

**The Families Moving Forward Project:
Promising Research Helps Families Raising Children with FASD**

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THIS ARTICLE CAN ALSO BE READ ON THE ICEBERG WEBSITE. ICEBERG IS A NEWSLETTER FOR PARENTS AND PROFESSIONALS CARING FOR CHILDREN WITH FETAL ALCOHOL SPECTRUM DISORDERS. THERE WAS AN EARLIER ARTICLE ABOUT FAMILIES MOVING FORWARD PROGRAM IN APRIL, 2004.

Systematic research on intervention has long been needed to assist families raising children with Fetal Alcohol Spectrum Disorders (FASD). Families want to know what works. Professionals assisting families have also needed information about scientifically tested interventions that can help them be as effective as possible. Fortunately, over the past few years, the pace of such research has accelerated. Now there are a number of promising intervention models being studied. Research on a variety of models is important because FASD is a multifaceted problem, and we know that a continuum of intervention services is needed.

Behavioral Consultation Services: An Essential Area of FASD Intervention Research

Behavioral consultation services for caregivers are a very important and high-priority focus of FASD intervention research. Specialized behavioral consultation can provide flexible, ongoing and comprehensive support that is carefully targeted to the individual needs (and strengths!) of caregivers raising children with FASD who have especially challenging learning and behavior problems. Studying how best to offer behavioral consultation for FASD is essential. Behavioral consultation can be provided at a clinic, in the schools or, if at all possible, in a home-visiting model. Behavioral consultation provided as a home-visiting service can reduce many treatment barriers and generate practical intervention ideas based on a real understanding of the child at home and at school.

Leading the way in study of behavioral consultation services is the Families Moving Forward (FMF) Project, a groundbreaking project funded by the Centers for Disease Control and Prevention (CDC) that began in 2001. The FMF model provides behavior consultation as a collaborative process between parents and a specially trained support specialist in every-other-week visits to the home. These home-based services make intervention accessible for families. The model includes targeted school consultation, when the support specialist can accompany the parent to the school to meet with the teacher (and sometimes other important school staff) at a time that is important for the child's school progress. If additional school consultation is needed, this can be done—but behavioral consultation with the family is the most important aspect in FMF program. The parent is usually the child's most important advocate across time.

The “Families Moving Forward” Intervention Model

What actually happens in the Families Moving Forward Program? More information will be provided in the detailed scientific and clinical write-ups that the research team is at work upon right now. But a brief sketch of the intervention model is described below.

Children clearly identified with FASD first receive neurodevelopmental testing, and their parents complete questionnaires and interviews. Home visits are then made over a 9 to 11 month period. In these visits, there is discussion covering a variety of topics to provide the parents support, specialized education, and practice on skills using a “family curriculum.” This curriculum includes fact sheets, work sheets, videotape and other specially designed materials to help parents feel more effective and hopeful, and to help them reshape their child’s behavior to be more adaptive (and less challenging) in everyday life.

At its heart, the FMF intervention model is aimed at providing ongoing support to parents and helping them better understand their children. The intervention team also aims to help parents hone skills they already have while adding specialized parenting techniques to their care-giving repertoire. These specialized techniques are based on what we theorize (based on research and clinical experience) are best practices for raising children with FASD. The FMF model was built on the clinical wisdom of parents and clinicians who, for years, have cared for children with FASD.

The intervention does not replace other community resources and providers that families find helpful, but adds value to these resources. With the help of their support specialist, families “move forward” on an improving life path. The FMF intervention is realistic—services are not expected to solve all problems; but interventionists join with families, hopefully helping to boost their progress in a positive direction and give them reason to be more optimistic.

The FMF program is both “manualized” (has certain core components and a specific session flow) and “individualized” (has special optional components that different families can decide to do). The session flow starts with core components of the curriculum. About halfway through the home visits, a “pizza planning” session is held. This particular home visit is called a pizza planning session because the whole FMF program is described to caregivers as a pizza, with core components seen as the necessary pizza ingredients and optional components seen as “special” ingredients that a family can choose to include before their sessions are done. An example of a core component that all caregivers discuss and learn is “reframing,” in which caregivers come to see their child’s behavior in light of their neurodevelopmental disabilities. An example of an optional component that some families might choose is a session on calming strategies that can be used for children with FASD.

