Recommendations to Improve Pediatric Specialty Care in New Mexico

Made by the
Pediatric Specialty Care Task Force

Presented to the
Legislative Health and Human Services Interim Committee

October 26, 2018

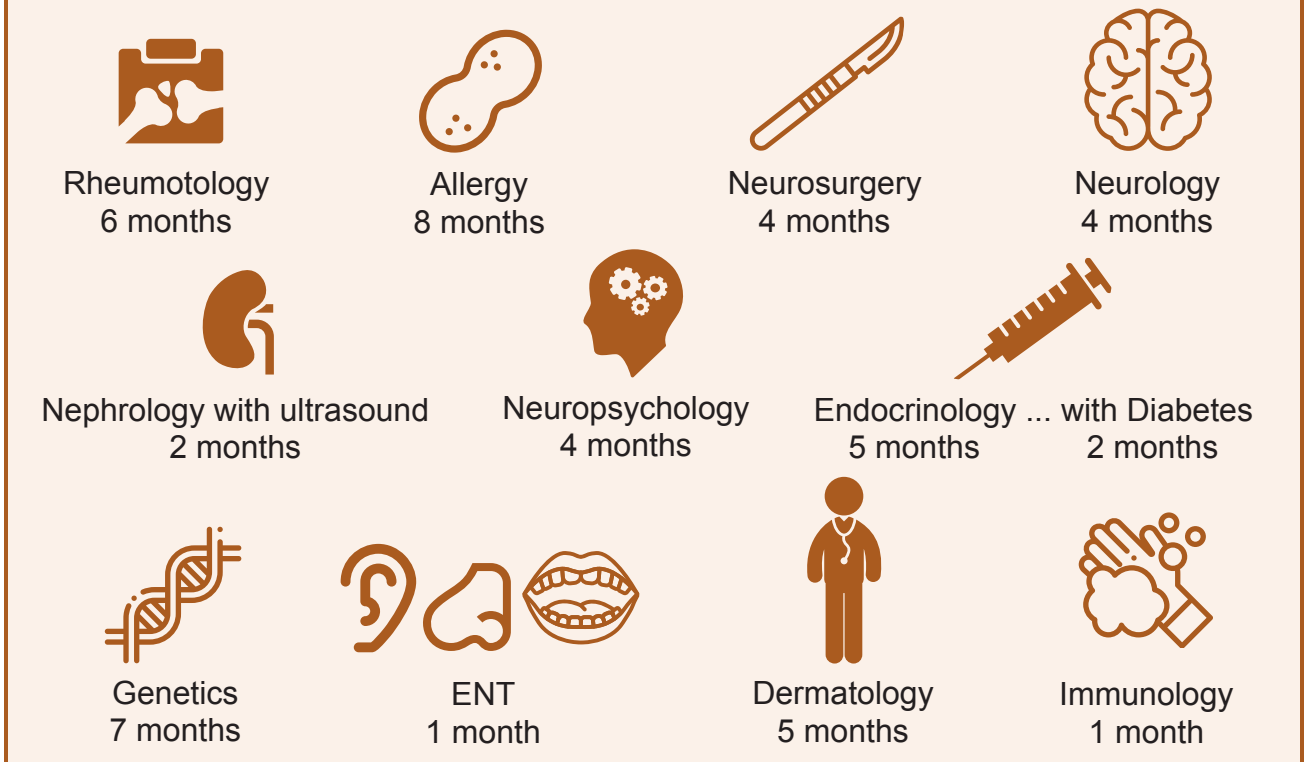
The History and Purpose of the Pediatric Specialty Care Task Force

The Pediatric Specialty Care Task Force (PSCTF) was convened to address concerns from parents, primary care physicians, pediatric specialists, and health systems regarding current difficulties in the access to and coordination of pediatric specialty care in New Mexico. Although there is considerable frustration with the current status of specialty healthcare services for children, we know there are many dedicated persons who want to work collaboratively to improve the lives of families with children requiring pediatric specialty care.

