Weaving a Resilient Basket of Hope

&

Filling It with Tools of Help

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It has been said that there would come a time when

there would be those born who would look different,

and with these differences, they would carry a

message that would change the people.

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Foreword

Fetal Alcohol Syndrome (FAS) and related conditions of Fetal Alcohol Spectrum Disorder have produced some of the most devastating effects impacting Native peoples within the twentieth century. Producing a spectrum of issues ranging from infant death to developmental, physical, cognitive and emotional delays that may be manifested in low self-esteem, learning difficulties, physical anomalies, impulsivity and poor judgment, FAS and related conditions are 100 percent preventable. However, just imparting this knowledge is not enough. We know so much. We have collected a large amount of information about the problem. We even know the solution. What we lack are the appropriate vehicles to get us to, or even effectively facilitate, these solutions. We must create an awareness that re-teaches and reinforces the knowledge taught by our ancestors that a child is a sacred gift. We must recognize that there are many among us whose lives are already impacted and for whom interventions will result in prevention for future generations. For our children and the parents of our children who are already affected, we must move beyond blame and gloom and doom to demonstrate interventions that successfully utilize the strengths of these individuals. We must also promote holistic healing through traditional, developmentally appropriate techniques that address the physical, intellectual, emotional and spiritual needs of individuals affected by an FASD integrating service provider and “natural helper community systems”. In this way, we must integrate traditional and clinical knowledge, filling our basket with tools of help borne of past and present generations.

To move forward in healing, we must
remember that as
Native people we do not live
in our communities, but our
communities live in us; then and
only then do we really recognize
what directs our decisions and
collects our choices.

Traditional childrearing techniques that apply to and combine with intervention strategies

As children we are shown many things by our family, our elders, our band and our tribal community. We have an opportunity to weave them together to create a fabric of understanding that acknowledges our relatedness to all. Our measure as a human can be said to be equal to the respect and compassion we bring to all these relations. Spirituality can be said to sit in the middle of the truth and honor with which we act in relationships and with which we are able to love our Mother Earth and the great mystery of creation.

This loving and appreciation of our natural environment directs our lives to the first principle of traditional childrearing: To show and share our respect for Mother Earth and understand our connectedness to all living creation. When we truly understand this connectedness, our desire to love and act with compassion is reinforced and our desire to hurt or react is diminished.

We are continually shown the power of nature and of our Mother Earth to heal. Given this backdrop of collective wisdom, we can understand the second principle of traditional childrearing: Family as the center of a child's constellation. Traditionally, family was never thought of as "nuclear," but expansive and inclusive of all relations. It is this environment of community and physical place that shapes a child. Genetic inheritance (or blood) plays a role, but the biggest role is played by the teachings given to us as we live and where we live.

We seek understanding of what our ancestors knew and performed so well in nurturing a child within his or her band of people, and on the child's Mother Earth. Teachings of natural and human responsibility were interwoven and demonstrated the interdependence of all life. If the village or community is the foundation upon which we build our childrearing and parenting practices, as parents, we come to realize the variety of resources and help available. Not only do we see the "system's" help, such as that from schools or agencies, but we also see who in our extended family circles, and what in our physical environment, will strengthen and build our children's minds, bodies and spirits. With this knowledge we can begin to understand, appreciate and use those sources of support and let go of the sense of

fear and frustration that comes with raising our children in isolation. We can move beyond the pain and hurt of our own childhood by proactively learning what to put in its place for our children, by learning acceptance and taking pride in the process shown to us by our elders.

For many of us, childrearing and parenting must be a dual process of healing ourselves and nurturing our children. No one's family circle is free of dysfunction, grief, or pain. Many, even some of our elders, have suffered too much to yet heal.

Our grandmothers still remember so many simple things that we must hold onto in this complex world. These teachings, these gifts of our ancestors, are our beacons for interpreting and walking in this life with balance. We must listen to those elders that carry our hearts. Our life and our children's lives depend on remembering their wisdom. This concept of respecting our elders becomes our third principle in childrearing and parenting.

As parents, once we acknowledge and show our respect for our Mother Earth, our community and our elders, we can busy ourselves with the functions of this respect. These functions are timeless and are functions that were the childrearing and positive parenting practices of our grandmothers, great-grandmothers and their grandmothers before them. We can offer the following as some of these functional concepts.

Observation as the key to understanding

We are a visual people. We need to show our children how to be. We need to show them by our own behavior and by what we choose to expose to them.

Fewer lectures and more attention to creating positive environments produce children who can find their way in a world of confusing choices. From the time they are first laced in the safe cocoon of a cradle board-a powerful first step in nurturing observation-our children use their observation skills to learn and shape their own lives. They see the people we bring into our homes, the TV programs we let them watch and the ceremonies to which we take them.

As parents, we need to understand and take responsibility for the impact that these exposures have on our children. Our actions as parents are more powerful than our words. We need to learn to be quieter in our directions to our children; we need to show them where and how to go.

Storytelling as the effective teaching of values

Stories have taught us who we are and how to be. Each of our peoples have stories that tell us where we came from, how we were created and how to walk with honor and balance within creation.

These stories belong to us, protect us and help us problem solve. They are the word pictures that teach safety, generosity, honesty and compassion. They show us the pitfalls of impulsiveness, selfishness, dishonesty and ego-driven greed. They are as relevant and applicable today as they were generations before us and as they will be generations after us.

A story does not convey personal judgment, so it does not create defensiveness. A story allows us and our children to use that intuitive interpretive power given to us by our Creator. We can take what is shown, apply it and use it to make our own good choices.

Group cooperative learning

Group (e.g., community, band, family) cooperative learning and action are more beneficial than individual competitive learning and action. Remembering the importance and impact of our family and community environments, as parents we need to nurture that cooperative process of problem solving with our children.

For example, within our own families we can have weekly family meetings that approach choices and problems from the perspective of consensus. Discussing and sharing information until everyone feels heard develops a spirit of cooperation that reduces future conflict.

Self-esteem and self-concept is understood within the context of relationship, not isolation. Individual happiness cannot exist at the expense of others. Winning occurs when the outcome is best for everyone.

Natural consequences as the primary managers of behavior

When we let life take its natural course, we remove ourselves from the seat of judgment and we observe what in the environment will naturally show our children the consequences of their behavior. For example, when a child continually refuses to share with a brother or sister or friend, the most natural consequence, the best lesson, will come from those siblings and those friends refusing to play with him or her in the future. After some lonely playing, our child will be ready to use the sharing skills that we have shown and reinforced through storytelling. As parents, our active role comes with the process of role modeling and storytelling after we see that our children's conflict and defensiveness have passed. When our child refuses to pick up his or her toys, we can say that we see that he or she has too many toys so we will be glad to put some away so that they can take good care of them. When our teenager first disrespects time and place guidelines, we can say they need to stay home so we can feel safe about them.

Praise as the demonstration of the love that motivates us

Over the past two decades, much has been made of the concept of *positive reinforcement* as an effective teaching and parenting tool. Our grandmothers have

known and used this tool for generations. They have used praise and ceremony, to celebrate the first catch, a brave deed or an honorable act. Punishment was never given by the parents. Even when it was done by an uncle or relative, it was not the kind of punishment that we do today that puts our children on the defensive.

Praise was used to reinforce children in what they were doing right. When we emphasize and acknowledge what our children are doing correctly or well, we are creating a positive behavioral map for them to follow. We shape their behavior far more powerfully than when we punish.' They learn what to do *more*, instead of just what to do less. They feel better about themselves and they feel better about their environment. When they feel better, they act better.

As Native parents, we have much for which to be grateful with our legacy of childrearing and parenting practices given to us by our ancestors. However, we must also be watchful in order to heal the hurts and grief that are now generational among our people. The tools of that legacy remain, and we have that strength to exercise and to use to heal our hurts. If we share in this healing process, our children will grow from that strength.

Within this process, each of us must recognize and respect the range of different interpretations within those traditional values, and we must identify our own place of understanding and action, our own particular choices as they relate to our children's development.

1 Punishment includes verbal and situational as well as physical acts.

threads (i.e., the principles) with which to weave. They gave us the understanding that it is this very process of interweaving the threads that is life.

In the end, we will never be perfect parents. Even with all the good intentions woven into this cloth of understanding and our own potential within the process of traditional child rearing, we make mistakes. We will get frustrated and angry. We feel we have failed. What we need to do when this happens is to take time out for ourselves. We need to do that activity, that prayer with sweetgrass, that walk to some place of beauty, to renew our spirit and to remind us of the beauty of our children, of our honor in being blessed with these sacred gifts.

Organization of the Manual

This is not a typical manual. It is not a training manual that tells you exactly how to train. It is not a cookbook of recipes creating specific outcomes. As stated in the acknowledgements, many excellent resources already exist in both manual and narrative form. The purpose of this project is to complement and perhaps extend the scope of these resources from both a developmental and cultural perspective. It seeks to provide a foundation from which parents, social service providers, educators and trainers can form their own prevention and intervention strategies. Proceeding from a family and community-focused, multidisciplinary vision, it has, at its heart, the mission and hope that we will all recognize our place in addressing the strengths and the needs of our peoples who are affected by fetal alcohol. It is also hoped that in recognizing "our place," we will recognize the interdependence and interrelationship of that place with others in our community. Our successes will be proportional to our ability to work together as individuals, families, spiritual advisors, mental health therapists, educators, counselors, speech pathologists, occupational therapists, physical therapists, juvenile service providers, and court and corrections professionals, to create a circle of compassion, care and commitment to our people.

Each developmental section begins with a story. These are real. These are stories about different people, in different settings and at different developmental stages. Stories are our traditional way of learning and are effective in creating holistic visual pictures. After each story is a short list of the desired outcomes for the section, followed by a narrative forming the foundation of thoughts and values, transitioning the reader from the strengths and needs to the strategies which apply to the specific developmental stage. Some of the strategies will be similar from stage to stage in their focus on common denominators of organicity and central nervous system function that are present throughout the lifetime of people affected by fetal alcohol exposure. These strategies are organized into four targeted components within each developmental stage. Since generalization and habituation are two critical keys to understanding. The intervention components target domains of development rather than physical settings such as home, school, work, etc… Successful acquisition of skills will be proportional to the consistency of strategies and interventions across all settings. The four components include:

- **Environmental design strategies** promoting memory and information processing and development
- **Behavioral strategies** promoting social and emotional development
- **Educational strategies** promoting cognitive development
- **Community strategies** promoting culturally congruent, holistically integrated service delivery.

These four components reveal the critical areas to address in an integrated multigenerational approach. Strategies for these components overlap and reinforce skill acquisition in all domains of development.

At the end of the manual is an addendum with added information, including reproducible pages for assessing community readiness and case management. There is a glossary of terms and a large resources section, along with other helpful pieces of information.

It is important that users of this manual understand that although there are common denominators of behavior, there is also a broad spectrum of strengths and needs, abilities and disabilities that affect the behavior, cognition and physical anomalies of this population. Characteristics within these domains vary greatly and are not necessarily defined by the amount of alcohol consumed by the pregnant mother. Variables of lifestyle, nutrition and general health care, as well as the father's using history (something we are just beginning to understand) also appear to play important roles in the fetal development of a child who is prenatally exposed to alcohol. We do know that appropriate interventions, which proceed from good observations and an understanding of behavior as communication, have a profound impact on the child or adult who has had prenatal exposure to alcohol.

1 Fetal Alcohol Spectrum Disorder

We must understand how young we are in our knowledge before we can begin our description and identification of what characteristics constitute a diagnosis of Fetal Alcohol Syndrome or what behaviors suggest fetal alcohol exposure. In a sense, we are in the youthful stage of both clinical and practical, as well as theoretical and functional, inquiry. FAS is not yet 30 years old in its existence as a defined syndrome; we have only to look at Down's Syndrome and Autism to realize how much evolution is ahead of us both clinically and practically.

When we have the privilege as caregivers or providers to work with people with disabilities, it is good to be humbled by the thought that "this is what we think we know so far."

What are FAS and FASD?

