Comprehensive ENgagement to Develop Enhanced Resilient Outcomes (CENDERO)

A recent story in Quartz[1] highlights the clinical practice of an esteemed colleague, Dr. Javier Aceves, the former medical director at a University of New Mexico primary pediatric clinic, and his care for "Juan" over 14 years. Juan grew up with a mother who had alcohol use disorder in her pregnancy and who had difficulty providing the consistent unqualified loving parenting Juan needed. Dr. Aceves, working in a clinic located in an area of Albuquerque with high health and economic needs, saw Juan from infancy until his early teens. The life long challenges ended for Juan when after dropping out of school he tragically died at age 14 or 15 from gunfire at a party. As the article quoted, Dr. Aceves observed, "We knew that this could happen and we couldn't change it."

The life trajectory that Juan experienced and that his mother and siblings experienced underlie the essential reality and challenge for New Mexico and health care systems. We live and work in a state ranked 50th among states for child well-being as measured by the 2018 Kids Count Data Book.[2,3] Along with the poor rankings, different parts of the systems working with families and children and high risk have begun to acknowledge the presence of Adverse Childhood Experiences (ACEs) that start in early childhood likely affecting almost 50% of children by age 5[4] and 60% by age 18[5]. We live in a state that fails in an essential societal obligation to prevent children from acquiring ACEs and failing to meet the needs of its children, particularly for those at highest risks. In part, the failures happen because the systems around children and families operate in service systems and funding mechanisms that make collaboration difficult. Though children and families demonstrate survival capacities, incomplete and siloed systems fail to integrate information and services that might enhance the inherent resilient capacities of children and families at risk.

The reality for children and families at high risks is that in pregnancy and early childhood through age five when children have many medical contacts, medical interventions focus on complex health factors affecting long term health and brain development. Health care providers know that children and families face more complex social challenges, know about the presence of potential ACEs in the lives of children, and yet health systems have not committed resources or talent to addressing the social conditions affecting children and families. Health care providers watch generations experience the same risk factors and feel helpless or blame the economic conditions of the families.

There is a transition for families at high risk to services in the educational systems. Teachers see children like Juan in their classrooms and know that resources at school are not adequate to direct much of the interventions that might reduce the effects of ACEs and other risks. There are no easy ways of bringing in health collaborations for children like Juan. From early adolescence into young adulthood, youth like Juan with risks began transitioning from the educational system to the mental health and criminal justice arenas. Again they do not receive integrated comprehensive services that work in concert to reduce the risks of the young person and their families for tragic outcomes. At each step the necessary systems fail to connect their work in ways that could change the life courses of children like Juan.

The challenges as described in the next paragraphs seem daunting, but health systems may be poised to provide leadership and working demonstration models that can connect health, education, and social determinant efforts together to directly improve the measures that have dropped New

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[1] Anderson J. "ROAD TO RESILIENCE: The scientific effort to protect babies from trauma before it happens." Quartz, June 22, 2019, at qz.com/1629793/the-scientific-effort-to-protect-babies-from-trauma/

[2] 2018 NEW MEXICO KIDS COUNT DATA BOOK, New Mexico Voices for Children downloaded from https://www.nmvoices.org/archives/12369

[3] **"New Mexico Rankings." Downloaded from https://www.aecf.org/m/databook/2019KCprofileNM.pdf**

[4] Hunt TKA, Slack KS, Berger LM. "Adverse childhood experiences and behavioral problems in middle childhood." Child Abuse & Neglect 67 (2017) 391–402

[5] **"Adverse Childhood Experiences Reported by Adults — Five States, 2009."** December 17, 2010. MMWR Weekly / Vol. 59 / No. 49

Mexico into the worst position in the US. Programs specifically designed to address the issues of drug use in pregnancy coupled with behavioral health support connected to programs that have developed at two-generation two-brain model of care may form the design of how health care systems can respond to the needs of populations of families excluded or marginalized by the existing systems. These programs can support the developmental growth of infants and young children while stabilizing the parents of the children through substance use disorders treatment and support and support for co-occurring psychiatric needs. The continuity of effort over the first two to three years of the child's life coupled with a comprehensive prenatal substance use program can build four years of support for families who previously would drop out of sight. Measures of progress for the family include improved biophysical parameters of the children, reduced numbers of young infants with developmental or socio-emotional risk factors, and increased numbers of children qualifying for regular education services, not Child Find special education, at age three.

