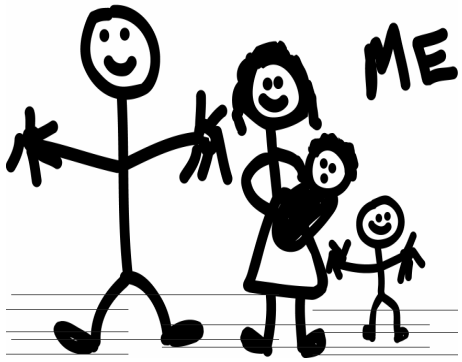
Parent Power



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Introduction

Where would we be without a support system in our lives? From the day we are born, our survival depends upon the support we receive to meet our physical, financial, emotional or spiritual needs.

For individuals who have special needs or family members and caregivers of children with special needs, family support provides a time to come together to share experiences, information and resources. We find ways to support each other while strengthening our own support system.

Parent Power is a collection of material designed to guide you through your journey of choosing a family support group or starting your own. In these pages, family support will be referenced as parent support, parent to parent, support network and family support network. Although some sources will be diagnosis specific, the information is suitable for any group.

Participating in a family support group is a little something you can do for yourself. It is not just another meeting or another obligation in your schedule. Give yourself, your family and your child this opportunity. You may be pleasantly surprised.

Best wishes to those of you who are interested in starting a family support group in your area. To all of you who have started a family support group or are participating and involved in the process of making your group a success, we extend a heartfelt "Bravo!" for your dedication.

Thank you to the parents and professionals who so generously shared their knowledge, resources and experiences with us.

Family Support Project (FSP)
Alabama's Early Intervention System (AEIS)
2129 East South Boulevard
Montgomery, AL 36116
1-800-543-3098

Alabama's Early Intervention System
www.rehab.state.al.us

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What is Family Support and How Does it Fit Into Alabama's Early Intervention System?

What is Family Support?

Family support occurs when families with similar interests or concerns meet to share a sense of community and understanding.[1] Family support groups may be formed around any interest or concern as long as there are people who wish to get together to help each other out.[2] In our day-to-day lives, we may be uncertain where our child or our family unit best fits. A family support group can offer an environment wherein we are welcomed, belong and are accepted.

Many families of young children with disabilities benefit from a family support group and a network of related resources to help them access information pertinent to their child's disability and family circumstance. Parents want to know the best ways to help their child and family, how to be effective advocates, and how to collaborate with professionals.[3] Family support groups or parent groups may meet for a variety of reasons. Primarily, they offer families a place and means to share information, give and receive emotional support, and work as a team to address common concerns. These parent groups may also allow families the opportunity to speak in a unified voice to express their needs and goals.

Family support is a societal investment in the promotion of the positive things families want for their children. Research shows this support improves parenting skills and self-confidence, the desire to attain greater education, and better knowledge of child development. Family support is a set of beliefs and an approach to strengthening and empowering families and communities so that they can foster the optimal development of children, youth, and adult family members.[4] Remember, you know your child better than anyone, and your knowledge and experience are important.

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What Support Groups Can Do

Now that we have some idea of what a family support group is, we should find out what it can do for us. Why would we want to become involved? The answer depends on what we need from others in similar situations and the impact such a group will have on our future.

Parent to Parent of Pennsylvania offers the following list of things support groups ***can*** do for families.

1. Provide a safe, non-judgmental, and confidential outlet for sharing with peers who have gone through similar experiences
2. Provide understanding and assurance for others in the group that they are not alone
3. Provide evidence that it is possible to feel better about dealing or coping with disabilities, and to develop positive attitudes about the future
4. Provide the opportunity for members to help each other through the sharing of knowledge and experiences
5. Provide ideas and avenues wherein members can begin to regain some control over their lives
6. Offer resources, speakers, information, and literature not readily available outside of the group
7. Provide the opportunity for the formation of new support relationships which may exist outside of the group framework[5]

"I have learned so much about health care issues and guidelines that have been beneficial to myself and my child. Being part of this support group prepares us for things in the future that could come up. It gives us resources for future use."
Tina Conn, parent

"I have met so many wonderful people." Michelle Norwood, parent

"We are always looking for activities that help our son fit into the norm better."
Shannon Burch, parent

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"We have created bonds with other families facing the same joys and struggles that we face." Anne Cline, parent

"I became acquainted with Dr. Melanie Cotter. She wanted to begin an autism support group. I attended and learned so much listening to other parents and how they handle life's experiences with their children who have autism."
Marie Bird, grandparent

What Support Groups Cannot Do

Some families may have unrealistic expectations or may not be emotionally ready to become involved in a family support group. Parent to Parent of Pennsylvania offers the following list of things a support group ***cannot*** do for families.

1. "Cure" people
2. Attempt or suggest therapeutic interventions
3. Diagnose, make psychiatric evaluations or recommend therapies or medications
4. Attempt to resolve conflictual or ambivalent emotions or feelings.
5. Address toxic issues[6]

Family Support and AEIS

In many ways, AEIS and family support groups are alike. Both help families meet the needs of their infants and toddlers by giving them a voice and encouraging their participation. Early intervention offers a system developed to identify and manage the priorities and concerns of eligible families for their children much like family support. Both AEIS and family support groups may inform families of local trainings and workshops of interest in the community.

Alabama's Early Intervention System (AEIS) provides coordinated services from many different state agencies and community-based service providers. These services are for infants and toddlers, from birth to 3 years, who are eligible because of special needs (developmental delays or diagnosed disabilities). The Alabama

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Department of Rehabilitation Services (ADRS), Division of Early Intervention, coordinates Alabama's Early intervention System.

Each child eligible for AEIS (a 25% delay in one or more areas of development or have a diagnosed condition which has a high probability of resulting in developmental delay) has an Individualized Family Service Plan (IFSP). Developing this plan provides ongoing opportunities for families and practitioners to identify the family's resources, concerns, and priorities. A service coordinator uses the IFSP to work with the family and coordinate the services from all agencies until transition occurs at age 3 years, or until the child is no longer eligible for AEIS. Communication with the family allows the service coordinator the opportunity to discuss goals for and meeting the needs of the child.[7] Many families benefit from contact with families with children who have a similar condition or diagnosis. AEIS service providers are also instrumental in connecting parents to the family support they need in their community. As the number of eligible children and families participating in the early intervention system grows, the need for family support organizations increases.[8] Providing information to families about the national, state and local family support organizations helps address potential needs for contact with other families or other community resources.[9] Families who have concerns about their child's development, but are not eligible for AEIS, may be interested in or involved in family support groups in their area.

"By participating in workshops, conferences, and Early Intervention coordinating councils one begins to feel real support." Marie Bird, grandparent

"I found out about the support group we are going to now from Hand in Hand Early Intervention." Jamie Larson, parent

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How Do I Start a Family Support Group?

Are You Sure About Starting a Family Support Group?

There are many reasons to start a family support group. There may not be a support group in your area to meet your family's needs or the needs of families in similar situations. You may know of an existing state or nationally organized group that would mentor and assist with starting a local chapter. You may also know of an early intervention program or interested professional who would help provide resources and assist you as you begin this journey.

You ***should*** start a support group if :

1. you have a sincere and genuine concern for people.
2. you are prepared for a long term commitment.
3. you can put your personal and religious beliefs on hold.
4. you don't need personal recognition for your efforts.
5. your personal reward come by seeing other people grow.

You ***should not*** start a support group if:

1. you have not successfully accomplished tasks required to integrate your own personal issues. It would be premature to start a group if you cannot serve as a role model in coping and adapting to issues.
2. you can't reserve significant time in your life to devote to the group and its administration. It takes an initial commitment to setup, organize, market the group and oversee it.
3. you don't have the understanding and cooperation of your family or significant others in your life.
4. you can't or don't want to share authority and responsibility. One person cannot handle the administration, facilitation and management of the group. [10]

Starting a family support group should be taken seriously. Be sure you have the time available and the emotional support of your family.

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"I decided to start a support group because I live in a rural small town with very few special needs children and I wanted to be around other families like us. Being part of this group allows me to give back to the community. We've been so blessed by Joseph and our experiences with him have been positive 99% of the time. I would like to help provide that for other families." Anne Cline, parent

"I started a support group with my church. It is a lot of work, but I always wanted to be around other families in the same situation as we are." Ivy Pittman, parent

Where to Begin

Once you have made the decision to start a support group, contact at least two or three people who share your interest. Let this be your core group. This group will share the responsibilities involved in getting your support group up and running.

In making decisions about forming the support group, consider these questions:

1. What is the primary purpose of this group?
2. What schools, disabilities, age groups, and geographical areas would you cover?
3. Who would join this group?
4. How will you communicate with or reach other people?
5. What is the underlying philosophy of the members?
6. What are your goals for this year? Can you list them in order of importance?
7. When do you want to meet?
8. How often do you want to meet?
9. Where do you want to meet?
10. Who will lead the meetings?
11. Will you need to raise money and charge dues or solicit contributions?[11]

When you and your core group have discussed the answers to these eleven questions, you may be ready to consider the suggestions given below.

1. Ask the professionals who helped you with different aspects of your child's disability if they know of other individuals that had similar experiences and

might be interested in joining your group.
2. Many cities have mental health associations which have a Self-Help Clearinghouse. These organizations can provide you with names of similar groups and often will help you start your own.
3. Find out if there is a National Organization in your field of interest that will help you open a chapter in your area. They can often supply you with start-up guidelines and supplementary material that can be very helpful.
4. Check the Community, Neighborhood, or Metropolitan sections of your newspaper for announcements of similar groups and their meetings. Contact a group leader and see if you can visit the group and see how it is run.
5. Churches, synagogues, and other religious or spiritual organizations can often provide you with a location or speakers for your group as well as alert you to similar groups within their institution.
6. Look in the Yellow Pages under social services for organizations you may wish to contact to let them know of your group.
7. Go to the library and check out books on the subject. Many books will include a list of organizations and useful resources for you to contact or use as group material.
8. Your local or regional psychological association can refer you to counselors who specialize in your area of interest and who might be willing to work with you in starting your group.
9. Subscribe to newsletters offered by organizations in your field of interest. Newsletters are a good source of information that can determine who is prominent in your field and where to find seminars or lectures to broaden your knowledge.
10. If you find a group with similar interests, call the group facilitator and ask if you can monitor the group and arrange a meeting to discuss ideas and concerns.[12]

Who Can Participate?

Deciding who may participate in your support group depends on the emphasis and size of group you want to start. Family support groups are often referred to as a parent groups. Both are group of parents, grandparents, aunts and uncles, siblings,

foster parents, primary caregivers, or anyone assisting in raising the child with a disability. These groups also often include members such as educators, medical professionals, social services people, policymakers, friends and others interested in the same issues.[13]

"I wish they would have more meetings just for grandparents and other family members to inform them about special needs." Lisa Williams, parent

"We have created an informal forum in which bewildered new parents can just drop in and find a group who knows what they are going through, and we offer a resource for medical professionals because they may direct any of their patients to us who need our support. We strive to be a 'very open' group. We want to create an environment where people feel comfortable sharing whatever is on their mind."
Anne Cline, parent

The First Meeting

Once you have made the decision to start a group, organized a core group, found resources to support your purpose and decided who to invite, it is time to prepare for you first meeting. Some suggested guidelines to follow are:

1. Determine leadership. Who will conduct the first meeting? Will you have officers, will you elect a leader, appoint a leader and get group approval, or elect several officers?
2. Develop an agenda for the first meeting. You may want to start informally and offer participants a chance to get together and talk or you may want to devote the first meeting to organizational issues. Do you want to invite a guest speaker, show a video or combine the meeting with a social event? Be sure the agenda is specific, goal oriented, and short enough that you can comfortably get through all items listed.
3. Arrange for the place of the meeting. Pick a convenient location that can comfortably hold the maximum number of people you expect to attend. This does not have to be a permanent meeting place, but pick some place easy to find. Be sure this place is accessible to individuals with disabilities and has plenty of parking available.

