

an educational
newsletter for
people concerned
about fetal alcohol
syndrome (FAS)
and fetal alcohol
effects (FAE)

■ ■ ■

because the
problems we
readily see
are only the tip
of the iceberg



System of care reform: *Implications for fetal alcohol spectrum disorder*



by Charles Huffine, M.D.

Unending challenges wear down many families raising children with fetal alcohol syndrome disorder (FASD), or related conditions involving the neurodevelopmental consequences of fetal alcohol exposure. Some families find ways of coping, but many families don't and are overwhelmed as the family seems to become unraveled. Within communities that have support groups and advocacy organizations for FASD, parents have learned the benefits of coming together as a community of people who can understand and support each other.

In the larger arena of children's mental health, many other families have suffered similar frustrations and despair. Few understand their problems. They become isolated from family and friends and accused of being either too indulgent or too hard on their kids. Even the professionals don't seem to grasp what it is like to raise a child with severe mental health problems.

Services for children whose problems involve many aspects of the system of care are rarely well coordinated.

- When a child is involved in problems at school, in the community, at juvenile court, and is going to counseling and drug and alcohol treatment,

how much time can a parent spend transporting a child to various agencies, and how many meetings can the parent be expected to attend?

- When each service provider seems to have his/her own idea on how to manage the child, which advice does the parent follow? These are the types of issues that have affected many parents raising seriously emotionally disturbed youth and have led to some new thinking about how our service system should be organized.

Teams are composed of those closest to the family.

System of care reform

In the mid 1980s Congress passed a law establishing the Child and Adolescent Service System Program (CASSP) as many reformers were documenting the gaps in the service system. This initiative pioneered a concept of "system of care reform" (SOC reform), which has evolved into concepts such as wraparound process, parent empowerment, and system coordination.

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System of care reform

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The Robert Wood Johnson Foundation and the early CASSP initiative began to experiment with these concepts by way of grant programs. These gave rise to a number of interesting experiments on better ways to serve youth with multi-agency involvement. The Center for Mental Health Services (CMHS), a federal agency responsible for the development of service systems for those with mental illness, has offered an enormous grant program over the last seven or eight years. CMHS is a component of the Substance Abuse and Mental Health Services Administration (SAMHSA) and is found on the Web at www.samhsa.gov.

These children's mental health initiative grants, offering communities a million dollars a year for five or six years, have begun to set in place these new concepts. Some of the most troubled children in U.S. communities have been served by the seventy or so such grants. Some of these children have problems secondary to prenatal alcohol exposure but have never been diagnosed. The mental health field has often failed to emphasize that damaged brains are a core part of some children's behavior problems and, if recognized, have few ideas on how to treat or manage such problems.

There are many children among those served by the grants whose difficulties are in part determined by fetal alcohol. Many of their families and caretakers, who know these children best, are valued by the professionals for their practical wisdom. The models of care embraced by SOC reforms work best when they offer the best of professional evaluation and treatment mixed with the practical common sense from family members who have become experts in managing their involved family member.

The elements of SOC reforms are taken from the values and principles of the original CASSP concept paper and mandate that services be family centered,

child focused, community based and coordinated, and culturally competent.

Family centered care

The principle of family centered care stems from the recognition that as families feel more frustrated and helpless in caring for very difficult children they rely more on service systems and professionals to handle crises, to advise on the nature of the services, and to be of support. Consequently, families feel more inadequate to deal with their child and give over ever more control to caregivers. Caregivers, also overwhelmed and feeling unsuccessful in their roles, begin to blame families.

These dynamics are subtle at first and are rarely extreme, but over time, families become even more helpless and dependent and feel as though their children belong to an agency of the system of care. They feel disempowered. Empowering families to take charge of their children is a primary goal of the SOC reforms.

