PATHWAY TO COORDINATED CARE SYSTEMS FOR CHILDREN

Desirable developmental footholds for identifying and addressing:

a. **The needs of pregnant women and young children to age 3,**
b. **Risk reductions for Child with Special Health Care Needs (CSHCN) for children at risk, e.g., children exposed to prenatal drug/alcohol use,**
c. **Desirable parental actions on behalf of young children experiencing neglect, and**
d. **Ascent to early adulthood.**

Prologue

The J Paul Taylor Task Force has spent the past years working to prevent child neglect and abuse. The work presented here builds on documents presented to the J Paul Taylor Task Force from 2015 to present and discusses how development of footholds at specific ages supports adequate and appropriate parenting while preventing child neglect.

The question is, what potential resources and coordination are (will be) needed – and available – to support pregnant women, parents, and young children to ameliorate or prevent the risks of Adverse Childhood Experiences (ACEs). ACEs include conditions such as neglect or abuse and drug/alcohol use that lead to a designation of Children with Special Health Care Needs (CSHCN). Ideally, resource, idea and implementation coordinators will incorporate a "2-generation 2-brain" set of plans and strategies that includes mothers, fathers and extended families for children from prenatal period to age 3 and young adults to age 25.

Epidemiology

Data indicate that as many as 60% of all people in the US (and specifically in NM) have experienced an Adverse Childhood Experience (ACE) before 18 years of age, and 50% of US children under age 5 have had at least one ACE. Systems surrounding children and families offer unique opportunities to act to prevent ACEs and to create pathways to better health outcomes for children who have experienced an ACE. To accomplish this will require all systems to identify and leverage key moments in the lives of families and their children when those opportunities arise. That would mean implementing prevention schemes which identify the presence of ACEs earlier and creating earlier pathways to better outcomes in the lives of affected children.

US data indicates 16-20% of all children have special and medical healthcare needs beyond those of the average child. Medically complex health conditions such as chronic diseases or genetically inherited conditions are a subset of this group. When including children with emotional and behavioral conditions (a group with incomplete epidemiological data) the proportion of children needing greater care services may well exceed the 20% baseline level of all US children. A diagnosis of a chronic health condition such as prematurity, developmental delay, chronic health condition or mental illness creates major perturbations to a family's systems when conceptualizing next steps for their child. Additionally, every child who experiences an ACE has increased risks for poorer health outcomes, higher health risk behaviors and poorer outcomes for any chronic disease condition. The parent of a child who has had one or more ACE or special child healthcare need experiences grief, anger, sadness, and being overwhelmed with limited resources – both immediately upon identification and over the child's life.

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Current care systems organize vertically to address specific diagnoses such as Child Abuse, Obesity, Smoking, Asthma, etc., and rarely extend horizontally or collaboratively to support overall physical and mental wellbeing of the family around the child. This substantially impacts overall outcomes. Additionally, care systems rarely identify goals for children transitioning into adulthood - because historically these children simply didn't make it into early adulthood.

Opportunities for creating developmental footholds

1. **Identifying at-risk nature of a pregnant mother (screening)(modeled after MILAGRO program)**
2. **Birthing of an infant (modeled on FOCUS Program)**
3. **Well-person care for mother and infant at regular intervals (modeled on FOCUS and EMBRACE programs)**
4. **Young child screening for ACEs at regular intervals and/or as reported by parent(s)**
5. **Supporting adolescents in avoiding high risk behaviors that interrupt educational progress (modeled on ADOBE program)**
6. **Supporting adolescents in fulfilling their education and/or employment/career opportunities**

Opportunity #1 - Identifying at-risk nature of pregnant mother (screening)
(Modeled after MILAGRO Program)

DESIRABLE PRECURSOR CONDITION – mother (and family support system) plans for and desires this birth versus, a mother does not want this birth or has an unplanned pregnancy without anticipating adequate support.

The couple anticipating a healthy pregnancy should plan and take steps to ensure their personal health issues are addressed before conception. When a mother becomes pregnant, a series of events become predictable and inevitable; both challenges – and opportunities – are set in motion. These become more manageable as they are acknowledged, communicated and receive appropriate and meaningful follow up. Lack of this planning results in either an infant with a less-than-optimal start in life or a decision for termination of a pregnancy.

