

House Memorial 9 Report

A STUDY AND REPORT

**WAYS TO IMPROVE THE SYSTEM OF HEALTH CARE
TRANSITION FOR NEW MEXICO CHILDREN AND
YOUTH WITH SPECIAL HEALTH CARE NEEDS**

**Respectfully Submitted
by the Health Care Transition
Task Force**

October 22, 2015

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Executive Summary

The Health Care Transition Task Force for New Mexico Children and Youth with Special Health Care Needs met from January through August 2015. The task force was formed to address the needs of the children and youth in New Mexico with special health care needs and/or disabilities, acknowledging from the start that for this population, the process of moving from pediatric to adult medical care is often difficult. This report is the result of eight months of study and deliberation. The task force members are very passionate about this topic and committed to developing recommendations for improvement.

Included in this report are the following recommendations:

A. Training of New Mexico (NM) Health Care Providers

Recommendation: Resource the NM Department of Health, Children's Medical Services to develop an online course with specific competencies for transitioning youth with special needs.

Stakeholders: DOH partners will market to health care providers and provide continuing education credits.

B. Guardianship

Recommendation: Resource the NM Administrative Office of the Courts to perform a gap analysis on resources and support services for families seeking guardianship and other legal approaches.

Recommendation: Resource the NM Developmental Disabilities Planning Council to develop guardianship services for families that otherwise do not qualify by income or citizenship.

C. Family Involvement and Education

Executive Recommendation: Request funding collaboration among state agencies of NMDOH, NMHSD, NMCYFD, and NMPED to dedicate \$25,000 annually to support families who have youth with special health care needs with per diem and travel expenses in order for them to serve as family representatives on state committees.

Recommendation: Resource the NM Department of Health, Children's Medical Services to develop, with partners, a Health Literacy training program reflective of the cultural and linguistic needs of families of youth with special health care needs.

Recommendation: Resource the NM Department of Health, Office of Health Equity to provide translation services for materials developed targeting the transition of youth with special health care needs to adult health care.

D. Access to Health Transition Services for Immigrant Youth

Stakeholder Recommendation: The Office of the Superintendent of Insurance (OSI), the NM Medical Insurance Pool, the DOH Office of Border Health, and the leadership of the HM09 youth transition task force (including DOH/CMS and CDD) develop policy recommendations that would improve access to health care for the immigrant population and report back to the Interim HHS committee with these recommendations by October 1, 2016.

E. Improving Payment/Reimbursement for Transition Services

Executive Recommendation: Request the NM Human Services Department to direct the MCOs to reimburse pediatric and adult medical providers for all currently approved CPT codes that would allow joint consultation around youth transition and transfer, and clarify with the MCOs that care coordination provided to youth with special healthcare needs should include a specific focus on facilitating the transition and transfer process.

F. Interagency Communication and Collaboration

Executive Recommendation: The Governor requests that the Children's Cabinet address issues of improving the transition process for youth with special health care needs; developing a formal plan for agency staff that would ensure collaboration around services; and mapping of systems and services available from each agency.

G. Complex Care Clinic

University of New Mexico Health Sciences and School of Medicine Recommendation: Facilitate a gap analysis documenting the potential need for

a Complex Care Clinic at UNM, and provide a preliminary plan and a financial feasibility study for the Clinic.

H. Improving Oral Health Care for Youth in Transition

Executive Recommendation: That the NM Department of Health, Children's Medical Services, in collaboration with partners, contact the initiatives being developed around the state to assess efficacy and impact as a prospective for future action.

I. Remedy for the Problem of Providers Leaving Network

Executive Recommendation: Request the Office of Superintendent to institute a rule for private health plans to publish and distribute changes in providers. Request the NM Human Services Department, State Medicaid Program include provisions for MCO contractors to advertise provider changes on a regular basis. Request the State Medicaid Program provide education to contractors and enrolled clients on the ability to change providers and the method to request a change.

Stakeholder Recommendation: Request the professional health care provider licensing entities acknowledge the issue of provider changes. Assist and identify the individual responsibility to track provider continuity with both the provider place of service and the health plan.

Introduction of Task Force

A 2010 national survey of children with special health care needs found that New Mexico had over 70,000 children and youth with special health care needs (CYSHCN). Children and youth with special health care needs (CYSHCN) between the ages of fourteen and twenty-one years of age are aging out of pediatric care and need to make a transition to adult health care providers; however, this can prove challenging. The survey found that only 35.7% of youth with special healthcare needs in NM receive the services necessary to make transitions to adult health care, compared to 40% nationally.

Few systems or resources are available to aid children and youth with special health care needs and their families in the process of transitioning from pediatric to adult health care. Children and youth with disabilities and their families report that they lack the information they need to successfully navigate the transition from pediatric to adult health care. Resources that are available, like those on the www.gottransition.org website, are not widely used, either by families or by health care providers.

Furthermore, policies, systems and services within the state tend to be fragmented and lack coordination. There is no overall system to support transition, and it is rare to find true coordination around the transition process occurring between the youth, family members, pediatric providers, adult providers, and case managers. This fragmentation of the transition health care system often has a negative impact on the health of patients throughout their life spans.

One component of the work of the task force was to examine transition-focused policies, programs and services in order to make recommendations on creating a more organized transition system that can reduce fragmentation, increase coordination between pediatric and adult health care systems and improve the quality of care for children and youth who are moving through the transition process.

The Task Force assessed the fragmentation that exists and identified strategies to address the barriers to effective health care transition and transfer services. The goals of the Task Force recommendations are to address barriers to effective health care transition for children and youth with special health care needs and increase the efficiency and effectiveness of services for children and youth with special health care needs as they make the transition from pediatric to adult health care services.