Syndromes describe a set of specifically defined and clinically documented characteristics. Fetal Alcohol Syndrome describes a specific pattern of morphologic abnormalities observed in children and adults who have been prenatally (in utero) exposed to alcohol. FASD, according to the FASD Center for Excellence, is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

Diagnostic, protocols and definitions change; however, what remains consistent within the context of diagnostic criteria are the following four criteria for an FAS diagnosis:

- History of alcohol exposure during pregnancy
- Particular facial or morphologic features
- Growth deficiency
- Central nervous system dysfunction

Diagnosis must be conducted by specifically trained professionals, using a team approach that includes input from an epidemiologist, psychologist, occupational therapist, physical therapist and speech pathologist. It is also important to have a family advocate on the team, someone who will be able to assist the family in negotiating not only the maze of service avenues but the emotional impact of the diagnosis on the parents or caregivers. Each of these individuals should have FASD as an area of their expertise.

Fetal Alcohol Spectrum Disorder (FASD) refers to the range of behavioral, physical and cognitive (intellectual or learning) disabilities resulting from prenatal exposure to alcohol. FASD is not a diagnosis but rather a descriptive umbrella of manifestations. FASD identifies not only the physical, cognitive and social/emotional impact of alcohol, but usually reveals the complicated and significant impairment resulting in mild to severe mental health issues. As these children age mental illness can become apparent and already complex treatment plans become less effective

because of lack of services and co-morbidities. The incidence of these secondary characteristics and co-occurring disorders can be diminished and mitigated by early intervention. (Ann Streissguth). This global neurologic impact of FASD within our Native communities serves to inform both the need for a comprehensive approach and a holistic perspective. Because of the potentially stigmatic nature inherent in addressing FASD, community readiness for such an approach merits careful and deliberate attention that proceeds from the premise that community awareness and information about FASD should help not hurt. (Kuerschner, Sho-Ban News, 2001). This premise helps to promote methodologies that are culturally congruent with a process orientation that engages all community stake holders and solicits community member response in identifying strengths that reveal commonly held community norms and values, and identified needs that reveal the goals that are barriered by both gaps in services and lack of integrated delivery. Such a comprehensive approach informs the need for multigenerational support that serves not only an individual with an FASD but the entire family through adulthood.

Some but not all of the primary diagnostic criteria for FAS can lead to the following diagnoses: Alcohol Related Neurodevelopmental Disorder (ARND), Fetal Alcohol Related Conditions (FARC), Alcohol Related Birth Defects (ARBD). Alcohol is a teratogen (toxin) that affects fetal development when a woman drinks. Whether or not her child has the specific physical characteristics of FAS depends on when she drinks.

Basic precepts or premises: Building blocks for intervention

- Watch and observe child/adult behavior and "way of doing" things
- Identify strengths and skills that can be applied and used to address the particular needs of the situation
- Understand behavior as communication
- Remember to "show" rather than to tell
- Understand the need for structure and a calm environment
- Understand the need for consistency
- Create positive behavioral maps showing and labeling what is being done "right"

- Understand the ramifications of concrete processing
- Beware of "ceilings" of expectation and "never" statements
- Assist in generalization
- Have and identify realistic expectations. Build for success
- Know that early identification and early intervention are keys to future success
- Know that it is never too “late” to provide successful strategies and preventions
- Understand how prevention and intervention are reciprocally reinforcing
  Create collaborative provider partnerships and multidisciplinary consortiums that create circles of case coordinated care

Potential interventions include:

- Creating an awareness of the problem, disseminating information and training
- Prenatal counseling and support services
- Identification and assessment of alcohol-affected individuals and referral to diagnostic evaluation
- Sensory motor therapies for infants and toddlers within a program
- Educational advocacy that provides strategies for successful integration within school settings (i.e., pre-school through secondary)
- Environmental structuring and positive behavior management for all populations
- Cognitive "re-tailoring" of chemical dependency treatment services
- Self-esteem and concept building by identification and utilization of an individual's positive strengths
- Identification of one's spiritual context and ceremony at the core of Native healing

2 Prenatal Development

- A Story -

Waves of hurt, waves of nausea, very much the same in producing the pain that reaches for the numbing power of alcohol and a way of being that medicates a life that is too awfully full to digest. A life habituated by multigenerational use and abuse and punctuated by self-recrimination and self-hatred that cannot find its way to the repeated rhythms of, or connections to Creator. By the time she realized she was pregnant, the baby had been swimming in ethanol for almost three months. The sign at the grocery store stating that alcohol can be harmful to the fetus stared at her and produced a brief anxiety as she set down the case of beer and bottles of Thunderbird ... but then the checker was ready and her friends were waiting with her boyfriend in the van....

The river was quiet, with the morning's moist pungent scents of sage and pine still clinging to the air. For a moment, the beauty pierced some part of her being that recognized motherhood, even embracing its sacredness, but almost immediately the darkness, the hurt, enveloped her. Watching her boyfriend put out his line, she thought of their love, their up-and-down relationship that had followed the course of their lives for a few years now, since they were 13. Would he, could he be a father ... what is a father? Her father loved her, she was pretty sure of that. But he also hurt her, hitting her body and spirit with harsh hands and words. Her thoughts made her stomach roll and her head hurt, but thankfully they were interrupted by her cousin and best friend handing her a cool bottle of beer...

The HIS clinic was filled as usual and she chose to deaden the sounds by focusing on the posters. Again she met the gaze of faces and words on these posters telling her that alcohol during pregnancy could hurt her baby. So, she thought, lots of things in life will hurt my baby, and besides my mom drank with all of us and maybe even grandma did with her. Why does everyone seem to want to blame alcohol and drugs for everything anyway, there's so much that's so sick about life that starts way before anyone starts drinking anyway. The nurse interrupted her thoughts, calling her name. Prenatal interview, I hate these, she thought. They ask too many questions that are none of their business. My miscarriages were my loss, not theirs! ...

For three months now her Cuthla and some aunties had been coming by several times a week to help with the cradle board. It was beautiful with its soft white buckskin against the dark calico corduroy. The wild rosewood bow was a perfect curve with special and sacred beads, given by different aunties and elders. The beauty, the love they held, caught in her throat clear down to her heart, maybe even down to her toes, as her mind retraced the last five months of struggle. Both she and her boyfriend arrested for "domestic violence." Mandatory residential drug and alcohol treatment. Thankfully they were placed together in a Native program that had both a child development center and an FAS project. But so much information, too much sometimes and too much confrontation, sometimes making it too hard to process everything. Then coming home to old friends and family who tried to pull them back into old habits, and ridiculed her and her boyfriend for not wanting to join them. It was the aunties and elders of the longhouse, though, who pulled harder and better, to show the way. Visiting often, taking them to ceremony, to dig roots, to pick berries and most of all, to help create this beautiful cradle board to hold and embrace her baby.

PRENATAL DEVELOPMENT

Desired outcomes

- Understand the complex and often multigenerational impact of alcoholic environments
- Understand the mental health issues implicit (or embedded) in substance abuse
- Recognize the traditional techniques, and cultural structures including extended family, that are relevant and applicable to use as prevention and intervention strategies during pregnancy
- Understand the need to integrate these traditional techniques with contemporary provider "systems" and services

PRENATAL DEVELOPMENT

Prevention and intervention

We must begin our discussion of this developmental stage with an understanding that neither prevention nor intervention stand alone but are cyclically reinforcing. When we speak of prevention even in its optimal sense within the context of fetal development, we understand the potential impact for the prevention strategies. One newly pregnant mother may be the equivalent of intervention strategies for her sister, her cousin, or her friend who is further along in her pregnancy. We also understand the potential for the "interventions" given to the child or adolescent to be the "preventions" for the next generation.

When we further consider the vast storehouse of teachings of our ancestors and our elders, we understand that the power of those teachings forms the foundation for our preventions and interventions. We also understand that the practice and traditions of these teachings can provide both the framework and methods of application for our strategies.

Within the context of prenatal prevention and intervention, we must move beyond judgment to form a compassionate circle of support for the pregnant women in our tribal and urban communities. Central to this support must be a sharing of our conviction that all life is sacred and that we must do all we can to "invite" this new

life into our world in the best possible way. Current research on brain development tells us about the impact of environment, as well as substance and nutrition, on the developing fetus. We now know that chaotic, violent prenatal environments do have an effect on the unborn child. Once again, "new" research echoes what our ancestors knew and practiced in preparation for new life. We have the opportunity to integrate these ancient teachings with contemporary knowledge and research to produce a continuum of care and support within new Native models. These models may utilize both "old" family and tribal structures and "new" non-Native service provider systems. Our ability to successfully integrate these structures and systems depends on our knowledge of where our families are in terms of their own place within their traditions and their nation's culture. As providers, we can then help our families select from the menu of of strategies that best reflect their perspective.

Let's talk about the father.

PRENATAL DEVELOPMENT

Characteristics of the mother may include:

- A genuine and sincere love for the baby within her
- A need and sense of expectation that her baby will finally be the one to provide the unconditional love she has never had
- A determination to be a good mother
- A chemical dependency or addiction to substances that will self-medicate her pain
- Poor nutrition
- Poor prenatal care
- Domestic violence, sexual, physical and emotional abuse
- Learning disabilities and poor judgment as a result of her own fetal alcohol exposure
- Low self-esteem and related mental health issues
- Barriers to accessing social services (e.g., geographic, cultural and educational)

Prevention and intervention strategies

- **Environmental design strategies** promoting memory and information processing and development
  - Family-focused residential treatment that integrates an array of Native spiritual and traditional practice with current drug and alcohol theory. The most effective treatment programs are those that have components addressing parenting, child development and mental health issues from a visual and experiential context that role plays and habituates skills creating programs that cognitively re-tailor strategies for adults and children affected by fetal alcohol exposure
- **Behavioral strategies** promoting social and emotional development
  - Prenatal medical care that is specific and concrete in terms of describing fetal development. For many young mothers, the ultrasound photographs and the obstetrician's calculations showing that "your baby is about this size and this weight" have been the concrete cues and reminders of their pregnancy. Some expecting mothers have even carried their ultrasound photo in their wallets and pulled it out throughout the day
- **Educational strategies** promoting cognitive development
  - Extended family, community and elder validation and congratulation of the pregnancy; modeling the concept of celebration and invitation to this new sacred life. Modeling may include ceremonies specific to certain nations and traditions
- **Community strategies** promoting culturally congruent, holistically integrated service delivery
  - Community "mentoring" or buddy systems that extend and reinforce the frequency and duration of "home visit" prenatal care provided by community health nurses and Healthy Start. Some women may need daily home visits in addition to outpatient treatment or "after care" following residential treatment. An effective model involves relatives, elders and others mentoring pregnant women and mothers, as well as public health systems

3 Infant Development

- A Story -

Crying, crying, ceaseless crying ... that's all he does. Tired, tired, terribly tired ... that's all I am. These were her thoughts as she once again tried to rock him to sleep. The rocking chair occasionally squeaked, sending him into an even higher pitch of screams. Nursing sure didn't seem like the "serene" experience described by the La Leche pamphlets. Good thing that the community health nurse and early intervention people had told her to anticipate a hard time. Otherwise, she knew she would have given up and given him a bottle, cross cutting the nipples like some of her friends. Who knows, maybe nursing was going to end up in failure like so many other things in her life anyway. Even getting him to sleep more than a half hour at a time seemed impossible. The cradle board was beautiful and he did seem to rest longer and better in it, but then taking him out for nursing or for putting him in his crib always threw him into fits. Maybe she was just going to be a failure as a mother period. Maybe somebody else could do better....

Her grandmothers and aunties and the Healthy Start and community health nurses were still visiting and his last weight was better, but he still seemed to startle over any changes in noise or temperature. Sometimes even one of the pretty, bright, hard plastic rattles seemed to startle him in his own hands. It was really cool, though, how her grandma and the early interventionist came up with the idea of putting him in his cradle board, into a thick blanket made into a hammock. Gently rocking side to side, he seemed like he was snuggled into his own cocoon, and he did sleep longer. Keeping him in his cradle board to nurse seemed to help that part too. But he was still cranky, and he was floppy whenever he was out of his board. He wasn't really rolling over, and her auntie said that by now he should be able to push himself up on his hands and be close to sitting up. Well, he wasn't-not even close. Becky, the occupational therapist, had made a bolster pillow that she could put under his chest when he was on a blanket on the floor and he was beginning to tolerate that, even like it when she did it in front of a mirror on the floor where he could see himself.

