

PARENTS' RESOURCE GUIDE

FOR SOUTH CAROLINA FAMILIES WITH
CHILDREN WITH SPECIAL HEALTHCARE NEEDS



Acknowledgments

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Developers and reviewers:

Walter Best	Janice Edwards	Connie Ginsberg*	Sherry Larson*
Gill Gunderson*	WC Hoecke*	Richard Lacy*	Crystal Ray*
Charles Miller*	Karl Smith*	Craig Jenkins*	

** Indicates a parent of a child with special needs*

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Family Connection of South Carolina Inc.

Family Connection is a support network for families who have children with special needs. Founded by parents in 1990, we are here to help thousands of children in South Carolina reach their potential by providing parent-to-parent connections, linking families to community resources, and sponsoring a number of educational and family support programs.

Family Connection of South Carolina Inc.
2712 Middleburg Drive
Suite 103-B
Columbia, SC 29204

Central Office: 803-252-0914
Statewide: 1-800-578-8750
Fax: 866-420-4082

E-mail: info@familyconnections.org

TABLE OF CONTENTS

Acknowledgments	1
Family Connection of South Carolina Inc.	1
TABLE OF CONTENTS	2
WELCOME TO HOLLAND	3
A NOTE FROM US.....	3
TELLING FAMILY AND FRIENDS	4
GET THE INFORMATION YOU NEED	4
THE THREE-LEGGED STOOL.....	4
Financial	4
Interventions/Educational and Medical	4
Support networks and other Resources.....	4
FLOW CHART OF HOW TO GET STARTED	5
FINANCIAL.....	6
Health Insurance.....	6
Private Insurance:	6
Medicaid.....	7
Medicare	10
OTHER PUBLIC PROGRAMS.....	10
Supplementary Income (SSI).....	10
Women Infant and Children Food Supplement Program (WIC)	11
Medicaid Waivers	11
Long Term Planning.....	15
INTERVENTIONS/EDUCATIONAL AND MEDICAL.....	16
Developmental/Educational Interventions	17
Medical Interventions	21
SUPPORT NETWORKS AND OTHER RESOURCES	27
Family and Friends.....	27
FAMILY CONNECTION OF SOUTH CAROLINA PROGRAMS AND SERVICES.....	30
STATE RESOURCES AND DISABILITY ORGANIZATIONS	34
Center for Disability Resources (CDR) Library	34

WELCOME TO HOLLAND

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this ...

When you're going to have a baby, it's like planning a fabulous vacation trip - - to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting!

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland".

"HOLLAND?!!" You say. "What do you mean, Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would have never met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills---Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever, go away...because the loss of that dream is a very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about HOLLAND.

By Emily Perl Kingsley

A NOTE FROM US

When you arrive in Holland, most people find it very helpful to talk with people who have lived there for a while. May we introduce ourselves? We are a group of parents who network together around the issues associated with our children's diagnosis.

We did not have a resource guide when our child with special health care needs was diagnosed. Reflecting upon our experiences, we thought it to be helpful, for your sake, to develop one. No guidebook will be complete, because each of our journeys is a bit different. Our hope is that these thoughts and resources, which are specific to South Carolina, will help you navigate through this journey in developing the best outcome for your child and your family.

We see that our children have introduced us to so many wonderful things. We have found portraits by Rembrandt and we have slowed down to even notice the tulips. Although the journey you are embarking on will be difficult, it will not be impossible and can have a whole different set of rewards.

TELLING FAMILY AND FRIENDS

There is no doubt that one of your most difficult tasks will be telling friends and relatives, particularly grandparents that your child has special needs. Give grandparents, spouses, aunts and uncles, siblings and friends time to process this unexpected information. They will need time to adjust, just as you will.

It is natural for families and friends to feel awkward. Many do not know what to say or do to help you deal with this stressful situation. Human nature causes us to want to pull away or “shut down” from uncomfortable situations. This is the body’s natural mechanism to extreme stress. It is not uncommon for people in shock to say the wrong thing at the wrong time. A technique you may find very helpful is simply called “applying grace.” Often someone will say something that could be construed as inappropriate. They often feel terrible about what they have said or the situation they now find themselves in and may pull away from you or your family, creating a greater sense of loneliness for you. Our goal as parents is to pull people back in to our circle of family and friends.

On the other hand, you may find that many people are drawn to your child and have a genuine concern for them. Creating a team/support network for your child will help tremendously in your child's future. As your child's number one advocate, helping people feel like they belong to your child's team is one of the single best things you can do for their long-term outcomes. We will discuss this in more detail under the section “Family and Friends” on page 27.

GET THE INFORMATION YOU NEED

Read books and research, but be careful what you read. Older and outdated material may still be available on library shelves. Seek out current information about your child’s diagnosis whenever you can. One of South Carolina’s finest and free resources is the Center for Disability Resources Library (CDR). The Center for Disability Resources Library (CDR) is discussed in greater detail on page 33. Your child’s future is much more positive than it would have been just 5-10 years ago. Great progress has been made in helping children with special needs achieve the best possible future. Talk with parents and professionals about reading materials. Meet with your Coach, or Family Partner/Support Parent. These are veteran parents who have been trained by Family Connection to help other parents of children with special needs.

THE THREE-LEGGED STOOL

As new parents, there are three areas that you may want to focus on for the next several weeks, and like a three-legged stool, each should be worked on equally to keep our lives balanced.

Financial

How do we provide for our child, especially if there may be added expenses such as extra medical expenses or therapies? You may need to reconsider questions about your resources, such as insurance. What new special issues need to be considered in long-term planning for my child?

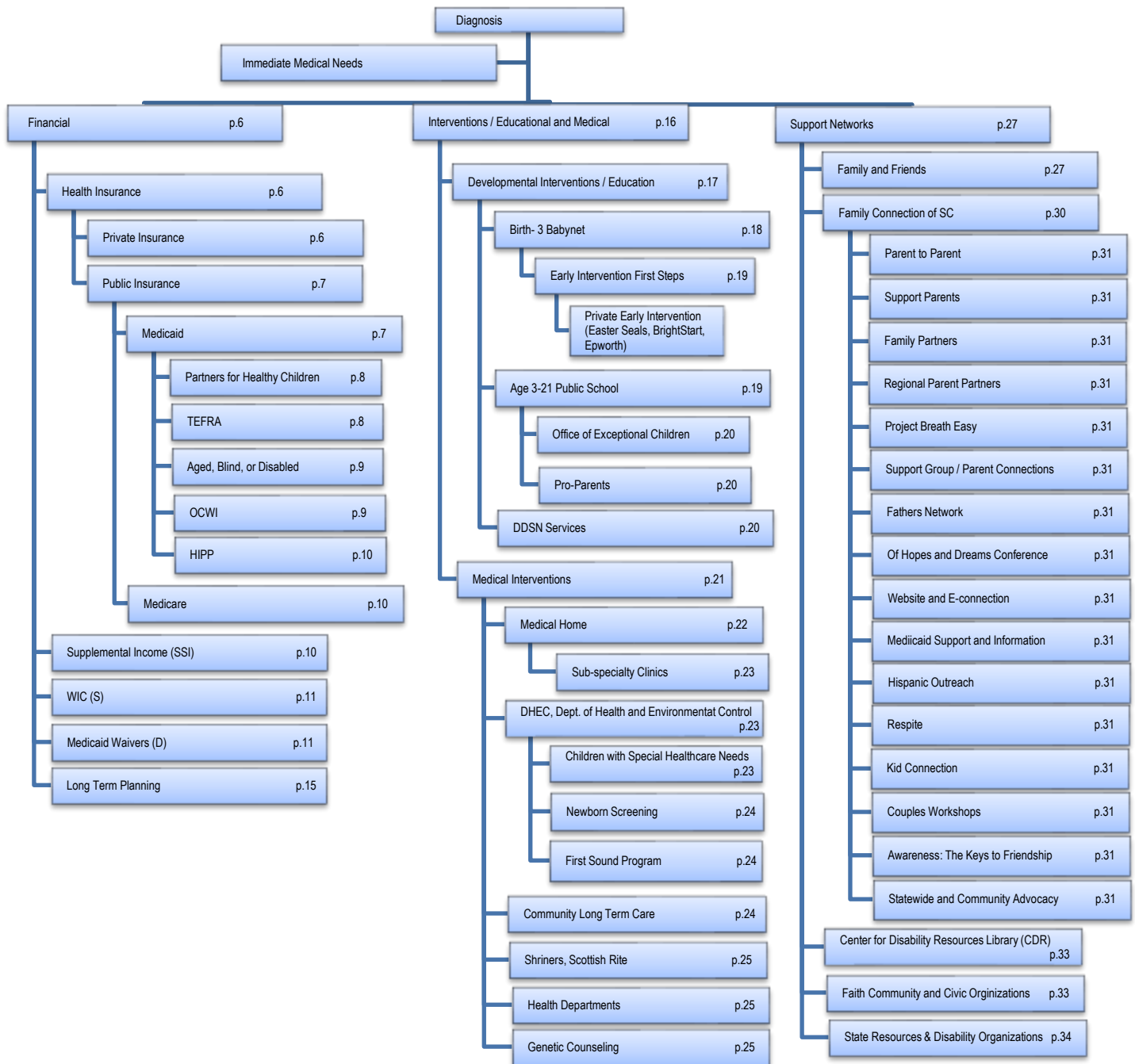
Interventions/Educational and Medical

What we mean by intervention is how we can intervene (get involved) in the life of a child with special needs to improve their outcomes. An example is use of specific targeted therapies to help an infant or young child. This can greatly improve a child’s outcome later in life.

Support networks and other Resources

How do you use the natural support your child already has around them to improve the future outcomes for your child? *Your Family Partner, Support Parent or Coach will help you walk through the following Flow Chart. Please don’t be overwhelmed. Depending on your child’s diagnosis only, certain parts of this chart may be applicable to your family’s situation. Family Connection can help you identify the best strategies to approach these tasks.*

FLOW CHART OF HOW TO GET STARTED



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FINANCIAL

Health Insurance

Health insurance is a general term used to describe many kinds of insurance coverage. Generally, when people say “health insurance”, they mean comprehensive medical and/or dental insurance.

This kind of insurance usually covers most of the costs of keeping you healthy and getting you healthy if you become ill. For children with special health care needs, this could include use of health insurance services to prevent further delays in development.

If you receive insurance from your employer, review your policy to see how disability sensitive it is. Does it pay for services such as therapy? Many families choose to apply for Medicaid as a secondary insurance. This could include help in paying co-pays and deductibles and/or for things not covered by your insurance. You will have to check with your physician's office to see if they will file Medicaid as a secondary insurance.

Private Insurance:

Group Health Coverage

Group health insurance is coverage through an employer or other entity such as an association that covers all individuals in the group. This is considered to be an employee benefit. There are some state and federal mandates on what must be covered but there can be vast differences between one group health insurance policy and another.

Individual Coverage

Individual health insurance coverage is purchased on an individual basis. The premium is usually higher for individual health insurance than for group health coverage. These policies are generally health underwritten. That means, you must submit health information. The insurance company will use this to determine if the person is eligible and the premium (if the person is eligible).

About Managed Care

In the past, parents of children with disabilities usually had an insurance plan where the provider charged a fee for each service. The insurer paid all or part of this fee. This kind of insurance was designed to cover large and/or unexpected health care expenses. Most insurance did not cover routine or preventive care, such as well-child visits.