4. Invite guests to the meeting. Do you want to control who is coming to this meeting or open it up to the public by advertising? You may wish to post notices in places like early intervention programs, clinics, schools, doctors' offices, libraries, the recreation center or other locations where your prospective members might see them. The local newspaper may have a section that announces local meetings.[14]

To ensure a successful first meeting, you might:

1. get there early and be sure everything is set up as you want it.
2. be sure to put signs at the door directing people to the meeting room.
3. have a guest list for people to sign as they arrive. It is always helpful to have a mailing list of potential members. You may also consider using a membership form.
4. provide name tags. Guests may not know each other.
5. you may want to take a few minutes to have everyone give his/her name, age of child, disability of child, and/or school child attends.
6. introduce the leaders of the group or candidates for office and any community leaders or school officials in attendance.
7. don't rush, but keep the meeting moving.
8. set a time and place for the next meeting and identify possible topics or activities.
9. allow time for socializing and discussion. It is important for members to be able to talk to one another, but don't let this "take over" the meeting.
10. end on time.[15]

Maintaining A Group

Communication is very important in maintaining your group. After your first meeting, it is a good idea to send a memo, letter or e-mail to each participant to thank them for their effort to attend. Give them some information about the group such as how many families attended and the ages and disabilities of their children. Identify any professionals who may have attended, giving their agency or organization affiliation.

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Support group members appreciate being kept up to date. Sending correspondence will refresh their memory of decisions made during the meetings. Remember, involve others, give them responsibility, and use the strength of your volunteers.

As your group becomes more established, there may be other questions to consider such as:

1. what are your group's long-term goals?
2. what do your members want to learn more about?
3. do you want to offer or participate in training programs?
4. who will arrange for speakers or topics for the meetings?
5. who will contact members and advertise the meetings?
6. do you want people to be able to reach your group by phone?
7. whose number will they call?
8. do you need to provide child care at the meetings?
9. how will you pay for this?
10. do you want to start and send out a newsletter?
11. who will write it? type it? mail it?
12. how will you pay for the newsletter and postage?
13. will this work be done on a volunteer basis or will someone need to be hired?
14. how much money do you think you'll need to carry out your plans?
15. do you plan to raise money and/or apply for funds?
16. will you need to make this a formal organization?
17. will you need to write by-laws?
18. do you need to apply to the IRS for tax exempt status? Do you need an auditor?
19. do you have someone with experience in organizing nonprofit groups to help formalize your group?[16]

The numbers of parents who attend your group will fluctuate over time.[17] Don't confuse interest or effectiveness with numbers. Announced topics of discussion may only attract a small audience, but may be of great interest and importance to those people. In general, more people will plan to attend than actually get there, especially when infants and toddlers are part of the family. Large attendance is not the key to success. Some people join groups for reasons other than attending all

the meetings. They may join to receive a newsletter, to be a part of a group that is working for the benefit of their child or to attend only one or two meetings of special interest.[18] As the needs of the members in your group will change over time, the group should be able to change to meet the new circumstances. Some parents will attend the group for a short period or sporadically while coping with particularly stressful life events. Others will attend faithfully as long as the group lasts. However, if too many parents are leaving the group, you need to determine why.[19]

Keeping a group going requires a lot of time, work, energy, and sometimes money. It is often harder to keep a parent support group alive and energized than to start a new one.

These suggestions will help to keep your parent support group alive and well.

1. Get a new focus.
2. Take on a special project that has long been needed.
3. Continue to have regular meetings.
4. Have an open door policy.
5. Function democratically – not as a social club.
6. Have an active membership committee.
7. Stay abreast and up to date on all action by local bureaucracies.
8. Keep the press informed of all important activities.
9. Don't become a "paper organization."
10. Don't become just a fund raising group.
11. Don't let your parent support group become just a gripe group.
12. Remember the purpose of your group.
13. Share the glory that comes to your parent support group.
14. Communicate with your membership on a continual basis.
15. Keep your members involved.[20]

Financing a Group

Many community facilities are willing to offer meeting location options for your group. Some may even provide refreshments. There are groups that are run entirely by volunteers and have no income other than possible membership

dues.[21]Many groups may continue to meet without financial support. However, the time may come when your group may consider adding special projects, a newsletter, a brochure, or inviting speakers who require financial support. Some qualified members of the group may wish to volunteer their time to participate on a financial committee or your group might consider paying someone to take care of the financial arrangements. Research any options of funding available to your group such as federal, state and local grants, philanthropic or private sector donations or community fund raisers. Have a purpose for the funds, but keep in mind that core functions may not be supported by short-term funding.

"Our one source of income is the Buddy Walk. It is an annual, nation-wide walk sponsored by the National Down Syndrome Society. We have corporate sponsors and individual, group or family sponsors. We set a budget for the year. If we make more than our budget through our Buddy Walk, we set some aside. Our expenses for each year are an administrative cost, setting aside funds to establish an Adult Down Syndrome Clinic, funding support to send physicians to workshops or trainings for adult Down syndrome care, media expenses for our Buddy Walk, outreach in the community, educational and advocacy meetings for parents and teachers, a quarterly newsletter, and maintaining a phone tree using Calling Post." Kara Bishop, parent, treasurer for PADS

What are the Features of a Good Support Group?

What Do I Look For?

Whether you are starting a support group or thinking about joining one, consider leadership, program quality and sustainability as necessary for a successful group. All groups need leadership, whether it is shared or rotated by vote as a group of officers. Good leaders are skillful in organizing, facilitating, and problem-solving. Pay attention to details such as the meeting location and accessibility, the agenda of the group, short-term and long-term goals that meet the needs of the group, discussion and socialization guidelines, the size of the group, and the ability and ease of making connections with the group members. Any family support group needs leadership to handle member or scheduling conflicts and dominance in

program planning and floor time. A good leader or group of officers should be able to provide quality programs while being aware of potential problems. To avoid many common problems, a group may have to set solid ground rules. Groups may also be formed to operate temporarily to reach short-term goals. Such groups usually follow a curriculum related to specific or requested topics. When the plan or curriculum is finished, the goal is met and then the group disbands.

"I chose the group I am involved in because it was a Down Syndrome New Parent Group. I was very interested in their speakers and the information they could provide." Tina Conn, parent

"I chose to attend the family support group meetings because they were close to home." Lisa Wilson, parent

"The meetings for my support group are held on Saturday mornings and are very convenient." Michelle Norwood, parent

"We try to choose things that don't require babysitting because it is difficult to arrange. If childcare is included, that is a plus. We also schedule things around school and work. It has to be convenient since we have two other children. We choose things that involve children like our son. We look for groups that have similar characteristics." Shannon Burch, parent

Ground Rules

Ground rules for support groups are important. These may be drawn up before the first meeting, but it is important that they be discussed and agreed upon by all participants at the first meeting and all subsequent meetings. Members should be able to suggest modifications or additions. This process not only establishes ground rules for the group; it also promotes ownership in the group by members and aids in the reestablishment of personal control.[22]

Some suggested ground rules are:

1. Define the purpose of the group.
2. Everyone will have a chance to speak, but will be under no obligation to do so.
3. Everyone agrees that any and all information disclosed in this group is private and totally confidential.
4. All expressions of feeling are allowed.
5. Full names of non-participants should not be mentioned.
6. No personal information will be released by this group to any outside agency or individual without the written consent of the member.
7. Participants should feel free to get up and move around during the course of the meeting should they feel the need to do so.
8. Participants are encouraged to exchange phone numbers and call each other between meetings.
9. THIS IS YOUR GROUP! If any member has any suggestions or criticisms, he/she is encouraged to voice them to the group facilitator or staff.[23]

By-laws

By-laws are not ground rules. Ground rules are terms to follow for conducting the meeting and membership rights. By-laws are rules an organization agrees to live by to help things function smoothly and efficiently. Most groups have the same basic rules. Keep yours short, simple and to the point. By-laws state the name, purpose, affiliation (if any), membership and dues of the group. Officers, board of directors and nominating committees (if those apply) are named and their duties outlined. By-laws may be amended at any regular meeting of this group by an affirmative vote of two-thirds majority of the members present.[24]

"Our officers provide a slate of board members or persons available to serve as board members from the community. Our officers are members of PADS who want to serve our group. The officers can be voted on by the membership. Usually there is no objection. We are glad when someone wants to serve. Our by-laws are available on our web site, www.downsyndromealabama.org."

Kara Bishop, parent, treasurer of PADS

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Are There Existing Organizations?

How Do I Find Them?

Instead of starting your own support group, you might like to plug into an existing one. There are many places to look for family support groups on the local, state and national levels. Locally, you may talk with the special education staff at schools, talk to social service departments and therapy departments at hospitals, talk to vocational rehabilitation counselors, group homes, and check in the phone book under either the specific disability or in the yellow page under Disability Services. Many churches sponsor support groups. Support group information may be offered at the area Chamber of Commerce office or tourist information center. Newspapers sometimes provide a community calendar of events that will include support group meetings. State and national support groups may be found through local affiliate chapters, newspaper links and by searching the Internet for general or disability specific information. Clearinghouses such as NICHCY offer statewide and national listings of family support groups. Family Support America is a national resource organization that provides a mapping project to assist with locating family support groups on the local, state and national levels. If your child is in early intervention, ask your service coordinator to help you make it a priority on your IFSP.

"I found our support group in the Montgomery Parent's Magazine."
Shannon Burch, parent

"Other parents at the Bell Center told me about the group supported by PADS."
Tina Conn, parent

How Do I Join?

When you have found a group whose goals and activities are similar to what you'd like to do, contact the group and ask how you would go about affiliating with it. If this group is a state or local affiliate of a national organization, ask how you join

with the national office. Talk to representatives of the group about assistance they can offer in getting subscriptions to relevant publications and locating resources in your area[25].

When considering membership in one or more family support groups, it is helpful to review your personal needs. Are you looking for moral support or advocacy training? Do you want to get to know other families who have a child like yours? Are you interested in hearing speakers on special education and disability topics? Are you interested in becoming involved in local decision-making processes for school and disability issues? Would you like to receive a newsletter on disability topics?[26]

Ask yourself what kind of "joiner" you are. Are you more comfortable with formal organizations or do you prefer less structure? Consider the types of groups around you and decide where you would feel most comfortable. Sometimes the best way to get involved with a new group of people is to volunteer to take an activity. By being a participant you will meet other members and learn more about the goals and functions of the organization.[27]

Even if your search does not result in a decision to affiliate with an existing organization, it will be useful to have contacts in the disability field with whom you can network.[28]

State Family Support Group Directory
(Listed by AEIS Districts)

Huntsville - District I
(Colbert, Franklin, Jackson, Lauderdale, Lawrence, Limestone, Madison, Marion, Marshall, Morgan, and Winston counties)

Bringing Up Down Syndrome (BUDS) is a non-profit organization to benefit families and others whose lives have been impacted by Down Syndrome. They meet the first Saturday of every month at 11:00 a.m. The location may vary between the ARC of Madison County Infant and Toddler Program, 312 Cahill

State Family Support Group Directory, continued

Drive NW, Suite A, Huntsville or Logan's Roadhouse, 6226 University Drive NW, Huntsville. For more information about this group or to confirm it meeting schedule, contact Jared Suter at 256-828-2167 or visit www.budsonline.org. This web site promotes advocacy of Down Syndrome awareness.