There are approximately 180,000 children in New Mexico who have at least one medical condition, and more than 90,000 of those have two conditions.[1] These children will certainly require specialty care at one time or another. We are fortunate to have two hospitals in New Mexico that offer many pediatric specialty services. The University of New Mexico (UNM) houses the state's academic medical center, which is a training institution for future practitioners and provides many specialty care services. Presbyterian Hospital provides many pediatric specialty care services, as well. Neither of these institutions is able to provide comprehensive care that is readily accessible and available to every child in our state. In addition, these services are currently concentrated in Albuquerque, and for New Mexicans living in rural parts of the state it is difficult – or impossible – to access these services.

Parents and practitioners report difficulty in accessing pediatric specialty services. This difficulty is due to: a profound lack of pediatric specialists practicing in the state due to problems recruiting and retaining them; complex care management needs in regards to securing appointments and tests; trouble arranging transportation for children with specialized health needs; and limitations and barriers imposed by health systems or health plans. Patients requiring multiple specialists face additional difficulty navigating multiple appointments when cared for by specialists in different health systems. Among the few pediatric specialists who practice in New Mexico, there are often long waiting times for appointments.

Typical Wait Times for Pediatric Specialists in New Mexico



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Some insurers contract with only one of two competing pediatric health systems. As a result, there have been times when patients have been sent out of state for insurance reasons rather than being given the option of seeing an "out-of-network" specialist here in New Mexico. Being sent out of state for services that could be provided within the state is, for some families, a significant financial hardship due to travel expenses, lost income due to absence from work, and separation of the child from one or both parents and from siblings who cannot travel with the patient.

To address these issues, Representative Debbie Armstrong introduced House Memorial 14 (HM 14) in 2018, and it was passed unanimously. HM 14 asked the New Mexico Pediatric Society (NMPS) to convene the PSCTF to evaluate and recommend improvements to the current healthcare systems for pediatric specialty care in New Mexico.

The PSCTF's recommendations are expected to follow the guiding principle that pediatric specialty care for children in New Mexico be "integrated, equitable, efficient, cost-effective, and family-centered." These words were carefully chosen to promote the following results:

Integrated – All parts of the system working together, not fragmented or separated.

Equitable – All children who need care have equal access.

Efficient – Makes best possible use of time, money, and other resources.

Cost-Effective – Produces the best possible outcomes for the money expended.

Family-Centered – Considers the family perspective as a focus for decisions and policies pertaining to child well-being and care.

As specified by HM 14, the broad overarching goals of this work are focused on three outcomes:

1. Improving health outcomes for children;

2. Improving patient and family satisfaction with medical care; and

3. Making the best use of the resources available in New Mexico in a cost-effective manner.

This is, of course, the Institute for Health Improvement's "Triple Aim," which has become the North Star for healthcare reform. When all three of these components are working well together, the result is a highly functioning healthcare system.

The Process

The PSCTF was co-chaired by the president and vice-president of the NMPS, and invitations were sent to a wide variety of stakeholders as specified by HM 14, including: family members and family organizations; hospitals and health systems providing pediatric specialty care; state agencies; community pediatricians; pediatric specialists; the New Mexico Medical Society; the Medicaid managed care organizations (MCOs); private insurance carriers; and Representative Armstrong. The meetings occurred in May, June, July, and August of 2018.

The group began by listening to families and practitioners about the current state of specialty pediatric care in New Mexico. This was done to allow everyone on the PSCTF to have a shared understanding of what families of children with chronic conditions are going through to access care, as well as what barriers keep them from accessing the care they need.

We organized our work around six categories: accessibility and the five guiding principles – integration, equity, efficiency, cost-effectiveness, and family-centeredness. Over the course of several meetings, issues and possible solutions were identified and developed for each of the six categories to ensure that each topic area was being addressed. Ultimately the proposals crossed over these artificial boundaries, with each one addressing multiple categories. However, each category is represented in the final recommendations.

