

Running Head: Implications for Child Welfare

Implications for Child Welfare
Teaching and Human Services Personnel Perspectives
Experiences of Children with Special Needs
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Abstract

This is a qualitative research study of the needs of children with developmental disabilities through the eyes of professionals involved in working with them. Developmentally disabled children and their families living in Red Lake Nation face a myriad of challenges and difficulties from accessing medical services, and securing social, financial and education services. Parents/Caregivers are often overwhelmed with sorting out service systems, and often face challenges such as substance abuse, mental illness, domestic violence, and poverty. This study employed four focus groups to access the voices of human service and teaching personnel at Red Lake Nation, to hear from their perspective the experiences and needs of developmentally disabled children.

This is a study of the needs of children with developmental disabilities through the eyes of professionals involved in providing services to them.

Developmentally disabled children and their families face a myriad of challenges and difficulties from fully comprehending the child's disability, to accessing medical services, and securing social and education services and resources necessary to facilitate the child reaching his/her full potential. Parents/ caregivers are often overwhelmed with sorting out service systems and the intricacies of these systems as they carry on their daily lives. These families and caregivers often also face challenges such as substance abuse, mental illness, domestic violence, and poverty.

Two years ago at 3 a.m., I transported a 13-year-old girl with leukodystrophy to the hospital. She had been in a vehicle with four adults stopped by law enforcement. Subsequently, the driver was arrested for a DWI, and the minor child was referred to social services and placed on a 72-hour hold. Upon evaluation in the hospital we found a yeast infection on her lower abdomen, and she had lice and fleas in her hair. After her initial intake, I traveled east to Redby to get her wheel chair, IV pole and diapers. The home smelled of cat urine, and it was dark and dirty. The child's mother had recently passed away due to a car accident and her father was a regular crack/ cocaine user. A young boy about 13 years old answered the door and let us in. He stated he hadn't seen his dad for two weeks. This girl deserved a better life. She has since passed away. Today I am hit with the heartache I feel for children, the devastation they endure due to social problems. I am left wondering what services are in place for children with special needs, and what exists to nurture their well-being and spirit. The following research inquiry examines the needs of developmentally disabled children, resources that are available and utilized for their care, and issues that present challenges through the voices of a small selection of teaching and human services personnel at a Native community.

General Overview, Background of Study

The Red Lake Nation is located in upper north-central Minnesota about 160 miles south of the Canadian border. It is a “closed” reservation, meaning all of its lands are held or owned in common by all enrolled members. It cannot be sold out of tribal ownership. The reservation land base encompasses an area of 1,259 square miles. It is a land of forests, rivers, streams and two vast inter-connected lakes, Upper and Lower Red Lake. The land and water are central to life at Red Lake, providing food, livelihood and spiritual connection and meaning. Along the south shore of Lower Red Lake are the three communities of Little Rock, Red Lake and Redby with the fourth community of Ponemah located on a peninsula between the two lakes. The Red Lake Nation is part of the greater Ojibwe or Anishinabe Nation, which is the third largest Native community in North America after the Navajo Nation and Cherokee (Roy, 2009). There is still retention of the original language, ceremonies, customs and beliefs while at the same time dealing with modern issues. While stubborn historical and intergenerational poverty, high unemployment and other factors have birthed extraordinary adverse conditions, many people cling to cultural traditions and strengths creating an underlying optimism and resilience.

Research indicates that the cultural extermination and displacement resulting in what we understand today as historical trauma has caused significant disruption and dysfunction in tribal families and in the community in general (Braveheart, 1998). This oppression is expressed in mental illness, despair, self-medication, addictions, poverty and deficiencies in independent living skills. Dywer (2003) correlated lower economic status, with an increase in stress levels and an increased risk of mental illness. The impact of poverty with mental illness often is charged with self-medication. Addiction, family and community violence, mental health challenges, chronic neglect, and poverty are the core of the many challenges that face Native American communities,

such as Red Lake. This hopelessness and helplessness circles back as posttraumatic stress symptoms related to the historical trauma endured by tribal people. This is devastating news to the next generation- already the stakes are high for the children of the Red Lake community.

Purpose of the Study

This qualitative research study will employed focus groups to access the voices of human service practitioners and teaching personnel at Red Lake Nation, to hear their perspectives of the experiences and needs of developmentally disabled children and their families.

The number of babies on the reservation described as medically fragile, babies born prematurely, drug or alcohol addicted or suffering from fetal alcohol spectrum disorder (FASD), has been growing rapidly (Minnesota Department of Health, 2004). Maternal substance abuse, poor nutrition, and high-risk pregnancies compromise the fetus. Although damage may not be seen at birth, these infants often have cognitive limitations that are irreversible, leading to more frequent mental health and behavioral problems. As Freeman et al's (2004) research indicates, American Indian children have a high prevalence of mental health problems, with 1 in 11 children diagnosed with a severe emotional disorder (SED).

An at risk child, raised in a home challenged by poverty, mental illness, and addiction stands a greater chance of being further compromised in terms of quality of life and realization of potential (Dwyer, 2003). Research suggests (Lukemeyer, A., Meyers, M., & Smeeding, T., 2000) 5% of children experience a condition that results in impairment or limitation of their ability to engage in usual activities of a child their age, but for children in low-income families the statistics rise to 40%. Dwyer's (2003) research indicates that parents of developmentally delayed children experience increased stress in parenting. For many single parent families already challenged, community and family support are critical for the additional demands of an at risk, special needs child.

Guiding Questions

This qualitative research study will employ focus groups of teaching and human services personnel. Separate focus group guides were developed for each group. Separate interview guides were developed for each participant group- human services and teaching personnel. The questions for the most part were parallel with a few exceptions asking the participants to comment from their professional and disciplinary perspectives. The following are the overarching guiding questions.

- Explain your roles and responsibilities as human services personnel with Red Lake Family and Children Services and as a teaching professional with the Red Lake School District.
- Describe the families and/or the special needs children with whom you work.
- Describe overall needs, resources, and services for the families and /or children you work with.
- Share the demographics of those serviced.
- Describe your experience of meeting the needs of children with disabilities and their families/self care.
- Describe the gaps in service.

Delimitations

This study was limited to a small sampling of teaching personnel with the Red Lake School District ISD # 38 and human service workers at Red Lake Family and Children's Services. Four focus groups were held. Three of the focus groups consisted of special education teaching personnel at the early childhood, elementary and secondary levels. The total special education teaching personnel in Red Lake District consists of 57 staff, with the interviews representing 16% of the special education personnel. A fourth focus group included three human

services personnel with Red Lake Family and Children's Services, representing 25% of the staff working directly with families.

Limitations

Among the participants there are some who live and work in the Red Lake community. A few have experienced living and working out of the community at some time in their adult lives. Three of the participants have special needs children themselves, which includes two biological children and three adopted children. An important factor is the interconnectedness of families in Red Lake Nation as close and distant family members and neighbors. This creates both challenges for teaching and human services personnel, at the same time the teaching and human services personnel are able to view families from an intergenerational perspective. The interviewees' own self-awareness skills and education affect responses, as this topic is personal and sensitive to one's own opinion.

Traditional Culture Values

It is crucial that teaching and human service personnel have an understanding of traditional culture and family life including gender relations and roles and child rearing values for effective intervention with families. The Chippewa have a traditional culture value of helping the extended family. Native people strive to maintain dignity and self-control. There is an emphasis on respecting privacy. The value of self-sufficiency may hinder a parent to reach out beyond the tribe for assistance and advocate for his or her special needs' child. There is an uncomfortableness with disclosure without prior gaining trust. There also seems to be a stigma attached to having a special needs child.

Potential Significance of the Inquiry

Accessing the voices of a sample of frontline personnel working with special needs children and their families provides a beginning glimpse of the issues facing children and families, challenges and frustrations of personnel, gaps in resources and services as perceived by personnel, and recommendations for more effective programming at Red Lake Nation. The potential significance for the inquiry is to hear the voices of professionals that work day in and day out either directly with children who have special needs, or with families of special needs children. Gathering of the information offers an exploratory look at whether social problems exacerbate the difficulty in providing effective services to children with special needs on the Red Lake reservation. By interviewing professionals in different areas, I hoped to learn what is unique about each group that provides services to youth with neurological impairment. Gaining information and educating others of services that are efficient and services that are needed ultimately it was hoped would tighten the gap on reaching all children who need intervention. Another potential significance influencing this inquiry was to gain insight for prevention for neurological disorders caused by substance use.

Literature Review

According to Freeman et al, (2004) many Native American communities continue to experience severe problems such as substance abuse, child abuse and neglect, teenage pregnancies, suicide, and out of home placement for youth. Red Lake Nation like other Native communities faces a myriad of challenges. Examining the experiences of special needs children through the lens of teaching and human service personnel, it is important to understand a number of issues – historical trauma and the lived consequences in individuals, families, and the community, such as substance abuse, mental illness, poverty, and fetal alcohol spectrum disorder (FASD). These factors are central to the disproportionate number of challenges faced in general by Native communities and American Indian children with special needs. It also affects interaction between the children and their environment -at home, at school, and in the larger Red Lake community. These issues shape and impact the context within which special needs children develop, experience family life, and receive services (O'Connell, 1985).

Historical Trauma

The American government came to take a devastating role in the lives of Minnesota Chippewa starting in the mid 1800's when treaties were made and reservations were established. Minnesota Chippewa began to feel the impact of federal government native policy as unfair treaties resulted in ceded lands and children were sent to boarding schools disrupting families and cultural communities (Schuiling, 1990). The treaty process started the impoverishment of the Chippewa, with a dozen treaties finally leaving them confined to their reservations, none which had the resources to support a truly self sufficient economy (Schuiling, 1990). The Bureau of Indian Affairs (BIA) established by the federal government to provide employment, economic

assistance, education and public works for Native communities, also operated to assimilate and acculturate Native people to Euro American culture.

Although the Red Lake Band of Chippewa Indians never ceded their home territory to the federal government, utilization of timber and fishing, wild rice, and wild game as economic resources have not been sufficient to engage the population in employment for adequate income and support (Hickerson, 1970).

American Indians were guided by an informal enculturation process, which can be attributed to the Social Learning Theory, a process of observing and modeling the behavior of others (Bandura, 1997). Enculturation was a common practice within tribal family systems to ensure continuity as a people, as it was a critical resource for passing down information for the purpose of sustaining values, beliefs, teachings, and meaningful interactions (Shriver, 1998).

The removal of Indian children to boarding schools enforced the process of acculturation where children shed their traditional culture, dress, and language. With several generations of children going to boarding schools, traditional language, songs, and culture were lost with the banning of spiritual and cultural practices. Raised in institutions, vulnerable to physical, emotional, and sexual abuse, Indian children also lost the model of family and community connectedness (Freeman, 2004). Separated from their families and communities, children returned infrequently, becoming strangers to their culture, and loosening the valuable family connections. Children raised in institutions experienced abandonment. This compromised their ability to bond and connect and to understand the basic tenets of family life and parenting (Braveheart, 1998). Subsequently these Indian children in adulthood were susceptible to self-medication through substance abuse, inability to attach to other adults and to parent with attunement. Bigfoot (2006) states historical trauma is the “cumulative exposure of traumatic events that affects an individual and continues to affect subsequent generations.” Historical trauma plays an important role in the contemporary problems of Native American with exposure to racism, warfare, violence, and catastrophic disease over the centuries.

Native American culture has endured harsh conditions, as they had to accommodate the conditions imposed by the American government (Hickerson, 1970). All factors represent a form of oppression with result an erosion of the culture. As Braveheart (1998) points out the resentment, grief and loss of a compromised childhood, (of a childhood shaped by deliberate detachment from family, community, culture, and enduring abusive treatment), and cultural community are seen today in Native communities. Further inability to deal with the economic stress have pushed these reservations into the oppression of poverty (BigFoot, 2006).