INFANT DEVELOPMENT

Desired outcomes

- Understand an infant's need for nurture
- Understand the need for calm, non-over stimulating environments
- Recognize the strengths and needs of this developmental stage
- Understand the variety of strategies that can be tailored to fit individual infant needs

Infant Development

Infancy is about fulfilling the need for nurture. Nurture for our infants prenatally exposed to alcohol is a very large and challenging task. For the mother in recovery it can be incredibly challenging to her sobriety. Relapse prevention and support is critical to addressing the old feelings of hopelessness and helplessness. Nursing helps extend the biologic commitment but is itself frustrating for the mother and the infant with a poor sucking reflex. If, in addition, the mother has been a victim of sexual abuse, then therapy needs to be identified and delivered in conjunction with lactation and nursing support in order for her to be successful. For the foster or adoptive parent who may not be able to nurse, close attention must be paid to the type of bottle, nipple and formula used. Using the same positioning during feeding, tight swaddling, monitoring of environmental textures and noise and consistent opportunities for massage and movement must be carefully and continuously offered. All parents must be well supported so that they have the energy and respite to provide the best possible nurturing. Again, we must use extended family and community resources to insure that the parents are nurtured physically, emotionally and spiritually. You cannot wring out a dry towel. You cannot pour water out of an empty cup; it has to be refilled.

INFANT DEVELOPMENT

Characteristics may include:

- ❖ Likes to be held and looked at by anyone
- ❖ Watchful and observing
- ❖ Small, failure to thrive, losing weight longer than usual after birth
- ❖ Floppy, weak muscle tone (i.e., hypotonic)
- ❖ Heart and other organ defects
- ❖ Spinal abnormality
- ❖ Hip dysplasia
- ❖ Susceptibility to pneumonia or ear infections
- ❖ Poor sucking reflex
- ❖ Exaggerated startle reflex
- ❖ Poor, unsustained and erratic sleep patterns
- ❖ Poor habituation, inability to create habits or patterns for feeding, sleep or movement
- ❖ Sensory integration issues with taste, smell, sight, sound, touch (tactile), movement (vestibular), body positioning (proprioception), motor planning (praxis)
- ❖ Difficulty crossing midline, inability to reach or make movements crossing left-to-right or right-to-left sides
- ❖ Easily over stimulated

INFANT DEVELOPMENT

Intervention strategies

- ❖ Environmental strategies promoting memory and information processing and development
  - ▫ Use a cradle board (swaddling or. baby basket carrier, whatever is your people's way) to establish security of body in space. It also provides good spinal stability
  - ▫ Use a hammock for side-to-side rather than back-and-forth movement. This helps to create a quiet cocoon that tends to decrease over stimulation
  - ▫ Nurse, if possible, for development of immune system, parent-child bonding and good oral development
  - ▫ If nursing is not possible, use bottle nipples designed to promote sucking and do not cross-cut them … babies need to suck. Swaddle baby closely to your body or hold closely around the cradle board. Feed in the same quiet, darkened place and hold baby in same way each time, thus minimizing potential distractions and creating structure for future habituation
  - ▫ Observe textures and temperatures most tolerable to infant. When selecting rattles, toys, blankets and so forth, try to choose wood and natural fibers that are neutral in temperature and texture
  - ▫ Slowly introduce new foods and textures for gradual transition. Observe infant responses for what is successful
  - ▫ Use a penlight and objects such as bells, beads and rattles, crossing back and forth from infant's right and left sides for visual tracking
  - ▫ Carefully and slowly massage and move extremities, paying careful attention to flex and cross the midline (i.e., cross right hand to left shoulder, left hand to right shoulder)
  - ▫ Place the infant in a variety of positions throughout the day. When out of the cradle board, place the infant on stomach (prone) sometimes using bolster and on back (supine)
  - ▫ Do not tickle, throw up in air or swing by arms
  - ▫ Observe and respond to what produces over stimulation in the infant
  - ▫ Do the same things (i.e., feeding, positioning, bathing) at the same time

each day, establishing a structure and a pattern of transition. Again, observe your baby and read his or her cries to establish that structure

- Learning strategies promoting cognitive development
  - Use movement and positioning as opportunities to talk about body movements and parts
  - Talk, tell stories and sing in calm, quiet, well-modulated tones
- Behavioral strategies promoting social and emotional development
  - Plan activities that help infants grow and are fun
  - Help infants know they can do things and are loved
  - Talk and sing to the babies when you feed, diaper, and clean them
  - When babies indicate that they want help, provide it. Infants learn trust and that they are loved when you respond to their needs for food, comfort, and attention
  - Rock and hold infants when they are upset
  - Consistently and appropriately respond to the infant's expressions of distress, interest and happiness
- **Community strategies** promoting culturally congruent, holistically integrated service delivery
  - Provide frequent and close monitoring of health and physical development through coordination of pediatric and public health services
  - Evaluate for developmental delays. If appropriate, refer for diagnosis
  - Begin to use a collaborative, team-driven approach to deliver interventions and strategies. Base this approach on observation of baby's behavior, knowledge of family and community context and traditions and the outcome of the multidisciplinary evaluation and medical diagnosis
  - Use a collaborative team approach to insure consistency in the delivery of services and supports

4 Toddler Development (Approximately 18 months-3 years)

- A Story -

She is so active now. So cute, so friendly to everyone. Darting, climbing, falling, rolling everywhere. Nonstop motion, nonstop babble and chatter punctuated by screams of joy when she gets her way and screams of frustration when she doesn't or can't do something. So much a toddler, but still so clumsy and so "out there" that she can't seem to grasp the simplest of directions. You say, "Go get your shoes" and she goes but seldom comes back. You say "shoes" and she might run over to them but then just stare blankly at them not knowing what to do. Everything has to be said over and over and over until you want to scream with frustration. Nothing seems ever to be remembered and certainly is seldom, if ever, applied to the next situation which is just like the one before. Take safety for an example. So many times told not to go in the road. Told why not to go in the road. Told to look at the cars going by in the road. "They might hit you," you tell her. She just laughs and claps her hands in that flapping motion.

So we put up a fence; we put up a gate; we even put on a safety latch that takes me 45 minutes to put together. She watches me and within 30 seconds has it figured out and open. I know I have to "show" her and as I think about a way to do that, I also think it kind of cruel but less cruel than letting her get hit by a car! So I ask her older sister to hold her and have her watch. Her sister tells me my idea is cruel. "It's child abuse and I'm going to call CSD," she says. I go ahead and do it anyway.

I put a big soft rubber beach ball in a pothole in the road right in front of the gate. I get in the car and drive it the same speed most cars travel in front of our house-not too fast, not too slow. I slam on the brakes and, skidding, the car hits the ball. It pops, rubber flying everywhere. I get out of the car and walk over to my little girl. Her eyes are big, she is flushed, but quiet. I say, "That could happen to you." She turns around and runs to the backyard and she never goes in the road again.

Several months later we are up at Lummi, and we are at a conference. We are standing in front of a hotel waiting for her Cuthla to be picked up to go to the

airport. She sees an auntie across the street and before I can grab her she's running across. I run and catch her as a car is coming and then I say, "You ran in the street." Correcting myself, I use the same language as at home and say, "You ran in the road." She looks at me like I'm nuts and, hands on her hips, says, "This is not my road!"

When everything stays the same and is in the same place, and when we follow the same pattern or sequence of structure, like laying out her clothes, she does quite well. She is even learning to retreat to her own little quiet space when the house is too full of relatives or her older sister's music and friends. But she seems happiest of all when she is with just one person and has their undivided, undistracted attention. She likes to sing by herself, not to "perform," except in ceremony-then she likes to sing with other people. She seems to like ceremony, longhouse and sweat lodge, but especially Sundance with its movement and songs that are repeated throughout the day for several days. By the second day, she seems so focused and so close to the spirit world, it tugs at my heart. I believe she sees things I will never see and her happiness and beauty radiates to all around her. I think what a blessing she is, and I forget the times of her nonstop movement and cries of frustration.

TODDLER DEVELOPMENT

Desired outcomes

- Understand the positive strengths of social and active behaviors while identifying the risks they produce
- Recognize what are normally developing toddler behaviors and what are the behaviors that may suggest alcohol exposure in utero
- Recognize the manifestation of sensory integration issues
- Recognize the language processing issues that affect cognition and behavior

Toddler Development

Under the best of circumstances, toddlerhood is an active, explorative, boundary-testing developmental stage. Toddlerhood can be an extremely trying time for parents and care givers of a toddler who has been diagnosed as FAS, or for whom alcohol exposure in utero has produced central nervous system effects. Sometimes this will be the first stage of the identification and diagnostic process. In this case, the processing of this new information, along with the nurturing and attention that must be given to eating, health and safety precautions, will seem like a monumental task. As parents, we must seek and use the support of our families and communities. As providers of medical, early intervention or social service resources, we must be attentive to the parents as well as the child. Again, we must surround the whole family with a community of care that recognizes the cultural, physical, educational, emotional and spiritual contexts from which the family operates. For the child, we must provide opportunities for exploration that are structured with conceptually concrete examples and boundaries. We must also remember that what is learned today may be lost tomorrow, and we must be patient with the process. We must show, not just tell, and when we tell we must do so with one part directions. We must remember that behavior is communication, and we must engage in positive behavioral mapping that describes what the child is doing right rather than what the child is doing wrong. We must provide a quiet place-even if it is just a spot or corner defined by hanging blankets-that is a safe, nurturing place for retreat, not punishment. These become our first steps and our toddler's first opportunities for developing an internal locus of control.

Characteristics may include:

- Active behaviors
- Friendly affect
- May exhibit delays in walking, toilet training and transition to textured foods
- Sensory integration issues may be apparent. Ability to receive and process information from the senses is often affected
- Extremely social personality
- A lack of stranger awareness
- A proclivity to be easily frustrated
- A continuation of physical anomalies
- Speech and language deficits-expressive language may be emerging, but receptive language (i.e., the processing of information or directions) may be more delayed
- Some language patterns may seem echolalic (i.e., as if they are echoing someone) or the pitch and tone of voice may seem odd
- Self-stimming behaviors such as hand-flapping and headbanging may emerge.
- Little or no sense of cause and effect
- Greater distractibility and hyperactivity may be more than is usual for a normally developing toddler
- May demonstrate an inability to adapt to or transition to new environments, settings or requests
- Temper tantrums, disobedience and frustrated behaviors may be excessive compared to normally developing peers

TODDLER DEVELOPMENT

Intervention strategies

- **Environmental strategies** promoting memory and information processing and development
  - Evaluate the child for developmental delays. Refer for diagnosis if appropriate. Document for referral to early intervention services. Seek eligibility under "other health impaired"
  - Establish a calm, structured home environment
  - Establish consistently sequenced home routines of eating, bathing, playing

and nap times. Many toddlers affected by prenatal exposure to alcohol will continue to benefit from two naps per day. The sensorial overload that occurs as a result of processing a confusing and frustrating environment makes them tired, but often their hyperactive behavior makes parents miss this cue.

