

iceberg

September 2002

volume 12 number 3

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



Parenting tips after nineteen years on the job

Part 2 of a 2-part article by Lindy Dunagan-Groger

[Volume 12 Number 2 (June 2002) features part 1 of this article]

In the year that Michael turned 18 years of age, Lindy and Michael transitioned into a new set of issues—those of parenting and being a young adult. This included officially obtaining disability status for Michael with the state of Washington. Lindy took on the challenge of finding financial support for Michael in this new phase with great vigor. She is pursuing vocational training, appropriate social experiences, and useful and enjoyable daily activities for Michael. Here are some of her specific suggestions. Parents might find these ideas helpful as they prepare to move into this phase of the journey with their older child with FAS.

Prepare for your transition to the adult systems with care and awareness

The application process can be very difficult for the caregiver. I want to warn everyone—the year your child turns 18 is going to be a hard year. I found the pressure to jump through all the hoops extremely stressful. I say this not to be negative, but to toughen others up. It was my first time through this process, and if I had not had a few people's hands to hold along the way, I wouldn't have made it. As I look back over these last 19 years, I know now why I'm tired. Keeping up with all that is required of us feels overwhelming most of the time.

In preparation, obtain and keep documentation

I am an organized documentation-person; I have kept all those papers and usually I can find them. Documentation is the name of the game. I can honestly tell you I had to provide every piece of documentation concerning Michael and me that I had during the year he was turning 18. Not only do you have to prove who the child is, but also you have to prove who you are.

Start now gathering all the paper work you will need. You can put it all in a handy-dandy file, and every time you run into something important, drop it in the file. During the transition year, I had to have the following—others may need more or less documentation:

- State ID. This was one of the worst steps. Since my child's and my own name didn't match, I had to provide birth certificates, marriage licenses, divorce papers, adoption papers. My name is hyphenated so I had to provide my remarriage papers, too.

**Documentation
is the name of
the game.**

CONTINUED ON PAGE 2

iceberg

P.O. Box 95597
Seattle, WA 98145-2597
iceberg_fas@yahoo.com

Iceberg is a quarterly educational newsletter published by FASIS (Fetal Alcohol Syndrome Information Service), a federally recognized 501(c)3 nonprofit, community organization. *Iceberg* is funded in part by a grant from the Washington State Division of Alcohol & Substance Abuse. Opinions expressed in articles or letters are not necessarily those of FASIS. Subscriptions are available on a prepaid basis (see back page). Letters and articles are welcome. Federal ID No. 91-1559149

FASIS BOARD OF DIRECTORS

Sandra Clarren
Sterling K. Clarren
Jim Fox
Katy Jo Fox
Julie Gelo
Charles W. Huffine
Tracy Jirikowic
Kieran O'Malley
Rose Quinby
Ann P. Streissguth
Marceil Ten Eyck
Marilynn Williams

EDITOR

Tina Talbot

Newsletter design/layout
by Dennis Martin Design,
206/363-4500.

All contents copyright
© 2002, FASIS. Permission
to reproduce in whole or
in part is granted with
the stipulation that *Iceberg*
be acknowledged as the
source on all copies.

Parenting tips

CONTINUED FROM FRONT PAGE

- Birth certificates. They must be certified, not photocopied.
- Social Security cards. My child didn't have one, so I had to get one for him.
- A medical doctor contact.
- Old medical records with birth measurements.
- Current medical records with an updated diagnosis of the disabling conditions. When you get the new physician report, ask the physician to stress that FAS is a lifelong, incurable condition.
- Developmental records of when he walked, talked, etc.
- Legal papers like adoption, divorce, marriage, etc.
- School records including individual educational plans (IEPs) and initial evaluation and reassessment reports. It is good to have the name of someone in the school district to contact. Try the special education director or the school psychologist you worked with.
- You will need a current psychological assessment including IQ test results and other important assessments. Check what other information is needed so you don't have to go back to the examiner.