The NM Department of Health Children's Medical Services (CMS) and the UNM Center for Development and Disability (CDD) initiated and led the task force with support from a federal grant from Health Resources Services Administration (HRSA).

Members of the task force included multiple members from state agencies: NM Department of Health; NM Human Services Department, State Medicaid Program; NM Children, Youth and Families Department; NM Developmental Disabilities Planning Council; NM Governor’s Commission on Disability; NM Office of the Superintendent of Insurance; UNM Hospital; and UNM School of Medicine.

Health and community professionals included; the Association of Developmental Disability Providers; HealthInsight NM; March of Dimes NM; National Association of Social Workers NM; Education of Parents of Indian Children with Special Needs; the NM Medical Insurance Pool; the NM Medical Society; the NM Nurses Association; the NM Pediatric Society; the NM Primary Care Association; Parents Reaching Out; and the ARC of NM.

The state managed care organizations participated: Blue Cross Blue Shield of NM; Molina; Presbyterian Health Plan; and United HealthCare.

The task force also included stakeholders and self-advocates – both young adults and family members.

Guiding Values and Principles

The organizers of the task force are dedicated to the needs of the population in their daily work and professions and exhibited this commitment by inviting representatives from diverse populations and backgrounds to participate. A guiding principle of the task force work was that everyone had an equal voice and everyone’s participation was equally valued.

The real-life experiences of the young adults and their families, specifically, were invaluable in developing and preparing these recommendations. Representatives from advocacy organizations, the state managed care organizations, insurance groups, medical societies and state agencies were considered valuable participants with their own expertise and knowledge of the current system, and as information resources for the larger group.

To ensure that everyone present had an equal and viable voice of participation, the task force utilized a facilitator to manage participation and help the task force members to accomplish the meeting goals.

Task Force Activities and Methodology

The task force met from January through August of 2015. The NM Department of Health Children’s Medical Services staff and the UNM Center for Development and Disability staff initiated the work by developing the list of participants and sending invitations. They set the stage for the work during the first meeting, providing an overview of the problem and issues related to youth transition in NM and nationwide, and set the parameters of the expected outcomes for the task force – recommendations for further action that could be short term, long term, low cost, and/or high cost.

Early in the task force meeting structure, all participants identified the need to gather information in order to study and discuss multiple topics prior to reaching any recommendations. The areas requiring the most background information and discussion were in Service Provision and in Finance. The following table lists the questions, needed information and issues that were identified by task force members. CMS and CDD staff then worked to either find the information requested or engage speakers who could inform the group with regards to the requested topics. Some of the requests overlapped or were duplicative.

Earlier meetings included “expert panels” on specific topics requested by the group, small group discussion, and large group discussion. Fifty percent of the participants served on an expert panel, and discussion was supplemented by outside experts. Later meetings focused on development of multiple recommendations, prioritization of recommendations, and the development of an action plan.

The facilitation of the meetings was supported by a HRSA grant focused on improving the system of care for youth in transition. Policy change was one of five goals of the grant, which was awarded to the DOH/CMS program in 2012 and ended in June 2015.

All meeting agendas and presentation materials can be found in Appendices B through F.

Issues, Questions and Needed Information Identified by the Task Force

Participant Input on Service Provision	Participant Input on Finance
<p>A. Data requests</p> <ol style="list-style-type: none"> 1. Workforce adequacy – map clients by county and map health care providers by county. 2. A flow chart of the system – showing how the medical community interacts with people with disabilities. 3. Information on tribal health 638 programs. 4. Review any specialty programs already existing. 5. Define the “transition” problem numerically and geographically. If there are 70k Children and Youth with Special Health Care Needs (CYSHCN) individuals in NM, whose are they and where are they? <p>B. Client</p> <ol style="list-style-type: none"> 1. How the transition process works currently in NM. 2. Self-empowerment if wanted. 3. Hearing from individuals and families that have gone through the transition in NM. 4. Legal / regulatory requirements for transitioning youth. 5. Would like case studies – family and child. 6. Can there be support for individuals who want to move to areas that have more providers available? 	<p>A. Data requests</p> <ol style="list-style-type: none"> 1. Need background materials before next meeting of current system vs. presentation on status quo. 2. Are significant clients on Medicaid, Medicare, or Uninsured? 3. Need age chart for all systems involved – CHIP, EPSTD, ACA, Medicaid, Guardianship, etc. (18-26) 4. Request Medicaid data - age distribution for regular and CHIP and expansion clients.- 5. Need number of young adults on parents' insurance. 6. Information on tribal 638 programs. <p>B. Global overview of health care financing involved including:</p> <ol style="list-style-type: none"> 1. Medicaid/ Medicare/ DD Waiver/ Private Insurance/ Insurance Pool 2. Interaction/interface of all financing mechanisms 3. Identify funding costs. 4. Identify funding resources. 5. Is lack of reimbursement for case management a problem? <p>C. Medicaid</p> <ol style="list-style-type: none"> 1. What/ where are viable sources of funding for those who lack the means to transition from child to adult? 2. Is there Gold or Platinum Quality Health Plans under Medicaid? 3. What does the Medicaid data show?