As with other Native communities, Red Lake Nation, its community, people and families have experienced historical trauma as a result of the disruption of individual family and community life (Hunt, 2006). In Red Lake there are evident social problems that disrupt individuals, families, and the communities with disproportionate numbers of out of home placements, substance abuse, family violence, and poverty resulting in increased mental illness, children with FASD and thus children with special needs demanding care neither the parents nor the community have the capacity to meet (Meyers, 2007).

Social Problems

According to Meyers (2007) Native American children under the age of 18 living in Beltrami County represent 24% of the population and they are 74% of the children in out of home placement. 88% of these children are enrolled in Red Lake reservation (Meyers, 2007). For the children and youth living on the reservation 61% live with their grandparents, 55% of 18-24 year olds have not completed high school, and 75% live in poverty (Meyers, 2007). At the present time there are approximately 500 Red Lake enrolled children tied into a child protection or child welfare county or tribal social service agency throughout all of Minnesota (D. Dietrich, personal communication, January 4, 2009).

The high number of Red Lake children in the local child welfare system is reflective of/ symptomatic of both the contemporary lived experience of historical trauma as well as perhaps

the lens of the social welfare system as it looks at and responds to Native American family needs and issues.

The suicide rate among Native American reservations is 250% of the national mean (Bureau of Indian Affairs [BIA], 2005), and depression is the top diagnosis among adults seen at Indian Health Service- Behavioral Health Services in Red Lake (G. Aurand, personal communication, September 26, 2006). It could be assumed that self-medication with alcohol and or other drugs is much more prominent in Red Lake than in any other rural areas within Minnesota. Cognitive disorders related to the nature of substance abuse and the response of the family and community environment are also more prevalent than in the general population, with one in eleven American Indian children classified as having a severe emotional disorder (Hunt, 2006). This picture of Red Lake mirrors statistics on the indicating factors that lead to the onset of children's developmental disorders and the risk factors associated with social and emotional health, affecting the safety and well being of children. Currently, there are approximately 1,200 students registered in the Red Lake School district, with approximately 200 of them requiring special education services, which represents 16% of the total population of students (Red Lake ISD #38, 2009).

Red Lake Nation experiences persistent difficulties in individual and family life functioning. As noted earlier the consequences of historical trauma are generational and pervasive. The stress of living in poverty, compounded with mental illness and or substance abuse, and teenage pregnancies exacerbate difficulties with parenting. This can create a despair/ hopelessness, which disrupts individual and family functioning. The following discusses more specifically the social issues that Red Lake faces in strengthening and empowering individual and family functioning.

Teenage Pregnancy Teenage mothers, most of whom are single, face difficulties in providing a stable, supportive environment for their children. Children born to teenage mothers are at higher risk for poor neonatal care, low birth weight and infant mortality (An-Pyng S.,

Freese M., & Fitzgerald, 2007). Teenage mothers can find it difficult to support a child. For those that do not complete high school it limits future job prospects. There is a high rate of welfare participation among the group (Lukemeyer et al, 2000). Of two communities in Red Lake approximately 48% of the population is under 18, compared to the Minnesota and national average at 26% (ESRI, 2007). In 2005, 26 births to minors were reported to Red Lake Family and Children Services, 21 in 2007 (B. Branchard, personal communication, February 24, 2009). Out of 1,097 total births at North Country Regional Hospital in 2008, 54 were births to a mother under the age of 18 and 25 or approximately 50% of these were Red Lake Nation adolescents (North Country Regional Hospital [NCRH], 2009).

Substance Abuse When a pregnant woman takes a hit of crack cocaine, the fetus loses sufficient blood and air and suffocates briefly (Red Lake Family and Children's Services, 2008). For the mother, the drug effect lasts only 20 minutes. For the growing fetus, the cocaine stays in the system for more than two weeks (Red Lake Family and Children's Services, 2008). In the womb the child is re-exposed because the cocaine does not pass through the placenta to the mother but remains in the amniotic fluid surrounding the baby. Alcohol exposure is also known to compromise a fetus, which increases the risk of FASD, stillbirths, and miscarriages. According to Minnesota Department of Health Data (2004) from 1998 to 2002 Caucasian reported alcohol use during pregnancy at a rate of .08%, while Native Americans reported 8.1%. Drug use during pregnancy was reported by Caucasians at 1% and American Indians at 10.6% (Minnesota Department of Health [MDH], 2004).

Special Needs Children At Red Lake Family and Children's Services there were 28 babies reported from North Country Regional Hospital testing cocaine positive in 2007. Since then the numbers have doubled, with 30 babies born cocaine positive from in the first six months of 2008 (B. Branchard, personal communication, February 24, 2009). Birth addicted babies and children with FASD are likely to have mental health and behavioral problems, as well as learning challenges. It is also more likely pre-exposed infants will be parented by young mothers

challenged by substance abuse (Wilson, 2005). Because of this, there is an increase in demand for services for children and parents leading to expensive costs. It is estimated that services for a child with FASD can cost \$1.4 million over his or her lifetime to address their unique psychosocial and medical needs (Minnesota Department of Health, 2004). Again, substance abuse pushes more costs into tribes and counties with the care of these children.

The out of home placements costs for a medically fragile baby that spends 2 years in care due to prenatal drug or alcohol exposure amounts to approximately \$100,000 or \$140/day x 30 days x 24 months (Meyers, 2007). This figure is low compared to the medical costs of neonatal centers and hospital stays, surgeries, and physical therapy. Red Lake Family and Children Services currently has 8 children in out-of-home care that have been classified with a permanency plan as needing long term foster (D. Dietrich, personal communication, January 4, 2009). They have been in medically specialized homes since birth, born significantly premature with excessive exposure to substances in utero.

Rural tribal areas are not equipped with the resources and services for effective care and intervention for developmentally disabled children. There are no local mental health diagnostic clinics for children, child psychiatrists, speech, occupational and physical therapists, also there are no medically licensed foster care homes in the Red Lake Community. The closest FASD clinic is in Staples, MN or Minneapolis, MN. North Country Regional Hospital is the closest facility (35 miles) for OB/GYN delivery services. The autism spectrum disorder room at Red Lake Elementary sends children home when the licensed teacher is absent, because substitutes for special education cannot be found. The US Department of Health and Human Services Administrations (2008) reports that in Minnesota in 2005-2006, 30% of children with special health care needs did not have access to family centered care, 18.9% had difficulty getting a referral when they needed one, and 30% of those insured had insurance that was not adequate. This same parent survey also reports that 13.4 % of families of children with special health care needs live 200% below poverty level.

Poverty Red Lake Nation exists in isolation, separated from mainstream society. The community is challenged by a significant unemployment rate of 63% (BIA, 2005). 2001 statistics show that 50% of families in the small community of Ponemah bring home less than \$15,000 a year. The median yearly income on the reservation was \$16,774 in 2001 (ESRI, 2007). Basic necessities, imperative for families, particularly families with special needs children, such as transportation and phone services often are a strain for day-to-day living. For families with a special needs child at home this produces an extraordinary burden and families are additionally challenged. Diagnostic and intervention services, often only available off of the reservation are financially and physically inaccessible.

As previously noted, Lukemeyer's et al.'s research (2000) suggests 5% of children experience a condition that results in impairment or limitation of their ability to engage in usual activities of a child their age, but children in low income families are more likely to suffer chronic illnesses and disabilities than their more affluent counterparts. His study also notes that the time required for childcare and specialized care reduces parents' ability to sustain paid employment, yet the average SSDI benefit nationally is only \$600/month. For many poor families, a small out of pocket expense can cause an extraordinary hardship if a family has few resources to spare. For the children that do remain at home, the costs of therapeutic and educational services, transportation and other special needs services constitute a heavy burden. With budget constraints for low-income families, children with special needs end up getting the bare minimum of care.

Parenting Parents of developmentally delayed children experience increased stress in parenting and are consequently at an elevated risk for psychological distress and physical illness (Noh S., Dumas J. Wolf L., & Fisman S., 1989). Factors that affect parents with special needs children are maternal depression, lack of competence in parenting, feelings of poor health, and problems in relationships (Heller, 1999). It is clear that the parenting role is more difficult in the presence of an exceptional child with the children's adaptability, high needs and demands,

distractibility and emotional and behavioral moods all factors that affect a parents' relationship with their child (Konstantareas, 1992). An example of this impact on parents is that research indicates mothers of autistic children are six times more likely to be at risk for clinically significant levels of stress than those parents of typical children (Noh et al., 1989). Noh, et al.'s study (1989) indicates that these mothers are more likely to experience depression, social isolation related to the attention demands of their children, and doubt their parental competence.

In Konstantareas' study (1992) parents self reported shorter interactions with autistic and mentally delayed children. In addition, parents report there is less reciprocal attachment, as with a child with autism frequently ignores, avoids, and actively repels social contact, which can be distressing for the parent. Or for the mentally delayed, mothers involvement is much more directed to care giving then playing or educating them. Crawley and Spike (1983) support this stating the lower the child mental development index the lower the degree of mother-child interaction.

At the same time, it is more likely that mothers take time off work. Grey (1990) poses the question "If fathers are less engaged in caretaking tasks with normal infants, how involved with caretaking would fathers of severely handicapped older children be?" Studies have shown that mothers experience greater stress in parenting exceptional children than fathers, and 57% of the wives reported they were more likely than their husbands to take time off work to meet family responsibilities (Grey, 1990).

Mental Health/ Sense of Despair/ Hopelessness The American Indian culture is comprised of kinship family with extensive relational ties. In this, women see themselves tied in the family role centered on a connection between relationship and responsibility, and the activities are primarily focused on serving others' needs. Research by Miller (1986) states that the American Indian woman's life is best described as "an active participation in the development of others." When a child at home has special needs, there is increased responsibility and the relationship between her and her child is impacted as the child develops. Research has looked at the family

life cycle in relation to raising a child with special needs (Harris, 1984). Mothers tend to find toddlers more exhausting. Prior to school age with early intervention children typically enter the special education setting. As a special needs child grows older the physical and emotional demands for care do not lessen. Children age physically but their cognitive and affective functioning can be significantly limited. When parents of typical children look forward to a time when there is self-sufficiency, parents of special needs children are forced to realize that preparations must be made for the adult life of the child. The plans need to be intricate and require the participation of siblings as they move into adulthood and the parents move towards elder years.

Compounded with the social issues on Red Lake including historical trauma, teenage pregnancies, alcohol and drug use, and poverty, many special needs children end up in out of home care. For the ones who stay at home their care may be compromised unless that parent has established self-care skills, a strong support system and an awareness of feelings and reactions to parenting a child with disabilities (Heller, 1999). Stress is reduced by improving mood state. But

...if a physical therapist attempts to teach the mother of a preschool autistic child how to be skilled at feeding and dressing but ignores the mothers' depression about the child's diagnosis and the fathers' lack of involvement in the family he/she is failing to do the things that have been deemed important to the child... (Harris, 1984).

In essence, a holistic healing approach needs to be taken with families, addressing the emotional, mental, physical, and spiritual needs of the whole family.

