A PRACTICAL NATIVE AMERICAN GUIDE FOR PROFESSIONALS WORKING WITH CHILDREN, ADOLESCENTS, AND ADULTS WITH FETAL ALCOHOL SYNDROME AND FETAL ALCOHOL SPECTRUM DISORDER

By

Robin A. LaDue, PhD

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Dedication

In the past, I have dedicated my works to those patients with FAS and FASD and their families who have taught me so much and have been guiding forces in my life. This book, however, is dedicated with deep love and gratitude to the one person who has stood beside me for the past twenty years. It is trite, but in this case, very true: there are simply no words of thanks that say enough to this person. So, in the best words I can find, this manual is dedicated to my husband, Marshall Bruce Harmon, who stuck to his vows of “Until death do us part” and back again.

Acknowledgments

Over the course of the past five years, it has been my great pleasure to work with Dr. Marlene Echohawk of the Indian Health Service. It is through her dedication to Native children and their families that this venture has been brought to fruition. No one person creates a work such as this on their own. There are, literally, hundreds of people who have contributed to this effort. While only a few can be named in these pages, this does not lessen the appreciation I have for all who have given so generously of their time and support.

Special thanks are owed to the hundreds of people that have shared their lives with the author for nearly twenty-five years. Without their courage, perseverance, and humor, none of this could be written. This is also true of a group of very special people in my life: Dr.'s Sterling and Sandy Clarren, Sharon Beck, and Julie Gelo. Love and thanks go to my nieces, Traci, Sydney, Taylor, Shannon, Jensen, and, most of all, to my beloved aunt, Lucile LaDue. A special thank you to Dr. Mary Butcher for ensuring I survived long enough to write this book.

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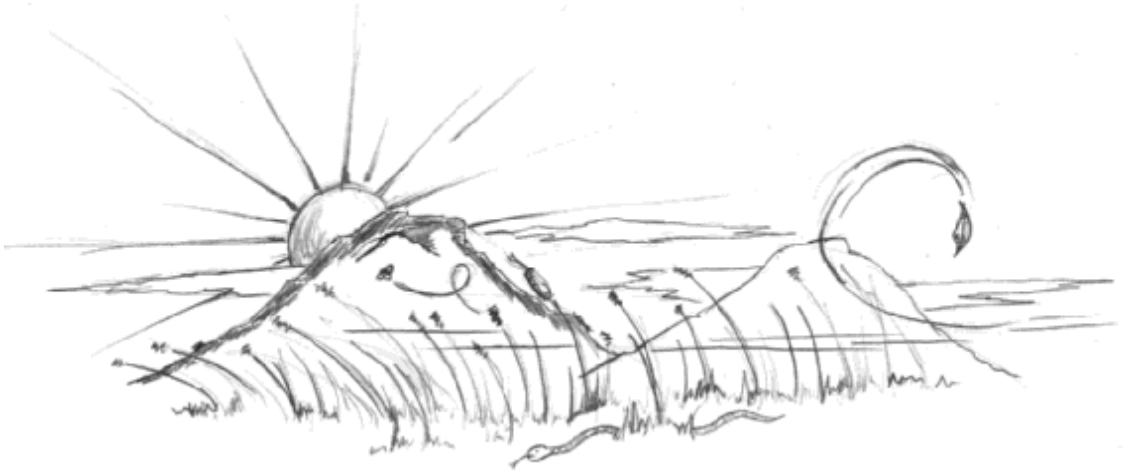
Prologue:

Coyote and Raven

From the time before, Coyote and Raven had watched their village. The summer winds blew sweet with the smell of grass and bees and snakes. The People gathered food for the coming winter. They worked together as one to ensure all survived. Coyote and Raven watched as winter came and the people moved inside to the warmth of their fires. Stories were told, songs were sung, people danced and prayed and they all worked together as one. The Old Ones were listened to and their wisdom valued and used. The Council of Elders gathered on many occasions to discuss problems and provide resolution to concerns.



The women taught their daughters about having healthy babies. The men taught their sons about being good fathers. The People worked together as one. Coyote and Raven watched as winter moved into spring and the little ones learned and grew. They watched as summer drifted into fall. The little ones of the village laughed and learned to help each other. Coyote and Raven talked with the Old Ones and passed on the ways of sharing and never using more than what was needed. And so, the years passed for countless generations and it was good.

Then, slowly, darkness and sadness began to creep over the land and the village. The Old Ones started disappearing. The little ones did not run and laugh as much. Their parents seemed sad and slow and neglectful of the old teachings. A sickness had come to the People. It came in bottles and cans. The ways of praying and preparing for the winter were lost. The sickness touched everything and everyone in its path. It brought anger and fighting, violence and despair.

Coyote and Raven watched as the village began to wither and die. It seemed an endless winter had come to the People. Coyote and Raven still spoke with the few Old Ones left who knew how to talk with the animals and trees, rocks and rivers, fire and rain. The Old Ones knew that the cause of the sickness was sadness, hopelessness, and grief. The Old Ones knew the loss of the old ways had opened a hole in the souls of the People. They knew that the sickness of alcohol had come to be used by the People to fill the emptiness in their souls. Instead, it was destroying the People, one at a time.

Watcher Woman, one of the Old Ones who knew the ways, came to Coyote and Raven one cold winter day to tell them of the spirit sickness that was hurting her village. She invited them back to her tiny house. The three of them sat by the fire and warmed their toes. Both Watcher Woman and Raven admired the fullness of Coyote's winter coat. It was so inviting, that at one point, Raven hopped down to wrap himself in the curl of Coyote's tail! Watcher Woman smiled at the antics of her two friends. Then, her face grew solemn and, with a heavy sigh, she asked her friends for help.

"Many years ago, alcohol came to our village. We three have watched the results. We have watched over and tried to help many of the young ones born to parents with spirit sickness. We have tried to help their children born with Fetal Alcohol Syndrome. But still, spirit sickness is here. We need to try something different. We need to rebuild some of the old ways.

"My People are dying," she said. "I cannot let this happen. I need a brave one to go to the city, to the places where there is learning and healing. I am asking one of you to go among the humans in the city. You are both known as Tricksters. I

know you to be smart and brave. Both of you know how to survive in even the hardest places, even in the big cities. I ask this for the sake of the People. Will one of you help us?"

Raven hopped up on the arm of the chair where Watcher Woman sat. His bright black eyes were shining with intelligence and a keen knowledge of the World.

"I will go," he answered. "People still fear Coyote. They feel anger when they see him. It will be safer for me to make the journey. Coyote can stay with you and watch our village. I will go, Watcher Woman, and seek the information and help you ask.

"I remember when I went before. There was a place of learning I visited. I can find it again and learn more. Maybe the knowledge I can gather will help our People.

"We know of two in the village who have been affected by spirit sickness. They have often been taken to the city for help. I have heard them speak of this place

they go. I have watched their travels. It is the place of learning where I went before. I will go with them next time they leave the village to go to this place. ”

With those words, Watcher Woman leaned back in her chair, sighed, and smiled. “Thank you, my dear friends. Now, let us enjoy the fire and watch the snow as it falls outside our snug little house. ”

The next morning, Coyote and Raven left the warm home of Watcher Woman and began to explore the streets of their small village. After observing the people walking along the roads of the village, Coyote and Raven spied two young adults they both knew had been affected by alcohol. These two young people were twins, one named East Light and his sister, named Shining Eyes. Held by both her hands between her mother and uncle was a five-year-old girl, Spring Song.

It was these two young people that Coyote and Raven had watched come into the World twenty years before. These young people had been exposed to alcohol while carried in their mother’s womb. Alcohol had played a devastating role in their young lives. In their twenty years, East Light and Shining Eyes’

parents had gone out of their lives. Their aunt and uncle had raised them. Watcher Woman, too, had been part of their lives as they struggled to overcome obstacles, misunderstandings, and hard times. She was there to celebrate their successes, joys, and growth.

When the twins were about five, their aunt and uncle had recognized many of the problems they were having. With the help of Watcher Woman, they had gone to the city to the place of learning Raven spoke of. There, the family learned of the difficulties and struggles that can occur from prenatal alcohol exposure. It was to this place of learning that Raven had volunteered to go once again.

He and Coyote watched as East Light and Shining Eyes, along with Spring Song and Auntie and Uncle, climbed into a car and began their journey into the city. With a loud caw-caw, Raven bid Coyote farewell and took to the air, following the car. After hours of flying, the car pulled into a parking lot behind an enormous building. Everyone climbed out and went inside.

Raven, trying not to lose sight of the group, flew to the ground and waddled in the door behind Auntie. There was a stout lady sitting at a desk right in front of the door. She smiled at East Light and Shining Eyes and pinched Spring Song's chubby cheeks. She did not notice the large black bird scuttling down the hallway at the heels of Auntie and Uncle.

At the end of a long hall, another door was opened by a smiling man in a white coat with a moustache and funny piece of cloth at his neck. Metal hung out of a pocket of his coat. He greeted the family warmly and invited them inside. Quicker than Raven could move, the door shut with Raven left on the outside. Now what was he to do?

Raven need not have worried. As he sat there, a young woman, also in a white coat, came scurrying down the hall carrying a box. The door swung open. Raven, close on the heels of the young woman, dashed into the room. He stopped in surprise. He had expected only the family and the man in the white coat. What he saw was a large table at which at least a dozen people sat!

Now, Raven was worried that he might be seen and chased from the room. As quietly as he could, he walked under a line of chairs against a wall. The other people in the room were men and women of many ages. They were intent on listening to what the man in the white coat was saying as he stood at the front of the room making marks on a board on the wall.

As Raven hid under the chairs, he noticed a window at the back of the room. Making himself as small as possible, a difficult task for a very large bird, he flew to the window and began to walk on the ledge. Then, as with the others in the room, he listened to the man in the white coat. In a short period of time, Raven realized that he was seeing a collection of special people gathered to help East Light and Shining Eyes, much as the council of elders came together in the past to help the People of the village.

The man in the white coat with salt and pepper hair was a special doctor who looked at East Light, Shining Eyes, and Spring Song's faces and hands. He measured how tall they were, how much they weighed and the size of their heads. Two other people in the room talked to Auntie and Uncle. They asked questions about how well the twins and Spring Song had done, their successes and their problems. Other people in the room talked to the twins. They gave

them special tests to do and listened to how they talked. They asked the twins about their lives and things they wanted to accomplish.

Raven hurried from ledge to ledge, trying to take in and remember all he heard and saw. There were strange names given to the people in the room: psychologist, speech therapist, speech pathologist, occupational therapist, educational specialist, family advocate, social worker, dysmorphologist, epidemiologist, pediatrician, legal aide, case manager, dentist, nurse, and physical therapist.

Raven had never heard so many strange words. Did these people have other names? Only later in the day did Raven realize these were not names like Raven or Watcher Woman. They were titles that described the type of work or activity the people around the table performed. Raven was amused. It seemed that humans would do anything they could to complicate even the most simple of situations! However, what Raven heard brought him both fear and joy. He could see that Auntie and Uncle, East Light and Shining Eyes were all hopeful and overwhelmed by what they heard.

At the end of several hours, the man in the white coat gathered everyone back around the large table. “Today,” he said, “we have met for our second time. The first time was fifteen years ago. How quickly the time has gone. Now, East Light and Shining Eyes are grown and the time has come to make decisions about how they will live their adult lives.

“All who are gathered here are helpers. We can answer your questions as best possible, give you suggestions and the names of people here in the city to talk to that can help,” the man in the white coat said.

“But,” he added, “You will need help and support when you return to the village. For that, we do not have much to offer. ”

At these words, Raven understood his purpose in coming to this place. It would be his job to help rebuild the council of elders in the village. How was he to do this? His tail feathers drooped in frustration as he pondered the situation. He was thinking so hard, he almost failed to notice that the family was saying good-bye and leaving the building. Raven quickly flew to a tree near where Uncle had parked the car. As the family got in the car and drove away, Raven, once more began to follow.

This time, after only a short drive, the car stopped and everyone got out and went into a small house. There, a woman of many years greeted the family. She took East Light and Shining Eyes into a room and spent some time talking to them. Raven searched in vain for an open window through which he could listen. Finding one, he took up his place to listen.

Soon, the family drove off again, this time to a group of large buildings. Raven flew to each building and sought out a place from which he could watch and hear all that went on. Finally, at the end of a long day, after several more stops and meetings, the family drove home. Raven was exhausted from flying around the

city and following the family and listening to what all the various helpers had had - to say. -

As they started the journey home, all but Spring Song failed to notice a large, tired Raven sitting on a wire as the car passed. Spring Song giggled as the dusty black bird cawed loudly and flapped his wings in greeting. She had watched the big bird as he had watched the family. Only she seemed to realize that Raven was there to learn. She giggled in such a way that her mother stopped her conversation and asked her daughter what made her laugh in such a delightful manner. This made Spring Song laugh more!

As the family drove out of sight, Raven swung on his wire for quite some time. “I have much to tell Watcher Woman and Coyote,” he mused. “Yet, I still do not know all I need to help our special souls. I will stay here in the city and see what I can learn. I will come back to the places of learning every day. I have an idea that those people were like our council of elders. But, I still do not know what to do to help. ”

“Well”, he sighed. “It is time for food and sleep. I will try again tomorrow. ”

Far off, the family drove back into the village. Sitting near the road at the start of the village was a brown Coyote, looking intently at each car that drove by. He came to attention when the family drove past him. Only the small girl inside noticed the attentive animal. When no Raven appeared above the car, Coyote lay down, his head on his paws, his ears twitching, and worried about his feathered friend.

Day after day, week after week, month after month, Coyote waited for his companion to return. In the village, the family continued their lives. More children were born with the same types of problems as East Light and Shining Eyes. More children lost their families to spirit sickness, the disease of alcoholism. More and more of the old ways disappeared. More and more, Coyote worried for his People in the village and for his large black feathered friend.

It was after the family made another trip to the city that Coyote, sitting on the porch of Watcher Woman’s tiny home, saw a black speck wheeling in the sky at sunset. It was Raven returning home at long last.

“I have many stories to tell you and Watcher Woman”, Raven sighed, “stories of hope and fear, stories of help and neglect, stories of joy and sadness. We have much to do. We need to rebuild our council of elders. We need to teach the People how to help our special souls. ”

“Yes”, Raven said, “we have much to do. ”

He cawed loudly and many times. Coyote joined him, howling in chorus with Raven. No one, however, in the village noticed or understood what they were saying, no one that is, but an old woman with a sweet smile and a tiny child with old eyes and dimples.

Introduction

Parents see their children in terms of their needs for any specific service, e. g. psychosocial needs, health issues and those needs at any certain time in their lives. Professionals see children in terms of their own specific domain, e. g. psychology, medicine, social work. My job, as a family advocate, is to be the spot where those two lines converge and can be incorporated.

- Julie Gelo, Family Advocate FAS-DPN, 2002

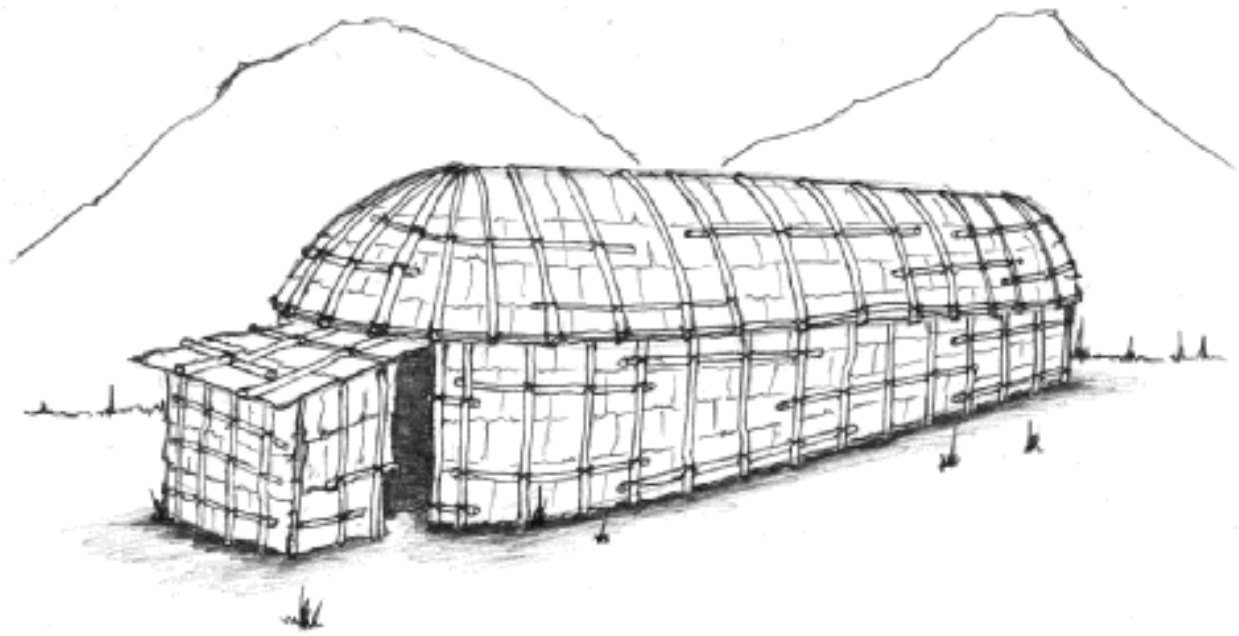
The primary roles of professionals working in the field of Fetal Alcohol Spectrum Disorder (FASD) are diagnosis, treatment, advocacy, facilitation, and support. Along the way, planning for the future and program development may also be included. These roles are similar to what was expected and provided by the council of elders and leaders in traditional Native communities. This manual is the companion to A Practical Native American Guide for Caregivers of Children, Adolescents, and Adults with Fetal Alcohol Syndrome and Alcohol Related Conditions.[1] That manual was written in a developmental manner, addressing needs, concerns, and interventions by specific ages, ultimately reaching across the lifespan. This manual is organized, as Ms. Gelo suggested, by specific domains that are addressed by professionals. Within each of these domains, the concerns and needs for that domain are addressed, where appropriate, in chronological order. This manual is intended to provide an overview of FAS and FASD and act as attendant guidelines for professionals working with this special population.

A Brief Historical Overview

In traditional American Indian and Alaska Native cultures, there was often a group of elders who took responsibility for making decisions in the community. The years of experience and knowledge resting in the elders was respected and used for

[1] LaDue, R. A. A Practical Native American Guide for Caregivers of Children, Adolescents, and Adults with Fetal Alcohol Syndrome and Fetal Alcohol Related Conditions. Rockville, MD: Indian Health Service, 2000.

ensuring the health of the entire community. In some communities, there was a leader for hunting, one for planting, one for fishing, one for healing, and one for commerce or trade, to name but a few.[2] In times of conflict, a council of elders would meet, discuss problems and concerns, and arrive at solutions. Knowledge flowed from one generation to another, as the rivers flowed and the seasons moved from one into another.



Life had been lived in this manner for many generations. After the time of contact, life changed drastically in Native communities. Disease, displacement, war, and governmental policies all contributed to dramatic alterations in the lives of Native people. Disease led to the decimation of communities, removing through death the elders and keepers of wisdom. The imposition of boarding schools disrupted language, traditions, healing, and culture.[3] The consequences of these disruptions have been detailed in thousands of articles and books. They include, but are not limited to, alcoholism, depression, violence, loss of parenting skills, and in the

[2] Vogel, V. J. American Indian Medicine (Civilization of the American Series). Vol. 95, Norman, OK: U. of Oklahoma Press. - 1990. -
[3] Mihesuah, D. A. American Indians: Stereotypes & Realities. Atlanta, GA: Clarity Press, 1997. -

present case, Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorder (FASD).

There is a caveat that needs to be stated at this time. There has often been a tendency to see all American Indian and Alaska Native people as one with the same traditions, religions, languages, and issues. In reality, there are hundreds of historical tribal groups. With legislation passed in the twentieth century, the legal tribal entities changed form.[4,5] The diversity and richness of American Indian and Alaska Native culture, despite the attempts at eradication, exists to the present day. In many communities, these traditions have formed the basis for a renewal of pride, sobriety, and rebuilding families.[6] It is important, in reading this document, that stereotypes and myths are not the basis of beliefs and practices.

This is particularly true regarding the use of alcohol in Native communities. There is a perception that all American Indians and Alaska Natives drink . In actuality, the consumption of alcohol varies greatly from group to group and community to community. Some studies find over half of all Native people do not drink at all. [7] This fact is very important in early identification and assessment of Native children, adolescents, and adults with FASD and for all Native children. It should not be assumed that all Native children with a learning problem, small size, behavioral problems, or a combination of these factors have FAS or FASD. A thorough history, including prenatal alcohol exposure, should be done with every child who is referred for the types of services discussed in this manual.

While stereotypes should not form the basis of assessment and identification, there are generalizations that can be made regarding traditional Native history.[8,9,10] In many, if not most Native communities, experience and tradition, family and

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[4] DeLoria, V. ; Wilkins, D. E. Tribes, Treaties, and Constitutional Tribulations. Austin, TX: University of Texas Press, 2000. -
[5] DeLoria, V. American Indians; American Justice. Austin, TX: University of Texas Press, 1983. -
[6] Bataille, G. M. and Sands, K. M. American Indian Women: Telling Their Lives. Lincoln, NE: U. of Nebraska, 1987. -
[7] May, P. A. "The Epidemiololgy of Alcohol Abuse Among American Indians: The Mythical and Real Properties. " American - Indian Culture and Research Journal. 18: (2), 1996, pp. 121-143. -
[8] Miller, J. American Indian Families (True Book) Danbury, CN: Children's Press, 1997. -
[9] Arbogast, D. (Ed.) Wounded Warriors: A Time for Healing Omaha, NE: Little Turtle Publications, 1995. -
[10] LaDue, R. A. "Coyote Returns: Twenty Sweats Does Not an Indian Make. " Women in Therapy. 15 (1994) 93-111. -

knowledge, were factors in determining who would be leaders. Children and adults with birth defects and problems were not shunned. Often they were viewed as people with gifts and valued for their special knowledge. This is a very different view of abilities and disabilities than is frequently held in contemporary communities.

In summary, the history of American Indians and Alaska Natives has often been one of cultural, community, family, and personal trauma and disruption. This disruption has come from the loss of life through epidemics, war, and the ravages of alcohol. Many, if not most, tribal groups were displaced onto land that was not traditionally theirs. In many situations, historical enemies were placed on the same reservation, leading to present-day political issues and conflict.

Due to the loss of traditional food sources and the implementation of other governmental practices, many Native people starved and were forced to change from a subsistence diet to commodities. The latter diet has frequently been associated with increased rates of diabetes and other health issues.[11] In addition, the loss of the family support through termination of reservations, relocation to cities, and boarding schools has led to emotional and spiritual devastation. All of these factors have led to increased levels of alcohol use, violence, physical and sexual abuse, and loss of Native children. A consequence of the increased alcoholism rates has been the appearance of Fetal Alcohol Syndrome in Native communities. All of these factors must be considered in working with Native individuals and families affected by Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder.[12]

Fetal Alcohol Syndrome: A History and Diagnosis

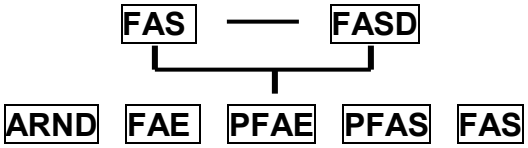
Stereotyping is not just an issue with Native people. There are also many stereotypes around people who drink, and around children, adolescents, and adults with FASD. As with any group of people, those with FASD are diverse and complex.

[11] Hutchison, S. H. "A Minority Under the Microscope: The American Indian Reaction." -
[12] Bataille, G. M. and Sands, K. M. American Indian Women: Telling Their Lives. Lincoln, NE: U. of Nebraska, 1987. -

The effects of prenatal alcohol exposure can range from memory problems and attention deficits to severe physical malformations and profound mental retardation.[13,14,15] It is important to ensure that any and all intervention and treatment programs are tailored for the individual versus taking a "cookie-cutter" approach.

The University of Washington in Seattle, Washington, is where FAS was first identified in 1973.[16] Over the past nearly thirty years, there have been many changes in the terms and criteria used to assess and diagnose people possibly impacted by prenatal alcohol exposure. The terms commonly used have included: Fetal Alcohol Syndrome, Fetal Alcohol Effects, Alcohol-Related Birth Defects, Alcohol-Related Neurodevelopmental Disorder, Probable Fetal Alcohol Effects and Syndrome (See Figure 1), Static Encephalopathy, Alcohol Exposed, and Fetal Alcohol Spectrum Disorders. For the purposes of this manual, Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorder (FASD) will be used. These are medical diagnoses and should be made only by a qualified physician.[17]

Figure 1
FAS / FASD Relationship
Changing Terms Across Time[18]

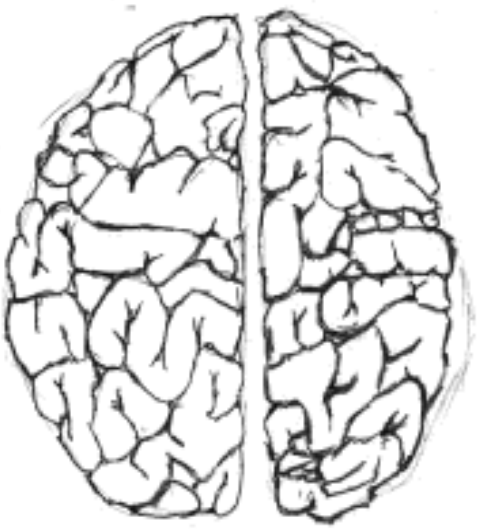


[13] Carmichael-Olson, H. "The Effects of Prenatal Alcohol Exposure on Child Development. " Infants and Young Children. 6(3) - 1997, 10-25.
[14] Carmichael-Olson, H. , Sampson, P. D. , Barr, H. M. , Streissguth, A. P. , and Bookstein, F. L. Neuropsychological Deficits - in Adolescents with Fetal Alcohol Syndrome. (Tech. Rep. No. 96-17). Seattle, WA: U. of Washington, 1996. -
[15] Institute of Medicine Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment. Washington, D. C. : - National Academy Press, 1996.
[16] Clarren, S. K. and Smith, D. W. "The Fetal Alcohol Syndrome. " New England Journal of Medicine 298 (1978) 1063-1067
[17] Astley, S. J. and Clarren, S. K. "A Fetal Alcohol Syndrome Screening Tool. " Alcohol. Clin, Exp. Res. 19 (1995) 1565-1571.
[18] Thank you to Alan Willoughby for his contribution.

It is recognized that it is likely Native American women who use alcohol also use other substances such as tobacco, cocaine, or methamphetamine. FASD is the focus of this manual and this term will be used to describe issues that may be a combination of alcohol and drug related issues.

In 1997, a formalized diagnostic categorization system was implemented. The criteria for diagnosing Fetal Alcohol Syndrome are as follows:

- Growth deficiency, at some time in the life span, in three areas: height and/or weight and head circumference.
- A specific pattern of facial abnormalities including small eyes, a long, smooth philtrum, and a thin upper lip.
- Brain damage including: mental retardation, attention deficits, behavioral and learning problems, microcephaly, and abstracting difficulties.
- Confirmation of prenatal alcohol exposure.



6 WEEK OLD "NORMAL BRAIN"

6 WEEK OLD "FAS BRAIN"

Each of these categories is rated on a 1-to-4 scale with 4 indicating significant deficits in the first three areas listed and with significant alcohol exposure. It is possible to have brain damage and confirmed prenatal alcohol exposure along with behavioral problems in the absence of the growth retardation and facial abnormalities.[19]

There are two other categories examined in the Fetal Alcohol Syndrome-Diagnostic and Prevention Network clinic approach. These are prenatal and postnatal factors. Prenatal factors of concern could include polysubstance abuse, physical problems, or illnesses on the part of the mother. Postnatal factors might include early childhood trauma, multiple living placements, neglect, abuse, and loss of family. [20] Too often, these factors are present. They will frequently determine what types of clinical services will be needed for the children and the mother and other family members.[21] Hopefully, the information contained in this manual will be of aid in identifying, screening, referring, and providing appropriate support and treatment.

There are a wide variety of effects possible from prenatal alcohol exposure ranging from the full Fetal Alcohol Syndrome to a lack of physical effects but with significant behavioral problems. That is the purpose for the 4-point code. This code allows a detailing of the variety of effects and appearances of difficulties. For the purpose of this manual, the term Fetal Alcohol Spectrum Disorder (FASD) will be used unless otherwise specified for a singular situation.

Alcohol is a potent teratogen, a substance that causes birth defects. Alcohol freely crosses the placenta with blood alcohol concentrations in the fetus reaching or exceeding those in the mother. The fetus has little ability to metabolize the alcohol.

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[19] Streissguth, A. P. , "A Long-Term Perspective on FAS. " Alcohol Health & Research World. 18 (1) 1994, 74-81. -
[20] Clarren, S. K. Teachings From The FAS-DPN Clinic. 1997-2001. -
[21] Stevens, S. J. and Wexler, H. K. , eds. Women and Substance Abuse: Gender Transparency. New York: Haworth Press, - 1998. -

Alcohol as a teratogen can affect and damage fetal cells as well as those in the placenta, umbilical cord, and developing brain.[22] Hypoxia (a lack of oxygen) can result from impaired placental/fetal blood flow, leading to increased risk of brain damage and subsequent cognitive, physical, and behavioral disorders.

Unfortunately, it is not generally possible to predict the occurrence or severity of alcohol-related birth defects. There is a multiplicity of factors that contribute to the presence of FAS/FASD. This includes, but is not limited to:

- Timing of exposure
- Duration of alcohol consumption
- Dosage (amount) of alcohol consumed
- Physical health and possibly, age of the mother
- Prenatal care
- Polysubstance use or abuse
- Combinations of one or more of the above factors

If possible, all of the listed information should be acquired when screening for and diagnosing FAS/FASD.[23,24]

Formation of the Treatment Team:

At all times, it is critical that each child diagnosed with FASD or suspected of having one of these conditions, be at the center of a treatment team. The treatment team should have a health professional, social worker, teacher, family advocate, counselor, and case manager, at a minimum. Any baby that is known or suspected of having such exposure should be screened at birth for the problems listed below

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[22] Masis, K. Personal communication, 2002. -

[23] Little, R. E. , and Streissguth, A. P. Alcohol Use and Its Consequences: Fetal Alcohol Syndrome. Hanover, NH: Dartmouth - Medical School Project Cork, 1988.

[24] Streissguth, A. P. , Aase, J. M. , Clarren, S. K. , Randels, S. P. , LaDue, R. A. and Smith, D. F. "Fetal Alcohol Syndrome in - Adolescents and Adults. " Journal of the American Medical Association. 265 (1991) 1961-1967. -

and be assigned a case manager who can coordinate the creation of a team and facilitate services for the child and family. The ideal, of course, is for all women to be prenatally screened for substance abuse and to receive adequate and frequent prenatal health care.

The model FAS-DPN diagnostic team at the University of Washington, consists of developmental and clinical psychologists, a pediatrician, school specialist, an occupational therapist, a speech pathologist, family advocate, and an epidemiologist. Its members are trained in FAS and its long-term effects. In turn, they have trained other professionals throughout the country and abroad. However, it may not always be feasible for communities to have all these professionals. In these cases, such as in rural areas, it is important that someone takes the lead of the team and finds other community resources with whom to coordinate.

Routes to Identification:

Rarely are children with FASD identified at birth. Doctors may have misconceptions about which women might be at risk for having children affected by prenatal alcohol exposure.[25] Woman who are drinking heavily and using other substances may not receive adequate prenatal care. If they are seen for prenatal care, they may not be asked about substance and alcohol use.[26] Information should be provided to all pregnant women about the possible risks of alcohol related birth defects, and screening should be done at any point when women enter the health care system, be it in the first week of pregnancy or at delivery.[27,28] Resources for screening questionnaires are included in the Appendices of this manual.

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[25] Wilsnack, R. W. , Wilsnack, S. C. Gender and Alcohol: Individual and Social Perspectives. New Brunswick, NJ: Rutgers - Center of Alcohol Studies, 1997.

[26] Comfort, ML & Kaltenbach, K. "The Psychosocial History: An interview for pregnant and parenting women in substance - abuse treatment and research. " In E. R. Rahdert (Ed) Treatment for Drug-Exposed Women and Their Children: Advances in - Research Methodology, NIDA Research Monograph 165. Rockville MD: US Department of Health and Human Services, 1996, - pp. 123-142. -

[27] Little, R. E. , Streissguth, A. P. "Reducing Fetal Alcohol Effects: The Seattle Pregnancy and Health Program. " Majewski, F. - (Ed.) Die Alkohol-Embryopathie. Frankfurt/Main: Umwelt & Medicin Verlagsgesellschaft mbH,1987, 197-203. -

[28] Streissguth, et. al. Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and - Fetal Alcohol Effects. Seattle, WA: University of Washington, 1996. -

It is more common for the child to be identified when they begin school and start displaying increasing learning and behavior problems. Many children with behavioral problems receive a diagnosis of Attention Deficit Hyperactivity Disorders (ADHD). Other children will be viewed as underachievers. In actuality, these children may be experiencing the problems that accompany prenatal alcohol exposure. In these situations, it is important that the teacher or other school personnel take the lead in ensuring the child receives appropriate screening, diagnosis and intervention.

Another common path for children to become involved in screening is through the social welfare system. Many mothers and fathers, as a consequence of their substance abuse, are not able to care for their children.[29] These children commonly enter foster care or group care. They may display many of the learning and behavioral concerns associated with prenatal alcohol exposure. [30] Alert social workers have been useful in facilitating screening and diagnosis as well as being part of a treatment team.

A Guide to this Manual

At the end of this section, there is another portion that contains information which is also presented in A Practical Native American Guide for Caregivers of Children, Adolescents, and Adults with Fetal Alcohol Syndrome and Alcohol Related Conditions.[31] Normal development, by age, along with developmental concerns associated with FASD, is listed. Specific interventions are outlined. In addition, there are matrices, by age, which address each of the domains to be covered in this manual. The purpose of these lists and matrices is to aid you, the professional, in formulating a treatment plan and making recommendations for the families and clients with FASD with whom you work. Included in this manual, is a section written

[29] Grant, T. M. , Ernst, C C. , Streissguth, A. P. , Phipps, P. and Gendler, B. "When Case Management Isn't Enough: A - Model of Paraprofessional Advocacy for Drug- and Alcohol-Abusing Mothers. " Journal of Case Management. 5(1) 1996. -
[30] Burgess, D. M. , Streissguth, A. P. "Educating Students with Fetal Alcohol Syndrome or Fetal Alcohol Effects. " - Pennsylvania Reporter. 22(1) 1990 1-3. -
[31] LaDue, R. A. A Practical Native American Guide for Caregivers of Children, Adolescents, and Adults with Fetal Alcohol - Syndrome and Fetal Alcohol Related Conditions. Rockville, MD: Indian Health Service, 2000. -

to help professionals working in this field to avoid “burnout” and isolation. Healthy professionals are as necessary as healthy parents to ensure the best support and services possible for families and individuals affected by prenatal alcohol exposure.

This manual is intended for a wide variety of professionals, including, but not limited to: nurses, physicians, teachers, psychologists, social workers, case managers, case aides, physical therapists, occupational therapists, school counselors, drug/alcohol counselors, early interventionists, lawyers, judges, correctional officers, and administrators. In some cases, special suggestions might be directed towards one specific profession. In general, however, the information and recommendations in this manual are guidelines to aid in recognizing concerns and strengths for patients with FAS/FASD and to help develop appropriate programs for clients with FASD. As a professional, you may not have everyday contact with children or adults with FAS. Nonetheless, understanding the skills, strengths and limits of patients with FASD can make you a powerful ally and aide in working with the person and family affected by FASD.

Sections II-VI cover a variety of domains commonly addressed by professionals including health concerns, legal issues, family/parenting issues and needs, psychosocial concerns, and educational/vocational needs. Each of these domains is intended to provide information across the lifespan of the patient. These issues and concerns that are seen in young children are often precursors to the problems reported in adolescents and adults. The interventions and structure that aid in younger children are also helpful for older people with FASD, albeit in a different form. It should be noted that not each and every issue could be thoroughly covered in a document this size.

Section VII, Family Issues and Needs, is a special section specifically intended to provide support for providers working in this field. Fetal Alcohol Syndrome is thought to be the number one known cause of mental retardation in the United

States and is totally preventable.[32] When a diagnosis of FASD is made, it is often a "diagnosis of the mother, the father, the community, and the society." These factors make it difficult for people to acknowledge and address this devastating birth defect. While there is often sympathy and support for individuals and families with other birth defects, there may be little for the women who produce children with alcohol related birth defects.

People who have FASD are commonly viewed as having hopeless defects with no chance of positive outcomes. Myths such as these have also led to professionals in this field being viewed as working in a "gloom and doom," hopeless situation. In reality, as will be seen in this manual, there is much that professionals and caregivers, working together with patients with FASD, can achieve. Practicality is a key in addressing all of these issues. Improving the lives of children, adolescents, and adults with FASD based on practical suggestions, structure, support, caring and concern is the goal of this manual.

At the back of the manual are several appendices. You will find information on diagnoses associated with FASD, medications commonly used in treating those with FASD, assessment tools that may be of use in working with this special population, a resource guide, and a glossary of terms. One of the primary concerns in the field of FASD, is the number of children that are not identified until well into the school years when their behavior becomes more concerning.[33] In addition to helping professionals design appropriate interventions for babies and children already identified, the information contained in these pages will encourage health professionals to become proactive in asking about alcohol use, screening, and identifying babies, children, and mothers and fathers at-risk.

As the title of this manual indicates, practicality is the key in working with families and individuals impacted by FASD. Keeping it structured, simple, concrete, and

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[32] Abel, E. L. , and Sokel, R. J. Incidence of Fetal Alcohol Syndrome and Economic Impact of FAS-Related Anomalies. Drug - Alcohol Depend. 19:51-70, 1987. -

[33] Burgess, D. M. , Streissguth, A. P. "Fetal Alcohol Syndrome and Fetal Alcohol Effects: Principles for Educators: *A* Special - Section on Children at Risk. " Phi Delta Kappan. 74(1) 1992 24. -

practical, with a healthy dose of humor thrown in, is the guiding principle for this manual and for the field of FASD. Hopefully, with these factors and approaches, we can be part of the solution for aiding and supporting these special people in our communities.

Three final comments before we get down to business! While this manual is written from and to a Native American prospective, it is important to remember that there are many sober families in Native communities and there are many people in non-Native communities who struggle with the disease of alcoholism and FASD. It is also critical to remember that FASD, while it is now thought to be the number one cause of mental retardation in this country, still carries a stigma and fear that few other developmental disabilities have. Approaching the people affected by prenatal alcohol exposure and their families with kindness, gentleness, and putting away any preconceived notion is crucial. Alcoholism and FASD are equal opportunity problems. Support should also be "equal opportunity"

Regarding the term "Native American," this term is intended to include Alaska Natives as well as Native people born in the contiguous United States and Hawaii. Given the diversity of groups and the variety of terms that can be selected, "Native American" was chosen for the sake of simplicity and is meant to cover all groups previously described. With these cautions in mind, it is time to fully address this devastating life-long birth defect.

Section I:

Developmental Milestones and Issues

Jerilynn was a twenty-five year old single woman of Native descent who had been adopted off a reservation in the Southwest when she was three years of age. She was the youngest of six children, all with different fathers. Her mother died of alcohol-related causes when Jerilynn was two. She was unsuccessfully placed in a relative foster home until her adoption into a non-Native family at age three. Her adoptive parents had concerns over her small stature, chronic ear infections, and behavioral difficulties. Only the ear infections seemed to resolve the older she became.

Jerilynn did well in her early years in school, but began to show significant learning problems as she entered third and fourth grades. These problems became more pronounced and, finally, Jerilynn dropped out of school at age 14. She began hanging out with a rough group of older youths, was picked up on felony assault charges at age 16, and had her first child within the next year.

It was suggested to Jerilynn on many occasions that she receive long-term birth control and return to school. She was on probation for multiple assaults and did well while in jail. However, once out, she would miss her probation appointments, begin drinking, and involve herself in situations that continually placed her at risk. At the age of twenty-five, she was in jail for multiple probation violations. She had lost custody of her five children due to abuse and neglect, despite repeated attempts by probation and children's services to involve her in support services.

Jerilynn is not a "real" person, but is a composite of many clients that the author has met over the course of the past twenty-five years. As you progress through this manual, Jerilynn's story and needs will unfold. At the end of each section, is a matrix for the concerns discussed in that particular section. These matrices are intended to aid the professional in identifying both concerns and resources for a

patient in each domain. Jerilynn's story will be addressed in these matrices to illustrate the ways in which professionals can identify and communicate needs and services. While there are similarities between patients with FASD, it is also important to remember each person is an individual and should be dealt with as such. The following tables were first published in A Practical Native American Guide for Caregivers of Children, Adolescents, and Adults with Fetal Alcohol Syndrome and Alcohol Related Conditions.[34] They are used here to help provide consistency of information from one manual to the other.

Normal Development by Age:

How can I know what is wrong with my baby if no one tells me what is right and what I should expect?

- A question posed by a 17 year old mother of a child prenatally exposed to alcohol and other drugs

It is a common ironic statement that children "don't come with a user's manuals." This comment is often accompanied by a wistful sigh. In fact, many people, professional and lay, do not always have a clear sense of what should be expected at any point in time in the development of a child, adolescent, and adult. Below are lists of common developmental milestones, by ages of birth to five years, six to eleven years, twelve to seventeen years, and eighteen years and up. A second group of lists details the issues and deficits commonly associated with prenatal alcohol exposure. These lists are intended as quick guides, not as complete references. It is important, however, to keep the differences between normal development and deficits in mind when working with the individual with FASD.

[34] , LaDue, R. A A Practical Native American Guide for Caregivers of Children, Adolescents, and Adults with Fetal Alcohol Syndrome and Fetal Alcohol Related Conditions. Rockville, MD: Indian Health Service, 2000.

Table 1

Normal Development

Ages One Month to Six Months

	One Month
	Turns head from side to side
	Hands are held in tight fists
	Brings hands within range of eyes and mouth
	Has strong reflex movements
	Moves arms in jerky movements
	Can focus on objects 8 to 12 inches away
	Eyes tend to wander and may cross
	Will prefer the human face to other objects
	Hearing is well developed
	Can recognize a variety of sounds
	Will begin to turn to familiar voices and familiar sounds
	Prefers soft touch and gentle handling
	Prefers sweet smells and avoids bitter smells
	Sleeps three to four hours
	Needs to be fed round the clock, every three to four hours

	Two to Six Months
	Raises head and chest when on stomach and progresses to rolling from front to back and back to front
	Stretches legs out, kicks, and then progresses to sitting and supporting his own weight on his legs
	Can grasp items and bring items to his mouth
	Starts to smile in response to others and is more expressive in other ways
	Starts to imitate others, e. g. waving
	Becomes interested in looking in the mirror
	Engages in and enjoys social play
	May sleep through the night
	Longer periods between feedings

The first month of a baby's life is a time of enormous change and growth. These milestones are used as marks to ensure the health of each child. However, it should be remembered that there are individual differences for each baby. Some babies will sleep through the night and eat on a regular schedule. A baby will lose weight right after birth but, in a short period, the baby will gain it back.

If you have questions, make sure you talk to your baby's doctor.

