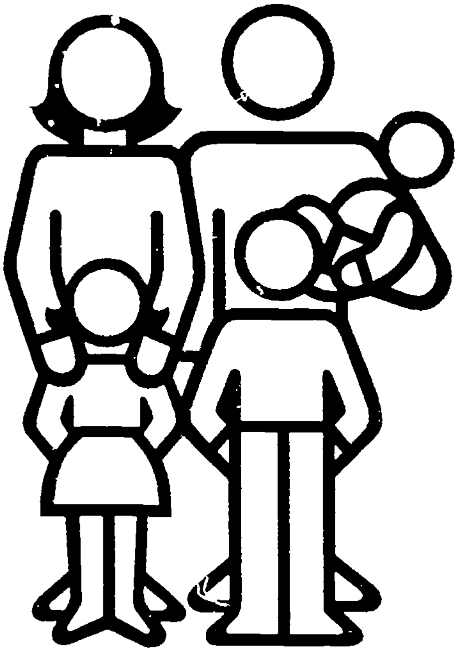
DOCUMENT RESUME

ED 355 747 EC 302 005

TITLE	Working with Families Who Have Special Needs. A Guide for Professionals.
INSTITUTION	South Carolina State Dept. of Mental Retardation, Columbia.
PUB DATE	1 Sep 92
NOTE	23p.; For a companion guide for parents, see EC 302 006.
PUB TYPE	Guides - Non-Classroom Use (055)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Agencies; Counselor Role; Decision Making; Family Involvement; *Family Programs; *Mental Retardation; Normalization (Handicapped); *Parent Participation; Placement; Professional Services; Referral; Social Services
IDENTIFIERS	*Parent Provider Relationship; *South Carolina

ABSTRACT

Intended for professionals working with people with mental retardation and their families, this manual begins with a summary of the principles and philosophy concerning family participation and agency responsibilities of the South Carolina Department of Mental Retardation (DMR). The importance of family involvement in determining the least restrictive setting is stressed. Ten to 20 principles and guidelines are presented for the following activities: providing family-centered services, working with parents who are just learning of their child's disability, working with families routinely, resolving conflicts, developing effective partnerships, and working with families who aren't eligible for DMR services. A summary of key principles (e.g., remember parents are the experts on their child, be knowledgeable about resources available to the child and family, connect parents to other parents, and return telephone calls promptly) completes the guide. An appendix contrasts traditional ideas with state-of-the-art ideas concerning perceptions of disability and family roles, and contrasts myths with realities concerning parent participation in the decision making process. (DB)

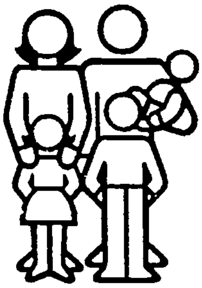


Working With Families Who Have Special Needs

A Guide for Professionals
Published by
The S.C. Department of Mental Retardation

EC 302005

P.O. Box 4346
Columbia, S.C. 29240



Working With Families Who Have Special Needs

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Principles

People with mental retardation or related disabilities should experience love, friendship and continuity in their lives. As with all people, they have ups and downs, peaks and valleys, favorable and unfavorable reactions to events in life.

People with mental retardation should participate as valued members of their communities. They should live with their families or in family-like settings, and participate in meaningful employment and other activities that contribute to their well-being.

People with mental retardation have a right to receive services from public and other agencies that ordinarily provide services to South Carolinians. Those services should be coordinated with extra services they may need because of their disabilities.

Philosophy

The S.C. Department of Mental Retardation encourages parents/family members to participate in all aspects of programs and services for individuals with mental retardation or related disabilities. Families, local county mental retardation boards, service providers and DMR regional centers will mutually accept responsibility for each individual's welfare.

DMR will support the family unit and, whenever possible, individuals will be served as close to their families and home communities as possible.

Family Participation

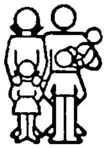
Families are encouraged and expected to participate in service plans and decision-making. Families should attend staffings and work with professionals as members of the program team.

Families should be encouraged to join parent/family organizations and participate as advocates for people with mental retardation or related disabilities.

If residential services are needed, families should continue to be actively involved. Family members should purchase clothes and personal items, participate in staffings, monitor progress and discuss future service needs.