After a child and family complete services for early childhood, some will have ongoing learning and behavioral challenges. Demonstration programs have begun exploring how to accept a warm hand off for integrated services wrapping around children and the families affected by familial substance use disorders, parental mental illnesses, or acquired ACES. This type of service model would collaborate with schools for children from ages three to teen years focused on children who have emotional behavioral issues that exceed what schools can serve. This type of program recognizes the potential impact of ACES affecting the parent and child generations and designs services through the employment of navigators (community health worker type positions) who will meet the families at schools and with their permission start home visits to assess possible social determinant issues affecting the family as well as helping access issues for mental health care or substance use treatment for family members including siblings. This type of program and the services provided might have changed the course of life for a Juan, his mother, and the extended family that Dr. Aceves served. For older teens who have encountered the criminal justice system, programs have started to wrap services around the young person and their families with the intention of reducing their risk of repeated incarcerations. The program has extended wrap around services including home-based navigation, educational supports, psychiatric and mental health care, and primary medical care to the siblings, parents, and relatives of youth released from incarceration. Due to challenges with the service systems, the program planning has recognized the need extends through the early twenties for youth.

The programs that exist in New Mexico start in prenatal care and provide the potential of connected continuity of care through at least 21 years for children and families with risks similar to those of Juan and his mother. The close affiliation of the programs with primary care providers working in a health system has created the essential collaboration to address complex health issues across generations and through the life span of children and families. The key has been the involvement of primary care providers, generalists, who have created and sustained the model programs.

The concept introduced in the description of CENDERO describes a path with many chances for families and their children affected by ACEs to have continuing organized primary care through primary care services coupled to teams of support staff from birth to early adulthood. The CENDERO model provides a template on which similar work can organize to address other major health care issues that affect patients in health care systems.

The CENDERO approach describes a response to the requests for a name to encompass all the programs that have grown up serving some groups of patients and families with high risk factors. The supporting rationale for connecting programs follows:

The potential of the programs grouped under the CENDERO banner responds to the current state of challenges for our state's population. The data from 2018 and the recently published 2019 Kids Count finds New Mexico with some of the highest rates of infants born at low birth weight, 9.5% compared to 8.3% in the US, a rate that has increased from 2010. Among families in New Mexico, child and teen deaths occur among 32 per 100000 compared to 22 per 100,000 in the US and adolescent abuse of alcohol and drugs is 50% higher, 6% for our state compared to 4% for the

nation. These statistics place New Mexico at 48th among states for health measures. We place 50th for family measures, and as an example we have among the highest rates of teen pregnancy, 28 per 1000 births compared to 19 per 1000 in the US, a rate 50% higher than the nation. 45% of children in New Mexico live in single parent households compared to 34% in the US.

The Kids Count data measures educational benchmarks, and New Mexico places 50th compared to the US. Of young children, 56% of 3 and 4 year olds do not attend school compared to 52% in the US. 75% of fourth graders do not read at level compared to 65% in the nation. Only 71% of youth in New Mexico graduate from high school on time compared to 85% for the US.

Economic indicators follow with the other low rankings for the state. New Mexico places 49th in part because 10% of teens are not in school or employed compared to 7% in the US. 27% of children in New Mexico live in poverty compared to 18% among US children, a 50% higher level of poverty that piles on the disadvantage for children growing up in the state.

There are a few bright spots. Only 5% of children in New Mexico lack health insurance, a rate that is the same as the US, and 50% lower than 2010. The numbers of households headed by an adult with a high school diploma has increased to 84% from 80% in 2010. Among households in the US, 87% have an adult who has graduated high school.

Examining the data available leads to an important recognition that the health of the peoples of our state has to include physical and mental health, educational progress and skill acquisition, and systems changes to reduce the impacts of health harming and education harming social determinants. The programs created at the Health Sciences Center and sustained over almost 30 years offer promising solutions.