As medical costs have increased, insurance has become very expensive. Managed Care plans are designed to reduce the cost of health care. How? Managed Care can help coordinate services so there is less duplication and less delivery of unnecessary services. It also helps keep plan members healthy by offering well-child visits and other preventive services.

Many employers are now offering employees Managed Care packages in an effort to reduce the amount employers spend on health insurance. There are also Medicaid Managed Care plans available to eligible children with special health care needs.

Health Maintenance Organization (HMO)

Health Maintenance Organizations represent insurance plans in which individuals or their employers pay a fixed monthly fee for services instead of a separate charge for each visit or service. The monthly fees remain the same, regardless of types or levels of services provided. Services are provided by physicians who are employed by, or under contract with, the HMO.

Preferred Provider Organization (PPO)

A PPO is a healthcare organization composed of participating (in-network) physicians, hospitals, pharmacies and other providers that agree to provide healthcare services at a reduced fee. PPOs offer

more flexibility than HMOs by allowing for visits to non-participating (out-of-network) providers at a greater expense to the member.

Point of Service Plan (POS)

A POS plan is a managed care plan that allows members to choose providers or specialists at the time services are needed. The member may choose to use a provider within the POS plan's network as referred by their primary care physician, or to self-refer to a provider outside the network at a higher out-of-pocket cost.

SC Health Insurance Pool

SCHIP is the South Carolina state high-risk pool. This program allows individual health insurance policies to be sold to people who might otherwise be considered "uninsurable" because of a chronic illness. Premiums may be high, and a pre-existing condition period may apply. Contact SCHIP for more information at 800-868-2500 ex. 46401.

Public Insurance:

Medicaid

Medicaid is a public health insurance program by which the federal government and the state of South Carolina share the cost of providing medical care for specifically, eligible individuals. However, not all Medicaid programs are based on income and can supplement private health insurance. Please read further.

Your benefits, within limits, under Medicaid will pay for services that are medically necessary. Some services you can get are:

- Hospital inpatient, outpatient, emergency-room;
- Lab and X-ray;
- Doctor office visits (physician, nurse practitioner, midwife, podiatrist, chiropractor);
- Well-child care-EPSTD (including immunizations);
- Well adult care – every five years;
- Vision;
- Dental;
- Prescription drug (not all drugs are covered);
- Family-planning;
- Medical equipment;
- Hospice;
- Ambulance and transportation to medical appointments;
- Nursing facility;
- ICF for Individuals with intellectual disabilities;
- Inpatient psychiatric care;
- Home health;
- Physical therapy, speech language therapy;
- Mental health service;
- Alcohol and drug abuse service;
- Family support services;
- Targeted case management;
- Behavioral health services for emotionally disturbed children;
- Home and community-based long-term care services;

Applying for Medicaid

You must complete an application and provide the proper required documentation in order to receive

benefits under the appropriate Medicaid program or other programs managed by the SC Department of Health and Human Services. To select the application that best fits your need go to:

<http://www.scdhhs.gov/service/how-apply>

If you need help, please call toll-free: 888-549-0820 or Family Connection at 800-578-8750

SC Healthy Connections Choices

South Carolina Healthy Connections Choices is a program that will help Medicaid members understand and enroll in the best Medicaid plan. The kinds of plans to choose from are Medical Home Networks, Managed Care Organizations, and regular “fee-for-service” Medicaid (fee-for-service is only available for certain categories.) Those individuals who are newly eligible for Medicaid or up for annual renewal will receive enrollment or outreach packets explaining the options available.

For your convenience there are frequently asked questions regarding Medicaid choices on Family Connection of South Carolina’s website www.FamilyConnectionSC.org and Healthy Connections Choices website www.SCchoices.com or to talk with enrollment specialist or to enroll, call 877-552-4642 or visit www.SCchoices.com.

In addition, Family Connection of South Carolina has a parent on staff that is trained in Medicaid. Please call 800-578-8750 or 803-252-0914 if you have any additional questions.

Partners for Healthy Children

Partners for Healthy Children is South Carolina’s name for the federal Children’s Health Insurance Program (or, ‘CHIP’) program. It is a free health-insurance program for children age one to nineteen and families with low income. For example in 2012, a family of four with a an annual income of \$38,825 would be eligible.

Coverage is reviewed and renewed annually. For details, call 888-549-0820, you can also go to this website and scroll down to find a current income chart for Partners for Healthy Children.

TEFRA Coverage also known as Katie Beckett

This optional coverage group is referred to as “TEFRA/Katie Beckett”, named after the first child to receive Medicaid under this ruling. Due to Julie Beckett’s unparalleled advocacy for her daughter, Katie, she received the first Medicaid waiver in the nation in 1982. "Katie Beckett" waivers have enabled many families to provide care for their children in their homes and communities, rather than in hospitals or institutions. Julie is also the co-founder of Family Voices. Thanks to the Beckett’s, Medicaid may provide your child’s primary coverage or provide secondary coverage for what your own insurance does not pay (you can read more about Katie and her mom under the ‘Medicaid Waivers’ link on this website).

Under Section 143 of the TAX Equity and Fiscal Responsibility Act (TEFRA) of 1982, states are allowed to make Medicaid benefits available to certain children with disabilities who would not ordinarily be eligible for Supplemental Security Income (SSI) benefits because of their parents’ income and other resources exceed the limit allowance. This allows states the option of extending Medicaid eligibility to children who would otherwise only be eligible in an institutional setting.

What are the eligibility requirements?

To be eligible for Medicaid coverage through TEFRA/Katie Beckett, a child must:

- Be age 18 or under;
- Be receiving appropriate care at home, at a cost less than care in an institution;
- Meet Supplemental Security Income (SSI) childhood disability requirements;
- Have low income and resources without counting those of the parents, and;
- Meet an institutional level of care.
 - The three levels of care are:
 1. intermediate care for the Intellectual disabilities(ICF/ID),

2. nursing facility (i.e., skilled or intermediate), and
3. hospital care.

Meeting level of care does not mean your child is institutionalized (see above)

A child who meets these requirements is eligible for the full range of state plan Medicaid covered services including doctor visits, specialists, prescriptions and therapies. If you would like to talk to the Medicaid Liaison contact Family Connection at 800-578-8750. You can also learn more about TEFRA through the DHHS website on TEFRA – www.scdhhs.gov

Aged, Blind, or Disabled (ABD)

The South Carolina General assembly required the Department of Health and Human Services (DHHS) to expand Medicaid coverage to individuals who are aged, blind or disabled with income at or below 100% of the Federal Poverty Level.

A person who may qualify for ABD:

- Is aged (65 or older), blind or totally and permanently disabled;
- Has countable income below 100 percent of poverty (\$903 for an individual and \$1,215 for a couple; and
- Has countable resources below **\$6,600** for an individual and **\$9,910** for a couple.

(OCWI) Optional Coverage for Women, Infants and Children

Optional Coverage for Women, Infants and Children is a program to help pay the medical bills for pregnant women and young children (birth to 1 year) with low family income below 185 percent of the federal poverty level (the 2012 level is \$3,554 monthly for a family of four, \$42,648 per year).

The types of medical services that will be covered are:

- Doctor visits
- Hospital care
- Medical transportation
- Prescription drugs
- Family-planning services
- Emergency room services

You should apply as soon as you know your pregnant. If you are applying for child services, you should apply as soon as possible after the child's birth.

You may apply for Medicaid at your county Department of Social Services (DSS). Some County health departments and hospitals have Medicaid workers to take your application.

What should you bring when you apply?

- Proof of your income (wage stubs or statements from your employer).
- Your Social Security card. If you do not have one, you will have to apply for one.
- Identification (driver's license, school ID card, voters registration, etc).
- A personal reference. The name and address of someone (not relative or family member) who can verify where you live and with whom.
- Proof of child-support/alimony payments if you receive any.
- Health insurance policy or ID card if you have other insurance.

If you cannot get this information, the Department of Social Services or the person who takes your application, is required to assist you.

Even if you have private insurance, Medicaid may pay for services that your insurance does not cover. For more information, call your county health or social services department or look under the listing of

social services.

HIPP

Medicaid may pay premiums for Medicaid recipients in order to keep their private health insurance whenever it is cost effective to do so. Persons who are eligible to enroll in a group health plan which Medicaid has determined is cost effective, and who are otherwise eligible for Medicaid, may apply for enrollment in the employer group health plan as a condition of Medicaid eligibility.

To have your Medicaid case evaluated for premium payment, tell your Medicaid worker you are interested in HIPP or contact the Department of Health and Human Services, Premium Payment Project at 803-264-6847 or 888-549-0820.

Medicare

Medicare is administered by the federal government and covers individuals with certain disabilities, in addition to people 65 and over. Medicare, the nation's largest health insurance program, consists of two main parts: hospital insurance and medical insurance.

OTHER PUBLIC PROGRAMS

Supplementary Income (SSI)

Supplemental Security Income is a program that pays monthly cash benefits to children and adults who are blind or disabled, and who do not own much or have a low income. Qualified applicants also receive Medicaid insurance.

To receive supplemental security income, persons must have a medically documented condition that keeps them from performing gainful activities and will last at least 12 months or to result in death. The medical eligibility for SSI is the basis for eligibility for many programs.

The primary benefit of SSI is monthly income check that will be determined by the income and resources. The secondary benefit is Medicaid benefits. An individual who qualifies for SSI will automatically receive Medicaid.

Call to make an appointment or to be sent an application, Toll Free 800-772-1213, or visit the web site: <http://www.ssa.gov>.

These documents are often needed for **SSI** application (not copies):

- Social Security Number for child;
- Proof of age (copy of birth records, birth certificate);
- Proof of citizenship or immigration status, if necessary, (green card, visa, passport, immigration or naturalization paper);
- Information about your child's disability or blindness such as Karyotype/Genetic report or Disability Diagnoses report (The more complete the medical information, the better the chances of a quick result);
- Earned income records (Wage stubs, or self-employed tax return showing records for past 3 or 4 months);
- Information about resources you could turn to cash (Bank statements for checking and savings accounts, saving bonds, stock certificates, and life insurance policies);

Ask if additional information is needed. **DON'T WAIT TO APPLY** - even if you do not have all documents.

Women Infant and Children Food Supplement Program (WIC)

Application for WIC is made available at health departments, primary care centers and physicians' offices. In most cases, eligibility is determined at the time of application. (*Translation services are available in all languages*) 800-922-4406.

Applicants must provide proof for the following information:

- Proof of residence
- Any child 5 and under who has Medicaid coverage regardless of income
- Have an income below 185 per cent of the poverty level. (Income is defined as cash income, such as wages, unemployment compensation or cash welfare).
- Must be certified as having a "nutritional risk" by a nurse, doctor or nutritionist etc. (Nutritional risk is defined as abnormal weight gain during pregnancy; history of high risk pregnancies, growth problems, iron-deficiency anemia, an inadequate dietary pattern, or other similar problems).

Medicaid Waivers

Through the state Medicaid Program, there are several waivers to the basic eligibility requirements. Due to Julie Beckett's unparalleled advocacy for her daughter, Katie, she received the first Medicaid waiver in the nation in 1982. "Katie Beckett" waivers have enabled many families to provide care for their children in their homes and communities, rather than in hospitals or institutions. Julie is also the co-founder of Family Voices. Thanks to the Becketts, Medicaid may provide your child's primary coverage or provide secondary coverage for what your own insurance does not pay.

