The role and efficacy of native paraprofessional home visitors in reducing behavioral health disparities in indigenous populations
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INTRODUCTION
1.1 General Introduction

Indigenous populations, including American Indians, face the largest behavioral health disparities in the world and formidable resource and cultural barriers to professional care in the behavioral health arena. Over the past 40 years, research examining the use of “community” or “paraprofessional” health workers to address behavioral health disparities in low resource communities has produced mixed results in terms of intervention effectiveness and, thus, failed to impact broad-based health policy or health system innovations.1 In American Indian communities, behavioral health disparities – such as substance abuse, intentional and unintentional injuries, conduct problems and high-risk sex – peak in adolescence, producing a high burden of years of productive life lost (YPLL).2 Negative behavioral health trajectories for American Indian youth are compounded by high rates of teen pregnancy, as the stressors of teen parenting add to teen parents’ and their children’s behavioral risks and perpetuate intergenerational cycles of poor behavioral health outcomes.3-6

Given the limited number of professionally trained behavioral health interventionists within American Indian communities, the Johns Hopkins Center for American Indian Health has conducted a line of research to evaluate the use of indigenous paraprofessional home visitors to impact American Indian behavioral health outcomes, focusing on teen mothers and their children. Home-based intervention was selected for: 1) its evidence of impact on maternal and child behavioral outcomes, albeit with nurse home visitors and not paraprofessionals and 2) the cultural relevance and acceptance of home- and family-based intervention by American Indian stakeholders participating in this research. This research involves a series of three randomized controlled trials of a home-visiting intervention, called “Family Spirit,” administered by Native paraprofessionals to American Indian teen mothers. The trials have demonstrated that the Family Spirit intervention is associated with significant improvements in parenting and maternal and infant behavior health outcomes.3,4,7 This dissertation reviews the Family Spirit intervention’s theoretical model and use of paraprofessional home visitors; evaluation methods and findings; the theoretical and clinical
relevance of the results; and recommendations for future research and intervention approaches.

This introductory chapter provides further background on: 1) American Indian populations; 2) the problem and opportunity being addressed by the line of research reported in this dissertation; 3) a review of the relevant literature; 4) a description of the intervention approach – including the paraprofessional provider rationale and the theoretical framework upon which the intervention is based; 5) an overview of the intervention studies presented within; and 6) a detailed outline of the remaining dissertation chapters.

1.2 Overview of American Indian/Alaska Native Population: Health Status, Health Care Access, Community Risks and Strengths

The ~1.9 million American Indians and Alaska Natives (hereon referred to as “American Indians”) who reside on reservations or trust lands in the United States (US) have the largest health disparities of any racial or ethnic group in the US. While infectious disease and infant mortality rates have fallen sharply over the past three decades in American Indian communities, behavioral health disparities – including drug abuse, diabetes, obesity, and intentional and unintentional injuries – are increasing, particularly among youth and young adults (see Fig. 1).

American Indian health disparities are related to both historical and contemporary factors that impact the lives of Native youth and their families. First, a long history of federal policies involving land subjugation and tribal community relocation has resulted in the loss of tribal territories, degradation of Indian political and economic systems, languages, traditions and cultures; in essence, the near destruction of the social fabric of Indian communities, which are now being rebuilt. Second, but not unrelated, day-to-day life for American Indian families is difficult. American Indian youth grow up in communities with serious problems of poverty, unemployment, challenged educational systems, and stressful home lives plagued by broken nuclear and extended family networks. For example, in 2006, 39% of American Indian
families with children <5 years of age were living in poverty, nearly twice the rate of the total US population. The median household income for American Indians in 2010 was $35,141 compared with $62,982 for US All Races. American Indians who live on reservations or trust lands generally suffer poverty rates that are 1.5 times higher than the all American Indian rate. Similarly, American Indians have the lowest rates of high school graduation and college attendance of any race in the US, and the highest proportion of single parent-led homes.

There are also vast regional differences – with southwestern and northern plains American Indians generally experiencing harsher living conditions. For the tribal communities that participated in this research, in 2010, 47% of youth were not graduating from high school; 61% of the population >16 years old were either “Not in Labor Force” or unemployed (compared to 14% for US All Races); and 57%-75% tribal members with children <18 were living below the federal poverty line. The complex forces of historical trauma and contemporary environmental stressors underpin the large burden of behavioral health disparities concentrating in American Indian youth.

Fig. 1: AI/AN Adolescent Health Disparities compared to US All Races

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trauma and contemporary environmental stressors underpin the large burden of behavioral health disparities concentrating in American Indian youth.

American Indian Adolescent Behavioral Health Disparities
Substance abuse is the most striking behavioral health disparity among American Indian adolescents. While binge drinking and heavy alcohol use peaks in 15-24 year olds in the general US population, American Indian youth are disproportionally affected. Rates of substance dependence and abuse are higher and start younger among American Indian youth, and the age-adjusted alcohol-related death rate for American Indian 15-24 year olds is 12 fold higher compared to US All Races (4.0/100,000 versus 0.3/100,000).