Take on the roles you will need to help your child in adulthood

- Apply for Supplemental Security Income (SSI). The Social Security office has lots of information. The office was my second home at first. I grabbed all the brochures on becoming a representative payee, etc. Reading it all takes awhile, but it familiarizes you with what you need to know as a caregiver. Also, be aware that your child will get Medicaid coupons automatically once SSI has been
- awarded. After you obtain SSI, check with your social worker if the coupons don't come after SSI has been awarded.
- Obtain power of attorney for your child. The forms for medical, legal and dual powers of attorney are available on the web. You can fill them out and go to a notary to have them witnessed. You may want to have the power of attorney in your name or use some other trusted, reliable person who will be there across the life span. This step can be confusing. When I made the initial appointment, the SSI folks told me to get power of attorney (I did), and then later they said I didn't need to have it. Different people said different things. It was frustrating.
 - Become a legal representative and representative payee while waiting for SSI to be determined. This role does not take the place of being a full guardian but helps fill the bill until the SSI status is obtained. I thank the supervisor that told me about this.
 - Open a representative payee checking account for your child. The brochure of how to do this is at the Social Security office. The number is 1-800-772-1213. Ask for form 1996. You can also get information on the Social Security web site at www.ssa.gov/ on the Internet.
 - Apply to become your child's legal guardian. This can be a long, expensive process. Your child will need a guardian ad litem appointed by the court; you will eventually need a lawyer and a court date. Just finding out about what needs to be done is an accomplishment.
 - Continue to keep the records. Again, pay attention to documentation. I cannot stress how important it was to have all the documentation including certified copies ready to go. It can really slow you down if you have to send for those certified records. Start gathering all this paper early and keep it all together. Every department wants different documentation. There does

not appear to be any rhyme or reason. Just bring it all.

- Apply to the Division of Vocational Rehabilitation (or your regional equivalent) when your child turns 21 years of age. This group helps people with disabilities find and keep employment. Wish us luck! This is our next step.

During this long process keep asking questions of the service agencies. Always ask, What should I do or expect next? What do you want me to have ready for you the next time we meet? Then write the answers down. Follow the suggestions to the letter; it shows good faith in accomplishing the task. The bureaucrats like that attitude and a person who likes you usually helps you along.

Keep all your award letters handy. You will need them to sign up for many other programs including Special Olympics and some parks department programs for the disabled.

Get help from the organizations in your community: groups to contact include Developmental Disabilities Division, the Association for Retarded Citizens (ARC), your parks department (some have programs for special populations), Special Olympics, your local FAS support groups, your state offices of public instruction, the ombudsman in the Governor's office, and parent support groups like Parent Coalition (King County, Washington), PAVE, and others.

Personal reflections on SSI and other systems

As caregivers, we are at a crossroads, you know, with FAS. FAS is still the new kid on the block with the SSI system. It is still not

perceived as a credible, lifelong, functional problem and disability. Every time we go before any system we are teaching the people that work there about the nature of FAS, and what future problems may be seen. We are educators for an antiquated system that is full of overworked and underpaid people.

So we care. We pass on the information we have learned, the experience we've gained, the names and the phone numbers of the professionals that help us with our child. We gradually gain the respect of the powers-that-be and help our kids improve the quality of their lives.

Last, but not least, take the long view

This is a long road. A wonderful, adventurous road that, though difficult, I would gladly have decided to drive on again. Without the help of professionals, be they teachers, aides, medical doctors, educational specialists and, yes, school recess helpers—I dare not think where our road could have gone.

I want to thank *all* the professionals in the FAS field on behalf of all the parents and caregivers who love and live with these children disabled by FAS, as do I. I remember 10 years ago, few people even knew what fetal alcohol syndrome was. Initially these professionals conducted a lot of research that validated what we saw as parents. Later, many of them went on to follow the lifelong course of this disability. Without these professionals, where would we be? I can't imagine not having had a professional's hand to hang on to as I walked this sometimes overwhelming path of parenting a child with FAS. ♦

Matrices track problems and interventions

by Sandra Clarren, Ph.D.

The FAS Developmental Matrices were developed to delineate and visually organize the complexity of issues that children with FAS demonstrate. Most of us rarely have to think about the overlapping parts of our lives—our needs and how we fulfill such needs in order to have happy, functional lives. However, for an individual with a disability, especially one like FAS, a casual view usually won't work.

For these individuals life can be very problematic and a more direct, planned and intentional approach is needed. This structural-matrices approach to organization may help in your journey with your special children.

Plot the problems for a specific child and track the interventions that are tried. One can begin to see the many domains that need attention and the possible solutions. As you can see in this schema, each problem at various stages is balanced with an intervention.

Note: The data in the matrix on the following pages is a compilation from a number of individuals and does not represent one specific person.

For an individual with a disability a casual view usually won't work.

FAS developmental matrices

Developed by Robin LaDue, Heather Carmichael-Olson, Sharon Beck and Sandra Clarren, 1996.