Decatur/Hartselle/Athens Autism Support Group offers support for families and caregivers of children and adults with autism. This group meets the fourth Thursday of each month at various locations. For more information about meeting dates and times, contact Jan Appling at 256-350-6879 or Cindy Morgan at 256-778-8137.

North Alabama Chapter of the Autism Society of America meets the last Friday of each month at 7:00 at Grace Baptist Church, 2611 Pulaski Pike, Huntsville. Childcare can be arranged by reservation. If you would like more information on this group, please contact Mary Kay Burns at 256-776-0505.

Birmingham – District II

(Cullman, Jefferson, Shelby, and Walker counties)

Down Syndrome New Parent Support Group meets the fourth Monday of each month at the Vestavia Methodist Church, 2061 Kentucky Avenue in Birmingham. Anyone in the area interested in this group is welcome to attend. For more information contact Laura Davis at 205-967-3722 or PADS at 205-988-0810. This group offers seminars on teaching children with Down Syndrome and potty training in children with Down Syndrome. Visit PADS on the web at www.downsyndromealabama.org.

Support Group for Caregivers With Children With Disabilities and Their Siblings meets the first Friday of every month from 6:00 p.m. until 10:00 p.m. at the St. Marks United Methodist Church, 2901 Columbiana Road in Birmingham. For more information call 205-822-5980.

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State Family Support Group Directory, continued

Amelia Center Grief Support Group meets at the Amelia Center, 1513 Fourth Avenue South in Birmingham. This group meets every first Monday of each month at 5:30 p.m. For more information about this group call 205-251-3430.

Positive Parenting Group is sponsored by The Exchange Club Family Skills Center. These groups are open to all parents wanting to learn more about parenting their children in a positive way in order to build healthy relationships with their children. Each parenting class meets weekly throughout the year and offers a combination of education and support. Class leaders provide information that is useful in helping parents work toward improving parenting skills. There is no attendance policy and parents may attend as often as needed. Classes are offered to parents with newborn children to children age 17. There is no charge for these classes and childcare is provided during the meeting time.

The locations listed are ***meeting sites only***. If you have questions about these classes or if you need directions to any class, please call the Exchange Club Family Skills Center.

Smithfield Library
This class targets issues important to parents with children ages birth-12.
It meets every Monday from 11:00 a.m. – 12:00 p.m. The library is located at 1-8th Avenue West, Birmingham. For more information call 205-324-8428.

Eureka Family Center
This class targets issues important to parents with children ages birth-4. It meets every Tuesday from 11:30 a.m. – 12:30 p.m. The center is located at 812 18th Way SW, West End. For more information call 205- 929-8185.

Baptist Church of the Covenant
This class targets issues important to parents with children ages birth-9. It meets every Tuesday from 6:30 – 7:30 p.m. The church is located at 2117 University Blvd., Southside. For more information call 205-320-7475.

Baptist Church of the Covenant
These classes target issues important to parents with children ages 10-17. It meets every Tuesday from 6:30 – 7:30 p.m**.** The church is located at 2117 University Blvd., Southside. For more information call 205-320-7475.

Don Hawkins Recreational Center
This class targets issues important to parents with children ages birth-4. It meets every Thursday from 1:00-2:00 p.m. The center is located at 8920 Roebuck Boulevard, Birmingham. For more information call 205-836-1611.

Bessemer Advocacy Center
This class targets issues important to parents with children birth to age 12. It meets every Friday from 10:00 – 11:00 a.m. The center is located at 1830 Dartmouth Avenue, Bessemer. For more information call 205-481-4155. *PLEASE NOTE…IF YOU WILL BE BRINGING YOUR CHILD WITH YOU TO THIS CLASS, CALL 879-4847 BY THE MONDAY PRIOR TO CLASS IN ORDER TO ARRANGE CHILD CARE*

Cullman/Blount County Autism Support Group meets the third Saturday of each month from 6:00 p.m. until 9:00 p.m. at the First United Methodist Church, 320 Third Street, SE, Cullman. Family members and caregivers of children of any age who have autism or developmental delays related to autism are welcome. For more information about this group contact Rhonda Davis at 256-734-1328.

Tourette Syndrome Association Mid-South Office provides a state contact for persons interested in finding out more about Tourette Syndrome. A new group will be forming in the near future in the Birmingham area. For more information about this group contact Linda Saunders at 334-502-0055 or tsamidsouth@bellsouth.net.

The **Birmingham Asperger Parent Support Group Meeting** is for family members of children diagnosed with high functioning autism, PDD-NOS, and Asperger Syndrome ages preschool to adult. Each meeting focuses on connecting

State Family Support Group Directory, continued

and learning from others in similar situations. Respite care is offered at St. Mark United Methodist Church, 3901 Columbiana Road, Birmingham, from 6-19 p.m. the first Friday of each month. You can make reservations by calling Susan Lee at 205-620-9497 at least one week in advance of the meeting. St. Mark provides free child care for children (infant to 21 years) with disabilities, chronic health concerns, terminal illnesses, and their siblings on the first Friday evening of each month. This meeting will coincide with the autism group and will start at 6:30 p.m. If you have questions about the group call 205-824-6734.

Talladega – District III

(Blount, Calhoun, Cherokee, Clay, Cleburne, Dekalb, Etowah, St. Clair, and Talladega counties)

Burton Center Family Support Group is available to all families whose children are served by the Burton Center in Talladega. This group meets each month and

the time and location vary. For more information about the meeting arrangements contact Tangie Collins at 256-362-1700.

Calhoun County Autism Support Group is inactive at this time. The contact person, Tina Usry, can be reached at 256-236-7639 or usryfamily@cableone.net. Tina will be glad to help anyone with resources, etc. or add name to e-mail list.

Gadsden Autism Support Group is inactive at this time, but is planning activities for the fall of 2006. Contact Stephanie Walker at 256-546-9796 for more information about their meeting schedule and events.

Jackson, Etowah and Dekalb County Down Syndrome Support Group meets the first Saturday of every other month. The time and location vary with each meeting. To find out more about this group and where it will meet contact Tonya Rowe at 205-589-4556.

Parent Power

State Family Support Group Directory, continued

Montgomery – District IV

(Autauga, Bullock, Chambers, Chilton, Coosa, Elmore, Lee, Lowndes, Pike, Macon, Montgomery, Randolph, Russell, and Tallapoosa counties)

Mo and Me is a playgroup and support group for parents of children with a disability. It meets twice monthly, on Fridays, from 10:00 a.m. until noon. The group locations rotate between Alabama Institute for Deaf and Blind (AIDB) Montgomery Regional Center, 2629-B, Eastern Boulevard, Montgomery and Early Infant Education Intervention Opportunities (EIEIO) at 119 1st Street, Prattville. For information call Sharon Wheelahan at AIDB at 334-273-9200 or Early Infant Education Intervention Opportunities (EIEIO) at 334-361-6008.

The **Montgomery Area Down Syndrome Outreach Group** for friends and family members of people with Down Syndrome meets the first Friday of every month at 6:30 p.m. at the Vaughn Park Church of Christ, 3800 Vaughn Road. Childcare is provided and there are social gatherings scheduled throughout the year. For more information call Laurie Helms at 334-279-0320, leave a message at 334-356-9048; write to P. O. Box 681474, Prattville, AL 36068 or visit www.montgomeryareadownsyndrome.com.

Parents Who Have Children With Learning Disabilities or Special Needs meets from 5:00 p.m. until 6:30 p.m. on the first Sunday of each month in the Adult Sunday School Classroom of the St. James United Methodist Church, 9045 Vaughn Road, Montgomery. For more information contact Chris Henderson at 334-215-0427 (home), 334-262-4850 (work) or chenderson41@yahoo.com.

Parents of Special Needs Children is a support group for parents and family members of children with special needs. As of September 2006, it will meet the second Tuesday of each month from 6:30 p.m. until 8:00 p.m. in the Cokesbury Room (located in the new building on the back side of Frazier near the library) at Frazier Memorial United Methodist Church, 6000 Atlanta Highway, Montgomery. For more information contact Carol Moore at 334-271-1419.

State Family Support Group Directory, continued

Tourette Syndrome Association Mid-South Office provides a state contact for persons interested in finding out more about Tourette Syndrome. A new group will be forming in the near future in the Birmingham area. For more information about this group contact Linda Saunders at 334-502-0055 or tsamidsouth@bellsouth.net.

Dothan – District V

(Barbour, Butler, Coffee, Conecuh, Covington, Crenshaw, Dale, Geneva, Henry and Houston counties)

Down Syndrome Fellowship Meal offers a fellowship time for all people with Down Syndrome and those who love them. This group meets the first Friday of every month at 6:30 p.m. in the Recreation/Fitness Center of Ridgecrest Baptist Church, 1231 Fortner Street in Dothan. Everyone is asked to bring a covered dish or dessert. For more information call Anne Cline at (334)897-1550.

FASE is Families with Autism Support and Encouragement. This group meets the fourth Tuesday of every month in the Physical Therapy Department at the Southeast Alabama Medical Center, 1108 Ross Clark Circle in Dothan. For information about this group contact Fran Heisner at (334)793-8714.

Hang in There offers support to any age group for special needs, learning disabilities, brain damage and physical disabilities. They meet the fourth Saturday of every month at 6:30 p.m. at the Southeast Alabama Medical Center, 1108 Ross Clark Circle in Dothan. For more information call Joy Coleman at 334-983-1736.

Autism Awareness in the Wiregrass is a support group for individuals or parents and grandparents of children within the Autistic Spectrum (including PDD and ADD/ADHD). This group currently meets every other Thursday at 6:00 p.m. at McDonald's, 3520 Ross Clark Circle, Dothan. For more information about this group, contact Carie Tenzel at 334-685-4437 or e-mail to autismawarenessinthewiregrass@hotmail.com.

State Family Support Group Directory, continued

Mobile – District VI

(Baldwin, Choctaw, Clarke, Escambia, Monroe, Mobile and Washington counties)

Mobile County Down Syndrome Support Group holds random meetings throughout the year at 7:00 p.m. at Goodwill Easter Seals, 10 Westminster Way, Mobile. Free child care is provided. Social gatherings are scheduled about three times each year. Mail-outs are distributed to members. For more information about this group or to receive a flyer contact Angel Lowen at 251-342-3122.

South Alabama Asperger's Support Group meets the third Friday of every month at St. Mark's United Methodist Church, 439 Azalea Road, Mobile. Anyone interested in learning more about this group should contact Candy Knickerbocker, parent coordinator, at 251-663-0109 or 251-767-0304 or cknick@bellsouth.net.

Baldwin County Autism Support Group meets the second Monday of each month at 6:00 p.m. at 750 Morphy Avenue, Fairhope. For more information call 251-990-1644.

Tuscaloosa – District VII

(Bibb, Dallas, Fayette, Greene, Hale, Lamar, Marengo, Perry, Pickens, Sumter, Wilcox, and Tuscaloosa counties)

Autism Support Group meets the second Tuesday of every month at 6:30 p.m. at the Christ Episcopal Church Parlor, 605 Lurleen B.Wallace Boulevard, Tuscaloosa. For more information about this group contact Ashley Ferry at 205-750-0458 or 205-613-1743.