Unintentional injuries, particularly deaths from motor vehicle accidents, are two to three folds higher for Indian youth compared with US All Races. Suicide death rates for American Indian youth and young adults also exceed other racial and ethnic groups. American Indians ages 15-24 years old have the highest suicide death rates (34.3/100,000 for 15-24 for 25-34 versus 9.8/100,000 for US All Races), with disparities differing by tribe and geographic region. In one of the southwestern tribal communities where this research took place, suicide death rates for 15-24 year olds were 12 times higher than US All Races during the study period. In contrast, in the general US population, suicide death rates rise in the 45-54 year old age range (15.9/100,000) and are highest among 75+ year olds (16.4-16.9/100,000). American Indian youth also have the highest and fastest increasing prevalence of type 2 diabetes of any racial group in the US, with a rate of 4.5 per 1,000 for 15-19 year olds. Similarly, American Indian children are two times more likely to be overweight and three times more likely to be obese than US All Races.

Teen Pregnancy
Reflecting and compounding behavioral health disparities for American Indian youth, adolescent child-bearing is common in American Indian reservations. Nearly half (41%) of reservation-based American Indian females have their first child in adolescence, compared to 21% of US All Races. Twice as many American Indian adolescents have two or more births
during adolescence than the general US population. American Indian females have the smallest intervals in birth spacing of any US racial or ethnic group, which poses additional risk factors for mothers and children. The adverse consequences of adolescent pregnancy for mothers, their babies and communities in the general US population are well documented, including higher rates of postpartum depression, domestic violence, and child abuse; poorer educational and employment outcomes for mothers and children; physical, cognitive and developmental delays for children; and communal financial burdens due to increased demand on public assistance services. The increased environmental risk factors for reservation-based American Indian adolescents magnify the normal stressors of teenage parenthood for American Indian mothers and their children, perpetuating an intergenerational cycle of behavioral health disparities for reservation communities.

**Health Care Provision and Access**

After European colonization and constitutional establishment of the US, the US federal government and tribal nations signed treaties in which individual American Indian nations agreed to cede vast segments of their homelands in exchange for significantly smaller tracts of land (now called “reservations”) where tribal members could remain living together and maintain the right to run their own governments. The US government “trust” responsibility to tribes was affirmed by law in the 1830s and included the protection of tribal rights, lands and resources, and guaranteed the tribes government services in the areas of health, education and technical assistance in perpetuity. Nevertheless, the dominant US society continued to enact federal and state laws that eroded tribal political rights, confiscated resource-rich American Indian lands and oppressed tribal language and culture. New laws in the 20th century, beginning with the Indian Reorganization Act of 1934, tried to reconcile some of the injustices and strengthen the concept of tribal sovereignty. With regard to the health arena, after tribal nations suffered from several epidemics of infectious disease, the Indian Health Service (IHS) was created in 1954 as the official agency responsible for providing federal health care to American Indians and Alaska Natives. However, Native populations’ wide geographic dispersion across rural and urban areas posed immediate challenge to IHS providers. In addition, IHS was never funded
adequately to provide the needed comprehensive care and today continues to experience resource limitations due to federal budget appropriations that do not keep pace with the considerable population growth and the needs of the Indian peoples. Thus, the IHS has been forced to give priority to building and operating reservation-based hospitals that focus on tertiary and emergency services, while programming for preventive care and health outreach is scarce.

It follows that American Indians on reservations receive inadequate health services. Particular to youth, a large cross-reservation study documented that American Indian adolescents are far less likely to access routine physical exams than other US racial groups and have poor access to behavioral and mental health treatment in spite of well-documented disparities. Barriers to health care extend to prenatal and postpartum care, with the lowest access among expectant adolescent mothers. IHS obstetrics and pediatric clinics are generally operated out of a centralized facility meant to serve catchment areas of 10,000 to 20,000 Indian residents, who may live more than 100 miles from the facility. Reservation clinics are generally understaffed and under-resourced, and providers are generally non-Indian, due to the low numbers of professionally educated American Indians. Further, access barriers reported by reservation-based American Indian women are transportation, linguistic and cultural barriers, family problems and missing school. Because little to no public transportation exists on reservations, younger and poorer residents have difficulty getting to clinics. Additional psychosocial and cultural barriers exist for those young pregnant women who can reach medical care facilities. These factors combined mean that American Indian teen mothers generally don’t receive prenatal care until well into their second trimester and sometimes not until their third.

Prenatal and well-baby visits are generally a primary setting for educating expectant mothers and their partners about pregnancy, nutrition and health during pregnancy, in utero exposure to nicotine, alcohol and street drugs, well-child care, child development, injury and poisoning prevention, immunizations, and physical, cognitive and behavioral milestones or abnormalities for their children. Traditional American Indian child-rearing practices and teachings, once shared by extended indigenous family
networks, have been eroded by the painful history of cultural oppression and resulting socioeconomic challenges, such as poverty, unemployment, substance abuse and despair. Thus, parenting education is sorely lacking for young American Indian mothers.