Home and Community – Based Services (HCBS) Waivers

Section 1915 (c) of the federal Medicaid Act provides the basis for Home and Community-based (HCB) Waiver programs. The Medicaid HCB Waiver programs allows States to provide services, some not available through the Medicaid State Plan, to individuals who would otherwise require care in an institutional setting. Prior to the development of HCB Waivers, the only Medicaid-funded long-term care benefit was an institutional placement. The Centers for Medicare & Medicaid Services (CMS) is responsible for approving and monitoring a State's Medicaid

HCB Waiver. CMS is a division of the U. S. Department of Health and Human Services.

An HCBS waiver is a Medicaid long-term care option which allows persons who are eligible to receive Medicaid, and who meet specific medical criteria, the opportunity to receive additional services and supports that enable them to live in the community or at home with their families.

Waiver participants can receive Medicaid funded services and supports in their own home and other community settings instead of a nursing facility or institution. The cost of Medicaid waiver services must be less expensive than or equal to the cost of institutional care.

As the State Medicaid Agency, the Department of Health and Human Services (DHHS) has administrative oversight for the 8 HCBS waivers in SC.

A) Three of the waivers are operated by the Division of Community Long Term Care (CLTC):

- a) Community Choices,
- b) HIV/AIDS, and
- c) Mechanical Ventilator Waivers

B) Four waivers are operated by the SC Department of Disabilities and Special Needs (DDSN):

- a) Community Supports Waiver (CS)
- b) Head and Spinal Cord Injury (HASCI)

- c) Intellectual Disabilities and Related Disabilities (ID/RD), and
- d) Pervasive Developmental Disorder Program (PDD)

C) One waiver is operated by Community Options at Department of Health and Human Services.

- a) Medically Complex Children's Waiver

A) Community Long-Term Care Waivers

Community Long Term (CLTC) operates home and community-based waiver programs for persons eligible for nursing home care, but who choose to receive their services in the community.

The CLTC program began statewide in 1983 after a three-year pilot program in the Upstate to meet the long term needs of the elderly or disabled persons who were not able to care for himself or herself independently.

a) Community Choices Waiver

This waiver allows elderly and disabled persons 18+ who meet the nursing facility level of care to remain at home. Services offered include:

- | | |
|---------------------------------|--|
| • Adult Day Health Care | • Institutional Respite Care |
| • Adult Day Health Care Nursing | • Limited Incontinence Supplies |
| • Attendant Care | • Limited Nutritional Supplements |
| • Case Management | • Nursing Home Transition Services |
| • Chore Services (Opt 4 only) | • Personal Care I/II |
| • Companion | • Personal Emergency Response Systems (PERS) |
| • Environmental Modification | • Respite in a Community Residential Care Facility |
| • Home Delivered Meals | |

Contact Information: 803-898-2702

b) HIV/AIDS Waiver

This waiver allows persons with HIV/AIDS who meet the hospital level of care to remain living at home and in the community. Services provided include:

- | | |
|------------------------------|--------------------------------|
| • Attendant Care | • Limited Incontinent Supplies |
| • Case Management | • Nutritional Supplements |
| • Companion | • Personal Care I/II |
| • Environmental Modification | • Prescription Drugs |
| • Home Delivered Meals | • Private Duty Nursing |

Contact Information: 803-898-2702 or contact the local DHHS Regional Office

c) Mechanical Ventilator Dependent Waiver

This waiver allows persons who are 21+ and who meet nursing home level of care and dependent on a life sustaining ventilator to remain living at home and in the community. Services provided include:

- | | |
|------------------------------|--|
| • Attendant | • Personal Emergency Response Systems (PERS) |
| • Environmental Modification | • Prescription Drugs – 2 above State Plan |
| • Institutional Respite Care | • Private Duty Nursing |
| • Personal Care I/II | • Specialized Medical Supplies |

Contact Information: 803-898-2702

B) Department of Disabilities and Special Needs Waivers

The SC Department of Disabilities and Special Needs (DDSN) operates four HCBS waivers; the Community Supports (CS) Waiver; the Head and Spinal Cord Injury (HASCI) waiver; the Intellectual Disabilities and Related Disabilities (ID/RD) waiver; and the Pervasive Developmental Disorder Program (PDD) waiver. Through a process of case management and an individualized service plan, waiver participants are able to successfully remain at home at a substantially less cost to Medicaid than the cost of institutional care.

HASCI & ID/RD Waiver Services are provided based on identified needs of participants and within certain limits. Enrollment in both waivers is based on a limited number of waiver slots available each year. Waiting lists are kept and families should apply for these services now so you will have them when you need them. For more information about the waiver call (Department of Disabilities and Special Needs) DDSN at 800-376-4636 or in Columbia 803-898-9600 and ask for your local contact number for your local Disabilities and Special Needs board and request to apply for the waiver.

a) Community Supports Waiver

The purpose of the Community Supports Waiver is to serve people with Intellectual Disabilities or related disabilities in the community, **whose waiver service needs will not exceed the individual cost limit set forth in the waiver**. It also offers opportunities for individuals to self-direct certain services if they choose.

Community Supports Waiver Services Include:

- Adult Day Health Care/Nursing/Transportation
- Behavioral Support Services
- Career Preparation
- Community Services
- Day Activity
- Employment Services
- Environmental Modifications
- In-Home Supports
- Medical Supplies, Equipment and Assistive Technology, and Appliances
- Personal Care I/II
- Private Vehicle Modifications
- Psychological Services
- Respite
- Support Center Services

b) Head and Spinal Cord Injury (HASCI) waiver

Initial enrollment into the HASCI Waiver is limited to people up to age 65 years. Persons already enrolled continue to be eligible after their 65th birthday if all other eligibility factors are met.

HASCI Waiver services are limited to individuals who are "physically disabled." Such disabilities include:

- traumatic brain injury (TBI) or
- spinal cord injury (SCI) or
- both TBI and SCI or
- similar disability (SD)

The South Carolina Code of Laws does not define a "**similar disability**", but stipulates that a similar disability:

- is not limited by early age of onset;
- is not a condition that culminates in death or worsens over time; and
- is not dementia resulting from chronic disease or alcohol/drug use;
- is not a neurological disorder related to aging.

To qualify for HASCI Waiver services, a person must:

- request HASCI Waiver through his or her HASCI Service Coordinator

- become eligible for Medicaid or already receive Medicaid;
- meet level of care (LOC) criteria for Nursing Facility (NF) or Intermediate Care Facility for the Intellectual disabilities(ICF/ID);
- have urgent circumstances affecting his or her health or functional status;
- be dependent on others to provide or assist with critical health needs, basic ADLS or require daily monitoring or supervision to avoid institutionalization; and
- need services not otherwise available within existing community resources, including family, private means and other agencies/programs, or have current resources that are inadequate to meet the basic needs which would allow him or her to remain in the community.
- Must have adequate natural supports to live safely in a private home or other community setting with the type/amount of services available from the HASCI Waiver.

HASCI Waiver Services include:

- | | |
|--|---|
| • Attendant Care/Personal Assistance Services | • Peer Guidance for Consumer-Directed Care |
| • Behavioral Support Services | • Personal Emergency Response System (PERS) |
| • Day Habilitation | • Physical Therapy |
| • Environmental Modifications | • Prescribed Drugs |
| • Health Education for Consumer-Directed Care | • Prevocational Services |
| • Medicaid Waiver Nursing | • Private Vehicle Modifications |
| • Medical Supplies, Equipment and Assistive Technology | • Psychological Services |
| • Occupational Therapy | • Residential Habilitation |
| | • Respite Care |
| | • Speech, Hearing and Language Services |
| | • Supported Employment Services |

c) Intellectual Disabilities and Related Disabilities (ID/RD) waiver

To qualify for ID/RD waiver services, a person must:

- Be eligible for ID/RD services (have Intellectual Disabilities or related disability);
- Be eligible for Medicaid or already covered by Medicaid;
- Meet level of care criteria for Intermediate Care facility for the Intellectual disabilities(ICF/ID);
- Have needs that can be met through the provision of ID/RD waiver services; and
- Choose to receive services through the waiver rather than in an ICF/ID facility.

Waiver Services are available based on individual need and may include specialized medical equipment, supplies and assisted technology as well as the following:

- | | |
|---------------------------------|----------------------------------|
| • Adult Attendant Care Services | • Occupational Therapy |
| • Adult Companion Services | • Personal-care services |
| • Adult Day Health Care Nursing | • Physical therapy |
| • Adult Dental Services | • Prescribed drugs |
| • Adult Vision Services | • Prevocational Services |
| • Audiology services | • Private vehicle modification** |
| • Behavioral Support Services | • Psychological services |
| • Day Habilitation | • Residential Habilitation |
| • Environmental modifications* | • Respite Care |
| | • Speech/language pathology |
| • Nursing Services | • Supported Employment Service |

*lifetime monetary cap of \$7,500 per recipient

**lifetime monetary cap of \$7,500 per recipient up to 2 vehicles

For further information go to DDSN website:

<http://ddsn.sc.gov/consumersandfamilies/divisions/hasci/hascidivision.htm>

d) Pervasive Developmental Disorder Program (PDD)

SC Department of Disabilities and Special Needs, in collaboration with the SC Department of Health and Human Services, developed a new pilot Medicaid Waiver program that serves children diagnosed with a Pervasive Developmental Disorder (PDD). To qualify, the child must be between 3 and 10 years of age, have been diagnosed by 8 years old and currently enrolled in the DDSN system. The diagnosis must be made by a qualified, licensed or certified diagnostician. Children who are currently eligible for DDSN under the Autism Division must meet these criteria.

If a child qualifies, he or she must meet the Level of Care for PDD as Intermediate Care Facility/Intellectual Disabilities(ICF/ID). A child who has completed all levels of qualifications for services will be able to receive services from the program when space is available. Services offered through the PDD Program are Case Management and Early Intensive Behavioral Intervention (EIBI).

Services offered through the PDD Program are Case Management and Early Intensive Behavioral Intervention (EIBI).

To apply for the PDD Program contact your DDSN service coordinator, early interventionist, or call the toll free number, 1-800-576-4658. You can also visit www.state.sc.us/ddsn for more information. To get the complete history on the program visit: <http://www.ddsn.sc.gov/NR/rdonlyres/223B7496-C232-4E68-AF35-32581D0505A2/0/PDDIntro.pdf>

C) Department of Health and Human Services – Community Options

a) Medically Complex Children's Waiver

This waiver at DHHS will serve children who meet the Nursing Facility level of care or ICF-ID level of care and **have** a chronic physical/health condition that is expected to last longer than 12 months. The child must also meet medical criteria defined by the state which makes the child dependent upon comprehensive medical, nursing, and health supervision or intervention. The services offered in this waiver include Children's Medical Day Care, Respite, Care Coordination, **and** Incontinence Supplies. The child must be under 18 years of age.

Contact information: 803-898-2644

Long Term Planning

Special consideration must be made when planning for the future of a child with special needs. The generosity of family members, friends and organizations giving gifts directly to individuals with special needs often has a detrimental effect on the individuals they desire to care for and could affect their ability to receive Medicaid. We recommend that you use advisers both legal and financial who are familiar with the many special considerations that apply to our children with special needs. A good question to ask is "How many special needs trusts have they established?" If they don't know what you are talking about, move on. A trust is a good way to ensure for the future of a child who has special needs.

Individuals with special needs are often eligible to receive Medicaid (Partners for Health) a state-funded program for individuals with disabilities or SSI (Supplemental Social Security Income). Some state programs have income eligibility restrictions. For example, current eligibility restrictions for individuals receiving TEFRA cannot receive monthly income that exceeds \$2,022 per month or they have no more than \$2,000 in personal savings at any time. (The TEFRA program looks at the income of a child and does not factor in the income of parents).