- Monitor physical development and health, insuring proper nutrition. Vitamins B and C seem helpful in calming and in building the immune system. They also work together for improved absorption
- Be patient with toilet training. Again, observe your child in terms of times of day he or she needs to go and build a routine. Go to the bathroom at the same time every day. Provide a potty-chair and slowly transition from diapers to "pull ups" and then to the use of a potty chair. Praise success and do not punish or shame failure
- Limit television intake to one time per day and choose nonviolent, appropriate programming that calmly presents developmentally appropriate material
- Establish a consistent bedtime ritual of quiet room or space, same stuffed animal or doll, storytelling and whatever closure is appropriate to your traditions. Blankets or textiles will muffle sound if the child occupies a sleeping space with others. Also "cocooning" your toddler in a blanket and putting on a quiet tape of soft music, such as flute music, may help to diminish noise and auditory distractions in a large household
- Eliminate or diminish milk intake. Many Native children seem to be lactose intolerant or react with excessive mucus accumulation. This problem is exacerbated by the frequent occurrence of small eustachian tubes or ear canals in this population, increasing their risk for middle-ear infections

❖ **Behavioral strategies** promoting social and emotional development

- Coordinate opportunities to play with same-age cousins or peers in small (2 to 4) group settings. Try to select playmates who demonstrate positive play behaviors
- Map positive behavior by paying careful attention to what toddlers do right and reinforce with praise. For example, tell them "I really like how you are sitting quietly." Whispering this type of praise in a child's ear is often most effective in settings such as ceremony. Do this at frequent intervals to maintain desired behavior

- Provide sensorial exploration but not over stimulation. Read toddler's cues and behaviors to determine the appropriate level of stimulation. Offer toys, watch and read toddler's response
- Begin to address safety issues with concrete methods of "showing." Understand the lack of stranger anxiety and use examples that create visual pictures like "we only hug people who have come to our house and have eaten at our table"

❖ **Educational strategies** promoting cognitive development

- Provide a small selection of toys and organize them on planks or shelves that have outlines and the picture of the toy. Help them replace the toys in that same spot. This will help future skills in categorization and will also make life easier for you! Use toys that visually carry skill building, not automated toys that don't teach cause and effect and may be over stimulating
- Give only one-part directions and even then, know that you may need to "show" what you want repeatedly when giving the direction. Make sure you do it kindly, slowly and calmly. It will pay off with compliance
- Support speech and language development with the use of sign language. Accompany direction-giving with these signs

❖ **Community strategies** promoting culturally congruent, holistically integrated service delivery

- Expose your toddler to routine ceremony or spiritual practice. Participate with your child in the spiritual way that belongs to you and your family. Use these opportunities to reinforce the concept that your child is a “sacred gift”

5 Early Childhood Development (3-6 years)

- A Story -'

She is beautiful and bright and generous in her love, beyond usual, gifting those around her with an energetic spirit that magnetizes and "re-stimulates" all, including herself. Sometimes her energy seems boundless and way beyond your own. Sometimes her energy seems heyoka (or contrary) to everything you are trying to do. And sometimes her energy is so quiet in a sad self-image of failure.

Somewhere between the boundless energy and the sad selfimage, there is a time of watchfulness, of observation of "how to be good." She has a genuine desire to please. My daughter, Kow-ish-kah-nee-xla, has worked so hard to learn to be good. She watches, she tries, she asks and she is broken-hearted when she sees herself as having "failed." The strength of her trying and asking tugs at my heart; her perception of her failure breaks it.

She has been lucky in her life because many have come forward to show her how to be. Elders and cuthlas (grandmas) show her how to be who she is, and in the showing have offered her a structure of skills. She has learned through watchfulness, respect and gratitude in ceremony and action that have honored her and become the foundation of her being. Aunties and uncles and two devoted nun-nahs (sisters) have loved her unconditionally. A Montessori pre-school guide and a warm and responsive kindergarten teacher have extended and reinforced rather than detracted from the traditional values of observation and respect. All of these teachers have valued my daughter, and have used her strengths to heal her weaknesses. They have honored her life with a structure of functional skills in concrete learning.

Together my daughter and I have learned many things. Some of them are:

- Her need to give and get love is real and almost insatiable, but I love the process of meeting this need
- Her difficulty in understanding and "behaving" in the midst of chaos and

confusion is at least as upsetting to her as to me. We should avoid noisy, overly active environments because as hard as she tries, it is just too much to process, and as hard as I try, my strategies for handling the stress may not work

- Her knowledge of what is going to happen ahead of time makes pre-planning extremely helpful in terms of both her cooperation and her understanding. Such pre-planning and foreknowledge also diminishes her impulsivity
- Her response to calm, single or one-part directions is immediate and cooperative. Her response to loud, hyper, many-part directions is one of trying, then becoming frustrated and irritated and then finally tuning out (or it used to be tantrums)
- Her appreciation of praise and all forms of positive reinforcement is obvious by her immediate repetition of those actions or behaviors that received praise
- Her visual memory is keen and incredible in its ability to later replicate and produce imitation of what she has seen. This ability coupled with her ability to observe means that curriculum materials, behaviors, language patterns and values that are "shown" and visually modeled will be the ones most remembered for later use. Their use will be almost exact by what she saw, and she will say what she has seen
- Her need to know who she is, both spiritually and culturally, is critical to building the resilient self-esteem that she will need to work her way through life
- Her need to know the name of her disability and understand what it does and does not mean. To do it in the context of her strengths, as well as her weaknesses, and to help her remember that she is, most importantly, a whole person, a Native girl with many characteristics and talents

When she was five, she knew she had "issues" and "needs," but I had not wanted to give her a label. Afterwards, she said, “Am I that thing you're always talking about?" (Professionally, I am a FAS Specialist.) Thinking her not old enough to understand, I tried to slide out from her questions, but she pressed on, so I said, "Yes." Her response was, "Well, thank goodness I'm not stupid! Now I know what's wrong." Afterwards, in the evening, she said, "When I grow up I want to be a brain doctor mechanic." I asked her what she meant and she said, "I want to be able to open up

brains like mine and find the wires that don't connect and then solder them together so they connect right."

Our children deserve to know. We must tell them. We must support them and then we must help them not to use it as an excuse, but as an understanding.
My daughter and I are still learning, but with the learning we continue to be grateful that there are so many who have come forward to love her and show her how to be. We have needed, and she has deserved, that honor that will reflect Kow-ish-kah-nee-xla's beauty and brightness, so that she can see it for herself, even when the letters, numbers and colors don't match.

EARLY CHILDHOOD DEVELOPMENT

Desired outcomes

- Understand the need for ongoing evaluation, referral to services and the integration of a school component
- Understand the continuing, and sometimes increasing, need to provide structure and consistency within all environments
- Recognize "behaviors" as communication
- Identify settings and contexts that produce opportunities for positive reinforcement

Early Childhood Development

Early childhood for the child with FAS or related affects from alcohol exposure in utero is often characterized by behaviors that are active, distractible, stubborn, excessively outgoing or social, and hyper-sensitive but overtly happy. Physical appearance is often elf-like in manner, short and small in stature. The need for demonstrations of love and physical contact seem insatiable. So is the need for praise. Like toddlers, but somewhat more advanced, their speech and language skills often seem to echo the patterns of those around them. Their expressive language, therefore, often continues to be better than their receptive. They can chatter incessantly but seldom seem to listen or process what they have heard. Poor judgment and a limited sense of cause and effect can put them at risk for wandering off and getting lost, for sexual abuse, or for eating poisonous plants or substances, simply because they looked good (and because often these young children are still developmentally in the oral motor exploration stage). Since this is typically a chronologic stage for preschool and kindergarten and the acquisition of pre-academic skills, enrollment in early childhood programming that proceeds from a Montessori visual/tactile/sensorial curriculum will probably best suit their needs.

Frequently, the child who has endured difficult, chaotic living situations or multiple foster placements may have some of the active, affable characteristics of this stage compromised by mental health issues. Coordination of community resources with the early education setting and proceeding from the context of a family-focused intervention is critical. Case management must also include preparation for the planned transition to the future elementary school setting.

EARLY CHILDHOOD DEVELOPMENT

Characteristics may include:

- An excessively social and outgoing personality
- Watchfulness and observation skills may emerge
- A need for praise, hugs and touching
- Extremely active but more coordinated physical (i.e., motor) movement
- Fine motor skills such as drawing or stringing beads may emerge
- A "scatter" of gross motor, fine motor, speech and language and cognitive skills manifested in assessments, with a wide range of skill levels within the same domain
- Behavior that may appear deceitful, i.e, answering our questions such as "Did you eat the cookies?" and they answer "No." Really they are just "reading" our faces, tone of voice and body language and telling us what they think we want to hear. They desperately want to please us!
- Central nervous system damage resulting in hyperactivity may manifest itself through distractibility and "hopping" from one activity to another
- Many of the same needs they had as toddlers, including self-stimulating and repetitive behaviors

EARLY CHILDHOOD DEVELOPMENT

Intervention strategies

- **Environmental strategies** promoting memory and information processing
  - Evaluate developmental delays. Refer for diagnosis and services, if appropriate
  - Continue calm structure of home routine and environment. Define an area for a nurturing retreat
  - Continue monitoring of medical, health and nutritional needs with emphasis on foods low in sugars and synthetic substances and high in vitamins B and C
  - Provide age-appropriate avenues to satisfy the need for self-stimulation (e.g., squeeze or squash balls, smooth rocks or agates). These objects can continue to be used as the child matures
  - Enroll in a preschool setting that is visually structured, limited in transitions and distractions and not over stimulating with bright colors and mobiles

- Provide mental health, occupational, speech and physical therapies. Inform therapists about the needs of children with an FASD

❖ **Behavioral strategies** promoting social and emotional development

- Guide and support continued positive behavioral mapping both at home and at school. Label and praise desired behaviors
- Lead your child to truth-telling; don't confront or "back him or her into a corner." Use body language, facial expression and tone of voice to solicit truth. Offer praise by saying, "I like how you tell me the truth" or "how it really happened"
- Help the child identify the "whats" and "whys" of his or her delays. It is not only appropriate but also helpful when done respectfully, concretely and compassionately. The child knows he or she is different, but just does not know why

❖ **Educational strategies** promoting cognitive development

- Use preschool and kindergarten environments that are conceptually organized with visual barriers defining small areas and pictures identifying the area's use. Curricula that limit transitions and proceed from a choice-making model (e.g., High Scope or Montessori) encourage focus and attention span, diminish tantrums over transition and help develop an internal locus of control. For example, such curricula permit a child to stay at the clay table as long as he or she wants before moving to a new activity
- Within the child's educational setting, begin the identification and transition into the goals and methodologies that will define his or her elementary school setting. Establish a "504 plan" or Individual Educational Plan, which incorporates activities that define and reinforce the child's strengths as well as address the child's needs

❖ **Community strategies** promoting culturally congruent, holistically integrated service delivery

- Provide coordination and collaboration among extended family, elders, community resources, social and educational services
- Continue spiritual practice and relationships with elders and spiritual leaders. This is critical for building the resilience that the child will need in future life experience

6 Middle Childhood Development (6-11 years)

- A Story -

She is nine years old now. Her grandmothers and aunties, uncles and cousins, her sisters, and now teachers and friends continue to shape and support, honor and respect that spirit that is my daughter: the wonderful singer, excellent observer, spiritually inspired, beautiful girl.

With laughter and kindness, with quiet introspection and stubbornness, she continues her journey through the developmental process of growing up with fetal alcohol effects.

She confronts academic frustration, social misconceptions and misinterpretations, but the survival skills, strategies and selfconcept developed in her early childhood have proven to be the basket of provisions and tools that sustain and build her growth. They provide resilience to meet these challenges.

The motivation and perseverance with which she confronts these frustrations and challenges are impressive. The attitude she maintains is outstanding. Very seldom does she sink into that sad self-image of failure so frequent in her early childhood.

At these moments, her stubbornness serves her well because it is complemented and reinforced by a confidence and a positive self-concept reflected in the environment in which she lives.

There is much in these past four years that I have learned as the parent of my daughter. All of it has been built upon the early foundations that recognize:
The need for environmental structure, visual cues and teaching methods that show rather than tell.