In summary, the challenges faced by American Indian teen mothers – their behavioral and environmental risks, lack of education and support for positive parenting and health access barriers are producing an intergenerational cycle of behavioral health disparities for reservation populations. These same challenges are shared by, and are often more acute in, other indigenous populations in Australia, Canada, New Zealand and Latin America.27-30 As noted at the close of the Decade of the World’s Indigenous Peoples in 2004, little progress has been made to address health and environmental conditions of indigenous peoples through broad-based global advocacy efforts.27

Innovative, evidence-based interventions that can be integrated into low-resource health systems are needed to address these challenges. Given 1) the intergenerational component of indigenous behavioral health disparities and 2) the high proportion of American Indian and other indigenous females who begin child-bearing in adolescence (the developmental period when behavioral stressors are most acute in reservation and other indigenous communities), a significant public health impact could be realized by affecting positive behavioral trajectories across teen mother-child dyads. Further, the opportunity to tap local indigenous cultural strengths can enhance this approach.

Strengths of American Indian Communities
The challenges posed by reservation life are balanced by a unique set of strengths that present distinct opportunities to improve the lives of American Indian children, families and communities.

Strength of family. American Indian cultures embrace “family” as the center of strength for individuals.21 As stated by a leading tribal agency, the White Earth Tribal & Community College, “The family, the roles played by family members, the functions of the family, the customs surrounding family
life and the spiritual dimension of family are the center of American Indian culture.”

There are numerous examples of how the culture and traditions of American Indians support “family” above other domains as the nexus of strength for individuals. Traditional American Indian family structure is extended, including mothers, fathers, grandparents, aunts, uncles and cousins, who share households or live in very close proximity. Traditional ideals favor the creation of strong family networks that foster healthy and broad-based interdependence among family members. Exemplifying these ideals, American Indians often introduce themselves by name and clan, underscoring the link between personal identity and family lineage. Many healing traditions and puberty ceremonies also involve family members, who represent stabilizing and restorative forces. In addition, ceremonies emphasize spiritual kinship, expanding the concept of family to include spiritual “god daughters,” “aunts,” “uncles” and “grandparents,” beyond bloodlines.

Indeed, recognition of the strength and resiliency of Native familyhood may explain strategies employed by the US government during eras when the federal leadership was intent on assimilating Native people. Legislation through the 1960s involved legal actions that split children from families by sending them to off-reservation boarding schools and split parents from children and extended family members by sending them to urban centers to assimilate through low income jobs programs. Further, while a body of literature over the past four decades has tried to draw associations between Indian spirituality and healthy lifestyles, evidence is mounting that the positive relationship between American Indian spirituality and health outcomes is acting through the strong value American Indian culture places on family; in other words, strong family values and relationships act as protective factors. In summary, family-based approaches to restoring and preserving individual and community health have intrinsic meaning and power within American Indian communities, and point to family and home-based intervention as a promising strategy for behavioral intervention development.
Strength and utility of available paraprofessional American Indian work force. In spite of the paucity of professionally trained and credentialed American Indian health professionals, there is a ready workforce of passionate, intelligent, empathetic and motivated American Indian community health workers or “paraprofessionals” (term defined and discussed in section 1.4, below) who are eager to address their communities’ problems. A suitably trained Native paraprofessional has the benefit of sharing a common history and similar challenges with the individuals whom they serve. They possess familiarity with community dynamics, kinship patterns, spiritual needs, values, attitudes, language, communication styles, and expectations. This common ground can facilitate rapport, trust and retention, and illuminate culturally meaningful aspects of intervention content. Native paraprofessionals also have natural capacity to navigate the cultural mores and bi-lingual language demands of home-visiting (i.e., homes are generally multi-generational, and older adults in the home tend to speak their Native language while young adults and youth speak English). The broader research related to the applicability of paraprofessionals to health system intervention is discussed further in section 1.4 of this chapter.

Tribal sovereignty. American Indians are unique in their nation-to-nation status with the US government (see Worchester v. Georgia, 515, 558 (1832)). Tribes have sovereignty to govern their lands. In the past three decades, new legislation spanning the Indian Health Care Improvement Act (Public Law 94-437), welfare reform and Temporary Assistance to Needy Families programs affords tribes greater flexibility and autonomy than ever before to restructure reservation-based health and human service systems. In addition, socially tight-knit reservation communities can generate rapid diffusion of innovations once there is clear proof of intervention effectiveness.

1.3 The Problem and Opportunity Addressed By This Line of Research
The research reviewed in this dissertation is aimed at addressing the challenges within American Indian and similar indigenous communities related to: 1) acute multi-generational behavioral health disparities; 2) high teen pregnancy rates that exacerbate intergenerational disparities; 3) a
paucity of professional health care providers; and 4) poor access to prenatal and postnatal care and health education. This research has also aimed to engage the relevant cultural strengths within Native communities, including: 1) strong cultural values that support family-based approaches; 2) the availability of a motivated paraprofessional work force; and 3) the capacity for innovation and scalability to other tribal and indigenous communities. Thus, the central question of this research is: **Can American Indian paraprofessional home visitors achieve measureable effects on maternal and early child behavior outcomes using a culturally appropriate, evidence-based home-visiting intervention and, ultimately, reduce intergenerational behavioral health disparities in reservation populations?**

### 1.4 Review of the Literature

This dissertation’s research hypothesis is that structured parent training by a competent and trusted indigenous paraprofessional home visitor targeting responsive, nurturing and attentive parenting coupled with maternal coping, problem-solving and conflict resolution will: 1) improve teen mothers’ parenting and psychosocial function and 2) affect positive early behavior outcomes in their children that predict better childhood behavioral trajectories.