Table 2

Normal Development

Ages Seven Months to Two Years

	Seven to Twelve Months
	Can get into a sitting position without help
	Crawls and progresses to standing and walking or preparing to walk
	Can put objects in a container and take them out
	Can use several objects correctly and often enjoys doing so, e. g. a telephone or cup
	Starts to help caregiver when getting dressed, e. g. puts out hand or leg
	Begins to demonstrate more language skills and receptivity, e. g. can respond to “No” and shake his head “No”
	Begins to babble, imitate sounds, and use simple words
	Easily recognizes several people and may begin to show anxiety when separated from mother or father, may be shy around strangers
	Starts to recognize people and objects by name
	Begins to have preferences for specific people and objects, e. g. favorite toy
	Begins to copy others in his play
	Begins to hold crayons

	One to Two Years
	Can walk alone, carry items while walking, and pull toy, e. g. pull wagon behind him
	Has progressed from simply walking to running
	Can go up and down stairs with support
	Can climb onto furniture without assistance
	Can begin to kick large objects
	Shows preference of one hand over the other
	Fine motor control becomes more developed
	Language skills begins to improve, e. g. making simple sentences, saying more words
	Can imitate and repeat words
	Is learning names of people, body parts, objects in his world
	Can begin to discriminate objects by color and shape
	Begins to demonstrate his imagination through play
	Interactions with others becomes more important
	Begins to demonstrate his awareness of himself as an individual and show separation anxiety
	May begin to defy parental directions
	Copies actions of others, adults and other children

Rapid changes continue as the baby grows and develops more of a noticeable personality. Baby’s likes and dislikes become more apparent. Baby’s brain shows rapid development during this time and, as he grows, baby begins to deliberately use his skills.

Table 3

Normal Development

Ages Two Years to Four Years

	Two to Three Years
	Motor skills increases, e. g. , able to pedal a tricycle
	Can climb, bend over, keep his balance and run easily
	Can hold a pencil and make more deliberate strokes
	Can open and close jars and turn door handles
	Begins toilet training, usually completed prior to age three
	Can follow more complex directions
	Speech improves and becomes understandable
	Sentence length increases
	Begins to use pronouns and words such as: “on,” ”in,” ”around,” ”under,” and “over”
	Play includes putting puzzles together
	Make-believe play increases and becomes more complex
	Begins to understand more complex concepts, including time, possession, e. g. , “his,” “mine”
	Becomes more sociable and can take turns

	Three to Four Years
	Gross motor skills improves, e. g. , standing and hopping on one foot
	Can toss ball, generally overhand
	Balance improves to allow forward and backward movement
	Fine motor skills increases, e. g. able to copy designs, use scissors
	Drawing of a person includes several body parts
	Understanding of complex concepts and appropriate use of grammar increases
	Sentence structure becomes more complex and child uses more words
	Imagination becomes more active, e. g. , tells stories; has imaginary companion
	Is less self-centered, understands sharing and cooperation
	Understands colors and knows their names
	Can follow increasingly complex directions
	Memory improves, e. g. , can recall stories he is told or read

Table 4

Normal Development

Ages Four Years to Five Years

	Four to Five Years
	Can hop, turn somersaults, swing, climb, and is learning to skip
	Fine motor skills continues to increase including dressing and undressing, using table utensils, caring for own toilet needs
	Begins to print
	Begins to understand and express more complex concepts, e. g. , future tense, name and address, game and household rules, and telling stories previously heard
	Begins to count, often up to ten objects or more
	Becomes more sociable, wants to please and be liked by friends
	Becomes aware of sexuality and gender
	Can usually tell fact from fantasy

Table 5

Normal Physical and Language Development

Ages Six Years to Eleven Years

	Physical Development
	Has reached most of their adult growth by age 11
	Motor control improved
	Uses cursive writing, not just printing
	Gross motor control improves; child can swim, ride a bicycle without training wheels, catch and throw balls, participate in team sports
	Visual/motor skills are well developed
	Most permanent teeth, with the exception of wisdom teeth, are present
	Begins to show signs of sexual maturity and the onset of puberty

	Language Development
	Can pronounce all letters of the alphabet
	Can “sort out” and selectively attend to important information from background noise
	Can attend to, recall, and repeat a list of various items
	Can recognize and use irregular verbs and plurals
	Can recognize and correctly use syntactic rules
	Can use language to articulate abstract concepts

Table 6

Normal Cognitive and Emotional Development

Ages Six Years to Eleven Years

	Cognitive Development
	Can grasp abstract concepts and formulate the same
	Can begin to separate reality from fantasy
	Can begin to predict the outcome of his or other's behavior
	Can understand and adhere to social rules and expectations
	Is able to read, write, spell, do addition, subtraction, multiplication, and division; and understand the value of money

	Emotional Development
	Can self-regulate, self-soothe, and work on their own for increasing periods of time
	Can inhibit own behavior
	Can enjoy and feel secure in their parental relationship and take an interest in parents and peers
	Learns to deliberately manipulate adults to get his own way
	Begins to learn and incorporate limits
	Can organize thoughts, including those related to feelings
	Can experience disappointment without displaying temper tantrums
	Can fully participate with peers, understands the principle of cooperation
	Begins to demonstrate interests in hobbies, games and fully understands the concept of possession and sharing
	Begins to understand other's feelings and how his behavior impacts others

Table 7

Day-to-Day Living Skills

Ages Six Years to Eleven Years

	Day-to-Day Living Skills
	Can choose his own clothes and fully dress self
	Can dress in anticipation of changes in the weather
	Can take care of basic hygiene needs without being reminded or having assistance, e. g. brushing teeth, taking a bath, combing their hair
	Can do basic chores, e. g. make bed, clean their own room, help out in the kitchen and in the yard

Table 8

Normal Physical and Cognitive Development

Ages Twelve Years to Seventeen Years

	Physical Development
	Full height is reached by most adolescents
	Bone growth is complete and musculature growth increases
	Internal organs increase in size
	Menstruation begins with most girls; if it has not previously started
	Secondary sexual characteristics are well developed, e. g. breasts, hips, and penis. Body hair is present, voice deepens significantly for males and moderately for females

	Cognitive Development
	Development of abstracting abilities and clearer understanding of abstract concepts
	Self-concept/Identity: Adolescent can begin to describe himself in terms of adjectives, e. g. “kind”, “smart”, “tough”
	Egocentrism: Adolescent can recognize others as having feelings, but still focuses on self as the “center of the universe”
	Development of more organized thought
	Able to link cause and effect
	Development of more detailed problem-solving strategies
	Are able to distinguish fact from fantasy

Table 9

Normal Emotional Development and Social Skills and Day-to-Day Living Skills

Ages Twelve Years to Seventeen Years

	Emotional Development and Social Skills
	Sexual identity development
	Moral development of a personal sense of what is right and wrong, and attempt to base behavior on their own personal morals and values
	Increasing dependence on and influence by peers
	Increasing desire and attempts at independence from parental rules and influence
	Clarification of values
	Dating and becoming sexually active
	Interests in vocational possibilities
	Recognizes and respects others' interests

	Day-to-Day Living Skills
	Able to take care of all aspects of personal hygiene, may need reminding at times
	Can do chores around the house and yard without assistance, may need reminding at times
	Able to perform routine tasks around the house
	Can choose own clothes
	May begin working, earning, and saving own money
	May begin to drive
	Can take care of his own health, e. g. making doctor and dental appointments, and being responsible for keeping them
	Can cook and clean up on his own, more so for older adolescents

Table 10

Normal Cognitive Development

Ages Eighteen + Years

	Cognitive Development
	Able to express empathy
	Able to put abstract concepts into action
	Able to use complex problem-solving skills
	Thoughts and actions are more organized

Table 11

Normal Emotional Development and Social Skills and Day-to-Day Living Skills

Ages Eighteen + Years

	Emotional Development and Social Skills
	Sexual identity is usually more stable
	Personal sense of right/wrong is more stable and is used as a basis for making day-to-day decisions
	Moving into long-term interpersonal relationships, marriage, and parenthood
	Moving into post-secondary education, e. g. college and vocational training, employment, and eventually retirement

	Day-to-Day Living Skills
	Can manage own funds
	Can work, earn, and save money
	Can meet all of own daily needs
	Can provide adequate parenting
	Can adequately provide for more than self, e. g. spouse and children

Developmental Concerns by Age:

The lists below are common characteristics and concerns expressed by parents and by caregivers of children, adolescents, and adults with FASD. A review of these deficits, shows the problems often seen in young children do not disappear, as the person grows older. The underlying etiology, specifically organic brain damage, remains even as the patient matures.

Table 12

Challenging Behaviors and Developmental Delays Associated with FAS/FASD

Ages One Month to Six Months

	One Month
	Is born with a low birth weight, needs a longer stay in the hospital
	Has problem sucking and thus, does not feed well leading to further concerns about the health of the baby
	Has an exaggerated startle response, becoming more aroused when there is sensory input, instead of learning to ignore unimportant information
	Is jittery well beyond the age most when most newborns overcome being jittery
	Does not sleep well
	Does not soothe
	Has failure to thrive
	Has heart, kidney and digestive problems

	Two to Six Months
	Is still very “colicky” and fussy, does not soothe
	Is slow in focusing his eyes, recognizing familiar faces or following moving objects
	Still cannot support his head by three months
	Is unable to roll over from side to side
	Is still having failure to thrive or other health problems
	Still shows exaggerated startle response
	Has repeated ear infections
	Still has sleeping and feeding problems
	Does not respond as well to people in his world, e. g. , does not smile and is slow to begin to make babbling sounds
	Does not reach for objects that interest him

The first month of a baby’s life is a time of enormous change and growth. These milestones are used as marks to ensure the health of each child. However, it should be remembered that there are individual differences for ech baby. Not all babies with FASD will necessarily experience all of the concerns listed above, Rather, this is a list of what might be seen. Some babies will sleep through the night and eat on a regular schedule. Baby will lose weight right after birth but, in a short period gain it back.

If you have questions, make sure you talk to your baby’s doctor.

Table 13

Challenging Behaviors and Developmental Delays Associated with FAS/FASD

Ages Seven Months to Two Years

	Seven to Twelve Months
	Does not respond to visual/verbal input by caregiver, e. g. , returning smiles
	Is unable to sit up by himself
	Cannot crawl
	Is not progressing towards standing and walking
	Has not learned to say simple words
	Language is not progressing towards talking
	Still has sleeping problems, is very fussy, and does not respond to soothing and affection from caregiver
	Does not respond to or copy simple gestures such as waving “Good-bye” or shaking/nodding his head
	Is still easily stimulated and hard to calm

	One to Two Years
	Muscle tone is poor
	Is just beginning to crawl or make moves towards walking
	Is walking, but not in a well developed manner
	Has poor balance
	Fine motor control is still not well developed, e. g. , cannot stack a small tower of blocks
	Has hearing problems
	Has difficulty remembering the names of simple or common items
	Cannot pull a toy behind him or push a toy
	Language is delayed, has not yet learned to speak at least 15 words
	Is still having trouble sleeping
	Is an excessively picky eater or does not seem to recognize when he is hungry
	Does not respond to affection in some cases, but is excessively “touchy” to others
	Is easily distracted by unimportant sounds or items
	Does not soothe easily
	Does not like the feel of rough or even some smooth cloth on his skin
	Shows little stranger anxiety

Rapid changes continue as the baby grows and develops a more noticeable personality. Baby’s likes and dislikes become more apparent. Baby’s brain shows rapid development during this time and as he grows, baby begins to deliberately use his skills.

Table 14

Challenging Behaviors and Developmental Delays Associated with FAS/FASD

Ages Two Years to Four Years

	Two to Three Years
	Still is not walking or continues to have problems walking
	Balance remains poor, falls often
	Cannot run well
	Fine motor control is not well developed
	Cannot hold a pencil or draw a circle
	Cannot remember or follow simple directions or limits
	Social skills remain underdeveloped
	Imaginary play is limited
	Is more comfortable with adults or older children than age mates
	Frustrates easily
	Is not easily soothed
	Is still not able to be toilet trained
	Has chronic ear infections and respiratory problems
	Sleeping and eating patterns are still of concern
	Vision is poor
	Has little sense of danger

	Three to Four Years
	Fine and gross motor skills are still of concern, e. g. cannot hop or stand on one foot, is clumsy
	Cannot catch or throw a large ball or kick one
	Cannot build a simple tower out of blocks
	Cannot string beads
	Cannot pedal a tricycle
	Language is lagging in development, e. g. does not know several hundred words and is still using two or three word sentences
	Is not learning to use pronouns or to understand more complex ideas
	Does not engage in imaginary play
	Does not remember, follow, or understand simple directions, rules or boundaries
	Is highly active and impulsive with little sense of danger
	Is easily frustrated and may be aggressive
	Throws frequent temper tantrums, sometimes with no apparent reason
	Is still not toilet trained

Table 15

Challenging Behaviors and Developmental Delays Associated with FAS/FARD

Ages Four to Five Years

	Four to Five Years
	Still cannot balance on one leg, hop, or kick
	Is still clumsy, falls a lot
	Cannot hold a pencil well or copy simple designs
	Cannot do simple self-care, e. g. dress himself, brush his teeth, wash/dry hands
	Has difficulty remembering/following simple directions
	Cannot follow two or three step directions
	Does not understand concepts such as “over,” “under,” “around”
	Cannot separate fact from fantasy
	Cannot give his first and last names
	Language is still delayed, has a small vocabulary, does not talk in five to six word sentences
	Language is not clear, e. g. has trouble with certain sounds
	Does not engage well with own age peers, is more comfortable with younger children or adults
	Does not understand concept of sharing and cooperation
	Is easily distracted and overly active
	Is small

Table 16

Challenging Behaviors and Developmental Delays Associated with FAS/FASD

Physical and Language Development

Ages Six to Eleven Years

	Physical Development
	Is still growth deficient in height, weight and head circumference
	Fine motor control and balance are still delayed
	Can print, but cannot use cursive writing
	Gross motor control is still poor; the child may be clumsy, cannot ride a bicycle until ages 9-11, has trouble throwing or catching a ball
	Visual/motor skills are not well developed
	Most permanent teeth, with the exception of wisdom teeth, are present, but there are often significant orthodontic problems
	Begins to show signs of sexual maturity and the onset of puberty

	Language Development
	May have articulation problems requiring speech therapy
	Is easily distracted, has problems attending and screening out irrelevant noise
	Has memory problems, cannot recall or follow more than one or two step directions
	Has difficulty remembering irregular verbs and plurals, may use pronouns incorrectly
	May have problems using syntactic rules appropriately
	Can use language to form concrete ideas, but has difficulty with abstract concepts

Table 17

Challenging Behaviors and Developmental Delays Associated with FAS/FARD

Cognitive Development, Emotional Development and Social Skills

Ages Six to Eleven Years

	Cognitive Development
	Cannot grasp abstract concepts or formulate the same
	Has difficulty separating reality from fantasy, or past from present
	Has difficulty predicting the outcome of his or other's behavior
	Has a difficult time understanding and adhering to social rules and expectations
	Is able to do basic reading, spelling and math. More difficult tasks such as division and multiplication are beyond the child's grasp.

	Emotional Development and Social Skills
	Cannot self-regulate, has difficulty calming himself down, and has a hard time working on his own for any length of time
	Cannot inhibit their own behavior
	Child remains egocentric, not recognizing or responding to other's values, needs and feelings
	Learns to deliberately manipulate adults to get his own way
	Has limited ability to recognize and integrate personal boundaries
	Has limited ability to organize thoughts, including those related to feelings
	May not be able to identify or label feelings, particularly those related to physical arousal, e. g. excitement, fear, sexual arousal
	Still has temper tantrums, is easily frustrated, and shows a higher rate of disobedience
	Cannot fully participate with peers, still has problems understanding the principle of cooperation
	Begins to demonstrate interests in hobbies, games, and begins to more fully understand the concept of possession and sharing
	Is socially immature, feeling more comfortable with younger children
	Is impulsive without understanding the possible consequences of his actions

Table 18

Challenging Behaviors and Developmental Delays Associated with FAS/FASD

Day-to-Day Living Skills

Ages Six to Eleven Years

	Day-to-Day Living Skills
	Can choose own clothes and fully dress self
	Can dress in anticipation of changes in the weather, if reminded
	Can take care of basic hygiene needs, but requires reminding or assistance, e. g. brushing teeth, taking a bath, combing hair
	Can do basic chores, e. g. make bed, clean own room, help out in the kitchen and in the yard, but needs reminding and assistance

Table 19

Challenging Behaviors and Developmental Delays Associated with FAS/FASD

Physical and Cognitive Development

Ages Twelve to Seventeen Years

	Physical Development
	Full height is reached by most adolescents. For adolescents with FAS/FASD, they may remain short with smaller heads, but gain weight, making them appear plump. This is especially true of adolescent girls.
	Bone growth is complete and musculature growth increases. However, for adolescents with FAS/FASD, there still may be poor muscle tone and a lack of coordination.
	Internal organs increase in size
	Menstruation begins with most girls, if it has not previously started
	Secondary sexual characteristics are well developed, e. g. breasts, hips, or penis. Body hair is present; voice deepens significantly for males and moderately for females.

	Cognitive Development
	Difficulty in understanding abstract concepts and using them in daily life is still limited
	Difficulty understanding social concepts of right and wrong
	Self-concept/Identity: Adolescents may begin to have low self-esteem related to peer problems, learning problems, and an increasing awareness of his limitations
	Egocentrism: Adolescents still focus on self as the “center of the universe,” and has difficulty recognizing or responding to other’s feelings and needs in appropriate fashion
	Thinking process still tends to be disorganized and inconsistent
	Difficulty linking cause and effect
	Problem-solving strategies still tend to be primitive
	Problems distinguishing fact from fantasy

Table 20

Challenging Behaviors and Developmental Delays Associated with FAS/FASD

Emotional Development and Social Skills and Day-to-Day Living Skills

Ages Twelve to Seventeen Years

	Emotional Development and Social Skills
	Sexual identity development
	Moral development is delayed, difficulty understanding social concepts of right and wrong
	Increasing dependence on and influence of peers
	Increasing desire and attempt at independence from parental rules and influence without understanding the consequences of his actions
	Desiring to date, but often making poor choices
	Becoming sexually active without a full awareness and ability to protect self from pregnancy or sexually transmitted diseases
	Unrealistic sense of skills and vocational possibilities
	Difficulty recognizing and respecting other's interests

	Day-to-Day Living Skills
	Able to take care of some aspects of personal hygiene, often needs reminding and assistance
	Can do chores around the house and yard with assistance and reminders
	Able to perform routine tasks around the house with reminding and assistance
	Can choose own clothes
	May begin working, earning, and saving money
	Driving is a desire, but adolescents often lack judgment, adequate reflexes, or ability to recognize potentially dangerous situations
	Needs help taking care of own health, e. g. making doctor and dental appointments
	Can do some cooking and cleaning on his own with reminding and assistance

Table 21

Challenging Behaviors and Developmental Delays Associated with FAS/FASD

Cognitive and Emotional Development and Social Skills

Ages Eighteen + Years

	Cognitive Development
	May still have problems identifying and responding to one's own feelings and needs, and those of others
	Abstracting abilities are limited
	Problem-solving skills are limited
	Thoughts and actions are still disorganized and immature

	Emotional Development and Social Skills
	Sexual behavior may be impulsive and without thought to possible consequences
	Adults often remain at higher risk for sexual exploitation or abuse
	Relationships may remain short-term and with many problems
	Behaviors may be similar to those of younger people and be seen as immature, intrusive and inappropriate

Interventions by Age:

The lists of interventions below, are examples of actions that parents and caregivers have used to aid their children in reaching their potential. These interventions have implications for professionals as well as caregivers. The rest of this manual will expand on the interventions below, as well as provide additional suggestions where professionals may help in developing programs for children, adolescents, and adults with FASD.

The following information was first published in A Practical Native Americal Guide for Caregivers of Children, Adolescents, and Adults with Fetal Alcohol Syndrome and Fetal Alcohol Related Conditions by Robin A. LaDue, PhD in 2000 and in Psychosocial Needs Associated with Fetal Alcohol Syndrome: Practical Guidelines for Parents and Caregivers by Robin A LaDue, PhD in 1993.[35,36]

[35] LaDue, R. A. A Practical Native American Guide for Caregivers of Children, Adolescents, and Adults with Fetal Alcohol Syndrome and - Fetal Alcohol Related Conditions. Rockville, MD: Indian Health Service, 2000. -

[36] LaDue R. A. Psychosocial Needs Associated with FAS: Practical Guidelines for Parents and Caregivers. - Seattle, WA: U. of Washington, 1993. -

Figure 2
Recommendations and Practical Suggestions

Ages Birth to Five Years

Early identification of at-risk children

- Important for implementing needed services.
- Help maximize the potential outcome for the child.
- Important for identifying women and families at-risk.
- Help in providing needed services for families at-risk and maximizing the chances for family to remain intact.
- Careful monitoring of physical development and health.
- Placement of child in preschool.
- Help the child to begin appropriate socialization, communication skills and behavior.
- Provide respite care for parents and caretakers.

Safe, stable, structured home

- Help child learn appropriate behavior.
- Help support the parents and caretakers, e. g. with sobriety, accessing social and health services.
- Setting appropriate goals and expectations.
- Help the parents and caretakers to better understand the child's methods of communication.

Adapting the environment to the child

- Low to moderate level of stimulation.
- Simple, concrete directions.
- Consistent, limited rules.
- Assignment of case manager to coordinate services for the child and family.

Intervention with and education of birth, foster, and adoptive parents

- Referral for alcohol treatment, if appropriate.
- Referral for subsidized adoption.
- Referral for parenting skills, if appropriate.
- Education regarding normal development.
- Education regarding possible health concerns and developmental delays.

Figure 3
Recommendations and Practical Suggestions

Ages Six Years to Eleven Years

Continued monitoring of health issues

- Safe, stable, structured home or residential placement
- Help caretakers/teachers establish realistic goals and expectations
- Help the child make healthy choices appropriate to their emotional and cognitive level
- Use of clear, concrete, predictable, and immediate consequences

Simple, clear and concrete directions of daily chores and activities along with positive consequences for appropriate behavior, listed in writing

- Structuring of leisure time
- Participation in organized sports, e. g. Special Olympics
- Participation in clubs for handicapped children
- Psychological/academic/adaptive evaluations on a regular basis
- Education of parents and caretakers regarding age-appropriate sexual development
- Case manager's role expands to include schools, mental and physical health providers, and social service agency personnel
- Documentation of health impairments and deficits in adaptive behavior to aid in acquiring SSI and DD funding

Respite care for parents and caretakers

- Continued support for parent's sobriety, if needed
- Appropriate educational placement
- Activity-based curriculum
- Focus on communication skills
- Focus on appropriate behavior
- Basic academic skills embedded within functional skills

Figure 4
Recommendations and Practical Suggestions

Ages Twelve Years to Seventeen Years

- Change focus from academic skills to vocational and daily living skills.
- Continued structuring and monitoring of leisure time and activities.
- Involvement in structured social and sports group activities.
- Anticipation of transition/crisis situations along with appropriate planning and early interventions.
- Continued listing of daily chores with increasing responsibility.
- Respite care for families.
- Caretakers support group.
- Help the patient to make healthy choices and to build on their existing skills.
- Education of parents, caretakers, and patients regarding sexual development, birth control options, and protection against sexually transmitted deceases (STDs).
- Education of parents, caretakers, and patients to help protect against sexual exploitation.
- Implement planning for future residential placement, financial needs, and vocational/educational training.

Figure 5
Recommendations and Practical Suggestions

Ages Eighteen + Years

- Guardianship for funds.
- Subsidized residential placements, including special monies for birth and adoptive parents to help defray costs for special needs.
- “Homebuilders” support to help the patient live as independently as possible and to help in teaching parenting skills, if the patient has children.
- Specialized vocational training or job placements.
- Medical coupons and care.
- Case manager to help patients and families access services.
- Drug and alcohol treatment for patient, if needed.
- Act as a liaison with court and other legal concerns, if necessary.
- Patient advocates to ensure the recommendations are acknowledged and implemented.
- Acknowledgement of the patient’s limitations, strengths and skills.
- Acceptance of the patient’s “world”.

Section II

Physical Health Issues and Needs

Jerilynn, at the age of six months, was diagnosed with a ventricular septal defect. Surgery was performed on her and she was returned to the care of her birth mother. However, due to her mother's alcoholism, Jerilynn did not get the follow-up medical care she needed after her surgery. Jerilynn was temporarily placed in a special foster home. After three months, when her post surgical wounds had healed, she was again returned to the care of her mother.

Jerilynn remained small and thin. She was a fussy eater and often refused food. By age two, she was showing significant cognitive and developmental delays. At this time, she was removed from the care of her birth mother and placed in a therapeutic, relative foster home until her adoption at age 3. Jerilynn had multiple dental caries, chronic otitis media, and remained thin.

She was diagnosed with FAS at this age and at the same time tubes were placed in her ears because of otitis media. Her weight stabilized, but she never achieved average height. Once she was eight, her health concerns became less of an issue. However, she still continued to have ear infections.

As Jerilynn grew older, she became sexually active. Over the course of time, she had three episodes of sexually transmitted diseases and, was pregnant by the age of 17. She refused birth control on several occasions, repeating her mother's pattern of multiple sexual partners and pregnancies, resulting in five live births.

This section is focused on the health needs of the child, adolescent, and adult with FASD and ways to address these needs. However, due to the wide spectrum of effects and lack of adequate information many physicians and other health care professionals have about FASD, many babies, children, adolescents, and adults with FASD may never be identified and diagnosed. This in and of itself is a risk factor for

children with prenatal alcohol exposure. Alcohol is the most widely used teratogen among women of child-bearing age.

It is crucial that prenatal screening for alcohol use be carried out as much as possible to identify at-risk mothers and babies. If the pregnant mother has not previously been screened, it is important that the hospital do so at the time of delivery. Examples of screening tools for pregnant women are listed in the Appendices and References.

Even though many patients with FASD have limited cognitive abilities, they should still be involved in the decisions that affect their lives. Consent forms to allow release of information should always be signed. If possible, summations of treatment, such as those contained in the matrices presented in this manual, should be provided to other professionals giving care to the same patient. Space does not allow for a full discussion of health factors associated with women and alcoholism. However, in the Family and Psychosocial sections of this manual, many of these issues and concerns are addressed.

One last caution: all providers should be aware of their pregnant patient's possibility of being affected herself by prenatal alcohol exposure. If possible, FAS/FASD screening should be part of an assessment as the cognitive defects associated with this disorder can well drive the interventions that may be most appropriate. On-going screenings and assessments should be done throughout the pregnancy, not only as a preventative measure, but also as a means of support and promoting change.[37,38]

People are not born into this world as unattached entities. Each child born with FASD is born to a woman at risk for premature morbidity and a host of other alcohol-

[37] Best Start: Ontario's Maternal, Newborn, and Early Child Development Center.
[38] Masis, K. Personal Communication, 2002.

related health problems.[39,40] A woman deep in her alcoholism may not provide a safe home for her child. This can result in neglect, abuse, poor bonding, a lack of adequate nutrition, and ultimately, the child being removed from parental care. An artificial division is made between health problems directly caused by prenatal alcohol exposure versus secondary health concerns such as the ones listed above. In reality, both must be addressed to ensure healthy functioning.

Health Concerns

The health issues and needs of children, adolescents, and adults with FASD, range from otitis media to heart conditions. They can be as simple as clinadactyly (crooked fingers) and as complicated as ventricular septal defects. This section will discuss the physical health concerns often seen in children, adolescents, and adults with FASD. Not every person with FASD will have every problem and not every problem will necessarily be discussed in this section. Suggested interventions and programs that may help address these concerns will be contained in the latter portion of this section.

Difficulties and Concerns

"I got good prenatal care. I saw my OB for the first time when I delivered my baby."

- 37-year-old mother of three with FAS describing her prenatal care

[39] Russell, M. , Czarnecki, D. M. , Cowan, R. , McPherson, E. , and Mudar, P. "Measures of Maternal Alcohol Used as Predictors of Development in Early Childhood. " Alcoholism: Clinical & Experimental Research. 15 (1991) 991-1000.
[40] Stevens, S. J. and Wexler, H. K. , eds. Women and Substance Abuse: Gender Transparency. New York: Haworth Press, 1998.

Ages Birth to Five Years:

Many women who are involved with alcohol either do not get adequate prenatal care or any prenatal care at all.[41] Nutrition may not be appropriate and there may be a higher risk of polysubstance abuse. These factors put babies at higher risk for problems that must be addressed by hospital and other health care staff. Failure to receive prenatal care may mean that the newborn does not get screened for problems associated with FASD. They may also be released to their mother's care and into a less than healthy environment. Labor and delivery staff should have some means of screening for alcohol abuse in a non-threatening and supportive manner.[42] It might also be a good idea for a hospital to provide a patient advocate to ensure that each new mother receives follow-up care and that the child and mother go home to a safe environment.

Alcohol is a teratogen, a substance that can cause birth defects. There are specific effects that occur based on the point of pregnancy at which the alcohol is consumed. The physical defects that are associated with prenatal alcohol exposure result from the impact of alcohol on the developing fetus. There are specific effects by trimester (see Figure 6). In the first trimester, most of the major physical malformations associated with the FAS physotype occur. After birth, these appear as the smaller eyes, long, smooth philtrum (the area between the nose and upper lip), and thin upper lip that make up the classic face of FAS.[43,44,45,46,47] A woman need not drink every day for the child to have the facial abnormalities seen in FAS. A woman who is binge drinking may consume alcohol during these developmental milestones and

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[41] Stevens, S. J. and Wexler, H. K. , eds. Women and Substance Abuse: Gender Transparency. New York: Haworth Press, - 1998. -

[42] Comfort, ML & Kaltenbach, K. "The Psychosocial History: An interview for pregnant and parenting women in substance - abuse treatment and research. " In E. R. Rahdert (Ed) Treatment for Drug-Exposed Women and Their Children: Advances in - Research Methodology, NIDA Research Monograph 165. Rockville MD: US Department of Health and Human Services, 1996, - pp. 123-142. -

[43] Aronson, M. , Kyllerman, M. , Sabel, K. G. , Sandin, B. , and Olegard, R. "Children of Alcoholic Mothers: Developmental, - Perceptual, and Behavioral Characteristics as Compared to Matched Controls. " Acta Paediatrica Scandinavica. (1985) 74. -

[44] Druse, M. J. and Tajuddin, N. "Effects of In Utero Ethanol Exposure on the Developing Serotonergic System. " Alcoholism: - Clinical and Experimental Research. 15 (1991). -

[45] Jones, K. L. "Fetal Alcohol Syndrome. " Pediatrics in Review. 8 (1986) 122-126. -

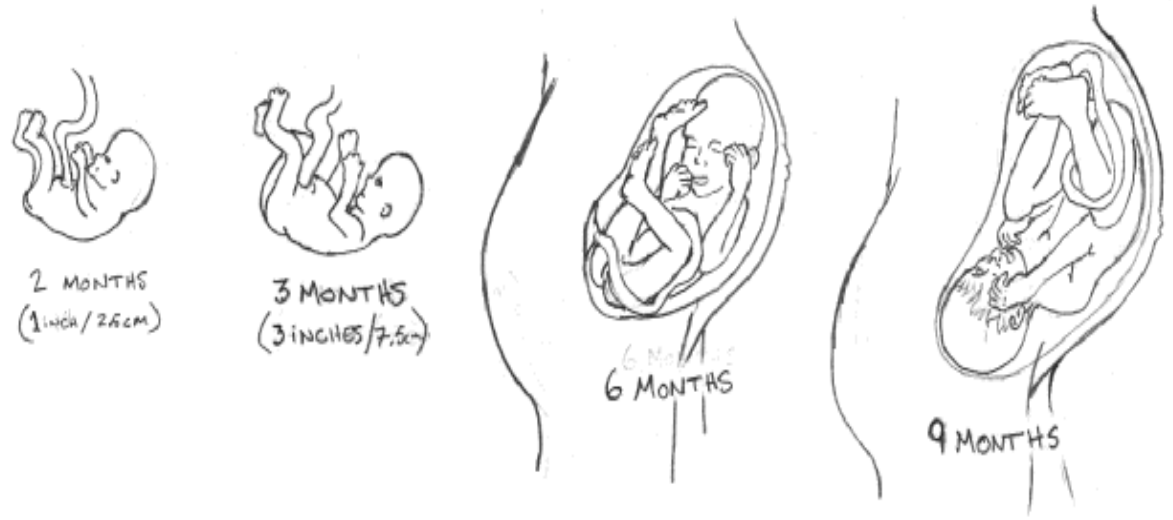
[46] Jones, K. L. and Smith, D. W. "Recognition of the Fetal Alcohol Syndrome in Early Infancy. " Lancet. 1973. -

[47] Little, R. E. , and Streissguth, A. P. Alcohol Use and Its Consequences: Fetal Alcohol Syndrome. Hanover, NH: Dartmouth - Medical School Project Cork, 1988. -

have a child born with the same features as a child who was exposed to prenatal alcohol exposure every day.[48]

Figure 6

Development During Gestation



A woman who begins drinking or continues drinking during the second trimester runs an increased risk of spontaneous abortion or miscarriage. Women who begin drinking in the third trimester or drink all through their pregnancies run a risk of a lower birth weight baby and increased rates of still-births.[49,50] A lower weight baby is often considered a higher risk baby. These babies are not necessarily premature, although that is also a possibility

The baby's brain is forming across the entire time of pregnancy and thus is vulnerable to damage regardless of the point in pregnancy that drinking occurs. It is due to the specific effects by trimester that many children may have brain damage

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[48] Little, R. E. , and Streissguth, A. P. Alcohol Use and Its Consequences: Fetal Alcohol Syndrome. Hanover, NH: Dartmouth - Medical School Project Cork, 1988.

[49] Little, R. E. and Streissguth, A. P. "Effects of Alcohol on the Fetus: Impact and Prevention. " Canadian Medical Association - Journal. 125 (1981) 159-164. -

[50] Martin, D. C. , Martin, J. C. , Streissguth, A. P. , and Lund, C. A. "Sucking Frequency and Amplitude in Newborns as a - Function of Maternal Drinking and Smoking. " Galanter, M. (Ed.) Currents in Alcoholism. vol. 5 New York: NY: Grune & - Stratton, 1979, 359-366. -

and behavioral and learning problems, even in the absence of abnormal physical features.[51]

The brain damage just mentioned is related to many of the health problems seen in young children with FASD. For example, many babies prenatally exposed to alcohol have a weak suck, making it difficult for them to feed. If they have a lower weight at birth and do not feed well, this increases the risk of possible problems and failure to thrive.[52],[53] Other manifestations of brain damage related to prenatal alcohol exposure may include microcephaly (small head), lower intellectual abilities, poor tandem gait, poor hand-eye coordination, neurosensory hearing loss, clumsiness, and structural brain anomalies. Issues related to learning and behavior will be discussed in greater detail throughout this manual.

Some of the direct health concerns associated with prenatal alcohol exposure are:

- Low birth weight
- Shortness of length
- Smaller head circumference
- Facial dysmorphology
- Lower IQ scores
- Behavior problems
- Failure to thrive
- Sleep disruptions
- Disorders of the palate
- Renal and unogenital defects
- Skeletal defects, e. g. , hip dislocations

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[51] Little, R. E. , and Streissguth, A. P. Alcohol Use and Its Consequences: Fetal Alcohol Syndrome. Hanover, NH: Dartmouth - Medical School Project Cork, 1988.
[52] Streissguth, A. P. , Barr, H. M. , Sampson, P. D. , Bookstein, F. L. , and Darby, B. L "Neurobehavioral Effects of Prenatal - Alcohol. Part I, II, & III: Research Strategy. " Neurotoxicology and Teratology. 1(5) (1989) 461-476. -
[53] Brazleton, T. B. Neonatal behavioral assessment scale. Clinics in Developmental Medicine, 50. London: William - Heinemann Medical books, LTD. , 1973. -

Babies born with FASD commonly have an exaggerated startle response.[54] They have difficulty screening out irrelevant information, making it difficult to feed or sleep if there is any "extraneous" light or sound. They may not like being held and may become rigid when picked up. This may make it difficult to bond with babies with FASD and, in other cases, it may be difficult to feed them.

Special care needs infants should be provided a quiet place to feed. Feedings should be held, whether in the hospital or at home, in the same place and time each day. Routine and predictability is the type of structure that will be needed for people with FASD across the lifespan. Helping the parent understand these concerns and set up routines to facilitate feeding and sleeping are important educational interventions health professionals can provide.[55] For more information on specific interventions that can aid parents in these areas, please see the A Practical Native American Guide for Caregivers of Children, Adolescents, and Adults with Fetal Alcohol Syndrome and Alcohol Related Conditions.[56]

Children with FASD often have distortions in their sinuses and Eustachian tubes. These distortions can lead to increased rates of otitis media and hearing loss. In addition, higher rates of neurosensory hearing losses are associated with FASD.[57] It is important that a child known or suspected of being prenatally alcohol exposed receive hearing screening as early as possible. If the parent is not capable of acquiring these services, a public health nurse should be assigned to the family and ensure the baby or child is screened.

Prenatal alcohol exposure can cause strabismus (crossed eyes) and ptosis (drooping eyelid) affecting the baby's or vision. Myopia (poor eyesight) is also a common occurrence. All of these factors need to be evaluated and treated. In some

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[54] Streissguth, A. P. , Barr, H. M. and Martin, D. C. "Maternal Alcohol Use and Neonatal Habituation Assessed with the - Brazelton Scale. " Child Development. 54 (1983) 1109-1118. -

[55] Williams, R. L. , and Karacan, L. Sleep Disorders: Diagnosis and Therapy. New York, NY: Johns Wiley & Sons, 1978. -

[56] LaDue, R. A. A Practical Native American Guide for Caregivers of Children, Adolescents, and Adults with Fetal Alcohol - Syndrome and Fetal Alcohol Related Conditions. Rockville, MD: Indian Health Service, 2000. -

[57] Streissguth, A. P. Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore, MD: Paul H. Brookes - Publishing Co. , 1997. -

cases, the strabismus and ptosis may be corrected through surgery. Myopia may be addressed through eye glasses. As with other health issues, if the parents are unable to meet the needs of their baby, a social worker, public health nurse, or case aide should take responsibility to ensure such care is received.

Cardiac concerns such as a heart murmur or ventricular/atrial septal defects are sometimes seen in babies with prenatal alcohol exposure.[58] While some of these problems may spontaneously resolve, others will require surgery. If the parent is drinking and not able to provide adequate care for a baby with special health needs, it will be crucial that a safe residential placement is provided until or if it is appropriate for the baby to be returned to the parent's care.

Another problem noted children with FASD is clumsiness, poor fine motor control, and gait problems. Many babies with FASD do not do "cross-body" crawling. This is where a physical or occupational therapist can be useful in developing programs to enhance motor coordination and the total development of the baby. There are programs such as "brain gym" which teach cross body motion. Cross-body training can be taught to the parent or caregiver. It often consists of helping the child move the opposing parts of the body, e. g. right-arm-left-leg. There is often a thinning of the corpus callosum in children with prenatal exposure.[59] Such exercises encourage brain connection development and motor coordination.[60]

"In working with clients with FASD, my job is like picking one role from column A and one from columns B and C. It may not be the same from day to day or person to person. Flexibility is the key flexibility and humor. "

- A case manager describing his job duties and role when working with substance abusing woman in an early intervention program.

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[58] Jones, K. L. "Fetal Alcohol Syndrome. " Pediatrics in Review. 8 (1986) 122-126. -
[59] Morse, B. Diagnosis and thereafter: What we know now and where we are going. In: Fantastic Antoine Grows Up. J. - Kleinfeld, B. Morse, S. Wescott (Eds.) Fairbanks, AK: University of Alaska Press, 2000. -
[60] Ratliffe, K. T. Clinical Pediatric Physical Therapy: A Guide for the Physical Therapy Team. Philadelphia: Mosby, 1998. -

In addition to the examples listed above, the role of the professional in addressing health concerns from the prenatal period to age five is often to:

- Develop effective strategies.
- Aid in ensuring the mother is screened for prenatal alcohol and drug use.[61]
- Facilitate the mother's entry into drug and alcohol treatment, if appropriate
- Aid the family in accessing needed social and health services.
- Serve as a liaison between the health care system and the family.
- Aid the mother in acquiring long-term birth control to ensure she does not have another child exposed to alcohol or other substances.
- Educate medical staff as to the needs of the mother and child. For example, many babies born with FASD do not feed well. If the hospital can set up a quiet room where the mother, father, or caregiver can concentrate only on feeding the child and bonding with the child, this may facilitate a closer bond and healthier parent/child relationship.
- Aid in establishing a team, such as the one described earlier, to provide support, follow-up, and long-term care for the child, the mother, and the family.
- Ensure that the child receives ongoing health care with a pediatrician.
- Ensure public health services are established for the family. This can aid in the child getting needed immunizations, well child care, and provide support for the family.
- Provide public health nursing care and other in-home services to ensure the home where the baby is going is appropriate and safe.
- Make contact with social services if it is not safe for the child to return home with the mother.

Any professional working in this area must be aware of the vulnerability and fear that many women have when the child is diagnosed with FASD. In some states,

[61] Center for Substance Abuse Prevention. "Maternal Substance Use Assessment Methods Reference Manual: A Review of Screening and Clinical Assessment Instruments for Examining Maternal Use of Alcohol, Tobacco, and Other Drugs" CSAP Special Report 13. DHHS Pub. No. (SMA) 93-2059. Rockville, MD: Center for Substance Abuse Prevention, 1993.

acknowledgement of alcohol during pregnancy may result in the baby being removed from the mother's care.[62] While the safety of the child cannot be compromised, any professional working with an at-risk mother can serve as an advocate to facilitate treatment and as a liaison with social services to minimize the chance of permanent removal of the child.[63]

Studies have demonstrated that the prenatal and perinatal periods are crucial time for intervention with substance abusing women.[64] Early identification and interventions have also been shown to lead to more positive outcomes.[65] An alert professional who recognizes an at-risk child and mother can be an asset in preventing the birth of another affected child. Support can aid the mother both in her sobriety and in keeping the family together. Specific resources that may be of help are listed in Appendix 7 at the back of this manual.

Ages Six to Eleven Years:

Many of the problems seen in younger children such as failure to thrive and heart problems have either been resolved or surgically corrected by the time children reach age six. However, other health concerns take their place. These concerns are more related to gait problems, slowness in development, and the consequences of neglect or abuse. The psychosocial aspects of the latter will be covered in Section III. Other areas of health concern include dental, vision, and hearing care. Vision and hearing become particularly important as the child enters school and moves out into the world.

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[62] Streissguth, A. P. Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore, MD: Paul H. Brookes - Publishing Co, 1997.
[63] Grant, T. M. , Ernst, C. C. , Streissguth, A. P. , Phipps, P. and Gendler, B. "When Case Management Isn't Enough: A - Model of Paraprofessional Advocacy for Drug- and Alcohol-Abusing Mothers. " Journal of Case Management. 5(1) 1996. -
[64] Carmichael-Olson, H. and Burgess, D. M. , "Early Intervention for Children Prenatally Exposed to Alcohol and Other Drugs. " - Guralnick, M. J. Baltimore, MD: Brookes, (Ed.) The Effectiveness of Early Intervention. 1997, 109-145. -
[65] LaDue, R. A. , Streissguth, A. P. , and Randels, S. P. "Clinical Considerations Pertaining to Adolescents and Adults with - Fetal Alcohol Syndrome. " Sonderegger, T. B. (Ed.) Perinatal Substance Abuse: Research Findings and Clinical Implications. - Baltimore, MD: Johns Hopkins U. Press, 1992, 104-131. -

Many children are identified as being at-risk of having FASD when they enter the foster care or adoptive care system. Many children who have FASD spend their early years in chaotic, alcoholic homes. Physical abuse and neglect or poor nutrition may have been a part of these children's lives. Another area of risk is the fearlessness shown by many children with FASD. Jumping off roofs and breaking bones are common concerns expressed by the parents and caregivers of children with FASD.[66] Not being aware of every day risks, such as crossing the street without looking, not wearing a coat in the cold, and not choosing safe friends are often concerns seen in children this age and beyond.

If the child remains with the substance abusing parent who cannot adequately provide for their care, it may be necessary for the school to ensure the child gets vision and dental care and at least one to two nutritious meals a day. School personnel may also need to take on the responsibility of notifying social services if there are safety concerns in the home. Being willing to exercise these responsibilities is part of serving on the team of a child with FASD.

