet 1 or more of the 5 criteria was subtracted from this total. A success rate was then calculated by dividing the number of children who remained by the total number of children with nonmissing data for all criteria. A similar estimation process was used for the other core outcomes. In each case, the results were statistically weighted to reflect population totals for noninstitutionalized children nationally and within each state.

One consequence of this strategy is that the proportion of CSHCN who meet an individual criterion can be lower than the proportion of CSHCN who meet the core outcome. This can occur if the criterion applied to only a few children (eg, few children may need care coordination) and if the criterion was rarely met for those children (eg, when received, coordination with service providers outside the health care system may be reported as less than “very good” or “excellent”). In this situation, the criterion may not be met for most children to which it applies, but because these children may be only a very small subgroup of the larger population, the results for this criterion reduce the overall proportion of children who meet the core outcome only slightly.

Some questions used to measure the core outcomes were added late in the survey. This was true for core outcomes 1, 5, and 6. Analyses of the proportion of CSHCN who met these 3 core outcomes excluded children who were interviewed before these questions were added. Consequently, a smaller number of valid cases were available for estimating the number of CSHCN who met these core outcomes. Analyses of the proportion of CSHCN who met each core outcome also excluded children with missing data for any criterion. Missing data could occur if the parent did not know the answer or the parent refused to provide the answer, but these types of missing data were relatively rare (see Table 1).

The National Survey of CSHCN and the NSCH are designed to produce state and national estimates. However, because the measurement of 3 of the core outcomes (1, 5, and 6) relies on survey questions that were added late in the data collection process, in some cases there are insufficient observations at the state level to permit baseline estimates with adequate statistical precision.

Data Sources

The 2 new national surveys of children are used to provide baseline information on each of the core outcomes. The MCHB sponsored both surveys, and they were conducted in partnership

with the National Center for Health Statistics of the Centers for Disease Control and Prevention.

The 2001 National Survey of CSHCN—which was conducted from October 2000 to April 2002—is used to estimate the proportion of CSHCN who meet the 5 core outcomes applicable to CSHCN.¹² It uses the CSHCN Screener to identify CSHCN; that screener is based on the MCHB definition of the population. This survey does not provide suitable data for monitoring the remaining core outcome: that all “children will be screened early and continuously for special health care needs.” This core outcome applies to all children, not just those with special health care needs. The 2003 NSCH will be used to monitor this core outcome because its sample frame includes all children. At the time of this writing, data from the NSCH were still being collected. Once the NSCH is complete and results are tabulated, a final baseline estimate will be created for this core outcome. For purposes of this article, however, data from the 2001 National Health Interview Survey (NHIS) are used to provide a preliminary estimate of the proportion of children who receive screenings for special needs.¹³

The National Survey of CSHCN and NSCH are list-assisted random-digit-dial telephone surveys administered to a representative sample of households in each of the 50 states and the District of Columbia. The State and Local Area Integrated Telephone Survey (SLAITS), conducted by the National Center for Health Statistics, was selected as the platform for both surveys. The SLAITS mechanism uses the same sampling frame as the National Immunization Survey (NIS). Sponsored by the Centers for Disease Control and Prevention’s National Immunization Program and National Center for Health Statistics, the NIS is an ongoing list-assisted random-digit-dial survey designed to monitor vaccination coverage levels among children 19 to 35 months of age in all 50 states and the District of Columbia. Approximately 1 million households are contacted and screened each year for the NIS. By using this large number of NIS-screened telephone numbers for its base, SLAITS has been able to economize on the cost of selecting and screening households. All households contacted for the NIS become potentially eligible for the National Survey of CSHCN and the NSCH, regardless of whether they are eligible for the NIS.

The parent or legal guardian who knows the most about the health and health care of the children in the household serves as the respondent for the interview. Follow-up telephone calls are made, if necessary, to contact this parent or guardian. Trained interviewers use computer-assisted telephone interviewing technology to conduct the interviews for both surveys.

Efforts to maximize the response rates to the surveys include the use of advance letters for households where a mailing address can be identified, multilingual interviewers for respondents who may choose to complete the interview in any 1 of 12 languages, toll-free callback numbers left on potential respondents’ answering machines, and calling strategies that attempt to reach households at times favorable for completing an interview. The response rate for the completion of the special-needs interviews in the 2001 National Survey of CSHCN was 61%. A total of 38 866 interviews concerning CSHCN who were younger than 18 years were completed in the National Survey of CSHCN. It is expected that the 2003 NSCH will include 102 000 children younger than 18 years nationally. The 2001 NHIS data used here for the preliminary estimates included 13 579 children from across the United States.

