



FLAME STARTERS

Strengthening and Broadening Family Support Efforts

Do you have questions or comments?

If so, please contact:

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Minnesota Technical Assistance for Family Support

Strengthening and broadening family support efforts

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Introduction

September, 2001

Interagency Early Intervention Committees (IEICs) are charged with designing, implementing and monitoring a system of early intervention for children with disabilities, ages birth to kindergarten, and their families. This system includes formal services for children, as well as systems of family support. Federal funding is allocated to local fiscal hosts by the Department of Children, Families and Learning, and each local IEIC submits an annual plan for the allocation of those funds.

MN*TAFS (Minnesota Technical Assistance for Family Support) offers training and technical assistance to strengthen and broaden family support efforts of IEICs. We are passionate about the necessity of supporting families, and frequently use a symbol of "fire" to represent the intensity and importance of it. These FLAME STARTERS are a tool, written by MN*TAFS and designed to assist you as your team works to support families raising young children with disabilities.

What is a "Flame Starter"?

A "Flame Starter" is something that ignites sparks or begins a fire.

We offer them here as topical papers, intended to initiate "sparks" within your family support subcommittee and IEIC. The provocative topics are intended to lead to growth and expansion of your attitudes, beliefs and efforts. They will be of interest to you as you work together as a team. There are 3 sections of Flame Starters:

1. IEIC and Family Support Background
2. Elements of Family Support
3. Concepts of Family Support

Suggestions for use:

- Review the "IEIC and Family Support Background" section as your IEIC looks ahead to create a common understanding and improve your work. Use these Flame Starters as part of your "Orientation Packet" for new members. Refer to them as issues come up regarding funding, recruiting new members, expanding efforts and supporting parent members.
- Discuss the "Elements of Family Support" in depth with your Family Support Subcommittee on an annual basis. Based on needs highlighted by families in your area, determine which elements are a priority. How will they be addressed?
- Use the "Concepts of Family Support" with the IEIC and Family Support Subcommittee. Each provocative topic here can offer an opportunity for rich discussion regarding your group's philosophy for supporting families. Is the committee "tinkering" with family support principles to simply plan activities? Or, are attitudes being transformed about how to work with families and enhance existing systems and efforts?

We welcome your feedback about these Flame Starters. Please share your thoughts with us!

Minnesota Technical Assistance for Family Support
Strengthening and broadening family support efforts



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Elements of Family Support

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FLAME STARTERS

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Minnesota Technical Assistance for Family **Support**
Strengthening and broadening family support efforts



FLAME STARTER (T)

Interagency Early Intervention Committees: An Overview

September, 2001

The crucial need for collaboration among local agencies serving children with disabilities and their families has long been recognized. In 1985, the Minnesota Legislature mandated local communities to work together to better address the complex needs of children with disabilities, ages three to five and their families. This legislation resulted in the formation of Interagency Early Intervention Committees (IEICs) across Minnesota. The legislation has since been further refined and teams are now asked to address the needs of children beginning at birth (to age 5) with disabilities and their families. There are approximately 95 IEICs throughout the state.

How are IEICs formed?

A school district, a group of districts or special education cooperative, in partnership with the county or counties in which the district is located can create an IEIC. An IEIC may be an active component of a Family Service Collaborative, a Mental Health Collaborative or part of another interagency structure (i.e., a Community Transition Interagency Committee).

Critical Questions:

*What are the current geographical boundaries for our IEIC?
Are they the most appropriate?
Are we linking with other collaborative initiatives in our community?
How?*

Who are members of IEICs?

By legislation (M.S. 125A), IEICs must include representatives of local/regional health, education, and county human service agencies, county boards, school boards, early childhood family education programs, current service providers, parents of children with disabilities (under age 12), and other private or public agencies, as appropriate.

Critical Questions:

*Do we have active participation of all mandated members?
How often are new members recruited?
Do we offer an orientation to new members?
Have we formalized our responsibilities for members?
How are parents reimbursed for their participation?*

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FLAME STARTER (1)

Interagency Early Intervention Committees: An Overview

(continued)

What must IEICs do?

Legislation directs committees to elect a chair, meet at least quarterly and perform the following duties:

1. Develop public awareness systems designed to inform potential recipient families of available programs and services.
2. Implement interagency child find systems designed to actively seek out, identify, and refer infants and young children with, and at risk of, developing disabilities and their families.
3. Establish and evaluate the identification, referral, child and family assessment systems, procedural safeguard process, and community learning systems to recommend, where, necessary, alterations and improvements.
4. Assure the development of individualized family service plans (IFSPs) for all eligible infants and toddlers with disabilities from birth to three, and their families; and individual education plans (IEPs), individual service plans (ISPs) and individual interagency intervention plans (IIIPs) when necessary to appropriately serve children with disabilities age three and older and their families; and recommend assignment of financial responsibilities to the appropriate agencies.
5. Develop a process for assuring that services involve cooperating agencies at all steps leading to individualized programs.
6. Facilitate the development of a transitional plan if a service provider is not recommended to continue to provide services.
7. Identify the current services and funding being provided within the community for children with disabilities under age five and their families.
8. Develop a plan for the allocation and expenditure of additional state and federal early intervention funds.
9. Develop a policy to enable a member of an interagency early intervention committee to allow another member access to data classified as not public.
10. Participate in needs assessments and program planning activities conducted by local agencies.
11. Review and comment on the early intervention section of the total special education system for the district, the county social service plan and the sections of the community health plan that address the needs of children with special health care needs.
12. Prepare a yearly summary on the progress of the community in serving young children with disabilities and their families including the expenditure of funds, the identification of unmet service needs identified on the IFSPs, and specification of policies impeding the implementation of this section.

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Interagency Early Intervention Committees: An Overview

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Critical Questions:

How does our IEIC address these duties?

How have things improved for children with disabilities and their families in the past few years?

What additional priorities have we identified for our particular community?

Have we developed a work plan to address these priorities?

Does our meeting schedule support the accomplishment of these activities?

Do we use task forces or subcommittees to address specific needs?

What decision making structure have we established?

Do we have a practical, effective set of "operating principles" or bylaws that assist in establishing a governance structure?

How are funds allocated to IEICs?

Three categories of funding are currently available to all IEICs on an annual basis. Each IEIC must develop an annual plan which indicates how the funds will be utilized. The categories of funding are:

1. Early Intervention Flow Through Dollars (Fiscal Source Code H)

- Target age group: children eligible for Early Childhood Special Education under age 3
- Funding source: federal discretionary money (Part C, Individuals with Disabilities Education Act - IDEA)
- Funding amount: based on the number of children with an IFSP from your local area (birth-3) as of December 1. Refer to the Annual Allocation Plan to verify the amount for the current year.
- Intended use:
- early Intervention Services where funding is otherwise not available (i.e. service coordination)
 - services during the pendency of a conflict procedure, or
 - interagency child find system activities

2. IEIC Funds (Fiscal Source Code I)

- Funding source: federal discretionary money (Part C; Part B, Section 619, IDEA)
- Funding amount: \$2000/IEIC, plus additional money per eligible child under age 3. Refer to the Annual Allocation Plan to verify the amount.
- Intended use:
- outreach and public awareness
 - stipends for family participation on the IEIC
 - training or technical assistance, or
 - meeting expenses

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FLAME STARTER (1

Interagency Early Intervention Committees: An Overview

(continued)

3. Family Support Funds (Fiscal Source Code J)

Target age group:	children eligible for Early Childhood Special Education under age 6
Source of funds:	federal discretionary money (Part C; Part B, Section 619, IDEA)
Funding amount:	\$2000/IEIC, plus additional money per eligible child under age 6 (as of December 1, annually). Refer to your Annual Allocation Plan to verify the amount.
Intended use:	provided in the Annual Allocation Plan

Critical Questions:

How are our priorities for funding determined?

Are the operating procedures of our fiscal host "family friendly?"

Are interagency activities in place on a year-round basis?

Are the annual allocation plan and budget shared with the committee members, with written updates provided at each IEIC meeting?

How are we determining the effectiveness of IEIC efforts and activities?

How does the use of these three sources of funding create a unified effort?





FLAME STARTER (2)

Role of Family Support Subcommittee

September, 2001

The Interagency Early Intervention Committee (IEIC) Family Support Subcommittee manages the IEIC Family Support Plan and its implementation. The focus on family support is an effort that began in 1995. The Family Support Subcommittee is required by the application process.

Membership:

Parent Majority

Each subcommittee MUST consist of a parent majority. Although every agency does not have to be represented on the subcommittee, professional representation is very helpful and strongly encouraged. A partnership between parents and professionals in planning shares the responsibility and enhances the ownership of the plan.

Criteria

Parent members must be the parents of children with special needs, but it is not necessary for parent members of this subcommittee to be members of the IEIC.

Where to Find Parent Members

Other parents	Early Intervention staff
IEICs	Direct service staff
Support groups	Medical center staff
Advocacy organizations	Disability organizations/associations
Agencies (education, social services, public health, child-care, etc.)	

Diversity Considerations

Aim for diversity in parent membership, keeping in mind such things as: gender, socioeconomic status, disability type, ethnic or cultural backgrounds. Committee membership should reflect the makeup of the community. CAUTION: Do not solicit your subcommittee membership from an exclusive group, such as a mom's support group, a Down Syndrome support group or a specific Early Childhood Special Education classroom.

Responsibilities:

1. Designate a Family Support Contact person.
2. Do a Needs Assessment of families in the area, both formally and informally.
3. Plan family support activities based on the data that was gathered.
4. Complete the "Annual Allocation Plan" as required by the Department of Children, Families and Learning. This would include:

- **Work Plan.** The more detail included in the work plan, the more effective

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Role of Family Support Subcommittee

(continued)

these efforts will be. Indicate specific activities, responsible persons, timelines, etc.

- **Budget** Detailed estimates and breakdowns of the budget will facilitate timely and appropriate expenditures. Professional input may be very helpful here. **SUGGESTION:** Request from an administrative designee a written description of the process and a completed sample form for requesting payment for expenses/reimbursement. If possible, also receive this information through a verbal presentation to the group.
 - **Changes/Growth.** Carefully consider where you were and where you are currently in your initiative to support families. Aim for changes. Watch for an increase in participation at events, greater diversity of approaches in how you address needs, improved quality at events, evidence of more community partnerships, greater parental involvement in planning, etc.
5. Manage the activities identified in the work plan. This entails either regular monthly or quarterly meetings to ensure that activities are happening as planned and that expenditures are on target. While the final authority for the implementation of your annual allocation plan falls to the IEIC and its fiscal host, the Family Support Subcommittee assumes a great responsibility in the daily operations of family support activities.
 6. Report to the full IEIC on a regular basis regarding: activities, ongoing needs, data and trends, successes and issues. Written reports and updates should be shared with the IEIC chairperson for documentation. Verbal reports given at meetings and parent stories are appropriate.
 7. Look for ways to combine resources, collaborate on projects and initiatives and strive to find ways to continue the support for families as their children get older.