- Behavioral strategies that reinforce positive behaviors and provide a map of what to do, rather than what not to do
- A spiritual base that makes her relationship to her Creator real. This provides a secure knowledge of her cultural identity and a resilience that puts the hard, stressful times in perspective. It pulls her out of those less frequent times of a "sad self-image of failure"

As extensions of those earlier foundations, some of the things my daughter and I have learned are:

- To specifically recall what has "worked" during the day, review the successes and apply them to existing problems as appropriate and relevant strategies. For example, to talk about how she solved one difficult social situation and then problem-solve together to apply it to another situation
- To role-play over and over positive methods to confront a difficult situation or to prepare for change and transition
- To use a daybook, or day-by-day calendar, that describes the day's schedule of activities both in words and pictures
- To select and interview next year's teacher the previous spring. Select the based on his or her demonstrated responsiveness to verbal and written information about Fetal Alcohol Syndrome. (Give it to all of them and see who gets excited and interested. Pick that one!)
- Within the school setting, to insist upon the development of an individualized educational program that identifies both strengths and weaknesses, and describes specific goals and methodologies for supporting the strengths and for addressing the weaknesses
- Within the school setting, to identify a resource room or other quiet classroom space where she can work without distractions by visual and auditory movement
- To provide a diet that is low in synthetic or natural sugars (despite the recent findings by the sugar manufacturer's lobby) and a diet that is high in grains and B vitamins
- To offer a daily schedule that has frequent periods of both structured and unstructured exercise but to unwind or slow down that activity pace step-by-step before requiring or asking her to sit still. In other words, if my daughter has been running or playing basketball, I cannot ask her to immediately come in and sit at the table, or to sit down and read. Her brain and neurology does not permit her to shift gears so quickly. She needs time to slowly and sequentially bring her central nervous system to that point of quiet
- To continue to give not more than two-part directions (and often only a one-part direction) such as, "Please come in and wash your hands." Then, "Please put the dishes and silverware on the table." Not, "Please come in, wash your hands and

set the table"

- To be alert to our children's responses. As my daughter gets older and understands more and more about FAS/FAE, she will sometimes say, "Oh, you know I have a bad memory, I forgot to clean my room," to which I say, "It's on your daily schedule, you only need to look at it." However, when I am rushing, running late for work in the morning, and lapsing into "hyper" behavior and multi-step directions, she tells me, "You are stressing me out. Please slow down and quiet down." That is a very appropriate piece of self-knowledge. Her behavior of absolutely stopping, sitting down and putting her hands over her ears is also a very effective visual cue for me!
- To provide a spiritual life of ceremony and practice that begins and ends each day. To practice the gratitude for the beauty that is in front of us if we will only choose to look, and to practice prayers during some days when we feel we want to give up
- To understand behavior as a form of communication, not as a "desire to be bad," and to respond to that behavior with natural consequences that are shown and can be understood. For instance, a messy room with toys all over doesn't result in a punishment of no TV but rather in a verbalized response of, "I see you have too many toys to keep them cleaned up. Let me help you by putting some away until you are able to keep a few put away"

Even more important than these consequences is the act of showing her what she is doing right, especially in the areas in which she still has problems. For instance, every time she uses her schedule, I tell her how responsible she is being and how it means I don't have to follow her around and "nag." These actions become her maps for good behavior.

Although I am also an FAS trainer and specialist with a formal education in this area, it is my daughter who has taught me and who has taken me from theory into function. It is my daughter whose courage has inspired me and shown me how to move beyond the "gloom and doom" and to remember and recognize-as our ancestors did-that each child is a sacred gift indeed; that each child has a special mission on our Mother Earth. I am so grateful for what my daughter-and all of the other children and adults I have had the honor to work with-has shown me. There

is hope and there is beauty in all that happens.

My daughter said it best one day at a training when she got up in front of the group of counselors, teachers and parents. She said, "My name is Kow-ish-kah-nee-xla. When I was born, the doctors said I would never grow to be normal size, that I was always going to need special education, and that I could probably not be in sports because of my heart. Well, they were wrong."

I am so grateful for all those who have helped her to make those doctors wrong.

MIDDLE CHILDHOOD DEVELOPMENT

Desired outcomes

- Understand the impact of the child's entry into elementary school and an academic setting
- Continue to recognize and understand behavior as communication
- Continue to identify ways of mapping positive behavior
- Understand the importance of evaluation and utilization of special education and Individual Educational Plans
- Understand the identification of strengths as a process of promoting individual specials skills and talents

Middle Childhood Development

Middle childhood is largely defined by a child's experiences in elementary school. For the child with FAS, or related neurologic effects from prenatal alcohol exposure, this setting often highlights the disturbances within the central nervous system. Academic struggles often surface in primary school (first through third grades), but are often mistaken for lack of maturity. Verbal skills (reading and writing) may not be as delayed as spatial and computation skills (math).

Hyperactive behavior may still be present, but is usually not received as being so "cute" as in early childhood settings. Difficulty in managing the hyperactive behavior sometimes results in an assessment of Attention-Deficit Hyperactivity Disorder (ADHD). Other times, it is defined as the results of a child "not really trying" or "just doesn't want to focus ... they could do it if they wanted to." Such comments by teachers and other school staff should be our cues and flags as parents, caregivers, social service providers and educators that there may be some organic issues present. Referrals for evaluation by Education Service Districts must define more than these attentional deficits. Speech pathologists may be the best early diagnosticians of the spectrum of auditory skill deficits present. The discrepancy between expressive and receptive language skills (with expressive higher than receptive) continues to be present and may itself be a diagnostic feature. Referral for further medical evaluation and for special education services is essential. With life beginning to be so stressful within the academic or educational setting, inappropriate behaviors may begin to escalate. Simultaneously, self-esteem

and self-concepts fall. Interventions which proceed from identification of the child's strengths and which provide opportunities for displaying these strengths or talents will be most successful. These will offer the building blocks for good self-esteem and resilience. Spiritual and cultural practices that guide and reinforce the child's sense of values and heritage provide the foundation for these building blocks. Coordination and integration of family, school and community services and resources are essential for services and supports to be effective.

MIDDLE CHILDHOOD DEVELOPMENT

Characteristics may include:

- Friendly behavior, but frequently missing verbal and nonverbal social cues from peers
- May form individual friendships with certain adults, but become easily upset or depressed if that adult corrects them
- Varies/vacillates in play from hyper-kinetic engagement with friends to isolating behaviors. Often feels peers are "being mean" when they reject the mannerisms of close physical proximity (too "touchy and feely") or "clueless" ability to engage in imaginative play
- Easily influenced by peers and may copy their behavior(s)
- Can't seem to predict or understand consequences
- Impulsive
- Difficulty with abstractions. Concrete thinking impacts ability to generalize
- Poor problem-solving strategies
- Confusion
- Difficulty understanding and transitioning to new activities, both academically and socially
- Low self-esteem
- Can give, but not take teasing
- Doesn't always understand sexual boundaries; may hug excessively or still jump onto people's laps. Continued lack of stranger awareness makes these children vulnerable to sexual abuse
- Defiance may begin to emerge, although without significant mental health issues; most children still want to please
- "Taking things they want" often results in being identified as stealing when they are only acting impulsively in response to something they see and like
- Present themselves as having more capability than they really have because of their often higher expressive and echolalic language skills, and because for many, the "morphology" or facial characteristics are either outgrown or not present. Like all children with "hidden disabilities," their needs are often overlooked

MIDDLE CHILDHOOD DEVELOPMENT

Intervention strategies

- **Environmental strategies** promoting memory and information processing
  - Continue to maintain a calm and quiet environment at home and at school. This means using quiet colors and textiles to absorb sound, defining conceptual and visual boundaries of different activity areas, and providing opportunities for single seating (e.g., separate desks, retreat spaces) in school
  - Use the same language and deliver content of rules in the exact same way each time
  - Provide ample opportunities for rest; the child may need a nap after school
- **Behavioral strategies** social and emotional development
  - Encourage participation in physical activities and in noncompetitive sports where they can be individually successful. For some children, their inherent compassion and social skills may suggest a "team sport" if their position on that team is positively defined
  - Transition the child from high activity to low activity settings sequentially, step-by-step. For example, have a child walk from the playground to the door then tiptoe inside, rather than just run in from the playground.
  - Continue to identify and map positive behavior at home and at school
- **Educational strategies** promoting cognitive development
  - Help the child identify special skills or talents, such as art or music, and provide frequent opportunities for successful demonstrations of these talents
  - When showing these students how to do an academic task, sit beside them, rather than across from them. This will diminish the "social" distraction of your presence. They will be more easily able to look at the paper rather than your smile or your earrings
- **Community strategies** promoting culturally congruent, holistically integrated service delivery
  - Identify, validate and provide opportunities for cultural and spiritual experiences on a consistent basis within the same settings and with the same people. Reinforce relationships with a few appropriate elders and provide consistent opportunities for the development of that relationship

- Watch for teacher comments like: "If he or she just tried they could do better." "They aren't reaching their potential." "I don't want to modify his or her assignments because that will just enable him or her." Enable what - their ability to be successful? Understand that teacher perspectives of control may come from their lack of knowledge. Facilitate opportunities for teachers to inquire into this subject by proactively providing support and advocacy through resources such as team meetings, videos, handouts and manuals. Tell stories that reflect the scatter of skills, gaps and developmental discrepancies that characterize the organicity (organic brain damage) of this population

7 Pre-adolescent and Early Adolescent Development (11-14 years)

- A Story-

His body seems so much quieter now, sometimes almost too quiet, but then exploding in a fury of activity only to fall quiet again. He can't seem to get enough sleep though. Maybe if he didn't spend so much time sleep-walking and talking at night he'd feel more rested. He has some friends, but the connections don't really seem to run deep, and often he doesn't get invited to parties with these friends. I'm worried about his school work, but really, the most disturbing thing is his change in social ability. He forms friendships but can't seem to keep or sustain them. The only consistent person he keeps in his life is our spiritual leader with whom he does ceremony. In fact, ceremony seems to be the only time our son looks truly happy and at peace with himself. I think if he could just sweat everyday he'd probably never come out of the lodge. His room is a mess, a stinky mess, except for the things he uses in ceremony; those he keeps in a special spot in a special way. At Sundance, he seems so strong, lost in his total connection with Creator. I am so glad that this experience has been consistent throughout his life, because some of his friends who have come and gone and been less consistent in their spiritual practice just don't seem so connected. Some don't even want to do it anymore.

He seems the opposite of organization, but if I don't insist and help him use his day-planner and organize his school things, his room things ... his everything ... he forgets things and then freaks out that he's a "failure." I wish I could help him find something at school that he's really good at so he could "shine" and feel good about himself. School sure seems the hardest place for him to be.

PRE-ADOLESCENT AND EARLY ADOLESCENT DEVELOPMENT

Desired outcomes

- Understand the shift in the manifestations of characteristics of FAS. Extreme sociability may combine with, or change to, more isolated and depressed behaviors
- Recognize the increased vulnerability to risk factors, such as poor peer influence and expectation of independence that impulsiveness and poor judgment don't support
- Understand how to provide and reinforce the resilience factors that stem from child and family strengths, and from cultural context

Pre-adolescent and Early Adolescent Development

This developmental stage is often characterized by a shift in activity level and more isolative behavior, particularly if the resilience factors, identification of special strengths and skills and opportunities for displaying those skills are not present. Life typically becomes much more stressful with academic expectations that are too abstract, school settings that are too transitional from one class to another, and where the extreme content and sustainability lacks friendlness. Poor self-concepts create vulnerabilities and risks for alcohol and drug experimentation, and misreading and misuse of sexual boundaries (or lack thereof). Motivation can seem at an all-time low. Many of the same behaviors and needs from earlier childhood may still exist, however, in a different form. Special education resourcing begins to feel stigmatic rather than supportive. Unless carefully framed and constructed, collaborative/community service models may feel oppressive and provide just one more example to the child of his or her "differentness." Solutions and recommendations for support in all domains must proceed from a strengths/enjoyment perspective.