Service Agency Responsibilities

DMR and county MR boards assure families that everything possible will be done to provide and coordinate services for people who need them, throughout their lives.



While citizens may receive services from more than one agency and may move from one type of service to another as needs change, county boards will coordinate these services and ensure they are adequately provided for each person.

DMR will try to provide services in the least restrictive setting possible with the following priority:

A. Support for families, including in-home family assistance, day program and employment services;

B. Alternate family-setting placement;

C. Residential placement in a community setting as close to the family's home as possible.

DMR and MR boards will support and encourage a continuing family relationship. To facilitate this, support services will be provided to help families manage and maintain people with mental retardation or related disabilities in their own homes. Services may include service coordination, early intervention, community based professional services, family care, respite care, short-term admissions and/or a day program.

Service coordination should be available to all citizens with mental retardation or related disabilities. Service coordinators should take the lead and develop joint service plans and/or joint funding plans with other state and local agencies.

At times, cooperative efforts between MR boards serving adjacent counties will be required. At other times, DMR may designate special statewide projects with other state or private agencies.

Involving Families

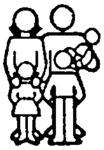
'..If we're going to be successful with families, we're going to need to reorient as professionals. We're going to need to look to parents as leaders, parents as experts, parents as bosses. We're going to need to ask them to join us cooperatively as equals in this partnership so that we create a reality there that matches what all of us want to see.'

Lisbeth Vincent

'..Parents have to be recognized as special educators, the true experts on their children; and professional people — teachers, pediatricians, psychologists and others — have to learn to be consultants to parents.'

Nicholas Hobbs

Involving families requires change and takes time. Families should be given unconditional, positive recognition for the important job they are doing. Over time, involvement should increase parents' feelings of control over their world and their child's development. Families should be encouraged to promote independence for people with mental retardation or related disabilities and other family members. Professionals should provide nonjudgmental support and access to information for families to help them become involved.



Providing Family-Centered Services

There are three driving forces of service delivery: system-centered, child-centered or family-centered. DMR is working to provide family-centered care.

Family-centered care is based on the principle that individual family strengths and needs drive service delivery. Family-centered services:

- Recognize that family is constant in a child's life, while service systems fluctuate;
- Facilitate parent/professional collaboration at all levels of services;
- Honor racial, ethnic, cultural and socioeconomic diversity of families;
- Recognize individual family strengths and respect different methods of coping;
- Share complete and unbiased information with families on a continuing basis and in a supportive manner.
- Encourage family-to-family support and networking;
- Recognize and meet developmental needs of infants, children, and adolescents and their families into service systems;
- Create policies and programs that offer families emotional and financial support;
- Offer accessible, flexible, culturally competent and responsive services.

Source: Adapted from Key Elements of Family-Centered Care,
National Center for Family-Centered Care,
Association for the Care of Children's Health.

Working With Parents Who Are Just Learning of Their Child's Disability

When parents learn about obstacles in their child's development, the information comes as a tremendous blow. One mother described her experience as entering a dark tunnel with little hope for the future.

Family experiences are unique, but families often have common questions, when learning of a child's disability:

- What caused my child's disability?
- Did I do anything to cause my child's disability?
- What did I do to deserve this?
- How could God allow this to happen?
- What will my child be able to do?
- Will my child need support forever?
- Who will take care of this child when I am gone?
- How will this child's disability affect my marriage?
- How will my spouse, my other children, my extended family, my friends accept this child? Will they love my child?
- Will I be able to provide for my child's needs? Will I be a good parent?
- Can I love this child?
- Will my child outgrow these special needs?

When learning their child has a disability some common reactions include:

Denial - "This cannot be happening to me, to my child, to our family."

Anger - Aggression toward the child, personnel or family members.

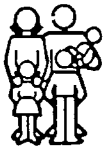
Fear - Suspicion of the unknown and future.

Guilt - Concern about what caused the problem.

Confusion - Not fully understanding new terminology or what is happening. Confusion results in inability to make decisions and mental overload.

Powerlessness - Inability to change what is happening.

Disappointment - Imperfection poses a threat to their ego and values.

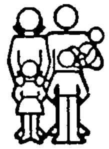


Rejection - Rejection directed at the child, personnel or family. Some parents report a "death wish" for their child.