The chief mechanism for family empowerment is the formation of child and family teams. These teams are different from treatment teams organized by a lead clinician. In the pure model, there may be only one professional staff on the team—the care manager—who provides a bridge to all professionals involved with the child. The teams are composed of those closest to the family or important members of its community. The team leader is the parent(s) when the child is young or severely disabled. It may be the child himself if he is older and has little or no support from a family, or the leader role can be shared by a youth and his parent(s). A child's grandmother or uncle could be on the team as well as close family friends, neighbors, or coworkers.

Some teams will invite a person in the community who may not have known the family well but has provided some support and has shown interest in the family's situation, such as a store clerk or hair dresser. A minister, rabbi, or priest may be involved, or a coach, teacher, or community leader. Key members of such teams may be family advocates—community

members who have had similar experiences to what the family is going through and can provide practical support and advice. In the case of an older youth, peers may constitute a major role on a team. Some families may feel very close to a particular caregiver and ask that he/she be part of the team.

The general rule is that teams should have fewer than half professionals but always have one professional serving as a “committee staffer.” Teams may be three or four individuals, or they may have ten or more. Larger teams may be cumbersome, but they offer the advantage of access to a larger network of support. The family, surrounded by such an active and organized cadre of supporters, can better face the many problems and crises that arise daily. In time, families can begin to plan for ways to take care of their children that are more grounded in the realities of their lives and that fit their unique family and community culture. This is the key element of a “wraparound process.”

Many incorrectly think that a wraparound plan involves adding ever more professional services to a child in a community setting. That may be part of the process, but fundamentally it is about grounding whatever plan emerges for the child in the realities of the family’s and community’s life. It seeks to actively involve the family with its community of extended family and friends and to develop solid connections with community-based institutions such as schools, sports teams, youth centers, and churches. How to do this with a family that has become isolated and hopeless is a skill that is taught and promoted by the technical assistance programs of the CMHS grants.

Family empowerment can be measured with instruments that have been studied and proven valid and reliable.

Child focused care

In SOC reforms, child centered care refers to the necessity of treating each child as a unique individual. The key is to understand the child not as a bundle of problems or pathology, but as an individual with strengths, hopes, capabilities, and needs. This strength-based approach assumes that the services to the child transcend a clinical approach or a social service approach. It becomes the challenge of the child and family team to identify the youth’s strengths and find means to support and promote these. It is the emphasis on strengths that allows for a de-emphasis on pushing a child or adolescent to do or be something that they can’t. It helps teams steer away from “cookie cutter” programs where one size fits all.

Parents raising children with FASD know that their children have very different capabilities from many of their peers. Families come to forgo dwelling on what their children can’t do. But this in no way precludes defining what a child or adolescent may need in order to proceed with honing strengths. These needs may indeed be defined as clinical or other service needs, thus providing a segue into finding necessary services such as linking with a psychiatrist who can provide much needed medications or a tutor who can help the child learn in his unique way and at his pace.

When practiced well, this strength-focused element of the wraparound process can change a dispirited family into a team that has clarity of direction and a vision for a positive future. The measure-

Circles of Care

Grants were awarded to tribal and urban Indian programs this year to develop a culturally appropriate mental health services model for American Indian/Alaska Native children with serious emotional disturbances and their families. The “Circles of Care” program is a collaborative effort to develop a model to meet tribally determined desired outcomes.

To learn more about the Circles of Care program on the Web, go to: www.mentalhealth.org/cmhs/childrencampaign/nativeamerican.asp.

For more information on systems of care and cultural competence, call CMHS at 1-800-789-2647.

ment of community connections and the meeting of needs have also been described by some grant programs. Such a child-centered approach is defined as a “best practice” by the technical assistance programs of the grants.

Community based and coordinated care

It is a goal of the wraparound process to shift in time from surrounding a child with professional services to using more normative

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Mo'Angels is makin' a difference

by Jodee and Liz Kulp

At twelve year's old Liz and I sat in a psychiatrist's office as we were handed the "sentence." "Liz has fetal alcohol—permanent brain injury. It means she can learn to do the wash, but not fix the washer." Since then she has broken the washer, but she has fixed the dryer with an appropriately placed kick. She has also rewired her phone system so she could talk secretly after we parents were sleeping. She has no idea how she "fingered it out."

