Make A Difference for Children with Disabilities

A Guide to Serving on a County Family Support Advisory Committee

Waisman Center
University of Wisconsin–Madison
University Center for Excellence in Developmental Disabilities
The Waisman Center is dedicated to the advancement of knowledge about human development, developmental disabilities and neurodegenerative diseases. It is one of 9 national centers that encompass both a Mental Retardation/Developmental Disabilities Research Center designated by the National Institute of Child Health and Human Development, and a University Center for Excellence in Developmental Disabilities designated by the Administration on Developmental Disabilities. The objectives of the Waisman Center are to promote:

- Research in behavioral and biomedical sciences relevant to human development and developmental disabilities.
- Scientific training in fields related to the study of human development and developmental disabilities.
- Training in the delivery of clinical, educational, and support services to people with developmental disabilities.
- A broad range of services for people with developmental disabilities and their families.

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This booklet is available at http://www.waisman.wisc.edu/wrc/pub.html
## Ideas

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Acknowledgement

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Preface

The concept of family support and the Family Support Program represents a unique partnership between the public and families of children with disabilities in Wisconsin. This partnership is built on trust and respect and the belief that families, as stewards of precious public resources, will make the best decisions they can about what they and their child need to be successful and supported members of their family and community.

This partnership is reinforced by the requirement, in the authorizing legislation for the Wisconsin Family Support Program, for a Family Support Advisory Committee. This committee should be comprised of a majority of parents of children with disabilities and should help guide program policies as priorities and resources shift overtime.

This booklet is designed to help families better understand the important role they play in shaping their local Family Support Programs and how they can become more effective participants and have their voice heard in Family Support Programs both locally and statewide.
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To all the families of children with disabilities who have, or will in the future, commit their precious time to efforts that make life better for other children and families.

The Starfish Story

(Adapted from The Star Thrower by Loren Eiseley)

Once upon a time, there was a man walking down a deserted beach just before dawn. In the distance he saw a human figure moving like a dancer. He smiled to himself at the thought of someone who would dance to the day, and so, he walked faster to catch up.

As he got closer he noticed the figure was a young woman, and what she was doing was not dancing at all. She was reaching down to the shore, picking up small objects, and throwing them into the ocean.

He went closer still and called out: Good Morning! May I ask what it is you are doing?

The young woman paused, looked up, and replied, “Throwing starfish into the ocean. The sun is up and the tide is going out. If I don’t throw them in, they will die.”

Upon hearing this, the man said, “But do you not realize there are miles and miles of beach and there are starfish all along every mile? You can’t possibly make a difference!”

At this, the young woman bent down, picked up yet another starfish and threw it in the ocean. As it met the water, she said, “It made a difference to that one.”

YOU TOO CAN MAKE A DIFFERENCE

Volunteer to be on your County Family Support Advisory Committee
Part One: Why and How to Get Involved

Parents on Advisory Committees: The Need

Your time is precious, but your knowledge, ideas and perspective as a parent of a child with a disability are needed.

In 1985, parents were instrumental in passing the legislation that established the Family Support Program (FSP) in Wisconsin. It was the commitment and power of parents that resulted in increased funds for the Family Support Program in 1994 and 2001.

Now you have an opportunity to make a difference. The Family Support Program is in crisis—there are more families on the waiting list than there are families receiving support. Each county has to make difficult decisions on how their program will operate in light of the growing waiting lists.

Your help is needed!

Parents on Advisory Committees: The Benefits*

The benefits of involving families on Advisory Committees are enormous. As a parent you may see problems or inconsistencies to which professionals have become accustomed. You often see solutions that may have eluded providers. Because you care for a child who has special needs, you are constantly required to adapt and to create solutions with few resources. Your resourcefulness can be an enormous benefit to the service system. When families are participants in planning and decision-making, the likelihood of developing effective, responsive services is greatly increased.

Parents are also tireless advocates. You can advocate for system and program changes in ways that professionals cannot. When families work side-by-side with professionals to design and implement programs, both are enriched. Both develop an expanded view of the other and gain an appreciation of the expertise and experience each brings.

Would I make a good member of a Family Support Advisory Committee?