Parent Advisory Committee (PAC) is sponsored by the Children's Rehabilitation Service of Tuscaloosa. This committee meets quarterly at the University Church of Christ, 1200 Julia Tutwiler Drive, Tuscaloosa. Parents, grandparents, caregivers and service providers of children with special needs are invited to attend. Topics of

State Family Support Group Directory, continued

discussion during the meetings vary depending upon the needs of the families and how to help them meet those needs. For more information about this group and meeting dates contact Vivian Spears at 205-759-1279 or 205-366-4322.

Out of the Box Support Group is a support group for families and service providers of children with special needs. This group meets each month at the Barrett Road Methodist Church, 615 Barrett Road, Selma. For more information regarding the meeting times, contact Tonya Gandy at 334-875-2100.

Teen MoMs is a support group for high-school age mothers in Tuscaloosa County. These groups have discussions on parenting skills, healthy relationships, nutrition, self-esteem, trust, and much more. They provide a mentoring program of women in the community who work to build relationships with the girls in order to meet the individual needs and provide support. For more information about this group call 205-752-3361 or e-mail to TeenMoms@tuscaloosayfc.com.

**Editor's Note: The information provided on the above mentioned family support groups is correct and accurate at the time this manual is published and is subject to change without notice. If you are interested in attending one of these meetings, you are encouraged to confirm the time and place by using the contact information given.*

Parent Power

Example of a Meeting Announcement[29]

A support group for parents of children with **learning disabilities** is now being formed. The format of the group will be **educational/support** with a speaker or specific topic for each meeting. The details of the meeting are:

Date:	**Third Tuesday of each month**
Time:	**7:30 p.m.**
Place:	**Classroom #2 -- Southland Church**
Address:	**5555 W. Southland Blvd.**
Format:	**Speaker and Parent Discussion**
Contact:	**Marsha Wright at 555-5555**

The speaker at the first meeting will be **James Spenser** talking about **initial referrals for special education services.**

We would appreciate your referrals to this group. If you or anyone would like more information about the group, please call **Marsha Wright at (214) 555-5555.**

A map with detailed directions is provided below, so you may copy this notice for all interested parties. We would also appreciate your posting this announcement on all appropriate bulletin boards.

Thank you so much for your cooperation. With your help we will be able to reach many more people.

Sketch of map

* In this example, substitute the information in gray with your own group's information.

Parent Power

Parents Together Support Group[30]
11111 W. First Street
Dallas, Tx 75555
(214) 555-5555

Dates: **March 29, 1992**

For Immediate Release

PRESS RELEASE (EXAMPLE)

Contact: **Marsha Wright**, Director: **(214) 555-555**

NEW SUPPORT GROUP FOR PARENTS OF CHILDREN WITH LEARNING DISABILITIES

A new information and support group for parents of children with **learning disabilities** is being offered to members of the community.

The group is for anyone parenting a child with a learning disability. Guest speakers will cover topics such as: **appropriate services, evaluations, education law, new techniques, and the IEP process.**

Parents throughout the community are invited to attend. There is no charge to participate and registration is not required. The new group, **Parents Together**, will have its first meeting on **Tuesday, August 20, 2000** at 7:30 p.m. in **Classroom #2 of Southland Church, 555 W. Southland Blvd.**, and meet **the third Tuesday** of **every month** thereafter.

For additional information, please call **Marsha Wright at 555.5555** or email at **parents@together.com**

*In this example, substitute the information that is in gray with your own group's information.

Example of a Member Profile Card[31]

Date of initial contact: _____

Name:_____ Phone Number:_____

Address:_____ City, Zip:_____

Spouse: _____

Significant Other: _____

Child:_____ Age:_____

Child:_____ Age:_____

Child:_____ Age:_____

Child:_____ Age:_____

Employer:_____

Referred By:_____

Reason for Calling Now?: _____

Background Information:

Important Dates:

Example Form for Organizing a Parent Support Group[32]

CALLING ALL PARENTS OF _____

A special meeting is being called to organize a PARENT SUPPORT GROUP at _____

_____

DATE:
TIME:
PLACE:

ISSUES AND CONCERNS TO BE DISCUSSED:

JOIN US!

For further information call:
YOUR NAME
ADDRESS
PHONE

Example of a V. I. P. Letter[33]

Dear_____,

Because you are a leading citizen of our community, we are inviting you to attend a public meeting that could have a profound effect on the lives of our _____ children. The meeting is about _____ and will be held on:
(date and time) at: (Place).

Appearing on a panel will be: _____

We hope this meeting will bring together parents and others interested in _____.

Won't you join us in this undertaking to provide better services for _____

_____.

Sincerely,
(Your Name and Signature)

Example of a Membership Letter[34]

Dear_____,

A new Parent Support group, _____, was born at a public meeting at _____ (Date of your meeting).

We have exciting plans: (list them).

Won't you join us in this new undertaking and become a member of_____

Dues are _____ per year.

(Signed by your Temporary Officers with their phone numbers.)

Example of a Volunteer Sheet[35]

NAME_____

ADDRESS_____
CITY STATE ZIP_____
PHONE _____Day _____Night
E-MAIL_____
AFFILIATION (PARENT, PROFESSIONAL, OR OTHER)
MY CHILD IS.
DEAF _____
HARD OF HEARING _____
VISUALLY HANDICAPPED _____
MULTIPLY HANDICAPPED _____
LEARNING DISABLED _____
PHYSICALLY HANDICAPPED _____
OTHER _____
I WOULD LIKE TO JOIN A PARENT SUPPORT GROUP_____
I ALREADY BELONG TO A PARENT GROUP _____
GROUP NAME _____
PROBLEMS I WOULD LIKE A PARENT SUPPORT GROUP TO WORK ON:

I WOULD BE WILLING TO WORK ON:

LEGISLATION	PROGRAM
PUBLICITY	FUND RAISING
PROJECTS	DRIVING
MAILING CAMPAIGNS	PICK-UP SERVICE
RESEARCH PROJECTS	
MEMBERSHIP	
TYPING AND OTHER CLERICAL JOBS	
SPECIAL PROBLEMS	
OTHER	

Parent Power

Example of By-Laws

NAME OF PARENT SUPPORT GROUP[36]

ARTICLE I – Name
The name of this organization shall be the
_____

ARTICLE Il - Purpose
The purpose of this organization shall be to _____

_____

_____.

ARTICLE Ill - Affiliation, Membership and Dues
The _____ is an organization of parents of _____, concerned citizens, and organizations of parents or professionals serving
_____. Any organization, individual, or family subscribing to the goals of _____ may become affiliated through membership.
Membership dues for a family or individual shall be $XX.xx per year. Organizational membership dues are $XX.xx per year or some higher amount.
Membership entitles a member to all mailings, monthly newsletter, meeting notices, the right to attend meetings and to vote for officers at the Annual Election Meeting. A person or organization wishing to subscribe to the monthly newsletter but not participate in other activities may do so for a subscription fee of $XX.xx. Other informative booklets
can be obtained for a nominal cost.

ARTICLE IV - Officers, Board of Directors and Nominating Committee
Section A – Officers
Officer's of_____ shall be:
President
Vice President
Secretary
Treasurer

The officers shall serve for a term of one year and shall be elected at the Election meeting.

Section B - Board of Directors
The Board of Directors shall consist of the officers and the committee chairpersons of all standing or special committees. The standing committees of the organization shall include:

Membership
Finance
Legislative
Publicity
Education

The Board of Directors as needed shall establish special committees.

Duties of the Board of Directors
The Board of Directors shall be responsible for overseeing the functioning of _____, shall participate in the selection and supervision of staff members, shall develop programs to accomplish the goals of the committees, and shall attend monthly Board of Directors' meetings.

Voting
Each member of the Board of Directors shall have one vote, except the President who shall vote only in the case of a tie.

Removal
A Board member may be removed for gross neglect of duty (Including three consecutive unexcused absences from Board meetings) by majority vote of the Board of Directors. Thirty days' notice must be given to any Board member before a vote for removal can be taken.

Vacancies
The President and Vice President shall be empowered to fill any vacancies in the Board of Directors with the approval of the majority of the remaining Board members

Section C - Nominating Committee

The Nominating Committee composed of five members at least two of who are not currently officers. The Committee shall be appointed by the Board at the _____ meeting to nominate officers and committee chairpersons. The report of the Nominating Committee shall be published in the newsletter prior to the (date) _____ Election Meeting.

By-Laws, continued

ARTICLE V - Meetings

Section A - Regular Meetings
Regular meetings of the Board of Directors shall be held the first week of every month except by special arrangement of the officers.

Section B - Quorum
Five members of the Board of Directors shall constitute a quorum.

Section C - Special Meetings
Special meetings of the Board of Directors or the membership to discuss and take action on emergencies shall be called by arrangement of the officers.

Section D - Election Meeting
All members shall be invited to attend the _____ Election Meeting of the Board of Directors. At this meeting officers shall be elected by majority vote of the membership Announcement of the Election Meeting, including the report of the Nominating Committee and an invitation to the membership to attend shall be published in the newsletter thirty days in advance of the meeting. Additional nominations shall be accepted if the names of the nominees and their qualifications
are submitted in writing at least two weeks prior to the _____ Meeting.

ARTICLE VI - Finances
The fiscal year of the organization shall be from January 1 to December 31.

Section A - Disbursement of Funds
The funds of this organization shall be deposited in a bank selected by
the Treasurer with the approval of the President. All financial obligations of the organization shall be discharged by check on approval of the
President and signed by any two of the following:
President
Vice President
Treasurer

Section B - Annual Report
The President and Vice President shall submit an Annual Report, including a complete financial statement, to the State of California in accordance with state laws.

Section C - Dissolution
In the event of dissolution of the organization, all assets remaining after all liabilities have been met shall be distributed to one or more not-for-profit organizations serving deaf and hard of hearing children selected by the Board of Directors.

Article VII - Amendments

Parent Power

People First Language

A commentary by Kathie Snow

Who are the so-called "handicapped" or "disabled"?

According to stereotypical perceptions, they are:

People who *suffer* from the *tragedy* of *birth defects.*
Paraplegic heroes who *struggle* to become *normal* again.
Victims who *fight* to *overcome* their *challenges.*

Categorically, they are called *retarded, autistic, blind, deaf, learning disabled,* etc., etc., etc., — ad naseum!

Who are they, really?

Moms and Dads. . . Sons and Daughters . . . Employees and Employers
Friends and Neighbors . . . Students and Teachers. . . Leaders and Followers
Scientists, Doctors, Actors, Presidents, and More
They are people.
They are people, first.

People with disabilities constitute our nation's largest minority group. It is also the most inclusive and most diverse: both genders, any sexual orientation, and all ages, religions, socioeconomic levels, and ethnicities are represented. Yet people who have been diagnosed with disabilities are all different from one another. The only thing they have in common is being on the receiving end of societal misunderstanding, prejudice, and discrimination. Furthermore, this largest minority group is the only one which *any person* can become part of, at any time! Some join at birth, others in the split second of an accident, through illness, or during the aging process. If and when it happens to you, will you have more in common with others who have disability diagnoses or with family, friends, and co-workers? How will you want to be described? And how will you want to be treated?