In clinical samples, many children with FASD are out of their mother's care prior to the age of five, due to maternal health concerns and substance abuse. Women who produce children with FASD have a significantly premature morbidity (death) rate.[67] While it is hoped that foster and adoptive homes are safe places, this is not always the case. It is crucial that the team members establish a safe residential placement for the child. This is not just for the physical safety of the child, but also to reduce or address the psychosocial concerns that are often a result of multiple placements, trauma, and the loss of the birth family.[68]

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[66] Streissguth, A. P. Personal Communication, 1992

[67] Streissguth, A. P. , Barr, H. M. , Kogan, J. , and Bookstein, F. L. Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects. Seattle, WA: University of Washington, 1996.

[68] Streissguth, A. P. , Barr, H. M. , Kogan, J. , and Bookstein, F. L. Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects. Seattle, WA: University of Washington, 1996.

"We have motion detectors, blinking alarms on the doors and windows, buzzing alarms on the outside doors, and little "yippee" dogs! This is all to make sure our sons are safe. The dogs are to keep them company if they, by chance, get out the front door. The dogs make lots of racket and herd them around, making them easy to track."

- A weary mother of three-year-old twin boys
with FAS on her "safety system."

While the critical health needs of otitis media, heart defects, and failure to thrive have passed by the time the child is in the latency (6-11 years; before puberty) period, there are still safety needs as listed above. The impulsivity and lack of judgment that began to be apparent in younger children often become more apparent in this time period. It is important that the family providing care for the older child with FASD also provide constant supervision and monitoring to ensure their safety. Resources for structuring the child's free time can include Special Olympics, clubs for children with special needs, and other community programs.

A health issue that is not formally documented but for which parents have provided anecdotal information, includes food and dye allergies. Parents have noted peanut and sugar allergies as the main culprits.[69] They report that consumption of these foods increases hyperactivity. However, as noted, there are no formal studies to verify, one way or the other, the veracity of this report. Such concerns should be discussed with the child's pediatrician prior to implementing any type of health, medical, or special dietary program.

Sleep problems[70] and "finicky" eating are reported as common problems in this age group. Some of this appears related to sensitivity to taste and texture many children with FASD seem to have. Sleeping problems can be exacerbated by a lack of

[69] Waller, A. Personal Communication, 2002
[70] Scher, M. S. , Richardson, G. A. , Coble, P. A. , Day, N. L. , and Stoffer, D. S. "The Effects of Prenatal Alcohol and Marijuana Exposure: Disturbances in Neonatal Sleep Cycling and Arousal. " Pediatric Research. 24 (1988) 101-105.

routine or quiet enough place to sleep. Some children complain about the feel of the sheets or of clothes on their body. Tactile sensitivity is a common concern expressed by children and adolescents with FASD. It may be subsequent to the neurological changes seen in children with FASD that make it difficult for them, from birth, to screen out irrelevant stimuli.[71]

In addition to the examples listed above, the role of the professional in addressing health concerns is similar to that for younger children.

- Aid in identifying and addressing alcohol use by the mother.
- Aid in ensuring the mother is screened for prenatal alcohol and drug use.
- Facilitate the parent's entry into drug and alcohol treatment, if appropriate.
- Aid the family in accessing needed social health services.
- Serve as a liaison between the health care system and the family.
- Aid the mother in acquiring long-term birth control to ensure she does not have another child exposed to alcohol or other substances.
- Set the child up for FASD diagnostic screening if this has not already occurred.
- Aid in establishing a team, such as the ones described earlier, to provide support, follow-up, and long-term care for the child, the mother, and the family.
- Ensure that the child receives ongoing health care from a family physician or a nurse practitioner. This is particularly true for vision, hearing, and speech screening as the child enters school.
- Ensure public health services are established for the family. These can aid in the child getting needed immunizations, well child care, and provide support for the family.
- Provide public health nursing care and other in-home services to ensure the house where the child resides is safe and appropriate.

[71] Streissguth, A. P. , Barr, H. M. and Martin, D. C. "Maternal Alcohol Use and Neonatal Habituation Assessed with the Brazelton Scale. " Child Development. 54 (1983) 1109-1118.

- Make contact with social services if it is not safe for the child to remain home with the mother.
- Monitor the safety of any foster/adoptive or group home where the child resides.
- Educate the family, in whatever form necessary, as to the health needs and concerns of the child with FASD.

It is clear from the list above, that there is a carry over of health issues from early childhood through the latency period and on into adolescence and adulthood.

Ages Twelve to Seventeen Years:

"I don't plan on screwing up. It just somehow seems to happen a lot!"

- a 13-year-old girl with FASD

As the child moves from latency and childhood into adolescence, sexual safety becomes a primary concern. Sexual health includes the person with FASD being able to make healthy choices about whether to be sexually active, whom to be active with, and protecting themselves from sexually transmitted diseases. One of the common results of the brain damage associated with FASD is a lack of connection between cause and effect and the understanding of long-term possible consequences. These deficits are particularly dangerous when coupled with making decisions about sexual behavior.

Children and adolescents with FASD are often impulsive and easily led. Without proper supervision and support, they are especially vulnerable to being led into possibly dangerous situations. Adolescents may not be open to the structure and constant supervision needed to ensure their safety. The conflict between needing

and accepting structure is one of the most common frustrations expressed by both the adolescent with FASD and the caregiver.[72]

"Oh Dad! We only had sex a few times. What's the big deal? I know all my girlfriend's past boyfriends. None of them look sick. If they aren't sick, why should we worry about using a condom?

-15 year old youth with FAS on why he chooses to not practice safe sex

Major concerns that arise as the person with FASD grows older are sexual and physical safety. These concerns become more apparent as the adolescent with FASD moves into adulthood. Contraception, such as condoms, birth control pills, and diaphragms may simply be too complicated and take too much planning for the person with FASD to use. Depo-Provera is a long-term solution to contraception; one shot every three months. Not every woman with FASD can use Depo-Provera or tolerate the side effects. To acquire adequate contraception, however, young women with FASD have to:

- Find a physician/health care provider to provide care
- Remember to get the shot if on Depo-Provera or obtain birth control pills, diaphragm, or condom, or foam
- Secure a ride to the clinic
- Remember to use protection against sexually transmitted diseases as well as pregnancy
- Find a means to pay for services received

These expectations may be unrealistic without someone to support the young woman with FASD and ensure she is able to access these services. In this

[72] McCreight, B. Recognizing and Managing Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects: A Guidebook. Washington, DC: Child Welfare League of America, 1997.

situation, the role of the professional is that of the advocate and in some cases the transporter. This requires a level of flexibility with which many professionals are not comfortable.

Sexual and safety issues for adolescents with FAS also include the risk of sexual and social exploitation. While young women run the additional risk of pregnancy, both sexes are vulnerable to exploitation. Young males with FASD are at greater risk for being involved in gangs and antisocial activities without understanding the possible consequences of their actions. One young man with FAS was constantly trying to “prove his colors” with the gangs in the neighborhood. He was beaten up on several occasions for antagonizing other youths but never seemed to learn from his past mistakes.

This type of problem may not be seen as a typical health issue. However, physical safety and well-being are serious health concerns for children, adolescents, and adults with FAS. Thus, poor peer relations and involvement with dangerous activities do need to be considered health concerns as well as other psychosocial issues. The prevention and interventions intended to reduce these risk factors are discussed in the psychosocial section later in this manual.

Many people with FASD have dental and orthodontia problems. Dental problems not attended to could lead to abscesses, severe pain, systemic infections, and lost teeth. These issues do need to be addressed, but the family in whatever form, may not have the emotional or financial resources to do so. If the adolescent has remained within the biologic family where either or both parent has continued to use substances, there might not be enough financial and parenting resources to ensure that adequate dental care is provided.

In foster care, there may be constraints due to budget limitations, frequently changed placements and frequently changing caseworkers. A team management approach with one case manager overseeing the care of the child is crucial in

ensuring adequate care. One case manager that stays with the child makes it easier to track what services the child has received and when. Other services such as vision and hearing care can be managed as well.

The role of the professional at this point becomes one of:

- Advocacy to ensure that the client receives needed medical services, regardless of insurance status, e. g. accessing local Planned Parenthood or public health clinics
- Providing adequate and concrete informatio about healthy sexual choices and ways of protecting one's self
- Continuing to aid in accessing dental, visual, and general medical care
- Educating the birth, foster, or adoptive parent about the adolescent's sexual needs and sexual health
- Ensuring the adolescent is residing in a safe place
- Working with the family to reduce the risk of substance abuse
- Helping the family access substance abuse and mental health treatment, if needed for either the parent or the child. It may seem surprising to some that a child might need substance abuse treatment at this age. Among many American Indian and Alaska Native families, however, substance use and abuse can begin as early as nine years of age or even younger[73]
- Helping the family provide appropriate structure on a 24/7 basis to ensure the safety of the patients and the entire community

Ages Eighteen Years and Up:

The health issues in adults with FASD are similar to those seen in late adolescence. Sexual safety and health, along with contraception, are at the forefront of safety for young adults. However, there are other issues that come into play as the person

[73] May, P. A. "The Epidemiololgy of Alcohol Abuse Among American Indians: The Mythical and Real Properties. " American Indian Culture and Research Journal. 18: (2), 1996, pp. 121-143.

with FASD moves into adulthood.[74] Continued dental care, vision care, preventive health maintenance, and medical care for normal illnesses, e. g. care for hypertension or arthritis and other health problems needs to be addressed.

People with FASD rarely have third party insurance or jobs that provide benefits to cover these needs. They may be out of their previous residential placement(s) and out of the state foster care system with the expectation that they will be providing for their own physical, emotional, residential, vocational, and health care. Adolescents and adults with FASD may also have their own children to care for.

Children born to women and men with FASD do not necessarily have FASD. This can occur only if the mother herself had been drinking during her pregnancy. However, as many women with FASD have difficulties meeting their own needs, it is often unrealistic to expect she will necessarily be able to meet the needs of her children. If a woman with FAS has children with disabilities, it is likely to put even more pressure on her, increasing the risk of the mother not being able to retain custody of her children. Some women may not disclose alcohol and other substance abuse during pregnancy for fear of losing their children.[75] Some states have enacted legislation that allows women to disclose and seek treatment without having their children removed from their care solely on the basis of their substance use.

People with FASD over the age of eighteen, due to the apparently increased risk of sexual and social exploitation and failure to exercise safe sexual practices than other peers their age, may be at greater risk for sexually transmitted diseases. During pregnancy, they may not receive adequate or any prenatal care. Services to address these concerns may be difficult for people with FASD to access. Medical services may come through emergency rooms or at the time of delivery of any

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[74] Rosett, H. L. "A Clinical Perspective of the Fetal Alcohol Syndrome. " Alcoholism: Clinical & Experimental Research. 4 - (1980) 119-122.
[75] Gallant, D. M. Alcoholism: A Guide to Diagnosis, Intervention and Treatment. New York, NY: W. W. Norton & Company, - Inc. , 1987 -

children. This is a costly method of care. It may not be preventive care and may provide less continuity of care.

"My older brother, he was adopted. He has FAS and Alzheimer's disease. He's 55 years old. I cared for him in his 20's after my parents died. Now, I am taking care of him again."

- *Sister of a man with FAS who has assumed full responsibility for her older brother*

All people are at risk for increased health issues as they age. This is true for people with FASD, too. But, as with many other issues, the person with FASD may not recognize their problems or services that might be needed to address them. They may not know how to access services or even be able to state to any health care provider what their needs might be.

For health care professionals working with people with FASD over the age of 18, their role now becomes:

- Identifying what health risks might be more prevalent as the person ages.
- Recognizing and aiding in accessing needed services.
- Being an advocate or informant in working with other health care providers.
- Providing direct services in a manner that allows the patient with FASD to understand information, identify options for services, participate in prevention activities, and receive regular care rather than services on an emergency basis.
- Aiding the parent in acquiring in proactive, long-term family planning.

In recent times, the need for sex education within a curriculum of social and decision-making skills has been advanced. Different programs have used food vouchers or recreational gift certificates as incentives for young women to participate

in contraceptive programs. [76] It is not known if similar attempts have been made with young women with FAS/FASD.

However, given the serious need for such measures with this population, it certainly appears worth the effort to design and implement such programs. These could be done through public health agencies or child welfare services. Strong social reinforcement for the use of contraception might also be useful for this population.

General Strategies for Health Care Professionals Working with Patients with FASD:

In summary, there are health concerns that may directly result from prenatal alcohol exposure. [77] The period of early childhood, particularly the first year of life, is often one of increased health risks resulting from the neurobehavioral effects of prenatal alcohol exposure. In later years, health concerns are the same as those that are more commonly seen in the general population. However, the patient with FASD may have more difficulty accessing needed services or making appropriate decisions regarding their health.

Many patients with FASD may not have the skills to be proactive in their own care. A routine health screening facilitated by caseworkers, nurses, and primary care physicians should be held at least once a year. Such screening can also serve as a positive means of preventing and facilitating early health care interventions.

Due to memory problems and other difficulties with organization, people with FASD may not follow medication regimens as needed. Depending on the health problem, this can be fatal. For example, a person with FASD with diabetes will need to be able to check their blood sugar and prepare an insulin injection on their own. This is

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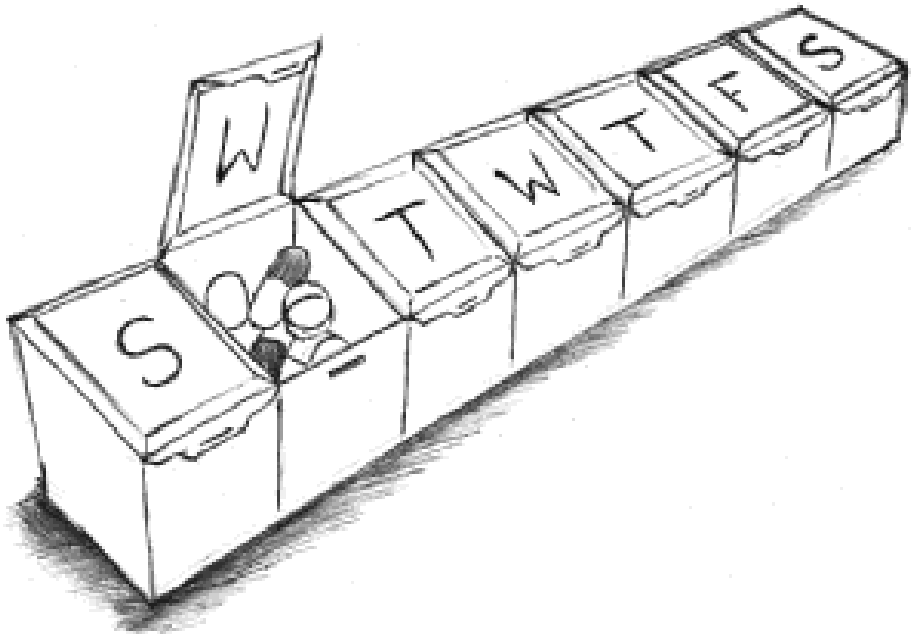
[76] Chernan, L. Personal Communication, August 2002

[77] Clarren, S. K. , Alvord, E. C. , Sumi, S. M. , Streissguth, A. P. , and Smith, D. W. "Brain Malformations Related to Prenatal Exposure to Ethanol. " Journal of Pediatrics. 92 (1978).

a complicated process with which many nonaffected patients struggle. In such a situation as this, the health care provider may need to aid in developing a team



including a public health nurse or in-home health care aides to ensure medication regimens are followed. Directions need to be simple and put in writing or used with visual cues, sometimes in simpler terms than many health care professionals commonly use. Below is a summary of interventions and approaches that health professionals in the field have found useful in working with patients with FASD:

- Health care providers should be aware of any limitations and special needs the parents might have that can impact their ability to provide adequate care to their child with FAS/FASD.
- Obstetricians and gynecologists should screen women patients of childbearing years for substance abuse and provide simple but comprehensive information on the possible effects of substance use during pregnancy.[78]

[78] Center for Substance Abuse Prevention. "Maternal Substance Use Assessment Methods Reference Manual: A Review of Screening and Clinical Assessment Instruments for Examining Maternal Use of Alcohol, Tobacco, and Other Drugs" CSAP Special Report 13. DHHS Pub. No. (SMA) 93-2059. Rockville, MD: Center for Substance Abuse Prevention, 1993.

- Health care providers should be aware of health related resources available in their community. If possible, this information should be provided in written and visual formats to their clients.
- Hospitals should routinely screen at delivery and birth for women using and abusing alcohol and other substances. If the screening is positive, hospitals should work to:

    - Ensure an early diagnostic evaluation is done
    - Ensure Child Protective Services are involved, if needed
    - Aid the parent(s) in acquiring needed services
    - Ensure the child goes to a safe home
    - Teach the parent effective feeding and basic child care
    - Make a plan for parental and child follow-up care with appropriate referrals to public health nursing, substance abuse programs, parenting classes, and family preservation services

Addressing health care needs across the lifespan for patients with FASD requires professionals to recognize that parents and caregivers, regardless of the home and family structure, will need education about the special health needs of their child. For adolescents and adults, sexual health, contraception, and acquiring basic health care are crucial. Simple, concrete information along with professionals providing support and follow-up is critical for all families and patients with FASD.

It is important to remember that physical health issues do not exist in a vacuum. While, as noted, there are primary health issues from prenatal alcohol exposure, there are also secondary health concerns. As detailed in the following section, secondary disabilities in the form of psychosocial needs are often debilitating for patients with FASD. Many, if not most, patients with FASD may not have the skills to be advocates for their own care. Therefore, professionals working in this area will need to be as flexible and proactive as possible.

Integration of Traditional Native Beliefs, Values, and Practices:

The medical model of health is the prevailing foundation for health care services in the Western world. In recent times, however, there have been efforts to approach illness and health from a more integrated physical, spiritual, and emotional view. Traditional Native beliefs on health often cite humans being “out of balance” as a

cause of illness. The use of alcohol, along with the loss of land, language, culture, and family certainly can cause emotional, physical, and spiritual imbalance.

Health care in traditional Native communities was commonly provided by healers (shaman).[79] If a special ceremony was needed, it was often done in the context of the community. Medications were obtained from plants that are often used today.[80]

Today, health care in Native communities is most commonly provided through the Indian Health Service (IHS) or clinics contracted by tribes through Indian Health Service. Accessibility of services can be of concern, however, due to budget constraints, limited funding, and long distances from health care facilities. There may be few health care providers who can adequately diagnose FASD. [81,82]

[79] Erdoes, R. and Ortiz, A. (Eds.) American Indian Trickster Tales. New York, NY: Viking Penguin Books, 1998. -
[80] Walker, R. D; LaDue, R. A. An integrative approach to American Indian Mental Health. Ethnic Psychiatry C. B. Wilkinson - (Ed.) New York: Plenum Press, 1986.
[81] Astley, S. J. and Clarren, S. K. "A Fetal Alcohol Syndrome Screening Tool. " Alcohol. Clin, Exp. Res. 19 (1995) 1565-1571. -
[82] Streissguth, A. P. , LaDue, R. A. , and Randels, S. P. A Manual on Adolescents and Adults with Fetal Alcohol Syndrome - with Special Reference to American Indians. 2nd ed. Albuquerque, NM: Indian Health Service, 1989. -

While all of these factors can inhibit adequate identification and diagnosis and increase the level of concern for at-risk children, mothers, and fathers, there are positive aspects of Native life that can be of help in providing health care to children, adolescents, and adults in Native communities. Traditional healers often hold an immense store of wisdom and knowledge. Ceremonies done with the extended family and community members can provide a sense of worth for the person affected with FASD. Chemical dependency programs that are based on traditions may serve as examples for positive structure, prevention and treatment for families.[83] Community health aides and community health representatives, funded through Indian Health Services and contracted health care programs, can aid in transportation and explaining services and health care programs to patients who might be impaired due to FASD.

Inclusion of traditional Native healing practices into Western style health care programs is happening on a more frequent basis than in the past.[84] Regardless of where the person with FASD resides, it is crucial that health care services are accessible, affordable, and appropriate for the population to be served.

Health Care Needs and Service Matrix:

At the start of Section I, a case study was detailed. Additional information was provided at the beginning of this section. Below is the health care matrix for Jerilynn across the lifespan. Please note the changes as Jerilynn grows older. With each section, a portion of the matrix will be completed with the full series of matrices detailed by the end of the manual.

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[83] Everett, F. , Proctor, N. and Cartmell, B. "Providing Psychological Services to American Indian Children and Families. " - Professional Psychology: Research and Practice. 14 (1983) 588-603. -

[84] Attneave, C. L. "Therapy in Tribal Settings and Urban Network Intervention". Family Process. 8 (1969) 192-210. -

Figure 7

Matrix I:

Health Care Concerns for Jerilynn

Ages 0-5	Low birth weight, failure to thrive, otitis media, developmental delays, atrial septal defect, feeding difficulties
Ages 6-11	Otitis media, dental caries and orthodonture problems, lack of physical coordination, visual problems, childhood diseases
Ages 12-17	Sexual health issues, contraception, sexually transmitted diseases, dental caries and orthodonture, prenatal care
Ages 18 and up	Birth control, sexually transmitted diseases, pregnancy and child bearing, prenatal care, medical care of alcohol intoxication, preventive medical care

Health Care Services for Jerilynn

Ages 0-5	Hospitalization for failure to thrive and heart surgery, pediatric care for failure to thrive and otitis media, physical therapy for muscle and physical development, in-home nursing care for post-surgical needs, dysmorphologist for diagnosis, cardiologist for heart care, dietician consultation
Ages 6-11	Dental care and pediatric care for childhood illnesses, such as otitis media, continued physical therapy, dental, vision, and hearing care
Ages 12-17	OB/GYN care for birth control, medical care for Detox, dental and vision care
Ages 18 and up	OB/GYN care for birth control, medical care for Detox and physical abuse, preventive care

Section III:

Psychosocial Issues and Needs

Jerilynn, as a young child, experienced significant trauma and neglect by her birth mother. Her birth father's identity was unknown. It is not clear if she was sexually abused, although this was suspected. Jerilynn, after the move to her adoptive home, was enrolled in school. However, she had poor peer relationships, impulsivity, anxiety, and, at age nine, began to show highly sexualized behavior. She did not appear to connect cause and effect and was frequently angry.

Her adoptive parents were concerned as Jerilynn seemed not to bond well with them or her adoptive siblings. She did not seem to understand social rules, jokes, or subtle social cues. She was easily frustrated and seemed not to grasp basic abstract concepts. Her social difficulties were the primary reason, along with her academic problems, that finally led to Jerilynn leaving school at an early age.

She seemed to have little sense of danger or how to recognize who was a friend and who was not. She became involved with multiple sexual partners, believing that each loved her. No matter how often her adoptive parents attempted to explain ways to keep herself safe, Jerilynn never quite understood her parents' concern. She resented rules and, in adolescence, refused to follow any of them. She ran away from home, became pregnant on numerous occasions, and ended up with her children being removed from her care. She was often homeless and frequently spent one or more days in jail for misdemeanor crimes, eventually being convicted on drug related charges.

Alcohol is a neurobehavioral teratogen and can disrupt brain cell migration in the developing fetus.[85] Secondary disabilities are difficulties that are the consequence of a primary disability, in this case, brain damage. In children, adolescents, and

[85] Coles, C. D. , Smith, I. E. , Fernhoff, P. M. , and Falek, A. "Neonatal Neurobehavioral Characteristics as Correlates of Maternal Alcohol Use During Gestation. " Alcoholism: Clinical and Experimental Research. 9 (1985).

adults with FASD, this damage presents as impulsivity, lower abstracting abilities, a lack of understanding of cause and effect, attention and memory problems, and learning difficulties. While the health issues described in Section II are serious, it is the secondary disabilities commonly experienced by children, adolescents, and adults with FASD that are the source of most of the long-term difficulties in this population. Secondary disabilities can range from homelessness, mental health issues, and drug and alcohol problems to a lack of a support system and poor peer relationships. Loss of residential placements, loss of child custody, and social and sexual exploitation are other concerns often expressed.[86]

Secondary disabilities may appear at an early age often depending on the environment in which the child resides. This section will address mental health, behavioral, and substance abuse issues and needs of the patient with FASD across the lifespan.[87] It will address the various types of therapy and behavioral management that have, anecdotally, been found to be useful with patients with FASD. This chapter is organized in the following manner:

- Special needs for parents and caregivers.
- Challenging behaviors associated with FASD across the lifespan.
- Interventions and therapy modalities likely to be effective with people with FASD.
- Integration of traditional Native values and practices into mental health services.

While there have been several longitudinal studies that document the psychosocial concerns associated with FASD, there is limited clinical research that demonstrates what therapeutic approaches are most helpful in working with children, adolescents, and adults with FASD. Dr. Ann P. Streissguth at the Fetal Alcohol and Drug Unit of the University of Washington conducted one of the seminal research projects on

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[86] Streissguth, A. P. Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore, MD: Paul H. Brookes - Publishing Co. , 1997.
[87] Healy, J. M. Your Child's Growing Mind: A Practical Guide to Brain Development and Learning from Birth to Adolescence. - New York: Doubleday, 1987. 1994. -

psychosocial needs and secondary disabilities for this population.[88] While highly useful, it is not clear if results from this study, which was based on a clinical population, would generalize to individuals with FASD not seen in clinics.

Dr. Streissguth's study showed that a significant percentage of adolescent and adult patients with FASD had been neglected, sexually and physically abused, had dropped out of school, and had mental health and legal issues.[89] Both sample groups, those with FAS and FASD, had the same types of secondary disabilities regardless of diagnosis or IQ. Those patients identified as having FASD had higher IQ scores. Despite the apparently higher cognitive abilities, the group with FASD actually had more secondary difficulties. They were identified at a later age, not commonly viewed as having a disability, and less likely to receive needed services.

The majority of patients in Dr. Streissguth's study had lived in multiple homes. The number of different home placements was as high as 25. A significant portion of these residential moves occurred prior to the child's fifth birthday. The young child was often moved due to the birth parent's substance abuse. Social services often stepped in, removed the child, and then attempted reunification. A lack of adequate foster homes addressing children with special needs and behavioral problems may lead to children being moved to multiple placements.

"I wish I could understand the jokes of the other kids at school. Someone tells a joke and everyone laughs at me. I laugh but, really, I don't understand what is so funny. "

- *11 year old boy with FAS talking about his frustration with his peers*

As the child grows older, it is usually the behavioral difficulties such as disobedience, defiance of authority, sexually inappropriate behavior, and failure to learn from past experiences that lead to changes in residential care. Poor communication skills are

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[88] Streissguth, A. P. and Kanter, J. (Eds.) The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. - Seattle, WA: U. of Washington Press, 1997. -

[89] Streissguth, A. P. , Barr, H. M. , Kogan, J. , and Bookstein, F. L. Understanding the Occurrence of Secondary Disabilities in - Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects. Seattle, WA: University of Washington, 1996. -

a limiting factor in the lives of children and adults with FASD. Not being able to adequately communicate one's needs and feelings, carry on every day conversations, and understand even simple jokes are frustrations the patients with FAS/FASD commonly reported by caregivers and patients. Communication difficulties can lead to frustration, social isolation, and depression. These secondary disabilities, mainly psychosocial issues, present the greatest problems for these patients.

Poor language development and articulation problems are concerns commonly cited for children with FASD. Language difficulties are also indications of problems with thought organization, comprehension, and communication abilities. Deficits in these areas frequently are problems for the child in school and social interactions.[90] Dr. Truman Coggins of the University of Washington Fetal Alcohol Syndrome-Diagnostic and Prevention Network (FAS-DPN) has evaluated the language of patients with FASD for many years. In his evaluation, he assesses sentence structure, content, language usage, and comprehension among other factors. From the results of the assessment, he is often able to provide information about the maturity of the patient's thinking and what areas of language and social functions might be impacted.[91]

An even larger issue than communication skills deficits is inappropriate behavior. Children with FASD frequently demonstrate challenging behaviors from early in their life. Behaviors that in early childhood are not necessarily of concern can become troublesome as the child grows older. These behaviors include being "huggy" and touchy, overly verbal with "empty" speech, cheerful and oblivious to other's input, and overly friendly. It is important, to begin as early as possible to set boundaries and limits to aid in preventing future, more serious psychosocial and legal problems.

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[90] Streissguth, A. P. and Kanter, J. (Eds.) The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. - Seattle, WA: U. of Washington Press, 1997. -

[91] Coggins, T. Personal communication, June, 2000. -

Streissguth, et. al.[92] described early identification and diagnoses, leading to implementation of appropriate services as significant protective factors against secondary disabilities for individuals with FASD. A safe, stable home with minimal disruptions has also been shown to reduce later problems and provide children with resiliency. This seems to be common sense yet, for many families, acquiring such stability is the most difficult accomplishment to achieve. Supporting parents and caregivers is as crucial in addressing psychosocial needs and secondary disabilities as it is in treating health concerns.

Special Needs for Caregivers and Parents:

"If we all work together, maybe we can change our little corner of the world"

- Parents of three adopted children with FASD

As stated above, psychosocial needs are concerns that will most likely be addressed by the mental health, developmental disabilities, or social services system. Many children enter these systems only when the parent's ability to care for their child is compromised to the extent it comes to the awareness of Child Protective Services. Dr. Streissguth's study suggests that those parents who produce children with FASD are at greater risk for neglecting and abusing their children. Children who have received such abuse and neglect may be more likely to demonstrate sexually aggressive behaviors.[93] Such behavior, whether in the home, school, or the community, is another the reason children come to the attention of counselors, school personnel, and the social service system.

Below are some of the issues and concerns that should be addressed by health care providers to aid parents and caregivers in meeting the needs of their children. The abilities of the parents will often determine the types of directions and interventions

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[92] Streissguth, A. P. , Barr, H. M. , Kogan, J. , and Bookstein, F. L. Understanding the Occurrence of Secondary Disabilities in - Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects. Seattle, WA: University of Washington, 1996. -

[93] Salter, A. Psychological Assessment of Sexually Abused Children, Adolescents and Their Parents. San Francisco, CA: - Sage Publications, 1995. -

that will be most useful and most likely to be followed by the parent. The ability of the parent(s)/caregiver(s) needs to be assessed by any provider working to set up a behavioral treatment program. The following are general suggestions that parents, caregivers, and providers have found beneficial in working with patients with FASD.

If needed, parents should be referred to an alcohol treatment program.[94] There are now programs that allow women to enter treatment with their children. The Birth to Three Program[95] in Seattle is an example of a program that provides extended treatment. Women in this program are encouraged to gain sobriety in conjunction with parenting skills, wrap-around services, and with a client-centered, case management approach.

If children remain with parents who are newly in sobriety, it is important to ensure that the entire family has in-home services to aid with establishment of structure This is important regardless of the basic cognitive functioning of the parent. People newly entering sobriety are often easily overwhelmed. Sobriety can change the dynamics of relationships. It is important that professionals recognize the changes that can occur and how they might impact family life.[96]

Respite care for parents and caregivers is one of the most important services that can be provided. Being able to take a break, have time for one's partner, and getting support from others is one of the main aids parents and caregivers cite as allowing them to retain their adolescent and even adult children in their care. Respite care can sometimes be obtained through state offices of developmental disabilities and children and families services.[97] Parents and caregivers who are newly in recovery or have disabilities may have difficulty navigating these systems

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[94] Drabble, L. "Elements of effective services for women in recovery: Implications for clinicians and program supervisors. " - Journal of Chemical Dependency Treatment 6(1/2):1–21, 1996. -

[95] Grant, T. M. , Ernst, C. C. , McAuliff, S. and Streissguth, A. P. , "The Difference Game: An Assessment Tool and - Intervention Strategy for Facilitating change in High-Risk Clients. " Families in Society. 78(4) 1997, 429-432. -

[96] Wexler, H. K. ; Cuadrado, M. ; Stevens, S. "Residential treatment for women: behavioral and psychological outcomes. " In: - Stevens, S. J. and Wexler, H. K. , eds. Women and Substance Abuse: Gender Transparency. New York: Haworth Press, - 1998. Pp. 213-233. -

[97] Giunta, C. T. and Streissguth, A. P. "Patients with Fetal Alcohol Syndrome and Their Caretakers. " Social Casework: The - Journal of Contemporary Social Work. 69(7) 1998, 453-459. -

on their own. Social workers, case managers, and other providers working with them can aid families in acquiring respite care funds by ordering the forms, helping people fill them out, and attending eligibility meetings with the client

The first step in aiding parents and caregivers is educating them about what are realistic expectations of their young child. Setting such expectations should be based on the child's strengths as well as their limitations. It is important that the parent or caregiver understand that they are not *lowering* expectations for their child but rather setting them at a level that can be obtained. This can help both the child and parents to feel more successful.

Education regarding realistic expectations can be provided through a health educator, family advocate, psychologist, pediatrician or other health care providers. The education of the parent or caregiver does not need to be complicated. It can be as simple as the lists enclosed at the start of this manual. One assessment tool that has been very helpful is the Vineland Adaptive Behavior Scales (VABS).[98] (See Appendix 5).

The VABS is given in an interview with either the caregiver or a teacher. While there are some concerns about geographic and cultural limitations, the VABS provides a chance for the parent or caregiver to discuss both their child's strengths and issues. It also gives a standard score and age equivalent that allows the parent to understand where their child may be functioning in comparison to other children.

Setting more realistic expectations can reduce frustration. While education and information can be provided at the time of the diagnosis, parents and caregivers may feel overwhelmed and unable to process what they are told until a later time. They may need to have the information presented and explained several times. A family advocate or case manager that has knowledge concerning FAS can serve in this capacity as well as be a source of referral information. With the emphasis on the

[98] Sparrow, S. S. , Balla, D. A. , and Cicchetti, D. V. Vineland Adaptive Behavior Scales. Cedar Pines, MN: American Guidance Service, 1984.

family, the term "family advocate" may be less threatening than a “professional” giving this information.

“I fell to the ground when I heard Cindy’s diagnosis. Ten years later, I am not sure if I am standing yet. ”

- Birth mother’s reaction to learning her daughter has Fetal Alcohol Syndrome

It is impossible to have healthy children if families and communities are not also healthy. Parents, whether birth, foster, or adoptive, need support, understanding, and care if they are to continue to provide the same in turn to their children. The next portion of this chapter focuses on the challenging behaviors present in patients with FASD across the lifespan. The diagnoses presented in Appendix 3 are based on these behaviors described below. They are manifestations of the brain damage associated with FASD. The behaviors and problems seen in young children are frequently precursors to those seen in older children.

A review of Piaget’s[99,100,101] theories of cognitive development is helpful in understanding the delays in the abstracting abilities associated with FASD. Moral development, according to Piaget, takes place in stages with moral maturity and comprehension progressing in a fairly orderly and predictable manner. Brain damage particularly in the frontal lobes appears to disrupt and delay abstract thinking and, thus, moral development. Disruption in moral development has serious implications for daily and social functioning.

Some of these concerns were detailed in Section II while the others are explained as follows:

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[99] Piaget, J. The Moral Judgment of the Child. Glencoe, IL: The Free Press, 1932. -
[100] Piaget, J. The Origins of Intelligence in Children. New York: International Press, 1952. -
[101] Piaget, J. “Intellectual Evolution from Adolescence to Adulthood. ” P. H. Mussen (Ed.). Carmichael’s Manual on Child - Psychology. 3rd ed. Vol. 1. New York: Basic Books, 1980. -

Challenging Behaviors Associated with FASD

Birth to Five Years:

Poor habituation and exaggerated startle response: Habituation is an adaptive response that can be demonstrated in newborns. For example, presenting a stimulus to a normal newborn that is not of importance, e. g. snapping fingers,[102] is soon ignored. However, babies with FASD are not able to screen out such irrelevant stimuli. In fact, when repeatedly presented with a stimulus, babies with FASD become more stimulated. This inability to screen out extraneous information is seen across the lifespan.[103,104]

Sleep disturbances: Infants and children with FASD frequently have disrupted sleep patterns. This may be due to abnormalities in sleep functions from prenatal brain damage, environmental disruptions, or both.[105]

Poor sucking response: Many infants with FASD have a weak suck.[106] They may not be able to concentrate on feeding if there are too many extraneous stimuli. Some-times babies with FASD do not have adequate muscle control to suck well. Feeding problems can lead to failure to thrive, putting the child at greater risk of health concerns.

Distractibility/hyperactivity: Poor habituation, the inability to screen out irrelevant stimuli, is related to the distractibility seen in patients with FASD all the way through adulthood. Children diagnosed with FASD are often hyperactive, for example, being restless or unable to sit still. This seems to be true for children with FASD.[107]

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[102] Abel, E. L. "In Utero Alcohol Exposure and Developmental Delay of Response Inhibition. " Alcoholism: Clinical and - Experimental Research. 6 (1982): 369-376. -

[103] Bond, N. W. "Fetal Alcohol Exposure and Hyperactivity in Rats: The Role of the Neurotransmitter Systems Involved in - Arousal and Inhibition. " West, J. R. (Ed.) Alcohol and Brain Development. New York, NY: Oxford University, (1986) 45-70. -

[104] Scher, M. S. , Richardson, G. A. , Coble, P. A. , Day, N. L. , and Stoffer, D. S. "The Effects of Prenatal Alcohol and - Marijuana Exposure: Disturbances in Neonatal Sleep Cycling and Arousal. " Pediatric Research. 24 (1988) 101-105. -

[105] Scher, M. S. , Richardson, G. A. , Coble, P. A. , Day, N. L. , and Stoffer, D. S. "The Effects of Prenatal Alcohol and - Marijuana Exposure: Disturbances in Neonatal Sleep Cycling and Arousal. " Pediatric Research. 24 (1988) 101-105. -

[106] Martin, D. C. , Martin, J. C. , Streissguth, A. P. , and Lund, C. A. "Sucking Frequency and Amplitude in Newborns as a - Function of Maternal Drinking and Smoking. " Galanter, M. (Ed.) Currents in Alcoholism. vol. 5 New York: NY: Grune & - Stratton, 1979, 359-366.

[107] Alexander-Roberts, C. The ADHD Parenting Handbook. Dallas, TX: Taylor Publishing Co. , 1994. -

Irritability, temper tantrums, impulsivity, and disobedience: These are common behaviors and concerns often expressed by parents and other caregivers regarding their children with FASD. In many cases, children displaying these behaviors are labeled obnoxious, uncooperative, and having Oppositional Defiant Disorder (ODD). In actuality, children with FASD are frequently overwhelmed by information and their inability to screen out irrelevant stimuli. As noted, this problem is seen from birth in children with FASD. It takes on more serious implications as the child grows older.

A rigidity of thinking and an inability to adapt to changes in the environment: The ability to read one's environment and make appropriate decisions based on such information is an example of abstracting abilities. Primarily a frontal lobe function, abstracting abilities can be negatively impacted by prenatal alcohol exposure. Not being able to read subtle social cues, make decisions about what clothes to wear, not being able to adapt to last minute changes, and not being able to make sense of even basic rules often leads children with FASD to feeling highly frustrated, angry, and rebellious. Eventually, acting out behavior may result.

Identifying changes in the environment and knowing how to respond to such changes requires a person to have adequate abstracting abilities. Young children have trouble accomplishing such tasks on a routine basis in complex settings. However, even the youngest of children begin to learn how to "work" parents, distinguish between friendly and not friendly faces, and learn how "red" can mean "stop" or "hot."[108] Children and adults with FASD may never learn to recognize subtleties or the importance of environmental changes. They may never have a repertoire of multiple responses to be able to use for varying situations responses. The inability to discriminate and generalize from situation to situation often leads again to frustration or to the child being viewed as disobedient.

Poor peer relationships: Children with FASD, due to the difficulties in abstracting abilities and delays in social development, frequently have peer problems. They

[108] Barrett, K. C. and Wilson, M. A. Child Development. Westerville, OH: Glencoe McGraw-Hill, 1994.

often do not understand the nuancesin social communications and may be seen as intrusive. These troubles often last the lifespan. In children, the poor peer relationships may be frustrating. As the person gets older, they can become involved in exploitive, destructive, and dangerous relationships.

Ages Six to Eleven Years:

"I like to play with four year olds but they just make me mad!"

- 8 year old boy with FAS

The problems first demonstrated in younger children with FASD may not seem overly significant or challenging. There are several reasons for this: the often outwardly verbal and gregarious appearance seen in children with FASD can mask true expressive language deficits, people have lower expectations for younger children, and many of the behaviors that become obtrusive in older children are viewed as "cute, cuddly, and adorable" in younger children. The behaviors described do not diminish as the brain damage does not repair itself. The presentation of the behaviors may change and other issues may emerge. Below is a list of challenging behaviors seen during the latency period:

Difficulty in abstracting abilities: These problems include the child having difficulty separating fact from fantasy and being easily influenced by others. Not being able to connect cause and effect can be viewed as not having a conscience. In reality, it is another sign of the brain damage associated with prenatal alcohol exposure. As the child grows older, they are at risk for increasingly dangerous behavior without understanding possible consequences.

Temper tantrums, lying, stealing, disobedience, and defiance of authority: These behaviors are often viewed as being deliberate on the part of the child. While that can certainly be the case, it is also possible that the child may simply not understand what is being asked of them. When the world is too confusing, and when abstract

concepts such as private property are not comprehended, frustration, temper tantrums, and acting out can occur.

Lying can be deliberate. However, many children with FASD simply respond with whatever is on their mind. An analogy the author commonly uses to describe the brain function of children with FASD is that of the "Magic 8-Ball." A person with FASD can be asked the same question ten times, but come up with ten different answers. Or conversely they can be asked ten different questions and supply the same answer. Just like with the 8-Ball, whatever answer is "floating" near the top is the one that comes out. The same is true on a behavioral basis. People with FASD may be more likely to act out impulsively with no thought to the possible consequences.

The more complex or complicated the situation, the more difficult it is for the child with FASD to respond quickly and appropriately. While all children can have episodes of irritability, temper tantrums, and disobedience, most children understand and recognize eventually what behavior is appropriate. Children with FASD are more easily confused and may not learn if information is presented in too complex a manner or if any specific situation is unfamiliar.

"How can the car I stole be private property if it was parked on a public road?"

- 16 year old youth with FASD on being arrested for grand theft auto

Private property and personal possessions are abstract concepts. Impulsivity and failure to understand these concepts often create situations where the child ends up "stealing" things. There is often no "buffer" between the thought and the action with children with FASD. The thought becomes the deed and often the deed becomes the problem.

Not having a good sense of cause and effect can put children and adults with FASD at a disadvantage. They can be easily led and negatively influenced. An example of this is where the children and adults with FASD have been told to "go into the store and get something."[109] The child or adult will proceed into the store and steal the item. When asked why they had stolen something, a common response is to look puzzled as no one told them to buy the item, simply to "get it."

Brain damage from prenatal alcohol exposure also affects the child's ability to understand and follow directions. Many children with FASD are viewed as disobedient and defiant when in reality they were given either too complex or confusing information. Multiple directions may mean either the first or perhaps the last direction is remembered.[110] There may be no recall of any information in the middle. This is not truly disobedience or defiance, but it is frustrating to parents, caregivers, and teachers.

Hyperactivity/distractibility: The inability to attend to one stimulus for any length of time or screen out irrelevant stimuli is seen in younger children and continues to be demonstrated as the child grows older. In addition, physical hyperactivity, and restlessness often become more apparent when the child enters schools.[111]

Memory deficits: As the child begins school, it is expected that they will remember rules and previously learned information and adhere to social norms. Yet, many if not most children with FASD do not have the brain development to meet these expectations.

Asking a child with FASD to respond to several questions or tasks at one time is likely to lead to failure to complete any of them. Failing to respond to the parent, caregiver or professional's expectations may lead the child to be viewed as

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[109] Streissguth, A. P. Personal Communication, 1984. -
[110] LaDue, R. A. Psychosocial Needs Associated with Fetal Alcohol Syndrome: Practical Guidelines for Parents and - Caregivers. Seattle, WA: U. of Washington, 1993. -
[111] Burgess, D. M. , Streissguth, A. P. "Educating Students with Fetal Alcohol Syndrome or Fetal Alcohol Effects. - "Pennsylvania Reporter. 22(1) 1990 1-3. -

uncooperative, disobedient, and irritable. In reality, they simply may not understand what is being asked of them. This is an illustration of communication problems for people with FAS that persist across the lifespan.[112]

Impulsivity and difficulty predicting or understanding the consequences of their own or others' behavior: Mentioned earlier were the difficulties children with FASD have in monitoring and controlling impulses. At any point where frontal lobe damage occurs, there can be an increase in impulsivity. This is true in children with FASD, regardless of their IQ scores.