PRE-ADOLESCENT AND EARLY ADOLESCENT DEVELOPMENT

Characteristics may include:

- Need for one good, trusted friend
- Ability to absolutely follow rules when they are concretely given, role-modeled and positively reinforced
- Strong engagement in ritual and ceremony
- Difficulty with abstract thinking. For this reason, many children seem to reach their academic ceiling within the school environment
- Emergence or escalation of mental health issues as a result of gullibility, vulnerability, poor academic performance and chaotic environments
- Low motivation for school academics, sports or organized activities because of the activities' competitive orientation and the adolescent's sense of frustration and failure
- Development of what looks like manipulative behavior, but is not pre-planned. Rather, it is a reaction to what they think people want
- Easily influenced, echolalic behavior patterns that "copy" what they see
- Still occasionally impulsive behavior lacking sense of cause and effect

PRE-ADOLESCENT AND EARLY ADOLESCENT DEVELOPMENT

Intervention strategies

- **Environmental strategies** promoting memory and information processing
  - Continue to provide a structured environment at both home and school
  - Use a planner to organize and schedule homework, activities, chores, etc. Use a planner that has a full single page for each day. Divide the page into school and home activity components
  - Offer praise and reinforcement as each task is completed
- **Behavioral strategies** promoting social and emotional development
  - Identify specific responsibilities and family chores. Document each task in a planner or provide a checklist
  - Engage in structured, supervised social activities
  - "Script" possible social and academic scenarios and "script" responses over and over
  - Use end-of-day review time to "re-script" responses in areas of difficulty. Be sure to identify and reinforce what the child did right
  - Lead adolescent to "truth telling." Do not confront and "back them into a corner"
- **Educational strategies** promoting cognitive development
  - May find it necessary to shift focus from acquisition of academic skills to more experiential skills and projects that will lead to future vocational training
  - Provide lessons, classes and/or opportunities for performance in areas of special strengths or skills (e.g., music, art, beadwork)
  - Continue to use classroom strategies and teacher and school communications discussed in middle childhood section
- **Community strategies** promoting culturally, congruent holistically integrated service delivery
  - Refer for evaluation and diagnosis, if identification hasn't already occurred
  - Present concrete, visual and role-modeled opportunities for drug and alcohol prevention. Provide education in sexual development and responsibility
  - Engage and role-model spiritual and cultural practice within the family context

- Provide and encourage consistent opportunities to engage in ceremony, cultural gatherings and other spiritual and religious experiences

8 Older Adolescence and Young Adulthood (16-26 years)

- A Story -

With shining hair and beautiful but dulling dark eyes, she approached the room. Her face carried the fatigue of failure and her body the worn defiance of survival. Another meeting! Another chance to hear what is "wrong" with her life. Juggling baby in her cradleboard and trying to calm her, she realizes that baby is probably just as overwhelmed by the room full of people as she is. If baby isn't good, maybe "they" will say she's a bad mom, and they'll try to take her. Well, they can try all they want, but she will run and hide, because this baby is the first person that has ever really loved her. They need each other, and no one is going to mess up this love. Neither of her parents will really be able to help her; they're still trying to climb out of their addictions. But at least they are getting some help from ceremony and sweat lodge-thank goodness for that-it was the only thing that got her to realize that her pregnancy was really a sacred gift. It helped her to be strong and stop drinking like the lady in the program taught her. She knew now why she had been such a failure in school-no one ever taught her mom not to drink when she was pregnant. She hoped that her stopping drinking during the first three months of her pregnancy would mean that baby would make it better in life than she had. Still, the fancy people, the "clinicians," said her precious baby was "developmentally delayed." Well, as far as she was concerned, baby is just perfect. Well, here it goes, time to go in the room and face the faces and hear the lists of needs to do ... things she could never possibly remember.

Entering the room, her eyes reflected the process of identifying all those seated around the table. Acknowledgement mixed with a tinge of fear belied her gregarious mask. How was it that so many people had a part in her life, and why did they have to know everything that the others knew? My "community of support," she had been told, but what if it meant that some would decide to "drop out?" After the introductions, the words lapped around her as she struggled to process all the possibilities of the services offered, services that she doubted could work because she had no transportation, and since she lived with her family "up the mountain," those people were not really her community anyway. Slowly she realized she was being addressed and hearing the words, "Who's missing here, who is part of your

life that is not here?" She responded, "My grandmother, my mother, my father, my brother, my auntie down the road, my ... well (with embarrassment remembering how some people called her cradle board a contraption and how the smoke from smudge that clung in its covering always made people wrinkle their noses and sometimes accuse her of smoking pot) ah ... my ... ah well 'spiritual advisor'." (That's what the lady at the program suggested she say if she didn't think these people would understand the words "medicine man.")

Just now she realized that the lady from the teen parent program was the one who was speaking to her. Cool, she was here to help ... maybe she could make the others understand her better. Oh well, maybe there was nothing really good to understand about herself anyway.

To her surprise, she heard the lady saying, "Well, since we are missing these important people in your life and some of them apparently didn't get invited, let's try again. I know that it is difficult for everyone's scheduling, but it's critical that all members of her support system come together to collaborate and plan with her. This is her community and the strengths, foundation blocks, on which we must build all planning."

With the words "cultural/spiritual," swimming distractedly in her head, she prepared herself for the second meeting. Somehow, for some reason, she felt a little less overwhelmed. Maybe because her auntie would be there and her grandma, but then when she thought of her medicine man, she felt a mix of worry and gratitude. What if "they" were disrespectful to him?

For just four months now she thinks, I've been meeting with Barb, Marsha, Marv, Seata Hut, Nisha, Lennie, Chuck, Auntie, Cuthla, my Nunnahs, Kevin and Linda. Having just completed that thought, she was suddenly struck with the fact that she was thinking of "these people" by first names, not as Dr. Richards, etc. And equally suddenly she realized that this must be the "community of support" that Marsha, the teen parent director, had been talking about. Because Marsha was the first agency person she had identified as feeling comfortable with, the team had chosen Marsha as her case manager. Boy, things seemed easier to figure out now; she was

no longer confused by who was supposed to do what. Marsha really helped her navigate through it all, kind of like a good "mother hen," and best of all, Marsha and Seata Hut (her medicine man) seemed to really enjoy working together and learning from each other. Best, best of all, baby was growing, and Mom and Dad were still going to sweat lodge. Smiling to herself she thought, "I really am part of a big community, and that community is really here for baby."

OLDER ADOLESCENCE AND YOUNG ADULTHOOD

Desired outcomes

- Recognize and understand the common denominators of behavior and cognition still affecting this adult stage of development
- Identify and understand the shift in manifestations of an FASD as they are manifest in adulthood. Observe and be watchful for the impact of the secondary characteristics of isolation, depression and other mental health issues
- Understand the effectiveness of collaborative community services. View these "collections" of family and community support as a return to our traditional village concept or to our circle of care and compassion
- Understand the need to integrate Native and non-Native services from a culturally congruent context. Pull these seemingly disparate supports and resources together for the benefit of all

Older Adolescence and Young Adulthood

Depending on the time of identification and the frequency and duration of effective interventions, this stage of development can either be a relatively successful or a disastrous stage. Often it is a combination, a fluctuation of both. In general, its success is proportional to the intervention strategies that have preceded it. However, concrete markers of what it means to be 18 or 21 drive an expectation for independence and autonomy that may not be commensurate or in keeping with, their emotional and/or cognitive development. Frustrations generated from this discrepancy may manifest in explosive episodes and erratic “bi-polar like” mood swings with multiple frequency throughout the day. The early childhood insatiable need for praise and reinforcement can now manifest in outbursts about “never being appreciated” and “always being told what they are doing wrong”.

All the basic premises for intervention still apply, but the need for these interventions to be presented in an adult-like manner must be respected. The young adult must increasingly be placed in a position of responsibility for selecting and controlling the interventions and strategies that will be most helpful to them, from their perspective. They should begin to emerge as partners and sometimes even directors of their own case management in the coordination of services. Within the context of collaborative services and community support, the young adult must continue to receive education and training. They must monitor,

reinforce and extend their academic and/or vocational skills in an organized, structured and consistent way that supports their strengths. For instance, if an individual's strengths include sociability and compassion, a career in a helping profession (such as elder care, child care, or assisting people with special needs) may serve to promote their strengths and self-esteem because they are contributing members of their community.

For some young adults, the impact of central nervous system damage or developmental delays may be profound enough that independent living will not be possible without supervised support. In this case, extended family members may be good candidates to assess when it is appropriate. For some parents, consistent, lifelong parenting classes and home visits may be adequate. For others, we must provide a continuum of support including proctor or supervised homes, not just as interim or transitional, but as lifelong settings.

OLDER ADOLESCENCE AND YOUNG ADULTHOOD

Characteristics may include:

- Developed skill areas in visual arts, fine arts, music, creative writing, storytelling and participation in ceremony and ritual
- Enjoyment of opportunities to deliver care and compassion, such as peer mediation, childcare and instruction of young children or children with special needs, or elder care
- Continued gullibility and vulnerability, placing them at risk for exploitation, sexual abuse and substance abuse
- Codependent behaviors and desire to "fix" things that can lead to poor relationships or at risk for future domestic violence
- Need to "get love," increasing the chance of teen pregnancy
- Academic failures and frustrations may cause them to drop out of school
- Poor vocational or job skills. Inappropriate placement with unsupportive employers may create failed job settings
- Victims of sexual abuse without therapeutic intervention may begin perpetrating similar acts
- May engage in suicidal ideation or actual attempts at suicide
- May engage in and lose self in fantastical thinking and lose consistent sense of reality
- May begin or increase addictive behaviors, including substance abuse. May not sustain recovery when placed in treatment settings, thus exhibiting cycles of recovery and relapse

OLDER ADOLESCENCE AND YOUNG ADULTHOOD

Intervention strategies

- **Environmental strategies** promoting memory and information processing
  - Establish a young adult as his or her own "supported case manager" and the coordinator of his or her services. Do this through support and careful transition of responsibilities over a period of time with the past case manager
- **Behavioral strategies** promoting social and emotional development
  - Reinforce and provide frequent opportunities for the young adult to perform and "shine" in areas of strength and skills (e.g., drama group leader, artist painting murals on community buildings or worker at child care center)
- **Educational strategies** promoting cognitive development
  - Provide opportunities for job placement with elder care, child care centers, and special needs services-providing the young adult has no history of aberrant sexual or violent behavior. Be prepared to train and coordinate with vocational services that place and provide training at job sites that employ people with special needs
  - Assess educational placement opportunities. Do not assume that higher education is inappropriate. Explore junior colleges, trade schools and four-year colleges in addition to mentoring and shadowing positions with para professionals in social work, child development and other social services
- **Community strategies** promoting culturally congruent, holistically integrated service delivery
  - Offer an in-depth, culturally and cognitively tailored menu of mental health therapies and drug and alcohol treatment, if needed, for the person whose environment has a history of chaos, drug and alcohol abuse or multiple foster placements. If drug and alcohol treatment is indicated, seek a place ment in a culturally appropriate residential treatment setting that restructures its curriculum for persons affected by fetal alcohol exposure. Further, insure that this treatment setting can be long-term (60-120 days), and has a relapse prevention component that can extend outpatient and home visit services for a minimum of two to five years. Involve extended family and community members in this process
  - Continue to reinforce and support (e.g., by providing transportation)

consistent involvement and participation in ceremony and religious/spiritual gatherings

- If appropriate, involve the young adult in a community support network for children and families newly diagnosed

9 Adulthood (26 -50 years)

- A Story by Carolyn Hartness -

"Compelling", said the psychiatrist, eyes mesmerized with commitment and awe, as he emerged from his first session with her. Tanya, however, seemed quiet and eager to leave. In the car, to Loretta's surprise, she said she had met her "soul mate" in this man, who had just spent his first hour with her as a therapist. "He knows exactly what is in my head and can say it better than I can", she said with relief and excited anticipation. At 29, she had begged for help, saying that she wanted to know why her brain shook in her head and why she acted the way she did. This was not the first time she had talked about evaluation. At 17, Loretta took Tanya's first two children in for diagnosis related to alcohol exposure in utero as she drank and had taken drugs during their pregnancies. During their diagnosis, she turned to Loretta and said, "I have this, don't I?" For the next several years, Tanya discontinuously considered the benefits of diagnosis for herself, interspersed with many attempts at counseling, dealings with child protective services, and medication experimentation (legal and not) related to a diagnosis of Bipolar Disorder that she received when she was 15, about the time of her first pregnancy, and of course, her inability to make healthy decisions on her own. She had several mental health and substance abuse treatments in her past in both inpatient and outpatient settings, one at 13 years old after her brother was killed and another at 18 while pregnant with one of her children.