Parent Power

The Power of Language and Labels

If thought corrupts language, language can also corrupt thought.
George Orwell

Words are powerful. Old and inaccurate descriptors, and the inappropriate use of these descriptors, perpetuate negative stereotypes and reinforce an incredibly powerful attitudinal barrier. And this invisible, but potent, attitudinal barrier is the greatest obstacle facing individuals with disabilities. When we describe people by their medical diagnoses, we devalue and disrespect them as individuals. Do you want to be known primarily by your psoriasis, gynecological history, the warts on your behind, or any other condition?

Worse, medical diagnoses are frequently used to define a person's potential and value! In the process, we crush people's hopes and dreams, and relegate them to the margins of society. If we know about (or see) a person's diagnosis, we (mistakenly) think we *know something important about him*, and we give great weight to this information, using it to determine how/where a person will be educated, what type of job he will/won't have, where/how he'll live, and more. *A person's future may be determined—based on his diagnosis—by those with authority over him!* Today, millions of children and adults with disability diagnoses are essentially "incarcerated" behind the walls of "special (segregated) places:" special ed classrooms, congregate living quarters, day programs, sheltered work environments, and more—all because of the diagnosis that's been assigned. *When incorrectly used as a measure of a person's abilities or potential, medical diagnoses can ruin people's lives.*

Inaccurate Descriptors

"Handicapped" is an archaic term (it's no longer used in any federal legislation) that evokes negative images of pity, fear, and more. The origin of the word is from an Old English bartering game in which the loser was left with his "hand in his cap" and was thought to be at a disadvantage. A legendary origin of the "H-word" refers to a person with a disability begging with his "cap in his hand." This antiquated, derogatory term perpetuates the stereotypical perception that people with disabilities make up one homogenous group of pitiful, needy people! Other people who share a certain characteristic are not all alike; similarly, individuals who happen to have disabilities are not alike. *In fact, people who have disabilities are more* **like** *people who don't have disabilities than different!*

"Handicapped" is often used to describe parking spaces, hotel rooms, restrooms, etc. But these generally provide *access* for people with physical or mobility needs---and they may provide *no benefit* for people with visual, hearing, or other conditions. This is one example of the

inaccuracy and misuse of the H-word as a *generic descriptor*. (The accurate term for modified parking spaces, hotel rooms, etc. is "accessible.")

"Disabled" is also not appropriate. Traffic reporters frequently say, "disabled vehicle." They once said, "stalled car." Sports reporters say, "the disabled list." They once said, "injured reserve." Other uses of this word today mean "broken/non-functioning." People with disabilities are not broken!

If a new toaster doesn't work, we say it's "defective" and return it. Shall we return babies with "birth defects"? The accurate and respectful descriptor is "congenital disability."

Many parents say, "I have a child with special needs." This term generates *pity*, as demonstrated by the, "Oh, I'm *so sorry,"* response, a sad look, or a sympathetic pat on the arm. *(Gag!)* A person's needs aren't "special" to him—they're ordinary. *I've never met an adult with a disability who wanted to be called "special."* Let's learn from those with real experience, and *stop inflicting this pity-laden descriptor on others.*

"Suffers from," "afflicted with, "victim of," and similar descriptors are inaccurate, inappropriate, and archaic. A person simply "has" a condition, period!

What is a Disability?

Is there a universally-accepted definition of disability? No! First and foremost, a disability label is a medical diagnosis, which becomes a *sociopolitical passport* to services or legal status. Beyond that, the definition is up for grabs! What constitutes a disability depends on which service system is accessed. The "disability criteria" for early intervention is different from early childhood, which is different from vocational rehabilitation, which is different from special education, which is different from worker's compensation, and so on. Thus, "disability" is a *social construct*, created to identify those who may be entitled to services or legal protections because of *certain characteristics* related to a medical diagnosis.

Disability is Not the "Problem"

Because society tends to view disability as a "problem," this seems to be the #1 word used about people with disabilities. People *without* disabilities, however, don't spend a lot of time talking about *their* problems. They know this would promote an inaccurate perception of themselves, and it would also be counterproductive to creating a positive image. A person who wears glasses, for example, doesn't say, "I have a *problem* seeing." She says, I wear [or need] glasses."

What is routinely called a "problem" actually reflects a *need.* Thus, Susan doesn't "have a problem walking," she "needs/uses a wheelchair." Ryan doesn't "have behavior problems," he "needs behavior supports." *Do you want to be known by your "problems" or by the multitude of positive characteristics which make you the unique individual you are?* When will people *without* disabilities begin speaking about people *with* disabilities in the respectful way they speak about themselves?

Then there's the "something wrong" descriptor, as in "We knew there was *something wrong* when..." What must it feel like when a child hears his parents repeat this over and over and over again? How would *you* feel if those who are supposed to love and support you constantly talked about what's "wrong" with you? Let's stop talking this way!

The Real Problems are Attitudinal and Environmental Barriers

A change in attitude can change everything. If educators believed children with disabilities are boys and girls with the potential to learn, who need the same quality of education as their brothers and sisters, and who have a future in the adult world of work, we wouldn't have millions of children being segregated and undereducated in special ed classrooms.

The difference between the right word and the almost right word is the difference between lightning and the lightning bug.
Mark Twain

If employers believed adults with disabilities have (or could learn) valuable job skills, we wouldn't have an estimated *(and shameful)* 75 percent unemployment rate of people with disabilities. If merchants perceived people with disabilities as customers with money to spend, we wouldn't have so many inaccessible stores, theaters, restrooms, and more. If the service system identified people with disabilities as "customers," instead of "clients/consumers/recipients," perhaps it would begin to meet a person's *real* needs (like inclusion, friendships, etc.) instead of trying to remediate his "problems."

And if individuals with disabilities and family members saw themselves as first-class citizens who can and should be fully included in all areas of life, we might also focus on what's really important: living a *Real Life* (like people without disabilities) instead of a *Special Life,* under the authority of others in the system, which often results in the social isolation and physical segregation of the "disability welfare state."

A New Paradigm

"Disability is a natural part of the human experience..."
U.S. Developmental Disabilities/Bill of Rights Act

Parent Power

Yes, *disability is natural*, and it can *redefined* as a "body part that works differently." A person with spina bifida has legs that work differently, a person with Down syndrome learns differently, and so forth. Yet the body parts of people without disabilities are also different. It's the *way* these differences affect person (or how a person is *perceived*) which qualifies him as eligible for services, entitlements, or legal protections, and this mandates the use of a disability descriptor in the service or legal system. One in five Americans is a person with a condition we call a disability!

A disability, like gender, ethnicity, and other traits, is simply one of many natural characteristics of being human. People can no more be defined by their medical conditions than others can be defined by their gender, ethnicity, religion, sexual orientation, or anything else!

In addition, a disability is often a consequence of the environment. Why are many children not diagnosed until they enter public school? Is it because physicians are ignorant or parents are "in denial"? Or is it because as toddlers, they were in environments that supported their learning styles? But once in public school, if a child's learning style doesn't mesh with an educator's teaching style, he's said to have a "disability." Why do we blame the child, label him, and segregate him in a special ed classroom? Why don't we modify the regular curriculum (per special ed law) to meet his individual needs?

When a person is in a welcoming, accessible environment, with the appropriate supports, accommodations, and tools, does he still have a disability? No! *Disability is not a constant state.* The medical diagnosis may be constant, but whether the condition represents a "disability" is more a *consequence of the environment* than what a person's body or mind can or cannot do.

Using People First Language is Crucial!

People First Language puts the person before the disability,
and it describes what a person *has*, not who a person *is*.

Are you “myopic” or do you wear glasses?
Are you “cancerous” or do you have cancer?
Is a person “handicapped/disabled” or does she have a disability?

If people with disabilities are to be included in all aspects of society, and if they're to be respected and valued as our fellow citizens, we must stop using language that sets them apart and devalues them.

Children with disabilities are *children, first.* The only labels they need are their names! Parents must not talk about their children using the medical terms used by professionals. Educators must

not use terms like "sped kids," "LD students," and other demeaning descriptors. Children in school are *students* and some *receive special ed services.*

Adults with disabilities are *adults, first.* The only labels they need are their names! They must not talk about themselves using professional lingo. Service providers must not use terms like "MR client," "quads," and other diagnostic terms.

The use of disability descriptors is appropriate *only* in the service system (at those ubiquitous "I" team meetings) and in medical or legal settings. Medical labels have no place-and they should be irrelevant-within families, among friends, and in the community.

We often uses a diagnosis to convey information, as when a parent says, "My child has Down syndrome," hoping others will realize her child needs certain accommodations or supports. But the outcome of sharing the diagnosis can be less than desirable! A diagnosis can scare people, generate pity, and/or set up exclusion ("We can't handle people *like that..."*). In these circumstances, *and when it's appropriate,* we can simply describe the person's *needs* in a respectful, dignified manner , and *omit the diagnosis.*

I use your People First Language article in my university courses (graduate and undergraduate). It's extremely well-written, clear, and user-friendly. Thanks for providing and sharing all your wonderful information.

Julia Scherba deValenzuela, Ph.D.
Assistant Professor, Special Education
University of New Mexico

Besides, *the diagnosis is nobody's business!* Have individuals with disabilities given us permission to share their personal information with others? If not, how dare we violate their trust! Do *you* routinely tell every Tom, Dick, and Harry about the boil on your spouse's behind? (I hope not!) And too many of us talk about people with disabilities *in front of them, as if they're not there.* We must stop this demeaning practice!

Attitudes and language changed as a result of the Civil Rights and Women's Movements. The Disability Rights Movement is following in those important footsteps, and similar changes are occurring.

My son, Benjamin, is 18 years old. More important than his diagnosis are his interests, strengths, and dreams. He loves history, burned fish sticks, classic rock, and writing movie reviews—and he's great at mimicking actors and politicians! He's earned two karate belts, taken drama classes, and performed in five children's theater productions. Benj is attending college and wants to be a film critic. He has blonde hair, blue eyes, and cerebral palsy. His diagnosis is only one of many

characteristics of his whole persona. *He is not his disability*. His potential cannot be predicted by his diagnosis.

When I meet new people, I don't disclose that I'll never be a prima ballerina. I focus on my strengths, not on what I cannot do. Don't you do the same? So when speaking about my son, I don't say, "Benj can't write with a pencil." I say, "Benj writes on a computer." I don't say, "He can't walk." I say, "He uses a power chair." It's a simple, *but vitally important*, matter of perspective. If I want others to know what a great young man he is—more importantly, *if I want him to know what a great young man I think he is*—I must use positive and accurate descriptors that portray him as a whole, real, wonderful person, instead of as a collection of "defects, "problems," or "body parts."

A person's self-image is strongly tied to the words used to describe him. For generations, people with disabilities have been described by negative, stereotypical words which have created harmful, mythical perceptions. We must stop believing (and perpetuating) the myths—*the lies*—of labels. We must believe children and adults who have been diagnosed with conditions called "disabilities" are unique individuals with unlimited potential, just like all Americans.

People First Language isn't about being "politically correct." It is, instead, about good manners and respect (and it was begun by individuals who said, "We are not our disabilities!"). We have the power to create a new paradigm of disability. In doing so, we'll change the lives of children and adults who have disability diagnoses—and we'll also change ourselves and our world.

Isn't it time to make this change?
If not now, when? If not you, who?

People First Language is right.
Just do it—NOW!