DESIRABLE PERSONAL ACTION – *planning for conception* – to the best of their abilities, before pregnancy a couple should address underlying health, behavioral health and personal problems including finances, access to health care, help for untreated or undertreated mental illness and/or substance use disorders, and (when appropriate) acquiring information related to genetic risks that couple may pass to their child. This would mean that from the start the woman's pregnancy will have the best health processes and outcomes possible.

DESIRABLE SYSTEM ACTION – *prenatal care* – the first prenatal visit sets the standard for prenatal care. However, that screening currently places greater emphasis on biomedical conditions than on biopsychosocial or health harming social determinant conditions that also have major impacts on pregnancy outcomes and infant health. What is needed is a comprehensive discovery conversation and exploration between a knowledgeable health provider and the parent(s) beyond the current standard first automatic intake procedure which only views social and health conditions.

A comprehensive discovery conversation can lead to improved preventive interventions to protect the pregnant woman. The resulting discoveries would contribute greatly to preventing onset of identified health or psychosocial challenges, reducing the effects of existing conditions,

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identifying health challenges to the developing fetus, reducing risks of premature delivery, and reducing risks of permanent health or social disabilities. The American College of Obstetrics and Gynecology, the American Academy of Family Practitioners and others identify comprehensive prenatal screening including health harming social determinant issues as required care. The obligation to screen also places an obligation on the providers and systems in which providers practice to have identified meaningful interventions for managing and reducing the effects of positive screen results.

DESIRABLE FACILITATOR – *integrated medical home office model of prenatal care providers* – the clinical setting should be organized and structured to provide comprehensive screenings and include appropriate supports within the office – or readily available with a warm handoff referral. This follows the Early Start program described by the Northern California Kaiser Permanente health systems that placed counselors and social workers into prenatal care clinics so that providers could make a "warm handoff" when screening found potential problems.

DESIRABLE FACILITOR – *MCO and Insurance Carrier care coordination* – should have access to a very user-friendly data portal containing comprehensive information on services available in the neighborhood, community, county, region, and state that can address the needs of the pregnant woman and her family: transportation, food, shelter, behavioral health care, substance abuse treatment, etc. The questions surrounding this are, what support service/provider databases are available, how comprehensive are they, are they really user-friendly/intuitive, is additional staffing needed to meet community needs, where will they be found, where fill funds come from? Also, the care coordinators should have capacity to view utilization of services to assist with coordinated planning.

POSSIBLE INHIBITOR – medical practice and health care organizations lack capacity for comprehensive prenatal care and specialist networks.

POSSIBLE INHIBITOR – insufficient MCO capacity for caseload care coordination and less-than-full knowledge of all available service systems.

DESIRABLE INTERIM OUTCOME – parent/family have increased engagement with behavioral health counseling services, psychiatric care, specialist health care and/or substance use disorder treatments.

DESIRABLE INTERIM OUTCOME – delivery of appropriate services with appropriate providers present or accessible through referral network (integrated care systems) that can intervene if necessary for emergency conditions affecting delivering mother and infant.

DESIRABLE INTERIM OUTCOME – parents (one or two), ideally with some extended family support and with identified and available financial resources.

OPPORTUNITY 2 - Birthing of an infant (modeled on FOCUS Program)

DESIRABLE PRECURSOR CONDITION – applying information obtained from appropriate and timely communications from prenatal care providers, a medical team prepared for the infant's delivery that understands the unique characteristics of each particular mother's and baby's needs.

DESIRABLE FACILITATOR – a facility and provider team prepared for both normal and emergency conditions around labor and delivery affecting infants. This includes commitment to

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standardizing procedures of post-delivery skin-to-skin care and support of breastfeeding in the labor room

DESIRABLE INTERIM OUTCOME – completed screening for health conditions affecting newborn including: evaluation of prenatal screening information (ID conditions, substance use, Coombs and AST screening, etc.). Results communicated appropriately to health providers involved in women's delivery with solid patient privacy safeguards.

DESIRABLE FACILITATOR – written medical discharge plans for mother and infant, such as the Plan of Care, with monitoring to establish and sustain continuity of support during first 3 - 5 years – ideally coordinated with the MCO.

DESIRABLE FACITATOR – *MCO care coordination* – What are the needs of this specific infant and parents? MCO Coordinator should have access to a very user-friendly data portal containing comprehensive information on services available in the neighborhood, community, county, region, and state that can address the needs of the new mother, infant and her family: transportation, food, shelter, behavioral health care, substance abuse treatment, etc. The questions surrounding this are, what support service/provider databases are available, how comprehensive are they, are they really user-friendly/intuitive, is additional staffing needed to meet community needs, where will they be found, where fill funds come from?