Participant Input on Service Provision	Participant Input on Finance
<p>C. Providers</p> <ol style="list-style-type: none"> 1. Health care providers and social services vs. medical focus only. 2. Training of medical and health care providers on transition issues. 3. Utilization of the Comprehensive Medical Summary. 4. Packets assist transition in rural areas. 5. Resident training for adult providers. 6. What are the approaches/tools of providers that excel in transitions? 7. What are some effective supports for providers to educate them to systems, approaches, etc? 8. How many care coordinators are involved – what agencies (healthcare providers, insurance companies, other advocacy organizations, etc.) Do they interact and know about one another? 9. Expect Centennial management of MCOs. 10. Identify providers available for DD populations vs. need in NM. 11. Social worker experiences with transition –positive and not so positive. 12. Who are available service providers? 13. A review of all the rural provider recruitment that is going on in NM. 14. How can best practices be tailored specifically to care transition? 15. Need adult medical and health 	<p>What happens to children who were identified as CSHCN and aged out? Does Centennial Care assist them into moving into Medicare?</p> <ol style="list-style-type: none"> 4. Request Medicaid data - age distribution for regular and CHIP and expansion clients. 5. Are there any MCO mechanisms/initiatives financially supporting transition? 6. What is the interaction between waivers and current transition systems? <p>D. Private insurance</p> <ol style="list-style-type: none"> 1. Have any of the major carriers developed case management or other programs to address transition specifically? 2. What gaps are most prevalent in private insurance? 3. What are the insurance barriers to transition? 4. Can insurance providers better aid transitions? <p>E. Providers</p> <ol style="list-style-type: none"> 1. Consider how payment and payor sources do not pay for or cover the additional costs to medical providers. 2. Pediatric and adult providers now cannot do joint appointments and both be paid for visit. This would facilitate transfer. 3. What policy decisions/actions could support the recruitment of providers that fill a service "gap"?

Participant Input on Service Provision	Participant Input on Finance
<p>care providers to discuss what would make them more likely or willing to accept CYSHCN in transfer.</p> <p>D. Other Issues</p> <ol style="list-style-type: none"> 1. Barriers with medical foster care (going from early childhood to pediatrics to adults on DD waiver). 2. Why don't systems mesh? 3. Does mental health fit here? 4. How does the Indian Health Service (IHS) handle the transition of youth to adult providers? 5. What is difference in youth vs. adult services? Need to develop a model and educate all on the model. 6. Who is doing well and why? 7. Consider that the issues around care are mostly the same from child to adult as moving a household from one location to another community program. 8. How can we make it easier for a caregiver to handle transactions w/ carriers and providers and agencies under HIPAA rules? 9. What can help this issue? Guardianships create barriers if legal papers are not current – for discussing health and financial issues. This relates to MCOs, private insurers, providers, etc. 	<p>F. General</p> <ol style="list-style-type: none"> 1. Don't forget to cover issues for undocumented or mixed documentation. 2. Learn more aspects of how guardianship works and other alternatives (i.e., power of atty., etc.) 3. What are the ways to finance guardianship? 4. What are existing best practices already out in the public domain that can be tweaked to fit our state? 5. How do coverage changes from youth to adult affect menu of services covered and paid for?

There were multiple recommendations that were received from participants and considered over two meetings. Participants then had the opportunity to prioritize the recommendations as individuals, in a small team, and as the group at large. Numerous recommendations from the following areas were considered: Technical Assistance and Training, Workforce, System Change, Interdisciplinary, Innovations, And Consumers and Families.

All of the category recommendations were prioritized, consolidated, analyzed, and summarized in the following section as Recommendations and Policy Implications to be presented to the Legislative Interim Health and Human Services Committee.

Recommendations and Policy Implications

A. Training of New Mexico (NM) Health Care Providers

New Mexico's youth with special needs interact with a variety of health care providers, depending on the services they require; however, finding these providers can be daunting as thirty-two of NM's 33 counties are federally designated full or partial Health Professional Shortage Areas (HPSAs). In addition, it can be challenging to find and establish a caring relationship with a primary care or specialist provider who has experience serving youth transitioning to adult status. The Task Force identified several specific, licensed professional groups that could be trained to assist in the transition process as part of either their basic pre-licensure education or their required continuing professional education.

Although there are as many educational pathways to health care providers as there are NM licensing entities and professional schools, the collective next step for all these would be a competency-based course that can be utilized at a variety of learning levels. This course could then be offered as a resource to pre-licensing and continuing education programs, as well as offered through the NM Department of Health and UNM Center for Development and Disability.

On-going efforts related to transition education for care providers:

- A variety of health care Residents may participate in some activities at the UNM Transition Clinic.
- UNM Center for Development and Disability's Leadership in Education for Neurodevelopmental Disabilities (LEND) Program may include health care providers in training. This is a broad program not exclusively highlighting transition issues, but preparing professionals to understand and work with those with special needs.
- Plans to include UNM Dental Residents in the LEND Program (above) are under way.

Action Requested:

1. NM Department of Health, Children's Medical Services program (CMS), in collaboration with partners, should identify the competencies needed by health care providers to include medicine, nursing, dental, physical therapy, psychologists, social workers, care coordinators and others who may have a significant provider role for transitioning youth with special needs. These competencies should include the range of developmental / intellectual special needs encountered by NM providers with an emphasis on youth transition. It is important to include particular cultural / linguistic needs of populations such as Native Americans, Hispanic families, LGBT and

other community groups with specific needs. With appropriate partners, the DOH (CMS) should work to develop these competencies into an on-line course to be considered for use by educational institutions and professional associations.

2. Following completion of the course described above, letters should be sent from DOH / CDD to all appropriate pre-licensure educational institutions (schools of nursing, schools of medicine, allied health schools and programs) to alert them to the need for culturally informed education regarding transition of those with special needs and their families.
3. After the development of the online course, DOH partners will seek appropriate continuing education credits for provider professional groups. This credit information will be included in the letters to the educational and professional associations.