PSCTF members who were present at the final meeting voted on the recommendations, and only those recommendations that received support from a majority of members were included in the final report.

Summary of Recommendations

1. Establish a single, unified Children's Hospital, incorporating all pediatric specialties available in New Mexico (page 4).
2. Encourage preferred use of in-state pediatric specialty resources to the fullest extent possible (page 5).
3. Establish a Pediatric Complex Care Clinic (page 6).
4. Enhance care coordination for children with medical and social complexities (page 7).
5. Reestablish a Governor's-level Children's Cabinet to lead the state in improving child wellness (page 8).
6. Fund a one-stop website for information on pediatric specialists, care coordination, and availability of outpatient appointments (page 9).
7. Support strategies that increase recruitment and retention of all types of pediatric practitioners (page 10).
8. Create a Community Advisory Board composed of key stakeholders such as select state agencies, UNM Health System, Presbyterian Healthcare Services, parents, and community practitioners (among others) to advise and assist in the development of a collaborative model of pediatric specialty care (page 11).
9. Improve information sharing and dissemination between health systems, practitioners, and health plans (page 12).
10. Increase access to behavioral healthcare for children (page 13).

Recommendation 1
Establish a Single, Unified Children's Hospital

In New Mexico, highly specialized pediatric care is currently split between Presbyterian Healthcare Services and UNM Health System, with partial overlap and duplication of services. This approach presents barriers for families when a child needs to be seen by specialists at both institutions and causes difficulty for the institutions in recruitment and retention of specialists, because of more rigorous call schedules, for example. If specialists had the ability to share patients, collaborate with each other, and share the on-call burden, it would benefit families and providers and likely lower costs and improve outcomes as well.

With pediatric surgery, for example, outcomes improve because the patient pool is larger, and surgeries occur more consistently. Consistent exposure to subspecialty patients improves the expertise of the doctors and nurses who care for those patients. Ideally, Pediatric Critical Care would be provided in a single PICU with 30 to 40 beds, 12 to 15 intensivists, and a fully functional sedation service. This unit could then provide support for a Pediatric Neurosurgery and Pediatric Cardiothoracic Surgery service, in addition to the Orthopedics, Trauma, ENT and General Surgery work already provided. Such a PICU/program could also support a pediatric critical care fellowship program to further develop New Mexico's pediatric subspecialty needs.

In addition to having all pediatric specialists working together, it is critical that specialty care be made more available in areas of the state such as Las Cruces and Roswell, for example. Outreach clinics put on by CMS, UNM and Presbyterian fill some of this need but for many families in rural areas specialty care is still not accessible. The PSCTF recognizes that this will be a long-term effort and recommends the following to work towards this goal of a single, unified Children's Hospital for New Mexico children:

1. The Legislature request UNM and Presbyterian to include, as part of their collaborative work and with the advice of the Community Advisory Board (established in recommendation 8), a feasibility study for a single and unified Children's Hospital, including regional satellite specialty centers in areas to be determined by the Advisory Board and a time line for this work;

2. They be directed to report back to the Legislative Health and Human Services (LHHS) Committee the results of this study by November 2019; and

3. That $100,000 be appropriated by the Legislature for this feasibility study.

Recommendation 2

Encourage Preferred Use of In-State Pediatric Resources

Health insurance plans may choose to limit their contracted network for various reasons, including cost, which, in turn, can lower premiums for consumers. This usually is not a problem for adult care when there are many providers from which to choose. For pediatric care, however, there is a dearth of pediatric specialists and hospitals capable of providing specialized care to children and infants. For some specialties, there may only be one pediatric specialist in the state. This makes it critical that all available specialists be utilized by all insurance plans, including the Medicaid managed care organizations (MCOs).