According to current law, any gift given to individuals with special needs or assets in his name in excess of these limits could make him ineligible for Medicaid services. Currently, gifts given to individuals with

disabilities, in excess of these financial requirements must be “spent down” (in most cases, these funds are spent for medical expenses that would have been paid for by Medicaid) before one can reapply for Medicaid eligibility. In some cases a two-year waiting period is then enforced. This means an individual with pre-existing conditions such as Down syndrome could be uninsurable through TEFRA for at least two years.

It is important that you tell this to all family members. The loving act of a grandparent with a will that leaves funds to all their grandchildren could actually hurt a child with special needs.

INTERVENTIONS/EDUCATIONAL AND MEDICAL

What we mean by intervention is how you can intervene in the life of a child with special needs to improve their outcomes. For example, research has shown that the use of specific targeted therapies to help children at young ages greatly improves their outcome later in life. We would encourage you to take advantage of resources and community services available to you. Our recommendation is to use these resources early in your child’s development. If your child achieves all of his/her goals and graduates out of a program or therapy quickly then you can only be seen as an overachiever. Many parents and caregivers who have said they originally did not think their child needed these services have regretted not starting them earlier. Read this section carefully and take advantage of every resource available.

What are Community Services?

Public and private organizations in your community, which provide health, education and other human services to the people living in your area, are called Community Services. The federal government as well as county and city government administers some of these public programs. Some of these public organizations include: SC Department of Education, Social Security offices, SC DHEC and County Health Departments, Department of Disabilities and Special Needs, Parks and Tourism Department, recreation centers, and the SC Protection and Advocacy agency. These are all “public agencies”. These programs and services are funded by tax dollars and therefore do not charge the people who use their services.

Private organizations also provide needed services. These private agencies may charge a fee for their services (sometimes on a sliding scale based on family income), or they may be funded to offer their services free of charge. Such private organizations concerned with disability issues include Family Connection of SC, the Easter Seals Society, March of Dimes, Lions Club, the Shriners hospitals, and other organizations that are listed on the State Resource Sheet at the end of this section.

What do Community Services Provide?

Community Services can provide special education services for children or instruction for special education professionals. They can provide early intervention programs, speech therapy, physical therapy, occupational therapy, recreation, modified housing, adaptive equipment such as wheelchairs or hearing aids, medical care or counseling for the entire family. Many of these services are either free of charge, based on family income, or covered by personal insurance. Private services may vary in price, and, like all purchases, their affordability is to be judged individually. It is always good to check to see whether scholarships are available.

How Do You Locate Services in Your Community?

Locating services and programs can be a challenging task the first few times you try it. Your Coach, our supporting parent is willing to help you through this process. As with many tasks, practice helps. There are several general guidelines to this process. Ask yourself several key questions before you begin: What does your child need? What does your family need to help your child? The next step is to formulate the specific questions you will ask the agency when you reach it.

It might be useful to write a list of your questions with spaces for the answers in a notebook. This is to help you to keep all of your information organized. Be sure to include a space for the name of the person

to whom you speak, the name of the agency and the phone number. Frequently, callers are transferred or referred to other offices, and the name of the contact person and phone number are not the first ones dialed. To avoid confusion and future repetition of calls, keep track of all contacts, even those who were not helpful. A contact of no help may be exactly who you need to talk to next year.

Funding streams

Understand that when applying for “Educational and Medical” services that different state and sometimes-federal funding streams are accessed. Different goals and objectives will be used when applying for these different services. An example would be that if my child needed help in developing better speech. I may receive speech therapy through the school district – “Educational” or I may receive therapies through my insurance with a prescription from my physician - “Medically”. The goals and objectives for this same therapy may have to be written differently to allow for different funders to pay for it.

Organize your files and keep your records in good order. Keep everything. Family Connection has a Care Notebook (http://www.familyconnections.org/public/files/docs/Care_Notebook_10.pdf) and a corresponding webinar that you may find helpful. Contact the Family Connection office for a copy of this resource or dates of the next webinar.

Developmental/Educational Interventions

About Therapy and Therapists

The more experience and training the therapist has with babies and children with special needs the better. It is important to locate a therapist who specializes in pediatrics if possible. Just as you may choose a pediatrician over a general practitioner to be your child’s doctor, a pediatric therapist has the best skills and experience to meet your child’s needs.

So much has been researched and written about the brain in recent years. This research is encouraging to us as parents of young babies with special needs. The research says that even early on, the brain is developing as it builds on previous and current experiences. And so when a physical, occupational or speech therapist works with your baby during the regular sessions and you then carry on with that work between sessions, you and the therapists will have provided “experiences” for your baby to build on and from which to move forward. Stimulating, fun activities and exercises with your child will go far in improving his/her developmental skills and even his/her ability to learn. Repeating these activities at home is highly important because repetition is key for any baby to learn to perform activities.

A very important suggestion:

- Take an active role in assisting the therapists, from providing them with information on what your baby is doing at home, listening carefully to what they say and watching what they do;
- If you or your spouse can’t be there, ask them to video the session so you can follow up on your own schedule;
- Follow through with what you’ve seen and heard during the session at home or whenever you find the opportunity to turn therapy into normal play activities;
- Always remember, even though you are working with a professional in the field, you know your baby better than anyone else;
- Do not be shy - ask plenty of questions;
- Be assertive and be honest with everyone involved;
- Make sure that the recommended exercises and activities are practical and can fit into your family’s routine;
- Lastly, be sure you can work on these things with your baby at home. Siblings can also be involved and will benefit from the involvement with the baby. It can be fun and rewarding working (playing!) with your baby and watching those smiles and milestones develop;

Physical Therapy

Physical therapy can help improve “gross motor skills” that is movements that involve the large muscles of our body. Gross motor skills include head control, rolling over, sitting up, creeping, crawling, pulling up, standing, walking, etc. Physical therapist also makes recommendations for equipment or orthotics (braces to help foot position), which, if needed, may help your baby’s development.

We want you to know that physical therapy is something even the youngest of babies with special needs can benefit from. Many of the physical differences, including low muscle tone (hypotonia), can be addressed early by a physical therapist.

Physical therapy can improve the very foundation of physical and mental development. Because gross motor skills tend to develop more slowly in our children, early intervention with physical therapy can and does help.

- The physical therapist works with your baby during scheduled sessions by doing exercises and activities as you watch while showing you how to do these at home.
- You can receive therapy in an outpatient clinic setting (where more specialized equipment is often available) or in your home (which may be more convenient for you).
- Some children participate better in therapy outside of the home and some do better in the home. You will be able to determine which is best for your child and family. (However, BabyNet will only pay for services provided in a natural environment, primarily the home). (More information on BabyNet Below)

Through appropriate exercises and activities, low muscle tone, for instance, can be strengthened. Babies and children under the guidance of a good physical therapist have demonstrated improved coordination and balance which, in turn, can assist in the fundamental development of the brain.

Occupational Therapy

The occupational therapist focuses on daily living activities such as feeding, dressing, washing, sensory integration, and holding objects. Proper positioning of a baby’s shoulders, arms, and hands while engaged in playful activities is important in paving the way for the next milestone. Improved “fine motor coordination” helps a child help them-self. Reaching for the bottle, grabbing for a pacifier, or splashing in the tub are good building blocks for future developmental milestones. The principles of starting early and following up at home, explained in Physical therapy, also apply to occupational and speech therapy.

Speech Therapy

The Speech-Language Pathologist/Therapists (SLP) are the professionals who will help in developing feeding, sucking, and language skills for your child. They focus on receptive (what your child is hearing and receiving) and expressive language skills (what your child is saying and communicating to others). You will soon become very familiar with speech intelligibility, fluency, oral-motor skills, feeding skills (dysphasia), etc.

Your SLP can give strategies that enable children and parents to communicate when there is little speech output. This may include pre-language skills, the use of sign language, gestures; identify pictures/objects, and speech imitation. These tactics help decrease frustration and undesirable behaviors in your child, but encourage communication attempts between the child and his/her environment. As your child’s speech develops, they naturally drop these gestures for the easier form of communication, verbal speech. You will also be able to impress your friends by demonstrating that your child is bi-lingual.

BabyNet

Young children learn and develop differently. One baby may walk earlier than another, while another baby might talk first. Often, these differences will even out. But, some children will need extra help. Look

for signs that an infant or toddler might need extra help. If you suspect a child may have a problem, the earlier you get help, the better. BabyNet will evaluate the child from birth to three years old at no cost to determine if they may be eligible for services. If a child is eligible for the BabyNet program, the next step is to prepare for the initial Individualized Family Service Plan (IFSP). The IFSP is a written plan for [Early Intervention Services](#) the child and family will receive. The family plays a key role in working with early intervention professionals to create this plan. The initial IFSP must be completed within 45 calendar days after the referral to BabyNet.

BabyNet serves the child and family in what are called "natural environments". These environments are part of the family's typical daily routines, activities, and places (i.e., family homes, childcare centers, community play groups or libraries, etc.). Everyday routines, activities, and places are unique to each child and family and are identified by the family as they talk about their typical daily activities, such as visiting grandpa, walking to the store, getting the mail, feeding the dog, and doing the laundry. These typical activities are the child's opportunities for learning and adults' opportunities for enhancing the child's development.

Contact Information: BabyNet 800-868-0404 or <http://www.scfirststeps.org/BabyNet.html>

Early Intervention (EI)

The services that are available to eligible South Carolina families who have children under age three with delays in development. Depending on each child's needs, BabyNet programs directly provide or offer access to 17 core early intervention services. The specific services a child receives is based on a custom-tailored plan for that child. The family plays a key role in working with staff to create this plan.

There are also private programs providing early intervention services under contract with BabyNet in our state. Check with your BabyNet service coordinator to see what services are available in your county. BabyNet 800-868-0404 <http://www.scfirststeps.org/BabyNet.html> (i.e. Local DSN board, BrightStart, Easter Seals, Epworth Early Intervention Services, Play Works Inc.). See resources for contact information.

Public school

There is a federal law known as the Individuals with Disabilities Education Act of 1997 (20 U.S.C. §1400, *et. seq.*), or IDEA, designed to outline services for children and youth with disabilities who require special education and related services. The law is divided into four parts:

Part A: General Provisions, Definitions, and Other Issues (explains the purpose of the special education law)

Part B: Assistance for Education of All Children with Disabilities School Services for children with disabilities 3-21 years old (Public education services 3-21 years are Part B services)

Part C: Infants and Toddlers with Disabilities Early Intervention Services for children under 3 years of age (BabyNet early intervention services are Part C services)

Part D: National Activities to Improve Education of Children with Disabilities (focuses on the quality and improvement of special education, through training of personnel, giving out information, and supporting research, etc.)

In brief, your rights under IDEA-Part B are:

The Individuals with Disabilities Education Act (IDEA) provides you, as a parent or guardian of a child with a disability, with certain rights in regard to obtaining and continuing services for your child. Many of these rights are similar to those you have with the BabyNet Program (IDEA-Part C). If you have been receiving services through the BabyNet Program, a transition meeting will be held at least 90 days prior to your child's third birthday to discuss possible service options and goals.

Written Notice

You must be notified in writing and give permission before any agency evaluates and/or places your child in special education. Also, you must be notified and give permission before any action is taken or recommended that may change your child's education or IEP.

Written Consent

You must give your written consent before your child is evaluated and/or receives special education services.