Projected Cost: \$100,000 for the DOH CMS program to develop an on-line course.

B. Guardianship

Many questions arise around legal responsibilities for young adults with disabilities and need for continuing support. Families and professionals need information and assistance to think through questions such as who will makes legal decisions and how to support young adults to assume greater responsibility for decision-making over time. Guardianship is one possible solution, but there are other legal approaches (such as Power of Attorney) that can support decision-making processes while still protecting as much independence as possible. Families and youth need access to accurate information and support services to facilitate appropriate, client-centered decisions.

There are on-going efforts underway such as:

- The Developmental Disabilities Planning Council (DDPC) Office of Guardianship provides assistance and guardianships that are publicly funded for income-eligible adults. The DDPC does not provide assistance to families who are over-income or undocumented.
- The University of New Mexico Medical Legal Alliance works with patients seen at UNM Hospitals and Clinics and can provide legal assistance around guardianship, kinship and power of attorney.
- The Native American Disability Law Center assists Native American families to determine the best option for their young adult.

Action Requested:

1. The Task Force recommends that the Administrative Office of the Courts (AOC) perform a gap analysis on resources and support services that are available to families who are over income for assistance through the DDPC or are undocumented, and who are seeking guardianship or other legal approaches to decision-making for youth with special needs transitioning to adult care at the age of 18. This analysis should also include a review of the existing law regarding guardianship/power of attorney to determine where it should be updated or strengthened. \$25,000.00
2. The Task Force recommends the Legislature appropriate \$300,000 to the Developmental Disabilities Planning Council to develop a program based on a sliding fee scale for families who are over-income for publicly funded guardianship assistance or undocumented. Funds should also be used to develop an educational campaign to better inform families of their options and the importance of addressing these issues at the age of transition.

Projected Cost: \$300,000 for DDPC, \$25,000 for AOC.

C. Family Involvement and Education

The promotion of family involvement, education and informed decision-making in health care issues such as transition is essential and important. New Mexico is diverse in culture and language. Integrating the needs of Native American families, immigrant families, and families where English is a second language is essential in building a comprehensive, coordinated system of care for youth in transition. There are on-going efforts underway such as:

- The Family to Family information center (F2F) at Parents Reaching Out (PRO) brings the family perspective to policy discussions through their work with local, state and national advisory boards of agencies and services providers. It also assists with development of training and educational materials for families around youth transition in general and specifically around transition for youth with special health care needs. The materials address the cultural and linguistic needs of New Mexico's diverse population, including Native Americans and monolingual Spanish families.
- PRO and Education of Parents of Indian Children with Special Needs (EPICS) are sister organizations of family advocates working to promote the voices of families. PRO and EPICS builds on each family's strengths and knowledge and celebrate

diversity. PRO and EPICS work for positive, family-friendly changes to systems and promote the importance of collaboration to create positive outcomes for families, children and communities.

- The Asian Family Center provides services that are culturally and linguistically appropriate for the Asian community including education programs, counseling, legal services and interpretation/translation. PRO and the Asian Family Center have recently begun to work closely together to increase their impact on this population.

Action Requested:

1. The Task Force recommends the Governor mandate Executive Branch state agencies (DOH, HSD CYFD and PED) to set aside \$25,000 annually to support families who have children and youth with special health care needs to serve as a family representative on standing committees statewide. Families selected should represent the cultural diversity of the State. Youth representatives are especially encouraged.
2. The Task Force recommends the Legislature appropriate \$100,000 to the DOH Children's Medical Services program to develop a Health Literacy training program reflective of the cultural and linguistic needs of families who have children and youth with special health care needs, with a special emphasis on health care transition. The Health Literacy program will focus on educating families on how to navigate the health care system, including filling out complex forms and locating providers and services, engaging in self-care and chronic disease management, and understanding health care terminology. The program will be based on a 'train the trainer' methodology and will engage multiple partners such as the family advocate organizations, Office of Indian Affairs, the managed care organizations' care coordinators, and others to be identified.
3. The Task Force recommends the Legislature appropriate \$50,000 to the DOH Office of Health Equity to provide translation services for materials developed targeting the transition of youth with special health care needs to adult health care.

Projected Cost:

\$25,000 set aside from each Executive agency to assure family representation at standing committees.

\$100,000 for DOH Children's Medical Services to develop a health literacy program for families with children and youth with special health care needs with a focus on health care transition

\$50,000 to DOH Office of Health Equity for translation of educational materials developed by the health literacy program.

D. Access to Health Transition Services for Immigrant Youth

The task force found that access to transition services is a problem for almost all youth in New Mexico; however, immigrants face additional hurdles in accessing these services. Overall, immigrants have less access to medical care than the general population, even when they are insured. But insurance remains one of the most significant barriers to accessing health care, especially for undocumented immigrants.

- According to the Medical Expenditure Panel Survey (MEPS), 47% of the immigrant (i.e. foreign-born) children made a medical visit in 2010, compared to 69% of native-born children. Additionally, data indicate that immigrants utilize emergency rooms more sparingly than the native-born, regardless of whether they were uninsured or had public or private insurance coverage.
- Insurance coverage does not by itself assure access to care, but lack of insurance is a significant barrier. Undocumented immigrants are ineligible for public insurance and are barred under the Affordable Care Act from purchasing insurance on the Health Insurance Exchange or receiving government subsidies to purchase insurance. Some immigrants in New Mexico have received denials when attempting to purchase off-exchange insurance plans, even if they are willing and able to pay the full price. The NM Medical Insurance Pool (NMMIP) remains the sole source of insurance coverage for many immigrants in New Mexico.
- In addition to insurance and financial barriers, other issues that limit immigrant access to healthcare include: language barriers, cultural differences, misunderstanding regarding the need for preventive care, and fears around deportation and the possibility of jeopardizing future citizenship status. Additionally, there are the barriers faced by all families due to the complexities of navigating the health care system.