Ask yourself these questions:

- Do you want to provide meaningful input into a program that assists your family and others who are caring for a child with a disability?
- Do you like working cooperatively with other parents and providers to develop the best policies when there are difficult decisions to make?
- Do you believe you can attempt to represent all families fairly and not just the interest of your own family?
- Are you a good listener and someone who feels comfortable expressing yourself in groups?
- Do you enjoy being a member of a team that is searching for the best solution to difficult issues?

If you answered yes to many of these questions, please call your county Family Support Coordinator and ask how you can become involved. You are needed!

Next Steps

1. How to get involved in your local Family Support Advisory Committee Just ask! Call your Family Support Coordinator and ask for more information on the committee and the appointment process.

2. Attend the next meeting! Even if you’re waiting for services, you can get involved. And if you can’t attend meetings, find other ways (e-mail, contacting parent members) to share your ideas, comments and questions.

3. To find your county’s Family Support Coordinator, call Wisconsin First Step at 1-800-642-7837 or TTY 1-800-282-1663. Or see a list of coordinators by county at: http://dhfs.wisconsin.gov/bdds/fsp_dir.htm


5. Learn more about advocacy to end the Family Support Waiting List Many parents and other disability advocates are working to increase the funding for the Family Support Program and therefore decrease the Family Support waiting list. Information is available at: the DAWN Website: http://www.dawninfo.org/advocacy/issues/fam_support.cfm. You can also join the Family Action Network by sending your e-mail address to: hecht@waisman.wisc.edu

6. Other opportunities for involvement in disability advocacy:

- Join the DAWN e-mail network and receive information on advocacy opportunities http://www.dawninfo.org/
- Look at the DAWN Website on children’s issues (http://www.dawninfo.org/advocacy/issues/child_fam.cfm)
- Develop a brochure about the FSAC and the important decisions it has made and will be making. If possible, include the name and phone number of a few parent members.
- Join Family Voices of Wisconsin. Family Voices is a group of volunteer parents and advocates of children with disabilities and special health care needs who work on influencing public policy on behalf of children and families. For more information go to the website at http://www.wfv.org/fv/
- Attend the annual “Circles of Life Conference” held every spring for parents and professionals who are concerned about children with disabilities. More information is available at http://www.wfv.org
Families will have convenient access to information and service coordination. Children and families want a trusted person to help them find out about and make use of services and supports. This service coordinator will be someone chosen in consultation with the family with whom they can work comfortably.

Collaboration is the best way to provide comprehensive services. No single agency is able to provide all services to all children and families. Cooperation among providers is necessary to provide a flexible, seamless system.

Family perspectives and presence will be included in all aspects of the system. Families and youth with disabilities will be partners with other families, providers and policy-makers in the areas of policy and program development, professional education, and in the delivery of supports and services. Family perspectives contribute to system-wide improvements and cost efficiencies.

Adapted from A Foundation for a System of Long Term Support for Wisconsin Children and Families. Developed by the Children’s Committee on Long Term Supports. For additional information on Children’s Redesign, contact Liz Hecht, Waisman Center, 1500 Highland Ave., Madison, WI 53705, 608-263-7148.

Why You are Needed: Current Dilemmas for the Family Support Program

In 2004, the number of families on the waiting list for the Family Support Program (FSP) in Wisconsin exceeded the number of families served. Also, families report the amount and type of support they were receiving is not adequate to meet their needs. The FSP is funded with money from the state of Wisconsin, but is implemented at the county level. Many of the important decisions that affect the program occur at the county level. These current dilemmas emphasize why you and other parents are needed to discuss these difficult issues confronting your county Family Support Advisory Committee (FSAC) and to recommend policies for your county’s FSP to guide decision making. Both parents in the Family Support Program and those on the waiting list are eligible to be on the FSAC.

This section provides examples of issues FSAC have addressed and policies they developed to address these issues.