Impact on Fetus and Newborns

The social problems described above impact the well being of fetus and newborns. The number of babies on the reservation described as medically fragile, babies born prematurely, drug or alcohol addicted or suffering from FASD, has been growing rapidly. The Center for Disease Control indicates that 21% of babies born on reservations have FASD, while the Indian Health

Service indicates that 29% or almost 1 out of 3 have FASD (Freeman, 2004). When a baby is born testing positive to drugs or alcohol at North Country Regional Hospital, the infant is placed on a 72 Hour Hold and the local county or tribal agency is informed. That agency then works with the parents to ensure the baby will receive adequate care and the mother will remain clean. Often the mother will be required to undergo a chemical dependency assessment and follow through with treatment before reunification occurs. To get around the 72 Hour Hold, mothers often quit using or clean out their systems a month before baby is due so they pass the urine screen.

Current Prevention and Intervention

Red Lake Family and Children's Services currently has 20 child protection cases open due to babes born drug positive (B. Branchard, personal communication, February 24, 2009). Red Lake Reservation Police Department charges a mother with "endangering an unborn fetus" if she is found using while pregnant. She will appear in court and prosecution pushes for a chemical dependency assessment to see if treatment is needed. The mother is out on probation and monitored until the baby is born. (G. Aurand, personal communication, September 26, 2006), from Indian Health Services hospital, Behavioral Health, remarked that, "If a parent has 5, 1:1 counseling sessions [while pregnant or before getting pregnant] regarding prenatal care and chemical use while pregnant, she will be less likely to use, but many women do not actively seek out counseling or help if they think they will be punished." Women are also deterred from getting prenatal care due to legal consequences of using.

Sometimes, if social services are aware the mother is using, coordination with the police and the hospital is necessary to hold the baby even if the baby is not drug positive. Alcohol is illegal on the reservation and there is criminal enforcement for drinking also.

Research Design

Researcher as Multicultural Subject

Several years ago, I worked as a personal care attendant (PCA) for a single mom in Bemidji and her developmental disabled children. Throughout my year-long stay at her residence, we became very close. Today we are good friends, and I continue to support her through her journey with her two special needs children, an 8 year old autistic child, and a 13 year old child diagnosed with ADHD, and pervasive developmentally disorder with autistic characteristics. Every morning at 6 a. m. her son wakes up everyone in the household shouting and yelling until his doses of morning triliptall, risperdal and adderall kick in. We would kid and say he was the “morning rooster.” Her daily struggles included her former spouse not being involved with the children, 12 hour work shifts as a registered nurse, leaving her kids with daycare, respite and PCA workers, Beltrami County Social Services involved with her regarding intervention with her older son who had juvenile delinquency proceedings, and the State of Minnesota requesting \$700 back pay in her sons’ SSI overpayments. As the stress escalated, her autistic son repeatedly had meltdowns at school, requiring secure holds. My friend struggled off and on with her own marijuana addiction to escape the overwhelming responsibilities. This past spring she admitted herself to Prairie St John’s Hospital in Fargo, ND for relief from her own unmanageability. She began living one day at a time, her eldest child placed at Mesabi Academy through Beltrami County Probation, and her autistic child in a group home. With her children spread across the state she struggled with her own depression, her competency of being a parent, and her hopes of reunification. The autistic child has since been reunified and she, the mother, has built up her support system, and remained clean and sober despite compounding responsibilities of her special needs child.

Today, after a decade of decisions, I have almost completed my bachelors of science in social work and blossomed from a shy girl into a woman with character, strength, and self-

sufficiency. I am also Caucasian and a single mother with two children, and continue to find empathy for those who are suffering. As a child protection case manager since June 2005 with Red Lake Family and Children Services, I witness the daily destruction substance use has as it takes a toll on the children in terms of being subject to adverse parenting and environments and in terms of genetic issues related to FASD. I see autistic children left outside without supervision or interaction, as they play quietly in a corner. Or physically handicapped children remain in their wheelchair in the same room all day. I see kids living in homes with no resources for transportation and groceries. I see children with special needs with no early intervention until the children reach head start age. I see parents who have no knowledge of skills and techniques to better handle the behaviors of their special needs children, and parents who have the trainings but no access to medication monitoring or therapy. I also see frustration and grief with the loss of a child when the social problems in the household are overwhelming and the child is removed. I also see triumph and strength when a parent surrenders their addiction and reunifies, sacrificing their freedom for the benefit of their children.

My hope is to continue my education and work in child protection case management with families to assist them with their own empowerment.

Methodology

The research design used for this study was qualitative. This research design was chosen due to its exploratory and unique features (Patton, 2002). Qualitative research design is flexible, with its features allowing a researcher to gain insight to understand a phenomenon based on observations (Golafshani, 2003). It is a way to generate useful data from personal opinion and understand general trends in the social world. Qualitative research is a “voice” for the participants to understand their point of view. In qualitative research design, the researchers come to embrace their involvement and immersion into the research process, as Patton (2002)

states, “a qualitative researcher is an instrument, the credibility of the research is based on ability and effort of the researcher.”

Focus groups were used to gather data, based on the researcher’s decision to gain a more ‘interactive’ approach. Focus groups allow for a safer, natural setting for flow of data. The focus groups versus individual interviewing have advantages including; allowing for more participant observation, more spontaneous discussion and disclosure, and permitting a greater emphasis on subjects’ viewpoints (Golafshani, 2003). Listening to how one group member responded to another provided for more insight in the opinions, experiences, and attitudes of participants. The focus groups also allow for the moderator to explore unrelated but anticipated topics as they arose. Disadvantages to focus groups are that the results obtained are influenced by the researcher, as he/she leads the discussion group questions, and that the information gained may not be necessarily a representative of the whole population (Taylor, 1998).

Participants/Setting/Site Because of the small size of the reservation, it is pertinent to not disclose any specifics regarding the participants to protect their anonymity. It can be stated that there was a mix of teachers, paraprofessionals, and human service child welfare personnel from those working with children with emotional behaviors problems to developmental and physical handicaps. Of the participants, six hold bachelor’s degrees in teaching and are licensed with the State of Minnesota. Two more hold associates degrees. One participant holds a bachelor’s degree in Social Work. Three interviewees are also parents of special needs children, providing more personal insight to the information gathered in the focus groups.

Data Collection The researcher sent a letter of inquiry to the special education department at each age level in the district and the human service agency. Then the researcher contacted each school and the human service agency and requested a date and time to hold a focus group. The participants were the personnel that attended by self-selection. Prior to the focus group interviews an overview of the research was provided, along with information about

participation. Participants were advised regarding confidentiality and contact information, and provided consent forms, which were signed prior to the beginning of the focus group.

Four focus groups were held. Two teaching personnel participated in a focus group at Ponemah Elementary, three teaching personnel participated in a taped focus group at the Red Lake High School, and four teaching personnel participated in a taped focus group at the Early Child Special Education in the Headstart/ Kindergarten building. Three human services personnel participated in a taped focus group at Red Lake Family and Children's Services. Each focus group lasted approximately 45 minutes, and notes were taken at all focus groups. The researcher facilitated the focus groups, with the participants not knowing the questions in advance.

Two interview guides were developed for each participant group- human services and teaching personnel. (Appendix A) The questions for the most part were parallel with a few exceptions asking the participants to comment from their professional and disciplinary perspectives. The first overarching area was explaining the roles and responsibilities as a human service or teaching personnel within Red Lake. Under this category all items were universal to both groups including: Describe current position and length of service. Describe a typical day. Discuss your preparedness for the position, and what would have been helpful to be more prepared?

The second overarching question was sharing a "picture" of the families participants worked with. Under this category the items that were universal to both groups included: Do you see intergenerational disorders? What is a family's response to having a special needs child? What is the impact of the special needs child on family as a whole? What are assets and strengths? What helps family members understand disability? And what gets in the way of understanding? Within this category the item that was unique to human service personnel was that participants were asked to describe the families of the special needs children they are involved with, whereas the item unique to the teaching personnel was they were asked to describe the children they work with.

The third overarching question addressed the families and children's needs, resources and services. Under this category, the items universal to both groups include: Describe overall what you see as the overall needs of special needs children and their families? How do needs change over time? How resources are accessed? What are barriers to access services and resources? What are creative resources? What are extra expenses occurred for the children? And how does this make a difference in the families' ability to care for a special needs child? Within this category the item that was unique to human service personnel was that the questions pertained to needs of the family, whereas the teaching personnel were asked in specific to the child.

The fourth overarching question was learning about the demographics of children and families served. The teaching personnel were asked directly regarding the children served, with questions: How many children are served? How many aides are in the classroom? How much time spent 1:1 with children? And what are the children's care needs? The human services personnel questions were directed to the families they serviced with questions including: How many families do you work with? How much time is spent on case management? How much time spent with entire family or with parent/caregivers? The universal questions included: Describe interventions utilized. How many are single parent families, or non-birth caregivers? And the categorizing of special needs into specific groupings.

In the fifth area of research both teaching and human service personnel were asked the same questions in regards to impact of self-care including: Describe your experience of meeting a child or families needs? What impact does not meeting families needs have on you? How do you handle stress? What is rewarding regarding your work? Both participant groups were also asked the miracle question- If things were the way you wanted them to be in the world of special education or child welfare what would it look like?

Validity and Reliability There is fundamental difficulty with qualitative studies that affects both reliability and validity. Validity is the degree of measuring to provide authentic conclusions. In qualitative research no set standards exists for evaluating the validity of

conclusions. The researcher can assess the credibility of the participant, and the focus group participants' spontaneous statements versus direct response to questions, as these are factors to consider when evaluating validity (Chambliss & Schutt, 2006).

Reliability is the extent to which the findings of a research design remain consistent over repeated tests under identical conditions, yielding the same results. Based on the participants' trustworthiness, dependability, and view and feelings, results may differ. The researcher influences the results obtained, as the methodology structure itself affects the answers. Using this researcher approach the researcher does not remain an observer but becomes a participant, which is taken into consideration when conducting the analysis (Stemler, 2001).

Data Analysis

Content Analysis After the data was collected the taped interviews were transcribed, reviewed and structured. Content analysis was employed to interpret the data using the interview questions as overall categories from which to generate themes into the literature review. As United States GAO (1996) states, "Content analysis enables researchers to sift through large volumes of data with relative ease in a systematic fashion." Responses for each research question were analyzed with all common responses inserted under the interview questions and literature review topics. This approach allows the researcher to examine trends and patterns, which becomes a useful technique to analyze data. Categorizing the data then becomes rich and meaningful, as Stemler (2001) remarks, "The words that are most often mentioned are the words that reflect the greatest concerns."

Operational Terms and Concepts

For the purpose of this study when referring to children that fall under more than one of the above categories, the term 'special needs' is used.

Autism Spectrum Disorder (ASD)- a pervasive developmental disorder with major deficits in language, socialization, and environmental relationships.

Fetal Alcohol Spectrum Disorder (FASD) - developmental problems caused by alcohol, a condition affecting babies born to women who drank excessive amounts of alcohol during pregnancy, characterized by a range of effects including malformed facial features and learning difficulties.

Learning Disabled (LD) -impairment related to the impairment relating to the process of acquiring knowledge by the use of reasoning, intuition, or perception relating to thought processes

Emotional Behavioral Disorder (EBD) - is a broad category which is used commonly in educational settings, to group a range of more specific perceived difficulties of children and adolescents. Both general definitions as well as concrete diagnosis of EBD may be controversial as the observed behavior may depend on many factors.

Severe Emotional Disorder (SED)- classified from damage in the brains development. (seen on diagnostic assessments criteria) .

Attention Deficient Hyperactivity Disorder (ADHD) A syndrome of disordered behavior, usually diagnosed in childhood, characterized by a persistent pattern of impulsiveness, inattentiveness, and sometimes hyperactivity that interferes with academic, occupational, or social performance. Also called *attention deficit disorder*.

Individualized Education Plan (IEP) -In the United States an **IEP**, is mandated by the individuals with Disabilities Education Act. This requires public schools to develop an IEP for every student with a disability who is found to meet the federal and state requirements for special education.