At thirteen, she announced she was writing a book to tell the world about fetal alcohol. It didn't matter to her that she could hardly write a sentence and did not understand how to write a paragraph. Six weeks of hard work and a two-inch stack of recipe cards churned out her portion of "The Best I Can Be: Living with Fetal Alcohol Syndrome or Effect."

Liz laboriously wrote a paragraph a day, each page of her handwriting taking almost thirty minutes.

At fourteen, Liz dreamed of winning the \$10,000 Tiger Woods Target Foundation Scholarship so she could speak with me in Australia on fetal alcohol. Liz completed her goals and developed a group of teen girls to help her "Make a

Difference" in fetal alcohol awareness. The group accompanied me to conferences and joined me in presentations. Liz came up with a strategy to encourage understanding by turning the audience into kids with FAS/E. Liz spoke to parents and professionals about what it is like having FAE. Her friends explained what they do to maintain a healthy friendship with Liz.

At fifteen, Liz dreamed of being a famous lyricist, rapper, singer, and dancer. She was secure in her abilities to gain stardom. She had written a total of one poem. She had never taken lessons in rapping, singing, dancing, or public speaking. Being a "good" mother, I sat down with her to discuss the "reality" of this—encouraging her to continue working with hair styling. Exhibiting the classic optimism attributed to children with FAS, Liz proceeded to find a producer on her own and to explain to him that she had a group and that they were ready to perform. Of course, at that point, there was no singing group, and the only singing performances were in the middle of the night in her bedroom or in the backseat of my car.

Liz doesn't take no for an answer. Her book-dream, "The Best I Can Be," is now a reality, and the scholarship from Tiger Woods Target Foundation (the grand prize) was used to pay off her book's printing bill and to begin producing a CD with her singing group, Mo'Angels. Her

song "FAS Affects" is available *free* at www.mp3.com/moangels. Liz is writing the lyrics of her own songs, and she and her group are performing at community events, churches, and social functions. The unsuspecting world is getting a closer look at fetal alcohol because of Liz and her dedication to this issue.

At sixteen, Liz and her Mo'Angels are heading to Chicago to research record labels—her dream remains the same "to help people with fetal alcohol become successful and build awareness to prevent it, graduate from high school, move away from home to 'Campcun,' Mexico, and become famous." Somebody just try to stop her ... she is FAStastic! ♦

*Jodee and Liz Kulp speak nationally on creative learning strategies for persons with FASD (www.betterendings.org). Liz and her group Mo'Angels sing wherever they get a chance. Jodee is the author of *Our FAScinating Journey, Families at Risk, and Journey to Life*. Jodee and Liz co-authored *The Best I Can Be: Living with Fetal Alcohol Syndrome or Effects*.*

The unsuspecting world is getting a closer look at fetal alcohol.

FAS Affects

Lyrics by Liz Kulp & Anna Watkins © 2002.
Produced by Aaron Jenkins & Andre Lewis.

Chorus:

*Don't you dare pick up that liquor
Don't you dare pick up that drink
Don't you dare pick up that liquor
You betta sit down and think*

*Jigga betta step back I'm about
to attack
you messin with the wrong set
of soldiers*

FAS it's not the best

I get down to the test

and make it to the best

*I represent it cuz it's in me
my momma drank*

*HEN and JUICE and JEN
with out knowin I'm within
failure-to-thrive*

Realize you have a baby inside

Chorus

*Too much liquor to my brain
it's driven me insane
too many drinks of liquor
while I'm in your womb
you really need to change
you're messin' up my brain
you need to keep it maintained
and not go down the wrong lane*