Action Requested:

1. The Task Force requests that the Office of the Superintendent of Insurance (OSI), the NM Medical Insurance Pool, the DOH Office of Border Health, and the leadership of the HM09 youth transition task force (FHB and CDD staff) develop policy recommendations that would improve access to health care for the immigrant population and report back to the Interim HHS committee with these recommendations by October 1, 2016.

Projected Cost: To be determined based on policy recommendations

E. Improving Payment/Reimbursement for Transition Services

For New Mexico's youth with special healthcare needs, the transfer of medical care from pediatric to adult providers can be problematic. This is true for both primary care and specialty providers. Pediatric providers may not understand how they can assist with this transition/transfer process or feel they have the time and tools to do so. Adult providers may not be aware of best practices around youth transition and may not be comfortable caring for young adults with disabilities.

The payment process can either facilitate or hinder the provision of these services. The task force heard evidence that existing barriers to transition services currently exist, including lack of provider knowledge about allowable codes for transition services (including consult codes, education around transition planning, and care coordination) and inconsistent reimbursement for these codes by the various insurance carriers and managed care organizations (MCOs).

Payment models should be optimized in order to:

- Facilitate a smooth transfer of care between pediatric and adult providers,
- Improve communication between pediatric and adult providers, families, and care coordinators,
- Reduce duplication of effort,
- Improve health outcomes for youth/young adults with special healthcare needs,
- Improve the patient experience of the transition process,
- Ensure that Medicaid codes currently available are utilized by providers to maximize reimbursement for transition-related services, and
- Incentivize adult and pediatric medical providers to do joint assessment and planning.

Action Requested:

The Task Force recommends that the Human Services Department (HSD):

1. Direct the MCOs to reimburse pediatric and adult medical providers for all currently approved CPT codes that would allow joint consultation around youth transition and transfer, including the possibility of joint patient appointments, conference calls, and/or telehealth consultation;

2. Direct the MCOs to provide outreach and education to providers so they are aware of the available codes and reimbursement;
3. Clarify with the MCOs that care coordination provided to youth with special healthcare needs should include a specific focus on facilitating the transition and transfer process; and
4. Work with their actuary to review the cost impact of providers utilizing codes for joint consultation around transition.

Projected Cost: Unclear: codes are currently allowable and may have already been factored into the MCO cost projections. Cost of services also might be made up by savings due to improvements in health outcomes and reduced duplication of tests and services during the transition/transfer process.

F. Interagency Communication and Collaboration

Youth in transition are served by several different agencies, but staff in these agencies frequently work in silos and do not coordinate transition efforts. The agencies most often involved (HSD, DOH and CYFD) are each headed by Cabinet Secretaries who serve on the Children's Cabinet. The NM Children's Cabinet, made up of the Governor's Cabinet Secretaries from Departments that serve children and families, meets multiple times throughout the year to hear reports and recommendations from children's programs and discuss child-related issues. Since 2005, the Children's Cabinet has produced an annual Children's Cabinet Report Card and Budget. The 2014 report can be found at <http://childrencabinetnm.org/>.

- A formal mechanism of interagency communication is necessary in order to foster seamless services and collaboration between agencies, promote sharing of information and ideas among staff from different agencies, and improve the healthcare transition process for youth in New Mexico served by these agencies and ultimately promote better healthcare outcomes for this population.
- This recommendation would also include communication and coordination with regards to the various waiver programs, especially between HSD and DDSD/DOH.

Action Requested:

The task force recommends that the Governor request the Children's Cabinet to discuss the issue of improving health transition for youth in NM, and specifically discuss improving the interagency communication around youth transition. In addition, we

request that the Cabinet Secretaries of the Human Services Department, the Department of Indian Affairs, the Children, Youth and Families Department, and the Department of Health each appoint a high-level staff person to provide joint oversight of this process and ensure its success. The process should include, at a minimum:

1. Improving the transition process for youth with special healthcare needs that ensures access to providers, continuity of care, and coordination between agencies involved;
2. Developing a formal communication plan for agency staff that would ensure collaboration around services including waiver services, among others; and
3. Mapping of systems and services available from each agency to aid in information sharing.

Projected Cost: None, other than staff time.

G. Complex Care Clinic

Complex Care Clinics, a relatively new phenomenon, are being established at hospitals and other health care organizations around the country. Complex care clinics specialize in care coordination to improve the quality of life for children and young adults with multiple chronic medical, developmental, behavioral, and/or psychosocial conditions – individuals who have the highest needs and are the highest users of inpatient and/or outpatient medical services.

Complex care Clinics are typically located at academic health centers and provide a comprehensive range of services, including:

- Inpatient and outpatient management of children and young adults with chronic, complex medical, developmental and mental health conditions;
- Education of patients and caregivers;
- Interpretation of subspecialty recommendations and coordination of care when multiple physicians and / or therapists are involved;
- Coordination of referrals, medical appointments, procedures and tests;
- Discharge planning;
- Guidance with guardianship and adult transition issues; and

- Assistance with palliative care and hospice issues.

Faculty from the UNM Department of Pediatrics are in the early stages of developing a plan for such a clinic at the University of New Mexico.