Evaluation

If you believe that your child has special needs due to a disability, your child can be evaluated at no cost to determine eligibility for services. You have the right to an independent evaluation in addition to the one provided by your local school district. Special requirements may apply.

Confidentiality of Information

The information about your child stored and used by your school district will be kept confidential and made available to you on request. This information is stored and released in accordance with the Family Educational Rights and Privacy Act of 1974.

Due Process

It is the intent of the IDEA to provide appropriate services to your child and resolve any disagreements at the local level. However, should you disagree with your child's identification, evaluation, and/or placement decision, contact your district's Director of Exceptional Children. He or she will give you a Handbook on Parent's Rights, if you need one, which will explain your child's educational rights and the procedural safeguards guaranteed to you as a parent or guardian.

The Office of Exceptional Children

The Office of Exceptional Children ensures that all children with disabilities in the state have available a free and appropriate public education (FAPE), protects the rights of these children and their parents, and provides leadership to school districts and state-operated programs in the provision of appropriate special educational services.

Links to resources for students with disabilities:

<http://ed.sc.gov/agency/ac/Exceptional-Children/>
- Phone: 803-734-8224

PRO-Parents

PRO-Parents a non-profit organization believes parents can be the best advocates for their children. Experienced advisors assist parents to become more aware of their rights and responsibilities through telephone counseling, workshops, and written material. With confidence and knowledge, parents can then participate as equal partners with professionals on behalf of their children. Regional Education Coordinators conduct free workshops throughout the state on several topics (See page 39 for further contact information).

DDSN Services

The SC Department of Disabilities and Special Needs (DDSN) is the state agency that plans, develops, coordinates, and funds services for South Carolinians with severe, lifelong disabilities of:

- Intellectual Disabilities and related disabilities
- Autism
- Traumatic brain injury
- Spinal cord injury and similar disability

DDSN works with other state agencies to tailor a comprehensive and practical service plan for each

person served. DDSN's specialized services supplement and enhance, not replace, services provided by other state agencies.

DDSN also advocates on behalf of all citizens with severe, lifelong disabilities and special needs to ensure that their needs are addressed by the appropriate state, federal, and local agencies.

How they deliver services

DDSN provides services to the majority of eligible individuals in their home communities through contracts with the local service-provider agencies. Many of these agencies are called Disabilities and Special Needs (DSN) Boards and they serve every county in South Carolina. There are also other qualified service providers available in certain locations around the state. 888-549-0820

Each local DSN Board serves as the initial entry point into the DDSN system, The DSN Board, or the information and referral system for persons suspected of having a head or spinal cord injury, will first screen an applicant to determine if an eligibility packet should be completed and sent to DDSN. At this point, the applicant can choose from a list of qualified service coordination or early intervention providers to assist them in the eligibility determination process.

Once a person becomes eligible for DDSN services, the Service Coordinator determines what level of service coordination the consumer will receive, based upon the assessed needs. As applicable, the Service Coordinator works with the consumer and his/her family and friends to develop a Person-Centered plan to address the identified needs and to monitor the implementation of the plan.

The consumer's Person-Centered plan is built on a person's strengths, interests and talents, and it targets the assistance to achieve results in the person's life. Consumers and others evaluate the actual result of and the satisfaction with the service and the supports he or she is receiving. If an individual is satisfied with the services and support he/she is receiving, he/she can choose not to change them.

Medical Interventions

Parent's Record-Keeping

The sample record-keeping information below can help you start a file of information about your child. As you contact different people and places, it's a good idea to keep records of people you've talked with and what was said.

Make sure you get copies of all written information about your child (records, reports, etc.). This will help you keep track of services and advocate for your child. Remember, as time goes on, you'll probably have more information to keep track of, so it's a good idea to keep it together in one place.

Many parents find it helpful to put all the information about their child in a notebook. Your child's Service Coordinator, Coach or Family Partner can help you set up a notebook.

Include:

- Letters and notes (from doctors, therapists, etc.)
- Medical records and reports
- Your child's developmental history, including personal notes or diaries on your child's development. A sheet documenting your Child's milestones. (When they sat up, stood up, walked, talked, etc.)
- Results of tests and evaluations
- Notes from meetings about your child
- Therapist(s) reports
- IFSP and IEP records
- Records of shots and vaccinations
- Family medical histories

- Insurance documentation including “explanation of benefits” (EOB).

ASK Questions About Your Child’s Medication

- What is the name of your child’s medication?
- Why is my child taking this medication?
- What time of the day and how many times a day should my child take the medication?
- Should the medication be taken on an empty stomach or with food?
- If I forget to give a dose of the medication, what should I do?
- Is it OK to take this medication with other medications? (Be sure to always tell your doctor and pharmacist about all the medications your child is taking)
- What problems (side effects) should I watch for and whom should I call if I have problems?
- When will my child start to feel better?
- Are there any special things I should know about this medication? (For example, keeping it in the refrigerator)

Be Smart

Always Keep a Record of All Your Medications. Remember the following hints:

- If you no longer take a medication, throw it away or return it to your local pharmacy for disposal. Flushing medications down the drain allows chemicals to be leached back into water systems.
- Never take a medication after the expiration date on the bottle
- Never share prescription medications with family or friends.

Oral Health Care for Children with Special Health Care Needs

Oral health is an important part of overall good health. Children with special health care needs often suffer from serious oral health problems either related to their condition or by neglect of their teeth because of the overwhelming nature of other health concerns.

The Basics of Good Oral Hygiene:

- Visit your dentist regularly starting at age 1
- Brush twice a day
- Rinse thoroughly after brushing
- Floss at least once a day to remove small food particles that are trapped in your teeth.

Medical Home

Does Your Child Have a Medical Home?

- Who is your child’s primary health provider?
- What health professional knows your child’s general health and specific diagnosis best?
- When you are faced with a difficult decision about your child’s health care, which helps you feel comfortable about what you are doing?
- Where does your son or daughter go for routine medical care, camp physicals, earaches, immunizations, and blood-levels?
- After surgery, who follows your child back home?

A Medical Home is a knowledgeable, loving health professional, chosen by the family to take care of their child’s health needs. They are accessible twenty-four hours a day seven days a week. This provider knows a child and his/her special condition, understands and respects his/her family, coordinates and works in partnership with parents, early interventionists, teachers, therapists, brothers and sisters, pediatric specialists, insurance companies, grandparents, nurses, care coordinators, child care workers, state health agencies, neighbors and friends. When a child has a Medical Home, the family is confident that a well-known and respected expert is always there to provide quality health services and care coordination.

A medical home has care that is:

- Accessible
- Family-centered
- Continuous
- Comprehensive, coordinated, compassionate
- Culturally competent

Sub-specialist and Specialty Clinics

In many of our situations our children may have regular medical or pediatric sub-specialists “experts” that they see regularly. These doctors have specialized in their fields such as Pediatric Ophthalmologist –(eye doctor), E.N.T. (Ear Nose and Throat Specialists), or Pediatric Cardiologist (children’s heart doctor). These sub-specialists will be able to advise us on the specifics of our child’s medical needs in the area of their expertise. One thing to watch for is not to neglect routine medical needs when dealing with specialists. One dad stated, “My son went a full year past the date of regular immunizations. With all the doctors we had been seeing, we thought that one of them would have seen that he needed his shots”. Again, we recommend a medical home where all of your specialists can send their records and one physician can oversee all your child’s medical needs.

South Carolina Department of Health and Environmental Control (SCDHEC)

Maternal and Child Health Bureau, Division of Women’s and Children’s Services (WCS)

Children with Special Health Care Needs Program (CSHCN)

DHEC services for children and youth with special health care needs and their families include:

- Information and linkage to agencies and organizations that can provide health or related services.
- Family centered care coordination services.
- Financial assistance with payment for medical services, supplies, or equipment related to chronic illnesses or disabling conditions.
- Camp Burnt Gin residential summer camp for children, youth, and young adults.

Eligibility

- Information about local and statewide resources, referral, and care coordination are available on request (contact information below).
- Financial assistance may be available to help with payment for physician visits and other medical services, orthodontic treatment for severe functional impairment, medical supplies, durable medical equipment (including hearing aids), prescription drugs (including blood products for home infusion treatment for hemophilia), or nutritional preparations needed to support growth and development. These services are available to children and youth with selected medical conditions.

Financial assistance is generally limited to:

- SC residents under age 18 (some exceptions apply)
- US citizens or lawful permanent residents
- Household income at or under 250% of federal poverty guidelines
- Qualifying medical condition

- No other source of payment for medically necessary services.

Additional requirements depend on medical condition and services needed.

- Selected services are provided to Medicaid recipients according to specific contractual arrangements between DHHS (Medicaid) and DHEC.

For more information

- Visit the DHEC web site www.scdhec.gov/health/mch/cshcn/
- Contact the nearest county health department or regional CSHCN offices (locations and other information posted on the website)
- Call CARELINE 1-800-868-0404
- Call state CSHCN office at 803-898-0784
- Send email message to cshcn@dhec.sc.gov

Newborn Screening

Newborn testing for phenylketonuria (PKU) began in 1965. A 1976 law made testing mandatory unless parents had religious objections. The SC newborn screening panel includes all 28 core metabolic conditions that are recommended by the March of Dimes and the American College of Medical Genetics. In addition it also includes screening for 24 secondary metabolic conditions that can cause severe problems if not found very early in life.

There is no DHEC consent form for newborn screening. The DHEC Newborn Screening Manual; Law, Regulations, and Official Departmental Instructions states, "The provision of the screening test is covered under the informed consent signed by the parents at the hospital." Parents may refuse the tests only on religious objections. (Taken in full from DHEC website <http://www.scdhec.gov/health/mch/nbs/index.htm>)

Contact Information:

- NBS general information: Kathy Tomashitis, MNS, RD, LD, 803-898-0619, tomashkf@dhec.sc.gov
- NBS laboratory information: John Reddic, PhD, 803-896-9725, reddicje@dhec.sc.gov
- NBS infant results: Linda Baker, 803-898-0593, bakerlb@dhec.sc.gov

First Sound Program

First Sound, South Carolina's Early Hearing Detection and Intervention (EHDI) program, functions under a legislative mandate that has been in effect since July 1, 2001. Key team members include South Carolina's hospitals that birth 100+ babies per year, audiologists and the Department of Health and Environmental Control. First Sound staff receives screening results from each screening hospital and tracks each infant that has been referred from ensuring follow up appointments are made with an audiologist through referring to Babynet, the early intervention program if diagnosed with a confirmed hearing loss. First Sound also tracks infants for three years if they pass their hospital screening but are at high risk for developing a late onset or progressive hearing loss.

Phone: 803-898-0708

Fax: 803-898-4453

The SC Community Long-Term Care Program

The SC Community Long-Term Care Program provides serves to children living at home. The "Children's

Personal Aide Program”, services individuals birth to twenty-one that are already eligible for Medicaid. The statewide programs provide Personal Care Aide’s to help families whose children need assistance in bathing, dressing, feeding, and incontinence care (self help skills). This service will need a doctor’s order and then a pre-admission screening. When approved, a list of providers will be suggested. Often families can receive two hours, five days a week of an in-home Personal Care Aide. Call for your local offices at 803-898-2590.

Shriners

Shriners Hospitals for Children is a network of pediatric specialty hospitals, founded by the Shriners, where children under the age of 18 receive excellent medical care absolutely free of charge. SC is fortunate to have one of these hospitals located in Greenville it specializes in orthopedics.