Inappropriate sexual behavior: One of the most distressing difficulties facing children with FASD and their caregivers is that of inappropriate sexual behavior. Children with FASD often have trouble understanding and recognizing personal boundaries. Social immaturity, impulsivity, and sexual curiosity are a mixture that often leads to problems in residential placements and, as the child gets older, legal difficulties. Many children with FASD have been sexually abused, often very early in their life. They are easily victimized and may be molested by other children or adults in the community.[113]

Children who have been sexually abused may be at greater risk for sexual acting out. If the child is demonstrating such behaviors, it is important to assess if there is a history of such abuse and determine if the child is still in a high-risk situation.[114] Appropriate action should be taken to ensure the child's safety

Not every behavior listed above will be seen in every patient with FASD. The severity of problems will also vary from patient to patient. Each child with FASD should be evaluated for the individual they are and with attention to their strengths as well as any challenging behaviors they might show.

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[112] Burgess, D. Presentation on FAS in Rolla, ND, April, 1992. -
[113] Streissguth, A. P. , Barr, H. M. , Kogan, J. , and Bookstein, F. L. Understanding the Occurrence of Secondary Disabilities in - Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects. Seattle, WA: University of Washington, 1996. -
[114] Salter, A. Psychological Assessment of Sexually Abused Children, Adolescents and Their Parents. San Francisco, CA: - Sage Publications, 1995. -

Ages Twelve to Seventeen Years:

"Why can't I look different so people know I have problems?

- 17-year-old young woman with FASD

Adolescence is a difficult time for many people whether or not they are affected with FASD.[115] It can be especially trying for those patients who have brain damage as a secondary result of prenatal alcohol exposure. The difference between chronological age and maturity level increases and becomes more apparent in many aspects of the patient's life. The concerns often expressed regarding challenging behavior continue as the patient grows into adolescence. The abstracting deficits noted in the latency period remain but can change in presentation. Deficits in abstracting abilities and the delays in moral development become more apparent and more disabling.

Faulty logic: Abstracting problems continue to be of concern. Difficulties in the patient connecting cause and effect are common, but may have increasingly severe consequences. It is often difficult for adolescents to discriminate between fact and fantasy. By this age, this ability should be well established.[116] In situations where good judgment, forethought, problem solving, and insight are important, the consequences of faulty logic can run from the comical to the tragic.

Increasing social difficulties and isolation: Social expectations increase the older a person becomes. The gap between capabilities and expectations increases. The rules become more complicated and people have less patience with displays of immaturity and impulsivity. The behaviors that appeared endearing when the child was younger now are seen as intrusive and inappropriate. The change of attitude toward the patient is often confusing and frustrating for them. The complaint many

[115] White, J. L. The Troubled Adolescent. New York, NY: Pergamon Press, 1989. -
[116] Piaget, J. "Intellectual Evolution from Adolescence to Adulthood. " P. H. Mussen (Ed.). Carmichael's Manual on Child - Psychology. 3rd ed. Vol. 1. New York: Basic Books, 1980. -

people with FASD have expressed to the author is that “the rules have changed and no one told me.”

Adolescents with FASD may have difficulty making and keeping healthy friendships. They are often:

- Egocentric
- Impulsive
- Aggressive
- Unpredictable in their behaviors
- Limited in their ability to express empathy

All of these behaviors make it difficult for people with FASD to function in a healthy manner. Not being able to manage impulsivity and keep appropriate boundaries can also lead, at this age and even younger, into involvement in vandalism and other criminal activity. One frequently asked question is whether adolescents with FASD are at greater risk to be involved in criminal activities.

It appears that the issue is not more inherent criminal intent. Rather, poor peer relationships, little sense of cause and effect, being accepted only by youths on the “fringe,” and being taken advantage of by others put adolescents with FASD at greater risk for being involved in such activities.

Low Motivation: This results in less participation in and difficulty performing necessary activities such as schoolwork, sustaining employment, and activities of daily living. Low motivation is often related to not being able to recognize the possible outcomes of any specific behavior. Another issue is failure to discriminate what is important from what is not, e. g. , it may be more important for a child with FASD to remember to bring his gum to school than to wear clean clothes or bring his pencil.

The intrinsic satisfaction thought to be associated with many tasks of work and daily living are not necessarily a driving force for adolescents with FASD. Understanding and delaying gratification can be challenging for anyone. For people with FASD, delayed outcomes may feel like desired behaviors are not being reinforced and frustration is increased.[117]

Pregnancy/Fathering a Child: Section II outlined many of the concerns about sexual health and contraception associated with this special population. There is limited information about men with FASD who father children. There are no firm statistics that indicate if these men are raising their children, married, or employed. There is only limited information available about women with FASD and their offspring. What is known is not encouraging. There appears, anecdotally, to be a higher rate of children being removed from women born to FASD[118] even if the offspring do not have FASD themselves.

Removal of children from the home of adolescent parents with FAS is likely related to difficulties that adolescents with FASD have in even meeting their own basic needs let alone those of a child. All of the health concerns associated with teen pregnancy come into play with adolescents with FASD. These adolescents have increased cognitive deficits, short attention span and concentration, and limited ability to follow through. These factors greatly increase the risk to any child born to an adolescent girl with FASD.

In the author's experience, teenage girls with FASD are less likely to use contraception, more likely to have multiple births prior to age 21, and less likely to be able to adequately provide for their children. Unfortunately, all of this is anecdotal information. If even a small portion of it is accurate, teen girls with FASD and their offspring are at an increased risk for parenting problems and all the attendant concerns.

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[117] Shaywitz, S. E. , Cohen, D. J. , and Shaywitz, B. A. "Behavior and Learning Difficulties in Children of Normal Intelligence - Born to Alcoholic Mothers. " Journal of Pediatrics. 96 (1980) 978-982. -
[118] Nelson, L. M. Personal communication, Sept. 2001. -

Many adolescent girls with FASD who are sexually active may also have multiple sexual partners and, thus, multiple fathers for their children. A tragic, but sadly common story in the author's experience is that of a young girl with FASD who was sexually abused, became sexually active at an early age, did not use contraception or protection from sexually transmitted diseases, had three babies by age 18, and was not able to keep any of them because she could not adequately provide even the most basic care for herself. Child Protective Services (CPS) removed her children from her care and another generation of children at-risk came into being.

One young woman of nineteen who was pregnant with her fourth child had been referred to the author for a parenting evaluation. Her first three children had been fathered by two different men. All were out of the parent's care due to allegations of neglect and severe abuse. CPS was poised to take the fourth child. The young woman was questioned about her intentions to use long-term contraception after the birth of this baby. The young woman indicated that she was not so inclined and stated she "was going to keep having babies until the State let her keep one."

In actuality, the State had no intention of ever allowing a child to remain in the care of this mother. Sadly, shortly after the fourth baby was born, prior to CPS taking action to remove this child, the child died of injuries suffered at the hands of the father who was 21 at the time. The father was sentenced to ten years in prison for the death of his child. The young mother was charged with failure to protect and was sentenced to five years. This case study is not typical in terms of such a horrendous outcome. It is, however, typical of the issues and vulnerabilities faced by young women with FASD as they move into adolescence and become sexually active and produce children.

Mental health issues are one of the most significant concerns to arise as the person with FASD grows into maturity.[119] Below are only a few of the concerns that are more frequent in adolescence. It should be remembered that many of these

[119] Novick, N. J. and Streissguth, A. P. "Part 2: Thoughts on Treatment of Adults and Adolescents Impaired by Fetal Alcohol Exposure. " Treatment Today. 7(4) 1995, 20-21.

concerns have their origins early in life, but may not be diagnosed until the patient enters their teens.

Sexual/Emotional Abuse and Trauma: Sexual abuse in early childhood or in adolescence can lead to sexualized behavior, indiscriminate sexual activity, being more vulnerable to sexual exploitation, and posttraumatic stress disorder[120,121,122,123,124,125] (See Diagnoses in Appendix 3).

Low Self-Esteem: This is commonly reported of adolescents with FASD. Their awareness of their limitations increases. Their ability to overcome these limitations unfortunately does not. The "gap" between expectations and abilities grows even greater. The inability to participate in social activities and compete and cooperate successfully with their peers leads to internalized lower self-esteem and depression.[126,127]

Depression: This can result from many causes, e. g. low self-esteem, feeling isolated, or unaccepted. Anger, withdrawal, sexual acting out, and mood swings can also be signs of depression.[128,129,130] As Dr. Streissguth noted in her 1996 study, adolescents and adults with FASD are at an increased risk for depression. What was not detailed, however, were specific etiologies that might have accounted for these results. Causes were postulated but this is an area where more research, both in cause and successful intervention, is desperately needed.

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[120] Nezu, C. M. Psychopathology in Persons with Mental Retardation: Clinical Guidelines for Assessment and Treatment. - Champaign, IL: Research Press, 1992.
[121] Herman, J. Trauma and Recovery. New York: Basic Books, 1997. -
[122] Keane, T. M. Clinical perspectives on stress, traumatic stress, and PTSD in children and adolescents [download] [view] - Journal of School Psychology, 34, 1996, pg 193-197 -
[123] Keane, Terence M; Weathers, Frank W; Kaloupek, Danny G. Psychological assessment of post-traumatic stress disorder. - PTSD Research Quarterly, 3, 1992, 4, pg 1-7. -
[124] Davis, D. Reaching Out to Children with FASD: A Handbook for Children Affected by Fetal Alcohol Syndrome. Paramus, - NJ: Center of Applied Research in Education, 1994.
[125] Famy, C. , Streissguth, A. P. and Unis, A. "Mental Illness in Adult Patients with Fetal Alcohol Syndrome and Fetal Alcohol - Effects. " American Journal of Psychiatry. 155(4) 1988 552-554. -
[126] Guilbert, P. Counseling for Depression. Newbury Park, CA: Sage Publications, 1992. -
[127] Guilbert, P. Depression: The Evolution of Powerlessness. New York, NY: Guilford Publications, 1992. -
[128] Beck, A. T. , Rush, A. , and Shaw, F. F. , and Emerg, B. Cognitive Therapy of Depression. New York: Guilford - Publications, 1979.
[129] Beck, A. T. Depression: Causes and Treatment. Philadelphia, PA: U. of Pennsylvania, 1972. -
[130] Burack, J. A. , Enns, J. T. (Eds.) Attention, Development, and Psychopathology. New York, NY: Guilford Publications, Inc, - 1997. -

Ann Streissguth's study of mothers who produced children with FASD indicated that 97 percent, had some form of mental illness with depression being the most frequent symptom. The predisposition for mental illness, particularly depression, is often inherited, thus it is not surprising that children with FASD also suffer from this condition. Depression is one of the more treatable forms of mental disorder. Psychotropic medication and cognitive behavior therapy, which would have to be modified by FASD, arecommonly effective in treating depression.

"I wasn't trying to commit suicide. I just like the taste of cough syrup."

- 16 year old girl with FASD upon being admitted to the emergency room for alcohol poisoning from drinking two large bottles of cough syrup

Suicidal Ideation and Attempt: There are no firm statistics regarding the number of people with FASD who have attempted and completed suicide. In the few situations the author is aware of such attempts have been done on impulse with little organization or advance thought. This is the good news. The bad news is the risk of harm or death if a person with FASD impulsively takes an overdose of pills or makes another type of attempt. Such impulsivity is yet one more reason why constant supervision and support is crucial.

Substance Abuse: This has been a concern most often noted if there is not a substance free environment. It has been hypothesized that there is a genetic predisposition for people with FASD to be at greater risk for alcoholism. To date, no alcoholism gene has been identified. As with many mental health issues, it is most likely a combination of both nature and nurture that contribute to a higher risk of alcoholism and other addictive disorders.

Loss of residential placement: This occurs more often than what might be expected for adolescents with FASD. The common reasons given for this are the challenging

behaviors described in this section. Adolescence is often a time for rebellion and assertion of one's identity. However, behaviors commonly seen in adolescence are often exacerbated by the secondary disabilities associated with FASD.

Adolescent rebellion: Together with poor judgment and impulsivity, this often leads adolescents with FASD to resent and resist, beyond normal, the structure that is so necessary for their survival. Leaving home with no resources, no support, and no sense of possible consequences puts the adolescent with FASD at serious risk of exploitation and abuse. It is the severity of these issues in adolescents with FASD that depletes the emotional and often financial resources of families causing a loss of residential placement, and at times, rejection by their families.

Ages Eighteen and Up:

"I am old enough to make my own good decisions. "

-17-year-old girl with FAS as she screamed and ran out of her therapy session upon being told she could not spend the night with her boyfriend

The problems and concerns seen in adolescents with FASD continue into the adult years but often without the benefit of any services, steady employment, financial support, or structure. Below is a listing of the issues and concerns frequently noted in adults with FASD. [131,132,133,134]

- Unpredictable and impulsive behavior
- Aggressive and violent behavior
- Depression/suicidal ideation and attempts

[131] Streissguth, A. P. "A Long-Term Perspective on FAS. " Alcohol Health & Research World. 18(1) 1994, 74-81. -
[132] Streissguth, A. P. , Aase, J. M. , Clarren, S. K. , Randels, S. P. , LaDue, R. A. and Smith, D. F. "Fetal Alcohol Syndrome in - Adolescents and Adults. " Journal of the American Medical Association. 265 (1991) 1961-1967. -
[133] Novick, N. J. and Streissguth, A. P. "Part 2: Thoughts on Treatment of Adults and Adolescents Impaired by Fetal Alcohol - Exposure. " Treatment Today. 7(4) 1995, 20-21. -
[134] Streissguth, A. P. , LaDue, R. A. , and Randels, S. P. A Manual on Adolescents and Adults with Fetal Alcohol Syndrome - with Special Reference to American Indians. 2nd ed. Albuquerque, NM: Indian Health Service, 1989. -

- Poor comprehension of social expectations
- Increased expectations of the patient by others
- Increased dissatisfaction towards the patient by others
- Withdrawal and social isolation
- Social/sexual/financial exploitation
- Mental health issues
- Lack of birth control use/pregnancy/fathering a child
- Child care
- Legal issues such as child custody or criminal incarceration

Not every person with FASD demonstrates all of these behaviors. Not every adult patient with FASD will necessarily show aggressive or violent behavior. It is not known if every person with FASD will have mental health concerns. What does appear to be the case, however, is that without structure and support, children, adolescents, and adults with FASD are at risk for a myriad of problems that become more complicated and challenging across the lifespan.[135,136] As previously stated, mental health issues become more imperative in adolescence and adulthood. The next section details the mental health and behavioral diagnoses associated with FASD.

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[135] Streissguth, A. P. , Barr, H. M. , Sampson, P. D. , Bookstein, F. L. , and Darby, B. L. "Neurobehavioral Effects of Prenatal - Alcohol. Part I, II, & III: Research Strategy. " Neurotoxicology and Teratology. 1(5) (1989) 461-476. -

[136] Carmichael-Olson, H. , Burgess, D. M. , and Streissguth, A. P. Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects - (FASD): A Lifespan View with Implications for Early Intervention. Zero to Three. National Center for Clinical Infant Programs. - 13(1) 1992. 24-29. -

Behavioral Interventions and Therapy Modalities for Working with Patients with FASD:

The problems seen in early childhood are precursors to difficulties experienced by this population across the lifespan.[137] Below are interventions that have been recommended for parents, caregivers, and professionals. As with the difficulties being present across the lifespan, the interventions listed below can be implemented and used to aid people with FASD of all ages in reaching their full potential.

Developing appropriate socialization and communication skills and behavior are two of the most important areas where professionals can aid families and patients affected by FASD. Structure, simple and concrete directions, and modeling are the primary methods of teaching children appropriate communication and social skills. Typically children learn these skills through normal life experiences while children suffering from brain damage, like those with FASD, need specific instructions such as social skills training. Eventually, the majority of children and adults learn to recognize and respond to social expectations and rules. They are able to incorporate a wide variety of responses into their behavioral repertoire and to discriminate in choosing which behavior is appropriate. For children with FASD, it is precisely these types of decisions that are most difficult.

Steps to aid children with FASD in acquiring positive communication skills include:

- Helping the parents and caretakers to better understand the child's methods of communication. This includes recognizing the child's nonverbal cues, e. g. starting to fuss when becoming frustrated, withdrawing when over stimulated, and throwing things when unable to complete tasks.
- Helping the child articulate speech by speaking low, simply, and clearly. [138]

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[137] Carmichael-Olson, H. , Sampson, P. D. , Barr, H. M. , Streissguth, A. P. , and Bookstein, F. L. "Prenatal Exposure to - Alcohol and School Problems in Late Childhood: A Longitudinal Prospective Study. " Development and Psychopathology. - 1992. -

[138] Krepelin, E. Sound and Articulation Activities for Children with Speech-Language Problems. West Nyack, New York: The - Center for Applied Research Education, 1996. -

- Ensuring that the child receives speech therapy when necessary.
- Teaching parents and caregivers to:
  - Model "positive feedback and respect."[139] It is not enough to simply tell the child to stop a specific behavior. It is important to tell the child what is expected and demonstrate the desired behavior at the same time as telling the child what needs to change.
  - Provide the child with a concrete means of communicating. Children with FASD may not be able to articulate their needs and feelings. Having a chart of facial expressions with the label underneath the face can help a child identify and express their feelings.
  - Use visual cues such as hand movements to reinforce words, e. g. holding out a hand when saying "Stop!"

It is not just parents and caregivers who can use interventions such as those listed. Professionals working with children with FASD can use them as well. In fact, when working with parents or caregivers of children with FASD, the professional can serve as a model for these behaviors and interventions. The following recommendations are loosely grouped in a chronological manner. Concerns seen in early childhood are frequently precursors to problems in adults; recommendations and interventions used in early childhood can be the formation to needed structure and support in later years.[140]

Professionals can help parents and caregivers in such prevention efforts in the following ways:

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[139] Brady, J. P. and Grollman, S. Risks and Reality: Teaching Preschool Children Affected by Substance Abuse. - Washington, DC: DHHS, 1994.
[140] Forehand, R. L. and McMahon, R. Helping the Noncompliant Child: A Clinician's Guide to Parent Training. New York, - NY: Guilford, 1981. -

Teach parents to:

- Identify the child's strengths and use them as a means of intervention. Every child has some talent or interest. Professionals can facilitate reinforcement of appropriate behavior by helping parents recognize options for positive responses to desired behaviors. Such reinforcement does not have to be monetary. It can be as simple as the caregiver or parent spending extra time with their child, going to a movie, or taking a walk. Encouraging parents and children to identify and discuss what is positive motivation for the child is another way professionals can be of service to families affected by FASD. However, in order to be effective positive reinforcement needs to occur as soon as possible when the child demonstrated the desired behavior.

- Redirect the child as soon as possible into positive behaviors. Reinforce the child whenever they are showing appropriate behavior. Early intervention to keep situations from escalating is not always possible, but can occur if parents and caregivers are able to recognize the first link in "a chain of behavior." For example, if the first behavior indicating a child is escalating out of control is the child clenching their fist, a parent could redirect their child into another activity at this point. Professionals can help draw out chains of behaviors with families and children to help them understand how one behavior leads to another. The child can also be taught relaxation skills and be cued to engage in these skills when they start to become upset.

- Rename the child's behavior from negative to challenging, e. g. seeing the child as frustrated and confused rather than as necessarily oppositional or defiant. [141] This is not to say that children with FASD

[141] Burgess, D. M. , Lasswell, S. L. , Streissguth, A. P. Educating Children Prenatally Exposed to Alcohol and Other Drugs. [Brochure]. Seattle, WA. Fetal Alcohol and Drug Unit, U. of Washington, 1993.

cannot be defiant. Any child can. However, children with FASD often do not understand what is being asked rather than intending to be "bad."

- Allow themselves as parents and caregivers to not "always" be perfect. Just as parents need to set realistic expectations for their children, they need to set appropriate expectations for themselves. Allowing for mistakes and natural frustration can take pressure off the whole family. Professionals working with families affected by FASD can provide reassurance about normal feelings of frustration along with helping develop multiple options for responding to challenging behaviors. Just as importantly, professionals can also reinforce for parents and caregivers the things they are doing correctly.

- Develop networks for support. Families in many communities started support groups to educate, support, and validate each other. These grassroots groups have been responsible for advocating and getting legislation passed to benefit their children as well as providing a safe forum for parents. Professionals can facilitate support groups, attend as guest speakers, and work in partnership to develop such groups. Professionals with an awareness of support groups in their community can make referrals to such groups when appropriate (See Appendix 7).

- Aiding the family in acquiring a case manager. This is an important service professionals can provide. The case manager's role is to help obtain and coordinate needed services. As the child grows older, this may include court and legal involvement and acting as a liaison. Acquiring services from social service agencies can be difficult and frustrating. Having a case manager aid families in obtaining needed services and support can help in reducing stress and tension. Professionals of all types can serve as case managers although the ideal is to have this as a full-

time position within an agency serving the family, e. g. the Division of Developmental Disabilities or Child Welfare Services.

A good example of this approach is the Community Protection Program funded through the Washington State Division of Developmental Disabilities (DDD). This program is for adults with developmental disabilities who have had legal issues or community protection concerns. This program provides 24-hour supervision and support. Participants in the program are able to work, go to school, and lead fairly normal lives, albeit with 24/7 supervision.

The professional in this role provides training in special needs and supervision guidelines, serve as therapist for the client, and aids in developing therapeutic and behavioral interventions.

Many individuals with FASD are not deemed eligible for Development Disabilities Services (DDS) due to their IQ levels being too high, or dual diagnosis. We should work toward all individuals diagnosed with FASD being considered eligible for DDS assistance.

- Establish low to moderate levels of stimulation. The patient's limited ability to deal with stimulation, as noted in previous sections, begins at birth. Individuals with FASD are often easily over-stimulated. Keeping the atmosphere as calm as possible helps children be less agitated and hyperactive. Professionals can explore the family situation within the confines of their office or make home visits. Regardless of where consultation takes place, the professional's role is to identify situations where the level of stimulation in the environment can be changed to meet the needs of the child. Examples of reducing the level of stimulation in the household can be as simple as turning the lights down low and closing a door when putting a child to bed. It can be more sophisticated such as

deciding how to decorate a child's room or setting up a structured environment for the entire family. The professional, in consultation with the family, can determine the what, where, and how to reduce levels of stimulation and promote a calming environment.[142]

- Provide simple, concrete directions , and give them one at a time. While all children need structure and rules, making a situation too complicated can make it difficult for children to remember and follow the required rules. Use of clear, concrete, predictable, and immediate consequences is crucial. Many people view consequences as negative. Consequences can be positive or negative, and if appropriate, highly effective in behavior change.

Given the difficulties connecting cause and effect that many patients with FASD have, it is important that any consequences be given immediately. Parents and caregivers may focus on challenging behaviors and overlook the positive. Professionals, with less emotional involvement can be of

[142] LaDue, R. A., Hartness, C. L. Journey through the Healing Circle. Olympia, WA: DSHS, 2001.

assistance in identifying appropriate interventions and designing behavioral programs. Involving the patient in such programs and ownership of such plans results in a greater willingness on the part of families to continue to support and participate in such behavior management programs.

- Provide a list of daily chores in writing with increasing responsibility as the child grows older. Professionals can aid in developing such lists and making sure they are appropriate to the child and the family environment. Each task is spelled out in simple terms with positive reinforcement for the completion of daily living skills provided on an every day basis.

"I won five gold medals and three bronze medals at the Special Olympics. I am so proud of myself. "

-43 year old man with FAS after participating in a local Special Olympics competition

- Structured leisure time, such as participation in organized sports, e. g. Special Olympics and participation in clubs for children with disabilities is often beneficial according to anecdotal reports. These can provide positive input and outlets for patients with FASD. The professional working with families affected by FASD can aid in identifying and accessing community resources. Recreational and sports activities can be used to provide structure to the patient with FASD. Such services are not just for younger children and adolescents. Adult patients can also benefit from participation in activities such as Special Olympics.

There is little clinical research that shows how successful patients with FASD are in such activities. However, patients are often positive in the recounting of simple participation and victories. Based on clinical and family reports, it does appear that participation in these activities can increase self-esteem, provide appropriate social contacts, and positively structure people's time.

Speech and Language Services:

As previously discussed, speech, language, and articulation difficulties are frequently seen in children with FASD. Speech and language limitations can negatively impact the patient's ability to communicate and also lead to lower self-esteem. Problems in language usage and comprehension may be overlooked due to the "chattiness" and outwardly verbal appearance of many patients with FASD. Part of the diagnostic evaluation through such clinics as the University of Washington FAS-DPN includes a speech and language assessment component. This assessment provides information on how well the patient comprehends and uses language as well as what areas might need remediation. [143],[144],[145]

Speech therapy to aid the patient in better articulation should be written in as part of an IEP and should begin as early as possible (See Appendix 6). Such therapy is frequently available through schools. Parents and caregivers should be taught techniques that can aid their child at home. Krepelin[146] has written a manual with easy to use exercises that can become part of a daily routine for the child. Encouraging a wide variety of language and different words to describe experiences is useful in developing a larger vocabulary. This can also be helpful in increasing overall verbal skills and comprehension.

Mental Health and Substance Abuse Treatment Approaches:

Behavioral therapy and drug and alcohol treatment[147,148,149] should not be based on a "cookie cutter" approach. They should be tailored to the individual with sound

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[143] Shaywitz, S. E., Caparulo, B. K. , and Hodgson, E. S. "Developmental Language Disability as a Consequence of Prenatal - Exposure to Ethanol. " Pediatrics. 68 (1981) 850-855. -
[144] Coggins, T. Personal communication, June, 2000. -
[145] Lubinski, R., Frattali, C. Professional Issues in Speech-Language Pathology and Audiology (2nd Edition). Canada: Singular, - 2001. -
[146] Krepelin, E. Sound and Articulation Activities for Children with Speech-Language Problems. West Nyack, New York: The - Center for Applied Research Education, 1996.
[147] Andrade, R., and Stevens, S. J. (2001). Reading between the Lines: Drug –Involved Women Seeking New Identities. The 63rd - Annual Scientific Meeting of the College on Problems of Drug Dependence, Scottsdale, AZ. , June 16-21, 2001.
[148] Stevens, S. J. and Wexler, H. K. , eds. Women and Substance Abuse: Gender Transparency. New York: Haworth Press, - 1998. -

therapeutic principles underlying the treatment program. Prior to the implementation of any treatment or therapy program, all providers involved should have a basic understanding of FAS/FASD, the patient's skills, deficits, and the environment in which the patient will reside. Psychological, academic, and adaptive evaluations should be done at the start of any such treatment or placement and continue on a regular basis. Assessment can direct therapy. Such evaluations can measure progress and redirect therapy, identifying new issues as they come to the forefront.

IQ tests, while generally valuable, are not always the most appropriate assessment instruments. It is not necessarily the intelligence of the person that decides their daily living success. The day-to-day world, managing personal affairs, and keeping out of danger are highly important skills.

The following section details the concerns of substance abuse and mental health assessment and treatment. To the author's knowledge, there have not been any large, formal outcome studies that detail what types of therapy are most useful for patients with FASD. This is a glaring area of omission that, hopefully, will be addressed by the scientific community in the near future.

Standard insight therapy is not generally recommended for patients with FASD. Baxter[150] states that traditional insight therapy can be useful, but the "key is to link talk therapy to physical representations of the issues." This is not traditional insight therapy, which relies on the client to come to an abstract comprehension of their behavior, the causes of their behavior, recognizing when behavior is appropriate, and being able to generate their own solutions and increase healthy behaviors.

Baxter makes several points that deal with providing talk therapy to clients with FASD. One is that people with FASD can have insight. Another is the need for people with FASD to learn to express and adequately deal with anger. It is

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[149] Streissguth, A. P. , Moon-Jordan, A. , and Clarren, D. K. "Alcoholism in Four Patients with Fetal Alcohol Syndrome: - Recommendations of Care. "Alcoholism Treatment Quarterly. 13(2) 1995, 89-103. -

[150] Baxter, S. L. Adapting Talk Therapy. In Fantastic Antione Grows up. (J. Kleinfeld, B. Morse, and S. Wescott, Eds.) - Fairbanks, AK: University of Alaska Press, 2000. -

important to allow people to tell their story and express their feelings. This is particularly true of people who have experienced trauma, grief, and loss. However, once the client leaves the therapy session, they still need to have skills and support to manage their behavior. This is an area where, in the author's experience, "talk or insight" therapy needs to have concrete connections to the "world" the client lives in.

It should not be assumed that simply because a person has FASD they cannot receive some benefit from insight therapy, nor should it be assumed that they can. Therapy should be tailored to meet the individual needs of the client. This requires the therapist to have a familiarity and comfort with a variety of techniques while providing stability and consistency at the same time. Part of the initial evaluation when a client begins therapy should be to gain as much information as possible to determine what variety of approaches might best meet the needs of the client.

Another therapeutic approach is positive behavior support.[151,152,153,154] This approach stresses short-term goals, emphasis on the patient's positive behavior, and redirection from challenging behaviors to appropriate actions. Concrete approaches, modeling, and aiding the patient in articulating their feelings and needs in a positive manner are important aspects of therapy and treatment.[155] Therapists should also be aware of and prepared for the emotional liability of patients with FAS/FASD.[156]

One therapeutic approach that has been utilized with patients with FASD, (See Appendix 7), is art therapy. Many children, adolescents, and adults with FASD are creative and enjoy art. Using art as a means of expressing feelings is not a new

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[151] Lewis, T. J, Sugai, G. , Colvin, G. Reducing problem behavior through a school-side system of effective behavioral - support: Investigation of a school-wide social skills training program and contextual interventions. School Psychology Review, - 27 (1998), 446-459. -

[152] Lewis, T. J. , Colvin, G. , Sugai, G. (in press). The effects of pre-correction and active supervision on the recess behavior - of elementary school students. School Psychology Quarterly. -

[153] Schleien, S. J. , et. al. Lifelong Leisure Skills and Lifestyles for Persons with Developmental Disabilities. Baltimore, MD: - Paul H. Brooks Publishing Co. , 1995. -

[154] Levitt, S. Basic Abilities: A Whole Approach: A Developmental Guide for Children with Disabilities. Chicago, IL: - Independent Publishing Group, 1997.

[155] Taylor-Greene, S. , Brown, D. , Nelson, L. , Longton, J. , Gassman, T. , Cohen, J. , Swartz, J. , Horner, R. H. , Sugai, G. , - Hall, S. School-wide behavioral support: Starting the year off right. Journal of Behavioral Education, 7, (1997) 99-112. -

[156] Masis, K. Personal Communication, 2002. -

notion. This is one approach that may well be worth cultivating. However, the effectiveness of this model has not been vigorously evaluated.

A common approach to therapy for trauma victims is "retelling and reframing" their experiences.[157,158,159] Reframing implies that the person has the cognitive and abstracting abilities to use these approaches. In actuality, the retelling of the story may be useful in working with patients with FASD who have been traumatized. Instead of cognitive reframing, however, identifying and reducing challenging or destructive behaviors that may result from trauma may be more useful. It is difficult to assess the efficacy of therapeutic approaches without outcome studies. Despite

[157] Herman, J. Trauma and Recovery. New York: Basic Books, 1997. -
[158] Beck, A. T. and Emery, G. Anxiety Disorders and Phobias: A Cognitive Perspective. New York: Guilford Publications, - 1985. -
[159] Barlow, D. H. (Ed.) Clinical Handbook of Psychological Disorders. 2nd ed. New York, NY: Guilford Press, 1993. -

the paucity of such studies, the therapist is encouraged to have familiarity with as many therapeutic approaches as possible.

"I drink because my friends all drink. I'm left out of a lot of things anyway. If I don't drink, no one will like me. "

- 29-year-old man with FASD on his substance use

Drug and alcohol treatment should be made accessible for patients with FASD, if needed. One of the first things given to people when they enter drug and alcohol treatment is structure. [160,161,162] One of the first things lost at the end of treatment is structure. It is the drug and alcohol-free environment, not necessarily insight that is of the most use to patients with FASD who enter drug and alcohol treatment programs. Without continued structure and support, sobriety is difficult for

[160] Goldberg, M. E. "Substance-abusing women: False stereotypes and real needs. " Social Work, 40(6):789-798, 1995. - (130909)
[161] Wilsnack, R. W. , Wilsnack, S. C. Gender and Alcohol: Individual and Social Perspectives. New Brunswick, NJ: Rutgers - Center of Alcohol Studies, 1997.
[162] Wexler, H. K. ; Cuadrado, M. ; Stevens, S. "Residential treatment for women: behavioral and psychological outcomes. " In: - Stevens, S. J. and Wexler, H. K. , eds. Women and Substance Abuse: Gender Transparency. New York: Haworth Press, - 1998. Pp. 213-233. -

anyone.[163,164] Following is a listing of areas of treatment to be addressed. For people with FASD who have impulse problems and poor peer support, provision of structure can be one of the most important aspects of treatment.[165]

Twelve-step programs provide valuable tools for many people in recovery. However, they are based on insight, introspection, and self-motivation. These are not commonly areas of strength for the patient with FASD. Professionals who are screening for substance abuse and providing treatment need to be aware of these factors and plan treatment interventions according to the ability of the patient.

Treatment programs need to be aware of the possibility that a significant portion of their patients may well be affected by prenatal alcohol exposure. Professionals that design and implement substance abuse programs will need to recognize the wide diversity that might exist among their patients in terms of abstracting abilities, behavioral control, introspection, and learning. A structured aftercare program addressing psychological and environmental needs may be more successful in aiding a person with FASD maintaining their sobriety. Based on the experience of inpatient treatment programs, the higher the level of structured aftercare, the greater the likelihood of success.[166]

Anecdotal data and limited clinical research available suggests that structure and consistency from the treatment setting to the home will be most effective.[167] Given the need for structure among patients with FASD, it would seem to follow that such aftercare and a substance-free environment would be even more important. There is need for long-term follow-up studies that determine which drug and alcohol treatment programs are most successful for these groups of patients.

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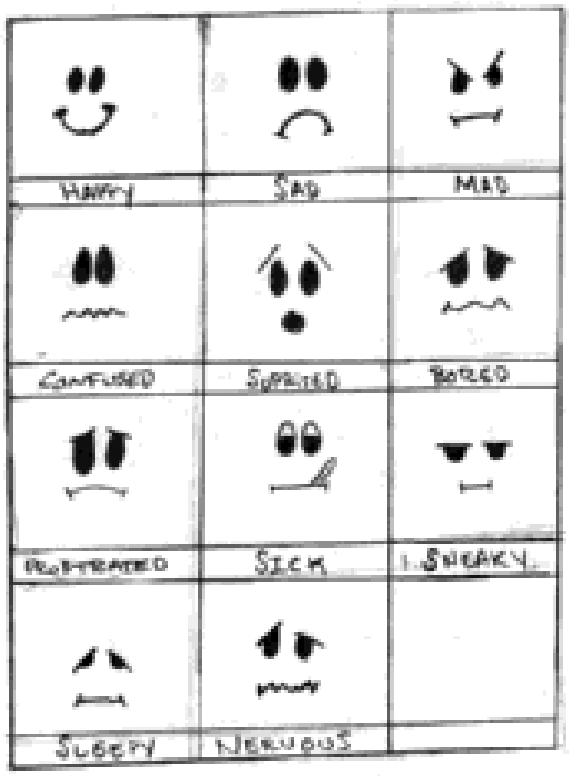
[163] Woolis, DD Family works: Substance abuse treatment and welfare reform, Public Welfare, 1998. -
[164] Comfort, M. ; Kaltenbach, K. ; and Loverro, J. A search for strategies to engage women in substance abuse treatment. In - Social Work in Health Care 31:4, pp. 59-70 (2000). -
[165] Boyd, G. A. Drugs and Sex. Drug Abuse Prevention Library. New York, NY: The Rosen Group, 1993. -
[166] Streissguth, A. P. Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore, MD: Paul H. Brookes - Publishing Co. , 1997.
[167] Streissguth, A. P. Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore, MD: Paul H. Brookes - Publishing Co. , 1997. -

It is important for the therapist to take a multimodal approach to therapy and treatment. Flexible structure and creativity are important tools for the therapist and the family to keep at hand. Specific examples of such flexibility include:

- Allowing the client to “take a break” at various points in therapy. Sitting in a chair for fifty minutes can be difficult for anyone. Talking about traumatic issues, coupled with the, perhaps, unreasonable expectation of the person with FASD to attend for nearly an hour, can create stress and frustration. Allowing the patient to change to a different topic when they feel highly stressed and then redirecting the conversation back to the topic of therapy can be helpful.
- Allowing children to color and tell stories about their drawings and using such stories to help them problem-solve is often useful.
- Providing a sheet with the faces of feelings and moods can be used as a model for the child to tell about their issues and/as a model for drawing out their feelings.
- Ensuring that the patient is allowed to give their input. Identifying and using positive reinforcements for appropriate behaviors that the patient views as important is more likely to increase participation.
- Participation of caregivers and families in therapy can be useful for a variety of reasons:



- It allows the therapist to model appropriate behaviors such as limit setting, clarification in communication, and healthy ways of expressing needs and feelings.
- It decreases the likelihood of the patient presenting diminished and false information.
- It increases the probability of consistency from one setting to another.

Sexuality and Sexual Issues:

"Sex!?!? Sex!?!?! My son can't be sexually active. I promised the judge when I adopted him that I would not let him have sex until he was 45 years old!"

- mother of a 19-year-old man with FAS upon learning her son had become sexually active

Sexual acting out and inappropriate sexual behaviors are of increasing concern among caregivers of people with FASD and professionals working with this special population. While these are commonly reported issues, they are some of the most difficult for both caregivers and professionals to address. Sexuality is a basic human need, but is often overlaid with cultural, personal, societal, and religious values.

Education of parents and caretakers regarding age appropriate sexual development is critical. Many parents and caregivers have difficulty when it comes to their children developing into sexual beings.[168] Yet, nothing is more natural or predictable.[169,170,171] While people with FASD may have cognitive deficits, physiological sexual development usually occurs in the normal timeframe. Helping parents understand what normal sexual development is and supporting parents through their child's sexual changes is an area where professionals can be of extra support.[172] Professionals providing such information and support need to be aware of their own issues and biases with regard to sexuality and sexual orientation and other issues such as masturbation.

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[168] Cole, J. , Tiegreen, A. (Illustrator) Asking about Sex and Growing Up: A Question - and Answer Book for Boys and Girls. 1998. -
[169] Streissguth, A. P. and Kanter, J. (Eds.) The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. - Seattle, WA: U. of Washington Press, 1997. -
[170] Boxer, M. C. , Cohler, B. J. , Herdt, G. and Irvin, F. "Gay and Lesbian Youth. " Tolan, P. H. and Cohler, B. J. (Eds.) - Handbook on Clinical Research and Practice with Adolescents. New York: Wiley, 1993. -
[171] Bell, R. Changing Bodies, Changing Lives: Book for Teens on Sex and Relationships. New York: Random House, 1988. -
[172] Graver, J. How You Are Changing: For Discussion or Individual use: For Ages 8 to 11 and Parents. (Concordia Sex - Education, Book 3). St. Louis, MO: Concordia Press, 1995. -

Parents, caregivers, and patients need clear and understandable education regarding sexual development, birth control options, and protection against sexually transmitted diseases (STDs). This is one of the most sensitive and difficult areas for caregivers and parents to discuss with their children. Professionals can facilitate communication by providing an opportunity for a straightforward, matter-of-fact conversation. Having materials that provide information visually as well as in written form are useful. Materials may be acquired from agencies such as The Arc and Planned Parenthood (See Appendix 7).

Education of parents, caretakers, and patients is crucial to help protect against sexual exploitation. This is an area where good judgment, thoughtful anticipation of possible outcomes, and positive peer support are critical. It is also where patients with FASD are most vulnerable. While it may seem a nearly impossible task, limiting access to negative peer influences is one of the most positive and proactive ways parents can help ensure the sexual and emotional safety of their children.[173] This can be difficult as children move into adolescence and the adult years. If such choices can be supported earlier in life, they may be more likely to be made at later ages.[174,175]

Therapy with children, adolescents, and adults with FASD who have demonstrated sexually aggressive or inappropriate sexual boundaries may be a demanding endeavor. The underlying goal, no matter what the situation, is to ensure safety for the community and the client. This basic goal needs to be stressed to the family and patient at the start of treatment and throughout the course of therapy. Professionals should be aware of applicable state abuse reporting laws.[176] The limits of confidentiality need to be conveyed, verbally and in written form, when therapy commences and on a regular basis.

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[173] Davis, F. S. Private Zone: A Book Teaching Children Sexual Assault Prevention Tools. Charles Franklin Press, 1984. -
[174] Engel, B. Beyond the Birds and the Bees: Fostering Your Child's Healthy Sexual Development. New York, NY: Pocket - Books, 1997.
[175] Krebill, J. , and Taylor J. A Teaching Guide to Preventing Adolescent Sexual Abuse. Santa Cruz, CA: ETR Associates, - 1988. -
[176] Revised Code of Washington (RCW 10. 77). Olympia, WA: State of Washington. -

For people with FASD who have deficits in abstracting abilities, it is important to explain the limits and bounds of confidentiality and reporting in simple and concrete terms. It is not enough to simply ask the patient if they understand what is being asked. Having the patient explain back to the therapist what they have heard, in their own terms, is a more effective means of determining if the client truly comprehends the concepts presented. These concepts should be clarified prior to the start of any therapy.

Sexual deviancy therapy is an area where there is an increasing body of literature. However, there is limited information on assessment and therapy with developmentally disabled sex offenders, including people affected by FASD. Anna Salter,[177] Fred Berlin,[178] Reid Meloy,[179] Nicholas Groh,[180] and Tim Kahn[181] are all excellent resources for designing assessment and treatment programs for sexually aggressive and deviant children, adolescents, and adults with FASD.[182]

This section will present only a few of the approaches that, based on anecdotal reports, appear to be successful in working with people with FASD with sexual issues.[183] Only very limited research has been conducted in this area. This is an area where it is critical that clinical and outcome research is conducted because this appears to be an area of increasing frequency and severity among this population

The following recommendations are based on a community-based approach where there are still family members or caregivers closely involved with the patient. Where there is not structure, support, or a family member or caregiver involved, it is far more difficult to ensure that safety plans, homework, thought-stopping techniques , covert sensitization, relapse prevention, and other common sexual deviancy

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[177] Salter, A. Psychological Assessment of Sexually Abused Children, Adolescents and Their Parents. San Francisco, CA: - Sage Publications, 1995.
[178] Berlin, F. S & Meinecke, C. F. (1981). Treatment of sex offenders with antiandrogenic medication: conceptualization, - review of treatment modalities, and preliminary findings. Am J Psychiatry, *138*, 601-7. -
[179] Meloy, J. R. The Psychopathic Mind: Origins, Dynamics, and Treatment Northvale, N. J. : J. Aronson, 1988. -
[180] Groh, A. N Men who rape: The psychology of the offender. New York: Plenum Press,1979. -
[181] Kahn, T. Pathways. Brandon, VT: Safer Society Press, 1998. -
[182] Valliant, P. M. , Asu, M. E. , and Howitt, R. "Cognitive Styles of Caucasian and Native Indian Juvenile Offenders. " - Psychological Reports. 52 (1983) 87-92. -
[183] Ryan, G. ; Lane, S. (eds.) Juvenile Sex Offenders. San Francisco, CA: Jossey-Bass, 1997 -

techniques are used on a day-to-day and consistent basis by the patient. For the reader not familiar with these approaches, see the Reference and Resource sections for trainings available in these areas. The following section will touch on only a few basic approaches.