Each example includes:
- a reference and language from the Wisconsin Administrative Code or the Family Support Program Guidelines and Procedures PSL-595
- discussions questions
- policy language adopted by FSACs around the state

The following are examples of policy decisions that FSPs have developed with input from their advisory committee. Although the examples of policy recommendations may not always be considered best practice, they represent a program’s best attempt to balance competing priorities with limited funding. Consider the following issues, which currently face many FSAC.
4. Part One: Why and How to Get Involved

**Issue: First Come First Serve**

**Program Guidelines.** The Family Support Program law requires that funding shall be allocated to families who meet the eligibility requirements on a *first-come, first-served* basis, except that a county may reserve funds for the following families:

1. families in a crisis situation,
2. families considering out-of-home placement for their child, and
3. families planning to bring their child home from an out-of-home placement.

(Wisconsin Administrative Rule HFS 65.05(1); paraphrased from Family Support Program Guidelines and Procedures, PSL-595, Revised 10/99, p. 19)

The County should develop criteria for determining which families will receive continuing services from year to year and criteria for determining under what circumstances a family on the waiting list might receive services as a priority over another family served during the previous year.

When the Family Support Program was designed, waiting lists did not exist, nor were they expected to develop. State funding was to equal the needs of families. Since state funding has not kept up with the need, each county’s FSAC must now decide how available funding should be used for families currently in the program, and for families with high needs who are on the waiting list.

**Family Values to Think About**

Since 1997, a group of parents and professionals have been meeting to design a better way to deliver services to children with disabilities. Their efforts are called “Children’s Redesign.” They have developed a set of principles important for all parents to think about as they work on improving children’s services in their community.

**A Guiding Philosophy for Systems, Programs, and Providers that Serve Wisconsin Children and Families**

**OUR VISION...**

Children with disabilities and their families will pursue their unique hopes and dreams with assistance that:
* Is family-designed and controlled,
* Is individualized and seamless,
* Lasts as long as needed, and
* Involves a variety of community partners.

**PRINCIPLES...**

*Children are Children First.*

All children need acceptance, love, nurturing and security. The focus will first be on the child as a child, and second on the problem or disability. The developmental, social, spiritual, emotional, and physical needs of the whole child, regardless of age, must be considered in the delivery of any service.

*Children are best served within their families.*

The best way to meet the needs of children is to support and build on the strengths of their families. Public policy will be supportive of what contemporary families need to survive and thrive. Policies and support systems will promote culturally competent practices.

Families are the best allies in any activity that serves the child.

Families have a great capacity to care for children with disabilities if given the supports they need. Families will have informed, real choices in selecting needed services and supports. Families will be the primary determinants of how they get the supports they need.

*Children and families are best supported within the context of their community.* The service system will enhance the opportunities that allow children with disabilities and their families to become connected to the community. Services will focus on supplementing, not replacing the natural support that people get from family, friends, neighbors and volunteers.

**IDEAS**
Discussion Questions

Should the Family Support Program only fund those families who are currently in the program?

How can the Family Support Program support families with young children or those who are newly diagnosed?

Should all families, including those on the waiting list, be evaluated each year with the funds distributed on an as needed basis?

Should all or some families receive one-time funding as opposed to on-going yearly grants?

Assuming the child is still age eligible, should there be a maximum number of years that a family can receive funds?

Examples of County Policy:

“During our 12/3/03 advisory board meeting, the committee voted unanimously to maintain the current “first come, first served” policy as children come off the waiting list, instead of making Family Support more of a crisis-driven program. Families are allowed to stay on Family Support from year to year, as long as they have ongoing needs.

St. Croix County 2004 Family Support Plan Update

“The advisory committee strongly supports the continuation of the current rotational system, but has agreed to increase the amount of crisis funds as an additional safeguard for families. If there is not a need for crisis funds by March 1st, $1,000 will be returned to the general FSP fund to be allocated to the next family on the waiting list…”

Waupaca County Family Support Plan Update 2004

Sponsor listening sessions where parents talk about their needs. It is a good way to hear what is happening with families and to recruit new committee members.

Contact local or statewide parent and/or disability advocacy organizations and parent leadership training programs and ask if they can recommend a parent for the FSAC.

Have FSP staff who do home visits help recruit and recommend prospective parents.

Include information on opportunities for parent involvement in all program surveys or program newsletters.

Put a story about a parent member of the FSAC in your county’s newspapers and profile different parent members in each FSP newsletter.