With the creation in the late 1980's of a comprehensive prenatal and substance treatment program demonstrated how primary prenatal care providers can deliver care to provide the best pregnancy outcomes for women identified with prenatal substance use disorders. The comprehensive prenatal care includes connection to medication assisted treatment for opioid substance use disorders, a major contributor to maternal morbidity in pregnancy, low birth weight infants, prematurity, and longer hospitalizations after birth. The implementation of buprenorphine medication assisted treatment with induction in pregnancy has resulted in increased rates of term and near-term deliveries and a reduction of numbers of infants born with prenatal opioid exposure requiring medication assisted treatment for Neonatal Opioid Withdrawal Syndrome (NOWS). The experts involved in the care of infants with prenatal opioid exposure report informally that the rate of prolonged treatment with medication for infants in the UNM Hospital nurseries to be less than 50%[6]. The hospital nurseries with the leadership of medical directors has implemented an innovative inpatient care model for mother-infant dyads affected by prenatal opioid exposure, the Eat, Sleep, and Console Model, that has further improved the hospital course of infants and supported the early parenting efforts of new mothers.[7] Those concepts are spreading to other hospital systems in the state resulting in reduced days of stay and better care for infants and mothers. A key feature of the comprehensive prenatal programs are the continuity of provider contact with pregnant and newly delivered mothers. The personalization of contact between the providers and the patients has created strong engagement with the process of care, the development of trust in the care received, a care model that supports better health outcomes. (See Opportunities 1 and 2 in PATHWAY TO COORDINATED CARE SYSTEMS FOR CHILDREN).

If reducing hospital days or delivering an infant at term were all that was needed to alter the life course of a child like Juan, Juan and his mother should not have had the disrupted course documented by Dr. Aceves. However, the complexity of Juan's mother's substance use disorder required a higher level of support through the early years of childhood because of the inherent challenges of parenting as well as the social contexts that enable relapse to use. Programs developed for infants with prenatal drug exposure began to provide coordinated care for infants with prenatal poly-substance exposure. The programs were designed to support the health of the young child, to monitor and intervene for developmental delays caused by alterations in brain systems by alcohol

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6 Personal communication from UNM FCM MCH and FCM and Pediatric ICN attending physicians, 2019

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and drug exposure in fetal development, and to prevent the infant from acquiring Adverse Childhood Experiences. The model hired the developmental specialists who created combined early education activities in the family homes over the first three years of life with care coordination for the children and families with a primary medical home. After several years, leaders of the program saw that provision of high quality primary care for only the children was necessary but not sufficient to alter the health course of the family. The program expanded beyond caring for parents with substance use to including parents with metal illness, domestic violence in homes, and unsupported teen parents. The goal of the organized care coalesced around the question that haunted medical providers when a young child asked "can you care for my mom like you do for me and brothers?"

The program has achieved better outcomes for many families that started like Juan's. Through collaborations with primary care providers staffing, the coordinated primary care model moved into community clinic settings where the medical team began addressing the health and mental health needs of parents in the context of the care of their young children. Coupled to the evolution of the comprehensive medical home, the program built and funded an early development team. The model of early intervention changed the community standard of center-based care to home-based services. During the transition, the new model required more structured and evidence based approaches that included multiple efforts to incorporate evidence based curricula. The development of services moved in parallel with sustained efforts to financially support the developmental team. The program leadership realized that to financially sustain the developmental program, the solution included bringing the early intervention program under the Family Infants and Toddlers funding from the NM Department of Health. As it became established as an early intervention program, the program was enfolded into the other academic centers to enhance the types of services available to young children. From the beginning, the program leaders recognized the provision of early intervention coupled with comprehensive primary care reduced parental distraction with substance use to focus on the needs of the young children in the home. Data for children "graduating" from the early intervention medical home program between ages two and three find 80% of children with prenatal drug exposure appear prepared to move into regular pre-school settings. 20% qualify for special education services for multiple areas of developmental delay, a rate similar to the 16 to 18% of all three year olds qualifying for special education services in the general population. (See Opportunities 3 and 4 in PATHWAY TO COORDINATED CARE SYSTEMS FOR CHILDREN).

However, working with some children to age 3 does not address the longer term challenges for families. Children move from the sphere of frequent medical contact after infancy, the period when primary care medicine may have a preventive role, into the sphere of education where the nascent skills built in early childhood confront increased expectations for acquisition of knowledge. Health systems have largely disengaged from the essential role good health plays in knowledge building restricting its involvement to sports physicals and acute care contacts.

The availability of universal early childhood education in the current school systems does not mean the systems have teachers or ancillary personnel with the experience to address the manifestations of a child's behavioral patterns who experienced ACEs in early childhood. The child's behaviors when stressed often result in classroom behaviors that prevent enrollment into pre-school or causes expulsion from schools. Young children with social-emotional disorders have a much higher risk of not completing primary education and dropping out of school. In addition, institutional failures in the implementation of the Individuals with Disabilities Education Act (IDEA) play a major contributing role in poor outcomes for many students with social, emotional and behavioral challenges.[8]

The concept of a newly developed program anticipates children entering schools with emotional behavioral challenges that exceed the capacity of school personnel to adequately address. Often children will start school with learning levels below their age without enough delay to qualify for the special education services called for in federal law, services such as Child Find services in New

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8 Yael Cannon, Michael Gregory, Julie Waterstone. "A SOLUTION HIDING IN PLAIN SIGHT: SPECIAL EDUCATION AND BETTER OUTCOMES FOR STUDENTS WITH SOCIAL, EMOTIONAL, AND BEHAVIORAL CHALLENGES." 2013. Fordham Urban Law Journal. Vol. XLI, 404-97. Available at http://ssrn.com/abstract=2417535.