Action Requested:

The Task Force requests that that the Chancellor for Health Sciences and Dean of the School of Medicine facilitate the following:

1. A gap analysis documenting the potential need for a Complex Care Clinic at UNM which includes data on the number of potential clients and their locations throughout the state;
2. A preliminary plan which describes (a) the composition of the clinic, (b) a staffing plan, (c) how the Clinic could be a statewide resource in serving children and young adults with complex medical health conditions; (d) plans for coordination with existing clinics such as the Transition Consultative clinic and the clinics at the Center for Development and Disability; and (e) possible duplication with the Complex Care Clinic at Presbyterian Hospital and possibly other organizations which may consider starting a Complex Care Clinic; and
3. A financial feasibility study which includes a preliminary budget for the Clinic including staff, space, travel and other infrastructure costs (e.g., telehealth costs) as well as an assessment of possible funding sources for the clinic.

Projected Cost: The costs of preparing these plans and assessments would be borne by UNM as part of the planning process. Because of the interdisciplinary nature of Complex Care Clinics and the comprehensive services they offer, the financial feasibility study will be especially important in determining whether such a Clinic can be self-supporting or will need ongoing funds from UNM or a legislative appropriation.

H. Improving Oral Health Care for Youth in Transition

An important part of health care for youth in transition - but one that frequently receives little attention - is oral health care. This includes regular oral exams, caries risk assessment combined with patient education and self-management goals, regular application of fluoride varnish as well as dental procedures such as extractions, and referral to specialists such as oral surgeons when required.

Three issues stand in the way of improving the oral health of youth in transition:

- Every county in New Mexico except one is a dental practice shortage area as well as a medical practice shortage area. The Legislative Finance Committee has estimated that the state needs an additional one hundred and fifty three dentists, the great majority of whom are needed in rural, underserved parts of the state.
- While Medicaid includes payment for dental services, Medicare does not. Unless they are dually eligible under both programs, those individuals on Social Security Disability Income are not eligible for dental services. In addition, many ICD-10 codes related to dentistry are not reimbursable under Medicaid, while codes for medical procedures are.
- Finally, many dentists are not trained in how to provide services to youth with intellectual and cognitive disabilities, resulting in an even greater gap in services. While there are limited options available for accessing dental care such as dental insurance through the health care exchange, there are three initiatives currently underway in the state that may potentially have a positive impact on the oral health of youth in transition that do not rely on large-scale systems change.
- Lovelace Westside Hospital is expanding dentistry services for children with special health care needs. In all of 2014, the hospital saw 211 dental patients. By July 1 of 2015, the hospital has already seen already 214 dental patients. To meet the anticipated demand, the hospital has hired two additional nurses and invested \$15,000 in dental equipment, and plans to add dentistry services at the Lovelace Regional Hospital in Roswell in the future. Reimbursement for services is enhanced by using medical – not dental codes – for billing.
- The University Of New Mexico School Of Medicine’s Department of Dental Medicine has received a \$2.5 million grant to create additional educational and clinical opportunities for UNM’s special needs dental clinic. The five-year grant from the U.S. Health Resources and Services Administration will provide a special needs coordinator to oversee the academic program and direct patient care experiences for dental residents enrolled in UNM’s dental residency program. As part of this effort, discussions are underway between the Residency Program and the Center for Development and Disability (CDD) at UNM to have residents participate in CDD programs for children with intellectual and cognitive disabilities, including possibly participating in the Center’s Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program.
- UNM’s College of Nursing, the Dental Residency Program and the Center for Development and Disability are collaborating to address the problem of inadequate oral care for children through two grants from the Health Resources and Services

Administration. The first grant, which is in its last year, developed and implemented an innovative program that incorporated oral health into a team-based primary care setting at two clinics in Bernalillo, New Mexico. The second grant, which began August 1st, will implement this innovation statewide in collaboration with the Medicaid managed care system of Blue Cross Blue Shield.

Together, these three initiatives represent possible models to increase the oral health care provided to children and youth with special health care needs in New Mexico. However, they are either recent or new initiatives, and as such remain “promising practices” that may or may not be able to improve oral and dental health for youth in transition.

Action Requested:

1. The Task Force recommends that DOH Children’s Medical Services program (CMS), in collaboration with partners it identifies, contact personnel involved in these three initiatives to gather more information about the operation of the initiatives and any data that is being collected regarding the efficacy of the interventions, including their impact on the oral health of children with special health care needs. The Task Force further recommends that CMS report back to Legislative Committees in the fall of 2016 on any findings, along with possible recommendations on implementing one or more of these in additional locations in the state.

Projected Cost: CMS and partner organizations should gather this information using existing funds. The fall 2016 report may include recommendations for additional funding for one or more of these initiatives.

I. Remedy for the Problem of Providers Leaving Network

Youth with special health care needs may have multiple, complicated health issues that require a consistent and knowledgeable health care provider. When a youth with special health care needs is followed by the same health care professional in a consistent manner, it enhances the provider’s understanding of their medical conditions. But often, health care professionals change contracts or lose their affiliation with the Health Plan. This can throw the person’s care into chaos and create financial issues for the client and family.