Families do want to have choices and the ability to access the best care for their children, even if that means going out of state when necessary. But for most pediatric needs, in-state specialists provide exceptional, world-class care, with the added benefit of a family not having to incur the expense of traveling, which also includes taking extra time off of work. Additionally, fully utilizing all available in-state pediatric resources would have other benefits, such as: pediatric hospitals would be able to build capacity by hiring more specialists; specialists in New Mexico would be able to attain the volume of patients needed to maintain and improve their skills; and state resources, such as the funding invested in Medicaid and other healthcare coverage, would remain in the state.

For those rare times when ultra-specialized care is required that cannot be obtained in New Mexico, a family should be referred to a center of excellence. By assuring that MCOs agree to contract with a limited number of specialized centers for this type of care, we can leverage our negotiating power to get lower prices, and families will receive consistent recommendations and referrals, regardless of payer source.

The PSCTF recommends that the New Mexico Human Services Department (HSD) be directed to facilitate the following deliverables:

1. Contracting between the MCOs and all pediatric specialists in good standing, and with all hospitals that employ pediatric specialists;

2. Contracting between the MCOs and a limited number of agreed-upon facilities out of state for ultra-specialized care that cannot be provided in New Mexico;

3. Requiring out-of-state hospitals to repatriate New Mexico patients when stable and coordinate their care with New Mexico physicians; and

4. Encouraging all pediatric subspecialty practitioners and hospitals in New Mexico to accept Medicaid.

Recommendation 3
Establish a Pediatric Complex Care Clinic

A Pediatric Complex Care Clinic (PCCC) could be a valuable resource for a segment of patients and their families when provided in conjunction with their primary care and specialist teams. The clinic would optimize the quality of life for patients with complex medical needs by providing comprehensive and focused assessment for the multiple physical and psychosocial impacts of patient's medical diagnoses and treatments. The PCCC would also facilitate intensive care coordination and support.

The PCCC would provide services for children as well as adult patients with congenital diagnoses, such as genetic syndromes and congenital heart disease. The clinic would coordinate with out-of-state centers and multiple specialists, and would work with local resources to provide referrals to appropriate agencies. The Complex Care Clinic at Presbyterian currently provides inpatient consultation at Presbyterian Hospital to provide continuity of care between outpatient and inpatient settings.

The PCCC can also become a centralized resource for training and ongoing education to work in conjunction with Children's Medical Services (CMS), medically fragile caseworkers, and the care coordinators from the MCOs. The PCCC would also have a unique opportunity to provide support groups and educational opportunities for patients with complex medical needs, such as cystic fibrosis, and to utilize integrative medicine in their care plans. The PCCC would be an ideal training ground for pediatric, family medicine, and internal medicine residents.

The PSCTF recommends that:

1. The establishment of a PCCC be part of the current joint initiatives planned between UNM and Presbyterian, and the clinic be jointly run by both Presbyterian and UNM Health Services;

2. The PCCC consist of both pediatric and adult primary care physicians with experience in medically complex patients;

3. The PCCC be housed in one building so patients could transition from pediatric to adult care by literally going across the hall, and also house a transition clinic for patients outside the facility and in other areas of New Mexico: and

4. A robust telehealth program be utilized for transition and consultation to providers around the state.

Recommendation 4

Enhance Care Coordination for Children with Medical and Social Complexities

Care coordination has been proven to improve outcomes, enhance patient satisfaction, and provide cost savings for the healthcare system. Care coordination for children and youth with special healthcare needs is especially challenging and is best provided by professionals with expertise in serving this population.

The PSCTF heard from both families and providers that the current provision of care coordination for children and youth needing pediatric specialty care is fragmented and difficult to access. We also heard that families feel strongly that there is a benefit to having a "neutral" care coordinator who works "for the family" as an advocate rather than for the MCO or insurance company. One example of this is the Children's Medical Services (CMS) program, which utilizes licensed social workers around the state to assist children and youth with chronic medical conditions. The CMS social workers do not duplicate the work of the MCOs but work in collaboration with the MCOs and health systems.