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While parents and caregivers may be involved in the therapy sessions, there will be times when the client will need time and privacy with the therapist. This should be respected. In sexual deviancy therapy, as much as possible, it is wise to include family members or caregivers in the therapy sessions. Inclusion of family members or caregivers can:

- Reduce the amount of false information presented by the client in a therapy session
- Provide family members and caregivers with intervention alternatives
- Increase the therapist's awareness of any family and community issues of which the therapist might not otherwise have knowledge
- Increase consistency from therapy to the home environment and vice versa
- Decease denial on the part of family members as regards to the seriousness of any sexual issues
- Minimize the secrecy that often surrounds inappropriate sexual behavior
- Increase accountability of the patient and any caregivers to ensure that safety plans put in place are closely followed

Development of a safety plan is one of the first steps when beginning therapy for sexual issues. The safety plan should be written and presented in concrete terms, and should specify:

- The triggers for reoffending (Danger Zones)
- Who can and cannot be unsupervised chaperones for the patient

- What area such as parks, zoos, schools, and roller skating rinks are not appropriate without line-of-sight supervision
- What steps should be taken to deescalate a situation
- What places of employment and school are appropriate

Other items can be included in the safety plan to tailor it to the needs of individual patients. One of the most important aspects of the safety plan is to make sure everyone involved, therapist, case manager, school personnel, employers, line staff, probation officer, and any others provide input. All needed parties should be given a written copy of the safety plan, and no significant changes should be made without notification of all of those involved.

Helping the client identify danger zones and responding to them appropriately is one of the salient features of offender therapy. Danger zones involve the offender's target populations. For young children and adults with developmental disabilities, this can be done very simply, e. g. "Do not look at children. Do not watch children on television. Do not watch, approach, or talk to children in the community."

The need to avoid danger zones should be reinforced on a regular basis. For some young children or disabled adults, the use of "red" for "unsafe" or "stop" and "green" for "safe" and "go" can be helpful. Tim Kahn[184,185] has written two excellent books on prevention of offending behavior. Roadmaps for Recovery is very good for young children and for use with developmentally disabled adults. Some modifications need to be made when using this book with adults due to some child-centered content. However, the concepts of prevention and consequences are presented in easy to understand, concrete, and highly useable ways.

[184] Kahn, T. Pathways. Brandon, VT: Safer Society Press, 1998. -
[185] Kahn, T. Roadmaps to Recovery. Brandon, VT: Safer Society Press, 1999. -

The second book, Pathways, is for young adults. It can be used with higher functioning developmentally disabled adults. It walks the patient through their offending pattern, victim empathy, and relapse prevention.

Thought-stopping and covert sensitizations are techniques where, when offending thoughts enter the patient's mind, they are to replace them. The patient is instructed to use the term "Stop!" every time these thoughts come into their head. For example, if a male patient fantasizes about offending a young girl, he is instructed to replace the thoughts with a chain of thoughts such as: "He sees the child, he begins to approach the child, the police come and arrest him, he goes to jail, everyone knows, and he feels ashamed and humiliated."

The basis for this approach is to ensure that fear, caution, and a change in behavior will result. It is important when using these techniques that the replacement thoughts be presented in very simple, concrete terms that the patient understands. The thought-stopping and covert sensitization techniques must be used every time the inappropriate thoughts occur. Situations that trigger these thoughts should be avoided as much as possible.

Fantasy logs are often required of sex offenders. These can serve useful purposes in letting the therapist be aware of who are targets of offending for the patients. This is critical information[186,187] as fantasies may be part of rehearsing for future offending. However, with people who persevere, which many with FAS/FASD do, asking them to keep fantasy logs on a daily basis may actually increase the inappropriate thinking. It is important for the therapist to check in and track the fantasies, but not allow the client to focus on them.

Many times, behavioral management and supervision are more critical than the therapy in ensuring a reduction in offending behavior. Constant monitoring and

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[186] Laws, D. R. , O'Donohue, W. (Eds.) Sexual Deviance. New York: The Guilford Press, 1997. -
[187] Salter, A. Psychological Assessment of Sexually Abused Children, Adolescents and Their Parents. San Francisco, CA: - Sage Publications, 1995. -

supervision can ensure the patient has no access to their offending populations. While such monitoring may be available in select programs, it may not be possible for people in the community at large.

In the latter situations, where the offending patient is not in a residential or monitored location, it will be critical for there to be some form of monitoring and structure. Unfortunately, once a week individual or group therapy or monitoring through probation may not be enough to ensure community safety. This is an area where it will be very important for professionals and families to work together to ensure the safety and protection of all.

Depo-Provera is a synthesized female hormone that is commonly used for long-term contraception. In a few reported cases of pedophiles and rapists, it has been used to lower the level of circulating testosterone and to reduce obsessive sexual thoughts.[188,189] There can be serious side effects with use of this medication. It should be taken only in rare cases where other methods have proved unsuccessful and under the careful monitoring of a physician. It should also be used only in conjunction with behavioral and other sexual deviancy therapy.

Structure and supervision appear to be the most useful tools in preventing offenders from re-offending. This is the goal of the Community Protection Program in Washington State. In this program, there is 24/7 supervision with chaperones, Employment, community outings, and schooling are supervised by the residential staff and others pre-approved by the sex offender treatment provider. Appropriate structure and supervision ensures the offender does not have any unsupervised contact with vulnerable adults and children. For people with FASD who are impulsive, such supervision and structure is a key to ensuring there is no more offending behavior.

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[188] Prentky, R. A. (1997). Arousal reduction in sexual offenders: A review of antiandrogen interventions. *Sexual Abuse: A Journal of research and Treatment, 9*, 335-348. -

[189] Meyer, W. J. , Cole, C. & Emory, E. (1992). "Depo Provera treatment for sex offending behavior: an evaluation of - outcome". *Bulletin of the American Academy of Psychiatry & Law, 20*, 249-59. -

Any therapist working with offenders with FASD must be aware of the concerns and special needs listed above. It is tempting to believe that sexual orientation and impulsivity can be "changed" or "cured." In reality, there is little empirical data to indicate such thoughts are more than "wishful thinking." Professionals would do their patients and the community a far greater service in ensuring that appropriate structure, supervision, and monitoring of the offender with FASD is in place. Open discussion of these concerns, along with appropriate therapy and implementation of safety plans are not fail-safe measures. These approaches could be positive starts to address these critical issues and prevent more abuse.

Many adolescents and adults with FAS/FASD are lonely and may be emotionally needy. Some one who "shows kindness" may also be able to influence the person with FAS/FASD into an inappropriate sexual situation. A means of preventing such exploitation may lay in teaching social skills in a group setting.

One such program for developmentally disabled adults is in place through Seattle Mental Health (SMH) in Seattle, Washington. SMH has relationship groups which also discuss sexual issues and boundaries. They also have dances. Activities such as these allow people with FAS to socialize in a safe environment and learn social skills that may help protect them within the community at larger.

Additional Therapy Modalities

Throughout this manual, early identification and diagnosis has been stressed. Early intervention is also as important. There are few, if any specific therapeutic programs that have been developed specifically for children, adolescents, and adults with FAS/FASD. There is, however, a substantial body of literature from the field of autism and attention deficit hyperactivity disorder. Included in therapeutic

approaches from the two fields are incidental teaching, discrete trial intervention, and prompt and prompt fading.[190,191]

The approaches are defined as follows:

Incidental Teaching:

This is "a process of getting elaborated language by waiting for a person to initiate a conversation" and a second "responding in ways, asking for more language from the first person."

The notion behind this is to build language upon the patient's interests. If a child with FAS is in a room with objects they are interested in, the therapist or teacher can respond when the patient initiates conversation about the object that interests them. Response is thought to encourage response, thus enlarging language and connecting language to the concrete.

In people of any age with FAS, such an approach may be helpful. Incidental learning can build on the gregariousness and chattiness exhibited by many patients with FAS. Encouraging focused and more structured responding through the natural interests or concerns of a patient can be applied in a wide range of settings.

Prompt and Prompt Fading[192]

Prompts are simply extra cues to aid people with disabilities such as autism in learning new skills. A prompt can be a variety of behaviors, verbal cues, or

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[190] McClannahan, L. E. ; Krantz, P. J. In Search of Solutions to Prompt Dependance. In: D. M. Baur E. M. Peindston (Eds) - Environment and Behavior. Boulder, CO: Westview Press, 1997 -

[190] Hart, B. M. ; Risley, . R. How to Use Incidental Teaching for Calaboratizing Language. Austin, TX:PRO-ED, 1982. -

[191] McClannahan, L. E. ; Krantz, P. J. In Search of Solutions to Prompt Dependance. In: D. M. Baur E. M. Peindston (Eds) - Environment and Behavior. Boulder, CO: Westview Press, 1997 -

[192] McDuff, G. S. ; Kramer, P. J; McClannahan, L. E. Teaching Children with Autism to Use Photographic Activity Schedules: - Maintenance and Generalization of Complex Response Chains. Journal of Applied Behavior Analysis (26) 89-95, 1993. -

instructions that "increase the likelihood that children will make the correct response." In every day life, this means supplying the patient with input through social or verbal cues or modeling.

The positive aspect of prompting is that the focus is on the acquisition of positive skills without loss of judgment or the application of negative consequences.

These approaches are very behavioral, but are grounded in the person's daily environment. They may, at first, require additional efforts of structure and interaction by the teacher and parent or caregiver. However, if implemented early, it is hoped that through repetition and success these interventions can provide a basis for appropriate behavior across the lifespan.

Another positive respect of these approaches is their conduciveness to a variety of settings and modifications as the patient grows. These skills can be easily taught to anyone living or working with the patient.

Transitions and Planning for the Future:

"Who will care for my adult child when I no longer can?"

- a common refrain heard from the parents of adult children with FASD

The next section focuses on transitions from age to age, and long-term planning. The professional's role in addressing these areas is to identify resources and to aid families in ensuring their children, regardless of age, have structure, support, and

safety across the lifespan. To accomplish these goals, professionals should strive to:

- Anticipate crises situations and provide appropriate planning and early interventions. Most people are creatures of habit and routine. This is even more so with individuals with FASD. It is considered common sense and good parenting[193,194,195,196] to have structure and predictability in a child's daily life. Given the difficulties patients with FASD have in setting their own structure, it is even more imperative that structure and supervision is provided on a consistent and day-to-day basis for them. Professionals who assist parents and caregivers in designing structure and supervision can also aid in teaching them to coach their children through changes and transitions.

- Giving information ahead of time, walking children through transitions, and explaining what might be expected as a result of changes are all methods of helping patients deal with transitions. One of the most difficult challenges facing parents and caregivers is staying calm in times of crises. Professionals can help in these situations by providing alternatives for parents and caregivers in terms of responses to challenging behaviors. Options and flexibility can help both parents and patients reach their potential by reducing undesired behaviors and increasing successes.[197,198,199,200]

- Implement planning for future residential placement and financial needs. A common concern for parents and caregivers is who will take care of their child when they no longer can. The answer to this question will vary from patient to

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[193] Wender, P. H. The Hyperactive Child, Adolescent and Adult. New York, NY: Oxford University Press, 1987. -
[194] Moise, L. Barbra and Fred Grownups Now, Living Fully with Developmental Disabilities. Fort Bragg, CA: Lost Coast Press, - 1997. -
[195] McCreight, B. Recognizing and Managing Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects: A Guidebook. - Washington, DC: Child Welfare League of America, 1997.
[196] Lawrence, K. E. , (Ed.) Niemeyer, S. Caregiver Education Guide for Children with Developmental Disabilities. 1994. -
[197] Alexander-Roberts, C. The ADHD Parenting Handbook. Dallas, TX: Taylor Publishing Co, 1994. -
[198] Antonello, S. J. Social Skills Development: Practical Strategies for Adolescents and Adults with Developmental Disabilities. - Needham Heights, MA: Allyn & Bacon, 1996.
[199] Carmichael-Olson, H. and Burgess, D. M. , "Early Intervention for Children Prenatally Exposed to Alcohol and Other Drugs. - " Guralnick, M. J. Baltimore, MD: Brookes, (Ed.) The Effectiveness of Early Intervention. 1997, 109-145. -
[200] Copeland, E. D. , Love, V. Attention, Please! A Comprehensive Guide for Successfully Parenting Children with Attention - Disorders & Hyperactivity. Plantation, FL: Specialty Press, 1996. -

patient. Few states, in these days of shrinking resources, have programs that allow for the type of structure and supervision needed by adults with FASD. One of the most difficult problems is finding residential placements that are safe and secure. Professionals can help parents and caregivers identify possible resources for safe and appropriate living situations. Structure and supervision can be provided along with help in activities of daily living. A healthy and safe family life can be a protective factor across the lifespan.[201] One of the possible options for care of adults with FASD may be the adult family home. These homes often consist of an adult with special needs living with a nonaffected couple and their children, other disabled adults, or a combination of housemates. Impediment to such placements can include a lack of funding, lack of availability of such living arrangements, available or resistance to living in such structure on the part of the patient. If these impediments can be overcome, however, such placements can offer a continued sense of family and support across the lifespan.[202]

"I want to buy my dad a video game. I think it costs the same as his new car and his big pick-up truck. "

- 14-year-old boy with FAS on buying Christmas gifts for his adopted father

- Safeguard financial resources. Mismanaging funds, giving away their money, and impulsive buying are often concerns expressed by parents and caregivers about the patient with FASD. If patients with FASD are not able to manage their funds, a guardianship for funds or a protected payee for patients might be helpful. Navigating the Social Security system or legal system to establish guardianship can be trying for families, particularly those under pressure from dealing with the needs of a child with FASD. Professionals can help provide

[201] Streissguth, A. P. , Barr, H. M. , Kogan, J. , and Bookstein, F. L. Understanding the Occurrence of Secondary Disabilities in - Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects. Seattle, WA: University of Washington, 1996. -
[202] Streissguth, A. P. and Randels, S. P. "Long-Term Effects of Fetal Alcohol Syndrome. " Robinson, G. C. and Armstrong, R. - W. (Eds.) Alcohol and Child Family Health. Vancouver, BC: U. of British Columbia, 1988, 135-151.

guidance in attempts to get Social Security funding and in establishing a protected payee.

- Patient advocates can act to ensure that the recommendations described in this section are acknowledged and implemented. A team approach where everyone is working together on behalf of the patient can reduce the sense of being overwhelmed and decrease potential burnout. Problems can be shared and solutions generated. Advocacy can be at the individual, family, community, and political level. It can be from as small an issue as writing an IEP to as major an issue as acquiring Social Security funding and a place to live. Advocacy can be as simple as designing a daily schedule to as complicated as writing legislation to ensure FAS/FASD is considered developmental disabilities. Regardless, serving as an advocate to help plan and implement services is one of the most positive roles professionals can take in working with patients and families with FASD.

- Acknowledgement of the patient's limitations, strengths, and skills is something that may be overlooked. Building positive programs should be based on what people do **right,** not just the behaviors they need to change. Acknowledgement of the positive can cause a positive shift in how families view the patient and in how they view themselves.

- Acceptance of the patient's "world" is, at times, one of the most difficult tasks families, patients, and professionals face. It can feel, as one parent told the author, that it is an "acceptance of failure and shame. " In actuality, acceptance of who the person is may not be the same as acceptance of all of their behaviors. Every person has something to offer this world. People with FASD, despite the challenges they face and may offer, can be beacons to show what communities can accomplish to support all members of the community regardless of whether or not they have disabilities.

Integration of Traditional Native Beliefs, Values, and Practices:

One of the strengths inherent in many Native communities is their sense of community.[203] In the past, regardless of disability, all members of the community were viewed as valuable. Traditional Native communities consisted of extended kinship groups. The input of elders and adults for their children and others in the community was desired and valued. In many of today's Native communities, these traditions and values are still in place.[204]

However, given the complexity of the psychosocial issues facing individuals and families with FASD, the community may not have enough expertise and resources to address then all. In today's intricate world, Native communities can bring forth their values and traditions and incorporate them with the programs and psychosocial interventions described above. A combination of these factors can bring structure, gentleness, and hope to all of those affected by FASD.

Psychosocial Needs and Service Matrix:

At the start of Section I, a case study was detailed. Additional information was given about Jerilynn at the beginning of this section. Below is the psychosocial matrix for Jerilynn across the lifespan. Please note the changes in needs and services required, as Jerilynn grows older. With each section, a portion of the matrix will be completed with the full series of matrices at the end of the manual.

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[203] Bataille, G. M. and Sands, K. M. American Indian Women: Telling Their Lives. Lincoln, NE: U. of Nebraska, 1987.
[204] Boyce, W. T. and Boyce J. C. "Acculturation and Changes in Health Among Navajo School Students. " Social Sciences and Medicine. 17 (1983) 219-226.

Figure 8

Matrix II:

Psychosocial Concerns for Jerilynn

Ages 0-5	Neglect and abuse, distractibility, hyperactivity, withdrawing, poor language development
Ages 6-11	Poor peer relations, anxiety, posttraumatic stress disorder, distractibility, hyperactivity, impulsivity
Ages 12-17	Poor peer relations, anxiety, posttraumatic stress disorder, distractibility, hyperactivity, impulsivity, sexual acting out
Ages 18 and Up	Poor peer relations, anxiety, posttraumatic stress disorder, distractibility, hyperactivity, impulsivity, sexual acting out, drug/alcohol use

Psychosocial Services for Jerilynn

Ages 0-5	Child protective services intervention, evaluations by developmental psychologist, early childhood developmental specialist, psychiatrist for medication
Ages 6-11	Adoption worker, individual and family therapist for behavioral management, psychiatrist for medication
Ages 12-17	Individual and family therapist, psychiatrist, DDD case manager, adoption worker for child
Ages 18 and Up	Individual and family therapist, psychiatrist, DDD case manager, drug/alcohol counselor

Section IV:

Family Issues and Needs

"Sometimes, we have to make new families. I lost the one I was born into so I just made a new one from my friends. "

- a 35-year-old man with FAS and also a trauma survivor

Jerilynn's birth family consisted of five siblings and her mother. Her father was not known. Her mother was not able to work due to mental health and substance abuse difficulties. The family was homeless at times. It was due to these difficulties that Jerilynn was eventually moved from her mother's home. Jerilynn had been placed into a relative foster home which failed due to Jerilynn's birth mother interfering with the placement. Finally, Jerilynn was placed with her adoptive family.

Her adoptive family had been aware of Jerilynn's issues and losses from the time that she was placed with them. Her adoptive father was a teacher and her adoptive mother was a nurse. As Jerilynn began to have problems, her adoptive parents implemented family therapy and behavioral programs. In spite of these behaviors, Jerilynn's behavior escalated out of control and she ran away from home. Her parents made several attempts to have her return home but without success.

Jerilynn's adoptive siblings were often resentful of the extra attention she received from their parents. After two years of family therapy, Jerilynn's brother and sister refused to participate any longer. After Jerilynn left home, her siblings, both adoptive and birth, no longer had any contact with her. Her adoptive parents, however, did continue to attend court with Jerilynn and were supportive. A significant issue arose when Jerilynn had her baby and her parental rights were terminated. Jerilynn had believed her adoptive family would adopt her child and was

very angry when they did not do so. Finally, after Jerilynn's last arrest, and the loss of four more children, her adoptive parents made the decision to cut ties with her.

Family issues have been touched on throughout this manual. The most important issue when working with families affected by FASD is establishing a safe and stable environment. This has, as noted, often been the most difficult accomplishment to achieve. The problems detailed below are only a few of those that affect families where parents may have FASD, alcoholism, or both. Claudia Black and Melanie Beattie[205,206,207] among others detail the emotional and social consequences of growing up in an alcoholic home. However, these books do not address the difficulty of dealing with concerns due to brain damage. Family issues related to FASD can include many of the issues described below:

Lack of Extended Family Support:

Alcohol abuse can lead to parents becoming isolated and not able to function in a manner that allows for adequate care. Many Native families have been displaced from their ancestral homes. Such displacement often leads to an increased risk of depression, alcoholism, and neglect and abuse.[208,209] These issues put children and families at risk for many of the psychosocial problems listed in the previous section.

With the displacement that often occurred from forced relocation, the boarding school, multigenerational abuse and loss, many traditional values and parenting practices were lost. Studies indicate that the further from one's home and extended family Native people are, the more they are at risk for problems.[210] If they are more at-risk for alcohol abuse, they are more at risk for producing children with FASD. In

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[205] Black, C. It Will Never Happen to Me. Center City, MN : Hazelden, 1987. -
[206] Beattie, M. Codependent No More New York, NY: Harper/Hazelden, 1987. -
[207] Beattie, M. Beyond Codependency. New York: Walker, 1990. -
[208] Gidley, M. (Mick) With one sky above us: life on an Indian reservation at the turn of the century. Seattle: University of - Washington Press, 1985, c1979.
[209] Sorkin, A. L. The Urban American Indian. Lexington, MA: Lexington Books, 1978. -
[210] Walker, R. D; LaDue, R. A. An integrative approach to American Indian Mental Health. Ethnic Psychiatry C. B. Wilkinson - (Ed.) New York: Plenum Press, 1986. -

addition, the lack of extended family can mean limited positive role models for parenting.

In the past, Native children were raised within an extended family structure. In some Native communities this structure still exists. However, in others, it has been devastated. The lack of role models for young parents or a shortage of sober cross-generational support can be even more devastating. Substance abuse frequently crosses familial and generational lines. If there are no sober relatives who can provide care for the child, it is even more likely that the family may be split up and the children placed into foster care.

Financial Concerns:

Generalizations should not be made about the socio-economic status of people who are alcoholic. However, parents and patients with FASD in clinical samples have frequently been from the lower socio-economic class. There may be a sampling bias in the studies available, but it is likely that fewer children from middle and upper class families are placed into foster care. An assessment of financial resources needs to be made at the initiation of any interventions. Limited financial resources can contribute to the stress of families who are struggling with the issues of alcoholism and meeting the needs of children affected by FASD.

Financial issues can impact every aspect of family life. If the majority of the family finances are going towards the purchase of alcohol and other substances, there may not be enough money for food, shelter, or clothing. Poor choices in how available resources are spent, are commonly noted in families where there is significant substance abuse. These choices can lead to neglect and CPS involvement, possibly resulting in the removal of the children from the home.

SAMPLE BUDGET LAYOUT.

1. RENT / MORTGAGE PAYMENT _____ $.
2. GROCERIES _____ $.
3. UTILITIES _____ $.
4. TELEPHONE _____ $.
5. MEDICAL _____ $.
6. ENTERTAINMENT _____ $.
7. SAVINGS _____ $.
8. WEEKLY CASH _____ $.

TOTAL: $.

In other situations, parents may not have any employment or financial resources. They may be on welfare or other disability monies. Due to the "Welfare to Work" program guidelines, there are now limits on the amount of time people can remain on welfare. Welfare-to-work programs are based on the assumption that everyone can gain and sustain employment. Losing welfare benefits after two to five years, without the benefit of Social Security, often puts families at greater risk for financial stress and pressure. Many people who have FASD, as well as those impacted by alcoholism, may not be able to sustain employment, or complete training without constant support and supervision. Without financial support and resources, families are at risk for even greater pressures and problems.

Parental Emotional Instability:

Dual diagnoses, specifically alcohol abuse and a co-occurring mental health disorder, are common.[211,212] Either one of these problems can create difficulty and instability for parents and the entire family. Adding FASD to these problems can make the situation even more unstable and the risk of secondary disabilities greater. People newly in sobriety are often encouraged not to make any decisions for the first year after entering sobriety.[213] While this may be the ideal, it may not be the reality for parents. In fact, parents may be losing or regaining custody of their children, changing residences, and dealing with many legal issues. All of these factors can contribute to the risk of instability in family life.

A chaotic home environment often results from mental health and alcoholism issues.[214] People with FASD have difficulty establishing their own structure. When the pressure of parenting is compounded by cognitive deficits or the consequences of alcoholism, it is apt to be very difficult for there to be "smooth sailing" in the home.

The average number of children born to alcoholic women and those affected by FASD is not known. Based on anecdotal information, it does appear that women in these situations may be less likely to use birth control, adequately care for their children, or manage their own affairs.[215,216] In any family, the more children present, the more parents have to adapt to a variety of children's needs, establish more structure, and be flexible within that structure. Such practices can be challenging for the most functional of people.

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[211] Flack, F. and Draghi, S. The Nature and Treatment of Depression. New York, NY: John Wiley & Sons, 1975. -
[212] Feighner, J. P. and Boyer, W. F. Diagnosis and Depression. New York, NY: Wiley Liss, 1992. -
[213] Alcoholics Anonymous, "Big Book. " New York: Alcoholics Anonymous, 1988. -
[214] Black, C. It Will Never Happen to Me. Center City, MN : Hazelden, 1987. -
[215] Wilsnack, R. W. , Wilsnack, S. C. Gender and Alcohol: Individual and Social Perspectives. New Brunswick, NJ: Rutgers - Center of Alcohol Studies, 1997.
[216] Hyson, M. C. The Emotional Development of Young Children: Building An Emotion-Centered Curriculum. New York: - Teachers College Columbia University, 1994. -

The potential for emotionally and physically absent parents is of concern when there is alcoholism, mental health issues, FASD, or all of these concerns.[217] Parents who are affected by one or more of these concerns may not be emotionally present for their children. They may not be able to meet their own needs let alone those of one or more children. Parents, at least those from lower socioeconomic levels, may be at more risk to lose their children, creating another set of problems for both the parents and children.[218] There have been many situations in the state of Washington concerning lawsuits over the possible devastation that children face when removed from parental care and when having multiple placements.[219,220] Certainly, children with FASD fit into this risk category.

Parents with FASD may be emotionally immature and incapable of recognizing the needs they or their children have. Proactive parenting requires the ability to recognize such needs, maintain structure and flexibility, and be responsive regardless of their own needs or concerns. It is not that parents with FASD are deliberately neglectful of their children, but rather they may lack the cognitive abilities needed to provide for their families.[221]

There have been studies from as far back as 40 years that demonstrate the need for children to have adequate stimulation to grow and mature in healthy ways. Without physical touch, stimulation, and nurturing, children may be less likely to have healthy physical, emotional, and social development.[222,223] People involved in alcoholism or who have FASD may not be able to provide the appropriate levels of emotional, physical, and cognitive stimulation needed to ensure healthy development for their

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[217] Bradley, K. A. , Badrinath, S. , Bush, K. , Boyd-Wickizer, J. , Anawalt, B. "Medical Risks for Women who Drink Alcohol. - Journal of General Internal Medicine. 13(1198) 627-638. -

[218] Streissguth, A. P. and Kanter, J. (Eds.) The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. - Seattle, WA: U. of Washington Press, 1997. -

[219] McKinney v. State, No. 64783-6, SUPREME COURT OF WASHINGTON, 134 Wn. 2d 388; 950 P. 2d 461; 1998 Wash. LEXIS 11, May 28, 1997, Oral Argument, February 5, 1998

[220] Braam v. State of Washington, Cause #:No. 98 2 01570 1 -

[221] LaDue, R. A. , Streissguth, A. P. , and Randels, S. P. "Clinical Considerations Pertaining to Adolescents and Adults with - Fetal Alcohol Syndrome. " Sonderegger, T. B. (Ed.) Perinatal Substance Abuse: Research Findings and Clinical Implications. - Baltimore, MD: Johns Hopkins U. Press, 1992, 104-131. -

[222] Shelov, S. P. "Caring for Your Baby and Young Child: Birth to Age 5. " The American Academy of Pediatrics. New York, - NY: Bantam Books, Inc. , 1993.

[223] Shelov, M. D. , FAAP, S. P. (Ed.)The Complete and Authoritative Guide: Caring for Your Baby and Young Child: Birth to - Age 5. New York: Bantam, 1991. -

children. These factors may put their children at risk for life-long social and emotional problems and cognitive and social delays.

Given the short amount of time that FASD has been a focus of research and public health interest, these concerns are more speculative than definitive. However, there is enough strong concern and possibility that further study is recommended.

Diversity of race, culture, and ethnicity among alcoholic and alcohol abusing families is a fact of life. It is estimated that over half of all women of childbearing years consume some level of alcohol.[224] These numbers are not simply reflective of those of lower income or women of color. In actuality, FASD are concerns in any community where women drink.[225,226]

Different families have different needs. Some families may not have financial pressures. In fact, by virtue of being from middle or upper class families, assumptions may be made that there is no alcohol abuse in the family. Upper and middle class women may not be appropriately screened for prenatal alcohol use.[227,228,229] Children, adolescents, and, later, adults born into these families may well have the same learning problems, behavioral issues, social difficulties, and employment problems as their less well-off counterparts. They may receive a variety of diagnoses, none of which may identify alcohol as an underlying causal factor. Failure to have an adequate, early diagnosis is shown to be a factor in the development of secondary disabilities.[230]

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[224] Centers for Disease Control and Prevention-FAS Home Page, 2002. -
[225] Streissguth, A. P. "The 1990 Betty Ford Lecture: What Every Community Should Know about Drinking During Pregnancy - and the Lifelong Consequences for Society. " Substance Abuse. 12(3) 1991) 14-127. -
[226] Glasser, J. "The Cycle of Shame**:** The heartbreak of fetal alcohol syndrome in South Africa" US News and World Reports. - May 20, 2002.
[227] Stevens, S. J. and Wexler, H. K. , eds. Women and Substance Abuse: Gender Transparency. New York: Haworth Press, - 1998. -
[228] Wechsberg, W. M. , Craddock, S. G. , and Hubbard, R. L. How are women who enter substance abuse treatment different - than men?: A gender comparison from the Drug Abuse Treatment Outcome Study (DATOS). In: Stevens, S. J. and Wexler, H. - K. , eds. Women and Substance Abuse: Gender Transparency. New York: Haworth Press, 1998. pp. 97–115. -
[229] Vannicelli, M. (1984) Treatment Outcome of Alcoholic Women: The State of the Art in Relation to Sex Bias and Expectancy - Effects, in Alcohol Problems in Women, ed. Sharon C. Wilsnack and Linda J. Beckman, Alcohol Problems in Women. -
[230] Streissguth, A. P. and Kanter, J. (Eds.) The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. - Seattle, WA: U. of Washington Press, 1997. -

Any child exposed to alcohol *in Utero* can be at risk. Any woman who drinks during her pregnancy puts herself and any fetus at risk, regardless of race, residence, or financial level. Without appropriate screening and diagnosis, there may be a failure to acquire appropriate services and interventions for either the child or the family.[231,232]

The concerns described above are but a few that might affect the family. Professionals working with families in this situation need to be aware of the possibility of multigenerational problems and deficits. Many of the interventions suggested in the previous section on psychosocial needs apply when working with families affected by FASD.

Interventions:

"Really, all I want is to know my child will be safe and healthy for all her life. If there are people who can help me understand her needs and make things better, I would be doing her an injustice not to make use of such services. I am ***way*** *past worrying about looking weak by asking for help. "*

- father of five adopted children with FASD

Interventions by professionals for families that have FASD; parents, children; or both affected with FASD should focus on helping reduce risk and increase the chance of positive outcomes. This can be done through a variety of avenues. Professionals should remain as flexible as possible and be open to the use of multiple interventions. Services for families can range from transporting the child and caregiver for a doctor's appointment to arranging for respite care, and from providing family therapy to identifying social support groups.

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[231] Little, B. B. , Snell, L. M. , Rosenfeld, C. R. , Gilstrap, L. C. , and Grant, N. F. "Failure to Recognize Fetal Alcohol Syndrome - in Newborn Infants. " American Journal of Dis. Child. 144 (1990) 1142-1146. -

[232] Grella, C. E. "Background and Overview of Mental Health and Substance Abuse Treatment Systems: Meeting the Needs - of Women who are Pregnant or Parenting Journal of Psychoactive Drugs 28 (1996) 319-343. -

Early identification and intervention are keys in:

- Ensuring no more children are born with FASD; and
- Increasing the likelihood of a positive outcome for parents and child. [233],[234]

When providing services to families affected by alcoholism and FASD, it is important to make sure services are given at a level that is appropriate to the family. Expecting a parent with FASD to be able to formulate and follow-through on complicated plans is not realistic or reasonable. It is important for the professional to help the family design and implement appropriate structure at a level the family will ultimately be able to manage and sustain on their own.[235]

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[233] Carmichael-Olson, H. and Burgess, D. M. , "Early Intervention for Children Prenatally Exposed to Alcohol and Other Drugs. - " Guralnick, M. J. Baltimore, MD: Brookes, (Ed.) The Effectiveness of Early Intervention. 1997, 109-145. -
[234] Guralnick, M. J. (Ed.) The Effectiveness of Early Intervention. Baltimore, MD: Paul H. Brooks Publishing Co, 1996. -
[235] Grafe, S. FAS; A guide for Daily Living. Victoria, BC: Society of Special Needs Adoptive Parents, 1994. -

Ensuring there is adequate parenting in the home can be a difficult task for social workers and other professionals. A parenting assessment is always indicated. In conducting a parenting assessment, items such as overall cognitive abilities, coping skills, anger management, ability to recognize their children's needs and meet these needs in an appropriate manner should be addressed.

This is one of the most difficult areas for both families and professionals. It touches the core of the human experience -- the raising of one's children. No matter what other factors drive the situation, the best interests of the child must come first. The difficulty comes in determining what this truly might be. Regardless of situations of abuse and neglect, children generally remain emotionally connected to their parents. The amount of bonding between parent and child should be considered in assessing what are appropriate placement options for the child.

Some parents with FASD may literally need to be parented as they parent. If there are wrap-around resources that allow this to happen, it may increase the possibility of parents with FASD keeping their children. If parents are newly entering sobriety, the strength of such sobriety and the extent of their sober support system should be considered during the assessment process.

Helping parents and caregivers develop appropriate discipline practices and proactive interventions is an area where professionals can be of significant help to parents and families with children with FASD. Developing a variety of interventions and ways to redirect children when they are having difficulties can take patience, forethought, and planning. Being able to control one's impulses and anger and act in a thoughtful manner with their children are goals most parents have. Of course, not every parent is fully able to meet this perfect standard!

However, parents with mental health concerns, sobriety issues, and FASD may be more easily aggravated, more impulsive, less capable, and more emotionally fragile. Because of these concerns, it is important that as much support as possible be

provided when these circumstances are present. One method of addressing these concerns is through Family Preservation Services or in-home therapy support. Teaching birth, foster, or adoptive parents how to "parent differently instead of just harder"[236] can reduce frustration and increase success.

There is often a disparity between chronological age and the maturity level of the child. Appropriate discipline should be directed at both the emotional and chronological age of the child. An adolescent with FASD may have the maturity, and understanding level of a six year old. This can make the application of discipline confusing and difficult. In this situation, discipline should still be concrete, simple, and consistently applied. Professionals can aid families in identifying interventions that are tailored to each child's level of cognitive functioning and emotional and chronological ages.[237,238]

Professionals can recognize family and individuals strengths as well as concerns. They may be more able to devise strategies and schedules to specifically address challenging behaviors. A neutral, detached party may be more able to facilitate implementation of discipline and positive support programs.

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[236] Hartness, C. FAS Summit, Anchorage, AK, November, 2001. -
[237] Fenwick, E. and Smith T. Adolescence: The Survival Guide for Parents and Teenagers. New York, NY: DK Publishing, - Inc, 1994.
[238] Greenspan, S. I. The Challenging Child. Reading, MA: Perseus Books, 1995. -

DAILY CHORE LISTS

CHILD	ADULT
1. BRUSH TEETH	1. MAKE BED, BRUSH TEETH
2. EAT BREAKFAST	2. MAKE BREAKFAST
3. GET DRESSED	3. CLEAN KITCHEN
4. GET READY FOR SCHOOL	4. CLEAN BEDROOM
5. GO TO SCHOOL	5. GO TO WORK
6. DO HOME WORK	6. START DINNER
7. EAT DINNER	7. EAT DINNER
8. GET READY FOR BED	8. CLEAN UP AFTER DINNER
9. GO TO BED	9. GO TO BED

Obtaining subsidized adoption monies, if at all possible, should be a priority when prospective parents make the decision to adopt.[239] Raising children affected by FASD is expensive with special services needed across the lifespan. Subsidized care, whether it is for birth, adoptive, or foster parents, should be in place across the lifespan. In some states, subsidized adoption monies pay for counseling, medical care, and respite care. All of these services can aid in families being able to keep their children in their homes in a safe manner. Healthy families make it far more likely that children will have healthy functioning, regardless of whether the child has FASD. The more support and structure families are provided, the more likely it is that the outcome will be positive.[240]

[239] Edelstein, S. B. et. al. Children with Prenatal Alcohol or Other Drug Exposure: Weighing the Risks of Adoption. - Washington DC: Child Welfare League of America, 1996.
[240] Guralnick, M. J. (Ed.) The Effectiveness of Early Intervention. Baltimore, MD: Paul H. Brooks Publishing Co, 1996. -

"What do I do to make Sam stop barking like a dog?"

- respite care provider on the phone about a 14-year-old boy with FAS after listening to him to bark for 8 straight hours.

"Tell him to meow like a cat. "

- parent's response

Respite care is often cited as one of the most valuable services families can obtain. Respite care provides parents with a break and allows them to rejuvenate when they are tired or emotionally drained. It can help in ensuring that parents can give more care and attention to other children in the family. Someone who understands the needs of children with FASD should provide respite care. The need for respite care does not diminish as the child moves into adolescence and early adulthood. In actuality, the necessity for family support grows, but the accessibility of resources shrinks as the patient grows older. Helping identify resources for respite care is an important way professionals can aid families.

The adolescent with FASD may resist respite care. Professionals can help facilitate respite care by identifying who within the family or support network might be safe and accepted by the patient. If the adolescent has sexual issues, it is especially important that there be no access to younger children or vulnerable adults either in the family home or while in respite care. The safety plan discussed in the last section should be put in place at any residence where the adolescent resides.

While many of the life-threatening issues that face children with FASD pass prior to the latency period, the need for preventive medical care, dental care, and possible mental health needs do not. Ensuring that such services can be obtained is an important concern that professionals need to address with affected families. Professionals involved can help the family identify providers who:

- Take medical coupons or Medicaid
- Understand the needs of patients with FAS
- Can provide long-term care
- Recognize, treat, and refer for mental health needs
- Recognize and proactively address sexual concerns and safety
- Recognize and refer for substance abuse problems, if appropriate
- Screen for substance use during pregnancy

No one person can provide all of the services listed above. With a team approach, however, it is more likely that the patient with FASD will receive needed services.

Establishing a safe, stable, structured home at a level parents and caregivers can maintain is crucial. A program that has been shown to be helpful is the family preservation program. This program is funded through the Washington State Department of Social and Health Services-Division of Child and Families Services. It involves working with high risk families to:

- Identify strengths and concerns
- Facilitate communication
- Increase structure
- Reduce stress

The advantage of this program is that it takes place in the home where changes can be implemented in a concrete manner rather than expecting people to understand abstract concepts and make changes on their own.

Helping the parents and caretakers to better understand the child's methods of communication is important from early childhood on. Children, even those who are nonverbal, are able to communicate in one form or the other. It may be through hand signals, temper tantrums, turning away from the parent, or being "demanding."

Dr. Donna Burgess, an FAS educational specialist, shares through her trainings[241] the example of a child banging a pencil on a desk. She asks people to guess what message the child is attempting to communicate through this behavior. The guesses frequently range from the child being obnoxious, to bored, to needing to use the restroom, to deliberately trying to irritate people around them. In actuality, a simple behavior, such as tapping a pencil, can mean any or all of the above plus more.

Dr. Burgess' point is to not make assumptions about what a behavior might mean but to interpret it in context and from the view of the child at any given time. This sounds simpler than is actually the case. It requires parents and caregivers to be patient, creative, and innovative. Parents and caregivers with deficits of their own may have a difficult time managing this. Professionals who actually go into the home and observe the parent-child interaction may be able to provide more insight as to what meaning any particular behavior might have. Modeling appropriate behavior and means of acquiring and using information can be where professionals are particularly helpful for families.

Adapting the environment to the child, rather than expecting the opposite, can be done by:

- Establishing, as much as possible, low to moderate levels of stimulation
- Using simple, concrete directions and consistent, limited rules

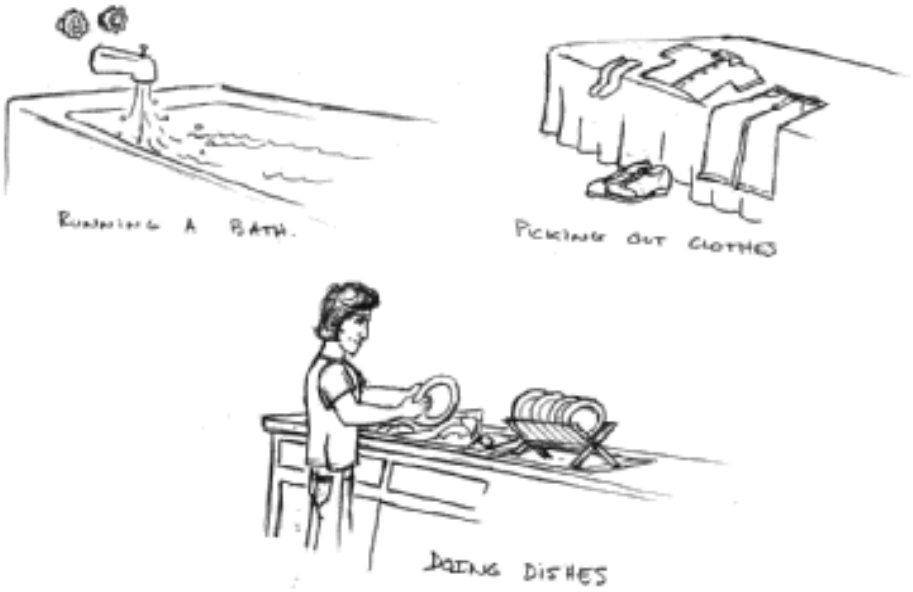
In-home providers or other professionals who are willing to make home visits can review the home environment and identify where it may be possible to change the level of stimulation. Sometimes something as simple as substituting incandescent or halogen lighting for fluorescent lighting, can reduce stimulation of the flicker and buzz of fluorescent lighting. Such input may help providers more adequately meet

[241] Burgess, D. Presentation on FAS in Rolla, ND, April, 1992.

the needs of both the affected child and the rest of the family. Predictability and consistency, which comes from such structure, are advantageous to everyone. Parents who are impacted by alcohol use, newly in sobriety, have mental health issues, or a combination of these factors, may have difficulty in determining what is an appropriate level of stimulation for children in the home. Understanding the actual physical setup of the home, the abilities of the parents, and needs of the child can facilitate a home atmosphere more conducive to maintaining control and increasing feelings of success for both the child and the parents.

By teaching parenting skills with pictures, demonstrations, and verbal cues can be effective. For example, parents learning to draw a bath and clean the child may need to be shown several times. Using drawings with verbal explanations underneath each picture can be used for parents having one or more of the difficulties just listed.

Visual and written cues can be used in a wide variety of settings. They may range from the example provided above to a schedule that sets up daily tasks and their frequency. As tasks and expectations change over time, professionals working with affected individuals and families can change these as appropriate. Different schedules and cues can be designed for various family members. Taken together, however, they can establish a more structured and calmer environment.



Set appropriate goals and expectations for both the parents and the child, regardless of age, intellectual abilities, and emotional maturity. These are points that have been made on several occasions. Creating an atmosphere for any family to work and live in relative harmony is a challenging task. Professionals can aid families affected by FASD in achieving this task by:

- Observing parent/child interactions.
- Helping to design and implement appropriate behavioral management programs.
- Providing a listening ear in times of frustration.

Family therapy should address the issues of loss, change, and anger that can accompany the impact of alcoholism.[242] The devastation of abuse, neglect, and premature maternal death are not just concerns that impact individuals. These losses take place in the context of families, communities, and society. Many of these concerns are cross-generational. Families impacted by alcoholism and FASD

[242] Malbin, D. B. "Stereotypes and Realities. " Kleinfeld, J. and Wescott, S. (Eds.) Fantastic Antoine Succeeds. United States: University of Alaska Press, 1993.

need to find ways to resolve these concerns, particularly as parents or caregivers - move into sobriety and family dynamics change.