A strong, well functioning IEIC Family Support Subcommittee is necessary for the success of family support efforts. This is a process that grows over time.





Parents on the IEIC

September, 2001

Parents have an important role in guiding system policy on a local level through the Inter-agency Early Intervention Committees (IEIC) and other collaborative efforts. Ideally, the perspective and guidance of parent members can keep the systems practical and useful, and reflective of the realities of family life. The presence and questions of parents keep the language understandable. For that reason, parent representatives are required by Minnesota Statute 125 A.30 subd.(a) as members of IEICs.

Recruiting parents and maintaining parent participation on the IEICs is often mentioned as a challenge. Parents process and function with great individuality and can bring a wealth of capacity and diversity. Some bring leadership skills that are a rich community asset. It works best when IEICs aim for having more than one parent representative, to avoid having a token parent or creating a situation where one parent alone becomes burdened with too many responsibilities, or having to represent the voices of all parents.

Only an active, responsive, interagency committee that functions in a respectful and open climate with a feeling of a "level playing field" will experience the meaningful participation of parents.

1. Invite parents.

- Briefly and clearly describe what the committee does
- Use many different strategies that are culturally appropriate, i.e., print, media, personal contact, letters with a follow-up call
- Describe the purpose and history of the IEIC
- Include a description of IEIC membership
- Identify meeting times and the expected time commitment
- List expectations and opportunities for parents who participate
- Distribute the invitation through service providers, support groups, advocacy organizations, medical staff, other parents
- Give an honest approximation of how much time this commitment will require

2. Provide community supports.

- Make parents aware of available supports
- Meeting stipends
- Childcare provided or reimbursed
- Transportation expenses, etc.
- Describe process for accessing supports

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Parents on the IEIC

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3. Validate the experience and the role.

Parents have a lifelong commitment and responsibility to their child with special needs and must guard their personal energy. In order to commit to a committee membership, they need to:

- understand the function and process of the committee
- feel comfortable enough in the atmosphere of the IEIC to ask the "obvious questions" that may clarify for the whole group
- have opportunity for responsibility and leadership
- see results for their efforts
- feel they are working as an equal partner on a level playing field, as evidenced by equal access to information or an equal voice

4. Adopt an active IEIC posture.

- Expect more of the committee process than simply processing through budgets and state driven rules and regulations.
- Go beyond giving agency updates as the whole meeting agenda.
- Work together to address community concerns. Those activity based outcomes or products have the natural effect of engaging new parents who bring new commitment and enthusiasm.

5. Strive to make IEIC meetings accessible for all.

- Meetings: Meeting time may be a factor for parent participation. Consider a meeting time and place that is "mutually inconvenient." When the group works from that framework, it is honestly possible to validate everyone's commitment and acknowledge in an ongoing way what each one gave up in order to attend.
- Diversity: Aim for diversity in parent membership; gender, socioeconomic status, disability type, ethnic or cultural background.
- Location: Look for a neutral, community-based site that is not affiliated with a specific agency.

Use the Family Support Subcommittee to increase ongoing awareness of the IEIC. As more parents participate in that role, developing family support activities and efforts, an increased awareness of the IEIC and its potential will follow. When parents see that their participation actually impacts the life of their child and family or someone else's, the time and effort directed toward **IEIC** membership becomes time well spent.





FLAME STARTER (4.

Recruiting, Orienting and Mentoring Parents

September, 2001

A focused and systematic plan to address recruitment, orientation, and mentoring of parents is critical to successful parent involvement. Recruitment addresses the question of how to find parents. Orientation and mentoring are equally important strategies to consider how to keep parents involved in a meaningful and authentic way. They are companion concepts and should occur together for success. Recruitment without orientation is not effective. Don't orient parents without mentoring them.

1. Recruitment:

Recruitment is everyone's job. While many think of this as a responsibility that belongs to a single person, or one particular group, it actually is bigger than that. Every contact sends messages, positive or negative, about the group to potential participants. Contact with **everyone**, from the administrators to the support staff who answers the phone, either welcomes parents as partners or distances them. Each staff member may have unique perspectives that can strengthen recruitment efforts. All staff members have repeated opportunities and a basic responsibility to spread the word, as do other parents. Everyone should have a common understanding of the group's mission, activities, and target population. Recruitment is:

- an ongoing process, not a one time event
- consists of communication and marketing
- includes formal systemic procedures, like canvassing all eligible parents, and informal approaches like word of mouth, or ongoing newspaper articles about events and opportunities
- occurs year round
- includes a periodic review of the process to ensure that efforts are effective
- includes a cross section of parents that is representative — more than one parent
- employs multiple strategies that are culturally appropriate
- occurs in print, media, personal contact, and letters with a follow up call
- is extended many times from multiple sources
- reflects cultural awareness and respect
- is user-friendly adapted for the audience they are intended to attract

2. Orientation:

Create a packet of informational materials that is used to orient new members and take the time to go over it with them. These materials may already be assembled. If not, be aware that most of this material has probably already been written and exists somewhere. It should not be necessary to create this entirely from scratch. The packet should include information about:

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FLAME STARTER (4.

Recruiting, Orienting and Mentoring Parents

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- the charge and history of the IEIC; the impact on the community because the IEIC has existed
- the structure of the group (IEIC)
- funding streams or the flow of dollars
- the mission of the group and how it connects to other efforts
- subcommittees and their mission
- membership information including terms of office and makeup of members
- responsibility of members, and supports available to parents participating

3. Mentoring:

- provide a mentor to help new parent members feel comfortable
- provide ongoing individual orientation through relationships
- create a welcoming and comfortable atmosphere
- include parents in casual conversations
- make introductions more than a name or title
- follow up after a meeting with a phone call
- provide support information on reimbursement, system of billing, helpful acronyms
- seek balance in the relationship; opportunities to give and take
- create opportunities for active participation, not just presence
- probe and suggest opportunities for growth

Recruitment, orientation, and mentoring need not be complex or cumbersome processes. It will require effort and determination to get started, but there will be visible rewards.

Reference:

D'Angelo, D. and Beckstrom, S. (1995). Resources for Recruiters, RMC Research Corporation, 1000 Market Street, Portsmouth, NH 03801.





FLAME STARTER (5)

Interagency Funding Practices

September, 2001

1. Why is the Department of Children, Families and Learning the lead agency for Part C Individuals with Disabilities Education Act (IDEA)?

The governors of each state are responsible to designate a lead agency in each state. In Minnesota, the Department of Children, Families and Learning has been designated as the lead agency. This agency was selected because extensive work was being done in the area of early childhood. Systems were already in place for the deployment of staff, distribution of funds and program financial accountability.

2. What does the term "Supplanting" mean?

Supplanting or non-supplanting are terms most often associated with federal funds and federal programs. Federal funds are generally appropriated to encourage program expansion and growth in targeted areas such as Part C. Supplanting occurs when federal dollars are used to fund services previously funded with state and local dollars. Accounting practices must track expenditures to assure federal funds increase and expand services and do not supplant services previously funded with state and local dollars.

The non-supplanting concept has also been used with Part C when referring to expenditure and responsibilities between and among participating state and local agencies. For example, several federal and state statutes have held agencies responsible to maintain a prior level of service and/or expenditure (i.e., maintenance of effort), prior to Part C, to prevent agencies from shifting program costs to another agency. Counties are to maintain their 1993 level of expenditures as required by M.S. 125A.

3. What is the process for interpreting what supplanting is? Who would serve as a resource?

Agencies must know the amounts expended in state and local resources in the prior year for any given activity. They must then expend at least that amount in the next year before allocating federal funds to expand and enhance the program. Accounting procedures and program records must be maintained that will ensure agencies are in compliance with this requirement.

Local Directors of Special Education, coordinators of ECSE programs and state level personnel should be able to address the non-supplanting requirements.

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Interagency Funding Practices

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4. Could you offer some specific examples of what supplanting may be in the arena of family support?

It is more important to follow the principle of non-supplanting after it is determined what activities are eligible for family support dollars. For example, if it is determined a particular activity is eligible for family support dollars through Part C and Section 619, and it has been funded in the past by a particular agency, that agency should continue to expend at the same level. Part C and Part B, Section 619 funds should be used to make it available to more people or to use the funds to enhance what is already being done.

5. What are the differences between "encumbered" and "expended"?

We use these terms to mean the following: You encumber funds when you inform the fiscal host of the intent to spend funds that have been budgeted. When you fill out a purchase order for a computer, the funds are in the budget and are encumbered so that they will not be spend on something else. The funds are expended when the invoice is received from the vendor and is paid.

6. What are the timelines to expend funds for the various funding streams? (Funding Source Code H, I, J)?

The timelines are July 1 through June 30 for all three of the funding sources. However, any unexpended amount of your entitlement under FSC H, as of June 30, is automatically carried over into the next fiscal year. The carryover amount is automatically the first money expended the next year. There is no carryover from one year to the next for FSC I and J.

Fiscal hosts may require that expenditures be reported to them prior to June 30 in order to close books for the year. This does not mean activities cannot be planned for June. However, there may be local reporting procedures in place of which you should be aware.

7. What fiscal reporting system is in place for family support funding? Can other agencies utilize this system?

The electronic data reporting system (EDRS) through the Department of Children, Families and Learning is the system for accessing family support funds. All expenditures must be reported on EDRS in order to receive reimbursement. It is the responsibility of the IEIC to work with the fiscal host to set up a process for expediting reporting and payment procedures. This is true for all aspects of the early intervention system.

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FLAME STARTER (I)

Interagency Funding Practices

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8. Can FSC H (early intervention service funds), I (IEIC) or J (family support) funds be contracted to other entities such as advocacy organizations, non-profits, and other local governmental bodies?

Yes, the fiscal host can contract with another agency or entity. The fiscal agent will report the amount of the contract on EDRS to receive the aid and issue a contract to the agency administering the funds. The contract will specify the activities and/or duties of the sub-contractor. The sub-contractor will need to maintain records of activities and expenditures and make those available for audit purposes. This applies to all aspects of the early intervention system.

9. Could you identify what IEIC family support funds cannot be used for?

Family support funds (FSC J) are designed to build and improve community partnerships, community capacity and enhance the continuum of existing family support programs available in the community. Funds are to address two or more elements of family support, as defined by MN*TAFS. Family support funds are not intended for the purchase of individual services, equipment or personal vouchers to families.

It is important to keep in mind that family support funds are only one of several revenue sources available to fund family support activities. Local IEICs receive funding through FSC J to develop and implement community based family support activities. These family support activities are distinct from and should not be used to fund such things as: Child find, service coordination, core services, special instruction and related services for eligible children, and additional services including respite care.

For example, for eligible children under age 3, service coordination and early intervention respite care as defined in M.S. 125A may be funded through FSC H when local funds are not available. Respite care may be available for children ages three through five who meet eligibility criteria in programs such as Developmental Disabilities and Mental Health. Respite care could also be available through Developmental Disabilities, Family Support or home and community-based waivers if eligibility requirements are met. In some counties, the local county social service plan includes respite care services under specific conditions. Informal community supports are another source to be considered. A community work group could be created to address this issue.