It is important for families to identify all potential feelings that may arise so that they will know they are not alone. All parents experience feelings of inadequacy at one point or another. The difference for parents of children with special needs is that feelings of inadequacy are greater and last longer. Professionals should support families and provide hope, so they will not feel isolated and alone.

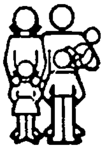
To be more effective in working with parents who have just learned that their child has special needs:

- Present a balance between reality and hope.
- Don't withhold information. Tell the parents as soon as possible, even if you only suspect a problem. This is not the time to use the phone for communicating.
- Schedule uninterrupted time and find a quiet, private place to meet as soon as possible. Have both parents present and invite extended family members if the parents want them.
- Build trust and rapport. Be honest and straightforward as well as compassionate.
- Tell the parents they have done nothing wrong.
- Acknowledge your own feelings. Don't rush through the explanation. Encourage parents to ask questions.
- Don't inject negative thoughts about the individual with disabilities or project doubts of the family's ability to handle challenges.
- Avoid negative connotations. For example, one should not say, "Down Syndrome is mental retardation." Instead, tell parents Down Syndrome is a chromosome abnormality. Then, tell parents the other characteristics of Down Syndrome, including mental retardation.
- Allow parents to express emotions, as well as time alone to grieve. Recognize that their feelings are, in all probability, very normal.
- Recognize the child as a "child first", pointing out normal and positive factors as well as disabilities. Always refer to the child by name.
- Encourage bonding between the baby and his or her parents. Set an example by touching, holding, smiling at and talking to the baby. Show respect for the child as an individual.
- Don't describe how much worse it might have been. At this point, the only child who really matters is their own.



- Admit you don't know all the answers. Express a willingness to search for answers.
- Demonstrate to the parents that they are needed as partners. Invite them to participate in decisions and care of their child. Participation will instill confidence in the parents.
- Know about community resources to assist the child and family, giving a message of hope. Link the child and family to social and medical support groups.
- Encourage the family to take advantage of respite care to take care of themselves.
- Make sure parents have a "primary provider" to help them sort information from many specialists.
- Repeat explanations several times during the early weeks and months as parents do not absorb everything at first. You may want to tape your explanation with the parent's questions and answers. Be available for additional contact and set an appointment for initial follow-up.
- Recommend that they see other parents. Get permission to give their name and phone number to a parent support group that can reach out to them.
- Take into account the family's age, educational level and social conditions.
- Be sensitive and alert to family needs, absorb new information and explore new options. Let parents set the pace.

Note: Respect the individual and apply age appropriate references to teenagers, young adults, and others even though they are the child of a parent.



Working With Families Routinely

It is important to meet the needs of the family at their level by supporting the family in the family setting. Determine family needs and expectations and how DMR and/or other agencies can meet these needs.

Families who have a child with a disability need information about the disability, services, laws and policies to help with their child. They also need support to live together comfortably while meeting everyone's needs.

After you help the family identify their needs, determine the best way to gain services and help the family obtain them. Be creative in seeking alternative funding sources and/or services to meet family needs. Always keep in mind that families on waiting lists are not receiving services or having immediate needs met.

It is important that each family know you are genuinely concerned about them and their child. Show concern by routinely contacting the family, not just in crisis situations. Return parents phone calls the day you receive them, or at least by the next day.

Should you resign, call the family to let them know you are resigning. If you know your replacement/or the person who will be working with them until your position is filled, give them that information, also.

Parents like to receive feedback about their child's progress and activities they can do to reinforce skills at home. Families of individuals who attend DMR day programs should receive this information at least monthly. Encourage parents to meet with staff to discuss concerns and/or suggestions that they may have.

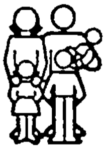
If working with families of preschool or school-age children, be sure that they understand you are a resource they can depend on in developing their child's individual education plan (IEP) or individual family service plan (IFSP).

Be well informed about services and resources from other agencies in the community. Inform, encourage and help parents receive services and resources like Medicaid, SSI, local health and/or mental health services, social services, etc.

When meeting with families, treat the individual with mental retardation with respect. Maintain eye contact with the individual and give them the opportunity and time to respond to your questions. Include them in your discussions.

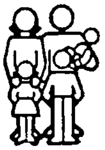
Other ways to improve your working relationship with families are listed below:

- Schedule meetings at a convenient time. Agree on the day, date, time and place of each meeting. Schedule meetings when both parents can attend.
- Before meeting, write down points and questions that need to be discussed and decisions to be made.