There is never a charge to the patient, parent or any third party for any service or medical treatment received at Shriners Hospitals. Shriners Hospitals accept and treat children without regard to race, religion or relationship to a Shriner. Any child may be eligible for treatment at a Shriners Hospital if the child is under 18 and if, in the opinion of the hospital’s chief of staff, the child has an orthopedic or burn condition that Shriners Hospitals can help (864-271-3444; www.shrinershq.org).

Scottish Rite Children’s Medical Center

1998 was an exciting and historical year for pediatric healthcare in Atlanta. That was the year that Egleston Children’s Health Care System and Scottish Rite Children’s Medical Center, two well-established children’s health systems based in Atlanta, officially merged to become Children’s Healthcare of Atlanta. Several SC families have children who have received care at these hospitals, which serve the southeast.

With a combined history of more than 165 years of caring for children, Children’s Healthcare of Atlanta embarked on a new beginning with an even stronger passion to ensure that all children have access to the specialized care they need. 404-785-5252 – www.choa.org.

They provide:

- One of the leading childhood cancer and blood disorders programs in the country
- One of the nation’s leading pediatric heart programs, providing multi-disciplinary transplant services to infants, children and adolescents

Health Departments

Available services vary by county.

- Provides free immunizations to all children under the age of 19.
- Provides comprehensive physical checkups for infants and children age 2 and under.
- May Provide EPSDT screening (The Early and Periodic Screening, Diagnostic, and Treatment service is Medicaid’s comprehensive and preventive child health program for individuals under the age of 21).
- May provide dental care to the Medicaid eligible children.
- May provide Home Health Care under direct doctor’s orders.

Look for local county listings in the blue pages of your local Phone Book.

Genetic Counseling

Meeting with a genetic counselor or geneticist is often suggested when a family realizes a child may have a special condition. The geneticist is a physician with special training in identifying genetic conditions, while the genetic counselor focuses on helping the family understand how genetics relate to their child’s health.

The genetics visit includes reviewing past medical records, a brief physical examination on the child, and possible blood tests as needed. The geneticist and counselor take time to explain their thoughts on the

child's condition and answer the families' questions. Those questions often include concerns like "why did this happen?" and "could this happen again?." The genetics visit focuses on answering these questions and helping the family gain a better understanding of their child's special needs.

SUPPORT NETWORKS AND OTHER RESOURCES

Family and Friends

Having healthy relationships and a good circle of friends is a basic human need for any of us. As the parent of a child with special needs, we need to understand that other people might not know how to appropriately talk about or act towards our child. We set the example that others will follow. How we approach, accept, include, and act toward our child will teach friends and family how to relate to our child. Others do not know what our special children are capable of doing. They also do not know what our children cannot do. This creates an awkward situation. The awkwardness of this situation for our families and friends can be greatly reduced if we will blaze the trail for them.

First, explain to people that you have a child. Secondly, explain to them that your child happens to have a disability. Help them to accept your child. Inform and educate them. Be willing to talk about your child and their disability as well. Enjoy your child and try to help family and friends to separate the person from the disability. You have a son or daughter and they are a person first.

Now hear us clearly, we are not saying, “You fake it till you make it.” We all will tell you do not ignore your feelings for too long. But we have learned that if we approach our child with a positive perspective others will follow.

“I love my son Karl. He has a distinct personality and in so many ways he acts just like me as a boy. I want people to know him as a person. As a person, one of the many facets about him is that he happens to have Down syndrome. I happen to wear glasses. But my glasses are not the all-defining facet of who I am any more than Karl’s Down syndrome is the final definition of who he is. Please see my son as a person first. Get to know the person and I promise you will be blessed for it.”
WC Hoecke

Many of us as parents will tell you that our own worldview and perspective of the value of individuals has grown.

How Networking Works For Men and Women

If you’ve been with your significant other for any time at all, you know that the way men and women approach a new situation can be very different. For issues very important to us, it can be even more difficult. There is no issue that we, as parents, are more intense about than the care of our children. Issues of parenting style, medical approaches, and family and friend interactions will force us to communicate about issues we may never have discussed. This is even more heightened when a child with special healthcare needs is involved.

Needless to say, the way we go about gathering information may be very different. Typically a woman’s form of networking is very social and men may only want the nuts and bolts.

The important thing to realize is that each approach has its advantages and neither is wrong. “My wife and I approach our child very differently. We never use the same approach but choose to talk it out to become one minded on the way we care for our son.” (a father)

Several fathers have commented that the greatest stressor of having a child with special needs is not the child itself, but rather dealing with their spouse being stressed. If you are finding it difficult to communicate about these issues, realize you are not alone. Family Connection has tools to help. See Couples Workshop on page 31.

The Effects of a Disability on a Family

- Adapted with permission from "About Special Kids" of Indiana ¹

Family members each cope with a child's disability or illness in their own way. Each member must adapt to the new situation. Relationships within the family, along with previously defined rules, values and roles, must be adapted. Such tremendous changes on everyone's part can cause stress on the family unit, as well as on individual members.

Mothers

In the initial crisis period, mothers may react differently from fathers or significant others. Mothers may be more emotional and may voice concerns about their ability to cope with the additional tasks of childcare. Usually, mothers are more encouraged socially to express their feelings, and they also receive the majority of support offered to the family.

Because mothers usually are the traditional caretakers in the family, they assume most of the additional work in caring for their child with special needs. They must learn how to make it all work together within the household routine. And, because they are doing much of the daily care, mothers may recognize and feel the reality of their child's special need earlier than the father.

With the responsibility for daily care often comes an additional role in the medical world, taking the child to clinics, school evaluations, consultations and other services. Thus, mothers become the primary information giver and taker for their family.

Fathers

Fathers may respond less emotionally at first than their partners, concentrating more on long-term concerns, such as prognosis, social stigma, financial effects and the child's future as an adult. It is not unusual for fathers, because of cultural and family beliefs, to cope by trying to be what society expects men to be: "Strong and silent." Thus, dads are discouraged from confronting and expressing their feelings. Fathers may be expected to assume the role of family leader, "the fixer," and the person in control. These roles may be difficult to maintain, adding to the stress created by such expectations. Fathers traditionally are the "breadwinners." In other words, their primary role in the family is making money to provide the family with what it needs. They may feel a tremendous responsibility for the financial burden that may accompany the disability, especially if the mother must quit her job to care for their child with special needs. More hours working means more hours spent away from the child, less time for receiving information and less opportunity to initiate professional and/or supportive relationship.

Mother-Father Relationship

The relationship between the mother and father usually is the initial bond within the family. That relationship is a partnership, one that sets the rules and roles for the family. Still, each parent is an individual who reacts uniquely to the responsibility of parenting a child with special needs. In fact, each may define the loss of their initial dream differently. These individual responses or reactions can cause a crisis in the relationship between the mother and father.

When a parent utilizes his or her own coping skills in this situation, the other parent may misinterpret this behavior. He or she may judge the partner's response as inappropriate within the situation, because it is different from the way they reacted. At times, mothers may label their partner's behavior as "cold" or "uncaring," when fathers are perceived to deal with their child's situation in an "objective" manner. Fathers may judge their partners as "overly-emotional" or "weak." Fathers may feel that they must take care of their partner in spite of having unmet needs of their own; mothers may feel the same way. Each partner may be unable to see beyond his or her own needs. Each can be unaccepting of the other's ways of

¹ About Special Kids - Central Office- 7275 Shadeland Ave., Suite 1 Indianapolis, IN 46250, 317-257-8683 <http://www.aboutspecialkids.org/>

coping. Each may become angry with the other for adding to the stress in an already-stressful situation.

Parents may have difficulty communicating with each other about their child's disability. One parent may want to share his or her feelings, but the other parent may be unable or unwilling to do so. This difference may set up a communication block and one-sided discussions. Fathers may have to rely on their partners to relay information from professionals, but the information they need may not be forthcoming. Mothers may understand what they heard but be unable to explain it fully. At times, parents may be reluctant to express their concerns to each other, fearing that such concerns only will add to the worry or depression for their partners. Consequently, each may attempt to protect the other by avoiding such discussions.

Each parent has his or her own value system, which was handed down from his or her childhood family. Differences in value systems may contribute to conflicts within the relationship regarding decision-making and the outlook for their child. Thus, the parental unit may become overwhelmingly burdened, and it may take much compromise to keep it intact. The mother-father relationship can survive the many changes it must endure, but parents must work to:

- Find a way to communicate feelings and concerns in a productive manner. They may need to seek guidance in this area, especially if effective communication has not been well established
- Develop a respect for each other's coping style. This, too, may require professional guidance.
- Re-examine individual roles and the rules within their family and together develop a new plan to meet their child's needs as well as needs of the other family members.
- Maintain their relationship as partners, apart from their relationship as parents. Parents need to have quality time together.

Single Parents

About one in four children with disabilities (24.5 percent) are cared for by single mothers, compared to 17.4 percent of children without disabilities. "The implications are that we have to pay attention to the needs and demands of these families of children with disabilities, which are more likely to be female-headed households," said Philip Cohen, a fellow at the Carolina Population Center at UNC. "The work-family balance issues that so many people are burdened with are especially challenging for families who have children with disabilities." Single parents do have a tremendous amount to juggle in addition to caring for their child with special needs. Because this can be overwhelming, it is very important that a single parent build a support network made up of friends and family. Let them take an active role in the care of your child. Consider finding a support group of other single parents or a group for parents of children with special needs. Give as much as you can without setting goals that are unrealistic for one parent to achieve. Don't beat yourself up for what cannot be. Recognize what you can do to create a good life for your child to the best of your abilities. Recognize signs of stress and know when you need to ask for help. Remember to take care of yourself.

A Special Perspective on Fatherhood

- WC Hoecke, *Karl's Dad*

If you are reading this, you may have just received the greatest sucker punch a man can receive. For me it was the words *Down syndrome*. I was forced into an arena and told to play a game that I knew nothing about and, frankly, had no desire to play. I hadn't trained and wasn't conditioned for it. I didn't even know the rules. I had envisioned a totally different game. But now my blue-eyed boy beckoned me to come and play.

Men thrust into this game will play it very differently. Some will be solo runners. They just want someone to show them the court and give them the ball and get out of their way. Others want a coach. Not someone who thinks they're better than them, but someone who has played the game before and can share the rules with them. The reality is that coaches know they are usually in the presence of better ball players than themselves. However, a coach knows the rules and how to work the field to the player's advantage. He may even be able to let you know where other sucker punches come into play. Other dads

want a team or a group of men who play the game together. Another select few will opt to forfeit the game and not play at all. The choice must be made by each father. I just know that when I chose to answer my child's call to 'come out and play,' I began to travel down one of the most rewarding roads I have ever traveled.

I have talked with hundreds of dads. One thing we all have in common is the sense of the loss of the dream we had of what our child may do and be. The reality is that few, if any of us, met the expectations of our own fathers. I never became the engineer that my father expected; you may not have been the ball player your dad anticipated. However, our parents had twenty to thirty years to discover that their dreams would be redirected. I had to digest this reality in the time it took someone at the hospital to say *Down syndrome*. The loss of this dream is real; and, it is quite natural to be upset.

Although I am not the engineer my dad wanted me to be, my parents', especially my dad's, encouragement has been the most significant factor in realizing the dreams that I have realized for myself. Your role, as father, is even more significant now. I have learned to take life at a little slower pace. I understand so much better the stages of development and how each builds on the next. You will hear a lot of us say that our children have made us much better fathers than if we had not experienced this world of disabilities.