Local IEICs and their family support subcommittees use a planning tools (needs assessment, participation data, and satisfaction surveys) in their efforts to develop a

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Interagency Funding Practices

(continued)

local system of family support. The elements of family support include: Parent-to-parent support; Information, referral and resources; Community support; Networking activities; Sibling and extended family support; Leadership and advocacy training; Training; and Support groups.

10. Fiscal reimbursement to families is often a complicated and lengthy process.

How can we simplify reimbursement to families for family support expenses?

Our recommendation is to clearly define what activities are eligible for family support funds. It is the responsibility of both the fiscal host and the IEIC to jointly develop timely reimbursement procedures for families. Sub-contracting with another agency may offer an option for easier reimbursement procedures.

11. Periodically, IEIC family support subcommittees have struggled to access funding on a year round basis. Do you have any suggestions for dealing with this issue?

All federal funds are set up on a fiscal year basis. Funds can be accessed from July 1 through June 30. Early on, become familiar with your fiscal host's year end procedures.

12. If parents are hired by a school district to implement IEIC family support activities, does their reimbursement have to correlate with school personnel salary schedules (i.e. paraprofessional, clerical, etc.)?

If a district were to employ a parent to carry out specific responsibilities, I would think the school board would have to establish an employment category and set an appropriate wage level.

13. Can a parent be employed as a consultant by a school district? What procedures would need to be in place? What are the benefits/drawbacks to this strategy? Are there any limitations in the number of hours they can be hired for?

Yes, a district may contract with a parent to carry out specific activities. This can be done through a formal contract to be paid when the conditions of the contract are met, or if a long-term contract, at certain agreed upon intervals. The benefits to a school district are as follows: The parent does not become an employee of the district, and the district pays an agreed upon amount of the contract and does not have to withhold FICA, taxes, etc. The disadvantage to the parent is he/she has to report to social security and submit estimated taxes to the IRS.

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Interagency Funding Practices

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14. Can a parent be employed by an agency other than a school district and be reimbursed to implement family support activities?

Yes, the agency would submit its invoices to the fiscal host so the expenditures can be entered on EDRS.

15. Do union bargaining rules apply or impact a parent being employed to complete IEIC family support activities? Any recommendations?

The union rules could very well impact a parent being employed by any of the agencies. This would depend on whether the position is considered permanent, long term and how the position is defined and classified within the organization.

16. What are the definitions for stipend, reimbursement, salary/wages and contract? How do they relate to taxable income?

Stipend: A fixed payment, usually for a specific task or activity. For example, a stipend might be paid for reading grant applications.

Reimbursement: To repay someone for expenses incurred. For example, to compensate someone for childcare expenses or travel expenses.

Salary/wages: A fixed payment, at regular intervals for work performed. A person receiving a salary is on the company or agency payroll, and usually a long-term commitment is established.

Contract: An agreement between two more or parties with expectations and outcomes clearly defined for all. Contracts are generally used for larger projects than are stipends.

When a person is salaried, the employer withholds and remits taxes and social security for the employee. Persons receiving a stipend or contract must manage taxes and social security payments themselves.

17. What happens to family support (FSC J) funds that are not spent at the local level?

If family supports funds are not spent within the fiscal year ending June 30, they will not carry over to the next year for that IEIC.





FLAME STARTER 6

Outcomes of Family Support

September, 2001

Families who are Supported Early On:

... have less need for advocacy and ultimately less litigation

Families who are supported early on have stronger relationships and more trust in the professionals who work and interact with their child and family. It is a trusting relationship that allows families and professionals to work out their differences and find common ground when there are challenges. Professionals who are involved with local family support projects have reported this.

... are more able to identify and voice their needs

Families who are supported early on have been shown the world of the possible: from other parents who are mentors or peer models, from professionals who share and fully disclose all information and options in an open manner. Parents who are supported are likely to have a more complete understanding of the choices and opportunities that exist for their child and family, have more confidence in the choices they make and are less likely to find themselves unhappy at a later date after discovering there were other choices and options they weren't aware of.

... don't get "stuck" in anger and denial

The Beach Center at the University of Kansas has done a long term study on family support and found that families who are supported are more able to move on from the anger and denial which may be present for parents of children with special needs. Parents who don't get bogged down in anger or remain in a state of denial find "normal" for their families faster and are better able to make choices regarding their child and family

...function better as partners with -professionals

Parents who have been supported by parents and professionals feel that people have walked through some of the hard times and challenges with them and have a better understanding of their lives and child. It has been reported on numerous occasions that when a parent feels valued and supported it is easier to establish a trusting relationship, which leads to real partnerships.

For families who are supported early on there are many positive outcomes. These positive outcomes can have tremendous impact not only on the family and child, but also on professionals who work and interact with children and their families.

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Outcomes of Family Support

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Family Support is both a *set of beliefs* and an *approach* to strengthening and empowering families and communities so that families and children can thrive. There are many ways in which a family can find support both formally and informally through a "resource-based" model. This can mean both emotional and informational support.

In a traditional "service based" model, services are designed and provided "to" or "for" families by professional service providers. Services are based on available personnel, eligibility criteria, funding sources, etc. In a "resource based" model, however, the strengths and resources of each family are used as a basis for reaffirming families. Every parent has used some sort of support system outside of his or her immediate family at one time or another. It might be a grandmother giving advice, a neighbor offering childcare, a faith community, a community service group, a doctor, teacher, or another professional. Whatever the offer, whatever the connection, the result builds a linkage that demonstrates care and gives the message that "you are not alone".

A "family supportive community" is one which connects and revitalizes families. It offers families better access to information and better access to each other. Better information and connections lead to more personal confidence.





FLAME STARTER (7)

Linking Your Efforts to Strengthen and Broaden

September, 2001

Since 1995, local family support teams of parents and service providers have been working together within the IEIC framework to find ways to help parents who have young children with disabilities get reliable information and find each other. These efforts include working in parent/professional partnerships to address eight elements of family support.

While the teams relate that these efforts are good and worthwhile, a frustration emerges that these efforts should not be limited to such a small group. Not only does having such a limited target audience prove unworkable in some geographical areas, it also creates what seem like artificial barriers in the minds of parents. For many years, families and service providers have used the term "The Black Hole" to refer to the vast area of need for information, connections, and support for families who have school age children with disabilities.

Families who have young children birth to school age are the primary intended audience for IEIC Family Support efforts, Fiscal Source Code J. Since this IEIC family support initiative comes with financial boundaries and requirements, it is not acceptable to simply dilute these dollars to address the needs of a larger group. But there is no issue with becoming more effective and expanding the results by working with partners and creating linkages to other groups, including families with school age children, all families and all children, and other family support teams regionally or in clusters.

Families with school age children.

Children grow up, and parents expect their experience of partnership and support that was present in early intervention to continue into the school age experience. Facilitating connections between families and establishing a reliable means for families to get information are particularly needed during these school years. Many children are not diagnosed until this time. Parents in this group may have the time and desire to become more involved with others and with system development. Connecting with a parent whose child is older or someone who has "walked the walk" and "knows the ropes" can be a benefit for parents of younger children.

Types of collaborative partners include:

- Parent Involvement Initiatives in the schools
- Local Arcs
- Children's Mental Health Collaboratives
- CTICs (Community Transition Interagency Committees) and transition groups

Shared efforts that may be successful include:

- parent-to-parent mentoring
- certain support groups

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FLAME STARTER (I

Linking Your Efforts to Strengthen and Broaden

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- trainings
- leadership opportunities
- newsletters

All families and all children in the community.

Linking with these groups reflects a desire for integration into the whole landscape of the community.

Potential partners include:

- Community education
- Head Start
- ECFE
- Week of the Young Child activities
- child care organizations
- Family Service Collaboratives
- other collaborative efforts

Possible shared activities include:

- community resource fairs and other awareness activities
- partners in training

Other family support teams regionally or in clusters. Many family support activities have greater momentum, impact, and networking opportunities if they involve families from a larger geographical area and age span.

Possible activities are:

- regional retreats
- specific support groups
- Parent-to-Parent Programs
- newsletters

Logic and common sense would suggest the benefits of using these IEIC family support dollars as "seed money" to broaden the effort to include families whose children are older, to make inclusive linkages to initiatives for all families and all children within the community and even with other families in similar circumstances in neighboring communities or counties. Linkages in family support are healthy and will accomplish more than if each group works in isolation. Our current systems that families must negotiate are fragmented and erratic. For too long there have been many parallel efforts with no connecting point. Making linkages that strengthen the effort and broaden the audience will be especially beneficial for families as time passes.





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FLAME STARTER (8)

Elements of Family Support

September, 2001

In Minnesota, on an annual basis/ each Interagency Early Intervention Committee (IEIC) is asked to develop an annual allocation plan. This plan addresses the local support needs of families and accesses funding available through Part C and Part B, Section 619 federal funding. Every IEIC develops a "family support subcommittee/" and this group is then responsible for the implementation of the "family support plan."

In addition to specific services, families often express a need for connections and resources. These might include: talking to another parent who has "walked the walk" they are now facing; getting all the information available about a specific disability; learning how to deal with sibling issues; looking for a support group.

These needs are most often met through local family support plans. Local IEIC Family Support work plans must address at least two of these elements:

1. Parent-to-Parent Networks

Using trained mentor or veteran parents to support other parents

2. Information, Referral and Resources

Linking to information, resources and services (newsletter, brochures, informational mailings and referrals to community resources)

3. Community Support

Contributions of formal and informal support that strengthens the family's ability to thrive and provide care for their child (*formal*: parent reimbursement for responsibilities provided by parents for family support activities, reimbursement for conferences, child care or mileage, flexibility and increasing community awareness of issues families face. *Informal*: Honoring support from friends, family and community groups.)

4. Networking Activities

Opportunities for family members to meet and network in a casual setting (outcome-based events, not solely recreational events)

5. Sibling and Extended Family Support

Activities that address the concerns and validate the roles of siblings, grandparents and extended family members (Sibshops, informal activities and networks, targeted resources)

6. Leadership and Advocacy Training

Activities and training to empower parents to be leaders and advocates (participation on boards, linking to advocacy organizations, creation of political action committees, etc.)

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FLAME STARTER (8)

Elements of Family Support

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7. Training

Plan, offer and evaluate conferences for parents, professionals and community members. Parents serve as co-trainers or presenters.

8. Parent Support Groups

Self-help, problem solving, topical or educational groups for exchanging information, emotional support, and resources.

Besides the immediate benefits these elements offer to families, research also tells us that families who are supported early on:

- have less need of advocacy and ultimately less litigation with agencies
- do not get "stuck" (in anger, denial, etc.)
- are more able to identify and voice their own needs
- function better as partners with professionals

In addition, research regarding the effects of support confirms that the positive effects of support provided by informal sources generally exceed the positive effects of support attributed to formal support services (Bess, Lingerfelt, and Nelson, 1990).





