

# FAS TIMES

FETAL ALCOHOL SYNDROME / FAMILY RESOURCE INSTITUTE NEWSLETTER

MENTAL HEALTH CARE REDEFINED

## Creating a Culture of Recovery: Part I

Jocie DeVries with Ann Waller

As advocates for children/adults with FASD, we know we need to understand the latest jargon in the various service systems in order to effectively communicate. So in the last couple of months, we were very interested not only to learn about a new definition of recovery, but to find out that recovery is considered to be the single most important goal for the mental health system according to the Substance Abuse and Mental Health Services Administration. <sup>1</sup> Recovery in terms of mental health is now defined as “a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential.” <sup>2</sup>

Although I had never thought about it this way before, I know a little bit about this type of recovery. Recovery is the place where you return after the nightmare.

In 1978 my husband and I adopted two children from the Washington State Department of Social and Health Services; we wanted to give back to our community, our nation, our God. We asked social workers what the current cultural issues were which brought children into Child Protective Services and how we could help. We were told that the primary goal of the system at that time was to place siblings together in adoptive homes instead of separating them, as so often had been done in the past.

We were children of the 50's. We were optimistic. We had a big house, a nice car and good jobs. We already had two children who were doing well even as teenagers. So we said, “OK, we'll take two.” We thought to ourselves, “How hard could this be?” We had no idea...

We weren't even daunted when we were told that they had been in twelve different foster placements in a period of only eighteen months. Neither were we deterred when we were told that they had been deliberately set on fire, they had been beaten about their heads with a lead pipe and the little boy had had his nose beaten flat. After all, everyone knew that children were born as a blank slate and that love and nurture could overcome ANY obstacle. After all, it was the 70's, we were good people, we had a lot of resources and yes, we were still optimistic.

When the children came to live with us they were two and four years old—absolutely beautiful Scandinavian children. The problem was they acted like little feral cats—they screamed and scratched and clawed each other trying to communicate. I kept circling around their entwined bodies, telling them that I was their mother—but that didn't help. So we began the long journey of learning about mental illness and co-occurring developmental disabilities. Eventually, we had a laundry list of diagnoses: autism, profoundly disturbed, mental retardation, depression, post traumatic stress disorder, attachment disorders and eventually, Fetal Alcohol Syndrome.

While living our nightmare, we suffered the heartbreak of learning about juvenile court, residential treatment and psychiatric placement...and feeling alone and isolated. At the same time, we were surrounded by professionals who couldn't recognize the FASD behavioral phenotype, some of whom laughed at us because they thought we were “the problem.” We also experienced the agony of giving up custody in order to access treatment for our son.

But we also discovered the amazing and wonderful friendships that were available with other parents who were traveling the same road we were. We experienced the joy of knowing other families who have

<sup>1</sup> SAMHSA Transforming Mental Health Care in America project

<sup>2</sup> “National Consensus Statement on Mental Health Recovery” brochure, U.S. Department of Health and Human Services, SAMHSA, Center for Mental Health Services (CMHS)

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### FAS TIMES

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lived through their own nightmares. And together we learned about the peace of “recovery.”

On Easter Sunday of this year we went to see one of these two (now adult) children, Russell, and his new family. He has twin boys who are four months old and as healthy and happy as two kids could possibly be. He is a loving, tender father, who is patient, and compassionate. He and his wife are spending the summer building their very own dream house. Through the great plan of God, they are living on 30 acres in the most beautiful wine country in the world.

His birth sibling, Cheryl, married a fine man who is also patient. This is a girl who was so fearful as a child that I had to take her with me when I bought her Christmas presents so she knew she would not be forgotten. She has held down the same job for five years now. She and her husband just bought a new house which they moved into in June. She understands mental illness and wants to help other hurting people understand that recovery is possible.

Our older son was asked once if anyone in his family suffered from a mental illness. He answered, “No. We all really enjoy it.” Part of the recovery process for some affected youth and family members involves an ironic sense of humor and that is certainly true for us.

For example, when our children were little, one of their favorite TV programs was *The A Team*. I faithfully watched this show with them every week. Each episode was filled with bigger-than-life characters, people who admittedly were mentally ill and some whose obvious antisocial behaviors certainly hinted of diminished capacity. But I loved it as much as they did because it made us laugh and cheer for the underdog. The innocent and funny antics reminded me so much of life at my house. I could appreciate the quirky heroes that weekly paraded through our living room—my favorite characters being Hannibal and Mr. T.

Each hour-long episode was action filled with irritable but clever verbal quips zinging between the characters. The interesting thing was that even with all the chaos in the show, no one was ever seriously injured or killed on *The A Team*. I waited eagerly with the children through the hour for the chaos to subside and the plot to come together. The grand finale of each episode was when Hannibal would stick a smoky cigar between his teeth and say with a wide grin, “I love it

when a plan comes together!”

I guess that sentiment kind of sums up my philosophy and attitude toward life while raising two kids with FASD. My top priority was to keep everyone as safe as possible and hope that at the end of the day the bedlam will settle down and everybody will relax into a quiet, “normal” evening. Not that it happened that way very often.

But, ever the optimist, I guess I still live in the hope that each day will end that way. Having several people with disabilities in my life, I am still amazed and thrilled when *any* plan comes together and we have time to sigh, look at the funny side of life and, sometimes for just a few minutes anyway, know that all is right with the world. That’s what recovery from mental illness means to me—ever increasing periods of stability with kids who have high self-esteem.

Moving from the personal, family level to the state level, I am excited these days about the plan that’s coming together in Washington State. In a previous issue of FAS Times about two years ago, we announced that we had finally found the “eligibility door” to services for individuals who had FASD and IQs in the normal range. That door was in the mental health system. We realized that finally the scientific advances in research in the mental health field in general and FASD specifically had progressed enough for their paths to converge. We had identified where services for FASD could and would fit and that, in fact, many of the people already in the mental health system may have undiagnosed FASD and consequently are not being appropriately served.

It would be good to back up a bit at this point and give credit to Dr. Brenda Scafidi, the Mississippi Mental Health Director, who played a key role in pointing us in this direction. We met her when we were promoting the Mississippi Town Hall Meeting on FASD in 2003. When we first met with her and she heard the Collective Family Experience on FASD, she immediately recognized that her state had a very large group of children who had been generally categorized as Severely Emotionally Disturbed (SED) but who had never even been screened for FASD. She also knew that alcohol abuse was another big issue in her state.

So together we promoted the Town Hall Meeting and worked with her and Dr. Larry Burd from the North Dakota FAS Clinic to set up a plan to teach public health nurses how to screen for FASD and train medical

doctors in the state health care system to diagnose these conditions. Then in 2004, Dr. Scafidi encouraged us to attend the mental health Training Institutes on Developing Local Systems of Care in San Francisco. That educational experience helped us realize that our determination to help those with FASD had converged with the scientific progress in the mental health field.

But, as everyone knows, it takes a lot of hard work, advocacy and education to make something move from theory into practice, especially when it involves large public agencies. So we rolled up our sleeves and went to work in this direction.

We started on the federal level by contacting project officers in the Center for Mental Health Services (CMHS) in SAMHSA to investigate if and how children and adults with FASD might fit under the umbrella of care in that federal agency and happily we found that, indeed, it did seem to be a real possibility.

Then, in the past year especially, our efforts at FAS\*FRI have refocused more on our state’s level of mental health care. Our public awareness efforts were geared to increase understanding among Washington State’s disability, mental health and substance abuse agencies on the necessity of identifying children and adults with FAS/ARND and co-occurring mental health and substance abuse conditions. One or more of our staff have participated in the following activities relevant to this goal in the past year.