The National Survey of CSHCN and the NSCH survey questionnaires were designed with the intended purpose of serving as a tool for monitoring the core outcomes. However, the core outcomes were still under development when the National Survey of CSHCN questionnaire was being finalized. To ensure that the core outcomes could be measured properly, we added 4 additional questions to the 2001 National Survey of CSHCN during the latter half of data collection, as indicated previously. These added questions were fashioned after consultation with the original workgroups responsible for the development of the core outcomes.

RESULTS

Estimates of the proportion of children who met each goal, along with the effective sample sizes used in computing our estimates, are presented in Table 1. We also present estimates of the proportion of children who met the component criteria for each of the

TABLE 1. Estimated Proportion of Children Who Met the Core Outcomes: United States, 2001

Criteria	Valid Cases (CSHCN)*	Valid Cases (All Children)†	Cases With Missing Data ("Don't Know" or "Refused")	% Meeting Criteria
Core outcome 1: families of CSHCN will partner in decision making and will be satisfied with the services received				
1.1 Doctors usually or always made the family feel like a partner	14 766		246	84.3
1.2 Family was very satisfied with services received	15 490		86	60.1
Proportion meeting core outcome 1‡	15 254		322	57.5
Core outcome 2: CSHCN will receive coordinated ongoing comprehensive care within a medical home				
2.1 The child had a usual source of care	38 628		238	90.5
2.1a The child had a usual source for sick care	38 744		122	90.6
2.1b The child had a usual source for preventive care	38 737		129	98.8
2.2 The child had a personal doctor or nurse	38 711		155	89.0
2.3 The child had no problems obtaining referrals when needed	20 042		154	78.1
2.4 Effective care coordination was received when needed	4356		350	39.8
2.4a The child had professional care coordination when needed	4527		179	81.9
2.4b Doctors communicated well with each other (excellent/very good)	3710		237	54.4
2.4c Doctors communicated well with other programs (excellent/very good)	3196		260	37.1
2.5 The child received family-centered care	36 018		1444	66.8
2.5a Doctors usually or always spent enough time	36 799		663	83.6
2.5b Doctors usually or always listened carefully	36 872		590	88.1
2.5c Doctors usually or always were sensitive to values and customs	36 425		1037	86.9
2.5d Doctors usually or always provided needed information	36 734		728	81.0
2.5e Doctors usually or always made family feel like a partner	36 837		625	85.9
Proportion meeting core outcome 2	36 710		2156	52.6
Core outcome 3: families of CSHCN will have adequate public and/or private insurance to pay for the services that they need				
3.1 Child had public or private insurance at time of interview	38 866		0	94.8
3.2 Child had no gaps in coverage during year before the interview	38 781		85	88.4
3.3 Insurance usually or always met child's needs	36 618		311	85.5
3.4 Costs not covered by insurance were usually or always reasonable	35 794		1135	71.6
3.5 Insurance usually or always permitted child to see needed providers	36 706		223	87.8
Proportion meeting core outcome 3	37 388		1478	59.6
Core outcome 4: children will be screened early and continuously for special health care needs				
4.1 Child had at least 1 preventive medical visit in past year		13 472	107	71.0
4.2 Child had at least 1 dental visit in past year		12 659	113	69.4
Proportion meeting core outcome 4		13 385	194	51.6
Core outcome 5: community-based service systems will be organized so that families can use them easily				
5.1 Services were usually or always organized for easy use	15 310		266	74.3
Proportion meeting core outcome 5‡	15 310		266	74.3
Core outcome 6: youths with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence§				
6.1 Child has received guidance and support in transition to adulthood	5414		228	15.3
6.1a Doctors have talked about changing needs as child becomes adult	5533		109	50.0
6.1b Child has plan for addressing changing needs	2839		191	59.3
6.1c Doctors discussed shift to adult provider	2871		159	41.8
6.2 Child has received vocational or career training	5554		88	25.5
Proportion meeting core outcome 6‡	5351		291	5.8

* Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2001.

† Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Health Interview Survey, 2001.

‡ Estimates are based on data from National Survey of CSHCN interviews conducted after July 5, 2001.