Parent-to-Parent Support

September, 2001

"I vaguely remember hospital staffs attempts to find us some support. I guess someone must have asked if we would like to be in contact with a parent who had a child with the same syndrome. I must have said yes. Within a few weeks I got a call from my parent match, although her child had been born several years earlier. I remember feeling a connection. We understood one another. She spent much of the time listening. I needed her to listen. I know this connection increased our quality of life."

— A parent

Parents whose children have special needs often feel helpless and alone. This can be true during times of stress, at the point of diagnosis, or when waiting, watching, and worrying that something is amiss with the child. Talking with another parent who has experienced a similar situation can help parents feel less alone and more hopeful. Findings from research and studies about the effectiveness of parent to parent support reveal the following outcomes:

- Parents' ability to cope is increased.
- Parent to parent support increases parents' acceptance of their situation.
- Over 80 percent of parents find parent to parent programs helpful.
- Parent-to-parent programs often begin spontaneously with grassroots effort, which validates the need and rationale that this initiative should be supported.
- This kind of support assists in the adjustment process and may avoid parents getting stuck in anger and denial.
- The kind of support parent-to-parent offers is unique and probably cannot come from any other source.
- Early connections with other parents leads to much lower utilization of advocacy later.
- Parents who are informed and supported learn to identify their own needs.
- Parents who are supported and informed are easier to work with from a system perspective.

The term parent-to-parent support refers to the various ways that one parent supports another parent in a one-to-one relationship. It refers to something different than a large group setting like a support group. There is a range of emotional and informational support provided to parents of children who have special needs in the various Parent-to-Parent Programs, with great variety in how formally the concept is designed or approached. It can include carefully made parent matches based on disability, child age, or family situation. Or, it can describe one veteran or mentor parent in a specific community

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Parent-to-Parent Support

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or geographical area whose role is to connect with all parents in the area whose children have special needs, making informal matches or connections between parents locally as appropriate. The level of documentation each program requires can vary depending on the model designed by a community. Each model may be based on volunteerism, paid time, or a combination of both.

Indicators of Quality for Parent-to-Parent Programs

1. Mentor parents are trained and supported. Appropriate oversight is in place.
2. Provision is made for a range of contact (i.e. face-to-face, phone, in writing).
3. Connections between parents are based on: disability, issues or concerns, family type or situation.
4. Response time between request for activity and contact is timely and respectful.
5. Appropriate referrals, resources and information are provided.

Establishing a parent-to-parent program requires the interest and willingness of experienced parents to connect and support new parents. That interest is, for many, a naturally occurring byproduct of their own experience and emotional acceptance of their situation. Establishing a successful program also requires the partnership and assistance of service system providers. When parents and providers work in partnership to establish and maintain this effort, the resulting program can meet the needs of parents in a most meaningful way.

References:

Santelli, B., Turnbull, A., Marquis, J., and Lerner, E. ((1997). *Parent-to-Parent Programs: A Resource for Parents and Professionals*, Journal of Early Intervention, 1997. Vol. 21, No.1,73-83.

Santelli, B., Turnbull, A., Lerner, E., & Marquis, J. (1993). *Parent to Parent programs: A unique form of mutual support*, Infants and Young Children, October 1995,48-57.

Parent to Parent of Vermont: A network of support and information for families, and a Resource for Professionals. Parent to Parent of Vermont, One Mail Street #69 Champlain Mill, Winooski, VT 05404. (802) 655-5290.

Pilot Parents of Northeast Minnesota, 201 Ordean Building, Duluth, MN 55802. (218) 726-4725.

Family Liaison Project, Arc Southeastern Minnesota, 903 West Center Street, Rochester, MN 55902. (507)287-2032.





Information, Referral and Resources

September, 2001

"It is much easier to work with families who are well informed." This quote, from a professional, has been echoed numerous times around the state.

Along with emotional support, the need for information is consistently one of the top supports preferred by parents of children of all ages, regardless of the severity of their child's disability. These findings are the result of a long-term study undertaken by the Beach Center on Families and Disabilities located at the University of Kansas. When the broad category of information was further analyzed, the following four informational areas have the highest expressed need;

- **Information about the disability**
Regardless of the severity of the child's disability, information about the disability was the type of information most often preferred by parents. Parents want to be informed and understand their child's disability.
- **Living with and caring for the child**
This type of information was most often requested by parents of children with mild, moderate and severe disabilities. Throughout their life span parents are looking for information from other parents and professionals on how best to live with and care for their child with disabilities.
- **Ways to find and get the best possible help**
Families want and need access to current and accurate information that will support them in making the best choices for their child. They also desire information on where and how to access that help for their child.
- **Community resources and services**
The need for this type of information was universal and did not differ based on age or the severity of the disabilities. Parents want to know what type of resources a community has to offer their child with disabilities. (Is there appropriate and accessible housing, recreational activities, transportation and community organizations?) Getting the appropriate services is an ongoing process for families because of the multitude of services available, various ways to access them and differing eligibility criteria.

Financial information and respite care information were also expressed needs, but ranked much lower. In Minnesota, local family support surveys support these findings from the Beach Center study.

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Information, Referral and Resources

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The information that families require is diverse and covers a broad spectrum of disabilities, issues and concerns. There are many ways and formats in which families or professionals who are supporting families can access information.

Resources and Materials that families find useful come in a variety of formats: newsletters, flyers, brochures, books, libraries, organizers/notebooks, videos, and the Internet, etc.

Technology, such as access to and the use of the Internet can play a major role in families' search for information. They can find specific disability information or look for local, state, national, and now worldwide resources. Parents can visit online websites and individual web pages created by parents of children with disabilities or enter chat rooms and talk to other parents.

Referral to both formal and informal community supports can be crucial to whether the family of a child with a disability simply survives, or thrives. When the word "referral" is used, it is often seen as synonymous with the formal service system. Referrals may be made by professionals, friends and family members, or community members. The study from the Beach Center on Families and Disabilities confirms the value of using informal supports and connecting families to other parents of children with disabilities. Receiving emotional support from another parent is important to the families' well being and the childrens' long-term outcomes.

A parent's need for information is paramount in their understanding and acceptance of their child's disability. By providing and helping families access current and accurate information they are able to make the best choices for their child, access the needed community resources and services, and find the emotional support they need to remain a healthy and thriving family.

Promising Practices:

- Share complete and unbiased information with parents.
- Support parents in their search for information through formal and informal connections, printed materials, web site addresses and organizational tools.
- Refer families to services, agencies and individuals who may be a resource.

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Information, Referral and Resources

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NOTE: *In the past, family support dollars (FSC J) have been dedicated to the development and expansion of family support libraries. Creating or adding to an unused family resource library is not an effective use of family support funds.*

Consider these questions as you develop this element and these strategies:

If you are buying books and developing a library, how do you measure and track the usage of those books?

Who and how will people have access to the library?

Should you consider working with existing libraries that are in the business of loaning books?

Is your purchase of books a way of spending (dumping) unused money at the end of the year?

What is the purpose of your newsletter, directory of resources, parent directory or flyer?

Is there another existing newsletter you could consider joining and working with?

Will you need to develop a mailing list for newsletters, flyers, brochures, etc.?

If so, how will you do that?

Is there already an existing mailing list or database? Can you access it?

Reference:

Santelli, B., Turnbull, A., Sergeant, J., Learner, L.P., Marquis, J.G. (1996). Parent to Parent Programs, Parent to Parent Preferences for Support, *Infants and Young Children*, 9 (1) 53-62. Aspen Publishers, Inc.





Community Support

September, 2001

Community Support refers to contributions of formal supports that allow families to participate and be involved and informal support that strengthens the family's ability to thrive and provide care for their child. Research shows that the positive effects of support provided by informal sources generally exceeds the positive effects of support attributed to formal support sources. Working within the formal system, it is obvious that there will never be enough money, enough time, enough professionals to do all that is required when families find themselves living in challenging circumstances.

Formal Support

This refers specifically to how "the system" makes support available.

1. Money

- reimbursement for childcare or to develop childcare capacity
- for personal care attendant (PCA) services to cover meeting time
- funds for stipends, for transportation, reimbursement for phone or other expenses
- payment for responsibility assumed such as editing a newsletter, serving as a parent-to-parent mentor, facilitating a support group, or family support facilitator

2. Flexibility

- meeting at different times or places
- contracting the fiscal host responsibility for the Fiscal Source Code J, or Family Support initiative, to an outside agency in order to;
 - avoid unnecessary procedural delays in reimbursement
 - allow flexibility regarding hiring, job descriptions, and reimbursement

3. Awareness

- promote community and professional awareness of issues families face when raising a child with special needs

Informal Support

Another facet of community support is the way communities, friends, and neighbors network to be of support to individual families. Life changes every day. Sometimes life becomes terribly complex and it is difficult to cope. Under those circumstances, parents often don't get rest, or have the time or emotional energy to tend to the routine details of life. Sometimes life can remain that way for a long time.

Friends, neighbors, relatives, and communities of faith are often invaluable at these times in their ability to create a web of support either for the short or long term. It is important to work closely with the family, operating from inside the basis of their personal choice and

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Community Support

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preference. It is not wise or respectful to make assumptions and proceed without the knowledge or partnership of the family: one family may be very grateful that someone would come in and do their laundry or housecleaning, another would feel violated.

Offer the concrete: "Can I mow your lawn?" "Can I bring you a meal on Tuesday?" "Can I watch your kids Friday after school?" Your contribution could be a donation of some time once, or on a regular basis, so the parent could nap, or have some respite. It might be a fundraising benefit, donations, or a gift of money. It could be ideas. It might mean just being available to listen and do whatever is needed.

The purpose is to provide support. It is not intended to create an unnecessary long-term dependency that enables negative patterns of coping. When approached thoughtfully from the family's perspective, building and participating with friends and neighbors in an informal network of support can be wonderful and life-affirming, while also providing invaluable resources.





Networking Activities

September, 2001

When developing a network of family support activities and practice, many communities look for ways to start by having some sort of get-together with a relaxed atmosphere that does not intimidate parents. For various reasons, many parents don't seem willing to participate in more structured events such as support groups or trainings as they begin their role as parents of a child with a disability. What seems to be more successful for parents who are entering the system is a casual and relaxed gathering, either for parents or whole families, to meet one another and begin to network.

Networking activities are valuable for parents as a non-threatening, undemanding place to begin to connect with others and learn. With new diagnoses and new parents entering the system all the time, it should remain as one family support strategy communities use in an ongoing way. However, family support teams should take the responsibility to move past this beginning type of activity, and use it as a way to expand to the other elements of family support, not as the only ongoing core family support function.