Please understand that your child will succeed in the things they choose to accomplish. Some of our children are holding down full-time employment, attending college, authoring books, and even getting married. Others may never meet those goals. Will my child reach those goals? No dad really knows; and, for me 'having to wait and see' is the hardest part of being a dad. Our children may amaze us with the things they are interested in and the dreams they will realize for themselves.

A realistic objective is to help them walk through all of the developmental stages to achieve their dreams. You have the opportunity to learn and understand all of the developmental stages that it takes to fulfill their dreams. We believe that information is power; and, you and your child have the power to succeed in whatever endeavors you take on.

FAMILY CONNECTION OF SOUTH CAROLINA PROGRAMS AND SERVICES



Parenting provides some of life's greatest moments, and every parent dreams of having happy, healthy children. So when a child with disabilities or special needs is diagnosed, it is rarely what the parents expected. Treasures are found in the unexpected, however, just as all children are a gift, Family Connection of South Carolina helps families recognize and celebrate the potential of that gift.

Family Connection is a support network for families who have children with special needs. Founded by parents in 1990, to help thousands of children in South Carolina reach their potential by providing parent-to-parent connections, linking families to community resources, and sponsoring a number of educational and support programs.

Our programs are centered on parent-to-parent networking because families with shared experiences are uniquely qualified to help each other. We match parents of children with disabilities and chronic illnesses with Support Parents/Coaches who have children with similar concerns. Support Parents/Coaches are an invaluable source of support and encouragement because they have faced similar challenges and celebrations.

Parent to Parent

No one quite understands like another parent who has “been there.” A Parent to Parent network creates a unique community of support for families. A parent can be matched with another parent based on the diagnosis or greatest concern. A national search can be made, if needed.

Support Parents

Support Parents are volunteers who have completed training and provide 1:1 support and information to other parents of children with special needs or disabilities. There are currently 600 active volunteers. Since April 1990, more than 23,000 matches have been made with trained Support Parents.

Family Partners

Family Partners are parents who have children who have benefited from BabyNet, the state’s early intervention program for children birth to three years old. Family Partners provide support to parents who have a child currently enrolled in the BabyNet program and help them navigate the world of early intervention. They also provide up-to-date resource information, emotional support and assurance. Family Partners are trained Support Parents and receive an additional 15-20 hours of training a year.

Regional Parent Partners

In collaboration with DHEC, Division of Children with Special Healthcare Needs, trained parents provide support and information to parents of children with special healthcare needs statewide.

Project Breathe Easy

Project Breathe Easy provides parent-to-parent for children who have asthma. Asthma is the leading illness for children in South Carolina and is one of the top reasons why children visit emergency rooms. Community Parents, who have a child who has asthma and is managed well and has received asthma management training, make home visits and provide follow-up support. Parents supported through this program receive an asthma management notebook and free pillow and mattress encasements. This program is currently offered in Anderson, Calhoun, Charleston, Columbia, Fairfield, Florence, Greenville, Newberry, and Orangeburg.

Parent Connections (Support Groups)

Family Connection creates informational and social opportunities for parents to meet together in the community. Currently, there are over forty Parent Connection gatherings statewide organized around specific disabilities or interests. Parents meet for playgroups, gather at coffee shops, and go out to dinner together. Parent Connections are an ideal way to learn from other parents and have a great time. Please contact Family Connection to see if there is a group near you. If there is not a Parent Connection group in your community, please call Family Connection and we can share ideas with you to get one started. Family Connection: 800-578-8750

Fathers Network

The Family Connection Fathers Network seeks to empower fathers of children with special health-care needs and developmental delays so they may be actively engaged in the lives of their children. Beginning in June 2003, Family Connection shifted its focus from primarily a support group model to include training of father-to-father mentors called Coaches. Fathers Network seeks to train volunteer fathers to support other fathers in a father-friendly manner, knowing that the issues and solutions will be addressed differently than the way a mother may address them.

Family Connection’s ‘Of Hopes and Dreams’ Conference

This statewide conference increases sensitivity and understanding of special needs and disabilities. It enables parents and professionals to expand their knowledge regarding disabilities, special needs, family support, and opportunities for children of all ages who have special needs.

Website and eConnection

As a nonprofit organization, Family Connection is regularly seeking cost-saving measures. Email and our website (www.FamilyConnectionSC.org) are ideal methods of disseminating general information, calendars and advocacy information. Please become involved and informed on what is happening in your community and state. If you are interested in receiving information, please email info@FamilyConnectionSC.org, and put e-connection in the subject line. Please state the county in which you live and the type of Family Connection news you are interested in receiving: 1. Monthly calendar of events (e-Connection) 2. The Link-2U which is a family focused newsletter 3. News alerts (Medicaid changes, legislative updates, etc.)

Medicaid Support and Information

Family Connection has staff trained in Medicaid, and they are also parents who have personally navigated and accessed Medicaid for their child. Please call Family Connection when you are uncertain if your child qualifies for a Medicaid plan, have received a denial, or when making a decision about the best medical home network or managed care organization. Family Connection: 800-578-8750

Hispanic Outreach

Family Connection provides information and support for the Hispanic community en Español.

Respite

Offering parents time away from care giving through respite cooperatives was initiated in 1998 with a grant from the Office of the Governor Developmental Disabilities Council. Additional funding came from the Robert Wood Johnson Foundation. Parents and volunteers form respite cooperatives primarily in faith communities. Parents alternate caring for one another's children so they can have a few hours for themselves. Parents know that their child with special needs and their siblings are in a safe and fun environment with planned activities. A notebook giving pertinent facts about the children is reviewed with parents and community volunteers before the respite cooperative begins. There are currently 11 Respite Co-ops throughout South Carolina. Please contact Family Connection at 800-578-8750 to learn how to find a respite program or start one.

Kid Connection

This special workshop for siblings of children who have special needs is offered free in Columbia, Greenville and Charleston. Small groups, ages 8-12, meet to connect with other children who have siblings with special health care needs. Through planned activities, trained professionals encourage children to explore their feelings and learn how to handle situations that may arise.

Couples Workshop

We view the Couples Workshops as a key way that we can strengthen families. Participants evaluating the entire workshop rated "the benefit of this workshop in its ability to improve our relationship in the future," at 92 percent. Using the Prevention and Relationship Enhancement Program (P.R.E.P.), couples are provided skills, information, and fun throughout a day-long workshop.

Awareness: The Keys to Friendship

The Keys to Friendship is an educational program for elementary and middle school students that teach understanding and sensitivity towards people with disabilities. This program offers activity centers which are set up in schools and are designed to give the students an opportunity to experience what it is like to have a learning disability, hearing impairment, visual impairment and physical disability. Forty schools are accepted each year. Please call Family Connection to find out how your child's school can apply. This program is sponsored by the South Carolina Department of Education, Office of Exceptional Children.

Statewide and Community Advocacy

Family Connection spends significant amount of time advocating in support of appropriate legislation for

families. Through a network of partner organizations, families work collaboratively to advocate at the local, state, and federal level for reform and changes that improve the quality of life for individuals with disabilities. Family Connection is widely known by state agencies and legislators for being able to mobilize large groups of families quickly that always work positively in addressing change.

Center for Disability Resources (CDR) Library

The Center for Disability Resources Library consists of over 5,200 books, videos, brochures, and audiotapes covering a variety of disability-related topics. You can also access the CDR by going to the Family Connection website under "Virtual Library." *Requests for information are accepted by mail, phone, e-mail, fax, and in person.

Books may be borrowed for a month. Videos may be borrowed for 2 weeks. Library materials and information can be mailed to your home or office. Postage-paid return mailers are available for materials sent to South Carolina families.

Contact Information:

Steve Wilson, Coordinator, CDR Library

Phone number: 803-216-3200

E-mail: Steve.Wilson@uscmed.sc.edu

Fax: 803-216-3223

Web: uscm.med.sc.edu/CDR/

Faith Community and Civic Organizations

One of the reasons many individuals attend a faith community or civic organization is that they want to help other people. An example, that we often see, is a local faith community will want to surround a member of their congregation with the birth of a new child. If this child has a new diagnosis at birth, the organization desires to help, but their fear of this new situation may cause them to be unsure of what they should do. Family Connection and other disability organizations have some resources that may be helpful to create inclusion in these organizations.

Our job as advocates is to help them know what they can do to support individuals with special needs and to endear our children to these congregations or civic organizations. We typically think that if we help someone they will be endeared to us, but the reverse is also true. If we help someone we also feel closer to him or her. Think of those you have worked on projects with or went to school with. Sharing experiences with others creates relational bonds.

Often, we do not actively seek help, but this can be detrimental to our child. If someone can help my child, they will feel connected to them. These relationships can be deepened and strengthened to build a circle of support for your child. You may need them some day to find a job, or a good place for assisted living. With the advances in medicine, many of our children may outlive us. The social supports we can create around our child will help them achieve their goals. As we inspire people to be our child's friend, we also train them to be inclusive of all disabilities and work to make our world a better place for all people.

STATE RESOURCES AND DISABILITY ORGANIZATIONS

Ahead Start

Ahead Start is a private, early intervention program.

Contact Information:

114 Laurens Rd.
Greenville, SC 29607
Phone: 864-569-9995
Fax: 864-235-3395
www.aheadstart-sc.com

The ARC of South Carolina

Advocates for the rights of citizens and provides service coordination services to individuals with intellectual disabilities and special needs.

Contact Information:

3214 Leaphart Rd. Suite C
West Columbia, SC 29169
803-748-5020
Fax: 803-445-1026
E-mail: thearc@arcsc.org
Website: www.arcsc.org

BabyNet

BabyNet is South Carolina's early intervention program for infants and toddlers under three years old with developmental delays or conditions associated with developmental delays.

Contact Information:

1300 Sumter Street Suite 100
Columbia, SC 29201
Phone: 800-734-0479
Website: www.scfirststeps.org/babynet.html

BrightStart

Main office: (serving Richland & Lexington Counties)
1514 Pickens Street
Columbia, SC 29201
Phone: 803-929-1112
Fax: 803-929-1418

Upstate office:
105-G Hunt Street
Greer, SC 29650
Phone: 864-627-5099
Fax: 864-627-5099

Center for Disability Resources (CDR) Library

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Steve Wilson, Coordinator, CDR Library

Phone number: 803-216-3200

E-mail: Steve.Wilson@uscmed.sc.edu

Fax: 803-216-3223

Web: uscm.med.sc.edu/CDR/

CHADD (Children and Adults with Attention Deficit)

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD), is a national non-profit organization providing education, advocacy and support for individuals with AD/HD.

Contact Information:

Phone: 800-233-4050

Website: <http://www.chadd.org/>

Children's Rehabilitative Services (CRS)

Children's Rehabilitative Services (CRS) strives to provide the best possible care for children ages 0 – 21 and some adults with special health care needs who have low to moderate incomes. Children's Rehabilitative Services (CRS) is part of the Department of Health and Environmental Control (DHEC), and has a multitude of services, including medical evaluation, counseling, immunizations, and hearing aids for children younger than 18 years old. For more information, please contact your local health department.

Commission for the Blind

See "South Carolina Commission for the Blind"

Community Long Term Care (CLTC)

Community Long Term Car (CLTC) offers programs to help individuals who want to live at home, need assistance with their care, and are financially eligible for Medicaid.

Contact Information:

Phone: 803-898-2500

Continuum of Care for Emotionally Disturbed Children

Advocates to ensure continuing development and delivery of appropriate services to those children with severe emotional disturbance and their families in South Carolina whose needs are not being adequately met by existing services and programs.