Problems and Concerns

	<i>Health</i>	<i>Psychosocial</i>	<i>Family/Parenting</i>	<i>Education/Vocational</i>	<i>Legal</i>
Birth – 5	<p>Vaginal delivery two weeks early, moderate Apgar scores, low birth weight and small head circumference</p> <p>Perinatal – poor suck, sleep problems, etc.</p> <p>Later – chronic ear & sinus infections</p> <p>Pneumonia, asthma</p> <p>Hyper-activity, impulsivity</p>	<p>Delays – motor, speech, cognitive, social adaptive</p> <p>Temper-tantrums</p> <p>Behavior & emotional regulation problems</p>	<p>Biofamily – Child Protective Services (CPS) referral</p> <p>Adoption at 3</p> <p>By age 4 parent intuit something is awry; worries</p> <p>Physical exhaustion of care taker</p>	<p>Problems in initial preschool, special ed kindergarten</p> <p>Uncertain of appropriate teaching methods</p>	<p>CPS – termination of parent rights</p> <p>Foster placement</p> <p>Adoption</p> <p>Attempt to obtain funds to cover costs for care of child</p>
6 – 11	<p>Asthma, ear infections</p> <p>Pneumonia</p> <p>Negative reactions to first medication for ADHD</p> <p>Irritability to other medications</p>	<p>Inappropriate behavior in school & community</p> <p>Aggression frustration</p> <p>Vulnerable to “tough” kids</p> <p>Bullying and teasing</p>	<p>Parents experience strain on their marriage</p> <p>Sibling issues</p> <p>Difficulty finding respite care</p>	<p>Schools uncertain of his needs – changing special ed categories</p> <p>Multiple school changes, self-contained to mainstream academics – slow progress</p>	<p>Different foster homes, residential placements</p>
12 – 17	<p>Allergies, sinusitis</p> <p>Asthma</p> <p>Child doesn’t say if he is having illnesses</p> <p>Puberty brings raging hormones & behavioral consequences</p> <p>Insurance payment issues</p>	<p>Poor judgment, vulnerability to peers, sexual interest, finding friends is hard</p> <p>Emotional distress as child realizes he is different</p> <p>Psychiatric disorders</p>	<p>Family moves</p> <p>Marriage issues, monetary difficulties</p> <p>Other residential placements</p>	<p>Home schooling may be necessary with lack of special ed support for needs in speech, OT etc.</p> <p>Hands-on learning and appropriate level instruction is not available</p> <p>Problems with peers at school</p>	<p>Shoplifting</p> <p>Vandalism</p>
18 & up	<p>Asthma</p> <p>Allergies</p> <p>Ongoing medical support</p> <p>Problems finding physicians that will take medicaid</p> <p>Obtaining private insurance</p> <p>Birth control</p>	<p>Peer relationships, play with young, like-developmental peers</p> <p>Poor judgment, vulnerability</p> <p>Sexual interest</p> <p>Productive use of free time</p>	<p>Plans for semi-independent living, contact with extended family</p> <p>Financial support in adulthood</p> <p>Issues of transition to adult system</p>	<p>Vocational training</p> <p>Education in functional skills</p> <p>Special ed program to 21 inappropriate or non-existent</p>	<p>SSI problems</p> <p>Possible difficulties with the legal system because of poor judgment</p>

Interventions

	<i>Health</i>	<i>Psychosocial</i>	<i>Family/Parenting</i>	<i>Education/Vocational</i>	<i>Legal</i>
Birth – 5	<p>Hospitalization and repeated sets of antibiotics</p> <p>Ear tubes</p> <p>Soft signs</p> <p>Neurology assessment</p> <p>ADHD diagnosis</p>	<p>Direct modeling, behavior mod for safety behaviors</p>	<p>Extended family support</p> <p>Daycare respite</p> <p>Behavioral support from visiting nurse</p>	<p>Preschool with a former special ed teacher</p> <p>Mom helps and learns in classroom</p> <p>Referral to special ed Childfind program</p>	<p>Adoption finalized</p>
6 – 11	<p>Psycho stimulant trials with eventual discovery of good medication</p> <p>Asthma monitoring and treatment</p> <p>FAS diagnosis</p>	<p>Assistance from school program teachers, counselor</p> <p>Assessed by UW FAS study</p>	<p>Learning through UW, CHILD, <i>Iceberg</i></p> <p>Parents find a respite and shared babysitting with capable adult</p>	<p>At school – therapy-speech, OT/PT, sensory integration</p> <p>Special ed self-contained</p> <p>Aide in mainstream</p>	<p>Developmental disabilities support</p>
12 – 17	<p>FAS clinic monitoring</p> <p>Allergy, asthma monitored</p> <p>Medication to assist with ADHD and anger symptoms</p>	<p>Testing FAS Clinic, Fetal Alcohol & Drug Unit</p> <p>Counseling from ARC</p> <p>Social skills training and intentional groups – Special Olympics and parks</p>	<p>Planning for connection to other family members for eventual long-term support</p>	<p>Home schooling</p> <p>Self-contained special ed/voc program</p> <p>Special Olympics.</p> <p>ARC summer program</p>	<p>Probation</p> <p>Placement in juvenile justice system</p>
18 & up	<p>Medical coupons – available services found</p> <p>Diagnosis to obtain SSI</p>	<p>FAS Clinic to have official diagnosis</p> <p>Language intervention for social skills</p> <p>Structured workshops</p>	<p>Extended family helps</p> <p>Family support organization</p> <p>FSO</p> <p>Parent support groups</p>	<p>Parks Department</p> <p>Continued education to 21</p> <p>Sheltered workshop</p> <p>Department of Vocational Rehab</p> <p>Structured employment</p>	<p>SSI obtained</p> <p>Designated payee and bank account</p> <p>Legal guardian</p> <p>Special needs trust</p>