The key components of this research require an understanding of: 1) the utility and effectiveness of paraprofessionals as behavioral interventionists; 2) the utility and effectiveness of home-visiting as a behavioral intervention; and 3) key targets for promoting early childhood parenting to impact children’s behavioral health trajectories. The extent literature for each component is reviewed below.

**The Utility and Effectiveness of Paraprofessionals**

There has been much debate in the literature regarding the effectiveness of paraprofessional health workers, often termed “lay health worker,” in the international literature. It is critical to this review to establish an accepted definition of “paraprofessional health worker.” Borrowing from the 2005 Cochrane review, “Lay health workers in primary and community health...
care,”¹ the following definition will stand as a point of reference for the level of providers reviewed in this section as well as the type employed by the research reported in this dissertation:

**Definition of “Paraprofessional” or “lay health worker”:** Any health worker carrying out functions related to health care delivery, trained in some way in the context of the intervention; and having no formal ...certified or degreed tertiary education.” ¹(p.1)

The Cochrane report aimed to examine the global evidence for the effects of paraprofessional-delivered, or what they termed “LHW-delivered” (LHW=lay health worker) interventions on health care delivery, patients’ health and well-being, and patient satisfaction with care. They reviewed 43 studies that met inclusion criteria as “randomized controlled trials.” The majority of studies compared LHW interventions to usual care, with only four comparing LHW interventions to professionally delivered interventions. The report had four main conclusions: 1) There is evidence for LHW effectiveness in the following specific domains: immunization uptake and promoting outcomes for acute respiratory infection and malaria in children, and to a lesser degree breast-feeding promotion and breast cancer screening; 2) Due to a lack of methodologically rigorous studies, there is insufficient evidence to effect policy or practices in other behavioral and mental health domains; 3) It is not clear what types of LHW training or intervention strategies are most effective; and 4) Evidence is lacking as to how and when paraprofessionals can replace professionals to impact lower health care costs and perhaps better match consumer preferences. The Cochrane review concludes with a strong recommendation for further high-quality research on the utility and effectiveness of LHWs in health education, health care promotion and the management of disease.

Other international research has provided additional evidence supporting the use of paraprofessionals compared to professional interventionists. Programs in Asia, South America, Africa, Australia and Canada have demonstrated that indigenous lay health workers avoid the cultural pitfalls of dispatching non-indigenous people into the home;⁴³ are more persuasive regarding risky attitudes and behaviors;⁴⁴ are more readily available than professional health
educators; and are more cost effective in impoverished or under-resourced communities.

In contrast to the international literature, US research – particularly in regard to home-visiting intervention, has focused more sharply on comparing nurse home visitors’ effectiveness to paraprofessionals. These US trials have suggested that nurses were associated with significant participant outcomes (while paraprofessional-delivered home visitation was not), including fewer injuries and ingestions in children; less abuse and neglect; greater workforce participation; and lower reliance on public assistance among mothers served. Nonetheless, commonly cited nurse versus paraprofessional home visitor trials have notable methodological limitations. For example, one comparison of nurse and paraprofessional home visitors excluded paraprofessionals if they had any college preparation in the helping professions, potentially creating a selection bias toward a less motivated worker. In the same study, it is not stated whether the intervention protocol relied on a manualized curriculum for both interventionists; whether the content was the same; or, whether both types of interventionists had to demonstrate mastery of their respective interventions before seeing participants. In addition, while preliminary results of the study at two years postpartum favored nurse home visitors, in a subsequent publication of the same trial at four years postpartum, the paraprofessional-visited mothers were found to have better mental health indicators, greater sense of personal mastery, fewer subsequent miscarriages and fewer low birth weight babies versus mothers visited by nurses, who had greater birth spacing, less domestic violence, and some indication of better child outcomes. Thus, it is difficult to dismantle what the key intervention components (i.e., provider type and experience, intervention content, participant-provider relationship) were in affecting participants’ specific outcomes. Due to a severe shortage of nurses on reservations and the greater cost of nurse versus paraprofessional home visitors, nurse home-visiting programs are generally not feasible for reservation communities at this time. Similar structural and resource limitations are also important considerations for other indigenous and developing world communities.
Efficacy of Home-Visiting Trials on Maternal and Child Health Outcomes

More than 50 studies have been published since 1976 supporting the short and long-term efficacy of home-visiting programs delivered during pregnancy and early childhood for low-income families in the US. \(48,49,50-63\) Dominant empirical findings include: improved maternal health outcomes; \(55\) improved parenting and the home environment; \(64\) increased birth spacing; \(49,55\) improved children’s health and behavior outcomes; \(65-67\) prevention of child abuse and neglect; \(50,52,68-70\) and reduced drug use. \(56,67,71\) However, none before the research reviewed in this dissertation has been rigorously evaluated with indigenous US populations, nor has proven impact employing paraprofessional home visitors to address behavior health outcomes. Furthermore, the most rigorous randomized nurse-delivered home-visiting trials have not been able to identify definitive infant/toddler behavioral outcomes (< 2 years postpartum). \(48,65-67\) Fortunately, new infant and toddler assessment measures with proven validity to identify externalizing, internalizing and dysregulation problems as early as 12 months of age \(72\) that predict behavior problems in middle childhood and adolescence \(72-74\) have become available to the scientific community in the past decade and were utilized by this research. Identifying meaningful short-term outcomes will improve behavioral researchers’ ability to evaluate the efficacy of home-visiting programs in clinical and implementation trials.