Chorus

FAS and all the rest

*baby gurl bout to brake it down
I'm gonna clown put it down
don't drink you betta think
a liter given you a fever
nine months later you gotta baby
she's driven you crazy
by the time she's a lady
she gotz her own baby
probably in jail
has life like hell*

Chorus

Mothers around the world

If you're drinking everyday

And you're having a baby

This what they say

Don't murder me

Quit hurting me

While you're drinking having

A good time stop doing

That I'm gonna react

Is what you don't realize

Stop choking me you're

Scaring me I'm gonna start

To cry what is your problem

Another bottle of vaca,

Beer or wine

It won't be long

You have been wrong

Your problem will be mine

◆

Article submissions welcome

Iceberg welcomes article contributions from parents, professionals, and others with stories to tell about fetal alcohol syndrome. To submit an article, please follow the recommendations below.

To submit an article, simply e-mail it to iceberg_fas@yahoo.com, or mail it to *Iceberg*, P.O. Box 95597, Seattle, WA 98145-2597.

Please indicate whether the article has or might appear in other publications in the proximate six months period from your submission date.

The *Iceberg* editor reserves the right to shorten or alter any submissions for publication within the bounds of accuracy and the author's intended meaning without notice to the author. ◆

Support groups listing online

It is difficult to keep parent support group information up-to-date with quarterly issues of *Iceberg*. Therefore, we refer you to an international list maintained online

at <http://depts.washington.edu/fadu/Support.Groups.html>. Please e-mail fadu@u.washington.edu or contact Katy Jo Fox at 206/543-7155 if you would like to add or update a listing or to request that a printed list be mailed to you. ◆



services that are available to all children in the community. Being “mainstreamed” in school, getting summer employment, taking music lessons, and playing sports are what most children and adolescents want to do. Providing for the needs of children marginalized by their difficulties so that they can be full community participants involves a sensitive balance between assessing needs, providing for those needs, and fostering strengths and successes.

Helping providers of services buy into a strength-based approach and shape their work with young people accordingly involves mutual learning and the development of a partnership. Professionals still can focus on problems, even on psychopathology, in their capacity

**FAS/FAE
advocates
can provide
leadership for
SOC teams.**

as technical support individuals, as this helps them address the needs of youth in a thoughtful and organized manner. But it is up to the youth, his parents, and the team to help the professionals see the larger picture.

The child who has been considered “to be his pathology” (i.e., the FAE boy) is transformed in the eyes of the professional worker into the amazing, energetic, strong, and charming boy who has brain incapacities due to fetal alcohol exposure that must be compensated for so that this wonderful child can be successful. What a radically different approach.

Individual service providers can’t get there alone. What they hear is the problems. If they are hemmed in by overwhelming demands in their jobs by a poorly staffed agency, or are rushing to do paperwork, they will not have

the gratification of seeing that they are partnered with hopeful people. Truly community-based care means, first, that professionals become aware that the child they are serving is the member of a community, a neighborhood, a school, and a team of people interested in him or her. Second, it means that the leadership of their agency values tapping into such a resource as a child and family team and seeks to modify agency policy and practice to accommodate such partnerships. Third, it means that all professionals involved with the child be aware of the needs that are being met outside their more narrow domain and that they value this array of services.

Professionals through their service organizations may develop mechanisms for closer collaboration in order to assure that their work fits together on behalf of the child and the family. The grants have a cadre of consultants who can consult with different elements of the service system such as juvenile justice, drug and alcohol programs for teens, special education programs for behaviorally challenged youth, and social service agencies. Each of these elements of the system of care may lose track of the need to empower families and older teens as they see too many families struggle with the tragedy of parental abuse and neglect or the extremes of youth misbehavior. It is the presence of a child and family team, grounded in the community that can revitalize the professional team as they create a partnership that invigorates and inspires the professionals.