When approached in this way, networking activities offer tremendous potential as a family support resource tool. Consider these possibilities to ensure that the gatherings are worthwhile and have meaningful outcomes to:

- offer access to pertinent information; brochures, flyers, books, videos
- build a parent database to communicate directly with parents
- provide a needs assessment opportunity; a simple survey or a focus group discussion to find out about their needs
- recruit parents to be part of family support or policy work
- be part of the family support planning subcommittee or the IEIC
- inform or motivate with a speaker
- create linkages by co-sponsoring an event with another group in order to bring older and younger families together

The goal for this kind of event is that parents and families make connections with one another for mutual support and/or have access to information. It is not primarily to entertain, or to provide respite from the children, although those things may certainly happen in a secondary way. Because the family support work of Minnesota's IEICs and family support subcommittees uses public funds, there are rules about its use. Any use of public funds must be fiscally responsible and avoid extravagant spending. Events that are purely recreational or social in nature, with no desired goals or outcomes are not an acceptable use of public funds. It is not acceptable for liquor to be served or paid for at networking activities. If the goal or idea is networking or bringing people together, avoid sponsoring an

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Networking Activities

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opportunity that doesn't allow people to come together, such as going to the movies or out shopping. Find creative ways to structure the environment of this activity in order to meet these goals.

The key is creating an atmosphere that is relaxed enough that people/ through these informal connections, share what is important for them. Once that happens, the group can brainstorm creatively and together develop a plan that invigorates, without draining the energy of those involved.

Questions to Guide Planning:

Are parents and professionals involved in the planning?

What are the specific outcomes we would like to see as a result of this activity?

How will we record or document the results of this activity?

What proportion of eligible parents do we hope will participate?

Who are our partners to strengthen and broaden this effort?





Sibling/Extended Family Support

September, 2001

The Role of Brothers and Sisters

Relationships between brothers and sisters are among the most rich and enduring bonds that children and adults experience. Brothers and sisters generally spend more time with one another than they do with their parents, not only during childhood, but throughout the course of their lives. The parent's role will fade, but the brothers and sisters will carry that relationship for a lifetime.

One of the most critical factors in siblings' functioning is the way they interpret their parents' attitude toward the child with special needs. The parents' emotional health and availability are a powerful influence in the siblings' ability to cope and find their own identity. If they are unable to claim an important place in the family based on their own individuality, siblings often try, usually unconsciously, to develop an identity or role related to the special needs; becoming over-protective and over-responsible caretakers, developing special needs of their own, striving to be perfect, or acting out in negative ways. Only recently has there been a general awareness that siblings have the same need for information and support as do parents when a child in the family has a disability.

Given that understanding, sibling support should include targeted appropriate material. Although it is a frequently used approach, sibling support does not only mean Sibshops, or other formal purchased materials or curriculums. Local family support teams who choose to acknowledge and support the fact that siblings are caught between two worlds, can utilize some excellent resources available. Just as for parents, often the first step in sibling support is an informal event for networking and connecting. Other useful components of sibling support training include: information, effective communication techniques and the use of "I" messages, and problem solving skills. Sibling groups provide a forum where siblings can discuss their experiences, share ideas and give each other support. Involving the siblings in planning training or events to reach a point of ownership and buy in is an important step.

Suggestions for parents from a panel of siblings:

- Accept their child's disability or chronic illness in order to help others do the same.
- Express their own thoughts and feelings to the whole family
- Regularly spend time alone with each child.
- Listen to siblings and allow them to express negative feelings.
- Tell each child what they admire about him and acknowledge his contribution to the family.
- Obtain children's books or other resources about special needs.
- Involve siblings in decision making and care of the child with special needs

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Sibling/Extended Family Support

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- while maintaining appropriate limits on how much they are expected to do.
- Allow the child with special needs to do as much as she can for herself.
- Use respite care and other support services.
- Be fair.
- Teach siblings positive ways to interact.
- Let siblings settle their own differences.
- Welcome other children and friends into the home.
- Recognize situations that are stressful for siblings and plan ahead to minimize negative effects.
- Encourage "normal" family life and activities.
- Join or promote the development of sibling programs and support groups.
- When appropriate, consult professionals to help siblings cope with stress.
- Don't expect siblings to be saints.

Grandparents and Extended Family

A grandparent's life is impacted by the birth of a child with a disability. Many resources refer to the double grief that grandparents experience, for both their grandchild and their child. But grandparents can influence a family's adjustment. They have the ability and are often called upon to provide support to the entire family. They can lend to both generations the strength and love of the extended family.

The diagnosis of a child's disability can dramatically alter parents' relationships with grandparents, relatives, and friends. Grandparents, relatives, and friends experience many of the same reactions that parents do: shock, denial, anger, sadness and depression. Yet each person grieves in a different way, at a different pace. The different attitudes and coping styles may be compatible, or they may create misunderstanding and hard feelings between parents and others. Grandparents, relatives, and friends can serve as a tremendous source of support, but this may not always happen.

Parents of children with special needs report that these responses from family and close friends can be especially challenging:

- needing long or repeated explanations in order to understand the disability
- requiring tremendous support from the child's parents in order to overcome their own fear and grief
- appearing uncomfortable talking or hearing about the child's condition
- denying a problem even exists
- embracing the child with special needs as a favorite
- not talking to or about the child with disabilities
- conveying their concern through incessant advice giving

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Sibling/Extended Family

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- feeling anxious or embarrassed about telling others that someone in their family has a disability

Grandparents ability or failure to be supportive and accepting of a child's special needs can have a significant effect on how other relatives, and even the child's parents, handle the situation. When they are unable to move beyond shock or denial and fail to accept the diagnosis, grandparents' feelings can be transferred to others and influence their behavior toward the child. On the other hand, when they are involved with the child and family in positive, supportive ways, it may encourage others to do the same.

Consider these tips on how grandparents, close friends, and family can best help their children and grandchildren:

- offer support but don't hover
- ask how you can help in practical matters
- learn as much about the disability or diagnosis as possible
- offer opinions only if asked
- accept your grandchild as he or she is
- take responsibility for your own grieving

To be an effective supporter, grandparents and others must first address their own needs and concerns. A grandparent-to-grandparent program can serve as a useful tool to meet and share with others, gain information, and to learn helpful support strategies to enrich and empower the entire family network.

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Meyer, D.J. & Vadasy P.F. (1994). *"Sibshops: Workshops for Brothers and Sisters of Children with Special Needs."* Baltimore: Paul H. Brookes Publishing Co., Inc.

Powell, T.H. & Gallapher, P.A. (1993). *"Brothers and Sisters: A Special Part of Exceptional Families."* Baltimore: Paul H. Brookes Publishing Co., Inc.

The Sibling Support Project, Children's Hospital and Medical Center, 4800 Sand Point Way NE, Seattle, WA, 98105. (206) 527-5712. email: dmeyer@chmc.org. <http://www.chmc.org/departmt/sibsupp>

LD Online: Tips for Grandparents, www.olonline.org/ld_mdepth/family/grandparents.html

PACER'S Grandparent to Grandparent Program, PACER, 8161 Normandale Blvd., Minneapolis, MN 55437. (952)838-9000. Fax: (952)838-0199., email: pacer@pacer.org, www.pacer.org/parent/grand.htm





Leadership/Advocacy

September, 2001

Leadership

The life-changing event of having a child with special needs will draw some individuals out and move them to take on a leadership role they may never have had if life had been different. They may discover an interest, passion or skill for leadership in themselves, that they were previously unaware of. Leadership is for some people. There will be a small number who will take on the mantle of leadership. Some individuals may have acted in a leadership capacity before; for others this may be the first time they have ever taken on such a role.

Leadership can come in many forms:

- facilitating a meeting or a support group
- organizing and overseeing an event
- educating other parents and individuals through presentations and speaking engagements
- rallying the support of other parents and individuals around issues through calls and personal contacts
- sharing their personal story
- participating on committees, boards and task forces at local, state and national levels
- drafting letters and documents
- testifying before boards and legislators

Leadership does not only come from the person who is standing at the podium speaking. Remember, sometimes it is the person behind the scenes who gets the most done.

Advocacy

From a family's perspective, advocacy provides information or a person who is an independent resource working only on the family's behalf and not someone who is beholden to the same system for their job.

Professionals may have a negative perception of advocates and advocacy for a couple of reasons. Historically, advocacy had the connotation of being combative, challenging or litigious in nature. In recent times, advocates can be viewed more as negotiators and mediators. A negative perception may also be present because of those few situations where there were bad experiences with an advocate. It is easy for feelings from a bad situation to linger and be carried forward to other situations.

An advocate's job is to be informed and to fully inform families of their rights, responsibilities and the existing laws. It is also the role of an advocate to let families know the reality

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FLAME STARTER (Jj)

Leadership/Advocacy

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of whether the laws and outcomes favor them or not. An advocate should work with the family to be good negotiators. For parents and individuals who are ready to advocate for themselves and other families, it is important that training in advocacy, negotiation, mediation and leadership skills is available.

As you think about supporting families and individuals in gaining and enhancing their advocacy and leadership skills, there are several state and national forums in which parents can participate:

- Governor Council on Developmental Disabilities - Partners in Policy Making
- Council on Parent Leadership
- PACER Center Training
- Learning Disabilities of Minnesota - Leadership Conference
- Local Trainings

Consider providing advocacy and leadership trainings locally. For some parents this will be their only exposure because of constraints such as time, family, money and careers. You may also find the hidden leader in the room who may have otherwise remained in the background.

Note:

Parents who are strong leaders and good advocates do more than support the rights of their child and family. History has shown that it is those parents who have impacted and created change that has benefited children, families and professionals, such as: TEFRA (Katie Becket Waiver), inclusion, Arc organization and the removal from institutions of people with disabilities.

Critical Questions:

Am I avoiding sending parents to advocacy and leadership trainings because:

- *it may cause "problems"?*
- *parents may know as much or more than I do?*
- *there may be militant parents there that will give our parents ideas?*

How much of a leadership role am I willing to take on?

How do I support leaders who are just emerging?

Is there any issue that makes me want to take on a leadership role?



Training

September, 2001

"If, in the last few years, you haven't discarded a major opinion or acquired a new one, check your pulse. You may be dead."

— Gelett Burgess

To grow is to learn. Learning is a lifelong process, and training is only one approach to gaining new information. Training sessions can take place in a variety of settings — classrooms, hotel meeting rooms, homes, outdoors, etc. To be most successful, keep in mind some basic principles of adult learning:

- **Learning depends on motivation.** Having a personal interest in the topic makes it easier to pay attention and gain new information.
- **Learning depends upon a capacity to learn.** Being open minded to new ideas and approaches and willing to try new things leads to increases in learning.
- **Learning depends on past and current experience.** Prior experiences and perceptions, as well as current knowledge and skills affect how eagerly new learning is embraced.
- **Learning depends upon active involvement.** Participants who practice new skills are more likely to remember and use them over time.
- **Learning depends on a climate of respect.** Trainers and participants recognize each other's strengths and respect each other's beliefs and skills.