- Be on time for meetings with parents. Their time is important.
- Focus on strengths—parents respond best to a positive approach. Help the parents keep negative thoughts in perspective.
- Be sensitive to emotions, supportive and "family-friendly". Show concern for the child and family.
- Discuss needs and strengths while being respectful of family dignity and privacy.
- Allow parents to decide if they want help and what kind.
- If you do not know an answer, get assistance from another professional.
- Make assistance match the family's need.
- Encourage feedback from families.
- Promote open communication and provide opportunities for parents to:
    - learn new skills;
    - learn more about each other's priorities;
    - share information;
    - learn each other's style of communication.

  Parents and professionals must understand each other. Undefined or vague terms can be a problem. Parents need lay terms to help them understand as well as technical language to communicate with professionals and research their child's condition.
- Let parents tell you about their child. Parents have vital information to share. They see the whole child - strengths and challenges, likes and dislikes.
- Don't blame parents for problems, but encourage their participation and involve them in decision making.
- Help parents see themselves as agents of change.
- Assume each family is strong and can become competent— build on what the family already knows.
- Provide informal support.
- Be flexible and creative about program plans, resources and funding.



- Be sensitive to family priorities for:
    - their child's program;
    - style, time commitment, cultural values, preferences, resources.

  Parents are responsible for implementing their child's service program and daily care. Parents must balance professional recommendations with family priorities for their child. Professionals and families must work together to establish a reasonable service plan. Without balance, programs may place unrealistic expectations and demands on parents. Home care plans may not be implemented, and families may experience guilt and frustration.

- Tell parents about their rights and their child's rights regarding:
    - eligibility for services
    - confidentiality and access to information
    - informed consent
    - grievance procedures and rights of appeal
    - policies, principles and standards governing service delivery.

- Help parents find other parents who have similar experiences, even if a formal support group isn't available.

- Give parents control. The family is the final decision maker. Professionals need to support, not replace, the family's role.

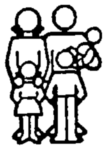
- Believe that all problems have solutions. Allow time to help. Don't give up. Turn the problems over to others when what you are doing isn't successful.

- Remember the parents are always right.

- Develop relationships with parents before you need them.

- Learn to accept criticism, even hostile criticism, from parents. Dealing with criticism is part of your job.

- Always let parents know when something negative or positive has happened to their child, especially when something negative has happened.



How To Resolve Conflicts

Parents may become angry when they do not feel their needs are being met or that you are not working on their behalf. Recognize and accept their feelings. Take time to discuss their concerns. Seek help from your supervisor and/or other agencies if needed. Never threaten to have a child discharged or dismissed from a program or service because a parent complains.

If you and the family disagree: 1) focus on the child's best interest; 2) emphasize what's right rather than who's right; and 3) begin with areas of agreement and work from there. When your views of "reality"differ, explore both views to understand each other's concerns.

Separate the people from the problem. People problems frequently fall into three basic categories: perception, emotion and communication. If perceptions are inaccurate, look for ways to educate. If emotions run high, find ways for each of you to let off steam. If there are misunderstandings, work to improve communication.

You must also learn to deal with your own problems. Don't let anger and frustration affect your relationship with the family.

Perceptions

How you see the world depends on where you sit. People see what they want to see. The ability to see situations from another point-of-view can help you solve problems. Understanding the other person's point of view is not the same as agreeing with it.

One way to deal with differing perceptions is to discuss them openly, without blaming anyone. Involve parents in the discussion. Agreement will be much easier if they feel ownership of the ideas.

Emotions

Recognize and understand family emotions, as well as yours. Why are you angry? Why are they angry? Are they responding to past grievances?

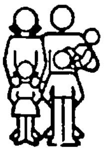
Talk about everyone's emotions. A good way to deal with family anger or frustration is to help them release their feelings by airing their grievances. Listen quietly without responding to attacks. Many times an apology can diffuse emotions effectively even when you do not acknowledge personal responsibility for the problem.

Communication

Communication is important in resolving problems. There are three basic communication problems: 1) You may not be **talking** to each other, 2) You may not be **hearing** each other, and 3) You may **misunderstand** each other.

What can be done about these three communication problems?