Examples of People First Language

Say:	Instead of:
People with disabilities.	The handicapped or disabled.
He has a cognitive disability (diagnosis).	He's mentally retarded.
She has autism (or a diagnosis of...).	She's autistic.
He has Down syndrome (or a diagnosis of...)	He's Down's; a Down's person.
She has a learning disability (diagnosis).	She's learning disabled.
He has a physical disability (diagnosis).	He's a quadriplegic/is crippled.
She's of short stature/she's a little person.	She's a dwarf/midget.
He has a mental health diagnosis.	He's emotionally disturbed/mentally ill.
She uses a wheelchair/mobility chair.	She's confined to/is wheelchair bound.
He receives special ed services.	He's in special ed.
She has a developmental delay.	She's developmentally delayed.
Children without disabilities.	Normal or healthy children.
Communicates with her eyes/device/etc.	Is non-verbal.
Customer	Client, consumer, recipient, etc.
Congenital disability	Birth defect
Brain injury	Brain damaged
Accessible parking, hotel room, etc.	Handicapped parking, hotel room, etc.
She needs . . . or she uses . . .	She has problems/special needs.

Keep thinking—there are many descriptors we need to change!

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Visit the Disability is Natural store to see the People First Language Poster, the Disability is Natural video/DVD and companion poster, and other New Ways of Thinking products!

The People First Language article by Kathie Snow is presented in *Parent Power* on pages 36-43.

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- Acronyms -

(used in Alabama's Early Intervention System)[37]

ADA Americans with Disabilities Act: A federal law that protects the rights of individuals with disabilities
ADRS Alabama Department of Rehabilitation Services: State agency that provides supports and services for individuals with disabilities and serves as lead agency for Alabama's Early Intervention System
AEIS Alabama's Early Intervention System: Statewide system of supports and services for eligible infants and toddlers, birth to age 3, with disabilities and their families (AEIS operates under federal and state law.)
AIDB Alabama Institute for the Deaf and Blind: ICC member state agency that provides supports and services for individuals with vision, hearing and other disabilities
CRD Central Resource Directory: Directory of statewide public and private service providers, family support organizations and EI programs
CRS Children's Rehabilitation Service: Division of the Alabama Department of Rehabilitation Services that provides supports and services to children with special health care needs
CSPD Comprehensive System of Personnel Development: Program that offers free workshops and training to parents and providers about AEIS and related topics
DCC District Coordinating Council: A group of parents and service providers who meet periodically to coordinate a districtwide plan of EI supports, services, workshops and family forums (There are seven district councils in Alabama.)
DEIC District Early Intervention Coordinator: AEIS staff who serve as the district contact point for referred families and who work closely with EI programs and district coordinating councils
D/F Data/Financial: Statewide system that compiles data and information on the cost and amount of services provided to eligible families
DHR Department of Human Resources: ICC member state agency responsible for supports and services to families and children in abuse or neglect situations
DMH/MR Department of Mental Health/Mental Retardation: ICC member state agency responsible for supports and services to individuals with developmental delays, mental illness and mental retardation
DPH Department of Public Health: ICC member state agency responsible for health-related services to families and children
DOT Department of Transportation: ICC member state agency responsible for state's highways and other transportation systems
DSP Direct Service Provider: Qualified individual or group that is authorized to provide specific early intervention services to eligible children and families
E & A Evaluation and Assessment: Required procedure by qualified personnel to determine a child's initial and ongoing eligibility for AEIS and the unique activities and supports needed by that child and family

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EI Early Intervention: Supports and services designed to meet the developmental needs of each eligible child, birth to age 3 (who has a developmental delay or a diagnosed condition that will probably result in developmental delay) and the needs of the family related to helping the child's development
EPSDT Early Periodic Screening, Diagnosis and Treatment: A statewide Medicaid program to screen, diagnose and treat health problems in children birth to age 21
FPSC Financial Planning Subcommittee: A standing subcommittee of the ICC that reviews and provides advice on AEIS funding and expenditures
FAPE Free and Appropriate Public Education: Education provided under public supervision and expense by State Department of Education
HCFA Health Care Financing Administration: A federal agency that administers Medicaid and Medicare programs
ICC Interagency Coordinating Council: A standing group of parents and providers appointed by the Governor to advise and assist the lead agency in the development of AEIS
IDEA Individuals with Disabilities Education Act: The federal law that provides directives to states on the development of early intervention systems and special education services
IEP Individualized Education Program: A written plan developed jointly by the family and school for eligible children ages 3 - 21 years
IFSP Individualized Family Service Plan: A written plan developed jointly by the family, EI service coordinator and providers for eligible children birth to 3 years, and their family
IHE Institute of Higher Education: A university, college or other post high school training entity
LEA Local Education Agency: The public entity legally responsible for the provision of public education within each community
LRE Least Restrictive Environment: An education environment where the eligible child's education needs can be met (Children should be educated in a setting that allows for opportunities to interact with non-disabled children to
the greatest extent appropriate.)
OT Occupational Therapy: Training and services administered by a qualified provider to aid development in self-care and in play to help motor development
PA Public Awareness Subcommittee: A standing subcommittee of the ICC that reviews and provides advice on AEIS outreach activities
PP&E Program Planning and Evaluation Subcommittee: A standing subcommittee of the ICC that reviews and provides advice on AEIS program and district activities

Resources

Advocacy and Public Policy

ADA Home Page
U. S. Department of Justice
http://www.usdoj.gov/crt/ada/adahom1.htm

Education News
www.educationnews.org

Family Voices
http://www.familyvoices.org/

FedWorld Information Network
Starting point for federal government information
http://www.fedworld.gov/

Justice For All
http://www.jfanow.org/

Project Vote Smart
Allows users to view voting records of members of Congress
http://www.vote-smart.org/

Wright's Law
www.wrightslaw.com

Assistive Technology

AbleData
http://www.abledata.com/

Abilityhub
This Assistive Technology website is for people with a disability, and will direct you to adaptive equipment for computers
http://www.abilityhub.com/

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Resources

Accessible Toys for Children with Disabilities
http://www.lekotek.org

Alabama's Statewide Assistive Technology Resource (STAR)
2125 East South Boulevard
P.O. Box 20752
Montgomery, AL 36120-0752
(334) 613-3480; (800) STAR656; (334) 613-3519 (TDD); (334) 613-3485 (fax)
http://www.rehab.state.al.us/star

Alliance for Technology Access
http://www.ataccess.org

Assistive Technology and Devices
http://www.ablegeneration.com

Auditory International
A private, non-profit membership organization that promotes listening and speaking as a way of life for children who are deaf or hard of hearing
http://www.auditory-verbal.org

NEAT
The website provides access to equipment and devices that can change the lives of people of all ages, with all types of disabilities, both temporary and permanent.
http://www.neatmarketplace.org

State of Connecticut Tech Act Project (CTTAP):
http://www.cttechactproject.com
Equipment Recycling and Loan Fund
http://wwwcttechact.com/loan
Assistive Technology Exchange in New England
http://www.cttechact.com/exchange/

Technology Assistance for Special Consumers (T.A.S.C.)
2075 Max Luther Drive
Huntsville, AL 35810
(256) 852-5600, ext. 103
tasc.ataccess.org

Resources

Clinical Trials

Center Clinical Trials Listing Service
http://www.CenterWatch.com/

ClinicalTrials.gov
http://www.clinicaltrials.gov/

Diagnosis or Disability Specific

ABA Educational Resources Ltd.
www.abaresource.com/resources.htm

Alabama Easter Seal Corporate Office
5960 Shirley Lane
Montgomery, AL 36117
(800) 388-7325
http://alabama.easterseals.com

Alabama Head Injury Foundation
3100 Lorna Road, Suite 200
Hoover, AL 35216-5451
(205) 823-3818; (800) 433-8002 (In AL)
Email: ahif1@aol.com
Web: http://www.ahif.org/

Alabama Institute for the Deaf and Blind
P.O. Box 698
Talladega, AL 35161
(256) 761-3200
Web: http://www.aidb.org/

American Foundation for the Blind-Southeast
100 Peachtree Street, Suite 620
Atlanta, GA 30303
(404) 525-2303
Email: literacy@afb.org

Resources

Angelman Syndrome
The paper on seizures in children with Angelman syndrome by Dr. Hutchison
http://www.angelman.org/angel/index.php?=89

Apraxia
Information about Childhood Apraxia of Speech for families, professionals and all those who care about a child with apraxia
http://www.apraxia-kids.org

Asperger's Syndrome
http:// www.udel.edu/bkirby/asperger

Association for Speech Pathologists and Audiologists
http://www.asha.org

Autism Center
The Autism Center in Portland, Oregon provides a variety of information on autism and related topics
http://www.autism.org

Autism Resources
Many well organized and informative links to other sites
http://www.autism-info.com

Autism Society of Alabama
4778 Overton Road
Irondale, AL 35210
(205) 951-1364; (877) 4AUTISM; (877)428-8476
Email: director@autism-alabama.org
Web: http://www.autism-alabama.org/

Autism Society of America
http://www.autism-society.org/site/PageServer

Autism Spectrum Disorders
http://www.nectac.org/topics/autism/autism/asp

Resources

Autism Topics
Lists of topics related to Autism
http://www.autism.org/contents.html#issues

Baby Hearing
Provides information for parents about newborn hearing screening, hearing loss, hearing aids ,etc
http://www.babyhearing.org

Board of Education Services for the Blind
http://www.ct.gov/besb/sitedefault.asp

CARE Alliance
A Connecticut-based, non-profit organization dedicated to improving the lives of children diagnosed with autism
http://www.ctautism.org

Children and Adults with Attention Deficit Disorders (C.H.A.D.D.)
http://www.chadd.org/

Children's Hemiplegia and Stroke Association
http://www.chasa.org

Children's Rehabilitation Engineering Team
Robert M. Perry
2771 Schillinger Road
Mobile, AL 36695
(251) 633-6035
The purpose the Children's Rehabilitation Engineering Team is to serve people with disabilities in the Alabama counties of Mobile, Baldwin, Choctaw, Clarke, Escambia, Monroe, and Washington by assisting them with their adaptive technology needs.
Email: perry1272@bellsouth.net
Web: http://www.childrensrehabengineeringteam.com/

Cochlear Implant Club International
A non-profit organization for cochlear implant recipients, their families, professionals, and other individuals interested cochlear implants
http://ciaci.org

Resources

Commission on Deaf and Hearing Impaired (State of Connecticut)
Information on services for persons who are deaf or hard of hearing
http://www.cdhi.ct.gov/cdhi/site/default.asp

Connecticut Autism Spectrum Resource Center
This center provides educational advocacy, support, information, and a comprehensive training series for both parents and professionals
http://www.ct-asrc.org

Connecticut Association for Children with Learning Disabilities
http://www.cacld.org

Deafness in Young Children
http://www.shhh.org

Disability Information & Resource Centre -
Fact Sheets on dozens of conditions
http://www.enable.net.au/

Ear, Nose and Throat Associates
Identifying deafness
http://www.entassociates.com/

Early Identification of Hearing Loss in Infants
Statistics about prevalence of deafness in the population, recommended age for screening, use of modern technology and consequences of delay in diagnosis
http://www.lhh.org

Endless Potential - Behavioral Intervention Solutions
495 Bethel Church Rd.
Guntersville, AL 35976
(256) 293-8455
Email: info@endlesspotential.org
Web: http://www.endlesspotential.org

Epilepsy Foundation of North and Central Alabama
1900 Crestwood Blvd., Suite 96
Birmingham, AL 35210

(205) 951-4151; (800) 950-6662 (In AL)
Web: www.needymeds.com/copay_diseases.taf?_function=detail&program_id=388

Epilepsy Foundation of South Alabama
Office Park 3
273 Azalea Road, Suite 310
Mobile, AL 36609-1970
(251) 432-0970; (800) 626-1582 (In AL)
Email: info@epilepsysouthalabama.org
Web: http://www.efa.org/local/southalabama/