Examining Canada's community support to young adults with FASD

by Kieran O'Malley, M.D.

Among the community supports currently available in Canada for young adults with Fetal Alcohol Spectrum Disorders (FASD), it is helpful to understand their strengths and weaknesses.

Universal health care

This is the primary aspect to the Canadian Health system that benefits young adults with FASD as they often have significant psychiatric or medical disorders that need management. The quality of “portability” of health care insurance is an invaluable component. For example, an impulsive adult with FASD who moves to a different province, or runs away if pregnant, is covered for health care in the new province with the coverage linked to the original province that insured the young adult.

Subsidized drug plan

This enables the young adult with FASD to afford the regular medications commonly prescribed (which sometimes includes injectable medication). Further coverage can be obtained if the young adult is First Nations or Metis and has treaty status and a Band number. This extra coverage pays for drugs not covered in the general drug plan such as naltrexone (revia), guanfacine (tenex) or melatonin.

No organized holistic “system of care” for young adults with FASD

Canada does not have any organized transitional medical, developmental, psychiatric or addictive

services available. These are all done on an “ad hoc” basis with no link between child/adolescent health services and adult services for the FASD population. Problems exist in the acute hospital management of adults with FASD, especially for those taking medication. Similarly there are problems obtaining a suicide-risk assessment of an impulsive young adult with FASD. The eastern provinces in Canada (Ontario, Quebec, Nova Scotia) are the least sensitive to the long-term issues of FASD.

Dual diagnosis concept

British Columbia was the first province to create a professional organization acknowledging developmental disability and psychiatric disorder. The U.S. has the National Association of Dually Diagnosed (NADD). No Canadian programs have integrated the FASD population. Many programs exclude patients with an addictive disorder and a developmental disability or organic brain dysfunction.

Financial support

Both mental health disability and developmental disability offer financial support. It is generally a better plan to have the mental health professional carefully document the mental health/psychiatric disorders and apply for financial aid through this route. Developmental disability funding still is determined by IQ, so a young adult with FASD with an IQ over 70 is commonly denied funding. Certain provinces, mainly in western

Canada, incorporate an assessment of functional ability, which is independent of IQ. Finally, provincial social assistance funding can reduce homelessness for young adults with FASD who are awaiting funding.

Guardianship

This can be obtained by the patient, private (adoptive or birth parent), or public entity (provincial or state). Issues of liability for the acts of a young adult with FASD are major emerging concerns. Establishing a guardianship for the young adult with FASD has proven helpful during the process of a developmental disability appeal, as it clarifies functional disability.

Trusteeship

This, again, may be the patient, private, or public. The trusteeship (called “protective payee” in the U.S.) is an essential means of controlling the impulsive expenditure of money so that minimal needs are met, e.g., rent, food. This is important to establish in tandem with guardianship for the developmental disability appeal.

Federal disability tax credit

This federal statute enables birth or adoptive parents to obtain some financial support for the chronic educational, medical, and psychiatric care needs of a young adult with FASD. Although the government forms are still outdated, dealing mainly with physical disability, the tax credit can be obtained with perseverance.

Support independent living

This program is an essential part of long-term planning and is normally obtained through the local developmental disability organization, church groups or by word-of-mouth. There is a general dearth of mental health housing in Canada. The mental health housing providers are really quite disconnected from the needs of this dual-diagnosis population where the psychiatric disorder is often the crux of the matter.