Those families who receive care coordination from CMS testified that CMS was helpful in coordinating necessary insurance and specialty care issues, both in and out of state. Families also testified that CMS assisted them with social and practical issues such as transportation, housing, and linking to programs. CMS is housed in the Department of Health and funded with federal and state dollars.

The PSCTF recommends that the Legislature:

1. Provide additional state funding to strengthen the existing capacity of medical social work through Children's Medical Services (CMS), housed in the Department of Health, Family Health Bureau, in coordination with case management through the MCOs in a regional fashion; and

2. Request HSD to designate CMS as the care coordination lead for all children meeting the criteria of medical or social complexity and require reimbursement from the MCOs for this effort.

Recommendation 5

Reestablish a Governor's-Level Children's Cabinet

New Mexico has been ranked 49th or 50th in the nation in overall child well-being for years, according to the Annie E. Casey Foundation's KIDS COUNT program. These rankings are simply unacceptable. Although our task force was focused on pediatric specialty care, the task force members recognize that health is not just about medical care. For children to be healthy they must also be safe, cared for, educated, and fed.

Children's Cabinets have been proven successful in other states to promote inter-agency collaboration and community engagement around child well-being. This kind of collaborative approach is sorely needed to address the poor state of child health and wellness in New Mexico. This problem can only be addressed through a collaborative effort across sectors, and with leadership and direction from the Governor. A Children's Cabinet was established in New Mexico under Governor Bill Richardson. By reconvening the Children's Cabinet, the new Governor would be making it clear that their new administration is prioritizing children's well-being and is dedicated to improving the lives of New Mexico's children.

The PSCTF recommends that:

1. The Governor re-establish the Children's Cabinet and direct the Cabinet Secretaries to develop and be held accountable for achieving shared goals and agreed-upon objectives to improve the health and well-being of the children in New Mexico;

2. The Children's Cabinet be directed to publish an annual report detailing progress towards these goals; and

3. The Children's Cabinet invite to its meetings a family representative, and representatives from the NM Pediatric Society and the Community Advisory Board for Pediatric Specialty Care Collaboration (see recommendation 8). Having other stakeholders at the table would add fresh ideas, create new partnerships for solving problems, and provide a measure of accountability for state agencies.

Recommendation 6
Fund a One-Stop Information Website

New Mexico does not have a current one-stop resource for the identification of pediatric specialists and services. There are many silos of information, but none is completely up-to-date or comprehensive. It is often difficult and inefficient for parents and practitioners to find the resources they need regarding specialty care for children in our state. Additionally, insurance plans may not be fully aware of the pediatric specialists who are currently practicing in our state, and thus will approve out-of-state care for their members. This wastes money and time for families and practitioners. To improve coordination of care, New Mexico needs a centralized database of information that provides reliable, current, and useful information for providers and families.

The New Mexico Pediatric Society (NMPS) is currently working with a team that includes representation from the New Mexico Department of Health (DOH), parents, NM Kids Resource and Referral, New Mexico's Act Early Ambassador, and others to delineate what it would take to have a current and comprehensive "one-stop" website for our state. Specifically, the website should provide information on current specialists including their practice location(s), insurances accepted, contact information, and approximate length of time for the next available appointment. Additionally, the website should contain contact information for care coordinators.

The team has identified the New Mexico Medical Home Portal as a resource that has the capability to meet the requirements for this "one-stop" website. The team has been collaborating with the Medical Home Portal, a project of the Department of Pediatrics at the University of Utah Health. The stated mission of the Portal is to provide a website "to assist and support professionals and families in working together to care and advocate for children and youth with special healthcare needs by providing reliable and useful information about their conditions and caring for them and knowledge of valuable local and national services and resources." The Medical Home Portal is currently contracting with the DOH and is already providing a state-specific portal for New Mexico. While there is support in Utah to maintain New Mexico's portal, what is being proposed is a much larger task.