Culturally competent care

The SOC reform process values individualized care tailored to the specific needs of a child and his

family. In a diverse society, there are many barriers to understanding the nature of strengths and needs between families, youth, and service providers. What factors may be in a family’s culture that serve as barriers to strength and needs assessments? Culture is so much more than race or nationality, although such factors shape culture greatly. But so do such things as immigrant status or economic status.

Each family and community has unique qualities that define its sense of culture. It is the child and family team’s responsibility to support the family through those painful moments where cultural factors disconnect it from service providers, or perhaps, from its own community due to shame or stigma. It is a team’s task to define ways to breach such gaps. Culture determines the way needs are defined or how fears stemming from behavior or learning styles are understood. Understanding culture helps determine the success of a strength-based approach to care.

Through a team process, a family can be supported to deal with cultural factors that disconnect it from providers or from its communities. It may be a team’s job to help the community examine its fears regarding a child with different abilities and to renegotiate cultural imparities vis-à-vis a troubled child so that the child’s strengths are better understood and promoted.

These profoundly humane and positive principles, which have shown so much promise as researchers evaluate the success of grant programs, are clearly applicable to families raising children impacted by fetal alcohol exposure. Some of the methods studied

within the grant communities have been spontaneously invented by families struggling with a child with FASD.

Many families have no clue that fetal alcohol exposure is a key feature in their children's brain functioning. They already deal with their children as unique individuals, as would be the CMHS emphasis in grants programs. They emphasize functioning and practical goals. But for the many families who fit the profile of becoming ever more discouraged and fragmented, these principles offer a great deal of hope.

I would urge all who have concerns about difficult and challenging youth to seek out news about SOC efforts in their communities. All states have, or have had, some CMHS children's mental health initiative grant program. It would be to the advantage of those experienced with FASD to explore these programs and to see for themselves how such children and adolescents fare in such programs.

Are programs born of such humane ideas adequately able to provide the structure and to endure over time to meet the needs of the children we know so well? How well are professionals orienting to the child and family team approach? Do the grant programs live up to the mandates of this model of care, or is a wraparound process subverted to be an excuse for ever more discouraging interagency staffings rather than a truly community-based approach to mobilizing supports?

It is my belief that advocates for young people with FASD are perfect for the job of mentoring families in the context of their roles on such teams. Family support organizations are always endangered species. There are difficulties in maintaining momentum while avoiding becoming one more service agency with an agenda. Clearly FAS/FAE advocates can very well provide much needed leadership in parent coalitions. I submit this perspective to you, the readers, eager for some dialogue in the FASD community regarding the SOC reform initiatives. ♦

Dr. Charles Huffine is a psychiatrist in private practice in Seattle, WA, specializing in the problems of adolescents. He is the part-time medical director for child and adolescent programs for the Mental Health Authority in King County. Through this role he has been involved with a SAMHSA grant that supports system of care reform.

upcoming events

FAS and Other Drug-Related Effects: Doing What Works

February 20–22, 2003

- Vancouver, BC
- Contact: Interprofessional Continuing Education, Vancouver, BC, Canada; 604/822-4965; fax 604/822-4835; interprof@cehs.ubc.ca

Fetal Alcohol Syndrome Course – HDCP 1400

March 2003

- Provided by Saskatchewan Institute of Applied Science and Technology (SIASST)
- Contact: thompsons@siast.sk.ca

Alcohol-Related Birth Defects Course

March 11–12, 2003

- Contact: Viola Fleury, Addictions Foundation of Manitoba; 204/729-3845; vfleury@afm.mb.ca

Fetal Alcohol Exposure: Looking Back, Looking Forward

April 10–11, 2003

- Ontario Province, Canada
- Contact: Best Start; 800/397-9567 ext-226; beststart@beststart.org

International FAS Awareness Day

September 9, 2003

- Contact: Bonnie Buxton or Brian Philcox, founding co-coordinators; 416/264-1652; fax 416/264-8222; ogrady@pathcom.com

If you know upcoming events our readers may want to know about, e-mail us at iceberg_fas@yahoo.com.

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