Day programs for young adults with FASD

A number of helpful adult programs throughout Canada have developed from the experience of working with young adults with autistic spectrum disorders. Unfortunately, the Adult Canadian Mental Health Services do not incorporate FASD as a chronic neurodevelopmental and neuropsychiatric population.

Job/occupational support

There is very little systematic support. Some vocational colleges have job coaches, but they appear to be too busy to deal with this population of impulsive, distractible and easily bored young adults. Recently a pilot project in Alberta has created FAS advocates or mentors, which may enter into this vital role.

Parent-child advocate support

A number of these programs are running in Manitoba and Alberta. They are modeled on Seattle's Parent-Child Advocacy Program (PCAP). The Canadian programs vary in effectiveness. No organized parent support after the child is three years old.

Legal issues

The high number of adults with FASD in prison has been systematically quantified and published in a recent book, *FAS and the Criminal Justice System 2000*, by J. Conry and D. Fast. Native/First Nations communities are using "sentencing circles" in western provinces. A recent peer-support program in the Yukon funded by the Crime Prevention Investment Fund is dealing with First Nations teenagers and women 15 to 30 years of age with FAS/FAE.

Dr. O'Malley is a psychiatrist and Acting Assistant Professor at the University of Washington and is affiliated with the Fetal Alcohol & Drug Unit, Seattle, WA. He has a small community psychiatric practice in Calgary, AB, Canada, dealing with FASD and autistic spectrum disorder patients.

upcoming events

Substance Use During Pregnancy: Effects on Infants, Mothers & Children

September 12-13, 2002

- Seattle, WA
- Contact: Continuing Nursing Education, University of Washington, 206/543-1047; fax 206/543-6953; cne@u.washington.edu

Understanding and Working with FAS/FAE

September 16-20, 2002

- British Columbia, Canada
- Contact: FAS/E BC Support Network, 604/507-6675; fax 604/507-6685; info@fetalalcohol.com

Practical Strategies for Perinatal Substance Abuse Intervention

October 4, 2002

- Sarasota, FL
- Contact: Kathryn Shea, 941/371-8820; kshea@cdc4kids.org

Reclaiming Our Voices 4

October 16-18, 2002

- Manitoba, Canada
- Contact: Kathy Jones, 204/985-4061; kathy@wrfs.mb.ca

Drinking & Pregnancy: Evidence & Responses

November 8, 2002

- Bristol, U.K.
- Contact: Conference secretary, 0117 344 8788; fax 0117 344 8421; Jan.Green@uwe.ac.uk

FAS Summit 2002

November 21-22, 2002

- Anchorage, Alaska
- Contact: Coordinator 907/465-3033 or 877/393-2287 (toll-free); heidi_brocious@health.state.ak.us

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

subscribe to ICEBERG

We depend on your support!

NAME

ORGANIZATION

ADDRESS

CITY / STATE / ZIP

PHONE

HOW DID YOU LEARN ABOUT ICEBERG?

Professional rates

- One year: \$20 US / \$28 Canadian
- Two years: \$30 US / \$42 Canadian

Family rates

- One year: \$10 US / \$14 Canadian
- Two years: \$15 US / \$21 Canadian

(Bulk subscriptions are also available. Contact iceberg_fas@yahoo.com for more information.)

- I am including an extra gift of \$_____ to further support the educational goals of Iceberg. (Contributions are tax-deductible.)

Total enclosed \$_____ (check or money order only)

Mail to: Iceberg, PO Box 95597, Seattle, WA 98145.

reprints of ICEBERG articles

NAME

ORGANIZATION

ADDRESS

CITY / STATE / ZIP

PHONE

Reprint packets

\$15 US / \$19.50 Cdn each

- From the parent and family
- Medical
- Community issues, public policy, & what you can do
- Prevention and intervention
- The last 15 articles published

(Each packet contains at least 15 articles, including ones written by people with FAS/E)

Iceberg Reprint Archive Book

- \$45 US / \$58.50 Cdn

(Includes all reprints from 1991 to present)

Individual reprints

(Available for \$1 US / \$1.30 Cdn. For a complete listing of reprints, please e-mail iceberg_fas@yahoo.com.)

Total enclosed \$_____ (check or money order only)

Mail to: Iceberg, PO Box 95597, Seattle, WA 98145.

iceberg

P.O. BOX 95597
SEATTLE, WA 98145-2597

ADDRESS SERVICE REQUESTED

PRSR STD
U.S. POSTAGE
PAID
SEATTLE, WA
PERMIT #5544