Findings

Relationship to Literature

Historical Trauma The first area of research focused on historical trauma and the residual factor this still has on contemporary families and children. Historical trauma is defined as cumulative emotional and psychological wounding across generations, including ones own lifespan (Braveheart, 2007). Teachers and human services workers commented repeatedly on the complexities of families' lives coping with extreme poverty and substance abuse as they attempt to cope with their children's special needs. Historically, Native Americans learned harsher discipline from the boarding school and this has crossed into their children's upbringing. Many of these parents never received nurturing. It is evident that professionals working with families see the historical impact, as one participant stated, "Parents can't give what they don't have." Because of this lack of belonging and love, young girls have children to fulfill their own needs for security and don't realize the real responsibilities of parenting. When asked to share a picture of the families they worked with, child welfare workers descriptions reaffirmed that historical trauma has been passed into the present as most of families in the child protection system have intergenerational abuse, and a cycle of neglect. In a small community with extensive family ties, unexpected deaths result in unresolved grief and loss in each generation.

Poverty The second area of literature research discusses how poverty impacts the care for a child with special needs. Living on the reservation in itself plays a part in this as one participant remarked, "environmental poverty is depressive." Many families are seen as having a lack of stability and living in chaos-which is also characterized within the culture of poverty. As teaching personnel accentuates, "It is a sad, sad, reality." When asked what financial assistance was available to assist families, Social Security benefits, grant monies from the Minnesota Family Investment Program (MFIP), and food stamps were described as the most utilized. Often children see their parents struggling on the welfare system, and have no concept of living outside

of the system. One benefit of Red Lake is that there is no limit on the number of years a family can be on MFIP, but there is a cap on the amount of children that qualify. If a sibling is born into a family that is capped, there will be no extra money to that family even if that child has special needs. MFIP requires job search hours, which interviewees stated is difficult for the parents to meet the requirements of, “especially when living over 20 miles away from the office with no transportation and having a child at home in a wheelchair.”

In Beltrami County 185, children under the age of 18 received Social Security Disability Income (SSDI) benefits, which is a fairly high ratio compared to other counties of Minnesota (US Census Bureau, 2000). But the reality is that this process is not so easy. One participant parent quit her job to remain home with her children. She states, “I did everything they told me to do, I got my kids a full psychological evaluation, it took me four months to get everything done and I was still denied. I applied again, my son has been turned down 4 times, my other kids twice, I said you know what-I quit”.

When participants were asked what impedes their children to get the services they needed, financial resources was the prominent issue. All children enrolled or eligible for enrollment do have free health care through the Indian Health Service hospital. When a doctor makes a referral for therapy or appointments out of the area, it is paid for and transportation is available from IHS. Medical Assistance then becomes the next option for health care for children, which most families qualify for. With medical assistance, and utilizing a doctor not through the IHS hospital, children may qualify for free transportation to medical appointments through the Medivan, and be allowed reimbursement for gas, and meals and lodgings. For the parents that are employed and do not fall into certain income guidelines, children may not have adequate health care. Utilization of services then becomes an issue. The process can be frustrating for parents, as one participant voiced, “It is like walking into a brick wall especially for those who find it difficult to navigate the system.” One human services personnel remarked

that a child she worked with, “needed physical therapy for 2 years and [the child] remained in out-of-home placement because the mom didn’t have adequate transportation.”

Out-of-home care is another option if the expenses and care are too much to handle. One teaching participant stated that is a two-fold problem though because many parents do not want to lose the SSDI benefits if that child needs to be placed out of home for specialized care. So many parents keep the high need children at home, even if that means less services the child is able to access.

Substance Abuse and Teenage Pregnancy As noted in the literature review, substance abuse and teenage pregnancy is becoming an increasing problem with the adolescent and young adults general population, and is disproportionate for Native American communities. Out of 125 OB-GYN positive drug screens at North Country Regional Hospital in the year 2008, 49 were women from Red Lake (NCRH, 2009). Of these only 13 resulted in a 72 hour hold, of which 6 were from Red Lake, 3 were Leech Lake, 3 were Cass County and 1 was for Beltrami County (NCRH, 2009). The following participant quote sums up the practitioners experience in relation to research, “We are seeing a high percentage of mothers whose babies are born having at least been exposed to drugs and alcohol. They may not test positive for drugs at birth, but throughout those nine months they are exposed.” One human service participant emphasized that generational alcoholism is one of the primary concerns among parents involved with the child protection system. It is seen as both nature and nurture- both hereditary and in the family environments.

The number of infants with developmental delays born to teenagers and substance abusing mothers is growing rapidly (MDH, 2004). Because of the circumstances of their birth and the dysfunctional dynamics of their family, these babies are assumed to be at high risk for abuse, neglect, and abandonment. Their health status requires monitoring, compliance with medical and developmental protocols, and timely interventions. Obligations that their parents, many of whom are chemically dependent and impoverished, find it difficult to meet. Denial

seems to hold up the progress of a mother working with interventions, as one child protection worker stated, “This mom had no communication skills because she was too busy blaming others for her own problems.”

When reviewing statistics of children between the ages of 0-19 years old in Minnesota in 2001, the percent doubles when looking at the same categorical age ranges for Red Lake Reservation (ESRI 2007), which demonstrates young women having babies. An interviewee articulated the reality, “We just see very young kids that are 12 and 14 and 13 years old having babies.” By the time the baby is a kindergartener that mother would be just finishing high school. One interviewee remarked, “Out of an average of 120 kindergarteners each year, the graduating classes sit at an average of 30 students.” With the district getting tagged with the No Child Left Behind Act, it reinstated its in-school day care for parents with the purpose to keep the youth in school. Today there are 19 babies enrolled to accompany their mothers to school.

Parenting and Stress Parenting in and of itself is stressful, with everyday developmental issues challenging even the most competent parents. Issues such as poverty, substance abuse, lack of social support, and domestic violence compound the tension of the parent child relationship. Add in the demands of a special needs child and the stress can be multiplied. Teaching personnel and human service participants often felt that the children’s medical educational and physical needs were compromised due to “social problems.” It is evident in interviews that they felt children’s needs are not met in the home with competent parenting, with one interviewee emphasizing, “We feel that a lot of our kids get parented by the path of least resistance, it’s easier to just give in and let your kid have what he wants, than it is to try to corral behavior.” One professional in an EBD classroom remarked that most of her students take care of themselves or are taken care of by older siblings. This perspective reflects compromised parenting, with abuse and neglect known to be the #1 indicator for the development of children’s severe emotional disorders, this affects the children’s emotional and psychological well being (Noh et al, 1989).

As children move into adolescence they become harder to manage, with one interviewee reporting hearing the same mantra from parents, 'I can't deal with this kid.' Another teaching professional reinforced this plea with her classroom of EBD children as she stated, "'I can't handle him' is a regular phrase I hear from parents." Passive parents then want to utilize the special education program in hopes things will get better. A high school teacher conveys the attitude of parents, "They expect their kid to behave in school, and expect them to pass their classes and expect to see an improvement at home, but the environment at home hasn't changed."

Parents of special needs children are challenged to provide a unique role that involves not only love and nurturing, routine and stability, and a safe environment, but also a substantial amount of extra personal care, behavioral management programs, and medical care that can become quite complex. In response to questions regarding what are the unmet needs of the children impacting their full potential, practitioners implied that the parenting is not sufficient enough to help the majority of the children. Instead of pushing to make the child become more independent or learn more skills it is almost sometimes easier to keep the kid in diapers. Families require more help with support; often there is partner conflict, depression, and extensive family issues that arise from the stress of a special needs child. One participant with three FASD kids vocalized her stress, "The first hour at home is like hell, and just cooking a supper today is really a lot sometimes. I can't do it sometimes. Afterwards I try to sit down and take some time to relax but 95% of time that doesn't work."

While teaching personnel interviewees commented more regarding parenting practices and consistency to maximize the child in an educational setting, the human service participant's voices emphasized the social/environmental restraints that inhibited parents to meet the needs of their child at home. These interviewees portrayed substance abuse as a common means to cope with the added stress, which leads to unhealthy discipline, abandonment, and emotional abuse. Often parents are unable to adapt to pressures a special needs child brings, they have low coping

and problem solving skills. The primary diagnosis can become a vicious cycle, parents get down on themselves, see themselves as a victim, and like to blame.

Hopelessness and Despair Caregiver burnout is a major challenge for families of special need children. The daily routines with parenting, along with providing the extra emotional and physical interventions can be exhausting. A parent participant commented, "My son is 5 foot 8 and 250 lbs. I am scared of him. When he goes on a spin I can't do anything. Putting him away was the hardest thing in the world." All this affects the normalcy of family life. Another parent participant highlights,

P.K. is always hurting his brother, or himself, or destroying something in his room. I buy huge bottles of germ ex and he cannot live without it, he would probably go ballistic if he didn't have it. I buy the big bottle and they last about two weeks. You can't touch anything of his, because it contaminates it and he won't touch it. So doctors label it obsessive-compulsive disorder but they also know it is fetal alcohol. It is scary. I about lost it when the doctor told me my son was schizophrenic. I asked where he got that. I can't handle my life. All I have been doing is crying, when you get to the end, where is the support for a single parent. As a whole, I think they [her three FAE kids] make family life really hard, you can't just focus on your family because every day your dealing with something new.....every day there a crisis of some sort,....it makes you crazy. That's what's happening with me, I don't know what to do. I called my kids doctor, she said-, "You need to help you before you can help them."

This parent participant goes on to say her son has shut down and hardly comes out of his room. "It's gone to the point where I can't do it anymore." Families are too overwhelmed and they want to give up. One human service participant shared this family reflection,

M.M. was born prematurely and stayed in ICU at Hennepin County for 3 months before transitioning to a foster care home in Red Lake. It was clear at the time the parents weren't stable enough to handle the young child's needs. She had required a catheter and

daily involvement with muscle tone for building strength. After 24 months the child was reunified. M.M. now 2 ½ yrs still requires physical therapy 3x a week, which is located 30 miles away. There have been many missed appointments since reunification and M.M. is falling behind in her gains. Her father debates whether to quit his minimum wage job to take his girl to therapy, frustrated he calls his case worker, 'Maybe you guys should just put her back in a home, this is to hard.'

Relationship to Theory

The base of this study can be attributed to several theories. The social learning theory correlates best with this study as it is grounded in learning from the environment, with an emphasis of observing and modeling the behaviors, attitudes, and emotional reactions of others (Bandura, 1997). Having an environment that is not supportive of health makes things difficult. In looking at the historical trauma, generations lost their cultural base and some families never learned positive parenting. Thus the passivity is a learned behavior. Social Learning Theory is geared exclusively at learning from our environment (Shriver, 1998). For children that are physically or cognitively disabled to be successful, an environment with predictability, routine familiarity, safety, and behavior modification principles is necessary.

This study is consistent with Maslow's theory of self-actualization (Shriver, 1998). Every day survival is present for the children wrapped in the child protection system, and there is trauma just in daily living. Most of the families on the reservation live on welfare, and don't have the money to care for their basic needs. Often, families don't have the resources or support to move them past the struggle to meet basic needs for survival. One teacher expressed her concerns for a child they routine intervene with in ECSE, "this poor kid, his dad is a recent widower, and he has 4 children age 5 and under."

The Native American Relational View approach to wellness is also worth mentioning as it also applies to this study. Relational View is one that represents the four areas of balance;

spiritual, physical, mental, and emotional (Hunt, 2006). In this approach, individual choices regarding healthy lifestyle affect their potential in the four areas. If an individual is off balance they are unable to walk the path and lead others towards wellness.