- Be a good listener. Pay close attention to what is said and ask the person to spell out exactly what they mean.

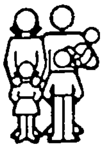


- Make sure the other person understands you.
- Speak for yourself, not for the other person. Tell how the problem affects you and the child.
- Be knowledgeable; but don't pretend to know everything.

Preventing Problems

The best way to handle people problems is before they become people problems. Build a working relationship with parents. Get to know them personally.

The next section will address how to build effective partnerships with parents/family members.



Effective Partnerships

"Parents and professionals have different relationships with the child. The parent's relationship is personal, lifelong and caring. The professional's involvement with the child is time-limited and objective. Neither relationship is better; they are different. As with most partnerships, bringing people together with differing skills and perspectives can develop a successful relationship.

Key points for developing partnerships:

- While families of children with disabilities may at times be families in crisis, they are not disabled families. They have capacities for creative problem solving and coping that professionals need to respect, promote and encourage.
- Parents and professionals may have different perspectives, experiences and goals for the child. Sharing and learning to understand these differing perspectives is an important part of care for the child.
- Some decisions may be best made by family members. Others may need input from a professional.
- In developing a partnership, professionals and family members should find an appropriate balance of support and dependence.
- Partnership and teamwork between parents and professionals is difficult. The easiest pattern is for the professional to adopt the traditional role of knowledgeable decision maker and the parents to adopt that of passive recipients. Changing these roles takes commitment by both parties.
- Lack of time and personnel continuity are barriers to commmunication.
- Professionals need to share large amounts of technical information with the parents of special needs children. To understand technical information, parents should ask questions, read and seek other resources.
- Service Coordination should allow professionals who build relationships with a family to take more responsibility for working with that family, and should also make sure that every family has an advocate.
- Parents of a "special needs" child do not automatically know how to voice opinions and interact with professionals. Professionals should help parents develop resources within themselves and within the service community.

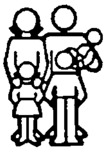
Source: Supporting Families with a Child with a Disability, Alan Gartner, Dorothy Kerzner Lipsky, Ann P. Turnbull, Brookes Publishing Company, 1991.

Working With Families Who Aren't Eligible For DMR Services

If an individual is not eligible for DMR services, steps should be taken to assist and refer the individual and their family to other appropriate local, state and/or national agencies.

The referral process should include, but is not limited to:

- Listing the name, address, telephone number and contact person of other appropriate agencies.
- Providing copies of DMR reports to assist the family when contacting other agencies for assistance.
- Contacting other agencies and informing them of the referral.



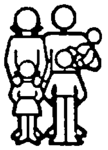
Summary

Ten Key Points to Remember in Working With Families:

- Remember parents are the experts on their child. You need to learn how to be a consultant to the parents.
- For there to be an effective partnership between parents and professionals there must be mutual respect, joint decision-making, sharing of feelings, flexibility and honesty in dealing with each other.
- Meet the needs of the family at their level and at their pace. Respect the family's dignity and privacy.
- Be knowledgeable about resources available to the child and their family. Be well informed of services and resources from other agencies in addition to DMR.
- Be willing to admit that you don't have all the answers and be willing to get assistance from your supervisor, administrators or other agency personnel.
- Connect parents to other parents with similar experiences.
- Return phone calls on the same day or following day.
- Do not keep parents waiting. Their time is valuable.
- If you and the family don't agree: 1) focus on the child's best interest; 2) emphasize what's right rather than who's right; and 3) begin with areas of agreement and work from there.
- If you are faced with a situation or complaint you cannot handle, talk with your supervisor.

"All of us have dreams, visions and anticipations for the future. Like everyone else, people with disabilities and their families have great expectations. Like everyone else, they too need help to be able to have their expectations come true. Professionals and other people without disabilities also need to have great expectations for people with disabilities. Great expectations include feeling control over one's life, a feeling of meaning in one's life, and a sense of one's own value."

Source: "Families and Disability Newsletter", Vol. 2, No. 1; Spring 1990, Beach Center on Families and Disability

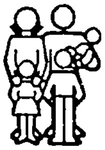


Today people bring important gifts to the community. This is true for people with disabilities, as well as people without disabilities. Too often, positive contributions made by people with disabilities have been denied or ignored. We have focused on deficits and negative characteristics and overlooked the gifts and capacities people with disabilities bring to the community. People with disabilities have the ability and right to enjoy the fruits of these contributions. For that reason, all of us should create opportunities for contributions to be given and expectations to be fulfilled.