Keep in mind these key components as you sponsor trainings. Effective training is:

1. **Based on a sound planning process.** Parents and professionals need to plan together. Consider what you want participants to learn.
 - How was the content of this training determined to be a priority? Who is requesting it?
 - Will parents and professionals be invited to attend trainings together?
 - Will they acquire new **knowledge**?
 - Will they develop new **skills**?
 - Is it a change in **attitudes** or **beliefs** that is anticipated?
 - What specific expectations are there for participants as a result of this training?
 - Strive for a balance between "content" trainings ("parent's rights", "third party billing", "who pays?") and "process" trainings ("grief process", "communication tips").
 - Consider how potential participants will receive information about the trainings. Personal invitations are always more effective than mailings or invitations through radio or print.

(continued)



Training

September, 2001

2. Delivered by an effective instructor.

- How are instructors/trainers located and chosen?
- Is the presenter well prepared, knowledgeable and enthusiastic?
- Will a variety of learning techniques be offered?
- Will there be interaction between participants?
- Can trainings be co-presented by a parent/professional team?
Much can be learned from each other!

3. Delivered in an environment conducive to growth. Consider the space you will use.

- Is it easy to find?
- Is parking free and accessible?
- Will someone greet participants?
- Are nametags available?
- What seating options are available (round tables are more conducive to interaction)
- Does the size of the room fit the size of the anticipated audience?
- What refreshments are offered?

4. Enhanced by appropriate incentives and rewards.

- Are all potential participants offered the invitation to attend?
- What would make them want to come?
- Is childcare offered or reimbursed?
- Will a certificate of attendance or continuing education units (CEUs) be offered?
- Are people clear about what they will get at this training?
- What follow-up support is planned?

5. Evaluated for its quality and potential impact.

- How will participant reactions, learning, behaviors and impressions be solicited?
- What will happen with the information that is gathered? How will it be used?

It is always important to affirm the desire to learn more. Remember, though, that learning new things does not always lead to using that knowledge to do things differently. Sponsoring a training and sending participants to a conference are easy to do. Before selecting this approach, carefully consider **what** difference is expected as a result of this training.... **why** this approach is chosen. ...and if a **single session training** is really the most effective strategy to choose. Other approaches to consider might be; hands-on practice, on site technical assistance and consultation, multi-session trainings with follow-up, or whole team trainings.

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FLAME STARTER **15**

Training

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Training can be offered within a single community or participants can attend training, specific to their needs, elsewhere. A process for accessing funds for registration and training costs needs to be in place, with funds easy to access. Look for opportunities to give others access to training, and avoid situations where the same parent or professional goes to every training. As funds are made available for training, determine ahead of time, how people who attend these conferences and workshops will bring back and share the information gained. The least effective way to change attitudes and behavior is through the attendance of one or two people at a one-day training!





Parent Support Groups

September, 2001

A support group (or self-help group) is a group of people with a common life situation or set of challenges, meeting together to help themselves by sharing their experiences, ideas, frustrations, successes, and hopes. Parents of children with disabilities often find they need to talk with other parents and share concerns and information in a group setting. Some parents find support and comfort in knowing that they are not the only person experiencing a particular problem. Others enjoy the give and take and interaction that occurs in a group. As parents help and learn from one another, a sense of involvement in a group, as well as feelings of encouragement and friendship, can develop.

Parent support groups can provide:

- emotional support, encouragement, and comfort to help themselves and their children
- a chance to communicate openly and effectively
- information and education on related topics and resources available
- a chance to help others while receiving help
- friendship and social opportunities
- advocacy when parents work together for a mutual goal

Support groups can be formed about a specific disability, age, or geographical location. They can be topical, such as coping with change and loss, treatment options, behavior, toileting, communication, or transition. They can be an informational series, such as six weekly sessions regarding local resources or funding options, etc. Support groups may be ongoing or they may be designed for a limited period of time, such as discussing a specific curriculum, or the chapters of a book. Parents may be more willing to attend if they know it will be a short term commitment.

Often creating activities or initiatives occurs with more energy than maintaining them. There is a natural ebb and flow to support groups. The need for them and their ongoing success will vary as time passes. When a group is that is no longer needed or well attended, this does not indicate that it has not been successful. It may simply reveal that something has changed and it is time to try a new approach. There seems to be a life cycle for support groups: after a time many groups lose their vitality. When that happens, let the group die or disband. When it becomes needed again, re-create it.

Consider an alternate name, rather than "support group." Many people don't like the term "support group" because it sounds needy. The words "discussion," "resource," etc., may not have such a negative image. Sometimes an existing group, like the family support subcommittee, which meets for a specific task, will incidentally become a network and

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Parent Support Groups

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support group for those involved.

Chat rooms or online support groups offer an alternative support system, one that in certain situations may provide a better match of situations due to responsibilities at home and time restraints, geography, or financial restrictions. They also come with their own set of risks, so the user must be aware and take responsibility for that.

Things to Consider in Setting up Your Group:

Self-help does not mean you do it all yourself. Find a few other parents who share an interest in helping to start (not simply joining) a support group. Check what other support groups exist in your area. Make whatever linkages are logical.

1. From the core group, designate a contact person.
2. Find a suitable meeting place and time.
3. Decide how to recruit and how to spread the word.
4. How will it be facilitated — self-facilitated, or from outside the group? If the group will be facilitated by someone within the group, training and facilitator materials may be helpful. Facilitators need a helpful attitude, a sense of accurate empathy, a sense of warmth, affirmation, and positive regard, genuineness, relevance and concreteness.

Core skills as facilitators are:

- structuring-defining what the group is here to do, the purpose, limits, and scope
 - listening
 - linking
 - intervening - avoid excessive negativity, system bashing, domination by one "loudest voice"
 - recognition when a professional referral is appropriate - mental health, chemical dependency
5. Plan the meetings carefully. It can be helpful if the meeting dates are set well in advance, then included on the school or organizational calendar. Decide what kind of support is targeted:
 - emotional
 - esteem
 - informational
 - companionship
 6. Develop ground rules. Some possibilities:
 - Confidentiality - Avoid gossip, agreeing that what is said in the room stays in the room. Encourage trust-building. To build connections,

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Parent Support Groups

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no one should remain nameless or anonymous.

- Nonjudgemental
- Respect those who are speaking
- Avoid side conversations
- Everyone has an opportunity to speak
- End on time

Research on support groups reveals that only 30 percent of the population will choose to join a support group. Attending to the needs of that large a percentage of a group is significant and worthy of the effort, yet it excludes enough people that there are obviously more elements of family support to consider. Other studies conclude that support groups are particularly effective at meeting the needs of white, middle class, well educated women.

Although support groups are just one of a broad range of family support options, they have served an important function for many years around a multitude of topics, and will continue to play an important role in the spectrum of family support.

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Minnesota Technical Assistance for Family Support
Strengthening and broadening family support efforts



FLAME STARTER 17

Planning for Effective Gatherings

September, 2001

Planning an event, a gathering, a retreat, a conference or a workshop is very rewarding but often requires a lot of work. The anticipation and excitement at the prospect of a group getting together for a purpose is invigorating for those involved in the planning. To gain the most from these events, follow these helpful tips and strategies:

1. Begin with the end in mind.
 - A. First of all, identify why this event is important.
 - B. Justify how the need for this gathering was identified.
 - C. Write down what you expect to happen as a result of this gathering - specifically what outcomes you hope to accomplish.
2. Plan ahead.
 - A. Who are the "workers" who will make this effort happen?
 - B. Select a date and site. Are you offering this gathering only once, in a centrally located place? Or in multiple sites, closer to where families live? Is the date convenient? Have you utilized feedback from families in choosing the time?
3. Promote and market the event.
 - A. How will you let people know about this opportunity? Allow ample advance notice (3 weeks minimum) and use multiple strategies (i.e., brightly colored flyer, newspaper notice, personal invitation, radio promotions, etc.)
 - B. Consider the use of incentives to increase attendance. Will there be a door prize for participants? Is there free childcare offered? Is a meal provided? Will CEUs or a certificate of attendance be offered?
 - C. Include the purpose of this event, provide good directions to the site and specify starting and ending times.
 - D. Are participants expected to pre-register? Is that clear in the directions?
4. Match the environment with the event.
 - A. Consider where the event will be held. Small groups get lost in large rooms. It may be difficult to hear. Does the size of the room match the size of the anticipate group? Is the parking free and easily accessible? Is the place easy to find?
 - B. Are children to be included? Will children be cared for in a separate room? If so, have arrangements for developmentally appropriate toys, supervised childcare, safe equipment, snacks, changing facilities, etc. been made?

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Planning for Effective Gatherings

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- C. How will the room be arranged? If participants are sitting, how are the chairs arranged? Sitting at round tables promotes more interaction than sitting in rows. Offering a table is preferable if there are refreshments.
 - D. Determine what refreshments will be provided. Always offer something.
 - E. Planners arrive early and have equipment, refreshments and room ready prior to participants arriving.
 - F. If a presenter or speaker is used, be sure to ask what audiovisual materials they might need (microphone, overhead projector, TV/VCR) and allow time to set up.
5. Welcome!
- A. Designate someone as "greeter". Welcome everyone as they enter; talk to them! Indicate where coats may be hung, where children can go; offer refreshments, etc.
 - B. Have nametags available for everyone. Encourage them to write their first names in large print.
 - C. Introductions. Depending on the size of the group, encourage introductions up front. Always introduce planners and sponsors.
 - D. Designate a host/hostess to answer questions.
 - E. Share expectations for the gathering. Offer a brief synopsis of goals and outcomes of the event.
6. Remember adult learning techniques.
- A. Start and end on time.
 - B. Have paper and pencils/pens available for use.
 - C. Vary the pace of the event — some quiet listening time, some active interaction time.
 - D. Be sure content is practical, applicable to participants and pertinent
 - E. Don't go longer than an hour and a half without a stretch break.
7. Closing and Follow-up.
- A. Always ask for participant feedback in writing. (What did they gain from coming? What was not important? What would they like to learn in the future? What are important topics or issues?)
 - B. Thank participants for coming.
 - C. Ask if they would be interested in getting notices of future trainings, events, etc., and offer a chance to sign up for a database.

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Planning for Effective Gatherings

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- D. Determine a time for the planning team to debrief. (Go over feedback sheets, evaluate who participants were, who was missing, plan next steps, etc.)

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This process is invaluable in setting the stage for effective gatherings. Planning and evaluating the effectiveness of an event are equally important as the event itself. Remember to allow adequate time and energy for it!!





The Continuum of Parent Involvement

September, 2001

There is ample research to prove that most children have better outcomes when parents are involved in designing their programs and work in partnership with service providers. Most initiatives that focus on outcomes for children and families acknowledge, at least on paper, that parent involvement or participation is an integral part of the process. Yet the difficulty in getting and keeping parents involved in meaningful ways is identified as the biggest frustration and challenge those initiatives face. IEICs have reported this as their biggest challenge for years.

Many families in our culture struggle with complex issues —not enough time, too many demands, life is hectic, etc. While those may be valid stresses, it would be a mistake to assume that parents are too busy, or that having parents actively participating is not worth the effort it requires. Some simple changes in perspective may be helpful and may suggest different approaches.