- Collaboration with the Divisions of Alcohol and Substance Abuse (DASA), Mental Health (MHD), and Developmental Disabilities (DDD) and the Department of Health to produce and facilitate a parent retreat in August 2005 (State MHD administrators were encouraged to attend in a role of listening and learning.)
- Creation and distribution of 1,500 posters for chemical dependency treatment centers to help identify disabled individuals who may be revolving in and out of treatment because they have not been provided with appropriate aftercare support.
- Hosting of a legislative reception in the state Capitol to increase public and legislative awareness about the success of the Parent Child Assistance Program in preventing FASD by educating, treating and supporting chemically dependent pregnant and parenting women.
- Collaboration with Governor Christine

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## Nobel Laureate Eric Kandel

by Susan Kruglinski

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Neurobiologist Eric Kandel's early fascination with how the mind works led him into training as a psychiatrist interested in psychoanalysis. But in the 1960's he traded a therapist's sport jacket for a lab coat and began studying one of the slimiest creatures on Earth. At a time when brain researchers thought nothing could be learned from invertebrates, Kandel stunned the fledgling world of neuroscience by uncovering the mechanisms of memory in sea slugs, which earned him a Nobel Prize in 2000. He also co-edited Principles of Neural Science, the book every medical student in America is required to read—all 1,414 pages of it.

In his new book, *In Search of Memory: The Emergence of a New Science of Mind*, Kandel examines the convergence of four critical fields—behaviorist psychology, cognitive psychology, neuroscience and molecular biology. Still busy trying to coax more information out of sea slugs, Kandel also serves as a professor of biochemistry, physiology, and psychiatry at Columbia University, where his laboratory is located.

**Your most recent lab work involves the potent emotion of fear. What have you learned?**

We have identified some of the genes in the mouse that are important for both learned fear and instinctive fear. We've shown that by knocking out the stathmin gene, we can produce a mouse that is relatively fearless.

**How does a fearless mouse behave?**

Normally, when you put a mouse into an open field, it walks along the edge of the field, where the walls are—the mouse is in an enclosed chamber with walls around it—because it's afraid of being attacked by an intruder and it makes occasional dashes into the center to make sure it's not missing some food or an interesting sexual partner. If you frighten a mouse, it stays in one corner and doesn't move at all. If you knock out this gene that is important for fear, the animal

spends a lot of time in the center. It is no longer afraid.

**Does the knockout shut down instinctual fear?** Yes, but it works on learned fear too.

**How do you study happiness?** In order to produce learned fear, you take a neutral stimulus like a tone, and you pair it with an electrical shock. Tone, shock. Tone, shock. So the animal learns that the tone is bad news. But you can also do the opposite—shock it at other times, but never when the tone comes on. Under those circumstances the tone indicates security and safety. We find that the animal acts as if it is content and secure, even more than it does without any shocks whatsoever. When we looked in the brain, we found that not only were the pathways that mediated fear turned off but also that happiness pathways were activated. The caudate nucleus, a part of the brain that mediates the effects of drugs that make you feel good, is lit up by this procedure.

**So fear and happiness are part of the same system?** That's right, but I want to be clear that the knockout mice and the happiness procedure are not identical. They are different experiments. We showed that fear comes to a certain neural circuit and that there are genes that control that neural circuit and you can turn that circuit on and off with specific genes. Period, end of paragraph. In a separate set of studies we

*Does psychotherapy work? We'd be a lot more certain if we slapped a little science on it.*

looked to see whether we can behaviorally—without manipulating genes—produce the opposite and that is happiness. And that is how we got onto this paradigm. They may be related—it may be the same genes that shut off fear and turn on happiness, but we don't know that yet.

**How is your research in memory related to fear and happiness?** Let's assume that you have a traumatic experience in childhood. Let's say you were sexually abused. You may or may not remember the cognitive components of it—the molester bothering you. But there are associated with the experience a series of autonomic and emotional changes that are implicit. And

that component is learned fear. Seeing a strange person may therefore elicit in you a response that may be completely inappropriate—that strange person may have nothing to do with the molestation event but somehow there are similarities that you recognize that bring this back. You learn emotional experiences as much as you learn cognitive experiences except that they are more unconscious. Sometimes one represses the cognitive component of it but it's often more difficult to repress the emotional component.

**You have written that your training in psychotherapy influences your neurobiological work. Isn't there a split between psychotherapists and neurobiologists?** Yes, but I think it's a temporary one and perhaps an unnecessary one. I'm on an advisory board for the Ellison Medical Foundation, which is exploring whether one can use MRI brain imaging to evaluate the outcome of psychotherapy.

**Haven't you questioned the value of psychoanalysis?** Early in my career, I was disappointed that psychoanalysis was not becoming more empirical, was not becoming more scientific. It was primarily concerned with individual patients. It wasn't trying to collect data from large groups of people who have been analyzed.

**Will the Ellison project address this kind of problem?** What our study group is discussing is whether or not the time is ripe to use brain imaging to evaluate the outcome of psychotherapy. There are now two forms of psychotherapy that have been medically proven to be effective. One is cognitive behavioral therapy, developed by Aaron Beck at the University of Pennsylvania. The other is interpersonal therapy, which was developed by Myna Weissman here at Columbia. Those are two scientifically validated forms of short-term therapy. In 20 sessions you can see improvements in mildly and moderately depressed patients. And there have been some preliminary studies with obsessive-compulsive neurosis where you can see a metabolic abnormality in the caudate nucleus in imaging. If you treat people with psychotherapy and they get better, that metabolic abnormality is reversed, which is the same thing that happens if you give them pharmacological treatment, like Prozac. So that's encouraging. We want to see whether there is a science

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## THE RIGHT TO TREATMENT

### Katie Dolan

Founder, Autism Society of Washington;  
Co-founder, Washington State Special  
Education Coalition

The Jansens are going to stay at the Ronald McDonald House while their daughter's recovering from a bone marrow transplant. Debbie will be carefully followed for the next seven years because she might need another transplant. George Jansen's insurance is paying for everything.

Teenage Bobby has cancer. His doctors are great at the Fred Hutchinson Cancer Center. Isn't that the same thing that Ted Kennedy's boy had when they amputated his leg? Look how great he is today.

These are families with a member requiring intensive, intrusive radical, perhaps even experimental medical treatment. I doubt if the teenage girl *wanted* to have a bone marrow transplant. But if her parents had refused consent, they might have been taken to court and threatened with losing parental rights for denying their child her "right to treatment."

Sixteen-year-old Bobby may be the luckiest of all. No one will accuse his family of causing his cancer. No lawyer will intercede and claim that Bobby will not have to take mind-altering medications if he doesn't want to. No court will question his (or his parents) right to mutilate his body by agreeing to an amputation.

Now let's look in on Bill Watson and his parents. In his second year of college, Bill became morose and withdrawn. One day he locked himself in his bedroom, refusing to come out, pacing all night. The mental health professionals denied him any help because they determined he "wasn't a danger to himself or others." His desperate parents finally took the door to his room off the hinges and found Bill hiding in the closet. He stayed in bed for several weeks. His mother thought he seemed better one day when he asked for her special pot roast. Later she found the meat wrapped in a handkerchief on a suitcase. That night Bill left home.

His parents didn't hear of Bill for six months, until a friend saw him living on the streets, dressed in filthy rags. At a guardianship hearing they arranged, Bill

showed up and said he didn't want his parents to be his guardians. He has been in and out of medical facilities for the last 10 years, with no treatment other than drugs he sometimes takes to suppress symptoms.

The first time he was hospitalized, Bill's parents weren't notified until the hospital business office called to check on his father's medical insurance. The insurance company had dropped Bill when he quit school and was no longer living at home. Now an attorney has demanded that Bill, and a class of people like him, not be forced to take any medications or undergo shock treatment or brain surgery if he doesn't want to. Bill's parents think that might be all right, but they wonder what treatment the attorney will demand for their very ill son. They also wonder what is wrong with Bill.

These are combined versions of real people in the medical systems in our state and country. The tragedy of the diagnosis of "mental illness" is not the disease or disorder. It is the lack of recognition as a true medical problem, resulting in a denial of scientific medical treatment. There are hundreds of disorders, diseases, and injuries which cause a person's brain to dysfunction. But unless tumors are found, recognizable epileptic seizures are documented, or gross functioning changes occur after infections, disorders of the brain are generally lumped into stigmatizing sub-categories of "schizophrenia," "manic depression," "bipolar," "psychoses," or, (among children) "emotionally disturbed." The patient is then in the never-never land of "mental health" and rarely gets comprehensive, scientific medical treatment. A doctor at the largest psychiatric hospital in Seattle, Washington, once told me, "we couldn't possibly afford to give everyone that comes in here a physical examination." And a woman who was threatening to blow up her parents was listed as a man for two days in that same hospital, until someone saw her in the nude.