Write articles for your local newspapers on some of the important decisions that the FSAC has had to make because of waiting lists. Place the same article in any disability newsletters in your county. Include in the article that you are looking for new FSAC members.

Invite parents who are on the waiting list to be on the FSAC.

Keep all parents informed about the important policy decisions that the FSAC has made using a newsletter, flyer or e-mail communication. At the same time, advertise that you are looking for new members.

Make it part of your outreach plan to mention the advisory committee whenever a staff member talks to a parent.

Be honest about the time commitment and positive about the work of the FSAC.

Sponsor a resource night with other agencies and groups where parents can learn about relevant activities and opportunities in their county. Have a table staffed by parents FSAC members to answer questions from prospective parents.

Develop a brochure about the FSAC and the important decisions it has made and will be making. If possible, include the name and phone number of a few parent members.
**Issue: Funding Allocations**

**Program Guidelines**: The County, with assistance from the Family Support Advisory Committee, shall decide how much money to use for current families and for families on the waiting list, as well as the amount to set aside for families in crisis. (Paraphrased from “Family Support Program Guidelines and Procedures” (PSL-955, Revised 10/99, p.19))

**Questions For Family Support Advisory Committees**:  

- Should all funds be distributed or should some be held back for emergency or crisis?  
- Should funds be set aside for the waiting list?  
- If set aside funds are not used, when will they be released and how will they be used?  
- Should all families receive some financial help or should the amount be based on individual family needs or should fewer families receive the maximum allowed?  

**Examples of County Policy**:  

- The Family Support Program Advisory Committee has approved a priority listing for reserved funds and exceptions to a waitlist. In Winnebago County, a family may wait for funds and still have the opportunity to work with a service coordinator to identify natural supports and other community-based funding options.  
  - The FSP allocates funds on a 12-month basis, first come first serve.  
  - $16,000 is set aside for emergency use. One-third of $16,000 is released every quarter to meet the waiting list needs.  
  - $50,000 is set aside for children who will be fully served by Family Support funds  
  - Remaining FS funds may be used for matching a DD waiver (CLTS, CIP1B)  

The first year the advisory committee established that they did not want to set aside emergency funds and that hasn’t changed. **Communication from the Polk County Family Support Coordinator, April 2004**

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**Ideas for Finding Parents for Advisory Committees**

**The goal is** to find parents to serve on the Family Support Program Advisory Committee who are able to represent the broad spectrum of families in your county. It may be helpful to make a grid representing the diversity of your Family Support Program in terms of culture, race, disability, geography and age. Look for parents to fill a specific need—it may be easier to convince a parent to join if they know they are really needed to broaden the representation in addition to their skills and background. At the same time, be clear that they will be representing all children with disabilities in their county. Ideally, invite parents who are articulate about their own needs and also indicate some awareness of systems issues beyond their own situation.

**Recruiting Parents**:  

- Invite prospective parents to a committee meeting. Be prepared with name tags and introductions. Have current members introduce themselves and say why they are on the committee. After the meeting, call the parent to thank him or her for coming and ask if they have any follow-up questions.  
- Ask parents who are currently on the committee to call prospective parents to invite them to a meeting and to answer any questions they may have.
How do “Robert’s Rules of Order” Work?

“Quorum” is the number of people who must be present at the meeting for official business to be conducted.

“Steps in Making and Passing Motions:”

The motions are proposals that can be accepted or rejected by the Advisory Committee.