Known Associations between Parenting Practices and Early Childhood Behavior Problems

Home-visiting intervention’s emphasis on parent training is based on a large body of research investigating how parenting mediates development of lifetime childhood behavior problems. \(75\) The earliest effects of poor parenting have been shown to result in infant and toddler externalizing behaviors. \(76\) Externalizing behaviors in early childhood generally track to poor school performance in the middle years, \(77-79\) and drug use, \(78\) anti-social, \(73\) delinquent and aggressive behavior \(76\) and high-risk sex in adolescence. \(73\) Early parent behaviors most associated with behavior problems in early childhood include: coercive interactions, \(76\) poor monitoring, \(80\) and harsh or unresponsive parenting. \(81\)
Parenting and Early Childhood Behavioral Problems That Predict Later Substance Abuse

Because substance abuse-related morbidity and mortality is the largest behavioral health disparity for American Indian communities, early intervention development for Native communities will benefit from reflecting current research findings related to parenting and early childhood risks for later substance abuse. Parenting factors most associated with children’s future drug use include: maternal drug use,\textsuperscript{82} multi-generational adversity,\textsuperscript{83} and poor supervision and monitoring.\textsuperscript{80} Longitudinal studies have identified specific early childhood behavior problems that predict adolescent drug use and adult dependency.\textsuperscript{84} Early childhood conduct disorder and aggression appear to be the most potent predictors of adolescent drug use and dependence.\textsuperscript{85,86} In addition, sleep problems between ages 3 and 5\textsuperscript{87} and externalizing and internalizing behavior problems by first grade have been linked to elevated risk for adolescent drug use.\textsuperscript{84} There is further evidence that attention deficit hyperactivity disorder, oppositional defiant disorder and generalized anxiety disorders mediate progression from early drug and alcohol initiation to adult dependence.\textsuperscript{85,88} Finally, conduct problems between ages 5 and 11 have been associated with increased risk for early drug use and high-risk sex in adolescence.\textsuperscript{73}

Protective Factors

Although the environmental and behavior risks for American Indian youth are commonly referenced, family-based protective factors in American Indian and other indigenous communities have rarely been the focus of epidemiologic or intervention research. Protective factors for drug abuse described in the general US population include: 1) strong bond between child and family; 2) high levels of supervision and monitoring; 3) parenting practices that nurture emotional, cognitive and social needs; and 4) clear, consistent and contingent discipline.\textsuperscript{89-92} Additional protective factors in Native communities may include a tradition of strong extended family networks and cultural practices that reinforce the value of family-centered healing and prevention.\textsuperscript{21,93,94}
Structural Factors Influencing Home-Visiting Intervention Success

Key factors that have been identified with home-visiting program success include participant, provider and program factors.95,97

Participants. Families who benefit most from home-visiting services are young, unmarried, low-income, first time, minority and socially disadvantaged parents, with limited access to existing health services58,66,95—a risk profile common to American Indian teen mothers.

Provider attributes. Past studies have shown paid interventionists are more successful than volunteers.55,98 In addition, home-visiting programs have been found to be more successful when providers and participants match on age, parenting status or history and race/ethnicity.95

Program factors. Positive home-visiting program results have been associated with an adequate dosage of home visits, retention of families, structured supervision and support for interventionists, and appropriate caseloads. Effective programs have ranged from 22-33 visits63,99 with a caseload between 20-30 participants per year.63 Retention of families has been linked to home visitors receiving more hours of direct supervision and training; flexibility in scheduling visits to mothers’ needs; and effective involvement of young mothers’ parents or families.100 Parent training programs that emphasize reducing coercive interactions and promoting consistent, responsive care and monitoring have demonstrated the greatest impact on positive child development.66

1.5 Description and Theoretical Background of the Family Spirit Home-Visiting Intervention Evaluated By This Research

A Community Based Participatory Research Approach

The home-visiting intervention evaluated by this research is called “Family Spirit” and was developed over a decade-long period via Community-Based Participatory Research (CBPR) methods by the Johns Hopkins Center for American Indian Health in partnership with its longest standing research collaborators, the White Mountain Apache, San Carlos Apache and Navajo
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While the historical factors that led to widespread family challenges were discussed, it was agreed that promoting effective and culturally competent parenting would be the starting point for change. Tribal stakeholders viewed family-based approaches as a powerful and culturally preferred strategy to avert intergenerational behavioral problems. They also identified the most vulnerable families – teenage parents and their children – as the target population. More than 130 in-depth interviews with teen parents across the participating communities and a series of round table discussions with community advisory boards were used to inform intervention content. Prioritized topic areas included: labor and delivery, parenting, child care and development, family planning, substance abuse prevention, and goal setting for education and employment. Potential intervention settings included schools, ob/gyn clinics, Boys and Girls clubs and homes. Tribal stakeholders felt that intervening with teen parents at home would reduce stigma associated with receiving services in public places and overcome the transportation, cultural and access barriers to clinics and schools, especially since a large portion of teens do not regularly attend school. Further, because most Native teen parents reside with their parents, aunts, uncles and older siblings who may also share in child care, home visits would allow home educators to influence child care practices of others caring for the child. Tribal stakeholders also recommended that local community health workers, with parenting experience and the capacity to speak Native and English languages, serve as home visitors. The shortage of American Indian nurses and cultural barriers to non-Native home visitors drove their argument to utilize lay home visitors.