Revolutionary new discoveries of biological causes of mental illness have gone almost unnoticed by the mental health medical community. Few know that fifteen years ago, Dr. Fuller Torrey, National Institute of Mental Health researcher, isolated two viruses which lodge in neurons of the brain [and are released when affected people are] between 16 and 22 years of age,

causing schizophrenic behavior.

In 2002 there was a news article about his "discovery" as if it was not only new, but extremely controversial. Little or no applied research involves mentally ill patients as partners. And thousands of mental health professionals are forced into process and paper work. More than 40% of mental health billions go to procedural actions by mental health professionals (MHPs), judges, lawyers, case workers, hospital and institution staff dealing with voluntary and involuntary commitments.

As for the legal professions, why has no one sued for a whole class of people who have been denied medical examinations?

*The tragedy of the diagnosis of "mental illness"...is the lack of recognition as a true medical problem, resulting in a denial of scientific medical treatment.*

Where are the malpractice attorneys to represent the man who was turned away from a voluntary commitment, then beheaded the next door neighbors in his family's up-scale neighborhood? Why can't police officers get a lawyer to sue the state when the patient the state neglected blows the head off one cop and wounds two others? (A man turned down for treatment, shot and killed his 6-month pregnant wife the next day in January 2003.)

[There are many things like this which could be done] to bring meaningful change in the way we deal with our fellow Americans diagnosed "mentally ill."

Dr. Oliver Sachs, best selling author of *The Man Who Mistook His Wife for His Hat*, headlined his lecture on mental illness with, "Let us not ask what disease the patient has, but rather what disease has the patient." Only when we realize the patient is not his disease will we free the person from his or her treatment-resistant disorder.

Maybe, just maybe, there is a question we should ask of attorneys, doctors, politicians, and all Americans. Do you believe in "the right to treatment" of people with mental illnesses? Or must we first "kill" the euphemistic mental-health system? ♥

*Postscript: This article has been revised from an article published in "Trial News"\* in May of 1990. It has been presented many times in the last years, but little has changed in the U.S. dysfunctional "Mental Health" system.*

\*the Newspaper of WA State Trial Lawyers

FAS Times Summer 2006

# Aiding the Mentally Ill

© Sharon Salyer

The Everett Herald, March 2, 2006

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For years, Jocie DeVries has fought to get help for children with fetal alcohol syndrome, including two of her adopted children.

When a woman drinks during pregnancy, the resulting damage to the infant can include lifelong physical and learning disabilities, as well as behavioral problems.

"I have been an advocate of children with these conditions for 16 years," said DeVries, of Lynnwood. "I could write a book on this."

She added that there are other health problems caused by fetal alcohol syndrome as well. DeVries spoke at a hearing Wednesday in Everett on problems with the state's mental health services. Like many of the other parents and adults who came to the meeting, she said much needs to be mended in treatment for the mentally ill.

DeVries said people working in mental health agencies have not been prepared or trained to deal with children with fetal alcohol syndrome. Kids often bounce between psychiatric hospitals and jail, she said.

"We need housing for people with these kinds of problems," she said.

The hearing in Everett, which was attended by about 60 people is one of a series across the state to find out what's wrong and what's right with the services provided to the mentally ill. The testimony will be included in a report to the governor on suggested improvements in state services.

For five consecutive years, Washington will get \$2.73 million from the federal government to improve treatment for the mentally ill. As one of only seven states to receive the grants, the goal is to not only strengthen the mental health system, but provide an example of what other states can do. "Part of the problem with mental illness is that people are reluctant...to say anything about it," said Jim Bloss, president of the local chapter of the National Alliance on Mental Illness.

"Whether it be themselves or a family member, the stigma is really the issue that has kept the mentally ill from actually

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## Creating a Culture of Recovery...for Migrant Workers

### Leticia Chavez

Bilingual Therapist and Intake Specialist

Central Washington Comprehensive

Mental Health

Sunnyside, Washington

Leticia Chavez came to America with her mother, father and siblings as illegal immigrants. They were completely alone, without any other family support, and they lived in their car. At the time, Leticia was the oldest child at five years old. As other children were born into the family, she was the designated babysitter while her parents worked in the fields of Eastern Washington.

"We lived on onions or apples basically, as the field bosses paid my parents much less than minimum wage. There were no facilities provided of any kind since our car was the family home. Of course we had no running water or place to take a bath.

"One day a social worker changed our lives. She went into the fields and talked to the parents there and connected us up with the Migrant Council. They helped us find a place to live and enrolled us children in school. To me, a little Hispanic girl, it was a miracle and I was so grateful that I vowed to never, ever forget from where I came.

"As migrant people we are accustomed to hard work and it is our tradition that what we do, we do well. Another tradition is that we tend to marry young and I also followed that tradition, marrying in 1985 at age 14. The match was not a good one and I was thrown into a life where domestic violence and constant verbal and emotional abuse were common. I gradually decided I wanted

to have a different life and since I couldn't change him I had to change myself.

So I decided to go back to school and get my GED. Even with that, the only jobs I could find were in the fast food industry and I couldn't make enough to take care of myself and my four daughters.

"But deep inside I still had this burning desire to help other people—that's what made the world go around for my soul. One day I met another woman who changed my life, and she helped me understand that I needed to go to college. She also helped me get a part-time job as a Spanish interpreter with

Children's Services in the Department of Social and Health Services. As I worked to raise my girls, do my job and finish my college education, my superiors noticed that I liked to work hard and liked to mentor others. Eventually, some people who worked in the Mental Health field called and offered me the job of my dreams as a bilingual therapist and intake specialist. Three years ago I completed my Master's degree.

"You ask me what is working well in the mental health field for migrant people. The first thing I noticed in my new job was that the staff who were working directly with the clients were not bilingual, even though 80% of the clients were Hispanic. Misunderstandings and miscommunications were commonplace. That was the first thing we changed. Another thing that's working in our community outreach is that we go to where people are and do not wait for them to find us. We have our meetings away from the office and clients feel much more relaxed. Most of the DSHS workforce only see clients at the DSHS office. We go to school settings to talk to parents and their kids and meet them somewhere in their comfort zones. We simply ask, 'How can I help? What do you need?'

"One of the most important things that I do (because I have walked in their shoes) is to educate them about what is meant by the term, mental health care. Typically people from the old country feel that if you need some type of mental health care, it means you are admitting that you are crazy and need to be locked away from your family. My job is to explain how good mental health care is part of good medical care and that you do

not need to feel afraid to ask for help.

"There are a few things that are not

working very well too. We live in a rural area and there is very little money for services. We have no support groups for example. The closest one is in Yakima but there is no public transportation to get there and if they did, they would not have any money to pay the fees. Many of our clients do have some form of insurance through Basic Health—for 12 mental health sessions a year. But the problem is that the professional criteria that are required by the

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*I was so grateful that I vowed to never, ever forget from where I came.*

# Creating a Culture of Recovery...for Children of African Americans

## Sekou Shabaka

Assistant Director  
WA State Division of Juvenile  
Rehabilitation

Interview by Jocie DeVries

In January 2006 I received an invitation to attend a Mental Health Youth and Family Forum from the Secretary of the Department of Social and Health Services (DSHS) at our state capitol in Olympia, Washington. The forum had been scheduled to create a time for DSHS leadership to take questions about the wide spread activities going on across the state to create a mental health system that is more directly responsive to the needs of consumers and families. I was genuinely impressed because in all my years advocating for children, youth and vulnerable adults I had never attended a public meeting where so many state policy makers were gathered in one place to listen. It turned out well from my view and I felt encouraged that the Secretary, Robin Arnold-Williams, had been willing to make her cabinet submit to questions from citizens, who by some accounts had been deeply hurt and disappointed from past interactions with agency personnel.