Professionals need to be aware of these possible changes. Family therapy to address these issues may need to be facilitated. One approach is through traditional psychotherapy, and traditional Native American ceremonies and healing practices. Given some of the cognitive deficits associated with FASD, other means of family therapy may be needed. Antonia Rathbun[243] discusses having family members each draw their view of the family and issues and then discuss them together. This can be a less threatening manner of presenting information and facilitating change. Combinations of psychotherapy and behavioral management may also be useful.

[243] Appendix 8, Resource Guide

The Role of the Professional:

"Flexible structure, and some humor, in me and people who work with my child… those are the things I need. If I can't laugh, I will spend all my time crying. "

- mother of a 5-year-old child with FAS

The concerns and interventions listed above are only a few of the areas where professionals can be of aid to affected individuals and families. In actuality, professionals will have many roles to fill. They may serve as a family therapist, a facilitator for communication, family advocate, and a case manager.[244,245] As shown in the next two sections, so do teachers, school personnel, probation officers, lawyers, pre-sentencing investigators, and judges all have critical roles to play. A team approach, such as those developed in Washington and Alaska,[246] has been shown to be more effective and useful than one professional trying to manage all of the families issues on their own.[247]

Professionals may have multiple roles when working with families affected by FASD. For example, a social worker may provide family therapy, but also be involved in legal situations as an advocate. A public health nurse may start out as a family health educator, but also may serve as a facilitator for team meetings. Professionals working on a team for affected individuals and families may want to consider having quarterly meetings to ensure all involved are aware of:

- Medications
- Behavioral issues
- Legal concerns and court dates

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[244] Grafe, S. FAS; A guide for Daily Living. Victoria, BC: Society of Special Needs Adoptive Parents, 1994. -
[245] Jacobson, J. W. et. al. Community Living for People with Developmental and Psychiatric Disabilities. Baltimore, MD: - Johns Hopkins University Press, 1992.
[246] Casto, L. D. Fetal Alcohol Syndrome: 2001 Status Update. Alaska Department of Health and Social Services; Office of - Fetal Alcohol Syndrome: Juneau, AK, 2002.
[247] Stengle, L. J. Laying Community Foundations: For Your Child with a Disability: How to Establish Relationships That Will - Support Your Child After You're Gone. Bethesda, MD: Woodbine House, 1996. -

- Changes in school or residential placements
- Possible family concerns and changes
- New members of the team or team changes
- Health concerns that may need to be addressed

Integration of Traditional Native Beliefs, Values, and Practices:

For Native communities, family has been a mainstay for thousands of years. Family, in Native communities can consist of the "nuclear" family, extended family, or non-related people living together in a family structure. The notion of kinship, while perhaps not as fixed as in the past, is still a value that is of great importance to Native people.[248,249] The fact that family remains so important can be either a damaging or protective factor. Family ties that are strong and sober can be a source of strength and support across the lifespan for people affected by FASD.

Professionals working with Native families should be aware of these values and strive to incorporate them as much as possible into treatment programs. Sober extended family members providing positive role models, sober living situations, and respite care for families affected by FASD are of great importance. Therapy services for Native families could include traditional healers as well as extended family members. A family based therapy model can be consistent with the types of structure and interventions traditionally used in Native families and communities.[250,251]

As important as it is to be aware of the strengths of Native culture and its value in working with families, it is equally crucial that professionals do not make assumptions that every Native client or family necessarily follows past cultural and tribal traditions. A thoughtful, thorough assessment of the client's cultural, spiritual, familial, and community identification should be made prior to implementing services

[248] Foxcraft, D. (Ed) The Sayings of Our First People. Penticton, BC. : Theytus Books, LTD, 1995. -
[249] Miller, J. American Indian Families (True Book) Danbury, CN: Children's Press, 1997. -
[250] Attneave, C. L. "Therapy in Tribal Settings and Urban Network Intervention". Family Process. 8 (1969) 192-210. -
[251] Mihesuah, D. A. American Indians: Stereotypes & Realities. Atlanta, GA: Clarity Press, 1997. -

to the family. If it is important for the family to have their Native culture and values incorporated into treatment, professionals can aid in facilitation of such services. Any positive means that allow families to stay together in a healthy manner should be considered and supported.

Family Concerns and Service Matrix:

At the start of Section I, a case study was detailed. Additional concerns related to family issues were discussed at the beginning of this chapter. Below is the family issues matrix for Jerilynn across the lifespan. Please note the changes in needs and services required, as Jerilynn grows older. With each section, a portion of the matrix will be completed with the full series of matrices completed at the end of the manual.

Figure 9

Matrix III:

Family Concerns for Jerilynn

Ages 0-5	Parental substance use, lack of safe residence, familial financial stress
Ages 6-11	Adoption issues, unrealistic parental expectations, need for respite care
Ages 12-17	Respite care, family communication difficulties
Ages 18 and Up	Lack of residence, financial stress

Family Services for Jerilynn

Ages 0-5	Foster care, family preservation services, child welfare services
Ages 6-11	Subsidized adoption, behavioral intervention services, establishment of appropriate expectations, respite care provider
Ages 12-17	Subsidized adoption, behavioral intervention services, establishment of appropriate expectations, respite care provider
Ages 18 and Up	Patient out of the home

Section V:

Educational / Vocational Issues and Needs

Jerilynn was in Special Education services for the entire time she was in school. Her IQ scores showed her to be in the borderline range with difficulties in abstracting, reading, and math skills. She did not have the capacity to translate her "book" knowledge into everyday life. The school attempted to mainstream her on several occasions, but she was not able to tolerate the level of stimulation in a regular classroom. She would become frustrated and refuse to complete her homework. Her adoptive parents felt Jerilynn had more ability than she was showing in her grades and would provide tutoring after school

Jerilynn was on an IEP during her time in school. She was furnished with a part-time aide in school to provide support and supervision. As she moved into adolescence, she became resentful of the supervision and made attempts to evade it on a regular basis. She began to cut classes and, finally, dropped out of school entirely. Her parents suggested obtaining a GED, but Jerilynn felt she would fail at this, too.

After she was picked up on her last probation violation, Jerilynn did enroll in GED classes and was working to complete them while incarcerated. She was also requesting special vocational services to have some vocational skills when she was released from jail.

There have been many excellent educators who have written about ways to address the educational needs of children, adolescents, and adults with FASD.[252,253,254] Educational concerns for children, adolescents, and adults may have a different focus over time, but the ultimate goal is the same - ensuring the person with FASD

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[252] Kopera-Frye, K. , Tsewenaldin, P. , and Streissguth, A. P. "Preventing FAS by Empowering Native American Chemical - Dependency Counselors. " The I. H. S. Primary Care Provider. 19(4) 1994, 66-69. -

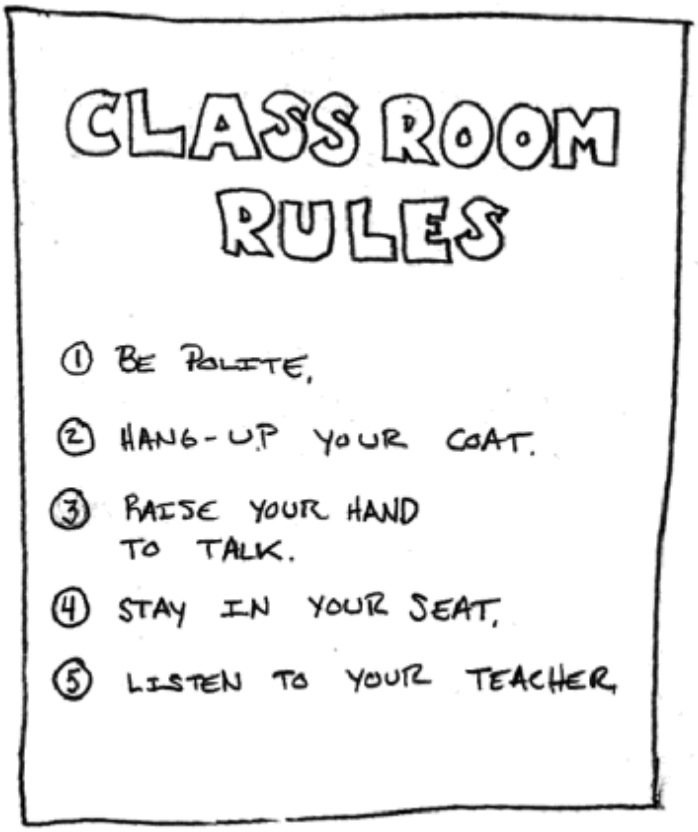
[253] Brady, J. P. and Grollman, S. Risks and Reality: Teaching Preschool Children Affected by Substance Abuse. - Washington, DC: DHHS, 1994.

[254] Burgess, D. M. , Streissguth, A. P. "Educating Students with Fetal Alcohol Syndrome or Fetal Alcohol Effects. " - Pennsylvania Reporter. 22(1) 1990 1-3. -

can live as adequately, safely, and independently as possible in their world. This section will explore many of these suggestions as well as the professional's role in implementing interventions. Much of the information in the following sections was synthesized and presented in books and videos authored by Brady and Grollman and other experts.[255,256] These principles have been refined and enhanced over the years but the basic concepts remain the same: structure, flexibility, helping children manage their behavior, and building links to the children's family.

"Communication and appropriate behavior are not add-ons to the curriculum for children with FAS. They ARE the curriculum. "

- Donna Burgess, 1992



[255] Burgess, D. M. , Lasswell, S. L. , Streissguth, A. P. "Educating Children Prenatally Exposed to Alcohol and Other Drugs". - [Brochure]. Seattle, WA. Fetal Alcohol and Drug Unit, U. of Washington, 1993. -
[256] Brady, J. P. and Grollman, S. Risks and Reality: Teaching Preschool Children Affected by Substance Abuse. - Washington, DC: DHHS, 1994. -

Preschool and Early Elementary Years:

Brady and Grollman[257] outline several concepts for working with prenatally affected children that center around the teacher "building a nurturing classroom. " Such a classroom allows children to fully participate, feel valued, and increase their skills, building on their potential.[258,259] Teachers do not make the diagnosis of FASD. However, teachers often see the behaviors that are commonly present in children who are prenatally exposed to alcohol. Ultimately, regardless of the cause, challenging behavior still needs to be managed!

Creating a positive environment for preschool and elementary children requires:

- Setting up appropriate physical structure and ensuring safety
- Setting up limited, consistent rules.
- Establishing appropriate expectations.
- Encouraging cooperation and improved social skills through play.
- Facilitating transitions.
- Connecting classroom learning to the "real world".
- Building strong links to families.[260]

These principles, and the roles of professionals, have been described in the previous sections. In reality, they are the guiding principles that allow for healthy functioning both in the home and in school. Setting up appropriate physical structure in a classroom can include using tape to mark specific areas for play, learning, or privacy. Putting tables together where children can engage, appropriately, with each other, but also work on their own is often helpful. Breaking up long stretches of floor

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[257] Evensen, D. Working with adolescents in high school: Techniques that help. In Fantastic Antione Grows up. (J. Kleinfeld, B. Morse, and S. Wescott, Eds.) Fairbanks, AK: University of Alaska Press, 2000. -

[258] Alexander, K. L. , Entwisle, D. R. , et. al. Achievements in the First Two Years of School: Patterns and Processes - (Monographs of the Society for Research in Child Development, Serial No. 218, V). Chicago, IL: U. of Chicago Press, 1974. -

[259] Boyd, T. A. , Ernhart, C. B. , Greene, T. H. , Sokol, R. J. , and Matler, S. "Prenatal Alcohol Exposure and Sustained - Attention in the Preschool Years. " Neurotoxicology and Teratology. (1991) 13. -

[260] Greene, T. , Ernhart, C. B. Ager, J. , Sokol, R. , Martier, S. , and Boyd, T. "Prenatal - Alcohol Exposure and Cognitive Development in the Preschool Years. - "Neurotoxicology and Teratology. 13 (1991). -

space “can decrease the use of such areas as race tracks”,[261] helping ensure children’s safety.

As in the home, having consistent and limited rules at school provides children a sense of structure and allows children to feel successful by being able to adhere to these rules. Rules should focus on helping the child feel safe and function within the classroom. Rules can be posted in conspicuous places around the classroom and also on the child’s desk. For children with impaired reading abilities, having pictures of the child participating in desired activities posted on a reminder board can be

[261] Brady, J. P. and Grollman, S. Risks and Reality: Teaching Preschool Children Affected by Substance Abuse. Washington, DC: DHHS, 1994.

helpful. In any case, the focus is on helping the child maintain control over their behavior and function to their full ability.

Brady and Grollman[262] also discuss the value of play for young children as part of the curriculum. The material presented by Evensen, Brady and Grollman reflect the point that Dr. Burgess[263] makes where "social skills and communication are the curriculum." It is felt that play among preschoolers and younger elementary children facilitate cooperation, communication, and social interaction. These are abilities that are likely to serve in positive ways across the lifespan. Play can also make the link between verbal and visual-tactile skills. Play can be used to express feelings, values, and concerns. Children can be encouraged to have activities and then share them with their peers.

Predictability, stability, and structure have been emphasized throughout this manual as means of aiding children in reaching their potential. Changes and transitions can cause disruptions in the school environment and be upsetting to children. Making children aware of what changes might be coming, providing them with ways of handling the change, and reassuring them through transitions can reduce acting out behaviors. Information can be as simple as telling the child to begin picking up their papers or that they have five minutes left on a task. While transitions in the classroom are much less life impacting than changes that might happen in the home, facilitating changes through information and preparation are still important.

Learning in the classroom can be connected to expectations and behavior in the "outside" world. Play can teach children ways to communicate with friends and family members. For example, teaching children to read street signs as part of a play situation or game can help increase reading skills and help make them safe. Teaching children through play and other classroom activities can also help them recognize danger and develop ways of avoiding potentially dangerous situations. It

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[262] Brady, J. P. and Grollman, S. Risks and Reality: Teaching Preschool Children Affected by Substance Abuse. - Washington, DC: DHHS, 1994.
[263] Burgess, D. Presentation on FAS in Rolla, ND, April, 1992. -

can aid them in appropriately expressing emotions and developing positive self-concept.

One example of how the classroom can be connected to life in the community is that of the teacher who taught her students to read store labels and purchase items instead of stealing them. This teacher set up a mock store in the classroom where the children were given play money to make purchases and pay for them prior to exiting the classroom area. Then under careful supervision, this teacher took her students out to a local grocery store to see how well they learned their lessons . The hands-on, repeated learning paid off; as not one chld shoplifted from the store .

Consistency for children affected by prenatal exposure is one of the most important parts of the environment. Connecting with parents can enhance facilitating a child's growth and learning. Approaching schools can be intimidating for many parents. For birth parents, dealing with the grief, anxiety, fear of judgment, and decrease in their child's potential can make dealing with the school system difficult. Professionals working with (possibly) prenatally exposed children can ease discomfort by focusing on the child's skills and exploring ways the parents can support their child's learning.

Foster parents may be left "out of the loop" with school personnel due to the possible temporary nature of foster placements. Regardless of the length of time of the placement, foster parents need to be involved and aware of the educational concerns and needs of the children in their care. Adoptive parents should be as included in their children's lives as birth parents. Prior to adoption, it is important that adoptive parents be made aware of the possibility of prenatal exposure and what services might be needed to address any special educational needs their child might have.

"It would help me as a teacher to know if a child I teach has FASD. Many times, I see challenging behaviors I think are from prenatal alcohol exposure. But… how do I ask a parent if they drank or are drinking without offending them?"

- Special Education teacher on her fears and frustration about working with prenatally exposed children

A highly sensitive issue frequently raised by professionals is how to appropriately and sensitively approach a birth parent who may be continuing to abuse substances as regards to problems their child may be having in school. The focus should continue to be on the needs of the child and ways to aid the child to reach their full potential. School personnel, however, may have to report child abuse and neglect, a possibility that cannot be ignored where there is probable substance abuse in the family.

A question frequently asked is how to approach parents whom teachers suspect may be using alcohol or whose child may be prenatally affected by alcohol exposure. There is no easy answer for this difficult question. Focusing on the needs and what is in the best interest of the child and aiding the parents in establishing structure can be positive interventions for all involved. School personnel, who approach parents and children from this angle, may be able to frame problems as opportunities for growth for everyone in the family. Despite the fears that many professionals have of offending parents, parents who have been involved in substance abuse may feel a sense of relief when the issue is finally dealt with in an honest manner.

Teachers who are mandated to report child abuse sometimes feel they walk a fine line between being advocates for the children in their classroom and reporters for child welfare services. Taking a stance in the best interest of the child is crucial. At the same time, teachers still need to be sensitive to issues of guilt, resentment, and fear that parents can feel when confronted on these concerns.

Parents who have a difficult time following through on programs for their children or understanding information given by teachers may not be "lazy," or "uninterested." In reality, the parents may be struggling with difficulties caused by the consequences of their own prenatal alcohol exposure. Information can be provided in a simple, concrete fashion and in a manner that encourages open dialogue.

Brady and Grollman[264] make the point that many teachers may have difficulty feeling sympathy for parents who are abusing substances. Remembering that a parent may also be affected by prenatal alcohol exposure and also recalling that alcoholism is a disease, not a moral issue, can help school personnel remain compassionate if not completely neutral. It can be difficult to maintain a nonjudgmental view of parents when children are suspected of being abused or neglected Yet, it is precisely this non-judgmental attitude that needs to be maintained in order to provide a safe place for parents and teachers to collaborate in meeting the needs of children.

Up to this point, the focus has been on behavioral concerns and educators connecting with parents. Preschool and elementary school is where academic learning commences. Many children with FASD appear to be of at least of average intelligence in preschool and the early elementary years. Basic academic skills are the focus at this time such as word recognition, simple reading, or math skills. Information should be presented in a multimodal fashion and in small pieces. Use of color and visual cues is helpful to most children, but particularly to those with the learning difficulties commonly associated with FASD. Keeping things simple is often quite useful. For example, rather than fifty math problems on a page, putting five problems on a page for ten pages can be less overwhelming for children.[265,266]

As with mental health counseling, each child should be assessed and a program designed for the child's special needs. For many children, academic interventions

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[264] Brady, J. P. and Grollman, S. Risks and Reality: Teaching Preschool Children Affected by Substance Abuse. - Washington, DC: DHHS, 1994.
[265] Greenspan, S. I. The Child with Special Needs: Encouraging Intellectual and Emotional Growth. Reading, MA: Addison-Wesley Longman, Inc. ,1998.
[266] Greenspan, S. I. Playground Politics. Reading, MA: Perseus Books, 1993. -

are formalized through the Individual Education Plan (IEP). This plan details the child's strengths, concerns, and what services will be needed to address their needs. The IEP often accompanies the child across their school years, being modified as is appropriate. The IEP allows communication between school personnel and from teacher to teacher over the years. For children prenatally exposed to alcohol, IEPs should be implemented as early in the child's school career as possible. Developing an IEP can encourage communication and cooperation between parents and teachers. For an example of an IEP and its content see Appendix 6.

Later Elementary School Years:

The principles outlined above are apt to be useful throughout the child's schooling. As the child moves closer to the middle school years, expectations increase and so can the child's frustration. Studies have shown that expressive and receptive language skills are areas that are often negatively impacted by prenatal alcohol exposure. These skills become more important in the upper grades as more self-expression is required in the classroom. Spelling requires the child to remember and use information, generalize and discriminate between sounds, and produce a response.[267,268] Verbal skills, overall, tend to slide at this age, while tasks using visual-spatial skills may show less of a decline. The difference between verbal and performance skills is commonly reflected in IQ scores and does not decrease as the child grows older.[269]

"Learning my times tables is the hardest thing I have tried. I am 15 and my 5-year-old sister does her times tables better than I can But, I can read better than her. "

- 15 year old boy with FAS

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[267] Sohberg, M. M. and Mateer, C. A. "Effectiveness of an Attention-Training Program. " Journal of Clinical & Experimental - Neuropsychology. 9 (1987) 117-130. -

[268] Soby, J. M. Prenatal Exposure to Drugs/Alcohol: Characteristics and Educational Implications of Fetal Alcohol Syndrome - and Cocaine – Polydrug Effects. Springfield, IL: Charles C. Thomas Press, 1996. -

[269] Brown, R. T. , Coles, C. D. , Smith, I. E. , Platzman, K. A. , Silverstein, J. , Erickson, S. , and Falek, A. "Effects of Prenatal - Alcohol Exposure at School age 11: Attention and Behavior. " Neurotoxicology and Teratology. 13 (1991) 369-376. -

Math is a common area where deficits associated with prenatal alcohol exposure begins to be noticeable in the later elementary years. Recognition of abstract principles underlying math problems may also be outside the grasp of many children with FASD. Division and multiplication are complex tasks requiring abstracting abilities, memory, and recall. Memorization of the multiplication tables can be an insurmountable task for children with FASD. In the early years of elementary school, simple addition and subtraction can be linked with visual cues, e. g. three blocks plus four blocks, two apples minus one apple. The more abstract math becomes, the fewer visual cues can be used. Without methods to translate math into "small pieces" or connect it to concrete, visual cues, the more challenging arithmetic may be for children affected by FASD.[270,271] Individualized programmed instruction such as computer assisted learning and specialized learning materials have been used successfully with children who have other development disabilities and may be helpful for children with FASD. These programs:

- Assess the child's current skill in the area
- Provide graded teaching and exercises
- Provide immediate reinforcement for correct responses

Reading skills may continue to be higher than math or spelling skills, but the ability to comprehend what is being read may be compromised. Comprehension of verbal materials becomes more important as the child progresses in school. Written materials are major sources of information for people in contemporary American culture. Not being able to comprehend and use reading materials on a daily basis can become incapacitating for children with FASD.

Increasing problems in academic learning can lead to increased frustration in both the school environment and the "real" world. Impulsivity, attention deficit problems, and lower abstracting abilities can interfere with learning. Social difficulties, as

[270] Kleinfeld, J. Fantastic Antoine Grows Up. United States: University of Alaska Press, 2000. -
[271] Kopera-Frye, K. , Dehaene, S. , and Streissguth, A. P. "Impairments of Number Processing Induced by Prenatal Alcohol - Exposure. " Neuropsychologia. 34 (12) 1996, 1187-1196. -

discussed in the previous section, may be more pronounced in the school setting. Social isolation, being "different," having poor communication skills, and failing to progress in school may make school an unpleasant experience for the child with FASD.[272]

According to longitudinal studies performed by Dr. Streissguth,[273,274] the academic ceiling is often reached in late elementary or middle school. This ceiling is commonly measured as being at the fourth grade for reading and the third grade for spelling and arithmetic. Lower academic abilities are seen in children and adolescents with FASD regardless of IQ or physical appearance. The child's intelligence and normal physical characteristics may cause educators to overestimate the child's abilities. The difference between academic achievement and IQ is consistent with the differences often seen between intellectual abilities and adaptive behavior. As an example, children may have a higher intellectual capability than their ability to function in a social setting.

These concerns need to be addressed in a proactive manner. It is important to recognize the differences in academic, social, adaptive behavior, and intellectual skills between children with FASD and their classmates. Assessments should be done on a regular basis to track the child's progress in the areas noted. The results of these assessments can guide the type of interventions and special services needed. Progress can be measured and additional interventions provided as indicated by evaluation results. Assessment and screening tools that may be helpful are detailed in Appendix 5.

Interventions in the child's academic career often include special education and tutoring services, and expanding the focus from academic skills, to daily living and vocational skills. As the child gets older, academic learning should continue to be

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[272] Evensen, D. Working with adolescents in high school: Techniques that help. In Fantastic Antione Grows up. (J. Kleinfeld, B. Morse, and S. Wescott, Eds.) Fairbanks, AK: University of Alaska Press, 2000. , -

[273] Darby, B. L. , Streissguth, A. P. and Smith, D. W. "A Preliminary Follow-up of Eight Children Diagnosed with Fetal Alcohol - Syndrome in Infancy. " Neurobehavioral Toxicology & Teratology. 3 (1981) 157-159. -

[274] Streissguth, A. P. A Long-Term Perspective on FAS. " Alcohol Health & Research World. 18(1) 1994, 74-81. -

included within functional skills. For example, learning how to read and use a cookbook, reading labels on grocery products, and being able to use a calculator and make change are all useful tasks. As the child grows into adolescence and beyond, the ability to make sense of one's world is more crucial. Classroom learning that integrates these skills can aid in the client gaining as much independence as possible.

As Dr Burgess[275] has indicated, "appropriate behavior and communication skills are the curriculum for children with FAS. " The need for positive communication abilities and being able to control one's behavior are even more crucial in adolescence than early childhood. Children and adolescents with FASD do not just demonstrate problems with academic skills. They also struggle with healthy relationships with their peers. Arguing, aggression, being easily influenced in negative ways, and disrupting class are common concerns that lead to classroom problems and possibly the suspension of the student from school.

"I'm not arguing with my teachers. I'm just trying to prove my point!"

- 12 year old girl with FAS on being escorted to the principal's office for the fifth time in a week

One of the primary goals at this point is to retain the child in school. School provides the structure and supervision that are necessary for children with FASD who are approaching adolescence and the stresses and dangers that this period in life entails. Given the psychosocial and academic problems commonly displayed by children and adolescents with FASD, it is important that preventive steps be taken to reduce frustration as well as subsequent resistance to attending school. Being aware of the student's strengths and areas of concerns can provide information allowing for changes in approaches to learning. Providing vocational and social

[275] Burgess, D. Presentation on FAS in Rolla, ND, April, 1992.

skills training that allows for reduction in frustration can help students feel more successful, encouraging them to continue in school.

Children with FASD who made it through the elementary grades in a typical public school setting may required special learning environments as they grow older, e. g. schools with more structure, smaller classrooms, greater focus on social and life skills. Such a private or alternative school should be made available to children with FASD just as they are now made available for children with other disabilities.

Conflict resolution skills and involvement in extracurricular activities are experiences that might be of value for children of all ages. For older child with FASD, these are steps to help the child feel mastery over their environment and begin to have more positive relationships with their peers. Being able to adequately communicate needs and feelings is a valuable skill for all ages. Being able to participate in sports, arts, social clubs or music, add joy and enrichment to their lives.

Middle School Years:

The move from elementary school to middle school can be a difficult transition. Children frequently go from one class, six hours per day, to six classes one hour per day. This requires children to make several transitions per day. They have to remember the order of their classes, where in the school each classroom is, and where the student sits in each room. This may appear to be a simple task, yet for children with memory problems and those who are easily distracted, making multiple changes during a day can be somewhat disconcerting and difficult.

Steps that can aid in such transitions can include having a mentor, a responsible older child, who can walk the child with FASD from classroom to classroom. Having a nametag attached to the desk and other visual reminders of limits and rules are helpful.

Patricia Tanner[276] discussed the need to focus on flexible structure and consistency in the classroom. These recommendations echo those from Brady and Grollman.[277] Dr. Streissguth suggested that the teacher assume the role of active listener and advocate, and make the classroom a safe place for the child on an academic and interpersonal level.[278] These are all approaches that are helpful in increasing the likelihood of school success in the elementary and middle school years. They are also helpful as the student enters high school.

High School Years and Beyond:

Many schools now incorporate vocational training into their high school curriculum for students with special needs. Additional accommodations allow certain students to remain in high school up to the age of 21. Extra school years can help provide continued structure and consistency, as well as allowing for more time for the student to mature. Linking high school to vocational training can prepare for stepping from school into employment and more independence. Vocational training should occur after an assessment is completed and the adolescent's interests, skills, weaknesses, and concerns are identified. A placement that addresses the health and safety needs of the patients as well as provides a place to safely learn and practice vocational skills is the ideal.

Gaining employment may or may not be an issue for the adult with FASD. Sustaining employment, however, is often a challenging situation for people with FASD.[279] If the job requirements are too confusing or there is not enough time for the adult with FASD to learn these requirements, frustration can set in. Poor social skills or communication difficulties can lead to conflict on the job, and thus, termination of employment often without the patient understanding the reasons this

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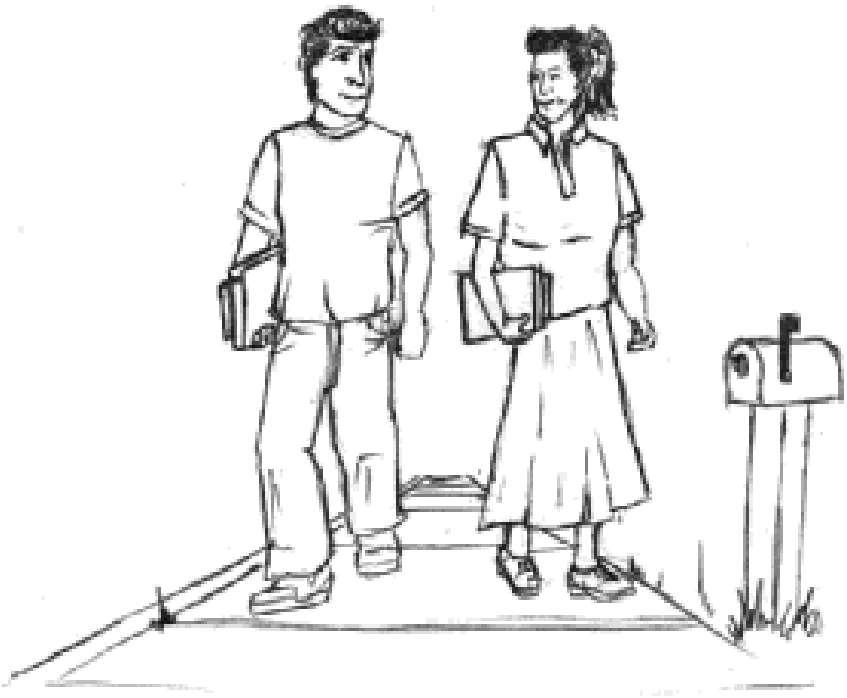
[276] Tanner, P. A Demonstration Classroom for Young Children with FAS. The Challenge of Fetal Alcohol Syndrome. - Streissguth, A. P. , Kantor, J. (Eds.) Seattle, WA :University of Washington Press, 1997. -

[277] Brady, J. P. and Grollman, S. Risks and Reality: Teaching Preschool Children Affected by Substance Abuse. - Washington, DC: DHHS, 1994.

[278] Streissguth, A. P. Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore, MD: Paul H. Brookes - Publishing Co. , 1997.

[279] LaDue, R. A. , Schacht, R. M. , Halverson-Tanner, P. , McGowan, M. Fetal Alcohol Syndrome: A Manual to Aid in - Vocational Rehabilitation. Flagstaff, AZ: Northern Arizona U. , 1999. -

occurred. Many people with FASD need constant support at the beginning of employment. Job coaches can eventually be phased out, if appropriate, and replaced by natural supports. It is important to clarify the roles of the job coach and supervisor to ensure conflicting and confusing information and directions are kept to a minimum.



"I just want to spend my first two paychecks. You can pay my bills for me, Dad "

- 17-year-old girl upon getting her first job

While structure is important in allowing patients with FASD to achieve their full potential, sheltered workshops may not be the best employment settings. A combination of structure and challenges, building on the patient's strengths, is the ideal. Such placements, however, may not be easily found. Below are some of the ways professionals can be useful in developing vocational training and placements for patients with FASD.

The Role of the Professional:

There are several roles that professionals can take in educational and vocational training.

Educators:

It is a misconception that all children with FASD need to be enrolled in special education services. In actuality, there is a very wide range of abilities in patients with FS/FASD. The role of the educator can include:

- Assessment of educational needs
- Assessment of student skills
- Development of educational programs
- Student/family advocate

Assessment of educational needs should include the level of the student's social and communication skills, emotional maturity,[280] verbal and comprehension abilities, and language usage. It is vital to assess strengths and concerns as programs should be built on the student's skills. A multi-faceted ecological evaluation should form the basis of the educational program as well as be a marker for the child's progress through school. In addition to academic skills, behavioral assessments should also be conducted. Educators who can provide such assessments and develop corresponding programs are valuable assets to their students.

Cooperation between parents and educators is a key factor in ensuring that students reach their full potential. Streissguth[281] and others recommend sharing testing

[280] Hyson, M. C. The Emotional Development of Young Children: Building An Emotion-Centered Curriculum. New York: - Teachers College Columbia University, 1994.
[281] Streissguth, A. P. Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore, MD: Paul H. Brookes - Publishing Co. , 1997. -

results with parents. This is the same type of "bridge" that Brady and Grollman[282] recommend. Prior to any assessment, parents should be informed that such assessments are being conducted and consents signed. When sharing the results of the evaluation and assessments, educators should keep terms simple and concrete. Recommendations should be made in ways that connect the home to the classroom. Encouraging parents to ask questions and provide input are valuable tools for developing positive relationships with parents.

Many older children, adolescents and young adults with FASD, recognize their differences from their peers, but often do not have a clear sense of how to express their needs and feelings about these differences. Educators can be sensitive to these needs and help struggling students to focus on their skills, strengths, and assets. Brady and Grollman[283] discuss creating "morning circles" where children are encouraged to talk about their lives and share things that make them special and unique. These suggestions are not helpful to just young children; they are recommendations that can be used with students of all ages.

Development of programs that emphasize communication and social skills within the context of the academic setting is another way educators can be supportive of students with FASD. This often requires educators to be creative and concrete at the same time. Identifying a list of areas where students will need positive skills, e. g. shopping, cooking and social activities are often helpful. Incorporating these areas into the IEP can be an important part of addressing needed life skills.

Earlier, it was suggested that assessment results be shared with the parents. It is also important that parents share their areas of concern with educators. If there are problems that the parents or caregivers note in communication and social skills or other areas, parents and educators can work together to help develop programs for remediation. This approach encourages structure and consistency, aiding the child

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[282] Brady, J. P. and Grollman, S. Risks and Reality: Teaching Preschool Children Affected by Substance Abuse. - Washington, DC: DHHS, 1994.
[283] Brady, J. P. and Grollman, S. Risks and Reality: Teaching Preschool Children Affected by Substance Abuse. - Washington, DC: DHHS, 1994. -

in increasing their functioning. The steps described beloware part of the partnership and teamwork between professionals and caregivers that has been stressed throughout this manual.

Vocational Counselors:

Vocational counselors are in a prime position to be of support to adolescents and adults with FASD. A manual specifically intended for vocational and rehabilitation counselors were developed by LaDue, Schacht, Tanner, and McGowan; and details vocational assessment and intervention.[284] The role of the vocational/rehabilitation counselor is to:

- Assess the student's vocational needs
- Assess skills that can be used to help develop job training programs
- Aid in placing the client in an appropriate vocational setting
- Serve as part of the team for wrap-around services

Vocational counselors have specific skills that help determine what their clients need to succeed in the job market. People with FASD often have difficulties adapting to the work environment. Anecdotal information presented by Kleinfeld[285] and Streissguth[286] describe the frustration commonly felt by people with FASD when they are in the working world. These stories often speak of the person with FASD:

- Having difficulty remembering and following directions
- Not comprehending the subtleties of tasks
- Not understanding the social aspects of their jobs
- Not being able to organize themselves to arrive at work every day
- Being confused by directions that might be given by different supervisors

[284] LaDue, R. A. , Schacht, R. M. , Halverson-Tanner, P. , McGowan, M. Fetal Alcohol Syndrome: A Manual to Aid in - Vocational Rehabilitation. Flagstaff, AZ: Northern Arizona U. , 1999. -
[285] Streissguth, A. P. Fetal Alcohol Syndrome: A Guide for Families and Communities. Baltimore, MD: Paul H. Brookes - Publishing Co. , 1997.
[286] Kleinfeld, J. Fantastic Antoine Succeeds. United States: University of Alaska Press, 1993. -

- Being impulsive and taking on tasks that are outside of their job duties
- Not fully understanding private vs. public property / taking or "borrowing" things from job site

Vocational counselors working with people with FASD can help facilitate communication between the client and supervisors in the job environment Setting up structure on the job site, establishing clear job duties, and keeping expectations reasonable for both employer and employee are ways the vocational counselor can help increase the probability of successful job placements.

Students with FASD often reach their academic ceiling at an early age, but can still benefit from school-based learning.[287] Making the vocational counselor a part of the service team in high school can begin facilitation of vocational training that will aid the student across their lifespan. Vocational training needs and services should be incorporated into the IEP. Information from the client's IEPs can be shared, ensuring a smoother transition from school to work. Shifting the focus from academic to vocational training can reduce the frustration many people with FASD experience in the school setting.

Vocational counselors, prior to placing clients into any specific job environment, should have an awareness of the special needs of the individual with FASD. The needs of the individual for structure, verbal, written, and visual cues and directions should be assessed prior to the client being placed in the job environment. Such an assessment can include:

- An IQ test
- An academic skills assessment
- Observations of the client in a job training setting
- Assessment of communication and social skills

[287] Streissguth, A. P. , Barr, H. M. , Kogan, J. , and Bookstein, F. L. Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects. Seattle, WA: University of Washington, 1996.

- Functional testing to identify level

Finding what areas of interest the client has should be considered when placing the client in any job setting. Helping the client maintain interest in their job is important but also one that is difficult. Attention and concentration skills are often limited in people with FASD. Finding a type of work that is built on the client's interests, coupled with either a job coach or natural support, can increase the chances of the client succeeding.

In summation, educational issues for the person with FASD do not subside with age. Indeed, the need for appropriate and long-term vocational training continues well into adulthood. Specialized and subsidized programs that include teacher's aides, linkages to the child's/adult's home, and focus on the client's strengths make it more likely that the client will acquire the confidence and skills to progress and thrive.

Integration of Traditional Native Beliefs, Values, and Practices:

Traditional learning often took place through stories, legends and oral history. [288,289] Visual learning was also important given the hunting, fishing, and subsistence living on which most cultures relied. Language and memory were important, but reading was not a traditional skill. In the past two hundred years, particularly in the last 100, reading became more critical for survival. However, it appears that many Native children still learn through oral and visual means versus reading. This skill difference can lead to lower scores on the verbal portions of IQ tests and other standardized tests that rely on reading. Any assessment should include consideration of cultural factors.[290]

When working with Native children, it is important that learning style be considered and included in any educational program. It should not be assumed that Native

[288] Erdoes, R. and Ortiz, A. (Eds.) American Indian Trickster Tales. New York, NY: Viking Penguin Books, 1998.
[289] Erdoes, R. and Ortiz, A. (Eds.) American Indian Myths and Legends. New York, NY: Pantheon Books, 1985.
[290] Sattler, J. M. Assessment of Children's Intelligence. New York: W. B. Sounders Company, 1974.

children are less intelligent or capable than their non-Native counterparts simply by virtue of their learning styles. For Native children with FASD, incorporation of traditional art skills can be helpful, e. g. beading and drawing. These skills encourage manual dexterity, coordination, creativity and planning. In some Native communities, elders are brought in to teach these skills. Still other communities have immersion schools, which teach only in the Native language.

An academic program that honors the child's culture, encourages multi-sensation learning, promotes inherent skills, and partners with the community can accomplish what Brady and Grollman,[291] Evensen,[292] Burgess,[293] and Tanner[294] all endorse through positive educational principles. Educational programs that are based in the community and build bridges to the community can also help ensure inclusion of families and reduce the anxiety and fear many parents may feel when dealing with the school system.

Educational/Vocational Concerns and Service Matrix:

At the start of Section I, a case study was detailed. Additional concerns related to family issues were discussed at the beginning of this chapter. Below is the educational needs matrix for Jerilynn across the lifespan. Please note the changes in needs and services required as Jerilynn grows older. With each section, a portion of the matrix will be completed with the full series of matrices finished by the end of the manual.

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[291] Brady, J. P. and Grollman, S. Risks and Reality: Teaching Preschool Children Affected by Substance Abuse. - Washington, DC: DHHS, 1994.
[292] Evensen, D. Working with adolescents in high school: Techniques that help. In Fantastic Antione Grows up. (J. Kleinfeld, - B. Morse, and S. Wescott, Eds.) Fairbanks, AK: University of Alaska Press, 2000. -
[293] Burgess, D. M. , Streissguth, A. P. "Educating Students with Fetal Alcohol Syndrome or Fetal Alcohol Effects. " - Pennsylvania Reporter. 22(1) 1990 1-3. -
[294] Tanner, P. A Demonstration Classroom for Young Children with FAS. The Challenge of Fetal Alcohol Syndrome. - Streissguth, A. P. , Kantor, J. (Eds.) Seattle, WA : University of Washington Press, 1997. -

Figure 10

Matrix IV:

Educational/Vocational Concerns for Jerilynn

Ages 0-5	Appropriate preschool placement, articulation problems, distractibility
Ages 6-11	Verbal learning deficits, attention and concentration problems affecting school performance
Ages 12-17	Verbal learning deficits, attention and concentration problems affecting school performance, patient cutting school and finally dropping out, defiance of teachers, refusal to complete work, deficits in daily living skills
Ages 18 and Up	Patient has no vocational skills, refusal to participate in DVR program

Educational/Vocational Services for Jerilynn

Ages 0-5	Specialized preschool, speech therapy
Ages 6-11	IEP focusing on academic and daily living skills, social skills training
Ages 12-17	Vocational training and daily living skills training,
Ages 18 and Up	Vocational training and daily living skills training, GED classes

Section VI:

Legal Issues

"Why waste my money buying things when I can steal them?"

- 17-year old girl with FAS after being arrested for shoplifting

A major issue facing people with FASD and their families is the reportedly high rate of legal involvement for a variety of reasons.[295] Legal issues range from custody concerns such as guardianship to criminal issues as severe as homicide.[296,297] The type of legal issues will vary from patient to patient and change across the lifespan. Another legal issue that has been raised includes wrongful adoption where adoptive parents were not informed of their child having FASD.

Criminal issues and mitigating circumstances may include:

- Being charged with any crime
- Competency and restoration of competency
- Capacity
- Diminished Capacity
- Decline/remand
- Mitigation

Civil legal issues may include:

- Wrongful adoption.
- Parenting/custody evaluation
- Termination of parental rights

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[295] Perske, R. Unequal Justice? What Can Happen When People with Mental Retardation or Other Developmental Disabilities - Encounter the Criminal Justice System. Nashville, TN: Abdingdon Press, 1991. -
[296] Fehr, L. "The criminal justice system and fetal alcohol syndrome. Counselor. 13(3), 1995. -
[297] Kleinfeld, J. Fantastic Antoine Succeeds. United States: University of Alaska Press, 1993. -

- Assignment or removal of guardianship/protected payee
- Adoption

Criminal Issues Associated with FASD:

A myth has been conceived and nurtured that people with FASD, simply by virtue of their disability, have a high likelihood of being involved in legal problems. Clinical studies such as Streissguth, et. al.[298] suggests a higher risk of such problems. In reality, the actual number of people with FASD having such problems is not known. What is clear, however, is that children, adolescents, and adults with FASD may be more easily led, subjected to negative influences, and unable to recognize the risks of certain behaviors. One of the major concerns when an adolescent or adult with FASD is arrested, is the risk of them providing incriminating and possibly false information to authorities.

People of all ages with FASD frequently have limited comprehension of social rules and expectations. They may not understand complex questions. They may not comprehend the notion of rights or the consequences of waiving their rights. On

[298] Streissguth, A. P. , Barr, H. M. , Kogan, J. , and Bookstein, F. L. Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects. Seattle, WA: University of Washington, 1996.

more than one occasion, the author has been involved in situations where an adolescent with FASD was arrested and “confessed” to a number of crimes because the police stated the person “could go home if they told the truth. ” This situation has been known to occur with many youth, who are questioned without a parent or advocate.

It is strongly recommended that children, adolescents, and adults be reminded not to talk to the police without their parents or caregivers present. This is often in contrast to the usual idea of “police being our friends.” In actuality, a balance needs to be struck between teaching the person with FASD to protect their rights while still viewing police as helpful Developing a plan that provides the patient with a means of responding to the police should the need arise, should be developed in early childhood and revised as needed as the child grows older.