Mexico. Lacking access to those services, many children start behind, face continual stresses in school and at home, manifest difficult classroom behaviors, and fall further behind their peers. A pre-school teacher told the story of her classroom of three year olds.[9] She knew three or four of her fifteen students came from home settings with many difficulties, homes like Juan's. She had to choose between using her class time to try to teach the eleven or twelve kids who could participate in a classroom or try to regulate the children with difficult behaviors who would otherwise disrupt the learning of the other children. These are impossible choices made more difficult due to the limited supports by social workers, counselors, and trained education assistants available to classroom teachers.[10]

Building from the identification of children with developmental delays combined with dysregulated emotional social behaviors served in early childhood programs that provide care for parents with substantial challenges, the newly conceptualized project will extend developmental specialist support in the form of designated navigators for the child in family homes and reach out to the schools where the children attend. Utilizing lessons learned from the programs that have implemented two-generation two-brain services approaches (described below), the navigators will provide care coordination for the family to identify family needs and issues that affect the children's school experiences. With the epidemiology of Adverse Childhood Experiences affecting 50% or more of all children, the new program model would plan to connect family systems to comprehensive primary and behavioral health care early in the lives of young children and continue that support as the children enter formal education settings. (See Opportunity 4 in PATHWAY TO COORDINATED CARE SYSTEMS FOR CHILDREN).

At the onset of early adolescence, a time when youth with high risks features start separating from their parents, they often disconnect with the educational process. Many youth manifest mental health problems, substance use disorders, and poor school attendance starting early in elementary school. The mental health and criminal justice systems are the next stops in systems that try to reduce risks and affect outcomes.

Programs have developed as a response to the needs of youth leaving incarceration in the Bernalillo County Detention Center with their complex mental health, behavioral health, and learning disabilities. The specialized program has created a wrap around model of service for youth and their families including educational liaisons to connect youth with education and navigators who working with the young person and family reduce health harming social determinant needs. The program has found that incarcerated youth need access to consistent primary care, access to consistent psychiatric care, initiation of substance use disorder treatment, stabilization of the families around the youth, and re-engagement with the educational system. The incorporation of child psychiatric care into the primary model of care has had increased the program's ability to quickly treat the psychiatric illnesses that youth have prior to and through incarceration. After two years of program activity funded by the Bernalillo County Behavioral Health funds, the program has demonstrated effectiveness. The detention center data systems established a baseline rate of return in the year after first contact for 70% for youth released. Young persons engaged with the specialized program for juveniles leaving incarceration have had a 90% rate of staying out of incarceration. The majority of them have initiated a plan for further educational or vocational training. From what the program has learned, the needs of youth served will require program involvement to age 25. (See Opportunities 5 and 6 in PATHWAY TO COORDINATED CARE SYSTEMS FOR CHILDREN).

Taken as a whole, the programs identified in this document provide a path, a "sendero," for families at high risk from prenatal care through early adulthood. The CENDERO concept describes a model of primary care coupled to substance use treatment, early intervention supports, coordination with community agencies, integration with schools, and organized transition of care with many community supports. The connected services will support young children and their family systems in preventing ACEs, to address mental health and psychiatric problems, and to move family systems

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[9] Personal communication with A. Hsi, MD, MPH with pre-school teacher at NM Association for the Education of Young Children annual pre-conference workshop, 1 March 2019, Albuquerque, NM.

towards better health and justice outcomes. Only with the coordination and collaboration of multiple departments and centers can the best results come together. The results we've seen in programs created for populations of patients at highest risk provide the foundation for envisioning a continuous care model for families at highest risks with the hope that at each stage, fewer children and families will need support from the next part of the program.

The concept of CENDERO describes a path with many chances for families and their children to have continuing organized primary care through dedicated primary care clinics such as those organized by the Family and Community Medicine Department coupled to teams of support staff like navigator and developmental specialists support. Beyond the work with those at highest risks, the CENDERO model provides a template on which similar work can organize to address other major health care issues affecting the health of New Mexicans.