Tanya and her siblings were removed from her mother's care when she was 2 years old. Tanya and her brother were adopted but the adoption failed due to fire starting and other out of control behavior. She was bounced from foster home to group home and back. She remembers stealing a horse in order to escape the unhappy environment of a group home. Tanya left school in the 8th grade after becoming pregnant. Instead of attending an alternative school, she opted to take the GED when she was 15 and passed the test. She had participated in special education from very early in her schooling. When she was 12, she was also diagnosed with Post Traumatic Stress Disorder due to a history of physical and sexual abuse, became emancipated at the age of 16, and lost her first three children to their father's families by the time she was 19.

Her lifestyle has been chaotic and dangerous, always filled with drama and failure and out of her control. In the last few years she has had several instances of self destructive behavior including cutting herself, an attempted OD on crack, and jumping off a building. She has had a number of outpatient mental health contacts and thinks that she may again need inpatient drug and alcohol treatment in order to get off marijuana and alcohol. She has been investigating a Native American treatment center where she will be able to keep her children with her and offers services that are geared toward spiritual Native American customs. She has been unable to maintain employment, or continue her education.

Tanya has a medical history that is significant for several serious head injuries from car accidents and violence. She says that she had difficulties with motor control, vision problems, and difficulties using tools effectively and felt very confused. She has a long history of sleep disturbance making it difficult to fall asleep, sometimes not until 3 am, and has difficulty maintaining sleep due to very active and disturbing nightmares. Her appetite has also been problematic for her over the years and she is self conscious about her weight, finding that she eats more during her depressed phases. She experienced one incident of seizures following over-dosing on crack. Tanya has a history of significant drug and alcohol use. She admits to having used alcohol, marijuana, cocaine, crack, crank, hallucinogens, ecstasy, and inhaling spray paint. Recently she admitted to using drugs including ecstasy in order to organize her house, cocaine, marijuana every other day and a fifth of hard liquor daily.

She has been raped several times by strangers, friends and family members. Prostitution, drugs and alcohol addiction, incarceration, depression and several suicide attempts tell her story. She has been the perpetrator of violence and she has been the victim. She experiences failed relationships with friends, family and lovers, and distasteful, unsuccessful interactions with social services all causing her to lose trust in systems and most people, even though she is very forgiving and eager to make new friends, forgiving family and trusting new service providers.

At 22, she was living with her boyfriend in a cheap motel on the fringes of a

metropolitan area. Waking up from a black out, Tanya found a note pinned to her sweater that read, “Call Loretta, she is the only one who can help you”. It was her handwriting. Loretta was awakened by the phone at 2:00 am. It was Tanya. “You have to save me”, she sobbed hysterically. At the time, Loretta was working on a Fetal Alcohol Syndrome project with the county health department. Tanya had frequented the Native American Street Youth drop-in center in the inner city when she was 13 years old. She had been in many placements, back and forth between family members and in and out of foster care. Her birth mother had 8 children by 8 different fathers and was only raising the last child. Tanya’s relationship with Loretta had been strong from the beginning, but disjointed because of her unhealthy lifestyle. “I will come and get you, if you will do whatever I say”, Loretta responded even though she knew Tanya’s reputation for being noncompliant. “If I say, stand on your head for two days, you will stand on your head for two days,” she said emphatically, knowing her words were not really being understood. Tanya moved in for a brief period, and was stabilized by the calm, structured, loving environment that Loretta created for her. She could not maintain that stability on her own, however. The experience brought them closer together and Tanya asked Loretta to become her mother even though her birth mother lived in the area.

Tanya and her boyfriend continued to ride their roller coaster together. They had both been heavily exposed to alcohol in utero and found a deep bond, feeling they had found true love, and their “soul mate”. In spite of these feelings and their desire to be together forever, they drank and drugged, fought but continued to be unable to negotiate the intricacies of establishing a healthy, long lasting relationship, which was their goal and prayer. At 25, they became parents to twins and revived the dream of being a “normal” family. Spirituality has sporadically been a powerful force in their lives. He expresses this as a powwow dancer; she loves participating in traditional Native American ceremonies like the sweat lodge. They both still possess many beautiful qualities. They can be kind, loving, forgiving, generous, and supportive. But, he isn’t faithful and she feels all the hurt of abandonment that has been her life experience. She can’t always control her rages or depression and he is left feeling attacked and unable to respond to her needs. They both feel like failures, trapped on a run away roller coaster fueled by

their organicity, always ending in a crash.

She wants to raise her children “normally”, and be the best parent she can be. Although her children were premature and have not met developmental markers, she claimed sobriety during this pregnancy. Ironically, her claim of sobriety kept her from being eligible for programs offering the support she need to be a good mother. “Where was the reward for making this right decision?” she exclaims. She is also hungry for independence and recognition for being a loving, caring, capable mother. People are beginning to seeing a certain level of maturation and her understanding of cause and affect seem to becoming evident in some of her decision making. Tanya recognizes that she needs help. With a circle of friends and providers, she is starting to understand her strengths and is identifying areas that require support.

Her recent request for evaluation led Tanya and Loretta to an expensive neuropsychological evaluation targeting adults who have been exposed to alcohol in utero. Here, she also finds someone she can talk to in spite of her initial feelings of mistrust and fear. In fact, she admits to drinking everyday again, feelings of suicide and other things that her mother was not aware of. Tanya is very good at creating a façade of normalcy, which is what has caused service providers to reject her appeals for help.

This evaluation, however, tore the mask off of any allusion of normalcy. Her scores were very inconsistent, disturbing and surprising to both of them. Even though her IQ is in the low average range with a score of 93 on performance, her equivalency scores were as low as 3 years, 11 months for her receptive skills; 7 years, 7 months for daily living skills, and 7 years, 10 months for her interpersonal skills. It is now wonder that she calls her mother to ask how to interact with her boys, when her ability to create play and leisure for herself is that of a child a few years older than the twins. It seems somewhat of a miracle that this young woman has survived as well as she has with the ability to understand what is being said to her of a 4 year old. It is no wonder that she can’t maintain relationships with her peers and other adults when she has an 8 year old’s ability to appropriately interact with others socially.

Today, Tanya still has custody of her boys, lives intermittently with their father, continues counseling, advocates for her children, forgets to take her meds, gets frustrated and tired from the rigors of motherhood, imagines a happy future for her and all of her children, fights with her boyfriend, makes and loses friends, finds unconditional love from her mother and on a good day, laughs and says, “Good times, good times”.

ADULTHOOD

Desired outcomes

- Recognize that apparent behavior may be masking a continuing lack of veritable developmentally appropriate behavior, even though maturation and skill building may seem to be established in certain areas
- Recognize and understand the common denominators of behavior and cognition still affecting this adult stage of development
- Identify and understand the shift in manifestations of an FASD as they are manifest in adulthood. Observe and be watchful for the impact of the secondary characteristics of isolation, depression and other mental health issues
- Understand the effectiveness of collaborative community services. View these "collections" of family and community support as a return to our traditional village concept or to our circle of care and compassion
- Understand the need to integrate Native and non-Native services from a culturally congruent context. Pull these seemingly disparate supports and resources together for the benefit of all

  Recognize that even though affected adults may begin to generalize, connect action and consequence and show other signs of maturing, especially in response to structure and intervention, they will continue to be in need of assistance and guidance
- Behavior can still be influenced by almost anyone or anything. Being a “moral chameleon” can contribute to success or failure
- Understand that common outcomes, especially without continuous intervention, are homelessness, incarceration and high rates of suicide and substance abuse
- Parents with an FASD may become parents of children with an FASD and in any case will need the assistance of supportive circles of care to parent

Adulthood

As in young adulthood, this stage of development can be relatively successful or disastrous and, as in the case of all stages of life for people with an FASD, success is dependent on continuous intervention. Ability, strengths, level of support and motivation all become determinants. This is also a time that many adults desire independence and a “normal” life. Living independently for many is certainly

possible but usually not without someone to provide consistency and guidance. Mental health issues may appear or worsen with explosive episodes and erratic “bi-polar like” mood swings with multiple frequency throughout the day. The early childhood insatiable need for praise and reinforcement can now manifest in outbursts about “never being appreciated” and “always being told what they are doing wrong”.

All the basic premises for intervention still apply, but the need for these interventions to be presented in an adult-like manner must be respected. The adult must increasingly be placed in a position of responsibility for selecting and controlling the interventions and strategies that will be most helpful to them, from their perspective. They should begin to emerge as partners and sometimes even directors of their own case management in the coordination of services.
Within the context of collaborative services and community support, the adult must continue to receive education and training. They must monitor, reinforce and extend their academic and/or vocational skills in an organized, structured and consistent way that supports their strengths. For instance, if an individual's strengths include sociability and compassion, a career in a helping profession (such as elder care, child care, or assisting people with special needs) may serve to promote their strengths and self-esteem because they are contributing members of their community.

For some adults, the impact of central nervous system damage or developmental delays may be profound enough that independent living will not be possible without supervised support. In this case, extended family members may be good candidates to assess when it is appropriate. For some parents, consistent, lifelong parenting classes and home visits may be adequate. For others, we must provide a continuum of support including proctor or supervised homes, not just as interim or transitional, but as lifelong settings.

This stage of life highlights the importance of relationships… marriage, parenthood and even becoming a grandparent. When fortune and fame are lost, we all recognize that ties to our friends, family and community are more valuable than any material item or accomplishment, yet often, the affected adult finds him or

herself unable to make new friends or maintain relationships in any area of life. They may experience periods of connection but often they are short lived. Some adults do find happiness, usually with someone or in a setting that offers structure, unconditional love and respect.

ADULTHOOD

Characteristics may include:

- Developed skill areas in visual arts, fine arts, music, creative writing, storytelling and participation in ceremony and ritual
- Enjoyment of opportunities to deliver care and compassion, such as peer mediation, childcare and instruction of young children or children with special needs, or elder care
- Continued gullibility and vulnerability, placing them at risk for exploitation, sexual abuse and substance abuse
- Codependent behaviors and desire to "fix" things that can lead to poor relationships or at risk for future domestic violence
- Need to "get love," increasing the chance of pregnancy
- Academic failures and frustrations may cause them to drop out of college or technical training institutes
- Poor vocational or job skills. Inappropriate placement with unsupportive employers may create failed job settings
- Victims of sexual abuse without therapeutic intervention may begin perpetrating similar acts
- May engage in suicidal ideation or actual attempts at suicide
- May engage in and lose self in fantastical thinking and lose consistent sense of reality
- May begin or increase addictive behaviors, including substance abuse. May not sustain recovery when placed in treatment settings, thus exhibiting cycles of recovery and relapse
- A concrete need for sense of independence accompanied by holes or gaps in development and maturity sometimes collide and disrupt any attempt at consistent structure within home, work and community settings. Depending upon life experience, a landscape of failure may predict difficulty in believing

there is a reason for following through

- Adults with an FASD say:
  - Remember my ability and desire to be social makes this my strongest link to learning
  - Engage with me and I will do anything to please you
    If you don't respond to me I will think you don't like me and I will quit trying
  - Remember I am wired to be extremely sensitive
  - Remember I am extra sensitive to my environment and I have a hard time not being distracted
  - Please keep lights and sound low
  - Please help me have an organized, structured and quiet place to work
  - Please don't seat me at group tables and expect me to focus on anything except socializing
  - Please show me what I'm doing right so I can do more of it
    I feel frustrated and like a failure a lot of the time…so giving up is easy, following through is hard

ADULTHOOD

Intervention strategies

- **Environmental strategies** promoting memory and information processing
  - Establish an adult as his or her own "supported case manager" and the coordinator of his or her services. Do this through support and careful transition of responsibilities over a period of time with the past case manager
- **Behavioral strategies** promoting social and emotional development
  - Reinforce and provide frequent opportunities for the young adult to perform and "shine" in areas of strength and skills (e.g., drama group leader, artist painting murals on community buildings or worker at child care center)
  - Reinforce positive relationships
- **Educational strategies** promoting cognitive development
  - Provide opportunities for job placement with elder care, child care centers, and special needs services-providing the young adult has no history of aberrant sexual or violent behavior

- Be prepared to train and coordinate with vocational services that place and provide training at job sites that employ people with special needs
- Assess educational placement opportunities. Do not assume that higher education is inappropriate. Explore junior colleges, trade schools and four-year colleges in addition to mentoring and shadowing positions with para professionals in social work, child development and other social services

❖ **Community strategies** promoting culturally congruent, holistically integrated service delivery

- Offer an in-depth, culturally and cognitively tailored menu of mental health therapies and drug and alcohol treatment, if needed, for the person whose environment has a history of chaos, drug and alcohol abuse or multiple foster placements
- If drug and alcohol treatment is indicated, seek a placement in a culturally appropriate residential treatment setting that restructures its curriculum for persons affected by fetal alcohol exposure. Further, insure that this treatment setting can be long-term (60-120 days), and has a relapse prevention component that can extend outpatient and home visit services for a minimum of two to five years. Involve extended family and community members in this process
- Continue to reinforce and support (e.g., by providing transportation) consistent involvement and participation in ceremony and religious/spiritual gatherings
- If appropriate, involve the young adult in a community support network for children and families newly diagnosed

10 Older Adulthood and Elder (50 years and older)

- Story -

After the F.A.S.D. presentation, he came up to the speaker, hanging back behind the others. He fidgeted until anxiously and expectantly his words burst forth, "I am that thing you're talking about. I know I am because you just described me…you just explained me better than anyone else ever has. I knew I wasn't stupid, just unsuccessful in what I try to do. Now I know why and what I can do. This is my 17th time at treatment…if that doesn't mark me as a complete failure, I don't know what could."