Go Hear
Explanation of the various degrees of hearing loss, actual sound to the deaf person, where common sounds fall on an audiogram, and an "animated tour inside the ear"
http://www.gohear.org

Growing Strong
This site is about helping people to find the tools they need to succeed and build physical, emotional, mental and spiritual strength in life
www.growingstrong.org/epilepsy/

Healing Well
Links to books, medical studies, chat forum, and excellent link to many epilepsy themed websiteswww.healingwell.com/epilepsy/

Hearing Professionals Page
http://www.hearingalliance.com

Language Development
http://www.hanen.org

Learning Disabilities Association of Alabama
P.O. Box 11588
Montgomery, AL 36111
(334) 277-9151
Web: http://www.ldaal.org/

Madison Learning Differences
Support group for parents of children with dyslexia and other learning differences

Resources

(256) 837-7936
http://www.geocities.com/madisonlearningdifferences/

Medicine Net - Diseases & Treatment Index
http://www.medicinenet.com/Script/Main/AlphaIdx.asp?p=A_DT

MedlinePlus
Health information from the National Library of Medicine
http://medlineplus.gov/

National Center on Birth Defects and Developmental Disabilities
Educational materials concerning early hearing loss detection and intervention
http://www.cdc.gov/ncbddd

National Down Syndrome Congress
http:// ndsccenter.org

National Down Syndrome Society
http://www.ndss.org

National Early Childhood Technical Assistance System
http://nectac.org

National Federation of the Blind
http://www.nfb.org

National Information Clearinghouse
A federally funded information and referral service established to collect, develop and distribute information to help improve the education and lives of children and youth who are deaf-blind, ages birth to 21
http://www.tr.wou.edu/dblink

National Institute of Neurological Disorders and Stroke Disorders Data Base
http://www.ninds.nih.gov/disorders/disorder_index.htm

National Organization on Fetal Alcohol Syndrome (NOFAS)
http://www.nofas.org

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Resources

NICHCY
http://www.nichcy.org/

NORD - The National Organization for Rare Disorders
http://www.rarediseases.org/

Office of Special Education and Rehabilitation Services (OSERS)
Information and resources in a publication provided regarding the use of technology and other support available to children with hearing loss and their families
http://www.ed.gov/about/offices/list/osers/products/opening_doors/index.html

Online Mendelian Inheritance in Man
From the National Center for Biotechnology Information, this database is a catalog of human genes and genetic disorders
http://www3.ncbi.nlm.nih.gov/entrez/query.fcgi?db=omin

Oral Deaf Education Library
Technology available today through hearing aids and cochlear implants
http://www.oraldeafed.org

Over the Mountain Speech, Language, and Learning Services, LLC
OTM provides speech/language/hearing/vision screenings, speech/language evaluations and therapy (office or onsite), academic tutoring, and staff development programs for child care professionals.
Jerri Smith, MCD CCC-SLP Speech/Language Pathologist
1050 Lake Colony Lane
Vestavia Hills, AL 35242
(205) 531-8998
Email: otmspeech@bellsouth.net

PEDBASE
The Pediatric Database contains descriptions of over 500 childhood illnesses
http://www.icondata.com/health/pedbase/pedlynx.hym

Pediatric Epilepsy Resource Handbook
http://professionals.epilepsy.com/pdfs/ParentsGuide2004.pdf

Resources

Reading for the Blind
http://www.rfbd.org

Rett Syndrome Research Foundation
This foundation has a focused mission of promoting, accelerating, and funding biomedical research for the treatment and cure of Rett Syndrome. For more information, contact Jennifer Endres, Family Resource Director, 513-874-3020 or e-mail at jendres@rsfr.org.
http://www.rsrf.org

Scottish Rite Clinic for Childhood Language Disorders
University of Montevallo, Dept. of Communication Sciences and Disorders
Station 6720
Montevallo, AL 35115
(205) 665-6720

Speech Pathology
http://www.speechpathology.com

Spina Bifida Association of Alabama
c/o Trish Switzer
140 Lansdowne Drive
Madison, AL 35758
or
P.O. Box 661424
Birmingham, AL 35266
(256) 325-8600
Email: AL_spina_bifida_support@hotmail.com

Spina Bifida Association of America
http://www.sbaa.org

TalkAutism
A communication service shared by many organizations who share a common database of resource directories, distance learning library, and special message boards to help you find resources related to autism
http://www.talkautism.org

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Resources

The Alexander Graham Bell Association for the Deaf and Hard of Hearing
An international membership organization comprised of parents of children who are deaf and hard of hearing, adults with hearing loss, and professionals who serve children with hearing loss.
http://www.agbell.org

Tuberous Sclerosis Alliance
Information and resources for families of infants and young children diagnosed with Tuberous Sclerosis
http://www.tsalliance.org

United Cerebral Palsy Associations, Inc.
http://www.ucp.org/

United Cerebral Palsy of Greater Birmingham
120 Oslo Circle
Birmingham, AL 35211
(205) 944-3939; 1-800-654-4438
Email: gedwards@ucpbham.com
Web: www.ucpbham.com

United Cerebral Palsy of Mobile, Inc.
3058 Dauphin Square Connector
Mobile, AL 36607
(334) 479-4900
Email: gharger1947@aol.com

Yale Child Study Center
http://www.info.med.yale.edu/chldstdy/autism

Early Intervention

The Family Village - Early Intervention Resources
http://www.familyvillage.wisc.edu/education/ei.html

National Early Childhood Technical Assistance Center
http://www.nectac.org/

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Resources

The Division for Early Childhood - DEC
http://www.dec-sped.org/

Zero to Three
http://www.zerotothree.org/

Programs for Children with Special Health Care Needs
Jim Harris, III, Assistant Commissioner Alabama Department of Rehabilitation Services
Children's Rehabilitation Service
2129 East South Blvd., P.O. Box 11586
Montgomery, AL 36111-0586
(334) 281-8780; (800) 846-3697 (in AL)
Email: jharris3@rehab.alabama.gov
Web: http://www.rehab.state.al.us/

Programs for Infants and Toddlers with Disabilities: Ages Birth through 2
Alabama's Early Intervention System
Department of Rehabilitation Services
Division of Early Intervention
2129 East South Blvd.
Montgomery, AL 36116
(334) 281-8780
Email: bdprince@rehab.state.al.us
Web: http://www.rehab.state.al.us/

Feeding and Nutrition

American Academy of Pediatrics
http://www.aap.org

Breastfeeding
http://www.bflrc.com/links.htm

Connecticut Association of Human Service Agencies and Kaiser Premanente
Food activities for children, parents and teachers
http://kidsfood.org

Resources

Food Pyramids
http://www.nal.usda.gov/fnic/Fpyr/pyramid.html

Gastroesophageal Reflux
http://www.reflux.org

Medela
Information on Haberman feeders and S&S feeding systems and breast pumps
http://www.medela.com

National Center for Health Statistics
Revised growth charts
http://www.cdc.gov/nchs/nhanes.htm

New Visions
Practical information on feeding, oral-motor skills, and mealtimes
http://www.new-vis.com

North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
http://www.naspgn.org/

Tips for Using the Food Guide Pyramid for Young Children 2 to 6 Years Old
http://www.usda.gov/cnpp

General and Miscellaneous

Alabama Virtual Library
www.avl.lib.al.us

BadgerLink
http://www.badgerlink.net/

Big Book Yellow Pages
http://www.bigbook.com/

Big Foot
http://www.bigfoot.com/

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Resources

Children's Rehabilitation Service
A Division of the Alabama Department of Rehabilitation Services
P.O. Drawer 2328
Birmingham, AL 35219-0848
(205) 290-4500; (888) 430-7423; (205) 290-4560 (fax)
http://www.rehab.state.al.us/Home/default.aspx?url=/Home/Services/CRS/Main

Division of Early Childhood
A non-profit membership organization for individuals who work with or on behalf of young children, from birth to age 8, and their families
http://www.dec-sped.org

Exceptional Parent Magazine
On-line resource for parents of children with disabilities
http://www.eparent.com

Family Village
A global community of disability-related resources
http://www.familyvillage.wisc.edu

Find Article
http://www.findarticles.com/PI/index.jhtml

Friends for Life NETWORK
6000 Atlanta Highway
Montgomery, AL 36117
(334) 271-3214; (334) 271-5643

Full Life Ahead Foundation
Lisa Manly, Executive Director
2908 Clairmont Avenue
Birmingham, Alabama 35205
(205) 439-6534; (866) 700-2026 (phone/fax)
Email: lisamanly@FullLifeAhead.org
Web: www.FullLifeAhead.org

Resources

Internet Resources for Special Children
http://orsaminore.dreamhosters.com/handy/links/uk_various.html

Legacy Financial Group
Jason Latham or Daryl Wilson
P.O. Box 608
Helena, Alabama 35080
(866) 371-5433
Experience in developing Special Needs Trust for families

LII - Magazine Topics
http://lii.org/search/file/magazines

Mag Portal
http://www.magportal.com/

Maps on Us
http://www.mapsonus.com/

Map Quest
http://www.mapquest.com/

Maternal and Child Health Library
www.mchlibrary.info/

Mobile Scottish Rite Learning Center
Inquiries: Scottish Rite Masonic Center
P.O. Box 70203
Mobile, AL 36670-1203
(334) 476-5300

National Information Center for Children & Youth with Disabilities
http://www.nichcy.org

News Directory
http://www.newsdirectory.com/

Northeast Alabama Scottish Rite Learning Center
Inquiries: Scottish Rite Masonic Center

Resources

314 Bob Wallace Avenue, S.W.
Huntsville, AL 35801-3811
(256) 539-1300

Office of State Coordinator of Vocational Education for Students with Disabilities
Education Administrator - Curriculum Innovation, Department of Education
Gordon Persons Building, Room 5234
P.O. Box 302101
Montgomery, Al 36130-2101
(334) 242-9108

Parents as Partners (formerly SEAC)
600 Bel Air Blvd., Suite 210
Mobile, AL 36609
(251) 478-1208; (800) 222-7322; (251) 473-7877 (fax)
Email: seacofmobile@zebra.net
Web: http://www.parentsaspartnersineducation.com/SEAC.pdf
Parent educators

Partners in Policymaking of Alabama
Alabama Council for Developmental Disabilities
RSA Union Building
100 North Union Street
Post Office Box 301410
Montgomery, Alabama 36130-1410
(334) 242-3973; (800) 232-2158; (877) 774-9520; (334) 242-0797 (fax)
Email: addpc@mh.state.al.us
Web: http://www.acdd.org/About/PIPA.htm

Protection and Advocacy Agency
Alabama Disabilities Advocacy Program (ADAP)
The University of Alabama
526 Martha Parham West P.O. Box 870395
Tuscaloosa, AL 35487-0395
(205) 348-4928; (800) 826-1675; (205)348-9484 (TTY)
Email: ADAP@law.ua.edu

Resources

Web: http://www.adap.net/

PubMed
From the National Library of Medicine
http://www.ncbi.nlm.nih.gov/PubMed/

State Developmental Disabilities Planning Council
Elmyra Jones, Executive Director
Alabama Council on Developmental Disabilities
RSA Union Bldg.
100 N. Union Street, Suite 498
P.O. Box 301410
Montgomery, AL 36130-1410
(334) 242-3973; (800) 232-2158
E-mail: acdd@mh.state.al.us
Web: http://acdd.org