1. A committee member makes a motion (“I move that….)
2. Another committee member seconds the motion (“I second the motion”). One does not have to be in favor of the motion to second it. By seconding the motion one is just allowing discussion to take place. Without a second, the motion dies with no discussion.
3. The Chair repeats the motion so that everyone is clear what proposal they are voting on.
4. The Chair asks for discussion on the motion. The chair will try to make sure everyone has an opportunity to discuss the motion. If someone tends to dominate the discussion, the chair can set up a rule to give others a chance to participate (e.g. members are only allowed to speak twice on an issue). The chair will determine the order for speaking; usually members raise their hands to speak. If someone speaks out of turn, the chair can ask the member to hold his/her comments until it is their turn.
5. Rules of discussing a motion: Keep comments relevant to the motion that is “on the table” (being discussed). Avoid personal attacks and remain courteous in your comments.
6. One can amend one’s own or someone else’s motion by adding or removing words or paragraphs or by substituting whole new sections into the motion. If a motion is amended, the chair will ask members to vote on whether they accept the amendment.
7. If a committee member says, “Call the question,” the chair can stop debate and bring the issue to a vote.
8. The chair asks members to vote on the motion (“We are now voting on the motion to….. All those in favor “raise your hand or say “Yea” and all those opposed same sign “raise hand or say nay.” If you are confused by what you are voting on, ask the chair for clarification. One may also abstain and not vote on a motion. All votes, including abstentions, should be reflected in the minutes.
9. Passage of a Motion: A majority of people must vote in favor of it. If there is a tie, the chair can break the tie or if the chair does not vote, the motion fails.
10. The chair will state whether the motion is carried (passed) or defeated.
11. Consensus: Sometimes, committees have motions that pass by consensus, (everyone agrees).

Issue: Definition of Crisis or Emergency

Program Guidelines: If the county reserves a portion of their Family Support Program funds for families in crisis, they must develop criteria and procedures for determining if a family is in crisis and the extent of their need (Family Support Program Guidelines and Procedures (PSL-595, Revised 10/99, p. 19).

Discussion Questions

How is crisis or emergency defined?

How is eligibility for crisis funds determined?

Are crisis funds available to families who are underserved as well as families on the waiting list?

Examples of County Policy:

“A portion of the FSP funds will be set aside for emergency funds for all families on the waiting list. We will set aside $4500 for emergency situations in 2001. An emergency is defined as the following three possibilities:

1. Family is requesting placement of the child into an institution or foster home.
2. Reunification of the child with his/her birth family can occur if the FSP becomes involved.
3. Child or parent has serious medical emergency or safety issues, which requires immediate response.

Oconto County Family Support Plan for 2001

Crisis is defined as follows:

A high level of stress in the family resulting in a loss of ability to provide sufficient care to the child including, but not limited to; an illness or urgent medical need of a caretaker, financial hardship due to lay off, job loss, or natural disaster.

Dodge County Family Support Program Plan for 2004
Issue: Waiting List Policies
Program Guidelines: The County, with assistance from the Family Support Advisory Committee, decides whether or not to prioritize the waiting list. If it is prioritized, then they must determine the criteria for prioritization (Paraphrased from “Family Support Program Guidelines and Procedures PSL-595, Revised 10/99, p. 4 (F), p. 19).

Examples of County Policy:
“Children are brought into the program from the waiting list when sufficient funding is available to meet at least some basic needs identified by the family. The order in which families are served depends on the child’s placement on the waiting list. The waiting list order is dependent on the date the child was referred to the program.”
Oconto County Family Support Program Plan for 2001
● Consideration for priority is given according to the following—no specific order:
  ● Risk of out-of-home placement, currently residing in their natural home
  ● Transitioning from an institutional or other out-of-home placement and returning to their natural home and meeting eligibility for Family Support/Long Term Care
  ● Children with high medical needs who require goods or services beyond the family’s resources
  ● Low income households as determined by the Federal Poverty Guidelines
  ● Families who are isolated from traditional resources for a variety of reasons
  ● Severity of “severe conditions” needs are beyond available limits and have exhausted all other funding sources
  ● Single parents or grandparents raising grandchildren
Winnebago County Wait List Policy-Family Support Program, March 2004

Questions For Family Support Advisory Committees:
As funds are available, do families come off the waiting list by the date they joined the waiting list, by family need, by crisis, or other criteria?
What criteria determine when a family on the waiting list receives support?
As funds are available, is priority given to families that are underserved (receive less money than their plan identifies) or families on the waiting list?

Hints for Feeling Comfortable at Committee Meetings
Do you sometimes feel awkward at committee meetings?
Are you unsure how voting works or when to ask a question?
Are you intimidated by people using acronyms such as CIP instead of the full program name (Community Integration Program)?