As Secretary Arnold-Williams introduced the DSHS staff, there was one man in particular who caught my attention, the Assistant Secretary of the Juvenile Rehabilitation Administration, Sekou Shabaka. When he introduced himself to the room full of families he told us what we wanted to hear. He didn't tell us about the distinguished academic degrees that he had earned, the prestigious titles or leadership positions he has held during his career or the world travel he had experienced; he told us about the ministry he was involved in at his church and the troubled children that he and his wife struggled to help. After the meeting I sought him out, gave him my card and asked him for an interview for FAS Times. He was cheerful, open and agreeable.

Sekou recently moved to Washington from the state of Virginia. However, this is not the first time he and his family have lived here. Previously Sekou had served in the Department of Corrections. He says he tried retirement in 2001 and moved back to Virginia but soon found himself volunteering

to help tutor children in the Ebenezer Baptist Church who were falling behind and dropping out of school. He eventually went to the school district to find out how minority students were doing and found out that minority students in the district were not doing well. For example, the drop-out rate was high, they were frequently suspended, and minority students were under represented in leadership, in the Honor Society and the other honor clubs. The statistics were just not good and he decided to get involved to see what could be done to improve the situation.

Sekou says, "We developed a grant proposal so we would have the means to provide support for African American students that would fit more comfortably with the cultural environment of their families. Our proposal was for the elementary and junior high students and it had three Head Start-like components:

- ◆ Tutoring in academic studies,
- ◆ Mentoring in social skills and
- ◆ Teaching the rights-of-passage into adulthood within the African American culture.

"To implement the programs we planned for support teams that would/could go into the homes to help kids. Many of the parents didn't realize that it was important to make sure that the children learned their basic colors, numbers and ABC's. The parents themselves needed to be taught basic parenting skills to know that their encouragement and support in these things could make a huge difference in their children's futures."

When asked where the passion came from that inspired these programs he began to share his own story. Sekou was born in Norfolk, Virginia and graduated from high school in 1956 at a time when all the schools were segregated. He attended an all black college in Petersburg whose professional staff were also black.

"The bad news was that the buildings in high school were all old and run down, we had old textbooks and there was never enough money to update any curriculum. The good news was that the college had an excellent, dedicated staff of teachers, counselors and athletic coaches who cared about you and would not let you fail.

"I was also fortunate to have parents

and grandparents who were well grounded and practical people who were spiritually, emotionally and mentally healthy up into their 90's--so I was the recipient of their nurture and wisdom for most of my adult life.

"This heritage served me well personally and professionally and gave me a passion to make sure that I give a rich cultural gift to the generation that follows mine."

To answer the question that is relevant to our subject, i.e., what's working in the mental health field today for African American children, Sekou chuckled and said, "Yes, you can tell I do have a strong belief system about how to develop healthy hearts and minds. My perspective comes from a combination of my own childhood experiences growing up as an African American child in an African American family, the academic training I received and the expertise I developed during my 40-year career. In short, I'll give you a five point synopsis to share with your readers:

"1.The first and perhaps most important factor is that children need to have self esteem as African American people. This creates a sense of empowerment within and helps them accept who they are as human beings--why their hair texture is the way it is, why they have broad, bold features and things like the significance of the color of their skin. They need to know these things so thoroughly that they are comfortable in their own skin and do not have a need to make excuses for who they are. When children are taught about this rich cultural history, it becomes a protective factor that prevents anyone else from defining them.

"2.The second and equally important factor is their connections with their families and the cities or towns where they grow up. This is their cultural foundation. I'm not just talking about the genetic family, but family as defined by who loves you and who cares about you. Because of the history of slavery, African American people have had to develop their own social support system to the point that now it's a tradition. Every child needs at least one person who is always available and for that to be so deeply engrained into the child's soul that they cannot abandon that heritage and tradition.

"3.Another factor is that every child must have a sense of community and know that in

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## Yvette Fitzjarrald

I was born in Juneau, Alaska, and immediately given up for adoption. Much later, when I found my birth mother, she told me that my birth father was a heavy drinker who had threatened to hurt or kill me if she brought me home. I think this was just an excuse, but who really knows?

My family, the only one I've really known, adopted me when I was four months old. I instantly had a brother who was three years older than I. Five years after that, my parents unexpectedly conceived and gave birth to a little girl.

So then I was the middle kid and became the "problem child," as middle kids are often known. We moved four times before leaving Alaska to move to Oregon so my dad could work in the building business. We lived in Oregon about five years. I was so sheltered there! I loved it. We lived in the middle of nowhere, literally. I had a dog, Pepper, who was my very best friend. My school was small—I had only eight other kids in my class! I was in heaven there, as much as a pre-teen/teen can be anyway.

Things really started to go my way in high school. One of my classmates, a boy that I liked very much, finally began dating me. Just when I thought things couldn't get better, my parents told me we were moving again! It was my junior year in high school, and we moved back to Alaska.

Alaska had changed. Well maybe it hadn't, but it seemed so. Hardly any of my old friends in school were sober. It wasn't that large of a high school but most of them smoked dope and drank, even during school. You do not even want to know about the weekends. Peer pressure took over, and I started doing those things too. I absolutely loved getting stoned. I always felt so giggly and goofy and relaxed when I smoked pot.

Drinking, I soon found out, was just as much fun—but dangerous too. I would get killer hangovers when I drank, and I usually threw up. Funny how, looking back, I can't imagine living like that, but back then it was all I lived for. I loved being high, being drunk—being ANYTHING other than my boring old self.

Soon after graduation, I met and later married my first husband. We moved to Oregon together where he started working as a mechanic. He was a drinker, much more

hardcore than I was at the time, and he got stoned a lot. It was a source of tension in our new home, where I knew that once you got married and "grew up" you stopped doing "those things." He also would hit me from time to time.

I quit drinking shortly after I learned that I was pregnant with my firstborn. Even with as little publicity as there was on the topic I knew, somehow, that alcohol could damage my unborn child. Making the choice to quit was easy. Doing it—living it—was difficult. But I did eventually abstain, with only a few relapses after I realized I was pregnant.

I didn't pick up the bottle again until my daughter was about five years old. At the time, reality had sunk in—here I was, married to an abusive man who didn't love me. Heck he didn't know the meaning of love anymore than I did—both of us were alcoholics! The feelings all came rushing back to me after that first sip, and I realized I had missed my old friend! It soon became a weekly occurrence. I'd go out on the weekend, without my husband—after all, we had a kid at home, so one of us would stay home to watch her.

By "going out" I mean I did all that "going out" entails—drinking and running around with different men. I was a whore to anyone who would buy me a drink. Sometimes I'd get clever and slip away toward the end of the evening before he realized that the girl he'd wasted all his money on was not going to go home with him!

Oh, my husband had his share of going out too. If I went out Friday night, he went out Saturday. And vice versa. He had his own life and own affairs, too. We just went on that way for about six years. Later, not surprisingly, that lifestyle led to a divorce, and I moved back to Alaska.

Unfortunately, I continued the lifestyle I'd come to know and love. My life was soon spinning out of control. A few times I got pulled over while drinking; I was not legally drunk the first time, so I never got a ticket. The second time I was only pulled over for going the wrong way on a one way street and the officer didn't do a Breathalyzer. I was surprised yet pleased, since I'd closed the bar and was way beyond legally drunk!

After two years of working, raising my daughter by myself (with help from my

parents), drinking and doing various drugs, I hit a new low. I began to contemplate sending my daughter to live with her dad. My reasoning...or lack thereof (due to drinking) was that I'd been raising her alone. Heck—he'd been having all this "freedom" to go party or do whatever, and I wanted that freedom! Without my little girl in the picture, I would be free to live as I wanted to live, party whenever, and not have to worry about anything else! It was the life I'd dreamed of...

Other things happened...getting pulled over was one of them...how embarrassing! I remember too, calling a cab because I figured I'd better not risk getting pulled over again. On the way home that night in the cab, I saw a couple walking a dog down the road. It hit me...they had a LIFE. I had...alcohol.

I said to the cab driver, "Why can't I just be normal?" I blurted this out without even thinking and he turned around laughing, and asked, "What's normal!?"

"Well," I said, "look at those people going for a walk. They aren't in a hurry to get to the bar!" He then invited me to an AA meeting!