Relationship to Practice

Special Education Early Childhood Special Education (ECSE) serves children birth to 7. The agency works with children of, as one participant commented, “any flavor of disability.....ECSE has a big wide door for referrals.” The referrals come from hospitals, child protection (CP) teams, other school districts, Early Childhood Family Education, or doctors. The participants described the process of how children come through the door. Birth to three children are screened and serviced with home visits. At Head Start all children are preschool screened and this brings in more children. One participant stated that every fall when kindergarten starts, “A cluster of kids are recognized that appear out of nowhere, having no previous referral for services.” After screening children on their skills, the ECSE team decides which children need further evaluation. This process involves interviews, observations, and testing in the areas of social, emotional, physical and cognitive development. After the evaluation is completed the team presents the plan to the family.

Through interviewing teaching personnel, it seems the school setting is the greatest resource for kids. The school special education teachers were positive about their ability to meet the needs of the children in the educational setting. Interviewees, Native or not, openly shared the reality of the environment even if it was close to the familiarity of their own life. Several shared personal examples of their own children having special needs, which gave perspective to the live experience, and of working in the field. The different personalities shone through into professionalism.

At Ponemah Elementary, it is indicated there were fewer resources. One participant felt a more space was needed, along with a self contained room. She felt her students were highly

needy, and their behavior in the mornings was a direct reflection of the stability of their night before. She stated she has sensitive, self conscious students, and they feed off each other's issues. In Red Lake the teachers felt they had all the resources they need for their special education students, like mats, balls, and trainings for staff. Staff felt equipped to handle most situations and felt the school had taking strides to improve communication with parents, school counseling programs and reports weekly coming home from the school.

When asked to describe a typical day, the reality of the students' care and assistance they need were illustrated. The reality is that the school handles a lot of basic needs. Teachers reported that hygiene like showers, brushing teeth, physical therapy, bathroom, and eating takes up 50% of the time. All teaching professionals agree with the mantra to 'start where the children are at' in the morning. The children literally sleep in classroom if they are tired. Staff have acclimated rules and expectations, each day depending on the child's emotional state and to meet the students' basic needs. For some children modified days (10:00am to 2:00pm) works best to avoid excessive tardiness and absences. In the high school there are 2 children who are autistic, 1 child with a brain injury, 12 developmental cognitively disabled (DCD) children, and 10 children that are classified with an emotional behavioral disorder (EBD). There are extensive independent life skills for the DCD youth, where the teacher addresses cooking, cleaning, basic reading and math skills, safety, job applications and resume building. The students are paid \$7.00 per hour when performing work skills, in the library, at the nursing home, or cleaning buses.

When asked about unmet needs, teaching personnel discussed one difficulty was the classification process for an IEP, stating, "FASD is highly notable with some kids, but they don't come into special education programming because they are able to handle things in the classroom. FASD does not qualify under an IEP, unless a biological parent indicates she had been using while pregnant." Without this verbal or written proof, and not enough measurements in the testing procedure for an IEP, the children fall behind. The reality is alarming as one parent participant stressed,

My daughter cannot cross the road safely. She can't tell time on a hands clock, and she is 18. She can't count money properly. The school says she doesn't qualify as a special needs child. She will end up sitting at home.

In essence, no one advocated for her and no one requested a 504 plan for her to receive special assistance in the school setting.

ADHD used to be a qualification for a child to receive special education services through the school district under an EBD category, but that has been discontinued. ADHD only qualifies under an IEP classification 'other health impaired,' but it has to be documented under certain guidelines. Teachers expressed their frustration because some kids just need a little extra assistance with attention-orientated tasks to be successful and the school isn't able to provide it unless there is extensive documentation where the ADHD impairs child's ability to function in school (Red Lake ISD #38, 2009).

Behavioral and Mental Health Behavioral and mental health issues are a theme that arose throughout the focus groups when participants were asked to describe the special needs of the children they worked with. In the human services realm, one participant estimated that out of a 100 families, 85% had a child with special needs. She elaborated that, "Most of these are seen as children with mental health issues, and they receive mental health services once a diagnostic assessment is completed." Another human services participant agreed, "The mental health kids are crossing to the forefront before the physically handicapped." This implies that when discussing children with special needs, there are more with mental health/behavioral difficulties. When asked why, the participant stated, "They are growing up faster than they should be because they don't have the parents at home." With some children cognitive defects aren't seen right away but there may be a learning disability (LD) or behavioral issue that is diagnosed when that child is school age. Participants agreed the behavioral issues and mental health issues are getting harder as they get older if not addressed at a younger age. Even in ECSE the transition back to Monday shows the difficulty a child has, as the staff literally "runs out of bodies to be in

mainstream with the kids who can't handle it." When asked how prenatal exposure plays a part in the children served one teaching personnel participant stated, "I think it is seen in the LD kids, but especially the DCD kids and the EBD kids at an extremely high rate." The teaching and human service personnel concurred from their perspective that a dysfunctional living environment definitely exacerbates symptoms, making a FASD child harder to manage in a home environment that is not supportive to his mental health needs.

Autism Autism was a theme that arose within the ECSE focus group when participants were describing the children and families they served. The ECSE participant shared a report from Fargo Merit Care Neuroscience (December 2007) on a 7 year old child, to capture a sense of the attributes of a child with autistic features:

The most prominent feature that I noted with X.Y. was her echoing behavior. She copied the phrases that I said to her with a high level of accuracy plus she would copy the tone, rate, rhythm, and inflections of the presented information. Some very good signs were noted in my evaluation. X.Y. would walk cross the room to get my attention, she would smile, tap on my arm, she on 2 occasions held my hand and walked down the hallway with me. I engaged in some silly behaviors. She expressed laughter. She engaged in some copying of the figures that I presented to her with on paper using a crayon. She laughed when the examiner 'galloped' down the hallway with her. All these signs would indicate to me that her social skills and interactive ability are coming along better than I had expected. On a couple of these occasions X.Y. engaged in some teasing behavior, for example, tapping on the examiners shoulder and then smiling at the examiner and showing him what she had done.

Currently this child's diagnosis under the Diagnostic Statistical Manual (DSM) is global developmental delays with autistic features. The ECSE participant explained that when in kindergarten this child spent modified days in the EFCE room, but the transition into first grade meant changing her IEP to Autism Spectrum Disorder (ASD), so she could continue to receive

the special services. The participant described how they request the doctor to state this recommendation in their reports, like wise, this is noted in the child's' neuropsychological exam, "X.Y. should continue her setting in the ASD self contained classroom." The teaching personnel stated spontaneous speech is 'nil' with autism so the ASD classroom structure is outlined with photo cards. These cards help the children verbalize what they need or want by getting the picture for eat, bathroom, etc.

When asked to describe demographics, ECSE teaching participants stated there are 6 children with autism currently enrolled in ECSE. Out of these 5 are non-verbal and 3 are still in diapers. In Red Lake the ECSE teaching personnel who assists with screening for children stated there was an increase from 2 children on the reservation identified as having autism in 2000, to a total of 15 children on the reservation identified as having autism in 2008. The same participant continued, "This rise is exploding, with 1 in 133 children in Minnesota with having Autism Spectrum Disorder, Bemidji School District identified 14 more children in just the 1st three months of the 2008-9 school year, bringing their numbers from 70 to 84 served."

Intervention Adequate follow through for intervention that affects the development for children with special needs was a theme that arose with the focus groups. ECSE services are voluntary. Families are not forced to participate, yet when they don't their child falls behind. Intergenerational services users are also seen at this level, a teacher discussed she had a boy on an IEP when he was in 1st grade and now two of his children are in ECSE. When asked what staff does in regards to children's needs not being met, it was stated that sometimes it amounts to a child protection issue. This was explained as a fine line- "with the basic developmental delays sometimes if the families aren't open to services we have to let it go- knowing the child will come up next year." ECSE teaching professional stated that there are very few families that refused the evaluation process, and they try to have as much empathy as they can.

Participants agreed that some children with delays cross the line into medical neglect. When a child is 3 and does not walk or talk and the parent is refusing to take him to physical

therapy, this report gets turned into child protection. Later into elementary school special needs children are tied into enough services that a provider would call social services to follow up if a parent was not following through. One family had 6 intakes before out-of-home placement occurred for the youngest son with spina bifida. He was neglected; his mother ill, and previous intakes were disregarded due to the alcohol use with siblings in and around the home. This youngster had to get braces on his legs and begin to use a crutch, something that should have been done several years prior. One teacher clearly expresses she sees a gap, "When child is involved in child protection, the child gets services; otherwise there is no follow through with the parents."

Human service personnel feel like they are not prepared with the increase in crack/cocaine users. "Going into a home and wondering what to do if there was no officer there, there is so much more crack houses and crack babies now then there ever was, dealing with these individuals is dangerous." In social services, participants felt frustrated when they could not meet families many needs, like the tribe, the 'program' failed. Often the result is the child is prematurely reunified with their natural parents, and because family dysfunction has not been adequately addressed, the child re-enters the social services system repeatedly. The frequent movement of children at a young critical age then could lead to a psychosocial damage.

When asked what challenges practitioners face paperwork was #1. It was expressed by the teaching personnel that they spend hours and hours on paperwork, often up to 50% of time. This is seen as a challenge to continue servicing kids. "We spend as much time as we can with kids. It is almost making direct care impossible, but we get creative with getting things done."

Community Role When participants were asked to illustrate the overall gaps for children with special needs community resources, a theme arose with deficiencies in area resources that affect the quality of life for children with limitations that reach adulthood. There is "absolutely nothing in the area." With an IEP, teachers are required to have transition plans two years prior

to graduation, and the high school tries to keep students enrolled until they are 21. One participant parent with a physically disabled son communicated her agreement,

Right now my son is just at home, and I wish I'd encouraged him to stay in school until he was 21, but he wanted to graduate with his friends. There no places for them to work, I thought about him applying at McDonalds but that would be a lot of travel.

There are no transitional housing units, assisted living units, and few if any employment options for special needs young adults. There are no specialized foster homes. There is no place to go within the community so children and young adults with special needs can be close to family but get the proper care. In Red Lake safety becomes an issue for a lower functioning or mildly impaired DCD children, due to being highly vulnerable. There no support services to enable young adults to live independently. One teacher asked her students where they are going to live after graduation and they stated, "home, 'till my parents boot me out."-that's a standard answer coming from any child, special needs or not, as this young generation just assumes that things are going to stay the same." There is no long term planning. Teaching and human service personnel saw families 'closed' to the idea of having their child placed outside of this area. Participants expressed a high need for more families to be willing to step up to the plate to intervene to keep young adults in their home, and allow the access to resources to build their independence.

Teaching personnel brought up an inter-agency connection as another gap for services for youth. They noted they had children wanting to sign up for Boys and Girls Club, Youth Build, New Beginnings, or the Red Lake Tribal College or other programs over the summer, but were unsure where or how to access the applications. There seemed to be no solid connection between these programs for transition services over the summer. Communication between programs was also seen as inadequate. Teachers expressed they saw sometimes an overlap of services that were provided at the school and required for families working through child protection. Also, that when children were placed out of home they were "the last to know." This seems to be a crucial

point for quality of effective ongoing case management for a child, as a teacher spends the most time with a child and sees him/her regularly.

When participants were asked to describe resources needed, speech and physical therapy was addressed as “lacking on the reservation.” There is only one physical therapist employee at the Indian Health Service hospital for all of Red Lake. Unfortunately, most of his time is spent providing inpatient services at the hospital or at the nursing home. The younger children are referred to Peak Performance in Bemidji, and the district pays the costs of reimbursement for gas mileage. The treatment plan is taken over by a paraprofessional in the school based on the doctors’ recommendations. Throughout summer and in most early intervention cases, the extra care is neglected, putting that child behind.