For example, one youth with FAS was alleged to have done inappropriate touching with a younger boy while in the school restroom. Police questioned the youth at school without his parents being present. During this questioning, the youth “admitted” he had sex with dozens of other boys. He was later charged with multiple counts of child molestation. After a more thorough investigation, it was revealed that the youth had not had any time alone with any child and, in fact, had no history at all of inappropriate sexual behavior.

As a result of this situation, the youth did receive counseling along with his parents. During the therapy sessions, a plan was made whereby the youth was given a written card to give police if he was ever stopped. The card provided the names and cell phone number of the youth’s parents. It was affixed to the youth’s identification card so that the youth would not have to remember to give it to authorities. Simple plans like this are vital to protect the safety of the client and their rights.

Competency: -

Earlier in this manual, the brain damage associated with prenatal alcohol exposure was discussed in detail. This damage results in lowered abstracting abilities, impulsivity, and a lack of comprehension of social rules and expectations. These are all skills that are needed to understand legal proceedings, charges, and to aid in one's defense in a reasonable manner. In many states, these are factors in determining if a client has the competency to stand trial. Competency evaluations are generally not conducted on children over the age of 12. They are usually done if there is a question as to the cognitive abilities of defendants over the age of 12 years and their ability to meet the criteria outlined.

Competency is crucial, as states and the federal government statutes commonly prohibit trying and convicting people for the commission of an offense if the defendant is incompetent.[299] Incompetence arises as a result of a mental disease or defect. This could well be the case with a defendant who has FASD. The concern is that many people, particularly those with FASD, are not identified. Due to the often verbal, gregarious manner with which many individuals with FASD present themselves, they may appear more capable than they actually are. Thus, they may be found to be competent in spite of significant brain damage.

For professionals conducting competency evaluations of people with FASD, it is important to detail for the court how the brain damage associated with this birth defect can compromise abstracting abilities, intent, planning, comprehension, and accurate reporting. In some cases, a person with FASD may be marginally competent. They may be able to understand the charges against them, e. g. stating that assault means hitting someone. The defendant with FASD may also be able to state that going to court means that "they may have to go to jail. " They may not, however, be able to accurately report their history, their actions, or provide their

[299] LaDue, R. A. , Dunne, T. "Legal Issues and FAS. " The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities. Streissguth, A. P. and Kantor, J. (Eds.) Seattle, WA: U. of Washington Press, 1997.

attorney with other needed information. Simply knowing who their attorney is or - what the judge's role is does not constitute competency.

Washington State has a "competency restoration"[300] program for people who have been found to be incompetent. They attend a program intended to prepare them for trial. This program consists of classes where defendants are taught about charges and legal proceedings. At completion of this course, the defendant is re-evaluated for competency. One of the concerns about such "competency restoration" is that it appears to be more of a memory course than cultivating true understanding of legal proceedings. Simply being able to repeat what one has heard does not imply comprehension. This is particularly true for people with organic brain damage such as those with FASD.

Professionals working in this area should be careful to assure that each part of the competency criterion is addressed separately. The defendant's ability to understand the abstract concepts is important versus their ability to simply repeat what has been told to them. If the defendant has deficits in their abstracting abilities and comprehension skills, it is crucial that these deficits be conveyed to the court.[301]

Capacity:

Capacity is generally based on age and may be similar to the guidelines for competency. In general, children under the age of eight are not considered able to understand legal charges and proceedings. Between the ages of eight and twelve, there may be questions as to whether the child has these abilities. If an individual with FASD is arrested, it is important that a capacity evaluation be done to address the issues listed above.[302] This is particularly important as many older individuals with FASD may have the comprehension capacity of a young child.

[300] Revised Code of Washington (RCW 10. 77). Olympia, WA: State of Washington. -
[301] LaDue, R. A. , Dunne, T. "Legal Issues and Fetal Alcohol Syndrome. " The FEN Pen. 3 1995, 6-7. -
[302] LaDue, R. A. , Dunne, T. "Capacity and FAS. " The FEN Pen. 5(1) 1996, 2-6. -

Diminished Capacity:

Diminished capacity is where the defendant's ability to form intent is impaired by a mental disorder or defect.[303] This can include a thought disorder or organic brain damage or a combination of the two. Many defendants with FASD have both conditions. In performing a diminished capacity examination, it is important that all of the following elements be evaluated:

- Family and personal history of mental disorders or defects
- Family history of alcoholism
- History of prenatal alcohol exposure
- Mental health diagnoses and any treatment
- Defendant substance abuse
- History of head trauma
- Any other evidence that suggests organic brain damage

For defendants with FASD, it is important that all of these factors be considered along with the deficits in judgment, behavioral control, understanding of cause and effect, and abstracting problems that are characteristic of their disorder. All of these factors enter into whether a person canform intent or if that ability is impaired

Decline/Remand:

Several states now have legislation that detail when a juvenile should be charged as an adult. For many states, that decision now rests in the hands of the prosecutor. For example, in some states, if a youth is under the age of 18 and is charged with second or first-degree murder, they are automatically charged as an adult. In other cases, there may be an evaluation conducted to determine if it is appropriate to retain the youth in the juvenile system or refer them to the adult justice system. If a decline hearing is recommended, the following should be included in the evaluation:

[303] Revised Code of Washington (RCW 10. 77). Olympia, WA: State of Washington.

- Level of risk the youth presents
- Family support, structure, and stability
- History of previous legal problems
- Susceptibility to the influence of friends
- Previous participation in services
- Intellectual ability
- Ability to understand cause and effect
- Capability of being maintained safely in the community[304]

These factors will vary from state to state. In some states, decline hearings have dropped significantly due to the changes in charging practices. Factors that are often used to determine if a child should be declined may be tilted against the defendant with FASD. Many children with FASD come from families that have little stability. They are often negatively influenced by peers and have limited ability to comprehend cause and effect. It is possible that, due to these factors, defendants with FASD may well be at increased risk to be declined into the adult justice system.

Mitigation:

Mitigation is a process by which certain factors are introduced to the court to decrease or modify the sentence received by the defendant.[305] This is the one area where the FASD diagnosis has been successfully used in legal situations. The manifestations of brain damage that are resultant from prenatal alcohol exposure have been described to the court as a source of difficulties leading to legal problems. An evaluation that details mitigating factors should include those listed in the previous discussions. It should also provide a plan as to what services should be used to address the needs of the defendant, rather than simply stating a lower sentence should be imposed.

[304] LaDue, R. A. , Dunne, T. "FAS and the Decision to Decline. " The FEN Pen. 5(2) 1996, 2-6.
[305] Ferry, D. "Fetal Alcohol Syndrome: An Effective Capital Defense. " CACJ/Forum, 24(2) 4-50.

Civil Issues Associated with FASD:

Adoption:

Many children with FASD enter foster care and may be placed for adoption. If this is the case, it is critical for the prospective parents to have as much information as possible about the short and long-term needs of the child.

Wrongful Adoption:

"Not being told your adopted child has FAS handicaps everyone in the family."

-Adoptive parents of two adolescent children with FASD

In the past several years, there have been multiple lawsuits against states and adoption agencies where children were placed for adoption with families, without them being adequately informed of the health issues and diagnoses of their children.[306] Failure to inform prospective parents that their children had FASD is alleged to have led to family problems, legal issues, and a high need for services. In some cases, had the adoptive families been aware, they might not have agreed to a standard, or even subsidized, adoption.[307] In some instances, these cases have been resolved in favor of the family with their receiving funds for needed services. Parents in these situations have strongly pushed for any and all pertinent information about a child they are considering for adoption.[308]

[306] Edelstein, S. B. et. al. Children with Prenatal Alcohol or Other Drug Exposure: Weighing the Risks of Adoption. - Washington DC: Child Welfare League of America, 1996.
[307] McKinney v. State, No. 64783-6, SUPREME COURT OF WASHINGTON, 134 Wn. 2d388; 950 P. 2d 461; 1998 Wash. - LEXIS 11, May 28, 1997, Oral Argument, February 5, 1998, Filed.
[308] Edelstein, S. B. et. al. Children with Prenatal Alcohol or Other Drug Exposure: Weighing the Risks of Adoption. - Washington DC: Child Welfare League of America, 1996. -

Parenting/Custody Evaluations: -

One of the most sensitive areas in the field of FASD is whether parents of children with FASD are able to retain custody. These issues are of particular concern if the parents themselves have FASD. Parenting and custody evaluations should consider, at the minimum, the following factors:

- The ability of the parent to adequately provide for the child and ensure their safety
- The stability of the family home and the ability of the parent to maintain such stability
- The intellectual capabilities of the parent and how these translate into daily life when caring for the children
- The level of drug/alcohol use of the parent and whether the parent has accessed treatment
- Who, if either parent, can best meet the needs of the child over a sustained period of time

Such evaluations should be conducted by professionals who have the training to conduct formal evaluations, and should be done in conjunction and collaboration with other professionals that have had sustained contact with the family. If at all possible, interviews with treatment providers and child welfare or caseworkers should be conducted. The more background information possible, the better.

It should not be assumed that all parents with FASD are unable to care for their children. However reports have suggested increased difficulties for parents with FASD in providing care for their children. There are also cases where, with support and wrap-around services, parents with FASD have been able to maintain custody of their children. In the latter case, wrap-around services including family preservation services, in-home parent training, public health nursing, long-term mental health services, drug/alcohol services, and childcare have been provided.

Termination of Parental Rights:

One of the most difficult situations for a parent is to be involved in the termination of parental rights. This is generally the final step in a long process of abuse/neglect, foster care, reunification, and subsequent abuse. In the past few years, federal legislation was passed that mandates a permanency placement plan be put in place within 18 months of the child's placement in foster care. The purpose of this legislation was to ensure that children did not languish in foster care and multiple placements for a number of years, as had often been the case .

Termination of parental rights is one of the most devastating situations that parents can face. Therefore, before this step is taken, it is vital that all efforts are made to engage the parents in services even as the children is protected. Parents who have FASD themselves may not be able to follow through on services, make plans, sustain a stable environment, or ensure their children's safety. For these reasons, they may be at greater risk to have their children placed in foster care and to eventually lose custody.

Before termination of parental rights occurs, a parenting/custody evaluation should be conducted. Services should be offered and assessed for success or failure and options for an open adoption with episodic visits discussed. One of the consequences frequently noted in situations where women lose their children is another pregnancy. The grief and depression many women feel over the loss of their children may be ignored in the termination process. An open adoption may provide continued contact, in a safe and supervised manner. This type of contact which may lessen the grief and also possibly reduce the risk of another pregnancy that might result in yet one more child being removed from the mother.

Guardianship:

"We had to take a guardianship of our adult child because he bought luxury cars three times without having any job."

- Mother of a 28-year-old man with FAS

Assignment or removal of a guardianship or protected payee is a less complicated legal issue than those previously discussed in either the criminal or civil sections. A guardianship can be put in place through the court for patients with cognitive and functional disabilities. Disabilities should reach the level of impairing decision-making, signing contracts and management of funds before such steps are taken.

The need for protection from exploitation does not decrease as the patient grows older. If the patient is on Social Security, is receiving per capitas or is working, a protected payee is often needed. There is a difference between a protected payee and a guardianship. A guardian can sign contracts, make long-term plans, and manage other daily aspects of the patient's life. A protected payee is simply someone who manages funds. Some adult patients with FASD may only need a protected payee while others with more impairment will need a guardianship throughout their lives.

The Role of the Professional:

"I have met children with FAS who are so vulnerable and gullible that I could get them to confess to any crime I choose. That is why people with FAS must have a legal advocate. "

- FAS Educator on the concerns of people with FAS in the legal system

The professional may have many roles in legal issues. Defense lawyers need to have an awareness of FASD to adequately represent their client. Prosecutors will need the same awareness to make more appropriate decisions in terms of what charges should be pressed, how plea decisions might be negotiated, and what recommendations might be made to the court. Pre-sentencing officers who have an awareness of FASD are in an ideal position to provide the court with information to make sentencing suggestions that more adequately address the special needs of the defendant with FASD. Psychologists and social workers can help make assessments to aid in referring the defendant to appropriate programs.

The role of the professional in criminal cases is to:

- Assess the abilities and possible mental health and cognitive factors impacting the defendant
- Educate the court as to the possible debilitating factors associated with FASD
- Provide information to the court as to alternatives to incarceration, if appropriate

The evaluator should request as much background information as possible prior to starting the evaluation process. Information should include school records, medical records, police reports, therapy records, witness statements, and, if at all possible, confirmation of prenatal alcohol exposure. Once the evaluation is completed, it should be written in a manner that outlines concerns and risk factors as well as possible interventions.

In civil cases, the role of the professional may also be to educate the court regarding options for placement, services and custody. It is truly in the legal arena that the skills of all professionals can come together as a team in the best interest of the child, the family, and the community at large.

In one homicide case, the defense attorney, prosecutor, pre-sentencing officer, child welfare worker, and psychologist all came together to assess the needs of the defendant. Because he was 16 years old and it was a second-degree murder charge, the youth was declined into the adult judicial system. Through the cooperation of all the professionals involved, a plan was made whereby the youth was allowed to plead guilty to a voluntary manslaughter charge and serve his time in a juvenile facility. The psychologist and social worker were given permission to meet with the youth on a twice-monthly basis while he was incarcerated. At the end of the 31-month sentence, the youth was placed on Social Security with a protected payee and enrolled in a vocational program. Because of the cooperative efforts of the professionals involved and the support of the judge, this case, although tragic at the outset, had a happier ending.

Integration of Traditional Native Beliefs, Values and Practices:

In the past, community concerns similar to today's legal issues were resolved through a council of elders. Conflicts and concerns were brought before the elders and decisions made based upon what was in the best interest of the community.[309] Today, while the council of elders may not exist as in the past, many tribes have formed their own courts and law enforcement services. Tribal courts may or may not address criminal issues. Tribal courts retain custody over children who are tribal members and make placement and custody decisions. Many contemporary tribal courts came into being after the implementation of the 1978 Indian Child Welfare Act (IDWA), which allowed the tribes to retain custody over their members.[310,311]

Legal jurisdiction in Native communities can often be confusing. In some situations, the tribe and county will hold cross-jurisdiction. In other situations, for violent crimes, federal jurisdiction is in place. In others, the tribal courts retain control. These cross-jurisdictions need to be addressed at the outset of any legal situation whether

[309] Zitkala, S. A. American Indian Stories. Lincoln, NE: U. of Nebraska Press, 1921. -
[310] Getches, D. H. , Wilkinson, C. F. , Williams, R. A. Federal Indian Law. St. Paul, MN: West Publishing Co. , 1993. -
[311] DeLoria, V. ; Wilkins, D. E. Tribes, Treaties, and Constitutional Tribulations. Austin, TX: University of Texas Press, 2000. -

it is criminal or civil. It is important that professionals understand the jurisdiction issues prior to their involvement in either criminal or civil cases that include Native children and families.

Many professionals who have limited contact with Native children and families may not fully understand the importance of legislation such as the ICWA, the Indian Self-Determination Act, and other applicable laws. The two Acts cited were written to ensure that Native children are not simply removed from their families and communities based on stereotypes and the actions of "well-meaning" professionals. Understanding the history and culture of Native people and that of any particular community is crucial when any professional is working in the legal realm. Today, it is important that courts do address the requirements of the Indian Child Welfare Act, both for legal and moral reasons.

Knowing the family history is very important, as many Native children are assumed to be alcohol exposed when in reality they are not. It is important that, when making parenting and custody decisions, culture, history, and connections to one's tribal community be considered. Professionals can seek consultation from elders, tribal social workers, tribal judges, and Native professionals at the time of their involvement in criminal and civil cases. The purpose of the 1978 Indian Child Welfare Act was to allow tribal people to retain control over their own children.[312,313] While it is not likely that the council of elders will be brought back to make legal decisions, it is important to recognize the wisdom in this model and to incorporate as many traditional values as possible in making legal decisions.

Legal Concerns and Service Matrix:

At the start of Section I, a case study was detailed. Additional concerns related to family issues were discussed at the beginning of this chapter. Below is the legal

[312] Wilkinson, Charles F. , American Indians, time, and the law: Native societies in a modern constitutional democracy. New - Haven: Yale University Press, 1987.
[313] DeLoria, V. The Indian Reorganization Act: congresses and bills. Norman, OK: University of Oklahoma Press, 2002. -

needs matrix for Jerilynn across the lifespan. Please note the changes in needs and services required as Jerilynn grows older. With each section, a portion of the matrix will be completed with the full series of matrices finished at the end of the manual.

Figure 11

Matrix V:

Legal Concerns for Jerilynn

Ages 0-5	Termination of parental rights, legal issues associated with abuse and neglect, dependency
Ages 6-11	Termination of parental rights, legal issues associated with abuse and neglect, dependency, adoption
Ages 12-17	Criminal charges, termination of parental rights, legal issues associated with abuse and neglect, dependency
Ages 18 and Up	Termination of parental rights, legal issues associated with abuse and neglect, dependency, custody concerns, criminal concerns

Legal Services for Jerilynn

Ages 0-5	Establishment of dependency, criminal charges against birth parents for abuse and neglect
Ages 6-11	Adoption
Ages 12-17	Evaluation for competency, assignment of legal counsel
Ages 18 and Up	Assignment of legal counsel, establishment of dependency for child

Section VII:

Avoiding Professional Burnout

Fetal Alcohol Syndrome is a relatively new area of research, study, and application in the field of developmental disabilities. With rare exceptions, notably the State of Nevada, most states do not recognize Fetal Alcohol Syndrome as a developmental disability despite the Surgeon General's warning about drinking during pregnancy

over twenty years ago, current CDC data suggests that the number of women drinking during pregnancy is actually increasing. [314] For many years, financial resources have decreased in spite of the need for such increased services. All of these factors can lead to frustration and, at times, isolation for professionals working in the field of Fetal Alcohol Syndrome.

One of the most common suggestions given to parents and caregivers of children, adolescents, and adults with FASD is to find or create a caregiver's support group. In several areas, formalized coalitions of professionals working together in the field of FASD have been formed. The Four State Consortium from Minnesota, North Dakota, South Dakota, and Montana is funded through the Center for Substance Abuse Prevention (CSAP) for the purpose of "reducing the risk factors that result in children being born affected by Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effect (FAE)."

Another effort to pull together community resources is through the State of Alaska Office of Fetal Alcohol Syndrome.[315] Through this office, community diagnostic teams were formed with trainings on FAS being held throughout the state. The FAS-DPN through the University of Washington is a model that is being replicated in both the United States and Canada. The FAS-DPN is training professionals throughout both of these countries. Such trainings and the formation of consortiums are helping

[314] Centers for Disease Control and Prevention, 2002. -
[315] Casto, L. D. Fetal Alcohol Syndrome: 2001 Status Update. Alaska Department of Health and Social Services; Office of - Fetal Alcohol Syndrome: Juneau, AK, 2002. -

address the issues regarding FAS, but also provide a network for professionals to discuss their concerns, knowledge, and efforts. Joint efforts by professionals and family members have led to proposed, and in some cases, passed legislation intended to aid those affected by FASD.[316,317]

In Wisconsin, the Family Empowerment Network (a project of the University of Wisconsin Medical School – Department of Family Medicine) with funding from the state's Bureau of Substance Abuse Services provides training throughout the state on FASD, and sponsors clinics to screen women and children at eight women-specific ADDA treatment centers. Once identified, FEN develops a family service plan to assist the family in negotiating with the health, social, and educational services maze for their children with FASD.

Networking efforts such as those described above, provide forums for professionals in the manner that parent support groups have allowed parents and caregivers to gain a sense of support and increased knowledge.[318] Aiding professionals in understanding FASD can help them establish reasonable expectations both for themselves and for their clients. Sharing information across professions can serve as a means to improve services, increase prevention efforts, and lessen isolation that professionals in this field may experience. The more professionals can educate others as well as set realistic expectations and goals, the more likely it is that burnout can be avoided.

One other project underway to improve professional communication and increase knowledge about FASD is the development of the FAS Center of Excellence, funded through CSAP. The Center is bringing together professionals from all disciplines and across the country to share their expertise. It is forming a partnership of professionals and family members. Hopefully, the Center of Excellence's efforts will

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[316] Indian Fetal Alcohol Syndrome Prevention and Treatment Act: Hearing Before the Committee of Interior and Insular Affairs, - House Representatives, 102nd Congress, 2nd Session. On H. R. 1322. Washington, DC, March 5, 1992. -

[317] Blume, S. B. What You Can Do to Prevent Fetal Alcohol Syndrome: A Professional's Guide. Edina, MN: Johnson Institute, - 1992. -

[318] Nevitt, A. "Fetal Alcohol Syndrome. " Drug Abuse Prevention Library. New York: NY: The Rosen Group Publishing Group, - Inc. , 1995. -

lead to more effective prevention efforts, as well as to provide a positive network for - professionals.

All of the efforts described are intended to improve services for clients with FASD. While they may not have the stated purpose of reducing burnout among professionals working in the field of FAS, they may, indeed, serve the purpose of enhancing client's lives.

In the past nearly thirty years, the field of Fetal Alcohol Syndrome has grown to become a major area of concern, but frequently remains an enigma to both professionals and the lay community alike. Hopefully, as consortiums are formed, diagnostic teams are brought together and information spreads, FAS will become the focus of legislatures, educational programs, and the community at large. Such efforts may aid in stopping the occurrence of this completely preventable birth defect and in providing more humane services for those affected.

Section VIII -

Epilogue:

Coyote and Raven

After Raven's return to the village, he often sat with Watcher Woman and Coyote and talked about what he had learned in the city. All three of them discussed ways they could share what they learned with the community. More than once, Watcher Woman sighed and said; "We need to rebuild the council of elders. We need to teach the People how to prevent Fetal Alcohol Syndrome. We need to help those who have been touched by spirit sickness."

How to make this happen seemed to be a puzzle that could not be solved. The trio, over the years, had talked to people here and there. One day, a young teacher came to work at the village school. Tall Cedar was a kind young man whom people liked as soon as they met him. His job was working with students who had special needs. He had heard that Watcher Woman was a wise elder who knew much about the People in the village. One day, he came to talk to her about the students he had in his classroom, those he believed might have FASD. He wondered how he might approach their parents and who else in the village may be able to help.

"I do not want to offend people by asking about their lives, but I want to help the children in the school. I think that many of my children must have been affected by their parent's spirit sickness. How can I help?" Tall Cedar asked Watcher Woman.

Tall Cedar, as he sat across the room from Watcher Woman in her tiny home, could not keep from noticing a large black raven that walked around the chairs where he and Watcher Woman sat. He was also startled to see a large, brown, bushy-tailed coyote peering from behind Watcher Woman's chair. Watcher Woman laughed as Tall Cedar's eyes opened wide at the sight of her faithful companions.

“Tall Cedar,” Watcher Woman chuckled, “Coyote and Raven have been my helpers for many, many years. Raven has gone to the city to the place of learning. He knows much about spirit sickness and what happens to children when their mothers drink during pregnancy.”

Then, her lined and lovely face became very serious. “We have tried, we three, to tell the People in the village about Fetal Alcohol Syndrome. Now that you are here, maybe we can start to build a team to help our children and their families. You were trained at the place of learning in the city. Maybe you could talk to people there and have them come to our village to help us. Maybe you could call a meeting of the other teachers. I will ask people I know to come.”

Tall Cedar nodded. “I think that is a wonderful idea! I will talk with the school principal tomorrow. Maybe we can all think of ways to talk to our children’s parents about spirit sickness and how we can all work together to help our special children.”

Then, Watcher Woman smiled a knowing grin. “I also know two young people in the village who have Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder.

They live with their auntie and uncle. Come with me and I will introduce you to this family."

Tall Cedar and Watcher Woman, accompanied by a laughing Coyote and Raven, strolled through the woods that separated Watcher Woman's tiny home from the rest of the village. Down the dusty main road they walked until they reached a home near the river. Watcher Woman knocked on the door, which was quickly opened by a short young man and a five-year-old girl.

"Teacher!" the young man exclaimed. "What are you doing here?"

The young man was East Light, a student in Tall Cedar's classroom. He was one of two children who had been born to a woman who suffered from spirit sickness. His

twin sister, Shining Eyes, was the mother of Spring Song, the young girl who stood next to East Light. Then, East Light spied Watcher Woman.

“Come in Teacher, come in!” he said excitedly. “Auntie and Uncle will be so glad to see you. Come in!”

Tall Cedar and Watcher Woman entered the tidy home and were greeted by Auntie and Uncle. East Light was so excited he almost seemed to dance. He and Spring Song showed Watcher Woman and Tall Cedar a place to sit. Auntie and Uncle joined them and began a conversation that was to change their lives. A short time after that, Watcher Woman asked where Shining Eyes might be.

Auntie sighed and Uncle shook his head. “She never wants to talk to anyone. Since that awful night in the woods nearly six years ago, she has been so afraid of people. She never leaves the house unless all of us are with her.”

Auntie, Uncle, and Watcher Woman all were silent as they thought of the night Shining Eyes was found in the woods, hurt and nearly frozen to death. That terrible night came after many years of Shining Eyes struggling with school, drinking, and being taken advantage of by her peers and older men. Shining Eyes was one of the People in the village about whom Tall Cedar and Watcher Woman were so concerned.

As the afternoon softened into evening, ways to bring a council of elders back to the village were discussed. Plans were made and discarded and made again. East Light offered many suggestions, most impractical but listened to carefully by the others. Finally, it was agreed upon that Watcher Woman would talk to the elders in the village and from other towns nearby. Auntie and Uncle would talk to all of their friends and other parents of special children. Tall Cedar agreed he would ask for help from the teachers and other people at the school.

After several hours of talking, Uncle and East Light brought out a meal and called Shining Eyes to come and join everyone. Spring Song ran into the bedroom she shared with her mother. She pulled her mother by the hand into the front room. However, when Shining Eyes saw a stranger in the dining room, she ran back into her room and closed the door. The others shook their heads in sadness and sat down to eat their meal. Spring Song gave thanks to the Creator and the rest said silent prayers that their plans would work.

The next morning, Tall Cedar talked to other teachers and the principal at his school. He spoke of his concerns and hopes for his special students. At first, the other teachers did not want to listen, as Tall Cedar was young and new to the village. But, day after day, Tall Cedar spoke of the things he knew that could help People in the village. Day after day, he spoke of changing despair to hope. Week after week, he shared the successes of his students. Finally, after several months, the principal of the school agreed that he would set aside a time for all of the teachers to come to a community meeting about spirit sickness and its effect on the community.

Meanwhile, Auntie and Uncle were having better luck with the People in the village who had children affected by alcohol. Many of the parents, birth, foster, and adoptive, were frustrated over the difficulties their children were having in school and in the community. They were eager to come together with others and talk about how they could help each other and their children. Auntie, Uncle, and their friends spoke to doctors, nurses, drug and alcohol counselors, day care workers, dentists, lawyers, police officers, and anyone who would listen about the meeting they wanted to have. The parents were relentless! They needed help and were relieved that the problems would finally be talked about.

Watcher Woman talked to the grandmothers and grandfathers in her village and those nearby. She spoke of the old ways and how it was time to rebuild what had worked in the past. She spoke of how people worked together and how it was time to bring back the wisdom of the elders. She spoke of the grief and loss of the People and how it had resulted in spirit sickness and children with FASD. She

spoke of the obligation elders had to take care of their People. She spoke of coming together and making a better world for all. She spoke of hope for the future.

Everywhere she went, she was accompanied by a smiling Raven and a laughing Coyote. After speaking to people, Watcher Woman, Coyote, and Raven would make their way home, talking all the way about their plans. Long into the night, the yips of a large brown coyote and the caws of a large black raven could be heard in harmony with the low, kind voice of a lovely old woman.

After talking to many others over the months, Auntie, Uncle, Watcher Woman, and Tall Cedar met again. They discussed how many had pledged to come to the meeting and where it would be held. Tall Cedar agreed to go with the family and Watcher Woman to the place of learning where Raven had gone before with the family. A time was set and, once more, a large Raven followed a car as it drove from the village into the city.

Auntie, Uncle, Watcher Woman, Tall Cedar, East Light, Shining Eyes and Spring Song joined the team of helpers. Raven, cawing loudly from the window, listened in. The team members eagerly agreed to come to the village and teach all who would gather. They agreed to help the village set up a team that could help the People. At the end of the day, a sense of hope and excitement filled the room. A date was set for the community meeting and everyone went home, tired, but ready to take on the task of changing the future.

Raven had flown ahead of the family, Watcher Woman, and Tall Cedar. He was perched on the porch of Watcher Woman's tiny house with Coyote sitting on the steps when everyone arrived home. Watcher Woman smiled a tired smile as she opened the door. The three went inside and soon were asleep, with dreams of healthy, happy children filling their minds.

Finally, the day came for the meeting. The principal had decided that he would allow it to be held at the school. It was a cool morning in late spring. The clouds were heavy and filled with the possibility of rain. Tall Cedar paced back and forth around the room as he anxiously awaited the beginning of the meeting.

“I am so worried that no one will come,” he confided to Watcher Woman.

“What will be, will be,” Watcher Woman replied. “People are afraid of being judged and many feel shame over their spirit sickness. But, my young friend, be patient and know that who should be here will come.”

Within a few minutes, the door to the room opened and people began to enter. Slowly, the room filled. Watcher Woman turned and smiled at Tall Cedar. She winked and made her way to the front of the room. She began to speak of how everyone in the community could make changes and work to overcome shame and fear. A beam of light shown on Watcher Woman’s face as she talked of grace and healing. Her words washed over the many people who had gathered. Soon, she

was joined at the front of the room by the members of the team of healers from the place of learning.

One by one, people in the room stood and told their stories. One by one, helpers and elders, parents, and those affected by Fetal Alcohol Syndrome expressed their needs and dreams. After many hours, it was agreed that a team would be built from the elders and helpers in the village. Teachers and doctors, counselors and parents, all agreed they would come together to help each other. As the meeting was nearly done, the door at the back of the room opened. A hush fell over the room as Shining Eyes, holding the hand of her small daughter came into the room and walked to the front to stand next to Watcher Woman.

“I have come to speak and to help. ” Shining Eyes said softly. “I am coming because I wish to no longer be afraid. I have come to make sure that no one else has to live with the shame of spirit sickness. I have come to make a difference.”

Tears began to flow from her eyes and from the eyes of many others in the room. But, they were not tears of sadness. They were tears of hope and healing. Watcher Woman smiled as she placed an arm around the narrow shoulders of Shining Eyes.

“We will all work together and rebuild the old ways of respect and love, caring and help. We will all come together to make our world a better place. Now, let us thank our Creator and go out into the World to start our jobs!”

As Watcher Woman stood to thank Creator, a shiny black Raven and a large brown Coyote raised their voices in song. And so, let us all join hands and walk with our special ones. Let them be the light to show the way to the future. Let us all work to rebuild the council of elders. And in the end, let us never forget that our special souls, those with Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder are our teachers. Let us join with Coyote and Raven and Watcher Woman and our special souls in thanking Creator for this beautiful World and all contained within.

Section IX

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Appendix 1:
Developmental Matrices for Intervention Planning
for
Individuals with Alcohol-Related Birth Defects[319],[320]

Areas of Focus

	Health	Psychosocial	Family/ Parenting	Educational/ Vocational	Legal
Birth to 5 Years					
6-11 Years					
12-17 Years					
18+ Years					

[319] LaDue, R. A. , Carmichael, H. , Clarren, S. , Beck, S. Seattle, WA: FAS-DPN, 1996. -
[320] Clarren, S. K. and Astley, S. J. "The Development of the Fetal Alcohol Syndrome Diagnostic and Prevention Network in - Washington State. " Streissguth, A. P. and Canter, J. (Eds.) The Challenge of Fetal Alcohol Syndrome: Overcoming - Secondary Disabilities. Seattle, WA: U. of Washington, 1997. -

Developmental Matrices for Intervention Planning
for
Individuals with Alcohol-Related Birth Defects

Interventions

	Health	Psychosocial	Family/ Parenting	Educational/ Vocational	Legal
Birth to 5 Years					
6-11 Years					
12-17 Years					
18+ Years					

These matrices are used in screening and diagnostic clinics to provide a summary of concerns and services of the individual patient. They are completed during the diagnostic evaluation and provided to the individual/family at the end of the evaluation.

Please Note:

LaDue, Carmichael Olsen, Clarren and Beck originally developed these matrices. The ones used in this manual are modified from the originals.

Appendix 2:

Case Summation Information

The case summation form in this appendix is a compilation of the diagnostic materials developed by Astley and Clarren[321] as well the clinical information that has been suggested for inclusion by research from a variety of sources, e. g. Streissguth,[322] Coles,[323] Burgess,[324] LaDue,[325] and Tanner,[326].

Growth*	Face*	Brain*	ETOH*	Prenatal	Postnatal

*Rated by level of severity from 1 (not present) to 4 (severe) - to be used for screening and referral. Only trained physicians should be making a diagnosis of FASD.

Family History:

School History:

Testing Scores:

Medical History:

Behavioral Concerns:

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[321] Astley, S. J. and Clarren, S. K. "A Fetal Alcohol Syndrome Screening Tool. " Alcohol. Clin, Exp. Res. 19 (1995) 1565-1571. -

[322] Streissguth, A. P. , and O'Malley, K. D. "Fetal Alcohol Syndrome/Fetal Alcohol Effects: Secondary Disabilities and Mental - Health Approaches. " Treatment Today. 9(2) 1997, 16-17. -

[323] Coles, C. D. , Smith, I. E. , and Falek, A. "A Neonatal Marker for Cognitive Vulnerability to Alcohol's Teratogenic Effects. " - Alcoholism: Clinical and Experimental Research. 11 (1987). -

[324] Burgess, D. M. , Lasswell, S. L. , Streissguth, A. P. "Educating Children Prenatally Exposed to Alcohol and Other Drugs". - [Brochure]. Seattle, WA. Fetal Alcohol and Drug Unit, U. of Washington, 1993. -

[325] LaDue, R. A. Psychosocial Needs Associated with Fetal Alcohol Syndrome: Practical Guidelines for Parents and - Caregivers. Seattle, WA: U. of Washington, 1993. -

[326] Tanner, P. A Demonstration Classroom for Young Children with FAS. The Challenge of Fetal Alcohol Syndrome. - Streissguth, A. P. , Kantor, J. (Eds.) Seattle, WA : University of Washington Press, 1997. -

Legal History: -

Goals for Youth While in Detention: -

Community Services Needed Upon Release from Detention: -

Team Members: -

Community Contacts: -

Appendix 3:

Diagnoses Commonly Associated with Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder

The following diagnoses are those frequently assigned to children, adolescents, and adults with FAS and FASD. There are few formal studies that detail the prevalence of FASD associated with these disorders or vice versa. The early childhood background of many patients and what clinical data are available suggest some diagnoses such as Posttraumatic Stress Disorder, Reactive Attachment Disorder; and Attention Deficit Hyperactive Disorder may very well be common among patients with FASD. But none of these diagnoses would necessarily open the door to Developmental Disabilities Services. For those with ADHD, some special education and vocational services might be available, but most individuals with FASD are far more disabled throughout their lifespan then those with ADHD alone.

The criteria for these diagnoses are generally based on behavioral observation and the person's self-report. Many different processes and environmental factors as well as brain damage and dysfunction can cause these behaviors and problems. A comprehensive family and prenatal history should be taken prior to assignment of any of these diagnoses. Genetic, environmental, social, and cultural factors should also be considered. While FASD is not necessarily a causal agent in any of the disorders listed, it can change the clinical presentation and articulation of symptoms by the patient.

Having one disorder does not rule out the possibility of another. In the experience of the author, and by many anecdotal reports available, multiple diagnoses appear to be the norm rather than the exception. This manual has repeatedly discussed the value of the multi-disciplinary treatment team. The team should include someone familiar with the possible effects of prenatal alcohol exposure and

psychiatric/psychological problems and what role prenatal alcohol exposure can play in terms of clinical presentation and treatment options.

The following list is not exhaustive, but intended as a guide to help health care providers and schools acquire services for children. The majority of children with FASD may not ever be diagnosed with any of the ailments listed below. With few exceptions, having one of the diagnoses listed below may be a means of acquiring services for a health impaired child if the state or district does not, as most do not, recognize FASD as a developmental disability in and of itself. However, most of these diagnoses other than Asperger's Syndrome and autism would still preclude Developmental Disability Services. The Diagnostic and Statistical Manual, Fourth Edition (DSM-IV) is the primary source of the diagnostic information listed below. For additional information, the reader is referred to the manual references.

An excellent resource for understanding developmental psychopathology is by Luthar, Burack, Cicchetti, and Weisz (1997). [327] It is interesting to note that, in this outstanding resource, while cocaine exposure and Fragile X are discussed, the devastating effects of prenatal alcohol exposure and its' links to mental health issues and diagnoses are not.

Antisocial Personality Disorder:[328],[329]

The hallmark of this diagnosis is a "pervasive" pattern of violation of and disregard for the rights of others. According to DSM-IV diagnosis,[330] people with an antisocial personality disorder "do not conform to social rules and expectations. " They are repeatedly involved in actions that can lead to arrest. Continual lying or attempting

[327] Luthar, S. S. , Burack, J. A. , Cicchetti, D. , Weisz, J. R. (Eds.) Developmental Psychopathology. Cambridge: Cambridge - University Press, 1997.
[328] Hare, R. D. Without conscience: the disturbing world of the psychopaths among us. New York: Guilford Press, 1999. -
[329] Hare, R. D. , Hart, S. D , & Harpur, T. J. Psychopathy and the DSM-IV criteria for antisocial personality disorder. Journal - of Abnormal Psychology, *100*(3), 1991, 391-398. -
[330] American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. (4th ed.) Washington, DC: - American Psychiatric Association, 1994. -

to mislead others for "personal profit or pleasure" is also diagnostic criteria of an antisocial personality disorder along with higher levels of impulsive behavior. Failing to plan or have a concern for possible outcomes are commonly seen in people with FASD, but are also included when assessing for an antisocial personality disorder.

Greater "irritability, aggressiveness, and a reckless disregard for the safety of one's self or others and irresponsibility as shown by difficulty in sustaining work or honoring obligations" were among the behaviors of concern listed in the challenging behaviors detailed at the start of this manual. These issues and concerns are also among the behavioral criteria for diagnosing antisocial personality disorder.

The person must be 18 years old and the behaviors present since the age of 15. Evidence of a conduct disorder should also have been present prior to age 15. These behaviors should not be due to Schizophrenia or a manic episode.

The assignment of this diagnosis is somewhat troublesome when discussing late adolescents and adults with FASD. Many of the behaviors and secondary disabilities are consistent with diagnosis of people not affected with FASD. It is possible to have FASD and an antisocial personality disorder, but it is unlikely as individuals with FASD historically do not have the understanding or social skills to meet this criteria. Prior to making an ASP diagnosis, it is important to assess motivation, understanding, and the presence of FASD. For an excellent discussion on antisocial personality disorder, the reader is directed to the body of literature generated by Hare, including the Hare Psychopathy Checklist-Revised [331] and Meloy. [332]

[331] Hare, R. D. The PCL-R assessment of psychopathy: Some issues and concerns. Legal and Criminological Psychology, *3*, - (1988) 101-122.
[332] Meloy, J. R. The Psychopathic Mind: Origins, Dynamics, and Treatment Northvale, N. J. : J. Aronson, 1988. -

Asperger's Disorder:

Asperger's Disorder is a disorder that is characterized by significant deficits in the use of nonverbal language and cues as well as significant delays in forming appropriate peer relationships. This disorder is more often recognized in children in the latency age period, but the onset may be earlier. Children, adolescents, and adults with this disorder often use repetitive motions or have fixed interests and routines.

There is no apparent delay in language onset or cognitive development. This disorder does lead to significant impairments in social, vocational, and other areas of the person's life. Impairment, for most people, is lifelong. Medication, social skills training, and psychotherapy may or may not be useful in treating this disorder. A psychiatrist, psychologist, pediatrician, or other physician or mental health specialist is generally qualified to make this diagnosis.

Many higher functioning individuals with FASD may look like those with Aspergers Syndrome; however, most individuals with Aspergers Syndrome are of normal or above normal intelligence, while many patients with FASD are of mild mental retardation or borderline IQ.

Attention Deficit Hyperactivity Disorder (ADHD)[333],[334],[335]:

This is a diagnosis that is commonly given to children with FASD. A child or adolescent's inability to concentrate or pay attention characterizes ADHD. A higher level of physical activity is also seen in children and adolescents with ADHD than their age-mates. The difficulties in attending to information, along with the higher level of activity must cause problems functioning in social, school, or work activities

[333] Burack, J. A. , Enns, J. T. (Eds.) Attention, Development, and Psychopathology. New York, NY: Guilford Publications, Inc, - 1997. -
[334] Kopera-Frye, K. , Carmichael-Olson, H. , and Streissguth, A. P. "Teratogenic Effects of Alcohol on Attention. " Attention, - Development, and Psychopathology. New York: NY: Guilford Press, 1997, 171-204. -
[335] Wender, P. H. The Hyperactive Child, Adolescent and Adult. New York, NY: Oxford University Press, 1987. -

in order for the child or adolescent to receive this diagnosis. Impulsivity, being fidgety, and impatience are among the commonly seen behaviors in children and adolescents with ADHD. Medication is often used and can be helpful, as is clear, concise, and consistent structure. [336]

These problems must be present prior to the age of 7 for ADHD to be considered an accurate diagnosis. A psychologist, psychiatrist, pediatrician, or other qualified health professional should make this diagnosis. If a child is displaying these behaviors, it is important that they be reported to the caseworker and physician or other health care worker. These issues need to be addressed as quickly as possible to prevent increased problems. These behaviors may also be a sign of child abuse or family problems, which will need to be addressed to ensure a healthy environment for all family members.

Many individuals with FASD have ADHD symptoms. However, according to Coles, the attention problems of ADHD and FASD children differ. In addition, children with FASD have more problems with social-communication, sensory integration, and fine and gross motor skills than those with ADHD.

Autistic Disorder:

The most commonly seen behaviors in a child or adolescent with Autistic Disorder include significant difficulties in social interactions and communication. Children with this disorder often do not form bonds with others. Language is often delayed or absent. Children, adolescents, and adults with this disorder often show repetitive behaviors such as finger-shaking, head-banging, and other self-stimulating behaviors. They have difficulty engaging in play as children and difficulties with positive social interactions as adolescents and adults. [337],[338]

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[336] Mannuzza, S. , Klein, R. G. , Bessler, A. , Malloy, P. , and La Padula, M. "Adult Outcome of Hyperactive Boys: Educational - Achievement, Occupational Rank, and Psychiatric Status. " Archives of General Psychiatry. 50 (1993) 565-576. -
[337] Achenbach, T. M. Developmental Psychopathology. New York, NY: Ronald, Press, 1974. -
[338] Cohen, D. J. and Volkmar, M. D. , Fred R. (Eds.) Handbook of Autism and Pervasive Development Disorders. New York, - NY: John Wiley and Sons, 1997. -

The onset of these problems is prior to age three and is the start of a behavioral pattern that lasts across the lifespan. Developmental delays occur early and in almost every aspect of the child's life, although, some areas of development may appear normal. Early intervention[339] along with special schooling and lifelong support are important. Medications may or may not be useful while behavioral programs often are. A psychologist, psychiatrist, pediatrician, or other qualified health professional should make this diagnosis.

Children with FASD often have symptoms similar to children with autism, i. e. , several social-communication deficits and repetitive behaviors. In addition, children from both diagnostic groups have sensory integration issues, resist change, and have significant developmental delays in multiple areas. However, most autistic children are mentally retarded and socially withdrawn, while children with FASD are overly talkative, with empty speech, are gregarious and have mild retardation to borderline IQs. Autism is the most severe form of pervasive developmental disorder and most children with FASD fit the criteria for the milder form of this disorder.