Me? In AA? I didn't need AA! That's for...DRUNKS!

Just about that same time, I ended up getting pregnant. When I realized I had a baby on the way, I tried hard to quit drinking. I would go to the bar intending to drink just water or soda, but end up drinking alcohol. Or I'd say, "I'll just have one or two," then I'd end up having more than that. How many did I have? That's tricky...more than five drinks, but less than...twelve?

I finally went up to the Alcoholism Counsel offices. I took a test there, and I came out really low on the test. I mean the test has a graph that is shaped like a V; if you score on the left top of the V it indicates that you are not a "problem drinker." If you score down toward the bottom, you're a "problem drinker." A lot of things became clear to me, when taking the test. I ended up scoring down towards the bottom of the V.

I brought the test home and stuck it to my fridge with a magnet. I would look at it from time to time, and contemplate it. But I continued to drink alcohol, and smoke dope until I was about 4 months along. Then my best friend (who we think is the father of my son) got very sick, and began vomiting blood. He scared me badly, and I called the

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# Culture of Recovery...

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Gregoire and her staff to produce an FASD public service announcement for TV and radio.

- Continued collaboration with Dr. Glenna Andrews at Northwest Nazarene University on our FASD Behavior Screening Tool (BeST) to refine the items, test for validity and specificity, and write the administration and scoring instructions. After initial testing, a cut-off score with a 90% hit rate was established and results indicated a high correlation with scores on the Auchenbach, so it was copyrighted. It is now available for use as a screening tool on children age five through adults who do not have the facial dysmorphism of FAS. (Contact Ann Waller <ann@fetalalcoholsyndrome.org> or 425-466-1918 for more information.)
- FAS\*FRI collaborated with the Children's Administration, the Division of Mental Health and other consumer and family-run advocacy groups to develop a family-friendly screening tool called the Evidenced-Based Matching Tool. This tool helps to determine which one of five programs in the Children's Mental Health Initiative might benefit youths and their families who are in need of family preservation services. Due to FAS\*FRI's involvement, FASD is now specifically included in the screening process.
- Participation as a member of the Governor's workgroup on the Mental Health Transformation grant to assess and transform the way mental health services are delivered in the state of Washington.

We are thrilled to report that in the last few months, during the initial stages of Washington State's Mental Health Transformation project (announced in the 2005/2006 Winter issue of FAS Times) and through many of these collaborative activities, we have been able to make contacts and train key state administrators on the issues of FASD and co-occurring conditions. These key policy makers now understand that individuals with FASD are already in the mental health system and through screening, diagnosis and training for the mental health workforce, we can help them appropriately meet the needs of these individuals in a way that is fiscally sound. As a result, definite progress is being made toward changing service delivery within the state public agencies

to identify, understand and care for not only those who are mentally retarded (served through the Division of Developmental Disabilities) but also for those who have normal IQ levels and co-occurring mental health conditions (served through the Mental Health Division).

We certainly acknowledge that tragedy still exists in the world of FASD. In fact, we know several families who have been in catastrophic crisis in just the last few months and our hearts and prayers, mentoring and advocacy are with them. But because of the help of some really good people who were *teachable* in our own mental health system (namely the director Richard Kellogg with Steve Norsen and Mary Sarno) we have hope that at least in Washington State we are developing a Culture of Recovery based on the data gathered from the Collective Family Experience. It has been a long and sometimes discouraging road but we truly believe the best is yet to come. One thing that was crucial in this journey was meeting new friends and allies along the way for which we are very grateful.

We hope you enjoy the articles in this issue which illustrate and detail some exciting new developments and possibilities for creating a culture of recovery. ♥

## Creating a Culture of Recovery...through New Leaders

### Gov. Gregoire Appoints New MHD Director

In January of this year, Richard Kellogg was appointed as the new director of the Mental Health Division (MHD) for Washington State. When the legislative session ended in March and his schedule wasn't quite so hectic, we met with him to talk about the needs of children, youth and adult consumers of mental health services who have disabilities from prenatal alcohol exposure and other co-occurring mental health conditions. The purpose of our visit with him was three fold:

- Acknowledge and endorse the work of other mental health consumer and family-run groups in motivating both houses of the state legislature and the Governor's office to fund and redesign this vital service delivery system through the Mental Health Transformation Project;
- Present the Collective Family Experience on FASD and co-occurring disorders that FAS\*FRI has gathered since 1990; and
- Ask him to consider bringing us to the negotiation table with other mental health consumer and family-run mental health advocacy groups.

A few months later we asked him for an interview for FAS Times. He readily agreed. When asked what motivated him to get into the field of mental health, he said, "It just seemed to me that people who have disabilities and mental health conditions have the right not only to treatment, but to receive the care they need with dignity. And I felt I wanted to do what I could to make sure that those civil rights were honored."

**What factors motivated you to take this job in Washington State?** Well my

wife and I were looking for a new challenge that would also provide a good place to resettle and raise our children. When we visited Washington State, we were taken by the beautiful mountains, lush evergreen forests and the beauty of Puget Sound and thought it would be a healthy place for our children to grow.

As far as the job is concerned, I was encouraged at the forward thinking and work by the advocates for the mentally ill in Washington State, the interest and fiscal support given to MHD to respond to the President's New Freedom Report in transforming the current system of care and the leadership of Governor Gregoire to make sure that Washington State was on track with the federal mission to create a system of care that is consumer and family driven. I wanted to be a part of the process. For example, the recent legislative mandates include directives to the Division to:

- Modernize clinic services into either:
  1. Evidence Based Practice
  2. Promising Practice or
  3. Emerging Practice.
- Review and make recommendations to improve aspects of involuntary treatment
- Develop and implement eight programs of assertive treatment/PACT teams.
  1. Each team will have 10 – 14 staff members including a psychiatrist, psychiatric nurse, psychologist, social worker, and case managers/support counselors.
  2. Each assertive treatment team will have a case load of 80 to 100 consumers who are at risk of psychiatric hospitalization
- Case managers will have a case load of 8 to 12 consumers. Their task will be to provide services and support 24/7 to meet crisis needs to prevent hospitalization.

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## Creating a Culture of Recovery...for Native Peoples

### Carolyn Hartness

FASD Consultant/Educator

In the early 90's, I worked as a Drug and Alcohol Prevention Specialist at United Indians of All Tribes Foundation's youth program, I Wa Sil. My position was funded by Seattle-King County Health Department. I taught parenting classes; coping skills to third and fourth graders living in alcohol- and drug-using homes; interacted with youth at the drop-in center in downtown Seattle; and facilitated a group for Native youth incarcerated at Echo Glen, Washington's juvenile detention center.

The goal was to help Native youth and their families understand the negative impact that alcohol abuse had on their lives. Many youth were of mixed blood and had identity issues relating to themselves as Natives. Major components of the therapy and education sessions were to introduce them to positive Indian role models, the truth about Indians' contributions to the advancement of our country and development of a positive sense of themselves as Indian people. The curricula helped them establish pride in their heritage through cultural activities such as the talking circle, powwow and sweat lodge.

We knew there was healing at Echo Glen when the older youth created a Wisdom Council, made us advisors (instead of leaders), and decided that new members had to be voted into the circle. This was the result of a powerful and healing talking circle the week before that allowed for deep disclosure and bonding between the youth.

In the school district, we changed from a curriculum to build coping skills (which was not culturally appropriate) to the talking circle and other activities to emphasize Native values and pride.

The parenting classes were part of the Huchoosedah Indian Education Program, a Native American cultural program in the Seattle School District. In the context of beading and talking circles, we were able to break through the silence of mistrust, denial and shame and talk openly about the reality of the families represented in our circle. Most of the people in attendance were grandparents raising grandchildren due to the parents being involved in alcohol and drugs.

As you may know, Indian people were severely traumatized in the late 1800s and early 1900s when the U.S. government

implemented a misguided "integration" policy. A generation of Indian children were removed from their families and reservations and taken to "Indian" boarding schools where they were taught to live, talk and think like the white man. This policy was very harmful to our people individually and to our cultural roots because children were not allowed to speak their Native tongues or be reared with their families in their cultures. So an entire generation grew up to become parents without Native role models to imitate.