§ Criteria are restricted to CSHCN 13 years of age and older.

core outcomes as a means for helping to identify where roadblocks exist in reaching higher levels of attainment of the core outcomes. Overall, 12.8% of children younger than 18 years, or 9.4 million nationally, were estimated to have a special health care need in 2001. These are children who have a chronic physical, developmental, behavioral, or emotional condition and have a functional limitation or require

health and health-related services beyond those of other children.

Core Outcome 1: Families of CSHCN Will Partner in Decision Making and Will Be Satisfied With the Services That They Receive

This core outcome focuses on the important role of the family in sharing decision making for their chil-

dren's health. The MCHB's goal is to ensure that all families of CSHCN have as much opportunity as possible to share in decisions about their child's care and that they are highly satisfied with the care that their child receives.

This goal was operationalized with 2 criteria presented in Table 1. An estimated 84.3% of CSHCN had doctors and nurses who usually or always made the family feel like a partner in the child's care; 60.1% of CSHCN resided in families that were very satisfied with the services that their child received. (Both of these estimates are based on data from interviews conducted after July 5, 2001, which was the date when the satisfaction question was added to the interview.) Taken together, results from the National Survey of CSHCN indicate that 57.5% of CSHCN nationally met both of these criteria and thus core outcome 1.

Core Outcome 2: CSHCN Will Receive Coordinated, Ongoing, Comprehensive Care Within a Medical Home

The concept of the medical home has rapidly gained attention in recent years. A medical home is an approach in which the care provided is accessible, continuous, comprehensive, compassionate, and culturally effective.¹⁴ 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. The MCHB's goal is to ensure that all CSHCN have a medical home by 2010.

The core outcome on medical home is operationalized by 5 criteria as shown in Table 1. First, an estimated 90.5% of CSHCN had a usual source of preventive care and sick care. Second, 89% of CSHCN are estimated to have had a personal doctor or nurse. Third, 78.1% of CSHCN who needed specialty care and needed referrals for such care were reported to have no problems in obtaining specialty care. Fourth, 39.8% of CSHCN received effective care coordination when needed. Fifth, 66.8% of CSHCN with at least 1 doctor visit in the year before the interview received family-centered care. All together, an estimated 52.6% of CSHCN nationally met the core outcome on medical homes.

Core Outcome 3: Families of CSHCN Will Have Adequate Private and/or Public Insurance to Pay for the Services That They Need

Health insurance plays a key role in removing financial barriers to care. The MCHB's goal is that all CSHCN have insurance. Furthermore, that insurance should be adequate to meet the child's service needs. The core outcome on health insurance was operationalized using 5 criteria that address presence and continuity of coverage, comprehensiveness of coverage, adequacy of financial protection, and choice of providers (Table 1).

First, 94.8% of CSHCN had coverage at the time of the interview. Second, 88.4% had coverage during the year before the interview and had no gaps in coverage during that time. Third, 85.5% of insured CSHCN had insurance that usually or always covered the services that the child needed. Fourth, the costs not covered by insurance were usually or al-

ways reasonable for 71.6% of insured CSHCN. Fifth, 87.8% of insured CSHCN had insurance that usually or always permitted them to see the providers that they needed. Overall, an estimated 59.6% of CSHCN met the core outcome on health insurance.

Core Outcome 4: Children Will Be Screened Early and Continuously for Special Health Care Needs

Primary and secondary prevention of chronic conditions and functional limitations is an important health objective. This core outcome is focused on early identification of conditions that may result in special health care needs. The reference population for this goal is all children, not just those with special health care needs.

This core outcome is operationalized by 2 criteria. First, all children should receive at least 1 preventive medical visit on an annual or more frequent basis. Second, all children should receive a preventive dental examination annually or more frequently. On the basis of data from the 2001 NHIS, 71% of children had at least 1 preventive medical visit in the year preceding the interview. An estimated 69.4% of children 12 months or older had a dentist visit during that year. Taken together, 51.6% of children met the core outcome on screening. It should be noted, however, that the estimated proportion of children with a dental visit was not limited to dental visits for routine or preventive care, which cannot be determined from the NHIS. The estimated proportion of children who met the core outcome on screening would likely be lower if the data for the dental component could be limited to preventive examinations.