Borderline Personality Disorder:

This personality disorder is often seen in people who have experienced some type of early childhood trauma. It is marked by an ongoing pattern of problems and instability in relationships, moods, and a person's self-image. Impulsivity, suicidal ideation, reckless behavior without any apparent concern over outcome, and a high level of difficulty dealing with interpersonal interactions are commonly seen. They are often fearful of abandonment and may over-react if they perceive any type of real or imagined threat. Afterwards, feelings of shame and embarrassment are seen, but the pattern continues without significant change.

[339] Davis, D. Reaching Out to Children with FASD: A Handbook for Children Affected by Fetal Alcohol Syndrome. Paramus, NJ: Center of Applied Research in Education, 1994.

This diagnosis would enable individuals to receive psychiatric services and would preclude Developmental Disabilities Services, unless the individual also was given a developmental disabilities diagnosis.

This disorder is often diagnosed in late adolescence or early adulthood, most often in females. It can significantly interfere with social, academic, and vocational functioning, although these problems may decrease with age.

Medication and psychotherapy are often recommended but, as noted, this is a pattern of behavior and social interaction that is seen, to some level, across the lifespan. A psychologist, psychiatrist, or other qualified health professional should make this diagnosis. For additional reading on Borderline Personality Disorders, the reader is referred to Dr. Marsha Linehan's work in this area. [340] Again, most individuals with FASD do not have the social intent that creates havoc in the relationships of BPD – the disorder appears to require a higher level of social-cognitive functioning than is commonly seen in FASD.

Conduct Disorder:

The most commonly described features of this diagnosis include an ongoing pattern of behavior where the person breaks social rules without regard for others. Aggressive behavior such as threatening others, animals or both is one area of concern. Lying or being deceptive along with ongoing and serious rule breaking is the fourth area of problem behavior. These behaviors occur in a wide variety of settings, such as school, home, and the community. These behaviors often are reasons why the person may be expelled from school, or may cause serious problems at home, e. g. running away or threatening family members.

This disorder can begin before the age of ten, although, there is another form that begins in adolescence (after the age of ten). This disorder can cause significant

[340] Linehan, M. Cognitive-Behavioral Treatment of Borderline Personality Disorder. New York: Guilford Press, 1993.

problems in social, school, and community functioning. People with conduct disorders often end up in detention or jail. Early recognition, along with school and family intervention may be of aid. Medication is often tried, but compliance among people with conduct disorder is low. A psychologist, psychiatrist, or other qualified health professional should make this diagnosis.

Depression:

This disorder is far more common in children and adolescents than is typically acknowledged. It is a disorder characterized by a depressed mood most of the time. Children often present as being irritable. Other signs of depression include a loss of interest in activities, sleeping too much, losing or gaining weight; feelings of low self-worth and low self-esteem, and difficulties concentrating and paying attention may also be seen. Children with depression may be aggressive and angry. Suicidal thoughts and attempts can also occur. [341],[342],[343]

This is a serious disorder that can occur throughout life and can be related to losses in the person's life. It may also have a genetic basis. There are many types of medications available to treat depression. Psychotherapy can also be useful. A psychologist, psychiatrist, or other qualified health professional should make this diagnosis. Depression may be a secondary disorder to FASD, particularly in adolescence and adulthood.

Learning Disorders:

These disorders include problems learning in the areas of reading, mathematics, and written expression. They are characterized by the person having significantly lower standardized test scores than their age-mates and there being a large

[341] Beck, A. T. , Rush, A. , and Shaw, F. F. , and Emerg, B. Cognitive Therapy of Depression. New York: Guilford - Publications, 1979.
[342] Flack, F. and Draghi, S. The Nature and Treatment of Depression. New York, NY: John Wiley & Sons, 1975. -
[343] Badal, D. W. Treatment of Depression and Related Moods: A Manual for Psychotherapists. Dunmore, PA: Jason Aronson, - Inc. , 1989. -

difference between a standard IQ score and scores on academic achievement tests. They can be caused by mental health problems, difficulties in sensory input and by cultural/ethnic differences in learning patterns. [344] All of these factors must be taken into account when making a diagnosis or providing treatment.

The course of these disorders can be mild to severe. Some children with learning disorders or those with intensive, early, and appropriate interventions can make progress. For some people, these are permanent disorders affecting the person's academic, vocational, and social functioning throughout their life. A school psychologist, clinical psychologist, psychiatrist, or other qualified specialist can make this diagnosis. If there is a history of head trauma or other medical problems (e. g. encephalitis), a physician should be on the diagnostic team.

Most individuals with FASD have one or more specific learning disabilities as part of a pervasive developmental disorder syndrome. Such a diagnosis may be helpful if the individual is specifically more impaired in one academic area, i. e. , dyslexia, mathematics, than others

Oppositional-Defiant Disorder:

The main components of this disorder include an ongoing pattern of defiant, negative, and angry behavior towards people in authority. Refusal to comply is also common. Children with this disorder often have temper tantrums, argue constantly with the adults in their life, deliberately irritate others, refuse to take responsibility for their own actions, and can be described as "mean". Parents and caregivers also frequently mention areas of concern in extreme stubbornness, not wanting to follow directions, and a continual testing of limits.

Children with FASD may become frustrated and irritated when over stimulated. They may be disturbed when they cannot understand what is being asked of them.

[344] Sattler, J. M. Assessment of Children's Intelligence. New York: W. B. Sounders Company, 1974.

Children with FASD often do not have the behavioral repertoire to respond with a variety of options. In situations where they have to generate their own answers or responses rather than having information given to them in simple and understandable ways, they are likely to be even more aggravated.

Children with this disorder often have poor or challenging peer relationship problems. They also have limited insight into their behavior, feeling that they are "right" in their actions. Medication may or may not be helpful. This disorder may be a precursor to what is seen in adults as an antisocial personality disorder. A psychologist, psychiatrist, or other qualified mental health specialist should make this diagnosis.

Pica:

Pica is an unusual disorder that consists of the child or adult consuming "non-nutritive" substances. According to the DSM-IV, the substances commonly consumed change across the lifespan. Pica is frequently associated with mental retardation and can be seen in other mental disorders such as pervasive developmental disorders. It is recommended that consumption of non-nutritive substances be assessed separately from an underlying issue of mental retardation.

Posttraumatic Stress Disorder (PTSD):

Posttraumatic Stress Disorder (PTSD) is a disorder associated with severe trauma in a person's life: something that involves a serious threat to the person's well being, e. g. , serious injury or death. It can also arise from observing another person experience such a threat. PTSD is commonly associated with sexual or physical abuse, particularly if it occurs at an early age. However, this disorder can arise at any point in life if the person is exposed to severe trauma.

The person with PTSD may feel as if the trauma is happening again, complete with anxiety, increased physical arousal, and fear. Recurrent and intrusive thoughts and

dreams are commonly experienced. Anything that resembles the trauma can cause - the person to feel agitated or anxious. Memory problems and not being able to recall the specific traumatic event are often complaints of people with PTSD, as are a "sense of doom," not feeling as if one will live long, and feeling emotionally disconnected from others. [345],[346] Sleeping problems (other than dreams) are also commonly reported.

In moderate to severe cases, the person can have significant impairment in social, academic, vocational, and daily living activities. Depression, suicidal ideation, survivor guilt, poor concentration, and anxiety are often reported. Medication as well as psychotherapy is often helpful. A qualified mental health specialist should make this diagnosis.

As noted, many children with FASD have been in neglectful and abusive situations. This may not just be in a home with the birth parents. A sad truth is that many children are abused while in the care of foster parents. This problem has been so pervasive that there have been lawsuits against states, leading to changes in state statutes. [347] Early childhood trauma and abuse often lead to children acting out in a variety of ways including with sexually inappropriate behavior, aggression, withdrawal, and volatile moods. These problems can last a lifetime and affect people's lives in a multitude of ways.

Behaviors such as sexual inappropriateness, aggression, withdrawal and acting out are also characteristic of FASD, and the neurological dysfunction that causes these disorders.

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[345] Herman, J. Trauma and Recovery. New York: Basic Books, 1997. -
[346] Keane, T. M. Clinical perspectives on stress, traumatic stress, and PTSD in children and adolescents Journal of School - Psychology, 34, 1996, pg 193-197. -
[347] Braam V. State of Washington, Whatcom County Superior Court under Cause #:No. 98 2 01570 1 -

Reactive Attachment Disorder: -

This disorder is distinguished by "markedly disturbed and developmentally inappropriate social relatedness. "[348] The diagnosis is typically divided into two presentations. The first is the "Inhibited Type" where the child is unlikely to initiate or respond to common social interactions. The other presentation is the "Dis-inhibited Type" where the child shows little sense of boundaries, poor social skills, or a lack of "selectivity" with whom the child attempts to bond. The primary source of this disorder is postulated to be poor care and "persistent disregard" for the child's emotional, physical, and mental needs. Change in residential care, as in multiple moves from foster home to foster home, or from foster care back to the mother's/father's care and then out again, is thought to be an etiology of this disorder.

Receptive-Expressive Language Disorder:

This disorder is based on standardized test scores (e. g. IQ test scores), as well as on behavior. It is characterized by delays and impairment in receptive language skills where the child has difficulty "translating" language into usable information and expressive language skills where the child has a limited vocabulary, difficulty producing words and using sentences, and not using tenses correctly.

Onset is generally before the age of four. However, this disorder can occur if there is some type of physical trauma later in childhood, e. g. a head injury. With intervention, some children can develop normal language. This may not occur in children with significant brain damage. If the disorder is severe enough, it may lead to a learning disorder. A school psychologist, clinical psychologist, psychiatrist, or other qualified specialist should make this diagnosis. If there is a head injury or other medical problem (e. g. encephalitis), a physician should be on the diagnostic team.

[348] American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. (4th ed.) Washington, DC: American Psychiatric Association, 1994.

Tourette's Disorder:

This disorder is defined by multiple motor and vocal tics. Such tics can appear concurrently or separately. It is thought to be neurological in etiology and begins prior to the age of 18. These tics occur on a daily basis with no more than 3 consecutive months of the person being tic-free. In diagnosing Tourette's Disorder, it needs to be determined that the tics are not from another underlying etiology, e. g. Huntington's Disorder.

Appendix 4:

Assessment and Screening Tools

This section is an overview of a variety of screening and assessment tools that can be useful in assessing clients with FASD over a variety of situations. Only a limited number of assessment tools are listed in the following section. These tests should be administered only by trained, certified, and licensed professionals. For a complete detailing of these instruments and others, the reader is referred to The Fourteenth Mental Measurements Yearbook. [349]

Adaptive Behavior Evaluation Scale: Stephen B. McCarney, Hawthorne Educational Services, Inc.

AD/HD Comprehensive Teacher's Rating Scale, Second Edition: Rina K. Ullman, Esther K. Sleator, Robert L. Sprague, and MetriTech staff; MetriTech, Inc.

Adolescent Psychopathology Scale: William M. Reynolds, Psychological Assessment Resources, Inc.

Alcohol Use Disorders Identification Test: Thomas F. Babor, Juan Ramon de la Fuente, John Saunders, and Marcus Grant, World Health Organization.

Assessment of Adaptive Areas: Brian R. Bryant, Ronald. L. Taylor, and Diane Pedrotty Rivera, PRO-ED.

Assessment of Parenting Skills: Infant and Preschooler: Gail Elliot, Village Publishing.

Attention Deficit/Hyperactivity Disorder Test: James E. Gilliam, PRO-ED.

Beck Depression Index: Aaron T. Beck, Robert A. Steer, and Gregory K. Brown, The Psychological Corporation.

Behavior Checklist and Revised Child Behavior Profile. [350]

Brief Neuropsychological Cognitive Examination: Jospeh Tonkonogy, Western Psychological Services.

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[349] Plake, B. S. , Impara, J. C. , Murphy, L. L. The Fourteenth Mental Measurements Yearbook. Lincoln, NE: University of - Nebraska, 2001.

[350] Achenbach, T. M. and Edelbrock, G. Manual for the Behavior Checklist and Revised Child Behavior Profile. Burlington, - VT: U. of Vermont, Department of Psychiatry, 1983. -

The CAGE (Alcohol Use): Ewing, DrugNET[351] http://www. drugnet. bizland. com/assessment/cage. htm

Caregiver-Teacher Report Form: Thomas M. Achenbach, child Behavior Checklist.

Child Sexual Behavior Inventory: William N. Friedrich, Psychological Assessment Resources, Inc.

Cognitive Symptom Checklist: Christine O'Hara, Minnie Harrell, Eileen Bellingrath, and Katherine Lisicia, Psychological Assessment Resources, Inc.

Conners' Rating Scales-Revised: C Keith Conners, Multi-Health Systems, Inc.

Davidson Trauma Scale: Jonathan Davidson, Multi-Health Systems, Inc.

Developmental Assessment of Young Children: Judith K. Voress and Taddy Maddox, PRO-ED.

Family Assessment Form: A Practice-based Approach to Assessing Family Functioning: Children's Bureau of Southern California, Child Welfare League of American, Inc.

Hare Psychopathy Checklist: Screening Version: S. D. Hart, D. N. Cox, and R D. Hare, Multi-Health Systems, Inc.

Human Figure Drawing Test: Jerry Mitchell, Richard Trent, and Roland McArthur, Western Psychological Services.

Independent Living Scales: Patricia Anderten Loeb, The Psychological Corporation.

Infant Development Inventory: Harold Ireton, Behavior Science Systems.

Learning Disabilities Diagnostic Inventory: Donald D. Hammill and Brian R. Bryant, PRO-ED.

Learning Styles Inventory {Educational Activities, Inc. }; Jerry F. Brown and Richard M. Cooper, Educational Activities, Inc.

Leiter International Performance Scale: Gale. H Roid and Lucy J. Miller, Stoelting Co.

Michigan Alcoholism Screening Test: Melvin L. Selzer, Melvin L. Selzer.

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[351] Johnson, T. and Hughes, T. L. Reliability and concurrent validity of the CAGE screening questions among lesbians. Under review, Journal of Substance Abuse Treatment.

Minnesota Multiphasic Personality Inventory-2: James N. Butcher, PhD; W. Grant Dahlstrom, PhD; John R. Graham, PhD; Auke Tellegen, PhD; and Beverly Kaemmer, NCS.

Movement Assessment Battery for Children: Sheila E. Henderson and David A. Sugden, The Psychological Corporation.

Neonatal Behavioral Assessment Scales, 3rd Edition: T. Berry Brazelton and J Kevin Nugent, Cambridge University Press.

Peabody Individual Achievement Test: Frederick C. Markwardt, Jr. , American Guidance Service, Inc.

Peabody Picture Vocabulary Test-III: Lloyd M. Dunn, Leota M. Dunn, Kathleen T. Williams, and Jing-Jen Wang, American Guidance Services, Inc.

Posttraumatic Stress Diagnostic Scale: Edna B. Foa, NCS.

Quick Neurological Screening Test, 2nd Revised Edition; Margaret C. Mutti, Harold M. Sterling, Nancy A. Martin, and Norma V. Spalding, Academic Therapy Publications.

The Renfrew Bus Story: Judy Cowley and Cheryl Glasgow, Centreville School.

Rey Complex Figure Test and Recognition Trial: John E. Meyers and Kelly R. Meyers, Psychological Assessment Resources, Inc.

Scales of Independent Behavior-Revised: Robert H. Bruininks, Richard W. Woodcock, Richard F. Weatherman, and Bradley K. Hill, The Riverside Publishing Company.

Sentence Completion Series: Larry H. Brown and Michael A. Unger, Psychological Assessment Resources, Inc.

Structured Clinical Interview for DSM-IV Axis I Disorders: Clinician Version: Michael B. First, Robert L. Spitzer, Miriam Gibbon, and Janet B. W. Williams, American Psychiatric Press, Inc.

Test of Early Language Development, Third Edition: Wayne P. Hresko, D. Kim Reid, and Donald D. Hammill, PRO-ED.

Test of Nonverbal Intelligence: Linda Brown, Rita J. Sherbenou, and Susan K. Johnson, PRO-ED.

Vineland Adaptive Behavior Scales: Sara S. Sparrow, David A. Balls, and Domenic V. Cicchetti, American Guidance Services, Inc.

Wechsler Adult Intelligence Scale-III: David Wechsler, The Psychological Corporation.

Wechsler Intelligence Scale for Children-III: David Wechsler, The Psychological Corporation.

Wechsler Memory Scale-III: David Wechsler, The Psychological Corporation.

Wide Range Achievement Test-III: Gary S. Wilkinson, Wide Range, Inc.

Wisconsin Card Sorting Test, Revised and Expanded: Robert K. Heaton, Gordon J. Chelune, Jack L. Talley, Gary G. Kay, and Glenn Curtiss, Psychological Assessment Resources, Inc.

Woodcock Diagnostic Reading Battery: Richard W. Woodcock, The Riverside Publishing Company.

Appendix 5:

Commonly Used Medications[352],[353] -

The following are medications that are commonly used to treat the mental health and behavioral disorders previously described. They may or may not be effective in children, adolescents, and adults with FASD and few studies have evaluated medication interventions with this population. There are three published medication studies with FASD. Two showed that stimulants were effective in controlling hyperactivity, but not impulsivity/attention problems. One study showed that stimulants had some effect but anticonvulsant mood stabilizers and neuroleptics were better. Medications should be prescribed by a professional licensed to do so, hopefully one with some experience with working with children, adolescents, and adults with FASD. One of the preeminent experts in the use of medications with patients with FASD is Dr. Kieran O'Malley, associated with the Fetal Alcohol and Drug Unit of the University of Washington. Dr. O'Malley often cautions that "None of these medications should be considered a panacea for the behavioral problems associated with FASD. "[354],[355]

Adapin, Sinequan (doxepin) antidepressant

Adderall (formerly Obetrol Now available as generic "amphetamine salts")

Anafranil (clomipramine) antidepressant, for OCD

Benzodiazepines for anxiety

Buspar (buspirone) for anxiety

Carbamazepine for episodic outbursts and aggression

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[352] Kapp, F. M. E. ; O'Malley, K. D. Watch for the Rainbows. Calgary, Alberta: Frances Kapp Education, 2001. -
[353] FASLINK – Internet connections for education and support for families of children with FAS. -
http://treefort. org/~tjk/faslink.htm -
http://www.come-over.to/FAS/faslink.htm -
http://laran.waisman.wisc.edu/fv/www/lists/FAS-LINK.htm
[354] Tupin, J. P. , Shader, R. I. , and Harnett, D. S. (Eds.) Handbook of Clinical Psychopharmacology. 2nd ed. Dunmore, PA: -
Jason Aronson, Inc. , 1989.
[355] Kelleman, T. "Starz" website, 2002 -

Catapres (clonidine) for anxiety, hypertension -

Celexa (citalopram hydrobromide) for depression

Compazine (prochlorperazine) anti-psychotic, anti-nausea

Concerta (time released Ritalin) for ADHD

Cylert (pemoline) for ADHD (may cause serious liver problems)

Dalmane (flurazepam) for sleep disturbances, anxiety

Depakote (Divalproex, Valproic Acid) anticonvulsant, ODD, aggression

Desyrel (trazodone) antidepressant (frequently prescribed for sleep disturbances)

Desoxyn (methamphetamine) stimulant for ADHD, narcolepsy

Dexedrine (dextroamphetamine) psychostimulant for ADHD

Effexor (venlafaxine) antidepressant

Elavil (amitriptyline) antidepressant

Eqanil, Miltown (Meprobamate) for anxiety

Haldol (haloperidol) for explosiveness

Klonopin (clonazepan) for anxiety

Lamictal (lamotrigine) anticonvulsant, mood stabilizer

Librium (chlordiazepoxide) for anxiety

Lithane Lithotabs (lithium) antipsychotic, bipolar

Luvox (Floxyfral, fluvoxamine) for OCD

Mellaril (thioridozine) for hyperkinesis, antipsychotic

Molindone (Lidone, Moban) anti psychotic

Neurontin (gabapentin) anti-convulsant, anxiety

Norpramin (desipramine) antidepressant

Paxil (paroxetine) antidepressant

Phenergan (promethazine)

Prozac (fluoxetine) antidepressant

Provigil (modafinil) for ADHD, narcolepsy, sleep apnea

Remeron (mirtazapine) antidepressant

ReVia (naltrexone) skin picking (Primarily prescribed for alcohol cravings, is an alcohol abuse inhibitor)

Risperdal (risperidone) antipsychotic, mood stabilizer

Ritalin (methylphenidate) for ADHD

Seroquel (quetiapine fumarate) antipsychotic (may increase appetite)

Serzone (Nefazodone) antidepressant, also for seizures

Stelazine (trifluoperazine) antidepressant

Tegretol (carbamazepine) mood stabilizer, anti-seizure

Thorazine (chlorpromazine) antipsychotic

Tofranil (imipramine) antidepressant, used for enuresis

Tomoxetine for ADHD (non stimulant)

Valium (diazepam) for epilepsy, anxiety

Wellbutrin (bupropion) antidepressant

Xanax (alprazolam) for anxiety disorders and aggression

Zoloft (sertraline) antidepressant

Zyprexa (olanzapine) antispychotic

Appendix 6:

An Example of an IEP

Individual Education Program (IEP) Services Description

Student_____IEP Date_____ DOB_____

IEP Responsible Educator _____Home School_____ Attending School_____

If student will not attend home school, list rationale_____

Educational Program and Related Services Projected/Anticipated Minutes Per Week_____
Starting Date_____Duration_____

Level of Special Education Services: List/Description of Specific Areas of Service (Please Check Only One)
__1. Regular Program w/Itinerant Service
__2. Special Education Resource Service
__3. Self-contained Special Education Service
__4. Specialized Self-Contained Service
__5. Out-of-Cooperative Program

Career/Vocational Education (14 years or older)

1. Regular Program Course/Placement Name:_____
2. Special Program / Describe:_____ Service Provider:_____
3. No Vocational Education___ Parent Preference_____ Other_____

Related Services
Service Provider:_____ CDS_____
Service Provider:_____ OT_____
Service Provider:_____ PT_____
Service Provider:_____ Other_____
Special Transportation Required: Yes_____ No_____

Evaluation for Service Recommendation:_____ Total Minutes of Special Education _____
(Attach Referral) Total Minutes of Regular Education _____
Total Minutes Per Week _____

Extent of Participation in Regular Education:_____
_____

Physical Education Program: Regular_____ Special Ed:_____ PE requirement complete____

Less Restrictive Placement Rejected for Following Reasons:
Academic Level_____
Behavioral Concerns_____
Unique Needs_____
Failure to Succeed in Less Restrictive Setting:_____
Opportunities for Nonacademic and Extracurricular Activities:_____

Extended School Year (ESY) Status: Each school year all students with handicapped conditions are considered for extended school year service.

Your Student_____

____ is recommended for ESY
____ is not recommended for ESY
____ will be considered for ESY services by May_____.

INDIVIDUALIZED EDUCATION PROGRAM
NOTICE OF INDIVIDUALIZED EDUCATION PROGRAM MEETING

Student_____ DOB:_____ Date:_____

Dear Parent: -

Your student is eligible for special education services. We need to develop an Individualized Education Program (IEP). - This letter is to confirm a meeting date to develop the IEP. -

The purpose of the IEP is to review your student's present school performance, decide upon annual goals, and discuss - specific services and placement options. It is important that you come to the IEP meeting. We need your help in planning - your student's program. We welcome your ideas about goals and objectives for your student's program. -

If you have questions regarding your student's involvement in the program at his/her school, please feel free to contact me. -

The IEP conference has been scheduled for: _____. -

Date:_____ Time:_____ Location:_____

People Invited to the IEP:	**Position:**
_____	_____
_____	_____
_____	_____

If for some reason, you are unable to attend, please call or write so that we can reschedule at a more convenient time. Thank you.

Sincerely,

_____
Principal or designee

_____
Phone

Appendix 7:

Resource Guide

There are, literally, thousands of web sites now devoted to Fetal Alcohol Syndrome and related effects as well as Native American mental and physical health concerns. The selection below is a sample of sites from around the United States and Canada. It also contains a variety of resources from online, family support resources, videos, and other media.

Selected Web sites:

Better Endings New Beginnings – Help for families and professionals dealing with high-risk youth, foster care, adoptions, kinship care, FASD, LD
http://www.betterendings.org/

Canadian Centre on Substance Abuse - Fetal Alcohol Syndrome-
National FAS center offers news, resources, prevention activities and a listserv.
http://www. ccsa. ca/fasgen. htm

Centers for Disease Control and Prevention-National Center on Birth Defects and Developmental Disabilities: Fetal Alcohol Syndrome
1600 Clifton Rd.
Atlanta, GA 30333

http://www.cdc.gov/ncbddd/fas/default/htm

Children's Center
415 S W 11th Street
or PO Box 484
Vancouver, WA 98666
Phone: (360) 699-2244 Fax (360) 699-1900
Antonia Rathbun, M. A. , A. T. R. , NCMHC
Special Needs Adoption Support Program Manager
E-Mail: antoniar@thechildrenscenter.org

The Clearinghouse for Drug Exposed Children
Newsletter Division of Behavioral and Developmental Pediatrics
University of California, San Francisco
1350 7th Avenue, Room 101
San Francisco, CA 94143-1311
Phone: (415) 476-9691

CSAP National Clearinghouse for Alcohol and Drug Abuse Information
Phone: (800) 729-6686

Epigee Birth Control Guide
A Simple Guide to Birth Control
http://www.epgee.org

Family Empowerment Network: Support, Resource and Referral Network
University of Wisconsin Medical School
Department of Family Medicine
777 S. Mills Street
Madison, WI 53715
Contact: Georgiana Wilton
Phone: (800) 462-5254
E-mail: fen@fammed.wisc.edu
http://www. fammed. wisc. edu/fen

Family Support Services:
The Arc of the United States
500 East Border Street, Suite 300
Arlington, TX 76010
Phone: (817) 261-6003
http://www.thearc.org

FANN – Fetal Alcohol Network Newsletter
158 Rosemont Avenue
Coatesville, PA 19320
Listing of National Support Groups
Phone: (610) 384-1133

FAS/ATOD Wed Resources – The Fetal Alcohol Syndrome/Alcohol Tobacco and Other Drug (FAS/ATOD) Prevention Outreach Project (POP) is a collaborative effort involving numerous community sectors and health, education, social service, law enforcement, and community groups.
http://www.uchsc.edu/ahec/fas/websites/

FASLINK – Internet connections for education and support for families of children with FAS.
http://treefort.org/~tjk/faslink.htm
http://www.come-over.to/FAS/faslink.htm
http://laran.waisman.wisc.edu/fv/www/lists/FAS-LINK.htm

FAS Community Resource Center-Provides a fetal alcohol syndrome fact sheet, - email support groups, and research articles. Find legislation updates, links and - personal stories. -
http://www.azstarnet.com/~tjk/fashome.htm -

The FAS Family Resource Institute (FAS-FRI)
P. O. Box 2525
Lynnwood, WA 98036
Phone: (206) 778-4048
http://www.accessome.com/~delindam/
E-Mail: delindam@accessone.com

FASD Newsletter
c/o Mailbag
P. O. Box 74612
Fairbanks, AK 99707
Support Group
Contact: Gail Hales
Phone: (907) 456-2866

Federation of Aboriginal Foster Parents
2680 East Hastings Street, #300
Vancouver, BC V5K 2A9
Phone: (604) 291-7091
Fax: (604) 291-7098
E-Mail: mailto:fafp@direct.ca

Fetal Alcohol Task Force
1016 East First Street
Port Angeles, WA 98362

Growing With FASD Newsletter
7802 SE Taylor
Portland, OR 97215
Phone: (503) 254-8129

Hazelden Hotline. A service of the Hazelden Treatment Program, helps people to overcome fears about talking to friends and relatives with addiction problems.
Phone: 1-800-I-DO-CARE

Iceberg Newsletter
P. O. Box 95597
Seattle, WA 98145-2597

INFORPACKAGE – Alcohol-Related Birth Defects – A Division of the Centre for Addictions and Mental Health Alcohol-Related Birth Defects Information Package Copyright, ARF Library, 1996.
http://www.arf.org/isd/infopak/arbd.html

IRSC - Cognitive Disabilities, Fetal Alcohol Syndrome
The Internet Resources for Special Children (IRSC) - Global disability resource is dedicated to communicating information relating to the needs of children with disabilities on a global basis.
http://www. irsc. org/fas. htm

Journey Through the Healing Circle
Washington State Department of Social and Health Services (DSHS), "Journey Through the Healing Circle" is now available to parents, schools, and other social service agencies as a series of videotapes, video CDs, and professionally illustrated workbooks.

A partnership of Washington State agencies, health-care experts, and traditional Northwest tribal storytellers has produced a collection of stories, health tips, and practical knowledge to help parents and foster parents learn about Fetal Alcohol Syndrome and understand how it affects their children- press release, DSHS, 2001
http://www.dshs.wa.gov/fosterparents/journey.html

Michigan Health and Hospitals Fetal Alcohol Syndrome (FAS) / Fetal Alcohol Effects (FASD) / Alcohol Related Birth Defects (ARBD)
http://mel.lib.mi.us/health/health-fas.html

Ministry for Children and Families Library Resource Centre FASD Introduction to Subject Guides | Library Home Page Additions Adoption Child Abuse & Neglect Child Welfare Children Disabilities Directories Education & Training Electronic Journals.
http://www.ssrv.gov.bc.ca/library/subjects/sub011b.html

State of Missouri-Fact sheet from the Missouri Department of Mental Health defines this condition and explains how to prevent it.
http://www.well.com/user/woa/fsfas.htm

MOFAS-Minnesota Organization for Fetal Alcohol Syndrome – This is a web site put out to aid parents, caregivers and professionals in obtaining information about and services for individuals and families affected by FAS.
http://www.mofas.org/resources/listserve.htm

NOFAS: National Organization on Fetal Alcohol Syndrome.
http://www.nofas.org

Office of Minority Health Resource Center. Conducts customized database searches, accessing information on health programs and organizations as well as funding sources and articles. A printout will be mailed to you at no charge.
Phone: (800) 444-6472

Office of Special Education Programs
US Department of Education
Positive Behavioral Interventions and Support Technical Assistance Center
Behavioral Research and Training
5262 University of Oregon
Eugene, OR 97403-5262
pbis@oregon. uoregon. edu
Phone: (541) 346-2505
Fax: (541)346-5689
http://www.pbis.org

Planned Parenthood Federation of America
810 Seventh Avenue
New York, NY 10019
http://www.plannedparenthood.org

Pregnancy Resource Guide: Internet Access Sites – The National Clearinghouse for Alcohol and Drug Information. A service of SAMHSA Pregnant/Postpartum Women and Their Infants: Internet Access Sites September 1997. Federal Resources Administration for Children and Families.
http://www.acf.dhhs.gov
http://www.health.org/pubs/resguide/pregnant/links.htm

Rehabilitation research and Training Center on Positive Behavioral Support
Division of Applied Research and Educational Support
Division of Child and Family Studies
University of South Florida
Tampa, FL
Phone: 813-974-4612
http://rrtcpbs. fmhi. usf. edu

Saskatchewan Fetal Alcohol Support Network, Inc.
210-2002 Quebec Avenue
Saskatoon, Saskatchewan S7K 1W4
Phone: (306) 665-7272
Fax: (306) 665-7274 (Fax)
E-Mail: fas.network@sk.sympatico.ca

Shodair Children's Hospital
2755 Colonial Drive.
Helena, MT 59601
Phone: 406-444-7500
http://shodairhospital.org

Society of Indian Dentists
PO Box 15107
Phoenix, AZ 85060
Phone: 602-954-5160 (Voice)

Spectrum/Fetal Alcohol Syndrome – FETAL ALCOHOL SYNDROME (FAS) and FETAL ALCOHOL EFFECTS (FASD)
http://comnet.org/local/orgs/spectrum/fas.html

Specialized Training Services
Drew Leavens, President
9606 Tierra Grande, Suite #105
San Diego, CA 92129
Phone: (858) 695-1313
Fax: (858) 695-6599
http://www. specializedtraining. com

State of Alaska FAS Coordinator
DHSS
P. O. Box 110607
Juneau, AK 99811-0607
Contact: L. Diane Casto
Phone: 1-800-478-2097
http://www.hss.states.ak.us/fas/

SUPER Group
Fairbanks, Alaska
Contact: Jennifer Smith
Phone: (907) 452-1776

Support Group for Adoptive and Foster Parents
Paramus, NJ
Contact: Ronnie Jacobs
Phone: (201) 261-1450

Tanana Chiefs Conference
122 First Avenue, Suite. 600
Fairbanks, AK 99701-5903
Phone: (907) 452-8251
http://www.tananachiefs.org

Texas Fetal Alcohol Syndrome Consortium Home Page
Texas Fetal Alcohol Syndrome Consortium is sponsored by the Texas Office for the Prevention of Developmental Disabilities (TOPDD) in collaboration with The Arc of Texas, and the Texas Department of Mental Health and Mental Retardation.
http://www.main.org/texasfasc

TRIUMF Project - Fetal Alcohol Syndrome
Comprehensive resource center offers a mailing list, software to download, and an archive of articles and links.
http://www.acbr.com/fas

Diagnostic Resources:

FAS– Diagnostic and Prevention Network
University of Washington
Susan Astley, PhD. , Director
Phone: (206) 526-2206

FAS Diagnostic and Prevention Network
Pacific Treatment Alternatives
1114 Pacific Avenue
Everett, WA 98201
Phone: (425) 259-7142
Fax: (425)258-4782
Karen Canida, Pregnancy Outreach Director

FAS Diagnostic and Prevention Network
Wilson Psychological Services
1240 SE Bishop Boulevard, Suite Q
Pullman, WA 99163
Phone: (509) 334-0782
Fax: (509) 334-0361
Greg Wilson, PhD.

FAS Diagnostic and Prevention Network -
Spokane Regional Health District –
Substance Misuse Clinic
1101 West College Avenue
Spokane, WA 99201-2095
Phone: (509) 324-1413 or (509) 324-1457
Fax: (509) 324-3622
Nancy Echelbarger, Clinic Coordinator
E-Mail: echelbarger@spokanecounty.org

“The Clinical Diagnosis of Fetal Alcohol Syndrome”. A video by Jon M. Aase, M. D. - shows complete and never-before-seen information on the clinical diagnosis of FAS. - The video can be purchased for the price of $150. 00 + $9. 00 for S/H: -
Flora & Company -
P. O. Box 8263
Albuquerque, NM 87198-8263
Phone: (505) 255-9988

Media Resources: -

"Alcohol, Pregnancy, and the Fetal Alcohol Syndrome": This Slide Lecture Unit from Project Cork of the Dartmouth Medical School contains 79 full color slides with accompanying text covering the effects of maternal drinking on fetal development. The slide unit is available from:
Milner-Fenwick, Inc.
2125 Greenspring Drive
Timonium, MD 21093
To order, call Phone: (800) 432-8433 or Fax (410) 252 -6316

"And down will come baby". A 17-minute video for teenagers that examines the specific health risks to the unborn child exposed to cocaine, heroin, alcohol, and tobacco. For ordering information, write to:
Scott Newman Center
6255 Sunset Blvd, Suite 1906
Los Angeles, CA 90028
Phone: (800) 783-6396

"The Early Years, Birth through Age 12" and "Independence, Ages 12 to Adult". Training Tapes for Living with FAS and FASD seek to assist those living with FASD and their families through a variety of challenges, from soothing a fussy baby to adaptive living skills. Each tape is 32 minutes long and costs $295:
Altschul Group Corporation
1560 Sherman Avenue, Suite 100
Evanston, IL 60201-9971

"Women of Substance" A new one-hour documentary on the barriers pregnant and child-caring women addicts encounter in their struggle toward sobriety. Call Video Action Fund for ordering information:
Phone: (202) 338-1094

Additional Resources:

Indian Health Service

Indian Health Service:
Area Office Addresses:
(http://www. ihs. gov)

Ask for Behavioral Health:

Aberdeen Area Office -
Office of Professional Services -
115 4th Avenue Southeast -
Aberdeen, SD 57401 -
Phone: (605) 226-7531 -
Fax: (605) 226-7321 -

Alaska Area Native Health Service -
4141 Ambassador Drive -
Anchorage, AK 99508-5928 -
Phone:(907) 729 - 3686 -
Fax: (907) 729 - 3689 -

Albuquerque Area Office -
5300 Homestead Road, NE -
Albuquerque, NM 87110 -
Phone: (505) 248-4102 -
Fax: (505) 248-4115 -

Bemidji Area Indian Health Service -
522 Minnesota Avenue. NW, Room 119 -
Bemidji, MN 56601 -
Phone: (218) 759-3412 -
Fax: (218) 759-3511 -

Billings Area Office -
2900 4th Avenue North -
Billings, MT 59101 -
Phone: (406) 247-7107 -
Fax: 406-247-7230 -

California Area Indian Health Service -
1825 Bell Street, Suite 200 -
Sacramento, CA 95825-1097 -

Operator Assisted Calls Phone: (916) 566-7001
Automated Calls Phone: (916) 566-7033
Fax: (916) 566-7043
E-Mail: Webmaster: Webmaster@cao. ihs. gov

Unlike most other Areas of Indian Health Service, the California Area is a total P. L. 93-638 Indian Self-Determination Act contract Area where the tribes maintain full responsibility for the development and operation of their own primary health care facilities, programs, and services.

Nashville Area Indian Health Service
711 Stewarts Ferry Pike
Nashville, TN 37214-2634
Phone: (615)736-2400
Fax: (615)736-2391

Navajo Area Indian Health Service
P. O. Box 9020
Window Rock, AZ 86515-9020
Phone: (520) 871-5811
Fax: (520) 871-5896

Oklahoma City Area Indian Health Service
Five Corporate Plaza
3625 NW 56th Street
Oklahoma City, OK 73112
Phone: (405) 951-3768
Fax: (405) 951-3780

Phoenix Area Indian Health Service
Two Renaissance Square
40 North Central Avenue
Phoenix, AZ 85004
Phone: (602) 364-5039
Fax: (602) 364-5042

Portland Area Indian Health Service
1220 SW Third Avenue - Room 476
Portland, OR 97204-2892
Phone: (503) 326-2020
Fax: (503) 326-7280

Tucson Area Indian Health Service
7900 S. J. Stock Road
Tucson, AZ 85746-7012
Phone: (520) 295-2405
Fax: (520) 295-2602

Selected Professional Organizations:

American Academy of Pediatrics
National Headquarters:
The American Academy of Pediatrics
141 Northwest Point Boulevard
Elk Grove Village, IL 60007-1098
Phone: (847) 434-4000
Fax: (847) 434-8000

American Academy of Pediatrics
Washington, DC Office:
Department of Federal Affairs
601 13th Street NW
Suite 400 North
Washington, DC 20005
Phone: (202) 347-8600
Fax: (202) 393-6137 (Fax)
http://www.aap.org

American Medical Association
515 North State Street
Chicago, IL 60610
Phone: (312) 464-5000
http://www.ama-assn.org

American Occupational Therapists Association
4720 Montgomery Lane
P. O. Box 31220
Bethesda, MD 20824-1220
Phone: (301)652-2682 or TDD 1 (800) 377-8555.
http://www.aota.org/general/about.asp

American Psychological Association
750 First Street, NE,
Washington, DC 20002-4242.
Phone: (800) 374-2721; (202) 336-5510. TDD/TTY: (202) 336-6123
http://www.apa.org

American Psychiatric Association
1400 K Street NW
Washington, DC 20005
Phone: (888) 357-7924
Fax (202) 682-6850
http://apa@psych. org

American Psychiatric Nurses Association
Colonial Place Three
2107 Wilson Blvd. , Suite 300 A
Arlington, VA 22201
Phone: (703) 243-2443
Fax: (703) 243-3390
http://www.apna.org

Association of American Indian Physicians
2423 Camino Del Rio South, Suite 103
San Diego, CA, 92108.
(619)683-2012
E-mail: aaip-ca@msn com.
http://www.aaip

Association for the Treatment of Sex Abusers
4900 SW. Griffith Drive, Suite 274
Beaverton, OR 97005
Phone: (503) 643-1023
Fax: (503) 643-5084
E-mail: atsa@atsa. com
http://www. atsa. com

National Association of Social Workers
750 First Street NE, Suite 700
Washington, DC 20002-4241
Phone: (202) 408-8600 or (800) 638-8799
http://www.naswdc.org

Society of Indian Psychologists
John Chaney, President
Oklahoma State University
215 North Murray Hall
Stillwater, OK 74078
Phone: (405) 744-6027
E-Mail: jchaney@okstate. edu

National Organization on FAS (NOFAS)
http://www. nofas. org

Appendix 8:

Glossary of Terms

Abstract Concepts	Thought or ideas expressed, a quality apart from an object
Advocate	One who argues or pleads another's cause
Articulate	Able to speak, express oneself readily and effectively
Benign	Of a gentle disposition, kind, good-hearted
Broach	To introduce a topic of conversation
Burnout	Exhaustion of one's physical or emotional strength
Clinadactyly	A common recessive birth defect resulting in a bend at the first joint of the fifth digit
Competency	To demonstrate ability, fitness, capability
Cognitive Development	Growth in conscious mental activity as thinking, remembering or learning
Colicky	Sharp, sudden abdominal pain
Concrete	Naming a real thing or class of things, actual or seen rather than implied
Croon	To sing or hum in a gentle murmuring voice
Culturation	Developing by education and training
Detention	A period off temporary custody prior to disposition by a court
Detoxified	To free an alcoholic from an intoxicating substance or from dependence on it
Developmental Milestones	Significant points in developmental growth
Discriminate	To distinguish, differentiate

Dysmorphologist	A physician trained to identify and diagnosis physical and genetic syndromes
Egocentric	Concerned or overly concerned with the self
Encephalitis	Inflammation of the brain
Eradicate	To uproot, eliminate
Exacerbate	To make more bitter or severe
Frontal Lobes	Front part of the brain that controls behavior, the understanding of cause and effect, abstracting abilities, and the integration of information from other areas of the brain
Generalization	A general statement, law, principle or proposition
Gravitate	To move or tend to move toward something
Habituation	The process of making habitual
Ideation	The capacity for or process of forming ideas
Impulsiveness	To act or prone to act on impulse, a natural tendency , without thinking
Incarcerate	Imprison, confine
Interdependence	Dependent upon one another
Intervention	To come in or between in order to stop, settle or modify, treatment
Intrusive	To enter or force in or upon, encroach
Jargon	Vocabulary used exclusively in a specific profession
Latency Period	Present by not visible or active, dormant, refers to the period before puberty
Manifestations	Displays, demonstrations
Monogamous	Marriage with but one person at a time

Orthodontic	Branch of dentistry dealing with faulty tooth occlusion and its correction
Otitis Media	Inner ear infection
Perseveration	Fixation on and repetition of thoughts, words, and movements, commonly associated with brain damage or certain psychiatric disorders
Precursor	One that precedes and indicates the approach of another
Predisposition	To incline in advance, making susceptible
Provocation	The act of provoking, to incite to anger
Psychiatrist	A professional in the branch of medicine dealing with mental disorders
Psychologist	A professional that deals with the science of the mind and behavior
Psychosocial	Dealing with the psychological and social environment and influences
Psychotherapy	Treatment of mental or emotional disorder
Respite Care	An interval of rest or relief for the caretaker
Sanctions	Authoritative approval designed to enforce a law or standard
Self-Regulate	To govern or direct oneself according to rule
Sequential	Chronological order, progression
Sobriety	The state of being sober or not drunk; not abusing alcohol or drugs
Socialization	To participate actively in a social gathering
Syntactic	The way in which words are put together to form phrases or sentences
Tactile	Relating to or perceptible through the sense of touch

Teratogen	A substance that can cause birth defects when used by pregnant women
Temper Tantrums	Fits of bad temper or sudden outbursts
Trauma	A bodily or mental injury caused by an external agent
Truancy	One who stays out of school without permission
Ventricular Septal Defect	A congenital defect of the heart where there is a hole in the heart. This may resolve on its own although it may also require cardiac surgery.
Vulnerability	Capable of being taken advantage of, open to attack