We need to work together to build on capabilities, adapt environments, build relationships, help individuals and their families identify what is important to them and empower them with decision-making and spending authority to act upon those choices.

"Visions, dreams, great expectations—the challenge faces all of us. But only if all of us have great expectations for each other, especially for people with disabilities and their families."

Source: "Families and Disability Newsletter", Vol. 2, No. 1,
Spring 1990, Beach Center on Families and Disability



Appendix

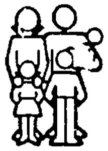
Perceptions of Disability

Traditional	State of the Art
People with disabilities are a burden to their families and society.	People with disabilities are valued and contributing members of their families and society.
Families are dysfunctional because of the burden created by the disability.	Society's reaction to and policies about families and disability can create dysfunctionality in families.
Families should have low expectations, expecting segregated services and second-class citizenship, because it's unrealistic for them to expect integrated services.	Families should have high expectations and skills to obtain integrated services and full citizenship.

Family Roles

Mothers are most interested in services for the child.	Every family should have the opportunity to designate appropriate members to take on various roles in the child's life.
Parents of adults overprotect them; so adults should be independent from their parents and rely on professionals as family substitutes.	Adults with disabilities have the opportunity to identify and act on preferences for family roles.
Siblings should take responsibility for long-term care of their brother or sister, both before and after their parents' death.	Siblings are entitled to normalization and their own lives. It should not be assumed that they will always have a major role regarding their brother or sister's care.
If any family member is severely "distressed" by the person with a disability, separation from the family is acceptable. The person with a disability should be placed outside the home.	There are many appropriate ways to support the family, so it can provide a supportive home to all members, including the person with a disability. Ensuring the person with a disability has a wholesome family life is especially important.

Source: Supporting Families With a Child With A Disability, Alan Gartner, Dorothy Kerzner Lipsky, Ann P. Turnbull, Brookes Publishing Company, 1991.

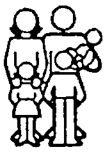


Myths & Realities

Myths about parent participation in the decision making process:

Myth	Reality
Parents are too emotional.	Because of life experience, parents who choose to participate in making decisions are nearly always realistic and knowledgeable.
Parents are too closely involved.	Because parents are so involved, they make effective decisions. They learn the system out of necessity and can help shape policies and services from their practical needs.
Parents are only concerned about their child.	Parents involved in public policymaking have learned that in helping themselves they may help others.
Parents always want more.	Parents want some control over services for their child with a disability.
Parents don't understand or appreciate funding problems.	Parents are also taxpayers and don't want to increase spending unnecessarily or irresponsibly. They are usually more sensitive to unneeded expenditures.
Parents are troublemakers.	Taking part in decisions that affect the lives of family members is being responsible, not making trouble.
Parents expect too much	Parents are aware that good programs and services can maximize their child's potential. Approaching that goal for people with special needs is cost effective, since they need fewer services when they gain independence.

Source: "The Speaker", newsletter of Sequin Retarded Citizens Association, 6223 West Ogden Ave., Berwyn, Il, 60402.



Acknowledgments

This guide was developed for professionals of the S.C. Department of Mental Retardation to provide suggestions for working more effectively with families.

To form effective partnerships between families and professionals, there must be mutual respect and joint decision-making, sharing of feelings, flexibility and honesty. Professionals and families need to work together to build capabilities. The challenge faces all of us.

Special Thanks to:

Deborah C. McPherson, Executive Assistant to
the Commissioner and Family Liaison, SCDMR

Dr. Philip S. Massey, Commissioner, SCDMR

Dr. Charles Chadwell, Piedmont Regional
Commissioner, SCDMR

Rebecca Worth -Jones, The Nurturing Center

Colleen Lee, Director, PRO-Parents of S.C.

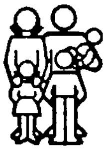
Sandy Poole, Parent and Advocate

Sandy Vaughn, Parent and Advocate

Dr. Deborah Valentine, Associate Professor,
University of South Carolina— School of Social Work

Jackie Robey, Parent and Advocate

Betty Neff, Parent and Advocate



September 1, 1992