Here are some hints to help you feel more comfortable and confident:
Rule One: The professionals on the FSAC are happy to have your input. If they use words for programs or refer to activities that are unfamiliar—raise your hand and ask them to explain. When people work in agencies, they develop the habit of using initials or other shortcuts for programs. There is no reason to be embarrassed if you don’t understand what they are talking about. Chances are someone else doesn’t know either. Ask questions.

Rule Two: Ask that agendas and written materials be distributed before the meeting. This will allow time to review materials and prepare questions prior to the meeting. You could also ask other members about issues the advisory committee will be discussing.

Rule Three: At meetings, rules of order are used to ensure that everyone has an equal opportunity to voice their opinions and to vote on decisions. Many committees’ use ‘Robert’s Rules of Order’ which ensures consistency in how meetings are conducted. Although these rules can be complicated, the following will help you to understand how Robert’s Rules work. If the committee has bylaws, these will provide some information on how the Family Support Advisory Committee works.
Children who are currently being served in the Children with Disabilities program may be placed on a "temporary" waiting list for needed services if, at the point the need arises, there are not enough funds to pay for the additional needed services. Any new or 'freed up' funds for needs for the children already receiving services shall be allocated prior to taking new children off the waiting list.

Richland County, 2004 Family Support Plan Update

Issue: Family Needs Assessment

Program Guidelines: The amount of Family Support dollars each family receives is based on 1) family need as identified in the service plan; 2) availability of resources from other programs and/or community resources to meet the needs; and 3) the annual maximum in Family Support funds per child with disabilities. The legislation set the maximum amount a child can receive at $3,000 per year unless a larger amount is requested by the county and authorized by the state. (Wisconsin Statute 46.985(6)(g)) and Administrative rule HFS 65.06).

Discussion Questions

What are the criteria used for determining individual family need?

What are allowable uses for the funds?
Examples of County Policy:

“When evaluating the allocation of any funds, questions the case manager shall ask include:
1. What services are the child/family eligible for through Medicaid fee for service?
2. Is there a health and safety risk for the child?
3. Is there a hospitalization/institutionalization that has lasted or is expected to last more than 30 days?
4. Is the crisis related to the child’s disability?
5. Will the requested service provide relief for the crisis?”

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“Only inclusive recreation (one which takes the child out into the community with their peers) is allowed. Examples are: Boy/Girl Scouts, health club membership, entrance fees to special events, swimming lessons, etc. Examples of recreation which is not inclusive and not covered would be movie or video games to watch at home or carry out food. ... Only specialized toys will be purchased, or those that a therapist recommends. Normal everyday toys may be purchased by the parents as any parent would do.”

Forest, Oneida and Vilas Counties 2004 FS program plans

Issue: Family Support and the Children’s Waivers

Program Guidelines: Any county can choose to participate in the Children’s Long Term Support Medicaid Home and Community-Based Services Waivers (CLTS Waivers) and use Family Support funds as match for CLTS Waiver services. Children enrolled in a CLTS Waiver can use Medicaid funds more flexibly than “regular” Medicaid card services.

accommodations would work best for them. By State Law, the FSAC must meet at least quarterly. Let the members know the committee meeting dates in advance so they can make arrangements for childcare and other family responsibilities.

- TRAINING: Provide financial support for parents to attend relevant conferences and other training events (i.e. Circles of Life). Educational and networking opportunities for parents can provide "perks" and allow them to enhance their abilities and re-energize themselves.

- SNACKS: Depending on the time you are meeting, members may not have had the opportunity to eat lunch/dinner. Having food available also makes the meeting feel more informal.

- SOCIAL INTERACTION: Committees function better if the members know something about each other. Take time to get to know each other. Advertise the meetings as a chance to meet other families.

- FEEDBACK: Establish a mechanism for feedback from committee members—one that feels safe for members to offer comments and criticism. It is a good way to check to make sure that the meetings are respectful of the membership’s diversity (cultural, racial, economic, and ability).

- REIMBURSEMENT: Consider reimbursement for time, childcare, and/or transportation for parents. If reimbursement is possible, make sure it is offered to all parent members and that the rules for being reimbursed are clearly stated. One county gives parent members mileage reimbursement from administration funds.
LOGISTICS: Talk with the parent members to

LEADERSHIP: If possible, a parent should be

EXPECTATIONS: Develop a shared understanding of expectations regarding meeting attendance. Develop a policy for a parent who may need to take time off from the committee but wants to remain a committee member. When possible, include absent members by conference call.