The PSCTF recommends that:

1. The Legislature appropriate $100,000 to develop the Medical Home Portal for New Mexico; with an additional $25,000 appropriated during year 2 for maintenance; and

2. The NMPS be the supervisor of the project with dedicated contacts at both UNM and Presbyterian to ensure that useful and appropriate information is continually accessible and up-to-date.

Recommendation 7
Support Recruitment and Retention Strategies

Children's hospitals across the country have significant shortages in pediatric specialties for multiple reasons including: dependence on Medicaid reimbursement for a large portion of patients; high student loan burdens; and much lower salaries for pediatric specialists as compared to adult specialists. These shortages affect children and their families' ability to receive timely, appropriate care. These issues are amplified in New Mexico, because 50 percent of children and 70 percent of births are covered by Medicaid. When successful, efforts at improving recruitment and retention of pediatric specialists result in better care of patients and significant cost savings to the entire health system by decreasing costs of ongoing recruitment and of sending patients out of state.

The state's major referral centers face challenges in the recruitment and retention of pediatric specialists, and at times this has resulted in certain specialties – such as pediatric neurosurgery, pediatric gastroenterology, pediatric rheumatology and others – not being available to pediatric patients in New Mexico. This lack of specialists adds to the strain on general pediatricians throughout the state and is most pronounced in rural areas where this lack of access compounds the demands on rural practitioners.

New Mexico has generous, targeted programs to develop and maintain rural primary care with regards to loan repayment programs and the rural healthcare practitioner tax credit program. Unfortunately, most pediatric specialists, being primarily based in the urban area surrounding Albuquerque, are ineligible for these incentive programs.

The PSCTF recommends that the Legislature:

1. Expand the eligibility of the New Mexico Health Professional Loan Repayment Program (HPLRP) to allow applications from pediatric specialists;

2. Request HSD develop a fee schedule for Interpersonal Consultation Services and widely disseminate guidance to practitioners and health systems regarding telehealth payment; and

3. Maintain and update the New Mexico Medical Malpractice Act in accordance with recommendations proposed by the NM Medical Society, New Mexico hospitals, and the NM Hospital Association.

Recommendation 8
Create a Community Advisory Board

Specialized care of pediatric patients is currently fragmented in New Mexico and needs improved accountability, transparency, and leadership. It is not easy for institutions to break down barriers and develop methods for the sharing of patients, physicians, and medical records. Much of the dysfunctional state of specialty services for children in New Mexico is a direct result of a lack collaboration, and could be improved by having a unified mission, accountability, and the direct involvement of those most affected.

The two largest pediatric institutions recently announced that they have begun discussing ways to work together more effectively. Efforts to collaborate and reduce fragmentation of care will be more successful if they are done in a transparent way and with input from those most affected by the issues, such as primary care practitioners and parents of children with special healthcare needs. A Community Advisory Board will ensure that a variety of voices are heard, and all parties are held accountable.

The PSCTF recommends that:

1. The Legislature create a Community Advisory Board to be responsible for advising UNM and Presbyterian on their efforts to improve coordination of specialty services and for developing a comprehensive plan to improve access to pediatric specialty care for children in New Mexico. This plan should include a Complex Care Clinic (recommendation 3) as one step ultimately leading to a single and unified Children's Hospital (recommendation 1);

2. The Legislature direct the current task force for HM 14 to draft a charter for the Community Advisory Board within four months and send it to the LHHS Committee Chairs for approval. The charter will specify the composition of the Community Advisory Board, taking into consideration all the relevant stakeholders, including parents. The charter will specify how members will be appointed as well as duration of service, and specify the role of the Advisory Board in coordinating reviews of how pediatric specialty services at UNM and Presbyterian can be better coordinated; and

3. The Community Advisory Board be responsible for providing an annual report to the Legislature/LHHS with their progress and recommendations.