One benefit of the school district is evaluation and assessment expenses are covered. Children are seen at Neuroscience Fargo Merit Care, Prairie St Johns Hospital, or Altru Clinic in Grand Forks, ND. Teaching personnel expressed frustration with parents following up with referrals for assessment appointments. Medication was another issue that teaching personnel stated as needing improvement, as “most kids only take their medication while at school.” Teachers felt the children they serviced would be more attentive, less combative, and less impulsive if on proper medications, yet stated that many parents disagree with medications. On a cultural level, one focus group participant noted,

Families are very forgiving of any differences. They accept all and any children as a gift.

They have the strength of being willing to care for any child, they have the ability to work with what they have and will keep on-keeping on.

Human service interviewees had a different view on families with children with special needs, that of a strong denial of the responsibility stating, “As parents receive the SSDI-it’s just money, they go about their business. Most cope by ignoring and drinking it up.” Human service interviewees implied that most of the families would deny there is any FASD as they don’t want to have the blame. One interviewee described further, “Even when babies are born drug positive

there is the issue of denial, with the mother stating she only tried it once.” Another issue brought up by both teaching and human service personnel was that families are reluctant to let a child go to a placement outside the reservation to get proper care. One human service participant described working with a young mother of a child who had autism, “The extended family fought the issue in court regarding out-of-home placement. The grandmother and aunt agreed to help the mother with transportation and support getting this child to physical therapy, but after reunification they were unwilling to follow through.” This mother was strong enough to meet her child’s needs on her own and has remain detach from her extended family, who are active users and unable to give her the support she needs.

Parents Role When asked to describe the children and families they work with participants’ voices give a clear picture of the issues that arise when working with a family with special needs. One theme that arises out of this qualitative study was the issue of parent comprehension. The focus groups in the educational realm felt parents have a difficult time understanding the nature and consequences of their child’s disability. When further prompted one participant commented, “understanding was probably compromised as a result of limited education or a lower reading level.” Another participant remarked, “They may have [a] slight handle on what’s going on but they don’t have an in depth.” Teachers felt parents were almost embarrassed to ask questions because they didn’t know the answers or are to proud and they won’t accept help,

One teaching personnal described a disability with a clear medical reason (like Down syndrome or blindness) was easier for parents to understand that that of a disability that cannot be seen. The participant elaborated, “Parents seem to have a more difficult time understanding cognitive deficiencies like processing information or impulse control.” The following quote sums up participants’ observations, “I’m not saying that all of our parents are low reading, some are very high functioning, and you work with everyone at their level. Some of them are still in denial

that their kids need help.” Parents want their children to be normal and want them to be just like the other children.

Parental involvement again becomes an theme when working with children who have special needs. There was a clear frustration in working with families. Out of 6 kids in ECSE that are autistic, not one parent showed up for a Discovery Learning series held at the school. Grandparents participate on a larger scale, and all teachers agreed with this. Teaching participants expressed their disappointment, “The mantra is school takes care of the child, and this gives the parent a break.” And, “One parent came and screamed at me, how you dare send home assessment papers on my son.” Another teaching participant nodded, stating whenever she would invite the mother to Head Start conferences, the parent would keep the child home for a while. Participants see this as a direct reflection of meeting the child needs, as one teaching participant remarked, “the parents with the least involvement were the ones that had the most problems” in the school setting.

Although teaching personnel reported giving parents lots of encouragement and support and use an array of strategies to get parents involved, there is not a lot of feedback. ECSE is attempting to eliminate all variables to bring a family in; they will provide transportation, childcare, and food. In elementary school, staff tries “everything in their power” to get parents involved; letters, notes, home visits, telephone calls, and meetings. In the middle and high school, the school system pays for parents to attend trainings and overnight retreats- but again there is not a lot of attendance. Regardless, the teaching personnel do what they can to meet the needs of the children, even if it means “parents peek out the window and answers questions” or “the IEP get signed on the hood of a car.”

Successes The little victories make it worthwhile. When participants were asked what was the most rewarding, the children won hands down. One teaching participant glowed when describing a proud 5 year old with developmental disabilities achieving potty training and clapping to himself. Another described with a smile, “my tunnel vision autistic child finally

shared his yogurt with a peer.” Human service participants felt satisfaction when watching a family reunify with success. “The reality is you wouldn’t be in this line of work if you didn’t like the kids.” For the children that have ongoing success, participants stated their families are strong. They are “willing to give up their freedom to properly care give and encourages the child to be independent.” They are supportive.

Utilization of the Findings

Human Services Training and Support

One theme that arose with focus groups was more training and support was needed for staff directly working with children with disabilities. One participant stated children might benefit if all head start teachers were required to fulfill a 4-year degree. Most of the current Head Start teachers on the reservation have a two years associate's degree but lack the professional training a bachelor's degree requires with a supervised teaching practicum and internship. Many Head Start teachers are "learning on the job". It was mentioned by participants that teachers for the young children could benefit from intensive classroom management skills because, "a child needs to know what kind of behavior is expected and have rules they need to follow."

Human service participants also expressed they have not felt "adequately prepared." The State of Minnesota Department of Human Services CORE training series is an option for training in tribal social services in lieu of a 4-year degree, but again this may not bring the intensive preparation to meet a child's needs in a professional realm.

Support to other area Bemidji resources for expanding their services to the area.

It is clear from the focus groups that young families need intensive support, especially with a child at home that has special needs. A barrier exists and "families are closed" when they have a child with a disability. They want to protect the child, and keep the child within the shell unit.

More programs increasing support are recommended by participants. Talking Circles support groups do exist, but there is nothing specific on the reservation for support for parents and siblings of children with disabilities. All participants thought this resource needed to come from an "inside community member, otherwise attendance will be an issue." Having an in-home mental health specialist is another need for families on the reservation. Children's Mental Health Case Management is also available through Beltrami County- but again there is difficulty in

accessing services off the reservation. Other ideas include CPR and first aid training to parents; self help parenting groups, respite, and special requirements for quality PCA employers that provide care for children.

Research shows there are obstacles in effective treatment in autistic children. Harris (1982) did a study on behavior modification techniques in small group sessions and home visits over a 10-week period. It was shown that parents were not likely to be using these skills one year later because of problem of maintenance. Parents were not consistent in follow through with the application of new skills. Thus, successful intervention would need to be consistent over time.

Spirituality was also thought of as an idea for help for families. The tribe taps into natural traditional support with using ceremonies, sweats, talking circles, and traditional healers. Symbols of water and smoke are used, along with the offering of tobacco. Long in historical tradition, the Chippewa never undertook an important action without first invoking the aid of a good spirit, and prayer is often today as a blessing and for guidance.

Bring education to the area to parents with children with developmental disorders.

When teaching professionals were asked to describe types of interventions they use the Discovery Series was depicted as a program parents “get something out of.” Discover Series is an interactive program put on by parents with ASD children, which comes yearly to the district. It was described as “the horses’ mouth right here.” A lot of the techniques used in the school currently are techniques learned from the Series. One technique is called guided discoveries, which is used with the kindergarten teachers. One participant described guided discoveries, “When you want kids to learn about a marker, first you introduce the marker, you talk about it, you open it and close it, you have the child listen to the sounds- click. You explain when we click it, it is closed and won’t dry. You let the kids try it, you guide them through it visually and verbally.”

ECSE does home visits for birth to three year old children. The focus of this service used to be modeling to the parent how you work with baby. Now, this focus is secondary, with visits more “hands on with the parents, guiding them in the positive interaction instead of modeling.” Human service participants also discussed that education that was needed, “Families need someone to guide them and teach them parenting skills.” Human service participants stated the common phrase reiterated to parents is that of the ideal environment for a child with a disability is one where there is “predictability, routine and familiarity, basic expectations, and safety”.

Research in the area of tribal code for enforcement to cease substance use while pregnant.

When human service participants were asked the miracle question, proper enforcement would be implemented to protect unborn babies. A lot of these families they worked with are “disturbing, with along history of drug abuse and alcoholism”. Legislatures in several states have formulated punitive measures to prevent such abuse. Under civil law, the statutes have used its power to remove infants from their mothers’ custody. Under criminal law, many approaches have been used by states that have passed legislation to punish a pregnant woman if her action amounts to fetal abuse. Child welfare workers and administrators have actively been involved in such cases against pregnant women in the country. In Wisconsin and South Dakota authorities can take a pregnant woman into custody for abusing alcohol or drugs (Montgomery, 2006). In September 2007 a young mother was charged with involuntary manslaughter death of her newborn, born at 2lbs and a few weeks premature. The baby’s blood alcohol level was at .18, and acute intoxication was stated as the leading cause of death (Bryant, 2007).

The Red Lake Nation Tribal Code, Chapter 502, Crimes against the Person, Section 502.06 was added to the Red Lake Tribal Code by resolution # 292-93 and addresses and lists endangering an unborn fetus as a crime that can be prosecuted by court. Subdivision 1 states any Indian woman who is pregnant and continuously, habitually and excessively abuses alcohol or controlled substances or inhalants, and is found, through legal testing to be under the influence of

alcohol or controlled substance is deemed to be guilty of a crime and upon conviction shall be sentenced as a misdemeanor. Sentencing options may include mandatory attendance at prenatal classes and chemical dependency treatment counseling. Subdivision 2 of Section 502.06 was added to the tribal code by resolution, which states any Indian women who endangers an unborn fetus by an action or omission including but not limited to kicking, pushing, or threatening to harm the pregnant women shall be guilty of a misdemeanor.

Although these policies are in place, it is very rare however, that a mother is kept in jail due to excessive use and/or to protect the baby. A human service participant reported a mother requesting house arrest in court after being picked up on a warrant. When required to do urinalysis testing (UA), she refused. Several days later, after picked up on non-compliance to the court order for the UA, she tested positive for cocaine, opiates, and marijuana. The participant stated when in court she requested this young woman remain in jail until her transport to treatment, but against recommendations, the mother was released by court. Two weeks later, upon her entry into treatment she testing drug positive again, at 6 months pregnant.

Revitalizing the family system / Healing historical trauma

Understanding the strengths of restoring traditional culture and family life is crucial for effective intervention with families that have children whose needs are not being met. The Red Lake Nation is part of the greater Ojibwe or Anishinabe Nation, which is the third largest in North America after the Navajo Nation. There is still retention of the original language, ceremonies, customs and beliefs while at the same time dealing with modern issues. While stubborn historical and inter-generational poverty, high unemployment and other factors have birthed extraordinary adverse conditions there remains an underlying optimism and resilience that clearly arises from the cultural strengths people and families cling to. Tapping into this, and healing the family together is really the key for maintaining success for special needs children and their families.

Historically, the clan or extended family has always been the primary social/economic/cultural institution and foundation of the Anishinabe way-of-life. More than 200 years of disastrous federal policies and decisions has systematically undermined this all-important institution. Thus the vision and work need to be geared to the re-empowerment of the Anishinabe extended family to its proper role and place within the life of the nation. Revitalization and healing the historical trauma and family together is key for success in this realm, with ongoing family therapy and family group work to strengthen the support systems for each client.

Implications for Future Research

It is evident with findings that more services are needed in Red Lake to adequately care for the children with special needs and this approach shall be consumer directed. Other question arose within the research that remains unanswered- Does alcohol and drug use specifically cause other medical issues? Is there a link between FASD and autism?

For the host of children that are exposed to drugs and alcohol another question remains- should a woman be forced to remain clean while pregnant? The answer comes down to moral issues, on how mothers, tribal agencies, and policymakers view an unborn child, and on adequate research to back up grant funding for programs for intervention. Regulating the rights of the unborn will need comprehensive planning with local tribal agencies for a collaborative system of enforcement, reporting and responding to substance exposed newborns.