LEADERSHIP: If possible, a parent should be the Committee Chair or Co-Chair.

AGENDAS: Although the business of the FSAC is important, the atmosphere of the meeting should feel relaxed and welcoming. Be as informal as possible. Build time into the agenda for sharing ideas and learning about each other. The agenda should be organized for productive meetings, but not so rigid as to prevent discussions that members feel are important. Always build into the agenda a time for introductions. Leave some time to hear from any non-members who are attending and to talk about new issues or issues the group would like on the agenda for the next meeting. Plan the next meeting together.

LOGISTICS: Talk with the parent members to find out the best length, time and location for the FSAC meetings. When a new parent joins the committee, ask these questions again. Just because the meeting was always held on Tuesdays from 6-8p.m. one cannot assume this will always work. Survey the parents on a quarterly basis, to see what

Discussion Questions
Can families reserve some portion of their family support allocation for non-waiver reimbursements if they chose? (Example-direct reimbursements to families for insurance premium payment).

Should a county offer the CLTS Waivers to families using Family Support funds as match?

Should families enrolled in a waiver also receive additional Family Support funds?

Should the FSP fund needs for children enrolled in a waiver that can not be paid for by the waiver?

Examples of County Policy:
“Remaining FS funds may be used for matching a DD waiver (CLTS, CIP1B)”
Winnebago County Wait list policy, March 2004

“At this time, Ozaukee County has not applied for Children’s Long Term Support Waiver funding or additional CIP 1B funding (for children) because the county is required to come up with county matching funds. In addition to the county matching funds requirement, Ozaukee County does not have the developmental disabilities case management staff time available to apply for this funding and case manage additional waiver cases in compliance with Medical Assistance rules and regulations.”
Ozaukee County 2004 Family Support Plan Update

“Rusk County is planning to use FSP funds as match to the Children’s waivers whenever possible. Some FSP funds will be used to fund items/activities that the Children’s Waivers do not allow. A policy will be developed to address the use of FSP funds.”
Rusk County 2004 Family Support Plan Update

“Family Support guidelines for coordination with Children’s Long Term Support (CLTS) waivers:
1. FS funds may be used in crisis situations for any children supported through the CLTS waivers.
2. FS funds may be used for match funds on individual service plans that are a CIP-1B or CLTS locally matched slot. Requests for services will be prioritized according to Sauk County FS policy as funds are allocated annually
3. Children that receive funding for intensive autism services through the CLTS waiver may receive FS funding for a crisis situation, if funds are available. According to CLTS waiver policy, children receiving intensive autism services cannot receive funding for any other services through the waiver during the 3 years they are receiving intensive services.”
Sauk County 2004 Family Support Plan Update
Other issues for FSAC to consider:

Other issues and policies that the county, with assistance from the Family Support Advisory Committee, must determine include:

- Policies on coordination with other programs
- Policies for developing and monitoring service plans
- Policies for a family modifying their service plan
- Policy on paying for the cost of child care above the normal rate charged for other non-disabled children
- Policy on child care for children above age 13
- Policy on respite care
- Policy on respite weekend away with and without child
- Policy on outreach to new families when there are waiting lists
- Policy on service coordination for families on the waiting list

Example of County Policy

“Respite weekend away: Family may choose to use funds for a respite weekend away and take their child with them. In this instance, up to $65/day lodging for a maximum of 3 days per year will be allowed (maximum per year $195). If a family consists of 6 or more up to $130.00 day is allowed so that either a suite or adjoining rooms to accommodate them will be allowed. Family consists of parent(s) disabled child, and siblings under 18. A family may choose to use their maximum $195.00 per year for camping fees instead of hotel lodging. No mileage allowance Forest, Oneida and Vilas Counties Family Support policies updated December 2003.

Part Two: Making It Work

Tips for Supporting Parents on Advisory Committees

Whether you are a new or current parent member of an Advisory Committee, a chair of the Advisory Committee, or a Family Support Coordinator, the following tips may help you increase the support and retention of parent members, and the committee’s effectiveness.