Putting the Information to Work

The FMF team finished intervention activities in 2004, and is now working hard on data analysis. Promising findings are beginning to emerge, and reports on the efficacy of the Families Moving Forward intervention model will soon be available. This project is another avenue by which the Washington State Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS

DPN), based at the University of Washington in Seattle, aims to serve those with FASD in Washington state and beyond.

Since the analysis of FMF data is still underway, findings reported here are preliminary, but several results are clear:

- Participating families were highly satisfied with services received in the FMF intervention research project, and felt they learned useful skills.
- The project demonstrated excellent family involvement, with 92 percent of the group of 26 families successfully participating in the full intervention.
- Analysis so far shows that FMF is a feasible intervention protocol. Support specialists who provided the intervention described the model positively.

Here's how information gained from the Families Moving Forward Project can be helpful to others interested in FASD intervention:

• An intervention model designed for families raising children with FASD is available for further research:

The FMF model of behavioral consultation services, specifically targeted to families raising children with FASD and challenging behavior problems, is now available for further testing. It is likely that this model and its treatment processes can be modified for use in clinic-based mental health settings and would translate easily to use in early intervention. Excitingly, more research on this intervention model is already underway! A new grant will transition services from their base in the University of Washington academic setting to a home-visiting community agency with multiple offices throughout Washington state. If research findings show the efficacy in the community setting that we expect, we hope that this agency will eventually provide services for families in need statewide (funded by sources such as Adoption Support or private insurance). The plan is also to train home-visiting agencies in other states to provide services according to the FMF intervention model.

• Specialized training on treatment processes helpful for FASD can be made available.

The FMF project has advanced our understanding of the specific treatment processes that may lead to improved outcome for families and children with FASD. These processes capture important parts of the collective clinical wisdom in FASD, combined with scientifically tested child treatment and parenting techniques. "Reframing," discussed earlier, is one critical process, as is creating "accommodations," – practical ways to modify a child's environment and daily routine. "Brainstorming," a third essential process, is a user-friendly set of positive behavior support techniques. And there's more to the model! Work on the Families Moving Forward Program has provided the foundation for developing specialized training for professionals who want to be more effective in the field of FASD. This training can be useful to treatment providers such as mental health professionals and social workers, juvenile justice workers, educators, early interventionists and others

Ideas for more interventions techniques sparked by FMF research:

Work of the Families Moving Forward (FMF) team has clearly defined a set of treatment processes and behavioral consultation techniques, and put them together in a practical model that can be cost-effective. But the team's work has also provided insights into other needed interventions for families raising young and school-aged children with FASD, and ideas for creating these services. FASD is indeed a multifaceted problem. Important among ideas sparked by what we've learned in the FMF research are:

- The urgent need for child and teen social skills groups that are specialized for children with FASD.
- The usefulness of sensory-based intervention techniques in treatment for FASD (these were integrated within the FMF behavioral consultation model and families found them very useful).
- The potential power of teaching children with FASD calming and self-regulation techniques.
- The crucial need for "peer-driven intervention"—in other words, community-based FASD family support and advocacy groups that can provide specific, useful information about community resources, as well as the embrace of parent support, whether in the form of summer camps, monthly groups, or an active listserv.

Of course, there are other interventions needed in the service continuum for families raising individuals with FASD, including effective respite care (which is so difficult to find), services for young adults, appropriate medication management, early intervention for learning problems, support within the juvenile justice system and more. Luckily, researchers and helping professionals are actively creating and evaluating such intervention programs now.

For more information:

Others interested in research and discussion about the Families Moving Forward model, or the ideas it has sparked, are invited to contact its director, Dr. Heather Carmichael Olson of the University of Washington, at a special email address:

fassg@u.washington.edu. Please also see the related article in the [April 2004](#) issue of Iceberg.

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