Based on this CBPR process, the Family Spirit intervention includes a basic structure for home visits for American Indian teen mothers, key curricular content, paraprofessional home visitors, and a theoretical model and conceptual framework predicting the hypothesized impact of the intervention.
Family Spirit’s Structure, Content and Providers

Structure. Family Spirit’s intervention structure is based on “Healthy Families America” home-visiting program, which was selected by the participating communities based on its cultural relevance. Healthy Families America embodies 12 key home-visiting principles regarding client service and case management, but does not include specific intervention content.

Content. Family Spirit’s curricular content was developed from: 1) community input on important content and format elements, with particular emphasis on cultural relevance and 2) child care and parenting information drawn from the American Academy of Pediatrics’ Caring for Your Baby and Child: Birth to Age 5. The three primary domains of curricular content promote: 1) parenting skills across early childhood; 2) infant development; and 3) positive maternal psychosocial function. There are 43 lessons taught from 28 weeks gestation through 3 years postpartum. Home visitors deliver lessons in participants’ homes using table-top flip charts. The flip chart is designed so that the participant views illustrated content often including a “real-life” scenario while the home visitor reviews an outline of key points relating to the scenario and illustration. Other family members (i.e., father of baby, grandmother) are invited to join if the participating mother so chooses. Home visitors are trained to use the lesson outline to create a comfortable teaching dialogue, rather than reading points by rote. They are also encouraged to develop a strong interpersonal bond to facilitate mother’s motivation to develop knowledge, skills and self-efficacy to meet her and her baby’s needs.

Providers. American Indian paraprofessionals taught the Family Spirit home-visiting intervention and were named “Family Health Educators.” They were female and, at minimum, had completed high school or received a General Educational Development certificate, the equivalent of earning a high school diploma. Several had received a two-year college degree, and one had a bachelor’s degree. All were bi-lingual in their Native language and English, had previous experience in health and human services, and were
respected members of their communities. The majority had personal experience with teen child-bearing. All were paid a salary commensurate with their education and job requirements in the local communities.

**Family Spirit Theoretical Model**

**Guiding Child Development Theory.** G.R. Patterson’s ecologically focused parent-child development theory underpins the Family Spirit intervention’s focus on parent training as its core intervention approach.\(^\text{103}\) Patterson’s model (Fig. 2) posits parenting as the critical link between parents’ personal characteristics and environmental context and their children’s individual risks and ultimate outcomes. In the participating American Indian populations, key **Parental Factors** may include substance use, depression and low parental self-efficacy. **Demographic** risks include young parenthood, poverty, low education and unemployment. Parent **Stressors** may include adverse life events, domestic conflict, and unstable home environments. **Family and Community of Origin** risks include historical losses of parenting traditions and the accumulation of historical trauma.

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![Fig. 2: Developmental Model for How Children Develop Behavioral Problems](image-url)

*Adapted from Patterson et al., 1989*
In the context of Patterson’s model, this constellation of risk is predicted to impede American Indian teen mothers’ parenting ability that will, in turn, impact poor behavioral outcomes for teen mothers’ offspring in early childhood and beyond. Fig. 3 illustrates how Patterson’s theory extends to show how poor parental monitoring and ineffective discipline in early childhood subsequently leads to developmentally specific problems in middle and later childhood, including school drop-out and drug use, common problems in the American Indian adolescence.

![Fig. 3: Impact of Negative Early Parenting on Long-term Child Outcomes](image)

Adapted from Patterson et al., 1989

Based on Patterson’s model, the Family Spirit intervention was designed to promote effective parenting, while assisting mothers in developing coping and problem-solving skills to overcome individual and environmental stressors (Fig. 4). The intervention’s therapeutic effect is hypothesized to operate through one-on-one teaching of highly structured Family Spirit content by a knowledgeable, empathic indigenous home visitor.
In the context of Patterson’s model, this constellation of risk is predicted to impede American Indian teen mothers’ parenting ability that will, in turn, impact poor behavioral outcomes for teen mothers’ offspring in early childhood and beyond. Fig. 3 illustrates how Patterson’s theory extends to show how poor parental monitoring and ineffective discipline in early childhood subsequently leads to developmentally specific problems in middle and later childhood, including school drop-out and drug use, common problems in the American Indian adolescence.

Based on Patterson’s model, the Family Spirit intervention was designed to promote effective parenting, while assisting mothers in developing coping and problem-solving skills to overcome individual and environmental stressors (Fig. 4). The intervention’s therapeutic effect is hypothesized to operate through one-on-one teaching of highly structured Family Spirit content by a knowledgeable, empathic indigenous home visitor.