Action Requested:

The Task Force requests that the NM Human Services Department Medicaid Program and all health care plans in the state offer a remedy for this situation as follows:

1. Private health plan policies – request the Office of the Superintendent to institute a rule for private health plans advertising changes and stating that their care coordinators would notify their youth with special health care needs members on a regular basis of provider changes so that advance planning and decision making can be made by the client for changes.
2. NM Human Services State Medicaid program (MAD) procedures for MCOs – 1. request MAD to include a provision for MCO contractors to advertise their current provider list for the upcoming year from September 15th thru October 31st (since open enrollment for Medicaid MCOs is October 15th through December 15th for the coverage starting January 1st), 2. Additional changes will be advertised quarterly by MCO care coordinators serving youth with special health care needs including changes needed to follow a provider to another plan or to a similar provider within the MCO. NM Human Services Department State Medicaid Program will provide education to contractors and enrolled clients on the ability to change providers and the method to request a change.
3. Provider responsibility (public and private) – request that the professional health care provider licensing entities and associations acknowledge the issue of provider changes and create informational letters or notices to their clients/patients.
4. Individual responsibility – educate clients and their families in methods to track provider continuity with both the provider place of service and the health plan. This could be part of an ongoing outreach and education or a larger Health Literacy pilot project in the state and will be included in Family Education recommendations.

Projected Cost: Not applicable

Appendix A:

House Memorial 9

A MEMORIAL

REQUESTING THE DEPARTMENT OF HEALTH'S CHILDREN'S MEDICAL SERVICES PROGRAM AND THE UNIVERSITY OF NEW MEXICO CENTER FOR DEVELOPMENT AND DISABILITY TO CONVENE A TASK FORCE TO CONDUCT A STUDY AND REPORT ON WAYS TO IMPROVE THE SYSTEM OF HEALTH CARE TRANSITION FOR NEW MEXICO CHILDREN AND YOUTHS WITH SPECIAL HEALTH CARE NEEDS.

WHEREAS, a 2010 national survey of children with special health care needs found that New Mexico had seventy thousand seven hundred twenty-four children and youths with special health care needs; and

WHEREAS, according to the national survey, the prevalence of children and youths with special health care needs between the ages of twelve and seventeen in New Mexico was seventeen and nine-tenths percent, compared to the national average of sixteen and eight-tenths percent; and

WHEREAS, children and youths with special health care needs between the ages of twelve and nineteen years of age are aging out of the pediatric medical environment and need to make a transition to adult health care providers; and

WHEREAS, there are few systems or resources available to aid pediatric and adult health care providers and children and youths with special health care needs and their families in the process of transition from pediatric to adult health care and

WHEREAS, numerous research studies have shown that policies, systems and services tend to lack coordination and are fragmented, and children and youths with disabilities and their families lack the information they need to successfully navigate the transition from pediatric to adult health care; and

WHEREAS, numerous research studies have shown that health care fragmentation and the lack of effective transition and transfer of health care services have a negative impact on the health of patients throughout their life spans; and

WHEREAS, optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care;

NOW, THEREFORE, BE IT RESOLVED BY THE HOUSE OF REPRESENTATIVES OF THE STATE OF NEW MEXICO that the department of health's children's medical services program and the university of New Mexico center for development and disability be requested to convene a task force on health care transition for New Mexico children and youths with special health care needs; and

BE IT FURTHER RESOLVED that the task force be composed of, among others, one or more young adults who are experiencing or who have experienced the transition process from pediatric to adult health care; and representatives of the university of New Mexico hospital, Presbyterian hospital, the medical assistance division of the human services department, parents reaching out, the New Mexico medical society, the office of superintendent of insurance, healthinsight New Mexico, the governor's commission on disability and special olympics New Mexico; and

BE IT FURTHER RESOLVED that the task force also include a family and community medicine physician, a pediatric physician and a psychiatrist specializing in services to children and youths with special health care needs; and

BE IT FURTHER RESOLVED that the task force also include representatives of the four medicaid managed care organizations providing services through the centennial care program; and

BE IT FURTHER RESOLVED that the task force be requested to identify and study existing barriers to effective health care transition and transfer services for New Mexico children and youths with special health care needs; and

BE IT FURTHER RESOLVED that the task force be requested to identify and study strategies to address the barriers to effective health care transition and transfer services, including evidence-based strategies that have been successfully used in other states; and

BE IT FURTHER RESOLVED that the task force be requested to make formal recommendations for changes to existing policies, programs and regulatory provisions or recommendations on new policies, programs or regulatory provisions that would:

A. address barriers to effective health care transition for children and youths with special health care needs;

B. result in more effective services for children and youths with special health care needs as they make the transition from pediatric to adult health care services;

C. improve the efficiency of the health care transition process;

D. ease the burden of the health care transition process both on patients and their families; and

E. maximize outcomes, including lifelong functioning and well-being, for children and youths with special health care needs; and

BE IT FURTHER RESOLVED that the task force provide a report of its review and recommendations to the secretary of health, the secretary of human services, the legislative health and human services committee, the disabilities concerns subcommittee of the legislative health and human services committee and the legislative finance committee by October 1, 2015; and

BE IT FURTHER RESOLVED that copies of this memorial be transmitted to the secretary of health, the secretary of human services, the chancellor for health sciences of the university of New Mexico, the director of the center for development and disability at the university of New Mexico, the president of the university of New Mexico hospital, the president of Presbyterian hospital, the executive director of parents reaching out, the executive director of the New Mexico medical society, the superintendent of insurance, the executive director of healthinsight New Mexico, the director of the governor's commission on disability and the executive director of special olympics New Mexico.

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Appendix B

Agendas

Health Care Transition Task Force

Agenda for Friday, January 16, 2015

9:00 am – 12:00 noon

DDPC Offices, 625 Silver Ave SW, Suite 100.

Parking is available in the parking lot on the east side of the building on 7th St..

Entry code to the parking lot is 6251.