At 72, he seemed a bit old to have been affected by prenatal exposure to alcohol…most people with an F.A.S.D. seem to have been born after World War II when mothers had started working in the shipyards or away from home with strange new exposures and experiences moving female use closer to the males. With these background thoughts the presenter, an F.A.S.D. specialist responded with, "Well, 17 times in treatment says much more about your sticking with something than it does about you being a failure…you must have a powerful motivation to keep coming back all these years."

"I do, he answered. I have three children and seven grandchildren and my children won't let me be with my grandchildren until I'm sober…I'm afraid I'm going to die before that happens…is there hope? Can anyone help me, really?"

Building on the strength of his motivation, a new treatment approach began with assessments, screening and diagnosis that revealed both the consequences of his prenatal exposure to alcohol and his many years without appropriate intervention and strategies generating secondary characteristics and mental health issues resulting in school failure, lost jobs and brief periods of incarceration. Against this landscape littered with grief and loss, blame and shame, he had persevered, however erratically with his dream of family, but always it was barriered with failure and the low self esteem that stunted every stubborn attempt to break through the hurt and trauma that seemed to paralyze every possible positive action until enough alcohol could numb the hurt away.

Looking at the precious but fragile hope with which he left treatment each time he began to see what the staff helped him to identify as “triggers” and realized that when his “old buddies” would come once he was back home he couldn’t resist their pull. Friends since they were young, were “always there for each other” and as soon as he would get home from treatment they would be on his doorstep wanting to celebrate his return. Usually he would tell them that he couldn’t celebrate but then they would say, “Fine, suit yourself, but you’re going to be awfully lonely when you don’t have any friends.” Then he would be out the door following them to the next drink to secure their enduring friendship.

So this new treatment plan focused on this scenario and scripted and role played a new response in which he would have food and a movie ready for his friends. When they arrived he would invite them in to his sober “celebration”. In addition to this small group role play his treatment plan increased his individual counseling sessions and time with a mental health therapist to address the overlay of secondary characteristics. The new plan also included work with the F.A.S.D. specialist to identify and strategize learning techniques that would increase his memory and ability to process information. General large group lectures and discussions were dropped from this plan to allow for more time for these individual and small group sessions and to permit the additional sleep time so critical to individuals with an F.A.S.D. who have to expend so much energy to deal with the cognitive sensorial frustrations borne of their neurology.

Returning home after treatment he employed his new skills and enacted his new scenario. His friends came and though some what puzzled by his new domesticity started using those nights for card playing and acknowledging that he did seem happier. Tentative at first his family did not immediately respond with the reward of time with his grandchildren. This was hard but eased through frequent home visits by outreach counselors who helped him understand the roots of his children’s mistrust, and perhaps most importantly, to help him build patience with the process.

In time he had his reward and now ten years later his children argue over with

whom he gets to stay with the longest and two of his three buddies have joined him in sobriety.

Clearly it is never too late to have hope.

Older Adulthood/Elder

The burden of prenatal exposure is profound and life long. This developmental stage reflects a population largely unidentified and undiagnosed and therefore having received few interventions. For many the landscape of their life is littered with trial and error and an ever-increasing sense of alienation and failure. Secondary characteristics borne of their unsuccessful interactions with their environment may produce profound depression and/or addictive behaviors. Some may have inherently understood their processing and memory needs such that they have structured some effective survival skills around visual learning and retrieval.

The presence of an F.A.S.D. at this stage of development identifies not only the physical, cognitive and social emotional impact of prenatal exposure to alcohol but may manifest in complicated and significant impairment resulting in mild to severe mental health issues.

Interventions for this stage must generate from a foundation that understands the often exhausting permeation of the global impact of an F.A.S.D. on people of this age. Identification of components for motivation and hope are essential to producing desire and momentum for change. Strategies that draw on the older adult or elder in a position of sharing their identified skills will be most effective. In addition these older adults and elders benefit and produce benefit when woven into prenatal strategies that can increase the frequency and duration of home visit prevention models.

OLDER ADULTHOOD/ELDER

Characteristics May Include:

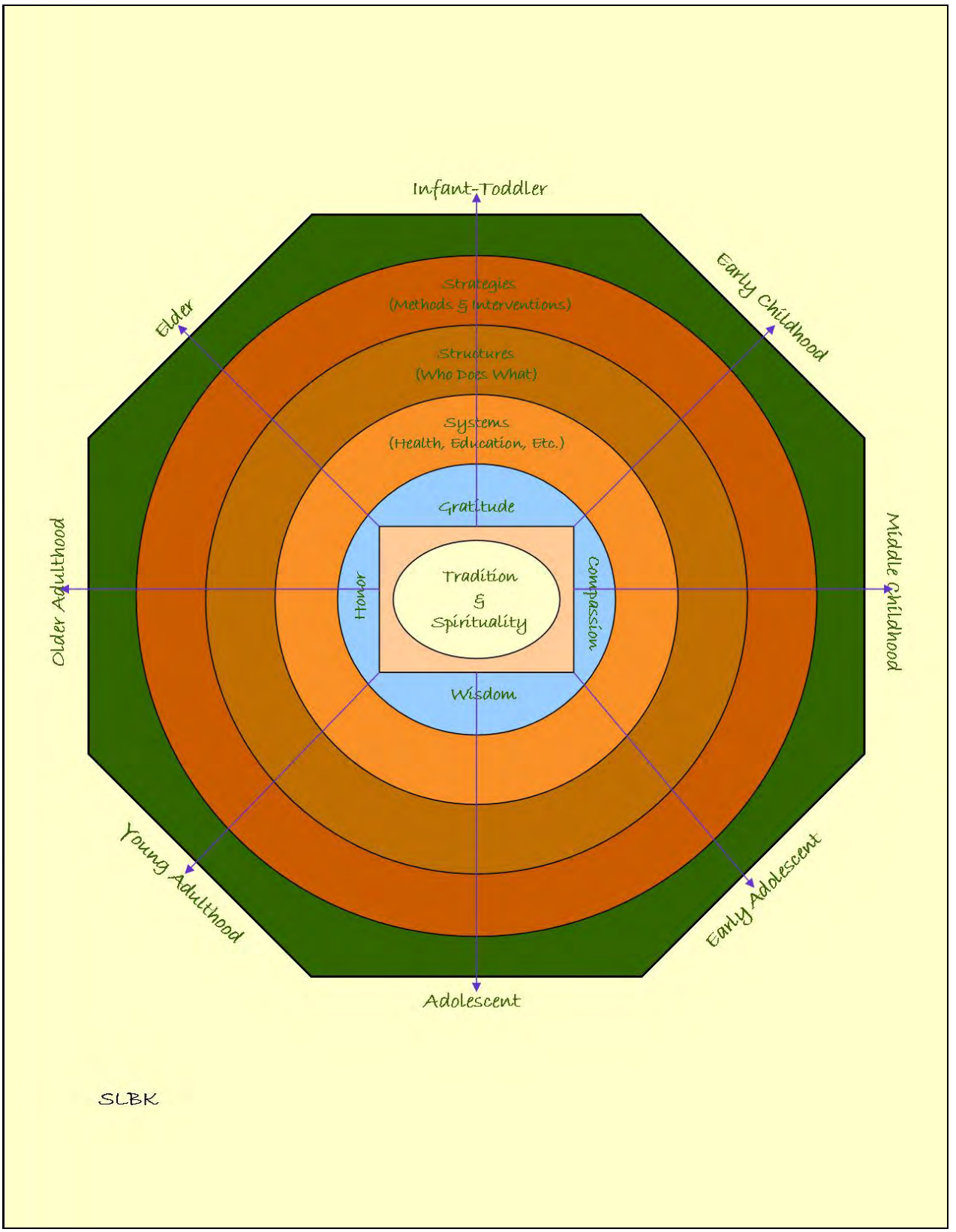
- Developed skill areas in visual arts, music, creative writing, story telling
- Leadership or helper roles within cultural and spiritual settings
- Marked increase in memory defects
- Marked increase or decrease in sensorial response to light, sound, touch
- Disorientation of time and place
- Increased or decreased erratic emotional behavior fueled by decades of frustration and failure
- Increase or decrease of substance abuse, but unable to achieve and sustain recovery
- Profound sense of isolation

OLDER ADULTHOOD/ELDER

Intervention Strategies

- **Environmental Design Strategies** promoting memory and information processing and support
  - Review and modify as appropriate current living setting using Public Health or Community Health Services
  - Facilitate visual structure and organization of home or elder care setting. Sort and categorize elements of physical/material environment to reinforce conceptual retrieval and habituates
  - Provide visual and/or tactile prompts for safety in living setting (lights, heat, cooking, etc.
  - Provide visual and or tactical prompts for consistent medication use
- **Behavioral Strategies** promoting social and emotional support
  - If appropriate, engage in long-term (90-180 day) treatment setting that is holistic in its culturally congruent delivery of cognitively re-tailored and integrated mental health and treatment therapeutic strategies that:
    - Identify and use successful, existing skills and motivation to form strengths-based approach
    - Increase individual counseling sessions structuring concrete plans with specific steps
    - Script and role play appropriate response to negative triggers
    - Identify positive extended family or social supports and integrate within context of residential treatment setting
    - Provide incremental transition steps back into community and living settings
  - Identify, review and deliver health screening that may indicate specific medical interventions. Develop new health plan that understands the increased risk for a person with an F.A.S.D. to have organ compromise, diabetes, joint and skeletal malformations. Also insure that the wellness
  - plan includes frequent and consistent sleep and/or nap opportunities
  - Provide and engage in opportunities to “mentor” or “buddy” in community Program such as prenatal support and early childhood education
    - Facilitate appropriate role by providing training and support

- **Educational Strategies** promoting cognitive support:
  - Engage in problem solving games and activities
  - If appropriate introduce and engage in development of computer communication skills
  - If appropriate engage in early childhood programming and curricula
  - If appropriate engage in story telling opportunities
- **Community Strategies** promoting culturally congruent, holistically integrated service delivery
  - Involve in community gatherings as organizers, coordinators, story tellers, as well as participants
  - Review and modify all services for structure and integration producing a Cooperative Circle of Care
  - Identify family and community natural support systems


Infant-Toddler
Early Childhood
Middle Childhood
Early Adolescent
Adolescent
Young Adulthood
Older Adulthood
Elder
Strategies
(Methods & Interventions)
Structures
(Who Does What)
Systems
(Health, Education, Etc.)
Gratitude
Honor
Compassion
Wisdom
Tradition
&
Spirituality
SLBK