Core Outcome 5: Community-Based Service Systems Will Be Organized So That Families Can Use Them Easily

One of the difficulties that families of CSHCN sometimes face is navigating the health care system to find the services needed by their children. Often services are fragmented and funded through a diverse set of programs, each with its own eligibility rules. Recognizing these challenges, the MCHB seeks to transform the service system for CSHCN to make services easily accessible.

This core outcome was operationalized with a single criterion: services should be organized for easy use from the perspective of families. On the basis of National Survey of CSHCN interviews conducted after July 5, 2001, 74.3% of CSHCN met this core outcome.

Core Outcome 6: Youths With Special Health Care Needs Will Receive the Services Necessary to Make Transitions to Adult Life, Including Adult Health Care, Work, and Independence

The transition to adulthood presents many challenges for CSHCN, especially those with significant impairments. The MCHB has designated successful transition to adult life as a key component of its objectives for 2010. Because transition issues apply to youths near the age of making the transition to adulthood, the reference population for this core outcome was restricted to CSHCN aged 13 years and older.

This core outcome is operationalized using 2 criteria as shown in Table 1. These criteria address the changing medical needs that accompany the transition to adulthood and the receipt of vocational or career training needed for employment as an adult. An estimated 15.3% of CSHCN who were 14 through 17 years of age received appropriate guidance and support in the medical aspects of the transition to adulthood. This estimate includes those teens whose doctors 1) have talked with them or their families about changing needs, 2) created a plan for addressing changing needs, and 3) discussed shifting to an adult health care professional. In addition, 25.5% of teens received at least some vocational or career training. Taken together, an estimated 5.8% of adolescents aged 13 to 17 years met this core outcome on transition to adulthood.

DISCUSSION

Our results indicate that, for the most part, the United States is well positioned to meet the 6 core outcomes. We are at the halfway point or beyond for 5 of the 6 core outcomes. Of course, much more work lies ahead before success can be claimed. This is especially true for the core outcome on transition to adulthood, for which only 6% of children in the target population are now meeting this goal.

The monitoring approach used here is family centered. That is, all of the results are based on family reports. This approach is unique and makes an important contribution to our thinking about how to monitor outcome measures that are principally focused on improving the service system for families. Nevertheless, MCHB recognizes that consumers are not the only source of information on all questions. Consequently, as the monitoring effort moves forward, the MCHB will assess progress in meeting the core outcomes from other perspectives as well, including those of health care professional organizations, service delivery agencies, and other organizations.

The importance of the core outcomes was underscored in 2002 by their incorporation into President Bush's New Freedom Initiative. On March 25, 2002, DHHS Secretary Tommy G. Thompson presented President George W. Bush with *Delivering on the Promise*, reports from 9 federal agencies outlining >400 specific solutions that the agencies can implement to support community living for the nearly 54 million Americans who live with disabilities.¹⁵ The DHHS report states that the "Maternal and Child Health Bureau will take the lead in developing and implementing a plan to achieve appropriate community-based services systems for children and youth with special health care needs and their families."

Implementation of the plan will require a strong public/private partnership and a concerted effort by federal and state programs that serve CSHCN, families, and health care professionals. At the federal level, the MCHB is providing financial support for a number of initiatives that underscore key aspects of the plan. These include direct support to state Title V programs in their efforts to move forward on full implementation of the 6 objectives and put in place a

system of universal, sustained services for all CSHCN in all states. The MCHB grants are supporting statewide implementation of family-to-family support programs, successful medical home models, and strategies for expanding insurance coverage and improving benefit packages, as well as strengthening the health care financing system. The MCHB is also funding the enhancement and integration of state newborn screening programs, in an attempt to better link metabolic and hearing screening with medical homes and family-to-family support. Other efforts are also under way, with MCHB support, to help states identify and implement successful models of service integration at the community level and to put comprehensive transition services in place for adolescents with special health care needs.

As an added impetus for action, the 6 core outcomes have been incorporated as performance measures for state Title V programs. State-level estimates of these performance measures¹⁶ are provided as benchmarks for gauging progress at the state level in achieving community-based systems of care. By incorporating the core outcomes as performance measures, a federal and state partnership has been created to achieve the plan. Partnerships have also been established with family advocacy groups (eg, Family Voices), the American Academy of Pediatrics, the March of Dimes, and multiple other partners to support key elements of the plan. It is through these private-public partnerships that an effective community-based system of care for all CSHCN is possible.