9:00 Welcome and Housekeeping - Liz Stefanics

- Restrooms, coffee, water, name plates, sign in sheet, etc
- Sponsors of this task force
- Role of Members
- Sponsors of memorials – Tony Cahill

9:10 Self Introductions

- Name, agency, specific relationship to interest

9:30 Overview of the Problem and Issues - Janis Gonzales

9:45 Comments from participants

10:00 Comments on Financial and Service Provision Aspects - Tony Cahill

10:15 Additions from participants

10:40 Break

10:50 Concerns from Participants

11:15 Parameters of the Task Force - Short Term, Long Term, Low Cost, High Cost - Susan Chacon, Janis Gonzales, Tony Cahill

11:30 Future Organization of Task Force

- Participant panels on areas of expertise (**March and May**)
- Small group discussion and recommendations (**ongoing**)
- Large group discussions and recommendations (**ongoing**)
- Action Plan Development (**June and August**)
- Final Recommendations - Regulations, Policies, Budget, Legislation (**August**)

12:00 Adjournment – Future Meetings – Fridays, March 27th, May 1st, June 26th, August 28th

March 27, 2015 Meeting

UNM Center for Development and Disability

Room 109 East Bldg, 2300 Menaul NE, Albuquerque

9:00 am – 12:00 noon

9:00 Welcome – Housekeeping – Reintroductions – New Members

9:15 Information Sharing

9:15 Data Maps – clients and health care providers (Susan Chacon and Janis Gonzales, DOH)

9:35 A Walk thru the Transition Process or Flow Chart of the Transition System (Tony Cahill and Elaine Brightwater, UNM CDD)

9:55 New Mexico Indicator-Based Information System Overview (IBIS) (Susan Chacon)

10:00 Panels

10:00 Clients and Family – Barbara Ibanez and Siri Guru Nam Khalsa

10:30 Social Workers and Social Service Agencies – Doris Husted, Madelyn Krassner, Cathy Castle Franklin

11:00 Health Care Providers – Sandy Whisler, Sheena Ferguson, Irene Moody

11:30 Group discussion of best practices in NM – Do they exist? Where?

Leave Behind - What is needed in NM to accomplish more successful transition?

12:00 Adjournment

Next meeting – May 1, 2015. 9:00 am – 12:00 noon

Topic: Finance

May 1,2015 Meeting
MCM Elegante, Atrium Ballroom
2020 Menaul Blvd NE, Albuquerque
9:00 am – 12:00 noon

- 8:30 Continental Breakfast
- 9:00 Welcome – Housekeeping – Reintroductions – New Members
- 9:15 Legal Panel
UNM Medical/Legal Alliance – Yael Cannon, Esq., UNM Law School
DDPC Guardianship - Marina Cordova, Esq., DDPC
Immigration Coverage – Maria Griego, Esq., NM Center on Law and Poverty
- 10:00 Finance Structure

Office of Superintendent of Insurance – Aaron Ezekiel, Director of ACA Implementation for the Office of the Superintendent of Insurance
IHS 638 Program – Dave Antle, CEO, Isleta Health Clinic
Medicaid Financing – Kari Armijo, Health Care Reform Manager, Medicaid
Medicaid EPSTD – Barbara Czinger, EPSTD, Medicaid, NM HSD
- 11:00 Individual Rankings

Small Group Discussion of Recommendations

Large Group Discussion of Recommendations

What is needed in NM to accomplish more successful transition? What recommendations are missing?
- 12:00 Adjournment

Next meeting – June 26th, 2015. 9:00 am – 12:00 noon, Location TBD

Topic: Refinement, Analysis, and Acceptance of Recommendations

June 26th, 2015 Meeting

UNM Center for Development and Disability

Room 103 East Bldg, 2300 Menaul NE, Albuquerque

9:00 am – 12:00 noon

- 9:00 Welcome – Housekeeping
- 9:10 Information Sharing by the MCO's
- 9:10 Blue Cross Blue Shield
 - 9:25 Presbyterian – Mari Spaulding-Bynon, ED, Clinical & LTC Operations
 - 9:40 Molina Healthcare – Cathy Geary, Director of Healthcare Services
 - 9:55 United HealthCare – Tena Ross, MCH & Specialty Programs Coordinator
- 10:15 NM Medical Insurance Pool – Debbie Armstrong, ED
- 10:30 Break
- 10:45 Priorities Missed or Not Stated – Group Vote of 50% to Include
- 11:00 Framing of Priorities – Janis Gonzales, Medical Director, DOH CMS
Participant Explanation of Priorities
Analysis of Suggested Priorities
- 11:45 Vote on Priorities for Report – 75% Threshold
- 12:00 Adjournment

Next meeting – August 28th, 2015. 9:00 am – 12:00 noon

Topic: Report Wrap Up

August 28th, 2015 Final Meeting
UNM Center for Development and Disability
Room 109 East Bldg, 2300 Menaul NE, Albuquerque
9:00 am – 12:00 noon

- 9:00 Welcome – Housekeeping
- 9:10 Reframing – Tony Cahill and Janis Gonzales
- 9:30 Review Priority Papers Individually
- 9:45 Presentation of Priorities to Large Group w/ Clarifications
- Change Enrollment Period (Remedy for . . .)
 - Training of Providers
 - Payment Issues
 - Improving Oral Health Care
 - Interagency Communication and Collaboration
 - Family Involvement and Education
 - Guardianship
 - Complex Care
 - Access to Health Transition Services for Immigrants
- 10:45 Break
- 11:00 Acceptance or Group Vote
- 11:45 Wrap Up, Next Steps, and Thanks
- 12:00 Adjournment

**Presentation to Legislative Interim Committee in Santa Fe at the State Capitol on
Thursday, October 22nd, 2015**