Alcohol and drug abuse in Indian Country is a natural result of historical trauma. There are many negative outcomes: denial, shame, blame, grief and hopelessness. The stigma against mothers who drink during pregnancy is especially difficult for Indian people. However, culturally appropriate education can give them an intellectual and historical context so they can understand the origins and consequences of alcohol use in our communities, such as FASD.

After several months in this position, I was asked to address FAS in my curricula. I asked, "What is FAS?" I had never heard of it. When I learned what it was, I realized I had been looking into the face of FAS every time I went to Echo Glen, entered those elementary school classrooms, talked with kids at the center and even in the parenting circles.

My heart and spirit felt broken. What did this mean to the past and future generations? I began to see and learn about the

at large. Fortunately, many Indian tribes and organizations are contributing to these efforts through the development of prevention programs and culturally appropriate intervention strategies. There are many curricula, posters, brochures, and videos produced by and for Indian people.

All professionals know that mental health care is a vital part of good medical care. The problem is that FASD primarily affects brain functioning in terms of learning, behavior, and mental and emotional processing so it doesn't look like a mental health condition. It is estimated that only about 5 out of every 100 of those with FASD have been diagnosed.

However, even with a diagnosis, "mental health" interventions are rarely available for affected individuals. This situation is grave. For example, I just read that the current budget proposal from President Bush will cut 17 of the 34 urban clinics for Indian people, including the largest one in Seattle. The White House, according to the news, claims urban Native Americans can seek health care at other types of facilities; but health care advocates, backed by key members of Congress, say that is highly unlikely. If this happens it will decimate the availability of health care for Indian people who no longer live on the reservations. These urban clinics are currently the only resource for dental, medical and mental health services for our people. The results will be disastrous.

For the past six years, I have been working with Suzanne Kuerschner, M.Ed., (a child development specialist with intensive

*...even with a diagnosis, "mental health" interventions are rarely available for affected individuals. This situation is grave.*

patterns of behavior that were unique to FAS and how many youths and their families were being impacted.

This began my journey into FASD. When we began teaching the dangers of exposing unborn children to alcohol and other drugs, everything changed. Consequently, I went back to school to increase my knowledge of chemical dependency because I was beginning to see how it influenced physical and mental health.

Preventing FASD in children involves an intergenerational effort in Indian Country, and collaboration with education, the justice system, social services, medical and mental health providers and communities

training and experience in FASD) on a grant through the Northwest Portland Area Indian Health Board. We are working with tribes in Washington, Oregon and Idaho and are in partnerships with Indian Health Service, University of Washington FAS/FAE Legal Issues Resource Center, University of Washington FAS Diagnostic and Prevention Network, Oregon State Department of Mental Health and Chemical Dependency, Washington State Governor's Office of Indian Affairs, Idaho Native American Families Together (project for advocacy for children in special education and parents), the FASD Center for Excellence, SAMHSA,

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## ...CD Treatment

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alcoholism counselor.

I was on the phone telling her how he needed to get help. But she asked me, "Have you ever considered getting help...?"

I began to cry and I said, "I do need help."

She immediately made arrangements for me to enter a treatment facility, and I did. That was December 28th, 1991.

I've been sober ever since. I still miss drinking at times. Living wild and free, with no accountability towards anyone. Being able to immerse myself in alcohol and just forget...Drinking is just taking a break from reality. Numbing yourself from the pain of life. For me, drugs and alcohol were the only way to kill the pain.

But I know that if I were to relapse, it would probably kill me. Even if I survived initially, it would be a slow form of death. I'd lose everything that is important to me. Knowing that is enough to keep me sober.

Soon after I got sober, I began to experience pain that I'd covered up while drinking. Things that I'd buried came surfacing up like a drowned body on a warm day...ugly things that hurt me deeply when they happened; but I'd been able to hang on and get to my best friend, the bottle, drink to numb the pain, bury it and forget it.

It hurt badly, and I would cry and call my counselor many times. She would talk me through it.

I survived. I felt tattered and torn when these painful

...we have to make the best life we can for our affected kids.

things would come up, but I got through them. I'm here today to tell you that you can get through it too.

My precious son, who is now almost fourteen years old, suffered and continues to suffer, due to my drinking while I was pregnant with him. Three years ago he was diagnosed with an alcohol related disorder. He has also been diagnosed with ADD, which is secondary to his alcohol exposure. He is very difficult to deal with at times. He has also been diagnosed mild CP (cerebral palsy), an anxiety depressive disorder, and OCD (obsessive-compulsive disorder), and most recently, Partial Complex Seizures. Kids with FASD often have multiple diagnoses, and Tyler is no exception. Parenting

him can be an arduous task.

I've somehow managed to get through that process, and I continue to fight for him today. I'd like to think that by my being open and willing to talk about my life, our story, I am able to help others who are facing similar situations.

When I was 21 or so, I located my birth mother. I found out that my father had passed away, a victim of alcoholism himself. My birth mom is still alive, although we are not in contact at this time.

As far as I can tell the odds are good that I was exposed before my birth to alcohol myself. By getting sober and teaching my own kids about the dangers of drinking while pregnant, I hope I am able to break that generational cycle. It is my dream to see Fetal Alcohol Syndrome and it's related conditions eradicated from the earth. Since we definitely know what causes this birth defect, it doesn't seem like such an insurmountable task.

An important protective factor for guarding against relapse is having a strong support system, made up of friends, family and a spiritual life. Sobriety consists of learning new coping mechanisms so that when those uncomfortable and painful feelings come upon us, we can deal with them instead of continuing to drown them.

One of the things I enjoy most is helping people. I believe that when people go through rough times in their lives, they are being shown how to help others and learn to have empathy for those in similar situa-

tions. As a recovered alcoholic with 15 years of sobriety, this is important for me to remember.

*It is painful to talk about how my son has a birth defect that I myself caused. It makes a lot of people uncomfortable, especially those who won't take the time to get to know me and those who become hostile to think that I harmed my child. But I won't stop talking about it—you know why? Because the people I've helped far outnumber those who can't accept me for who I am and what I did.*

If you look at the surface, I'm an awful mother—I drank while pregnant! But I also got sober while pregnant. And I am raising my children to be sober, and to say NO to drugs and alcohol. I'm fighting for my son in school to make sure they give him the education he deserves.

I'm just a human being, like you are. But all of us touch lives in ways we can't always comprehend simply by BEING THERE...by following God's prompting, sometimes without knowing why we are doing it. Those are the moments when we are all heroes!

I didn't believe this, until I started hearing from people who needed and wanted to hear what I had to say. If you would like to read more, see my website at <http://members.aol.com/Alphamom33/birthmom.html> ♥

## ...Mentally Ill

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receiving help and treatment," Bloss said.

Parents at Wednesday's hearing talked of the frustration of not being able to get proper treatment for their children or grandchildren with mental illness. Some committed suicide. Others were left to suffer.

One parent talked of losing his daughter after she walked into traffic at a busy Everett intersection and was struck by a car.

Mariska Alexander works at the Darrington Family Support Center, part of Deaconess Children's Services. Mental health services are badly needed in rural parts of the country, including Sultan, the Skykomish Valley, Granite Falls and Darrington, she said.

"If you don't have private-pay insurance and don't have transportation, you're not able to access any mental health services," she said.

Lisa Osborn of Everett, who has a child who suffers from psychosis, talked of the need of families with children with mental illness or other special needs to receive respite care. Such care provides someone to look after the children briefly to allow parents a break.

"Parents of kids with special needs are desperate for respite," she said. "There's nothing out there."

Darlene See of Camano Island said she has an adult child who has been mentally ill for 30 years.

"Mental illness is not a 9-to-5 illness," she said, "It's 24-7."

Most parents "have no idea how to handle this," she said. "I'm just coasting in the dark about how I can help him." ♥

## ...Changing Field

Continued from page 3

here, whether or not the foundation should get interested in it. And people like Tom Insel, head of the National Institute of Mental Health, are going to participate as evaluators.