Adapted from Patterson et al., 1989

**Guiding Behavior Change Theory.** While Patterson’s model explains why the Family Spirit intervention is focused on mediating positive parenting to impact maternal and child behavioral outcomes, the Theory of Planned Behavior forms the theoretical basis for explaining how Family Spirit’s paraprofessional delivered approach will affect adoption of targeted maternal behaviors (i.e., parenting and positive maternal life skills).

The Theory of Planned Behavior (Fig. 5) postulates that adoption of a targeted behavior will be based on: 1) the mother’s beliefs or attitudes toward the value or importance of adopting the behavior; 2) existing social norms that influence behavior adoption (i.e., is there social motivation to adopt the behavior?); and 3) her perceived power or belief that she can or knows how to carry out the behavior. These three factors in combination affect her behavior intention (i.e., ‘Yes, I will breast-feed;’ ‘No, I will not use substances while I am caring for my baby’). Finally, if her intention is
positive, it is the strength of (3) her perceived power or self-efficacy that will predict her ultimate adoption of the behavior. Formative research with representative American Indian teen mothers, fathers and community stakeholders during the design phase of the Family Spirit intervention identified strong community will within the target population to renew positive parenting practices.6

The target populations’ current attitudinal and normative facilitators and barriers to behavior intention and adoption were thus incorporated into the curriculum content. Our application of the Theory of Planned Behavior model also dictated that curricular sessions should be both knowledge and skills-based, and they should incorporate activities in which Family Health Educators could model and practice the behaviors with the mother to promote self-efficacy. Family Health Educators were also trained to encourage participants to involve other family members (baby’s father and grandmother) in the home-visiting lessons to promote normative values and
family of origin acceptance.

The third chapter of this thesis\(^6\) provides further detail on the combined theories of child development and behavior change that underpin the intervention. It also includes the intervention evaluation’s conceptual framework that illustrates the expected short, medium and long-term impacts on maternal and child behavioral and emotional outcomes. Ultimately, the theoretical framework predicts reducing maternal and child emotional/behavior problems in early childhood will codify a more positive behavioral trajectory for mothers and children over the life course.

1.6 The Present Research

This dissertation reports a series of three randomized controlled trials (1:1 design) to evaluate the paraprofessional delivered Family Spirit intervention with American Indian teen mothers and infants. The study sites included four communities within three reservations in Arizona and New Mexico in the southwestern US (see Fig. 6).

These communities are rural and isolated, with populations of 15,000-25,000 spread across large land masses (1.5 to 2 million acres for each community). Like other American Indian reservations, these tribal nations are striving to maintain the strengths of their indigenous cultures and languages, while struggling against economic hardship and stressed educational systems. They also experience behavioral health disparities that are above the average all American Indian rate (Fig. 1), and several times higher than US All Races, including for substance use, injuries, suicide, obesity and diabetes.\(^{105}\)

All study subjects were voluntarily consented/assented to participate in these trials. Institutional Review Board (IRB) approval was received from all relevant tribal, Indian Health Service and Johns Hopkins University review boards. The first study enrolled \(n=53\) American Indian mother-child dyads from July 2001-February 2002 who received Family Spirit intervention and assessment from \(\leq 32\) weeks gestation to 6-months postpartum. The second study enrolled \(n=167\) mother-child dyads from May 2002 to May 2004 and intervened and assessed participants from 32 weeks gestation to one year
postpartum. The third trial enrolled n=322 mother-child dyads from May 2006 to September 2011 and intervened and assessed participants from 32 weeks gestation until 3 years postpartum. Given the nature of this research and the goal of a generalizable outcome, broad inclusion and minimal exclusion criteria were utilized for all three trials. In summary, pregnant American Indian females 12 to 19 years old at time of conception and with a gestational age of 32 weeks or less (to allow completion of the prenatal intervention prior to delivery) were enrolled. Parent/guardian consent was required for youth under 18 years old.

Each trial was conducted via a two-stage process. In Stage 1, participants were screened for eligibility, consented/assented, and completed baseline assessment (including participant baseline characteristics and assessment of the study’s dependent variables). In Stage 2, participants were randomized to receive the Family Spirit intervention or a beneficial control condition. Methods and results are described and discussed in detail for each study in Chapters 2, 3, 4 and 6.
Outcome Assessments
Outcome assessments and assessment methods also evolved in rigor over the course of the three trials. Appendix 1 shows the full list of assessments that were used by the final study, followed by information about each instrument, including psychometric properties and time burden for participants. Study measures were carefully selected as the best or most widely used for their purpose, and carefully adapted for cultural appropriateness. All measures have been previously or are currently being used within American Indian communities. There was planned overlap among some measures for validity purposes. Self-report instruments were read to participants who had difficulty reading.