POSSIBLE INHIBITOR – weak or non-existent communications between prenatal care providers and health services systems where women deliver infants.

POSSIBLE INHIBITOR - insufficient MCO capacity for caseloads care coordination and less-than-full knowledge of all available service systems.

DESIRABLE INTERIM OUTCOME – mother's continuing primary care is coordinated with peri-partum care, using an explicit model of warm handoff that interfaces with treatment for substance abuse disorders, gestational diabetes, hypertension, etc. as necessary.

DESIRABLE INTERIM OUTCOME – mother has continuing psychiatric and/or behavioral health care coordinated with peri-partum care, using an explicit model of warm handoff that interfaces with treatment for substance abuse disorders, mental illness, postpartum depression, etc. as necessary.

DESIRABLE INTERIM OUTCOME – infant primary care is coordinated with mother's care. This would include mother's peri-partum care information, using an explicit model of warm handoff that applies to infants affected by prenatal substance abuse, gestational diabetes, hepatitis C, etc. as necessary.

MEASURABLE OUTCOME – infant and mother successfully transition from peri-partum care in good health with interim challenges resolved such as successful breastfeeding, jaundice, maternal glycemic control, delays in infant growth, etc., as necessary.

Opportunity 3 - Well-person care for mother and infant at regular intervals (modeled on FOCUS and EMBRACE programs)

DESIRABLE PRECURSOR CONDITION – mother and infant have access to primary care and other health care specialists as necessary with access to specialized care when appropriate.

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DESIRABLE FACILITATOR – ideally coordinated with MCO, this facilitator should establish sustainable continuity of support during the first 3 - 5 years. This care should continue the written discharge plans for mother and infant with monitoring of access to care, interventions for any positive screens, and facilitated access to referral care sources. (Medical guidelines under Medicaid address health maintenance, the EPSDT model for children until age 21 with interval contact, and appropriate screening for biopsychosocial conditions affecting health outcomes. These guidelines reflect consensus agreements, not evidence-based prospective population health services studies. US Preventive Services Task Force also has guidelines for adult health maintenance from at least consensus statements.)

DESIRABLE FACILITATOR – inclusion of any appropriate screening for legal conditions affecting child/family health outcomes; this may include establishing medical-legal partnerships.

DESIRABLE INTERIM OUTCOME – mother has continuing primary care that documents appropriate screenings at appropriate intervals for family violence (Survey of Well-being of Young Children Family Questions), mental illness (PHQ2 or PHQ9), substance use disorders 9Ps Plus, CAGE, etc.), diabetes, cervical cancer, etc.

DESIRABLE INTERIM OUTCOME – mother has primary care with appropriate discussions of reproductive health at appropriate intervals with full access to al contraceptive methods.

DESIRABLE INTERIM OUTCOME – mother has access to continued psychiatric and/or behavioral health care coordinated with primary care and with early connection to services in rural and urban communities that have capacity to provide care for substance use disorder, mental illness, behavioral health issues affecting chronic health conditions, etc.

DESIRABLE INTERIM OUTCOME – child has continuing primary care that documents appropriate screenings at appropriate intervals for family violence and/or parental substance use disorders or mental illness (Survey of Well-being of Young Children Family Questions), child substance use disorders (Bright Futures HEEADSS Screening), BMI, BP, etc.

DESIRABLE INTERIM OUTCOME – child has access to continued psychiatric and/or behavioral health care coordinated with primary care and with early connection to services in rural and urban communities that have capacity to provide care for substance use disorder, mental illness, behavioral health issues affecting chronic health conditions, etc. through childhood into early adulthood.

MEASURABLE OUTCOME – mother successfully progresses towards improved health conditions from screenings and early detection leading to management of mother's health towards reduced T2DH, overweight, cervical or breast disease, etc.

MEASURABLE OUTCOME – child successfully transitions from preschool to primary school, from primary school to middle school, and finally achieves high school Diploma or GED.

Opportunity 4 – Young child screened for ACEs at regular intervals and/or as reported by parent(s) for prevention of child neglect.