1. Look at parent involvement as a continuum.

When viewed as a continuum, there may be strong parent presence in areas not previously considered, while other areas emerge that could be improved. Narrowing the area of focus in this way may make efforts to increase parent involvement seem less daunting. Keep in mind that this continuum is not hierarchical: parents do not need to work their way from one type to another, but can engage at whatever point best suits their individual personality or ability.

Consider the continuum of parent involvement:

- **Parenting.** Parent involvement at the most basic, most important level; i.e. caring for their child, establishing a bedtime ritual, eating together, modeling problem solving, reading to their child, attending conferences, attending the child's activities, being involved in the development of IEP or IFSP activities.
- **Participating** in family support activities. Taking advantage of and creating opportunities for self growth: i.e., reading a newsletter, requesting and using a parent to parent match, going to a parent support group, attending a workshop or training about their child's disability, attending an information fair, attending a parent retreat.
- **Planning** family support activities. Looking at the bigger picture to organize and plan activities for other parents; i.e., planning a parent retreat, facilitating a support group, contributing to or editing a newsletter, organizing a Sibshop, being a parent mentor, helping tabulate data from a needs assessment survey, organizing refreshments for a gathering, designing orientation and information

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The Continuum of Parent Involvement

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packets for new IEIC and committee members, setting up a mentor program for new IEIC and committee members.

- **Policymaking.** Partnering with professionals in making policy decisions about various efforts and initiatives; i.e. IEIC participation, setting priorities and planning for the Part C allocation plan, writing or calling legislators regarding a policy impacting families, designing a model for service coordination, etc.

2. Consider parent needs.

- For some parents, parenting a child with a disability is a new situation, and they have energy for only simple tasks, such as reading a newsletter or meeting with a mentor parent.
- Participation can be very threatening for some parents because it requires public and private acknowledgement of having a child with special needs.
- Some people like to work in groups, others prefer to work alone.
- There are individuals who are cautious and like to check things out first, and others who do not feel like they are helping unless they can jump right in head first.
- Others may lack confidence and feel they won't be of much help.
- The right fit may be a creative venture for some, a concrete task for others.
- There are always other priorities for the parent or family, and parents need to guard their energies for the long haul.

3. Consider individual differences and abilities.

- Be alert for skills or characteristics a parent may bring such as enthusiasm, friendliness, good people skills, community knowledge, a knack for numbers, or formal training in certain areas, and find a way to use them.
- Make opportunities for involvement clearly defined and time limited, i.e. one meeting, one year, one mailing, one set of phone calls.
- Be sure the work is worthy of their time.
- Give a clear picture of how this will improve or change things for their child, their family, or other families.
- Recognize and appreciate their efforts.

There is no single approach that will be successful in increasing parent involvement. Strive to continue to make available an assortment of ways that parents can be involved with your IEIC. Parent involvement is an ongoing process, with parents cycling in and out of the pattern and at some point, as their children grow, they will eventually move on. As each new parent enters this new world, they, too, will need the opportunity to be nurtured and to discover what a valuable asset they are.





Parents and Professionals in Respectful Partnerships

September, 2001

A relationship between parents and professional service providers that is based on mutual trust and respect is probably the most critical factor in the development of a quality system of family support and intervention services. Its presence is as necessary as air, so basic that it can be invisible.

The relationship between parents whose children have disabilities and the professionals who provide services to them can be quite complicated. Part of the adjustment process for parents can include mixed feelings, including a certain animosity toward professional service providers who may represent lost dreams. Parents may feel that while their children need and depend on those services, if life were unfolding to their hopes and dreams, the presence of service providers would not be necessary.

Both parents and professional service providers want what is best and are focused on the child with a disability, but their perspectives are very different:

Parents:

- Understand that they have lifelong commitment and responsibility for their child
- View the present as one small segment of a long distance marathon
- Assume complete responsibility for their child
- Do not choose this role

Professionals:

- Do not typically have long term contact or follow up for a number of years
- Address a deeper, narrower segment of life, compared to "running a sprint"
- Are responsible to various governing boards and/or taxpayers
- Choose this role in life

Parents and professional service providers need one another. They cannot afford to become adversaries, because neither alone can do what needs to be done. Real partnerships are one of the best ways to keep the most important needs addressed in an efficient manner. On a larger scale, the political reality is that children with disabilities are a very vulnerable population, particularly when most services that support and maintain them are dependent on tax dollars. Adversarial relationships between parents and professional service providers can threaten the very existence of the help that has been so tediously gained legislatively over a period of many years.

We know that respect and trust can only genuinely be earned, as part of the process of building a relationship with another individual. Developing a respectful and trustful

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Parents and Professionals in Respectful Partnerships

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relationship will not happen automatically, only by the choice of **both** parties. It is important enough to keep an ongoing effort in place to do so, even though it may seem tedious, unnatural, and illogical at times. A relationship based on trust and respect will not be accomplished if we bring old negative attitudes or adversarial biases to our dealings with one another. When either party continually guards their own position of power, respect and trust are defeated. The following should be kept in mind:

We cannot control what other people say and do, but we can control our own response.

Do I give honest credit to you, and believe you participate for the right reasons?

Do I believe that you are capable?

Do I reframe behaviors that irritate me, looking for the positive as well as negative characteristics of the same behaviors?

Do I make an effort to "walk in your shoes," learning to see things from another direction?

We can practice basic rules of courtesy, treating others as we would like to be treated.

Do I say what I mean and mean what I say?

Do I follow through and do what I say I will do?

Am I respectful of your time?

Am I respectful of your opinion?

Do I use the opinions and expertise of the whole group in decision making, not functioning as a solo act with my own self interest in mind?

We can decide to reduce tension between us by maintaining ongoing communication with one another.

Do I check in with you regularly enough to ensure that the direction of our thoughts and efforts are mutually understood?

Do I talk with you directly if I have an issue with you, avoiding a gossip triangle?

Am I available and easy to reach, keeping appointments and returning calls promptly?

Do I listen and respond honestly to what you say?

Building a relationship of trust and respect is worth going beyond our level of comfort to accomplish.

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Parents and Professionals in Respectful Partnerships

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Kathryn Barnard, Ph.D., R.N. *There seem to be stages in achieving a family-professional partnership, stages which go something like this:*

- *First, we begin to talk. "Yes, parents should be involved." We talk about parents' involvement and we talk about getting them on committees.*
- *The next stage comes when the service delivery system says, "Parents are involved. They are working in our center, they are deciding some of our policies."*
- *The third stage is one I hear reflected in the phrase, "We use parents as part of our service delivery program."*
- *And what to me seems to be the goal that we're working toward is reflected in the statement, "Parents are the core of our team."*





Needs-Rights-Responsibilities: A Balancing Act

September, 2001

Families and formal systems have been working for many years to establish and fine tune a system of services and supports that honors the rights of each individual within his/her family and makes adaptations for individual needs. Within this effort, a primary training emphasis has been **rights** and **needs**. As time has passed, many have voiced frustration that this emphasis is somehow incomplete and lacks balance.

Within our system of family support, in order to find the balance that becomes sturdy and functions well, we need to consider not only rights and needs, but also **responsibilities**. We need to think about family support as a stool with three supporting legs—**rights, needs** and **responsibilities**.

Rights: We live in a land that is founded on a firm belief in the rights of its people. The Bill of Rights, written at the founding of our country over 200 years ago, entitled its citizens to life, liberty and the pursuit of happiness. It affirmed and explained the rights of each and every individual.

Individuals with disabilities had their rights to a public education clearly described with the enactment of IDEA. This landmark legislation included specific terms and concepts, such as: free and appropriate public education, least restrictive environment and individualized plans and other services.

With the passing of the Americans with Disabilities Act (ADA), the power of these laws and the Civil Rights Act, specifically for people with disabilities was further directed toward equal access in five specific categories: employment, state and local services, public accommodation and transportation, communications and miscellaneous areas such as insurance.

We know the purpose of the laws. In reality, though, regardless of how carefully they are worded, laws are subject to interpretation and misinterpretation. When we make a point of focusing on the spirit of the law, the letter of the law can be more easily discerned.

Needs: We are familiar with Maslow's hierarchy that identifies the levels of human need. At a most basic level, we have economic and physical needs (shelter, safety, food, clothing, and a stable income). These are the necessities for survival. In addition, we also have vocational/educational and medical needs, as well as recreational, emotional and social needs.

Within our system thinking, a need has been defined as "something that is lacking but necessary in order to achieve a desired outcome." In our time and culture, the line between needs and wants has become very fuzzy. Knowing the difference between needs and wants

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Needs-Rights-Responsibilities: A Balancing Act

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is important, particularly now as we are realizing that all needs are not necessarily satisfied by jumping to services as the solution.

We can all probably relate to the excitement that preparing for each grade brought when we were in elementary school. We brought home a list of materials needed for the year, and undoubtedly, crayons were listed. How delighted we were when we could convince our parents that we 'needed' (wanted) 48 or even 64 of those lovely new Crayolas — when in reality 16 would have done just fine!

Responsibilities: The responsibilities of families involve raising the next generation of learners, workers and citizens. That includes providing basic needs, such as food, clothing and shelter. The family assumes responsibility for the development and well-being of children through love, nurturance and limits, demonstration of work ethic, of moral values and spiritual growth. Another task within a family is to provide a family heritage or a sense of roots as a companion to encouragement that gives children confidence or wings.

The responsibility of service providers is to provide appropriate individualized services from a family centered perspective, recognizing and honoring that families are the constant in a child's life. Within that framework, service providers have the responsibility of supporting the efforts of parents in raising their children by working in respectful partnerships together with families.

Actually, service providers and family members are all individuals. As individuals, we all have the obligation to own our responsibilities, being unwilling to play the victim in this culture that has made victimization attractive and lucrative. We all have the responsibility to stop passing the buck and blaming the other guy. We all have the right to be treated with respect. We all have the responsibility to give respect in return.

We have created an imbalance over time with the current notion that all needs must be fixed with services and money. This has professionalized the lives of families. There is currently much controversy and political debate about the role of services in the lives of families. It is clear that we never have enough teachers, nurses, social workers or other care providers to do what we have set out to do. The solution comes when each of us, as individuals, claims our rights, declares our needs and assumes our responsibilities. When that happens, our system will be in balance, serving as a sturdy support that functions for us all.