Summary of Potential of Research
Demonstrating the role and efficacy of American Indian paraprofessional home visitors to improve behavioral health trajectories of children in rural, underserved reservation settings may have generalizability to indigenous populations worldwide and applicability to the mental health field, which grapples with similar intergenerational disparities and health access barriers in low income communities. This research may also make original contributions to the existing knowledge base in prevention science by showing how pregnancy and early childbearing may provide a pivotal developmental time point for affecting lasting behavior change in high-risk mothers and children. Because a large proportion of American Indian and other indigenous women begin childbearing as teenagers, if study aims are met, the proposed interventions have important public health potential for breaking multigenerational cycles of behavioral health disparities in targeted communities. Findings may also have import to other disadvantaged populations who suffer low socioeconomic status and a history of racism and unequal economic, social and educational opportunity that drive multigenerational cycles of behavioral health disparities. These vulnerable populations exist in inner cities and rural outposts throughout the world.

1.7 Outline of Thesis

The research questions of this dissertation are investigated in subsequent empirical chapters. Chapters 2-7 comprise a series of published manuscripts.
There is some overlap in content between chapters, since each chapter was published independently.

**Chapter 2** reports the methods and results of the first pilot randomized controlled trial of the Family Spirit paraprofessional delivered home-visiting intervention with 53 participating American Indian teen mothers and their offspring from pregnancy to 6 months postpartum. The main research question was to assess the impact of the paraprofessional delivered home-visiting intervention on teen mothers’ child care knowledge, skills, and parenting involvement from baseline (28 weeks gestation) to intervention graduation (6 months postpartum). The main outcome measures were mothers’ child care knowledge, skills and involvement. The children were too young (6 months of age) at the end of the study period to assess infant behavioral outcomes.3

**Chapter 3** reports the methods and results of the second randomized controlled trial of the Family Spirit intervention with 167 participating American Indian teen mothers and their offspring from pregnancy to 12 months postpartum. The longer intervention and study period allowed the investigators to initiate child behavior outcome measures at the first developmentally appropriate time point (one year of age) and to track maternal psychosocial outcomes as teens began transitioning back to normal routines after recovery from child delivery. The main research question was to assess the impact of the paraprofessional delivered home-visiting intervention on teen mothers’ parenting knowledge and involvement. The secondary research objective was to study intervention impact on children’s emotional and behavioral outcomes at one year of age, and on mothers’ psychosocial outcomes at one year postpartum, including stress, social support, depression and substance use.4

**Chapter 4** describes the study rationale, methods, theoretical basis and baseline characteristics for the third and largest randomized controlled trial of the Family Spirit intervention with n=322 mothers and their children who were intervened with and assessed from pregnancy to 3 years postpartum. This chapter provides in-depth information on the community-based participatory research process that shaped the Family Spirit intervention
design and successive evaluations. It also provides detail on the Family Spirit intervention structure, content and theoretical design. Finally, baseline data are reported and define a high-risk profile for teen mother participants, and by extension, their offspring. The discussion articulates a clear need for interventions like Family Spirit to break the cycle of behavioral health disparities in American Indian youth.6

Chapter 5 employs baseline data from the third trial described in Chapter 4 to explore correlates of drug use within the sample of n=322 participating expectant mothers, including socio-demographic, familial, cultural and lifestyle risk factors. Consistent with the theoretical model and the behavioral target of the Family Spirit intervention described in Chapter 4, the primary aim of this baseline analysis was to investigate relationships between drug use and expectant mothers’ family of origin functioning. The study team hypothesized that mothers who reported higher drug use would report lower family functioning. Further, we predicted stronger affinity with traditional values would correlate with more positive family functioning and lower drug use. Finally, we hypothesized that negative demographic factors could exacerbate poor family functioning and ultimately affect mothers’ capacity for positive parenting if not addressed. Results showed mothers who reported lifetime and pregnancy substance use also reported more family dysfunction in their family of origin. Further, mothers with stronger traditional cultural identity had lower lifetime and pregnancy drug use. Residential instability was the primary demographic factor correlated with more lifetime and pregnancy drug use.106

Chapter 6 reports one-year outcomes from the third randomized controlled trial of the Family Spirit intervention, in which mothers and their children were intervened with and assessed from pregnancy to 3 years postpartum. Primary study aims were to assess intervention impact on: 1) improved parenting knowledge, self-efficacy, and behaviors; 2) reduced maternal psychosocial and behavioral risks (drug and alcohol use, depression, conduct problems) that could impede parenting; and 3) improved infant internalizing and externalizing outcomes. Primary outcome measures included parenting knowledge, self-efficacy and parenting behaviors; maternal externalizing and internalizing outcomes; and children’s internalizing and externalizing
outcomes. This study employed more rigorous research methods, including use of blinded independent evaluators and novel attrition prevention and sample maintenance strategies, compared to the two previous trials (Chapters 2 and 3). The discussion of the results provides further detail about the hypothesized mechanism of therapeutic effect of the intervention and the clinical relevance of the findings.7

Chapter 7 presents a brief editorial on the potential translation of the behavioral health intervention findings to innovations in indigenous mental health systems, given the high rates of mental health disparities and shared structural, cultural and resource barriers to clinical mental health treatment in reservation and other low-resource settings.107

Chapter 8 summarizes the empirical findings and discusses the methodological strengths and limitations of the research. Implications of the study methods and results for general practice are reviewed, with a particular focus on relevance to indigenous settings worldwide. The chapter concludes with recommendations and directions for future research.
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REFERENCES