**No one has ever conducted studies like this?** It has never been done systematically. We would like to consider doing it on a larger scale, maybe having several universities studying patients with different diagnostic categories to see how a controlled psychotherapy trial produces psychical brain changes as a result of treatment.

**Why has no one used imaging techniques to study psychotherapy before?** The field is very young. It's only recently that people got confident that psychotherapy under these circumstances works. The imaging methodology is relatively new, and the resolution is not that great yet. *We need biological markers for each mental illness in order to see whether or not they can be reversed.* [Emphasis mine] So there are lots of technical problems. You know, our understanding of the mind is at a very early stage. These are the most difficult problems in all of biology.

**Which illnesses might be considered for study?** Primarily obsessive-compulsive neurosis and anxiety disorders, such as post-traumatic stress disorders.

**When did you first begin questioning psychotherapy?** I guess when I was at the National Institutes of Health and when I came back into my psychiatric residency, which was in the 1960's. I was 30 years old. I was training as a psychiatrist. I had a personal analysis as part of my training. But it was not my personal analysis that caused me to question it. I actually benefited greatly from it. It was the fact that psychoanalysis as a discipline was not becoming scientific.

**What do you think of psychotherapy these days?** Well, it is a little chaotic because there are lots of competing therapies out there. We might want to compare modes of therapy. I mean, who knows which is best? It's possible that you might benefit from one and I might benefit from another. The different kinds of patients, different kinds of disorders, might be selectively treated by one kind of psychotherapy versus another. But that, I think, requires an independent standard for

evaluation. And I think imaging might be one of the tools that provides that.

**Do you think that some of the therapies are problematic?** I have no way of knowing that. I think it's problematic that people have not gone to the trouble to study this.

**Has the psychology-neurobiology split hurt patients?** I think that psychopharmacological treatments have revolutionized psychiatry. On the other hand, I think anyone practicing psychiatry realizes that drug therapy is very effective but not perfect, that there are some patients who don't benefit from it, that there are some patients who benefit from drugs together with psychotherapy, and that in some cases psychotherapy by itself works. There was a time when psychoanalysts wanted nothing to do with biology, and biologists didn't want to touch psychoanalysis. That's changing. Now we need to have a systematic approach to the psychotherapeutic component of treatment, just as we have to the psychopharmacological aspect of treatment. That has not been done. What the Ellison foundation and I are hoping to encourage is a more holistic approach to psychiatry in which psychotherapy is put on as rigorous a level as psycho-pharmacology.

**What does a psychotherapist need to know?** First I think that people working in psychiatry should have a background in neuroscience, because psychiatry is in fact a form of clinical neuroscience. Second, that insofar as there are psychotherapies that are made available to patients, they should be shown to be effective. I am proposing a demanding criterion: that you be able to detect abnormalities in patients beforehand by such brain imaging techniques as functional MRI (which measures blood flow in the brain), and then use imaging to see whether or not there is a change in those markers for the disease as the therapy progresses. Therapists need not necessarily use the insights of biology in the therapy but they should be aware of what the [indicators] are, have their patients imaged and be able to follow the outcome.

**Has any recent research in neuroscience surprised you?** Oh...there are lots of things. For example, the study of decision making in the brain by people like Paul Glimcher is very interesting. William Newsomes's work on the importance of value in decision making.

Giacomo Rizzolatti's work on empathy, on how monkeys copy one another is of profound significance. The work on smell by Richard Axel and Linda Buck is extremely interesting. I think the work on the molecular basis of sociological phenomena by Tom Insel and Cori Bargmann is very interesting. And Tom Jessell's work with neuronal networks is extraordinarily important. Sten Grillner's work on the workings of complex neurocircuitry is also of extreme importance. I would say the progress in understanding motor systems, the cognitive role in motor systems is a brilliant advance and has revolutionized our understanding of how the nervous system is wired.

**Does the research trickle down to therapists?** Yes. I would think that residents in psychiatry should be trained in neuroscience, like residents in neurology are. And this is happening. In fact, I see them as being sort of interrelated disciplines. I mean, the modes of therapy are different, and the character of structure of the practitioners is different. But they are both treating the brain as an organ that is the target of disease.

**But that isn't really happening, is it?** I don't think that's fair to say. Fields move slowly. It's happening. Nothing happens as fast as I would like it to. Even Discover Magazine doesn't publish things as rapidly as I would like it to! (laughs)

**What are the big unanswered questions in neuroscience?** I think we need to understand how sensory information is translated into action. We need to understand how unconscious mental processes develop. Where do they occur? What are the processing steps? What is the nature of decision making? Of free will? Can we get a vantage point on consciousness?

**How close are we to understanding consciousness?** I think we have not made much empirical progress. But I think we have made a fair amount of conceptual progress. The work of Gerald Edelman and Antonio Damasio and of Christof Koch and Francis Crick has been influential in getting people to think about these problems in a useful way.

**What do you think researchers will find consciousness to be?** Oh...I have no guesses. I think it's a very deep problem...♥

# FASD: Survey Results from Consumers & Families

When we learned about the statewide survey of consumers and families sponsored by the Mental Health Transformation Project, we at FAS\*FRI immediately made plans to send the survey questions out, so adults with FASD and parents of children with FASD would have an opportunity to have their voices heard about the state of mental health services in Washington State. To those of you who participated, we want you to know how much we appreciate your response. Each time you reach out and share your experiences you are adding vital information to the Collective Family Experience data base. Below is a summary of the questions asked and the varied answers that were shared. (Look for more in our next issue.)

## What's working?

- When parents educate a counselor or therapist about FASD and how it presents itself in their children and the counselor stays with the children/family in a long-term relationship.
- When the affected person has an FAS or ARND diagnosis, the co-occurring disorders are known and associated interventions are appropriate and he knows that his disability is respected, along with being allowed to be as independent as possible. This type of support and intervention produce a child with a good healthy sense of self-confidence and self respect.
- Nothing.
- The DDD program which supports parents as care providers for their adult children.
- Constant supervision works, but it is a terrible strain on parents and siblings.
- When we have medical care and mental health care working in collaboration.
- Residential care for those with severe neurological damage to replace the 24/7 supervision that parents have been providing. These programs provide peer-to-peer anger management, counseling and educational transition via life skills, at sites like Northern State Hospital, Western State Hospital or independent service delivery agencies that contract with the state MH agency.
- Getting an FAS or ARND diagnosis makes things slightly easier.
- When systems actually do communicate and coordinate services.

## What's not working?

- 24/7 supervision is typically necessary and supplied by isolated families; when the child/youth or adult descends into a behavioral crisis there is nothing available in a timely manner. Broken families, kids placed back into foster care, running away without any way to get the youth back home—in these situations there is nothing available but jail or psychiatric placement and that's a more restrictive environment than they typically need.
- The wrap-a-round system which brings the affected child and family into public disclosure or deep and sensitive discussions of medical problems with professionals or paraprofessionals who are not trained on the FASD core behavioral phenotype but who are gatekeepers of funds for services.
- Professionals who are not being trained that conditions such as FAS and ARND are medical conditions which do not get better with talk therapy. The workforce has not been trained on the FASD core behavior phenotype and on how to differentiate between those behaviors and co-occurring mental health conditions. Consequently, medications are being pushed onto kids and families by mental health professionals who are not equipped to know what they are doing.
- Individuals with FASD are typically undiagnosed and consequently not understood as having a medical condition (neurological brain damage). Because the mental health workforce does not know or understand the FASD behavioral phenotype, gatekeepers in the various systems such as Developmental Disabilities, Education, Mental Health, Chemical Dependency, SSI and Medicaid do not know that an inability to understand and follow rules is a direct manifestation of the disability and is not necessarily willful. So they are kicked out of what could be effective programs for deliberately breaking the rules when in fact, it is because they are cognitively disabled.
- Those with FASD and co-occurring mental health conditions who are chemically dependent do not have access to appropriate treatment and are using residential treatment sites for housing alternatives

when the weather is bad and they can't figure out how to get services any other way.

- Chemical dependency treatment for adolescents with FASD and co-occurring mental health conditions is not available.