Family Support Drawing on Natural Resources

September, 2001

Throughout life, there are times when it becomes precariously unbalanced. During those times, we need to look outside ourselves to go on. Do you have the support you need on a day to day basis? Consider your answers and fill in the blanks to the following questions:

- _____ 1. If my child is sick and I need to go to work, who will I call to help me out?
- _____ 2. Where do I get information about specific medical specialities?
- _____ 3. Who can I talk to when I think about my child, and wonder what life may be like down the road?
- _____ 4. How do I connect with others who may have encountered a similar situation?
- _____ 5. If my car breaks down on the way to a doctor's appointment with my child, who will I call?
- _____ 6. What resources are available when I am worried, or have a really bad day?
- _____ 7. How long has it been since I've had a break or gotten away without my children?
- _____ 8. When was the last time I enjoyed an individual hobby or interest?
- _____ 9. How often do I spend time alone with my children without disabilities?
- _____ 10. Where do I get advice about planning for the future for my child with disabilities?
- _____ 11. Do I build in time to have fun?
- _____ 12. Who can help support or assist my child's acceptance in the community?
- _____ 13. Who helps me work through medical bills, government applications and the mountains of paperwork?
- _____ 14. At the time of a family crisis, who will provide us with "hugs and hotdishes"?
- _____ 15. What am I doing now to build the supports to get me through a crisis?
- _____ 16. Is my family "thriving" or "only surviving?"

It is the stamina and resourcefulness of each family that will provide the strength and continuity necessary for the long haul. Every single paid professional who enters the life of a family with a child with a disability will only be involved with that family on a short-term basis. Communities and families need to work together and plan ahead for those times of need proves to be a good approach to "keepin' the home fires burning."

- As a family and as a community, are we doing everything possible to invest formal and informal resources to support families?
- As an individual family, have we identified what supports we need to stay healthy and grow?

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Family Support: Drawing on Natural Resources

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Are communities connected? Do resources build on each other, rather than compete and duplicate efforts?

Are extended family networks evident?

How active are neighborhoods and communities of faith?

At a time when you are able, how can you be a support to others and offer something back to your community?





Core Concepts of Family Centered Practices

September, 2001

1. The family will remain the constant in a child's life, while service providers will come and go.
2. All families have strengths and their own personalities. Along with that personality comes different ways of coping.
3. It is important that parents are recognized as the primary decision makers for their child, and that parents and professionals work in partnership. Both bring valuable pieces to the table.
4. A family's race, their heritage, their financial status and where they live all impact a family and how they function. These differences need to be recognized and respected.
5. Complete information which is not over shadowed by judgments or personal opinions should be shared with parents in a timely manner, on a continuing basis and in a way that will be supportive of parents.
6. Connections to other parents and families in similar situations is encouraged and arranged.
7. Children are continually developing and changing, and have different needs than adults. Systems, such as education, public health, social services, health insurance companies, and health maintenance organizations (HMOs) must all take this into consideration.
8. Policies, programs and services are able to change and be flexible enough to meet the individual needs of families.
9. Systems and services make it easy for families to get to them and to understand and to use them.

These core concepts of Family-Centered Care are impacted in a daily way by the actions and attitudes of parents, service providers and formal systems of service. Actions can be changed by mandate, but changing attitudes requires a conscious and personal effort.

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Core Concepts of Family Centered Practices

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Recognizing Family Centered Services

If we can recognize what is driving our programs, services and the way we support families, it will be easier to explore new options and ways to be more family centered. In the following exercise, determine what forces drive the statements below.

Use the following key to fill in the blanks:

S System Centered: The strengths and needs of the system drive the delivery of services and supports.

C Child Centered: The strengths and needs of the child drive the delivery of services and supports.

F Family Centered: The strengths and needs of the family drive the delivery of services and supports.

The family must bring the child to the office for case management services.

A complete assessment is done on the child.

Occupational therapy sessions are arranged according to the family's schedule.

Child care is provided for siblings while the child with special needs receives treatment.

The physical therapist sends the order home with the child for a seating device.

A preschool center-based option is offered, with parent conferences held twice a year.

Parent support groups may use the facility's conference rooms in the evenings.

Medical records for a child are available 3-5 days after a release of information is received.

The speech therapist comes to the home twice a week for an hour session with the child.

A care plan developed by a multidisciplinary team is given to the parent.

Parents identify feeding as the priority issue. All team members write goals to address this.

The hospital social worker arranges for all the medical equipment for the child ordered by the doctor.





Family Centered Tips and Strategies

September, 2001

The concept and meaning of family centered care continues to grow and change. It is important to use strategies that are family centered and allow for change. Incorporating these strategies into daily actions and attitudes can improve our success in working with children and their families.

Consider these strategies to increase family-centered practice.

1. Start with family priorities

- What is their response to the referral to you, your services or your system?
- Be aware of their perception of the situation and what they see or believe to be their child's disability.
- Start with where they are. Maybe this is a crisis to them and maybe it's not... find out!
- Start with their questions, not yours.
- Ask if they have specific concerns, fears and thoughts.
- Is early intervention for their child a priority of the family? Are there other issues, challenges and concerns that are more immediate and pressing for the family?
- Does the family see this as a big enough issue to want to make any changes?
- Echo the words and terminology the family uses and make sure you understand what they mean.
- Listen more than you talk!

2. Use family strengths and capabilities

- Watch and listen—You can learn volumes about a family by what is said and what is not said.
- Identify something good about this family and state it.
- Say something REAL about the child that is positive. It may be the only positive thing they have heard about their child.

3. Identify supports and resources

- Offer information, offer information, offer information! It may be on the first, fifth or the tenth time that you offer something that a family hears it or realizes that what you are offering might be useful to them. We remember far less than what we hear. Under stress it is difficult to retain what does not appear to be essential immediately.
- Connect parents to other parents and families in similar situations.
- Look for the informal supports that already may exist for a family recognize,

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Family Centered Tips and Strategies

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build, validate and use those supports. It is the most natural support that exists for many families.

- A family's life is bigger than formal services and requires more than those to be supported. (Research proves that the positive effects of support provided by informal sources generally exceeds the positive effects attributed to formal support sources.)

4. Honor Family Values and Beliefs

- A family's religious beliefs and lifestyles are integral to how they function.
- Ethical and moral choices are the family's domain.
- Ethnic and cultural customs need to be recognized and may not be obvious.
- Alternative medicine is now a real choice for families. Support them in their choices by encouraging them to ask appropriate questions and seek accurate information.
- Not all families will choose to utilize services. Choosing not to access services does not make the family uninvolved or neglectful.

5. Problem Solve Options

- As you listen to a family, record, sort and organize issues, themes and activities for them to use in planning.
- Ask probing (not prying) questions in order to get to priorities. "What have you tried so far? What do you want to see happen? Where do you want to start?"
- Every once in a while you will hit a brick wall and work with an extremely difficult family. Don't assume it is the norm. Don't let it eat you alive. Bring it back to the team and seek support.

6. Develop a Relationship

- Be patient...it takes time to develop any relationship.
- You are not going to "click" with every family. If you aren't the best match for a family, do not take it personally. Go back to your team and ask for input and help to decide if there is another person who may have better rapport with the family.
- When we reach a point that we are asking ourselves "What good is THIS family?" We probably should be asking ourselves, "What good are WE to this family?" Be honest with yourself when a negative attitude is pervasive regarding a family.
- Encourage a proactive partnership.
- Realize the feeling of inequity that exists. One day a parent may be capable and

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Family Centered Tips and Strategies

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competent, the next day they are suddenly "needy" of services and supports. Professionals appear to have all the power, money and information. Strive to find equity. Let the family reciprocate, even if it seems small or unimportant to you.

- Make a concerted effort to spend a small amount of extra time developing a relationship. Studies show that an additional 3.3 minutes of interaction is all it takes to help establish a relationship and reduce litigation.
- Actively seek opportunities to build a relationship.
- Talk a bit about yourself. The old way of thinking was to keep your life private and separate. Professionals are now encouraged to share a bit about themselves so that families can see them as people with lives and families too.
- Be aware of your own feelings and history. Recognize that we all have our own history, background and baggage, which may influence how we perceive and work with families.
- Be authentic. It is the quickest route to a trusting and respectful relationship.

REMEMBER...A change in thinking will lead to a change in actions. A change in actions will lead to a change in thinking.



Ready, Fire, Aim: Needs Assessment

September, 2001

The saying "build it and they will come" is not necessarily true. Most of us have organized a workshop, support group or activity of some kind and only a few people or no one came. Perhaps a few people had mentioned it and thought it would be a great idea. This scenario begs the question: **Did it really meet the needs of the larger audience?**

Often a needs assessment is the last thing we think of, or it is done as an afterthought. A planned, well-thought needs assessment, which is accomplished using the right tools, is of benefit to ALL families, and makes the organizer's efforts worthwhile.

Benefits of a Needs Assessment:

A needs assessment:

- Allows for a thorough and systematic opportunity to assess the needs of ALL eligible families in your service area (not just those who are already participating or those who are a part of a planning committee)
- Identifies major gaps in the availability of family support
- Helps to avoid launching family support efforts that are already available
- Solicits open and honest feedback if it is anonymous
- Enhances already existing family support initiatives, while keeping costs down and fostering collaboration

Needs Assessments: Three Options

- 1. Inventory** of available family support approaches. A compilation of the family support approaches that are currently available in a specific geographic area. Inventories usually result from a systematic survey of agencies and groups who sponsor or provide formal or informal family support. Specific considerations:
 - *What do we want to inventory?*
 - *What specific information do we want to collect about each inventoried item?*
 - *Which agencies and groups are providing family support?*
 - *How do we want to collect this information (phone, personal interview, written form?)*
- 2. Survey** of eligible families. This allows for direct feedback from eligible families. Needs assessment surveys often ask participants to choose among various alternatives. Specific considerations:
 - *Where will we obtain a list of eligible families who will be surveyed?*
 - *Will we survey all eligible families in our geographical area or a sample of families?*

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Ready, Fire, Aim: Needs Assessment

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- *What is the most efficient way to guarantee a good (50 percent or more) response rate? Is it a brief phone interview, or a face-to-face interview, or part of another scheduled meeting?*
- *Who will distribute the surveys, make calls or do the interviews?*
- *Will we offer incentives for participation?*

3. Parent Focus Groups gauge the reactions of families to particular family support approaches, both those that are currently available, and those that could be developed. The interaction of participants spurs new and additional ideas which provides a unique source of information and serves to check the validity of one another's reactions. Specific considerations:

- *What type of families are in the best position to answer the focus group questions?*
- *Where will the group meetings be held so that they are convenient and comfortable for participants?*
- *Who will select and invite families to participate?*
- *Who will serve as facilitator and note taker?*
- *Who will summarize the findings and write a brief report?*

Selecting the best Needs Assessment option:

Answer the following questions to help you decide which is the best option for your use:

What information do we already have about the needs (and how current is it?) and what information do we still need?

Who is available to design and coordinate the needs assessment procedure?

Who is available to help collect additional information and how much time do they have available?

Who is available to help summarize any information collected and how much time is available?

How much time do we have before the information is needed?

Will the procedure give us information about (and from) families who are already participating in formal/informal family support and those who are not?

Not every option will work in every situation. Sometimes more than one option is utilized to gain different types of information.

A needs assessment does not have to be a huge, overwhelming process. The time and energy devoted to doing a needs assessment is a wonderful way to set priorities and make sure the family support needs of ALL families are addressed.