State Mental Health Representative for Children and Youth
Steve Lafreniere, Director
Office of Children's Services
P.O. Box 301410
Montgomery, AL 36130-1410
(334) 353-7110
Email: steven.lafreniere@mh.alabama.gov
Web: www.mh.alabama.gov

State Mental Retardation Program
Alabama Department of Mental Health and Mental Retardation
RSA Union Bldg.
100 N. Union Street
P.O. Box 301410
Montgomery, AL 36130-1410
(334) 242-3107
Email: jhouston@mh.state.al.us
Email: ADDPC@mh.state.al.us

State Vocational Rehabilitation Service
Department of Rehabilitation Services
2129 East South Blvd., P.O. Box 11586

Resources

Montgomery, AL 36111-0586
(334) 281-8780; 1-800-441-7607
Email: sshivers@rehab.state.al.us
Web: http://www.rehab.state.al.us/Home/default.aspx?url=/Home/Services/VRS/Main

Switch Board
http://www.switchboard.com/

The Arc of Alabama
300 S. Hull Street
Montgomery, AL 36104
(334) 262-7688
Email: info@thearcofalabama.com
Web: http://www.thearcofalabama.com

The Council for Exceptional Children (CEC)
http://www.cec.sped.org/

The Dads – National Center for Fathering
www.fathers.com

The Internet Public Library
http://www.ipl.org/div/serials/

University Centers for Excellence in Developmental Disabilities
Civitan International Research Center
University of Alabama at Birmingham
1719 Sixth Avenue South
Birmingham, AL 35294-0021
(205) 934-8900
http://www.circ.uab.edu/

Yahoo Maps
http://maps.yahoo.com/

Resources

Yahoo People Search
http://www.yahoo.com/search/people/

ZIP Code Lookup and Address Information
http://www.usps.gov/ncsc/

Health Care

Bright Futures
Promoting and improving the health, education and well-being of children and adolescents, ages 0-21, and their families
http://www.brightfutures.org

Developmental-Behavior Pediatrics Online Community
http://www.dbpeds.org

Developmental Disability Health
Current clinical information about caring for persons with developmental disabilities
http://www.ddhealthinfo.org

Healthnet
http://library.uchc.edu/departm/hnet

Immunization Schedule
http://www2a.cdc.gov/vaccines/recs/schedules/child-schedule.htm

Maternal & Child Health Clearinghouse
http://www.ask.hrsa.gov/

Medline Plus
http://www.medlineplus.gov

National Association for Children's Hospitals & Related Institutions
http://www.childrenshospitals.net

National Center for Education in Maternal & Child Health
http://www.ncemch.org

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National Health Information Center
http://www.health.gov./

National Healthy Mothers/Healthy Babies Coalition
http://www.hmhb.org/

Medical Reference

Merriam Webster Medical Dictionary
http://www.intelihealth.com/IH/ihtIH/WSIHW000/9276/9276.html

Medical Dictionary
http://www.medicinenet.com/Script/Main/AlphaIdx.asp?li=MNI&p=A_DICT

Laboratory Tests
http://www.merck.com/pubs/mmanual/tables/296tb2.htm

Procedures & Tests - Medicine Net
http://www.medicinenet.com/Script/Main/AlphaIdx.asp?li=MNI&p=A_PROC

The On-line Medical Dictionary
http://cancerweb.ncl.ac.uk/omd/

Parent Support and Parent Matching

American's with Disabilities Act
Commonly asked questions about child care centers and the American's with Disabilities Act
http://www.usdoj.gov/crt/ada/childq&a.htm

Birth Defect Research for Children
Matches for parents of children with any disorder, especially birth defects
http://www.birthdefects.org/

Children's Health Information and Resource Page
http://www.health.gov/nhic/NHICScripts/ENtry.cjm?HRCode=HR2577

Resources

Chromosome Deletion Outreach
Matches for families of children with chromosome deletions, additions, inversions, translocations and rings
http://www.chromodisorder.org/

Connecticut Parent Advocacy Center (CPAC)
http://www.cpacinc.org

Little Hearts Parent Matching Program
E-mail support group for families of children born with congenital heart defects
866-435-HOPE (4673)
www.littlehearts.org

MUMS National Parent to Parent
Matches all disorders
http://php.com/include/agency/agency_item.php?AgencyID=254

National Parent Network on Disabilities
http://www.npnd.org

Our Kids
http://www.our-kids.org

Parent Forum
http://www.parent-forum.com/forums/fusionbb.php

Parents Helping Parents
http://www.php.com

PATH
http://www.birth23.org/Resources/ParentsAvailable.asp

Rare Disorders
A support e-group for families and others interested in sharing questions or information on specific rare diseases
http://www.rare-disorders.com/

Resources

Regional/State Parent-to-Parent Programs
http://www.familyvillage.wisc.edu/cof_p2p.htm

STOMP
National Parent Training and Information Center for military families providing support and advice to military parents irregardless of the type of medical condition their child has
http://www.stompproject.org

The MAGIC Foundation
Matching for families of children with similar growth disorders
http://www.magicfoundation.org/

The Resource Foundation for Children with Challenges
http://www.specialchild.com/RFCC

Pharmacology

MEDLINEplus: Drug Information
http://www.nlm.nih.gov/medlineplus/druginformation.html

RxList - The Internet Drug Index
http://www.rxlist.com/

RxMed
http://www.rxmed.com/

Preemies

Genetic Alliance
International coalition working to enhance the lives of everyone impacted by genetic conditions
http://www.geneticalliance.org

March of Dimes
http://www.modimes.org

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Medline
Health information and statistics on a variety of topics, including babies born prematurely
http://www.nlm.nih.gov/medlineplus/prematurebabies.html

Office of Rare Diseases (ORD)
http://rarediseases.info.nih.gov/

Prematurity
Volunteer website covering issues of preemie parenting and support from a family to family perspective http://www.prematurity.org/
Information and statistics regarding premature births
http://www.marchofdimes.com/prematurity/5415.asp

Recreation

The Family Village
Recreation and Leisure for People with Disabilities
http://www.familyvillage.wisc.edu/recreat.htm

Research

Bottomlines
1-2 pages summaries for parents and practitioners on practices used with young children with disabilities
http://www.researchtopractice.info/products.php#bottomlines

Civitan International Research Center
http://www.circ.uab.edu/

Respite Care

Alabama Lifespan Resource Respite Network
www.alabamarespite.org

ARCH National Website
Fact sheets on training childcare providers for young children with developmental disabilities
http://chtop.org/ARCH.html

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Individual and Family Support Service
Financial assistance for many services, including respite
www.ifsonline.org

The National Respite Locator Service
http://www.mostonline.org/preemieBB/viewtopic.php?p=43&sid=2f2ea15c90b380cfb71659836681cf84#43

Siblings

Family Village Sibling Resources
http://www.familyvillage.wisc.edu/general/frc_sibl.htm

Sibshops
For siblings of children with special health and developmental needs
http://www.chmc.org/child_health_safety/special_needs/sibshops.asp

The Sibling Support Project
http://www.siblingsupport.org/
http://www.thearc.org/NetCommunity/Page.aspx?&pid=214&srcid=217

Understanding Sibling Issues
http://www.nichcy.org/pubs/outprint/nd11txt.htm

Special Education

Ed Law
http://www.geocities.com/kerimuller/page2.htm

ERIC
Educational Resources Information Center
http://www.eric.ed.gov/

Individuals with Disabilities Education Act
http://www.ed.gov/offices/OSERS/IDEA

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PACER / TA Alliance
http://www.pacer.org/
http://www.taalliance.org/

Programs for Children with Disabilities: Ages 3 through 5
Education Specialist/Coordinator 619
Contact State Department of Education: Special Education
http://www.alsde.edu/html/sections/section_detail.asp?section=65&footer=sections

Programs for Children with Special Health Care Needs
Alabama Department of Rehabilitation Services
Children's Rehabilitation Service
2129 East South Blvd., P.O. Box 11586
Montgomery, AL 36111-0586
(800) 846-3697 or contact: Melinda Davis at (334) 281-8780
http://www.rehab.state.al.us/

Programs for Infants and Toddlers with Disabilities: Ages Birth through 2
Alabama's Early Intervention System
Department of Rehabilitation Services
Division of Early Intervention
2129 East South Blvd.
Montgomery, AL 36116
(334) 281-8780
Email: bdprince@rehab.state.al.us
http://www.rehab.state.al.us/

SERI (Special Education Resources on the Internet)
http://seriweb.com/

Special Education Resource Center (SERC)
Information on training opportunities for professionals and parents
http://www.ctserc.org

State Department of Education: Special Education
Alabama Department of Education
Special Education Services

Resources

P.O. Box 302101
Montgomery, AL 36130-2101
(334) 242-8114
Email: mabreyw@alsde.edu
www.alsde.edu/

The Family Village School Links
http://www.familyvillage.wisc.edu/school.htm

The National Early Childhood Technical Assistance Center
Supports the implementation of the early childhood provisions of the Individuals with Disabilities Act (IDEA)
http://www.nectac.org/idea/idea.asp

The Special Ed Advocate
http://www.wrightslaw.com/

Yahoo: Education: Special Education
http://chirp.partnershiphp.org/HealthLinks.aspx

Support Group Directories

American Self-Help Group Clearinghouse
http://www.mentalhelp.net/selfhelp/

Canadian Directory of Genetic Support Groups
http://www.lhsc.on.ca/programs/medgenet/

Directory of Digestive Diseases Organizations for Patients
http://digestive.niddk.nih.gov/resources/patient.htm

Directory of Kidney and Urologic Diseases Organizations
http://kidney.niddk.nih.gov/kudiseases/pubs/kuorg/

Family Support America – Nationwide database of family support programs and articles and links on family support
www.familysupportamerica.org/

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National Center for Family Support
Website providing training and technical assistance on family support
www.familysupport-hsri.org/

National Information Sources on Disabilities
http://www.naric.com/search/

Neurological Disorders: Patient Resources, Foundations, and Support Organizations
http://www.ninds.nih.gov/find_people/government_agencies/govt_orgs_index.htm

NORD - National Organization for Rare Disorders
http://www.rarediseases.org/

Organizations for Endocrine and Metabolic Diseases
http://www.niddk.nih.gov/health/endo/pubs/endorg/endorg.htm

Pediatric Stroke Network
www.pediatricstrokenetwork.com/about.html

The Alliance of Genetic Support Groups
http://www.geneticalliance.org

The Family Village Library
http://www.familyvillage.wisc.edu/library.htm

**Editor's Note: The resources reported in this section of Parent Power were researched and updated in January 2008. The information given is subject to change without notice. Families are not limited to the resources provided. For more information regarding the list provided visit Birth to Three, www.birth23.org/Hotlinks/default.asp, the Alabama Yellow Pages for Kids, www.yellowpagesfor kids.com/help/al.htm, the Alabama State Resources, www.nichcy.org/stateshe/al.htm, or the individual website or contact number.

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[33] Ibid.
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Alabama's Early Intervention System coordinates a statewide system of services and supports for infants and toddlers younger than 3 years old with developmental delays and their families. With the assistance of eight other state agencies working through an Interagency Coordinating Council (ICC), district staff and community EI programs, AEIS provides a coordinated, family-focused system of services which depends upon the involvement of parents and other family members in planning, development and evaluation.

Infants and toddlers may be referred to AEIS by calling the toll-free
Early Intervention Child Find Hotline
1-800-543-3098
Espanõl: 1-866-450-2838