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Appendixes

Addendum A- Interview Guides for Participants

Addendum B- Researchers Resume

Addendum C- Copy of Human Subjects Review Board

1. Explain your roles and responsibilities as a child welfare worker with Red Lake Family and Children's Services.

- Length of service?
- What other positions have you held with the agency?
- What is your current position?
- How long have you been in your current position?
- Describe a typical day.
- What prepared you for this position?
- What would have been helpful – In what areas have you not felt well prepared?

1. Explain your roles and responsibilities as a teacher with the Red Lake School District.

- Length of service?
- What other positions if any have you held with the School District?
- What is your current position?
- How long have you been in your current position?
- Describe a typical day.
- What prepared you for this position?
- What would have been helpful – In what areas have you not felt well prepared?

<p>2. Share with me a “picture” of the family. Describe the families and the special needs or developmentally disabled children.</p> <ul style="list-style-type: none"> • Describe the other members – adult caregivers, extended family, siblings, etc. in a family with a special needs child/children. • What impact do you think the special needs child / children has/ have had on the family as a whole? <ul style="list-style-type: none"> ○ On the individual members? • What family characteristics or qualities provide assets/ strengths for parenting a special needs child? • What helps caregivers/ family members and the child understand the disability? <ul style="list-style-type: none"> ○ What gets in the way of this understanding? • What if any other challenges compound the family parenting and caring for a special needs child – substance abuse, mental health issues, violence, etc.? • Discuss any intergenerational disorders (neurologic, etc.) or challenges faced by the families you work with. How does this shape your approach to the family and your interventions? • What is the family response to having a special needs child/children? 	<p>2. Share with me a “picture” of the families: Describe the special needs or developmentally disabled children you work with. As best you can, describe the other family members – adult caregivers, extended family, siblings, etc. Describe the kind and extent of contact you have with the family/ caregivers of special needs children. From your perspective...</p> <ul style="list-style-type: none"> • What impact do you think the special needs child / children has/ have had on the family as a whole? <ul style="list-style-type: none"> ○ On the individual members? • What family characteristics or qualities provide assets/ strengths for parenting a special needs child? • What helps caregivers/ family members and the child understand the disability? <ul style="list-style-type: none"> ○ What gets in the way of this understanding? • What if any other challenges compound the family parenting and caring for a special needs child – substance abuse, mental health issues, violence, etc.? • Discuss any intergenerational disorders (neurologic, etc.) or challenges faced by the families you work with. How does this shape your approach to the family and your interventions? • What is the family response to having a special needs child/children?
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<p>3. Families and Children – Needs, Services, Resources...</p> <ul style="list-style-type: none"> • Describe overall what you see as the needs of families with special needs child/ children. • How do the needs of the families and special needs child/ children change/ shift over time? Why does this shifting take place – age of child, increased experience of the family, changes/ stressors in / with the family, progression of disease/ disability, • What services/ resources/ financing, etc. are you able to access, that help and enhance the families and children? How do you access these resources? • What would help/ is needed by the families and special needs child/ children to reach full potential, to have a quality of life, to meet basic needs that you are not able to access? <ul style="list-style-type: none"> ○ Why can't you access the service, resource, etc? - Don't exist? Too much \$? ○ What do you do when the need of the family/ child is unmet? ○ What kinds of creative resources are available? How do you access these resources? ○ What are extra expenses incurred for children with special needs? ○ How does this make a difference in the family's ability to care for child? 	<p>3. Families and Children – Needs, Services, Resources...</p> <ul style="list-style-type: none"> • Describe overall what you see as the needs of the developmentally disabled children with whom you work. • Describe overall what you see as the needs of families with special needs child/ children. • How do the needs of the families and special needs child/ children change/ shift over time? Why does this shifting take place – age of child, increased experience of the family, changes/ stressors in / with the family, progression of disease/ disability, • What services/ resources/ financing, etc. are you able to access, that help and enhance the children? How do you access these resources? • What would help/ is needed by the families and special needs child/ children to reach full potential, to have a quality of life, to access education that you are not able to access? <ul style="list-style-type: none"> ○ Why can't you access the service, resource, etc? - Don't exist? Too much \$? ○ What do you do when the need of the family/ child is unmet? ○ What kinds of creative resources are available? How do you access these resources? ○ What are extra expenses incurred for children with special needs? ○ How does this make a difference in the
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	family's ability to care for child?
<p>4. Demographics:</p> <ul style="list-style-type: none"> • How many families do you work with? • How many are single parent families? • How many have non birth parent caregivers? <ul style="list-style-type: none"> ○ With one parent? _____ ○ With no parent? _____ • How many of the parents/ caregivers are employed? • How many children total are in the families for whom you provide services? _____ • How many of these children have special needs? <ul style="list-style-type: none"> ○ Please give a guesstimate of the following: <ul style="list-style-type: none"> _____ Brain Injury _____ Autism _____ Developmental Cognitive Disorders _____ Emotional Behavioral Disorders _____ Learning Disabled _____ Fetal Alcohol Spectrum Disorder _____ ADHD _____ Developmental Disability _____ Other Nerve Damage/Disease • How much time do you spend on Case Management? • How much time spent 1:1 with the children? <ul style="list-style-type: none"> ○ How much time with caregivers/ parents? ○ How much time with the entire family? • Describe the types of interventions you use. What works and why? What doesn't work? Why? 	<p>4. Demographics:</p> <ul style="list-style-type: none"> • How many special needs children do you work with? • How many aides are in the classroom? • How many are single parent families? • How many have non birth parent caregivers? <ul style="list-style-type: none"> ○ With one parent? _____ ○ With no parent? _____ <p>Please estimate the number of children you teach with the following:</p> <ul style="list-style-type: none"> ○ Please give a guesstimate of the following: <ul style="list-style-type: none"> _____ Brain Injury _____ Autism _____ Developmental Cognitive Disorders _____ Emotional Behavioral Disorders _____ Learning Disabled _____ Fetal Alcohol Spectrum Disorder _____ ADHD _____ Developmental Disability _____ Other Nerve Damage/Disease • What are the children's care needs? What assistance do they need? <ul style="list-style-type: none"> _____ Eating _____ Bathroom management _____ Self regulation of emotions and responses _____ Ambulation _____ Sitting independently _____ Wheel chair bound • How much time is spent in 1:1 tutoring with the children? <ul style="list-style-type: none"> ○ How much time with caregivers/ parents to explain the children's needs and to suggest at home

	educational support?
<p>5. Impact on self: Self-care:</p> <ul style="list-style-type: none"> • Describe your experience of meeting the needs of children with disabilities and their families. • What impact does not meeting the family/ child's need have on you? • How do you handle the stress attached to the work you do? Exercise, meditate, family time, sweats, etc.? • Internal resources. External resources. • Talk about what you find rewarding or meaningful about your work. 	<ul style="list-style-type: none"> • Describe the types of interventions you use. What works and why? What doesn't work? Why? <p>5. Impact on self: Self-care:</p> <ul style="list-style-type: none"> • Describe your experience of meeting the needs of children with disabilities and their families. • What impact does not meeting the family/ child's need have on you? • How do you handle the stress attached to the work you do? Exercise, meditate, family time, sweats, etc.? • Internal resources. External resources. • Talk about what you find rewarding or meaningful about your work.
<p>6. Miracle Question: Suppose when you wake up tomorrow, the world of child protection will be the way you want it to be. How would this look? What would be different?</p>	<p>6. Miracle Question: Suppose when you wake up tomorrow, the world of special education will be the way you want it to be. How would this look? What would be different?</p>

Sarah Huesmann

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Blackduck, MN 56630
218-556-9111
sarahhuesmann@yahoo.com

Education-

Bemidji State University, Bemidji MN
Bachelors of Science, Honors Program
Anticipated Graduation Date Feb 2009, GPA 3.34
Major- Social Work
Minor- Chemical Dependency
Minor - Psychology
Recipient- Child Welfare IV-E Stipend

Northwest Technical College, Bemidji, MN
Completed Coursework- 18 credits
Principles of Bookkeeping, Payroll
Business Math/Calculators, Business Law
Leading Teams, Business Communications

Passed MN-LSW exam in September 2008.

Employment -

Red Lake Family and Children's Services, Red Lake, MN

June 2005-Present Child Protection, Case Management

- Assess needs and strengths of families and establish case plan for reunification.
- Produce CW-TCM billings with all contacts and keep files up to date.
- Prepare for and attend court hearings for CHIPS cases.
- Coordinate with other service providers regarding Placements, School, TX, and MH services for clients.
- Advocacy and support for children and parents, foster and relative placements and families.
- Complete MA, IV-E packets, and documentation in SISS system for all IV-E cases
- Case planning and home monitoring to ensure safety and welfare of minor children involved in CP

City of Blackduck, Blackduck, MN

Dec 2000-Sept 2004 Administrative Assistant

- Provide secretarial assistance and receptionist duties for City of Blackduck.
- Daily bank deposits and entering all receipts into the computer
- Bi weekly payroll and all quarterly documents
- Monthly utility billing

Workshops and Certificates-

- Historical Trauma: Understanding the Past, Empowering for the Future, BSU, October 2008, 5 Contact Hours
- Engaging Dads in Supportive Healthy Development of Young Children, October 2008, 6 Contact Hours
- Managing Emotions Under Pressure, Rational Emotive Learning Course April 2008, 6 Contact Hours
- Dating Discovery, February 2008, 16 Contact Hours
- Structured Decision Making, MN Child Welfare Training Series, January 2007, 6 Contact Hours
- MN Child Welfare Training Series, Rule 79 Children Mental Health Case Management Training Series, April- August 2006, 48 Contact Hours
- MN Child Welfare Training Series, Sexual Orientation in Children, July 2006, 6 Contact Hours
- Impact of Methamphetamine on Children and Families Research and Community Response Training, February 2006, 9 Contact Hours
- Bureau Of Indian Affairs, Social Services Basic and Intermediate Training, September 2005, 32 Contact Hours
- Choice Theory and Reality Therapy, Basic Intensive Week, 40 Contact Hours, June 2005

Presentations-

- My Time Panel Women as Leaders, My Hero, Fall 2005
- Student Achievement Conference Women as Leaders, Spring 2006 Panel Presentation
- My Time Panel Women as Leaders, Oppression and Expression, Spring 2006
- Student Achievement Conference, Psychological Oppression and Spiritual Expression, April 2006

References-

- Lisa Peterson, LADC, Rational Alternatives, Supervisor at Little Fork TX Center, 218-556-8099
- Dan Dietrich, BSW, Beltrami County, Red Lake Family and Children's 218-679-2122
- Mary Ann Reitmeir, MSW, LISW, Bemidji State University, Social Work Department, 218-755-2835



BEMIDJI
STATE UNIVERSITY

Addendum C

Master of Arts
English

SCHOOL OF GRADUATE STUDIES

Master of Education

Date: October 7, 2008

Master of Science
Biology
Counseling Psychology
English

To: Sarah Huesmann
64 Carl St
Blackduck, MN 56630

Environmental Studies
Industrial Technology
Technology/Career &
Technical Education

From: Patricia L. Rogers, Ph. D, Human Subjects Committee

PLR 10/12

Mathematics
Science

Subj: Human Subjects Request

Special Education
Sports Studies
Education

Re: Perspectives of Human Service Practitioners and Teachers on the Experiences and Needs of Developmentally Disabled Children: Implications for Service Delivery

Master of Special Education

The Human Subjects Committee has approved your request for your study. A copy of the approval form is enclosed. We have a copy of your proposal on file in the College of Professional Studies office along with the original approval.