- PARENT ORIENTATION: This is placed first on the list because no parent should be placed on a committee without receiving an orientation to the committee. The orientation can be one-on-one, with a few members or the whole committee. Orientation should include relevant program information (committee’s mission, staffing, facilities, budget, previous policy decisions, and committee’s operating rules). Consider pairing a new parent member with a veteran parent member who they can call with questions or for advice.

- KEEP IT MEANINGFUL: Make sure the committee discussions and decisions are important and relevant to services for children with disabilities. There are many issues for the Family Support Program—make sure the committee includes some of the “big” ones.

- INFORMATION: Provide each member with a notebook which includes:
  1) Name and contact information for each committee member;
  2) Staff names and contact information
  3) List of established committee procedures including selection/election of chair;
  4) List of meeting dates for the year;
families in a crisis situation or families who are bringing a child home from an out-of-home placement. (The Department of Health and Family Services, Bureau of Developmental Disabilities Services, December 2003.)

2004: The number of families waiting for the Family Support Program is higher than the number of families actually served. In 2003, there were 3300 children on the formal waiting list for Family Support.

For more information on the Family Support Program contact your county’s Family Support Coordinator or the Wisconsin Department of Health and Family Services. (608.266.7469). To locate your county FS Coordinator, call Wisconsin First Step (800.642.7837 or TTY 600.282.1663) or locate the information on the Internet at http://dhfs.wisconsin.gov/bdds/fsp.htm.

The Family Support Program Guidelines and Procedures (PSL-595, revised 10/99) is a detailed description of the program. Ask for a copy from the State or from your Family Support Coordinator or view it on the web at http://www.waisman.wisc.edu/FAN/

What Is The Family Support Advisory Committee (FSAC)

Wisconsin law requires that every county appoint a Family Support Advisory Committee that has parents of children with disabilities who are under 21 as the majority on the committee. The parents can include families that participate in the Family Support Program and families that are on the waiting list. Ideally, parents would represent the cultural, economic, and disability diversity that is represented in the Family Support Program.

In addition to a majority of parent members, the group must also include representatives from the county department of human services or community programs, county department of social services, school districts and public health agencies. At least one member must be a person who provides community services to children with disabilities or families eligible for the program.

A county can combine the Family Support Advisory Committee with other committees that advise programs for children with disabilities. In some counties the FSAC has been combined with Birth to 3 or other committees or advisory boards for children’s services.
A Short History of the Family Support Program in Wisconsin

1985: The Wisconsin Legislature and the Governor agreed that family’s raising a child with a disability at home deserve assistance. The Family Support Program was established to provide the individual supports that help keep families together and to allow children to remain in their homes and participate in their communities.

In-home support for families who have children with severe disabilities. The Family Support Program provides individual services and supports to families who include a child with severe disabilities. The Program recognizes that meeting the needs of children who have severe disabilities may place hardships on a family’s emotional, physical and financial resources.

The Program offers:
- Information and help in finding services and maximizing community resources;
- Limited funding to buy needed services and goods that can’t be bought through other sources;
- Help in linking families with other families to strengthen natural supports.

Program Guidelines
The foundation of the Family Support Program is the belief that parents of children who have severe disabilities know best what they need. Family Support Coordinators and parents work together to develop an individualized service plan for each family. Home modifications, transportation, specialized equipment, nursing care and respite are examples of items and services the Family Support Program can help the family purchase.

Who is Eligible?
Families are eligible for services if they have a child with a severe disability, under the age of 21, and living at home. A severe disability is a physical, mental, or emotional limitation that seriously restricts the child’s ability to carry out basic daily living activities such as self-care, learning, communications, mobility and self-direction. Although family income is not a basis for eligibility, cost-sharing may be required on a sliding fee scale.

Will the Program Meet the Needs of all Eligible Families?
Family Support is a state-funded program. Because each county has limited funding for this program, eligibility does not guarantee a family will receive services. Agencies may have waiting lists for services and assessments. Administering agencies make the final decision on who is served and approve each family’s service plan. Priority for services may be given to...