DESIRABLE PRECURSOR CONDITION – regular developmental screenings such as Survey of Well-Being of Young Children (SWYC). SWYC has Family Questions that address many known ACEs: maternal postpartum depression, smoking in home, excessive use of substances by

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adult caregivers, conflict among adults in home. SWYC also screens for with infant and young child development problems from 4 months to 60 months of age.

DESIRABLE PRECURSOR CONDITION – all primary care providers agree to ACEs screenings as the standard for health practice and the integration of health care systems, including IT systems, with insurance carrier systems. In particular, insurance carriers should make reimbursement schedules for screenings available – and – participate in these screenings as part of their new insurance client health risk assessment to identify those with higher risk profiles.

DESIRABLE PRECURSOR CONDITION – a positive screening results in actions by those obtaining the data. Health systems commit to networking services required to address the identified challenges, such as support for parents who indicate a wish to stop smoking.

POSSIBLE INHIBITOR – lack of appropriate services for family referral when the screening shows positive screen results. Successful referral completion depends on identification of, and accessibility to, providers in the family's geography and/or network of providers.

POSSIBLE INHIBITOR – current EMR systems do not allow entry of screenings form child development data that would allow for inquiry and analysis. This means providers cannot track screenings results to observe whether ACEs risks are increasing or decreasing over time.

MEASURABLE OUTCOME – sequential tracking of the screening forms through childhood shows reduction of or zero child ACEs.

MEASURABLE OUTCOME – the family creates an emotionally and intellectually supportive home environment. The child experiences family involvement with educational progress. The family supports child development intervention when implemented. The child is not referred to Child Protective Services for substantiated child neglect.

Opportunity 5 - Supporting adolescents in avoiding high risk behaviors that interrupt educational progress (modeled on ADOBE program)

DESIRABLE PRECURSOR CONDITION – adolescent has experienced successful primary school completion and has developed appropriate cognitive skills to support success in middle school.

DESIRABLE FACILITATOR – child has internalized appropriate emotional and behavioral regulatory skills through preschool to third grade to meet or exceed the increased educational, social and emotional expectations from third grade onward.

DESIRABLE FACILITATOR – families have had necessary financial, legal, behavioral, and physical health support so they could enhance and ensure their child(ren)'s educational progress.

POSSIBLE INHIBITOR – schools lack appropriate services for addressing individual child needs. For example, young children who have experienced ACEs in family life manifesting excessing shyness, withdrawal, inattention, impulsivity, aggression, bullying, or defiant behaviors.

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POSSIBLE INHIBITOR – communities lack appropriate services for addressing individual child needs. For example, lack of local behavioral health care providers, lack of access to adequate finances, poorly coordinated health care systems, health care providers not screening appropriately for emotional or behavioral problems.

MEASURABLE OUTCOME – child is successfully progressing towards significant educational progress. For example, demonstrating improved readiness for formal learning, improving peer interactions, demonstrating critical thinking, individualized trajectories showing annual progress, etc.

MEASURABLE OUTCOME – child experiencing family involvement and support for her/his educational progress. Family attends school conferences, events, celebrations.

Opportunity 6 - Supporting adolescents in fulfilling their education and/or employment/career opportunities

DESIRABLE PRECURSOR CONDITION – adolescent graduates from high school or attains GED with demonstrated critical thinking abilities and an effective ensemble of skills that will support them in achieving their future goals.

DESIRABLE FACILITATOR – plans and financial support are in place and social determinant factors are addressed to facilitate achievement in additional education.

DESIRABLE FACILITATOR – vocational opportunities with possibilities for further skill enhancement and career advancement are accessible. Social determinant factors have been addressed to facilitate participation in the job or entrepreneurship economy, employment free from harassment, etc.

POSSIBLE INHIBITOR – families and their systems surrounding the young person do not have capacity to provided needed supports or protect the young adult from adverse experiences such as, abuse, sexual exploitation, criminal justice system encounters, substance use, etc.

POSSIBLE INHIBITOR – continued supports are lacking for adolescents or young adults with chronic developmental delays or mental health challenges.

MEASURABLE OUTCOME – adolescent or young adult achieves personal financial independence and security. They can access appropriate familial and/or social assistance to support these accomplishments.

MEASURABLE OUTCOME – adolescent or young adult with ongoing needs receives appropriate social services support, financial guidance, care coordination, health coverage, and other supports to optimize conditions of individual independence with a plan for transitioning and sustaining supports when family systems can no longer provide them.

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