Thank you for submitting your request in a timely manner. Should you have questions, please do not hesitate to contact me.

cc: Mary Ann Reitmeir

APPROVAL FORM AND ALL ATTACHMENTS MUST BE TYPED!

Appendix C
Section A

**Bemidji State University
Human Subjects Committee
Human Research Approval Form**

Title of Study: Perspectives of Human Service Practitioners and Teachers on the Experiences and Needs of Developmentally Disabled Children: Implications for Service Delivery

Date Submitted: July 21, 2008 Project starting date: October 15, 2008 Project ending date: December 15, 2008

Principal Investigator(s): Sarah Huesmann

Street Address: 64 Carl Street Telephone: 218-56-9111

City, State, & Zip Blackduck, Minnesota 56630

E-mail Address: sarah.huesmann@st.bemidjistate.edu

Co-Investigators:

Faculty Advisor/Sponsor: Mary Ann Reitmeir, Associate Professor, Social Work

Request: ☒ Expedited Review (include reasons below) ☐ Full Review

Is the submitted document in **draft** form yet to be pre-tested? ☐ Yes ☒ No
(If Yes, a final copy of the survey instrument must be re-submitted upon completion.)

Can the title of this study be made public before the completion date: ☐ Yes ☒ No

The student's faculty advisor must first approve all student research. Signature denotes the advisor's approval of the project and must be obtained prior to forwarding to the HSC.

Mary Ann Reitmeir 10-1-08
Signature of Advisor/Sponsor Date

HUMAN SUBJECTS

COMMITTEE RECOMMENDATION:

Exempt Review

Approved Revise and resubmit Not approved

☒ Expedited Review

☒ Approved Revise and resubmit Not approved

Full Review

Approved Revise and resubmit Not approved

[Signature] 70608
HSC Chair's Signature Date

Human Subjects Committee (HSC) Submission Checklist
PLEASE SUBMIT WITH PROPOSAL

Project title: Perspectives of Human Service Practitioners and Teachers Concerning the Experiences and Needs of Developmentally Disabled Children and Their Families: Implications for Service Delivery

Principal Investigator(s): Sarah Huesmann

The HSC will NOT review proposals that do not include:

Applicable/Not-Applicable*

- | | | |
|--|-------------------------------------|------------|
| 1. Completed HSC Human Research Approval Form and Ethical Compliance Questionnaire (See Section A) and attach it to the documents being submitted for review. | <input checked="" type="checkbox"/> | Applicable |
| 2. A 100-150 word abstract or summary of the proposed study. | <input checked="" type="checkbox"/> | Applicable |
| 3. A complete statement of the research methods, including copies of the instrument(s) being used to collect data. (Do not include literature review chapters or proposals.) | <input checked="" type="checkbox"/> | Applicable |
| 4. Informed Consent Form(s) – See Section B for further description and sample consent form. | <input checked="" type="checkbox"/> | Applicable |
| 5. Signed letter of permission from institution if research to be conducted is in an institution such as school, hospital, etc. | <input checked="" type="checkbox"/> | Applicable |
| 6. Debriefing Statement – See Section C for further information and sample. | <input checked="" type="checkbox"/> | Applicable |
| 7. a) The original and one (1) copy of this information are required for an Expedited Review. | <input checked="" type="checkbox"/> | Applicable |

OR

- b) The original and six (6) copies of this information are required for a Full Review

☐ Click for drop-down menu

*Please indicate those items not applicable. Thank you.

July 2007

APPROVAL FORM AND ALL ATTACHMENTS MUST BE TYPED!**Section A**

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Human Subjects Committee
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Co-Investigators:

Faculty Advisor/Sponsor: Mary Ann Reitmeir, Associate Professor, Social Work

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Is the submitted document in **draft** form yet to be pre-tested? ☐ Yes ☒ No
(If Yes, a final copy of the survey instrument must be re-submitted upon completion.)

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The student's faculty advisor must first approve all student research. Signature denotes the advisor's approval of the project and must be obtained prior to forwarding to the HSC.

Signature of Advisor/Sponsor

Date

-----HUMAN SUBJECTS

COMMITTEE RECOMMENDATION:

Exempt Review

Approved

Revise and resubmit

Not approved

Expedited Review

Approved

Revise and resubmit

Not approved

Full Review

Approved

Revise and resubmit

Not approved

HSC Chair's Signature

Date

Complete all items on this form and/or on separate sheets of paper attached to this form.

I. Subject Recruitment and Requirements (includes subjects recruited for pre-testing).

1. What type of human subjects will you require? (gender, age, location, affiliation, special characteristics)

A selected group through snowball sampling, 2 -3 each of human service employees (child protection case managers) and public school teachers working with developmentally disabled children/youth and their families.

2. Where and how do you propose to recruit participants/subjects?

Participants will be recruited through the school superintendent and the family services director (see attached letters of permission.)

3. If your study involves subjects in institutions (schools, hospitals, other agencies), how will institutional consent be obtained? A single letter of permission from an institutional representative is required. Attach copy to proposal.

See attached letters from Sandra J. Parsons, Executive Director, Red Lake Family and Children Services and Brent Gish, Superintendent, Red Lake Nation School District.

- 4a. Will your study use minors (subjects under 18 years of age)?
☐ Yes ☒ No

If No, go to 5a.

- 4b. How will consent be obtained if subjects are minors and/or incapable of giving legal consent?

- 4c. Is informed consent form attached? ☐ Yes ☐ No

- 5a. If subjects are of legal age, how will consent be obtained?

Letter of invitation to participate along with an enclosed consent form for signature. A copy of the signed consent form will be given to the participant and the original kept on file in the faculty advisor's office. The consent form contains information about the availability of the final research report. A copy will be available in Sandra Parsons' office at Red Lake Nation Family and Children Services.

- 5b. Is informed consent form attached? ☒ Yes ☐ No

6. How much time will be required of each participant?

About 1 hour to 1 1/2 hours

7a. Will subjects be compensated for participation? ☐ Yes ☒ No

7b. If yes, please specify:

8a. Is confidentiality assured? ☒ Yes ☐ No

8b. If Yes, how?

Researcher will meet privately with each participant. Records will be kept confidential. The research report will reflect themes that emerged in the data collection (interviews) in composite form. No comments will be attributed to any individual participant.

8c. If no, why not?

9. What benefits do subjects obtain by participating?

There is evidence that in engaging in an interview, in verbal narrative, new insights and awarenesses occur as the participant shares their experiences and perspectives.

II. Subject Risk

Certain practices are generally to be avoided. If any are included in the proposed study, check the blank next to the appropriate category and justify with attachments.

☐ Deception

☐ Pain, threat, or aversive stimulation

☐ Embarrassment

☐ Invasion of privacy

III. Debriefing

1. When and how will subjects be provided with feedback about the study?

- 2a. Is a debriefing form attached? ☒ Yes ☐ No
(Include debriefing statement when applicable)

Attached find a copy of the thank you letter that will be sent to each participant following their interview. Included in the letter is contact information for the researcher and the faculty advisor should the participants have questions or concerns.

- 2b. If deception has been used, how will the subject be informed?

2. What follow-up supports will be available if subjects experience undesirable consequences of participation?

Attached find a copy of the thank you letter that will be sent to each participant following their interview. Included in the letter is contact information for the researcher and the faculty advisor should the participants have questions or concerns.

IV. Materials

1. What questionnaires, inventories, tests, or other instruments will be used? Attach copies unless the instrument is universally familiar.

See attached interview guide.

2. What electrical, electronic, or mechanical equipment will be used? If any have been specially constructed or modified for use in this study, provide a description with sufficient detail so that any physical danger may be assessed. Supplementary documents may be attached if necessary.

A hand held tape recorder will be used.

**FEDERAL GUIDELINES REQUIRE ALL RECORDS AND DATA BE
KEPT FOR THREE YEARS.**

Debriefing

I am writing to thank you for participating in my Qualitative Research study entitled Teaching and Human Services Personnel Perspective on the Experiences of Children with Special Needs. The purpose of the study is to gain insight for further research and inquiries to resources for the special needs population of Red Lake reservation.

A copy of this project will be located with Sandra Parsons, Director of Family and Children Services after April 30, 2009. If you feel you have undesirable consequences from participating in interviews or if you have further questions please feel free to contact myself, Sarah Huesmann at 218-679-2122. I will be available to discuss any question you make have and will have number available if you need further assistance.

Informed Consent

September 18, 2008

You are invited to participate in a study of human services personnel for children with developmental disorders. The purpose of the study is to gain insight for further research and inquiries to resources for special needs population of Red Lake reservation. I hope to discover where there are community resources and gaps. You were selected as a possible participation in this study because you are an employee working with families that have children with developmental disorders, or are a working directly with the children with impairment.

If you decide to participate, I will be in contact with you via phone to set a date and time and place for interviews. Discomfort and risks to be expected with the interviews is having to voice your opinion in the presence of other staff, as I am hoping to have a group interviews. Benefits to be expected with the interviews will be to share your ideas and opinions with other staff members.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and not be disclosed. There is no compensation for this participation. Your decision whether or not to participate will not prejudice your future relationship with myself or your agency of employment. If you decide to participate, you are free to discontinue participation at any time without prejudices.

A copy of this project will be located with Sandra Parson, Director of Red Lake Family and Children's after April 30, 2009. If you feel you have undesirable consequences from participating in interviews or after if you have further questions please feel free to contact myself, Sarah Huesmann at 218-679-2122. I will be available to discuss any question you make have and will have numbers available if you need further assistance

If you have any questions please ask me. I will be happy to answer questions. If you have any additional questions at a later date please feel free to contact my advisor Mary Ann Reitmeir at 218-755-4880.

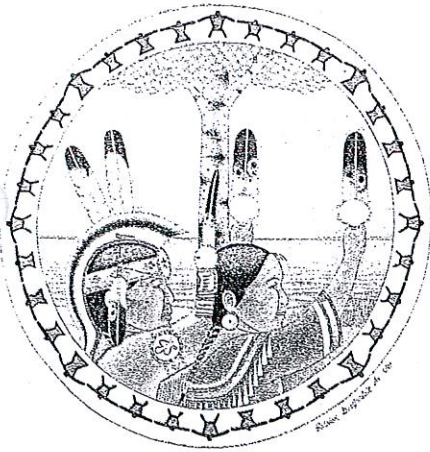
You will be offered a copy of this form to keep. By signing this form, you are making a decision whether or not to participate. Your signature indicates that you have read the information provided above, and have decided to participate. You may withdraw any time without prejudice after signing this form.

Signature

Date

Signature of Investigator

Date



RED LAKE BAND of CHIPPEWA INDIANS

Family & Children Services

PO Box 427 • Red Lake, MN 56671
Phone 218-679-2122 • Fax 218-679-2929

August 14, 2008

Bemidji State University
Human Subjects Review Board-

I am writing to allow permission for Sarah Huesmann to interview staff in a study of human services personnel for children with developmental disorders.

Sarah has discussed with me the purpose of her study, and the participants she plans to interview.

I have also been informed of the interviewees' confidentiality and my decision to allow this research or not. Given all of the above information, I do allow Sarah Huesmann to proceed with her study.

Sandra J. Parsons PhD

Name

Executive Director

Position

Independent School District No. 38

Box 499 • Red Lake, Minnesota 56671 • Phone: (218) 679-3353 • FAX (218) 679-2321

Addendum C

August 14, 2008

Bemidji State University
Human Subjects Review Board-

I am writing to allow permission for Sarah Huesmann to interview staff in a study of human services personnel for children with developmental disorders.

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Name

Position

Pat A. Grier *Superintendent* *August 20, 2008*