CONCLUSION

As a nation, the United States is on the threshold of solving an issue with which we have grappled for many years: how to ensure that all of our children, including those with special health care needs, and their families can receive the services that they need to live and flourish in their own communities. We have taken initial steps to ensure the implementation, in every state, of coordinated, comprehensive, family-centered, community-based service systems for children and youths with special health care needs. A national agenda has been developed and is now part of a major presidential initiative, legislation has been passed, family/public/private partnerships have been built, and national health goals have been articulated. Implementation efforts are under way at the community, state, and federal levels; core outcomes for the service system have been articulated; and a monitoring strategy to measure our success has been put in place. What is critically needed now is concerted action, by all of us, including public agencies, professional organizations, family leaders, private philanthropy, businesses, and many others, to finish the job and put universal, sustained services in place for these children—and for all children.

REFERENCES

1. Brewer EJ Jr, McPherson M, Magrab PR, Hutchins VL. Family-centered, community-based coordinated care for children with special health care needs. *Pediatrics*. 1989;83:1055-1060
2. Hutchins VL, McPherson M. National agenda for children with special health needs: social policy for the 1990s through the 21st century. *Am Psychol*. 1991;46:141-143

3. Narkewicz RM. Family-centered, community-based coordinated care for children with special needs. *Pediatrics*. 1989;83:1061
4. US Department of Health and Human Services. *Report of the Surgeon General's Workshop on Children With Handicaps and Their Families*. Washington, DC: US Department of Health and Human Services; 1982. DHHS Publication no. PHS-83-50194 Available at: profiles.nlm.nih.gov/NN/ListByDate.html. Accessed May 13, 2003
5. US Department of Health and Human Services. *Surgeon General's Report: Campaign 87—Commitment to Family-Centered, Coordinated Care for Children With Special Health Care Needs*. Washington, DC: US Department of Health and Human Services; 1987. DHHS Publication no. HRS/D/MC 87-2. Available at: profiles.nlm.nih.gov/NN/ListByDate.html. Accessed May 13, 2003
6. National Maternal and Child Health Resource Center. *A National Goal: Building Service Delivery Systems for Children With Special Health Care Needs and Their Families—Family-Centered, Community-Based Coordinated Care*. Iowa City, IA: National Maternal and Child Health Resource Center; 1989
7. US Department of Health and Human Services. *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*. Washington, DC: US Department of Health and Human Services; 1991 (DHHS Publication no. [PHS] 91-50212)
8. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102:137–140
9. US Department of Health and Human Services. *Healthy People 2010*. Conf ed. Washington, DC: US Department of Health and Human Services; 2000
10. Health Resources and Services Administration. *National Agenda for Children With Special Health Care Needs: Achieving the Goals 2000*. Washington, DC: Health Resources and Services Administration; 1997
11. Health Resources and Services Administration. *National Agenda for Children With Special Health Care Needs: Achieving the Goals 2000*. Washington, DC: Health Resources and Services Administration; 1999
12. Blumberg SJ, Olson L, Frankel M, et al. Design and operation of the National Survey of Children With Special Health Care Needs, 2001. *National Center for Health Statistics. Vital Health Stat 1*. 2003;(41):1–136
13. Centers for Disease Control and Prevention. National Center for Health Statistics. *2001 National Health Interview Survey (NHIS)*. Hyattsville, MD: National Center for Health Statistics; 2002. Available at: www.cdc.gov/nchs/nhis.htm. Accessed May 13, 2003
14. American Academy of Pediatrics, Medical Home Initiatives for Children With Special Needs Committee. The medical home. *Pediatrics*. 2002;110:184–186
15. US Department of Health and Human Services. *Delivering on the Promise: Self-Evaluation to Promote Community Living for People With Disabilities: Report to the President on Executive Order 13217*. Washington, DC: US Department of Health and Human Services; 2002. Available at: www.hhs.gov/newfreedom/final/hhs.html. Accessed May 13, 2003
16. Centers for Disease Control and Prevention, National Center for Health Statistics. *Progress Toward Implementing Community-Based Systems of Services for Children With Special Health Care Needs: Summary Tables From the National Survey of Children With Special Health Care Needs, 2001*. Hyattsville, MD: National Center for Health Statistics; 2003. Available at: www.cdc.gov/nchs/slats.htm. Accessed May 29, 2003

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