## What would the ideal mental health system look like?

- The social service workforce, such as the professionals in mental health, juvenile justice, criminal justice, education and chemical dependency treatment, would be trained to recognize the core behavioral phenotype of FASD.
- A consumer or parent would be able to access care in an emergency without all the red tape and hassle—without forms, paperwork and home studies being done over and over and over again. Families with children who have other medical conditions such as Down Syndrome are treated with dignity and respect instead of being scrutinized as being part of the problem and banished time and again into personal therapy for being a bad parent. FAS and ARND are physical [neurological] problems which are expressed through atypical behavior which can be mistaken for laziness, lack of discipline or rebellion.
- Consumers and families would be able to access crisis services as they are needed instead of having to wait 3 to 4 weeks for a phone call to be returned. This delay is a severe risk factor in parental burnout and puts the child at high risk of having to be placed in a [therapeutic] foster home or inpatient psychiatric care.
- Appropriate mental health care would be available and individuals with FASD and co-occurring mental health conditions would not have as many suicide attempts.
- A clubhouse system would be readily available for adult and adolescent consumers to have natural support socially, in therapy and mentoring, a place to hang out and have a bite to eat and for job and housing information.
- Job coaches through the Division of Vocational Rehabilitation for consumers with FASD and co-occurring behavioral conditions, who would not abandon them

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## ...Migrant Workers

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insurance companies are of such a high standard that there are no providers who live in our area. I don't know why the state did away with the sliding scale standards to access mental health care, but that is the current policy and it has greatly reduced the availability of migrant workers to access appropriate care.

"Other things that would increase the efficiency of my job would be:

◆ Increase public awareness about the definition of mental health care. These messages need to be in Spanish so the people can hear about it in their own language.

◆ Streamline paperwork. Over 60% of my time is spent on paperwork. That means I only have 40% of my time to see clients.

◆ Increase the availability of prescription coverage. For instance, many of my clients are depressed and they often drink alcohol and take methamphetamines or other drugs as a way to self medicate. This is not good for the parents and it is especially not good for unborn babies." ♥

## ...African Americans

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life you cannot stand alone. We all need someone to embrace us—a conviction of 'I am because we are.'

"4. African American people are deeply spiritual people—not necessarily in formal religion although that's important. It's just a part of who we are and our children need to be reminded of the significance of their souls. They need to be made aware that it's a natural tendency inside each of us—a belief in truth, justice, order and peace that centers you and gives you a passion to pass that heritage on to others. For example, my 96-year-old grandmother reminded me my entire life of the importance of these things and created in me the need to pass on this great heritage.

"5. When things get rough in life these are the things that center me and keep me going. My grandmother was charitable and we as African American people are charitable. Our children need to know that it is their job to give back. She used to say to me, 'Sekou, you are no better than what you give back.' Her philosophy is what keeps me sane in a troubled world."

Mr. Shabaka recommends the following two books for further reading:

◆ Post Traumatic Slave Disorder Syndrome by Professor Joy D. Leary at Portland State and

◆ Black Psychology, a textbook written by 20 to 30 psychologists and social workers, which explains what are normal African American mental health standards. ♥

## ...Native Peoples

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National Indian Justice Center, and the Skagit County FASD Juvenile Court Project including four tribes: Sauk-Suaittle, Upper Skagit, Swinomish, and Samish.

These tribes have identified strengths and issues in their communities relating to FASD and are continuing to work toward implementing collaborative family services, developing task forces and diagnostic resources. Our goal is to increase healthy outcomes and reduce the risk of producing babies with FASD by providing referrals, diagnostic services and single-source case management.

We offer community training and encourage collaboration from a non-judgmental perspective and "willingness" of participants. Collaborative partners include health education and professional service providers, spiritual leaders, elders, community members and family advocates. It is important to develop global prevention and intervention strategies from the contextual understanding of issues of grief, hopelessness, shame, blame and denial surrounding FASD.

It is also important, as Suzie Kuerschner's manual title directs, to go "Beyond the Gloom and Doom" and look at FASD as an opportunity to change what does not work for our children. Our prophecies tell us that these children have been sent to us to show us what is wrong with our society.

Obviously, if you ask about how to transform the Washington State Mental Health System from the viewpoint of Indian people, it is not looking very hopeful, but using our knowledge of alcohol's impact on our society and the strength of individuals, families and communities, we can create a better life for the next seven generations. ♥

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## Survey Results...

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for getting kicked out of a job.

- Schools would have available mental health resources which would/could help transition them into life skills programs starting at 14. In order to do that, mental health care would need to be available in the early grades instead of allowing a child's mental health and self-esteem to deteriorate until he/she drops out of school as a "bad and uncooperative" student.
- Residential care, which would include good medical and mental health care, would be available as needed.
- Coordination and communication between professionals would be a natural thing.
- Nurse Practitioners would be trained to help and support consumers and their families.
- Safe housing options would be available for adult consumers.

### How will you know when the mental health system is transformed?

- The mental health workforce will be trained to identify the core behavioral phenotype of FAS, ARND and co-occurring conditions.
- Respite care and/or mental health supervision and support will be actually available and accessible during a crisis.
- Public awareness about where to go and what to do will have risen to the level that when consumers or family members have a crisis, they will know who they can call for immediate help.
- Consumers or family members will have mental health therapists who are consistently available to them over the long term.
- Those with mental illnesses will have enough housing, residential care and appropriate treatment so that they are not just warehoused in jail and prison.
- The number of people who are living on the street will be diminished.
- The basic workforce in schools will have enough training to understand that students with FASD and co-occurring conditions need treatment instead of being repeatedly suspended and/or permanently expelled.
- Families will have enough support services so that when a crisis arrives, they won't have to take off work and jeopardize their employment. ♥

## ...New Leaders

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- Each team must reduce the use of 20 state hospital beds by the end of the second year of implementation.

The other thing I thought was unique was the Mental Health Transformation process that the legislature and governor convened, with the realization that what was needed to start the process was a large-scale effort to get public comment on the state of mental health services in Washington. They had the wisdom to understand that the mental health division does not typically have the fiscal resources to initiate a large-scale effort to access comment on what citizens want, and need, i.e., their concerns and complaints. Consequently a method was funded to accomplish that goal by:

- Setting up and conducting various town meetings across the state,
- Collecting and assembling that data through sub-committees that are at least 51 percent consumers and families,
- Analyzing the data collected and organizing it into themes,
- Developing recommendations and outcomes from that data,

- Creating strategies to produce the outcomes folks want and
- Designing an evaluation component so we can find out when and if the outcomes are being met.

I understand that any large-scale plan has flaws. But if we want to move forward, we have to believe that we can succeed. I saw this statewide collaboration as a positive endeavor and one that I wanted to join.

**We have talked to you several times about those with FASD and co-occurring conditions that are already being served in MHD. Now that you've had a chance to think about it, how do you see FAS and ARND fitting into the Mental Health Division?** Well first of all, you folks have convinced me. [chuckling as he spoke] I can see that ignoring FASD is not helpful. The

division is obviously serving folks with FAS or ARND and co-occurring disorders, especially those who have IQ levels that are in the normal range. You've also helped me see that the division may be spending money trying to get rid of behaviors that have an organic root cause. The presentations that you gave us brought us on board as you know and we look forward to your help in learning how to distinguish the FASD behavioral phenotype (identified by the Collective Family Experience) from other co-occurring conditions. Your efforts have moved this issue not only into our awareness, but also to the [discussion] table of how to provide more appropriate care and care with dignity not only to vulnerable consumers but their families and advocates as well. We look forward to working with you toward that goal. ♥

### ***FAS Times Available Via the Internet!***

We are now posting FAS Times on our website at [www.fetalalcoholsyndrome/publications.html](http://www.fetalalcoholsyndrome/publications.html). If you send your e-mail address to [vicky@fetalalcoholsyndrome.org](mailto:vicky@fetalalcoholsyndrome.org), she will remove you from our hard copy mailing list and notify you when a new issue is posted. However, if you prefer to continue receiving a hard copy, we request (but do not require) an annual donation of \$20 (US funds) to help us keep up with the ever increasing costs of printing and mailing. Thank you for your faithful support. Your donations help cover the costs for families who may not have the funds to send.

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