Recommendation 9

Improve Health Information Access and Sharing Across Systems

Since the first clinical information system was developed in the 1970s, information technology developers have sought to improve Electronic Health Records (EHR). Under the Affordable Care Act (ACA), the meaningful use of EHRs was promoted and incentivized, but unfortunately it did not require standardization of the EHRs in a way that allowed health information to be easily shared between systems and providers. To provide optimal medical care and avoid unnecessary duplication of costs and effort, health care providers – including pediatric specialists and primary care physicians – need to access a patient's full health history, regardless of where that care was provided or what information system houses that information. Connecting different information sources is also the key to successful telehealth and population health management strategies.

New Mexico's Health Information Exchange has not solved these problems to date. True meaningful use requires that healthcare data be readily accessible, either through interoperability of systems or, ultimately, by establishing patient ownership and control of their own medical data in a portable format that can be shared as needed.

In our meetings we heard primary care practitioners voice their frustration with not being able to access their patient's medical records from a tertiary care center; parents said they spent hours going from facility to facility to collect test results and other information to share with specialists; and pediatric specialists stated that tests were often repeated due to the inability to retrieve and share medical records. We cannot achieve the triple aim of improved health outcomes, lower cost, and improve patient satisfaction without fixing this problem.

The PSCTF recommends a step-wise approach to this issue:

1. As a first step, all pediatric primary care practitioners and pediatric specialists should have fully functional and immediate access to the Electronic Medical Record systems at both UNM and Presbyterian;

2. Practitioners at both institutions need to be given access to charts in either system; this is a basic need to facilitate shared patient care, including cross-coverage and shared call; and

3. The NM Health Information Exchange needs to be utilized in a more comprehensive and universal manner. This is something the Legislature could incentivize to promote its use with providers and hospitals, which would make it more functional.

Recommendation 10
Increase Access to Behavioral Healthcare

Access to behavioral healthcare for children is essential to achieving good healthcare outcomes. Pediatric primary care practitioners have an essential role to play in identifying and treating behavioral health problems in children. Primary care practitioners throughout the state experience challenges with referral to diagnostic evaluation, medical management, and support.

Behavioral health problems affect one out of five children nationally. These issues affect a child's school success, social relationships, and put a child at risk for future physical and behavioral health problems.[2] Large swaths of New Mexico are lacking in mental health practitioners and access to child psychiatry. The majority of children in New Mexico with mental health issues never receive care for them.[3] Current strategies focused on improvement, such as the Behavioral Health Collaborative, have been insufficient in addressing mental health issues at the level of primary care.

The PSCTF recommends that the Legislature:

1. Request that the Pediatric subcommittee of the Behavioral Health Collaborative and the Adolescent Substance Use Reduction Effort (ASURE) research program models, such as the Massachusetts Child Psychiatry Access Program (MCPAP), that could be implemented in close collaboration with specialty services at UNM and Presbyterian. MCPAP is a system of expertly trained children's behavioral health consultation teams designed to help primary care practitioners and their practices promote and manage the behavioral health of their pediatric patients as a fundamental component of overall health and wellness;[4] and they report their findings to LHHS Committee by summer 2019;

2. Request HSD fund and promote Telehealth services between primary care and behavioral health practitioners to make fullest and best use of our available resources; and

3. Expand the eligibility of the New Mexico Health Professional Loan Repayment Program (HPLRP) to allow applications from child psychiatrists in metropolitan areas.

Endnotes

1. Data Resource Center for Child and Adolescent, www.childhealthdata.org
2. *Results First, Children's Behavioral Health*, 2017. Program Evaluation Unit of the Legislative Finance Committee, the Human Services Department, and the Children, Youth, and Families Department
3. Substance Abuse and Mental Health Services Administration. *Behavioral Health Barometer: New Mexico*, 2015. HHS Publication No. SMA–16–Baro–2015–NM. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2015
4. John H. Straus and Barry Sarvet, "Behavioral Health Care for Children: The Massachusetts Child Psychiatry Access." *Health Affairs*, 33, no.12 (2014):2153-2161

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