Contact Information:

1205 Pendleton Street, Suite 372

Columbia, SC 29201

Phone: 803-734-4500

Website: www.continuum.sc.gov

Department of Disabilities and Special Needs

The Department of Disabilities and Special Needs (DDSN) is the state agency that plans, develops, coordinates, and funds services for South Carolinians with severe lifelong disabilities, including autism, intellectual disabilities, traumatic brain injury, and spinal cord injury. Please contact the South Carolina Department of Disabilities and Special Needs to get the number of your local DSN Board.

Contact Information:

3440 Harden Street Extended
Columbia, SC 29203
Phone: 803-898-9600
Website: [www. http://ddsn.sc.gov/Pages/default.aspx](http://ddsn.sc.gov/Pages/default.aspx)

Department of Health and Environmental Control- CareLine

Provides information about prenatal care, infant health care, and transportation to medical appointments, Family Planning services, well child checkups, immunizations, and services for Children with Special Health Care Needs (CSHCN), BabyNet, and Medicaid.

Hours of Operation: 8:30-5:00 Monday - Friday

Department of Education: Office of Exceptional Children

The Office of Exceptional Children ensures that all children with disabilities in the state have available a free and appropriate public education (FAPE), protects the rights of these children and their parents, and provides leadership to school districts and state-operated programs in the provision of appropriate special educational services.

Contact Information:

1429 Senate Street Suite 808
Phone: 803-734-8224
Fax: 803-734-4824
Columbia, SC 29201
E-mail: mametts@ed.sc.gov

Department of Mental Health

SC Department of Mental Health makes needed services available to any citizen of South Carolina. Some consumers have private insurance or are eligible for Medicaid or Medicare. For consumers who do not have insurance but are unable to cover the full charges, the Department's mental health centers have a hardship reduction policy, which can result in reducing the fees. A payment plan can be worked out to help meet these medical expenses.

Contact Information:

Administration Building
2414 Bull Street
Columbia, South Carolina 29202
Phone: 803-898 - 8581
TTY For Deaf Services: 864-297-5130

Department of Social Services

Child Care: ABC Special Needs Care Vouchers for children under 19 who have deferring abilities and developmental delays such as autism, mental retardation, Down Syndrome, or brain and spinal cord injuries. A child may also be eligible if they are receiving physical therapy, occupational, or speech therapy through their local county school district and have an Individualized Education Plan (IEP). Families may qualify for special child care vouchers (slots) if the parent is employed, or is enrolled in a school or training program, or is also disabled. Special Needs applications are available through the agencies below:

- Local County Departments of Disabilities and Special Needs
- The SC School for the Deaf & Blind
- The BabyNet and CRS Offices located at the county Department of Health and Environmental Control offices
- For questions regarding the ABC Special Needs Voucher program, call:
 - Donna Casteen at 803-898-9735 or email her at: donna.casteen@dss.sc.gov

Contact Information:

P.O. Box 1520
Columbia, SC 29202-1520
Phone: 803-898-7601
Website: <http://dss.sc.gov>

Disability Action Center

Provides: Advocacy, Peer Support, Independent Living Skill Training, Information and Referral

Contact Information:

115 Belleview St
Columbia SC 29201
Phone: 800-681--6805

330 Pelham Rd., Ste 102-B
Greenville SC 29615
Phone: 800-681-7715
Website: www.dacsc.org

Easter Seals SC - State Headquarters

Provides services to people with disabilities. Teams of therapists, early interventionists, and other health professionals help each person overcome obstacles to independence and reach his or her personal goals. Funds Project Action – a national program for solving transit accessibility issues.

Contact Information:

P.O. Box 5715
Columbia SC 29250
Phone: 803-256-0735
Fax: 800-951-4090
Website: sc.easterseals.com

Epworth Early Intervention Services

Epworth Early Intervention Services provides services to young children with developmental delays and disabilities and their families. More specifically, Epworth Early Intervention services have an early intervention preschool program home-based intervention services, and a monthly respite care program.

Contact Information:

2900 Millwood Ave
Columbia, SC 29250
Phone: 803-212-4768

Family Connection of South Carolina Inc.

The mission of Family Connection of South Carolina is to strengthen families of children with special needs through parent support.

Contact Information:

2712 Middleburg Dr. Suite 103
Columbia, SC 29204
Main Office Phone: 803-252-0914
Statewide Phone: 800-578-8750
Fax: 866-420-4082
www.FamilyConnectionSC.org

Federation of Families of SC

An advocacy, information and referral organization for families of children and adolescents with

emotional, behavioral, or psychiatric disorders. The Federation of Families of South Carolina is a nonprofit organization established to serve the families of children with any degree of emotional, behavioral or psychiatric disorder. The services and programs offered by the Federation are designed to meet the individual and varying needs of families around the state. Through support networks, educational materials, publications, conferences/workshops and other activities, the Federation provides many avenues of support for families of children with emotional, behavioral or psychiatric disorders.

Contact Information:

P.O. Box 1266
Columbia, SC 29202
Phone: 866-779-0402
Web: www.fedfamsc.org

Greenwood Genetic Center

The Greenwood Genetic Center to provide diagnostic services, treatment and prevention programs to reduce the risk and severity of disabling conditions. The Greenwood Genetic Center works closely with the South Carolina Department of Disabilities and Special Needs.

Contact Information:

One Gregor Mendel Circle
Greenwood, SC 29646
Phone number: 864-941-8100
Website: www.ggc.org

Healthy Learners

Provides: Access to healthcare for uninsured and underinsured students, whose families are unable to afford self pay services. They Provide services to students in Allendale, Dillon, Georgetown, Greenwood, Richland, and Lexington Counties.

Contact Information:

2711 Middleburg Drive Suite 206
Columbia, SC 29204
Phone: 803-454-0350
Website: www.healthylearners.com

Muscular Dystrophy Association

MDA combats neuromuscular diseases through programs of worldwide research, comprehensive medical and community services, and far-reaching professional and public health education.

Contact Information:

Phone: 803-799-7435
Fax: 803-799-3046
Email: columbiascscservices@mdausa.org
Website: www.mdausa.org

National Association of Mental Illness of SC (NAMI)

A nonprofit organization dedicated to improving the quality of life of people with serious mental illnesses and their families through support, education, and advocacy.

Contact Information:

P.O. Box 1267
5000 Thurmond Mall Boulevard Suite 205

Columbia, SC 29202
Phone: 800-733-9591
Fax: 803-733-9593
Website: www.namisc.org

Partners for Health

Partners for Health is the eligibility process for all of South Carolina Medicaid Health Insurance Programs for children and adults. It is based on income. For further information, please contact: 888-549-0820

Play Works Inc.

Contact Information:

555 John B. White, Sr. Blvd.
Spartanburg, SC 29306
Phone: 864-814-2230

PRO-Parents

Parents Reaching Out to Parents of South Carolina, Inc., is a private, non-profit organization that provides information and training about education to families of children with all types of disabilities. PRO-Parents believes parents can be the best advocates for their children. Experienced advisors assist parents to become more aware of their rights and responsibilities through telephone counseling, workshops and written material.

With confidence and knowledge, parents can then participate as equal partners with professionals on behalf of their children. PRO-Parents also serves professionals in education and related fields throughout South Carolina.

Contact Information:

652 Bush River Road Suite 203
Columbia, SC 29210
Phone: 800-772-5688
Fax: 803-772-5341
E-mail: PROParents@proparents.org
Website: www.proparents.org

Protection and Advocacy for People with Disabilities (P&A)

Established in 1977 as the protection and advocacy system for the State of South Carolina, P&A is a member of the National Disability Rights Network (NDRN) and is mandated by state and federal law to protect the rights of people with disabilities in South Carolina.

- P&A's Mission: Protecting and advancing disability rights
- P&A's Vision In SC, individuals with disabilities will be fully integrated into the community with control over their own lives; be free from abuse, neglect and exploitation; and have equal access to services..P&A's services are provided statewide.

Services are NOT limited by age, race, sex, type of disability, income, residency, or religion. There are no fees for services.

Contact Information:

3710 Landmark Drive Suite 208
Columbia, SC 29204
Phone: 866-275-7273
(TTY) 866-232-4525
Website: www.pandasc.org

Social Security Administration (SSI)

•The Social Security Administration is responsible for the following benefits:

- Disability benefits
- Retirement benefits
- Survivor benefits
- Supplemental Security Income Program (SSI). The SSI program makes payments to people with low income who are 65 or older or are blind or have a disability. Amount of monthly payment is dependent on income.

Contact Information:

Strom Thurmond Fed Bldg.
1835 Assembly Street
Columbia, SC 29201
Phone: 800-722-1213
(TTY) 800-325-0778

SC Children's AIDS Care System

Phone: 803-898-0291

SC Assistive Technology Program at USC

SC Assistive Technology Program at USC is a federally funded program concerned with getting technology into the hands of people with disabilities so that they might live, work, learn and be a more independent part of the community. For further information, please contact:803-935-5263

SC Autism Society

Provides information and referrals to individuals, professionals and people with autism and their families.

Contact Information:

806 12th Street
West Columbia, SC 29169
Phone: 800-438-4790
Fax: 803-750-8121
Website: www.scautism.org

SC Commission for the Blind

Their mission is to provide quality, individualized vocational rehabilitation services, independent living services, and prevention of blindness services to blind and visually impaired consumers leading to competitive employment and social and economic independence. These services are made available with state and Federal funding, and there is no charge to consumers for services.

Eligibility for most services is contingent upon meeting the legal definition of blindness. having a central visual acuity of 20/200 in the better eye with best corrective lens, or a visual field of 20 degrees or less. Individuals with a severe visual disability that will result in legal blindness also are eligible for services. Legal blindness must be verified by an acceptable eye examination. There are financial eligibility requirements for some services.

Contact Information:

1430 Confederate Avenue
P. O. Box 2467
Columbia, SC 29202
Phone: 800-922-2222
E-mail: publicinfo@sccb.sc.gov
Web: www.sccb.state.sc.us

SC Department of Health and Human Services

The mission of the South Carolina Department of Health and Human Services is to manage the Medicaid program to ultimately provide the best healthcare value for South Carolinians.

Contact Information:

P.O. Box 8206
Columbia, SC 29202
Phone: 888-549-0820

SC Department of Mental Health

The South Carolina Department of Mental Health gives priority to adults, children, and their families affected by serious mental illnesses and significant emotional disorders. The South Carolina Department of Mental Health is committed to eliminating stigma and promoting the philosophy of recovery.

Contact Information:

2414 Bull Street
Columbia, South Carolina 29202
Phone: 803-8998-8581
Website: <http://www.state.sc.us/dmh/comments.htm>

SC First Steps

SC FirstSteps helps young children prepare for school through programs that strengthen families, improve children's health and well-being, increase the quality of child care and early education opportunities, and help transition rising kindergarteners into school. Every South Carolina county has a First Steps office that identifies local needs and collaborative opportunities to help South Carolina's youngest learners be better prepared for school.

Contact Information:

1300 Sumter Street, Suite 100
Columbia, SC 29201
Phone: (803) 734-0479
Website: <http://www.scfirststeps.org/>

SC Health Insurance Pool (SCHIP)

SCHIP is a state health insurance program administered by Blue Cross Blue Shield for individuals who are refused insurance coverage for health reasons or whose rate is more than 150% of the SCHIP rate. For further information, please contact: 800-868-2500 ext. 42757

SC Independent Living Council (CILC)

The council seeks to provide leadership to empower people with disabilities. The SCILC conducts a variety of activities and provides support and assistance to centers for independent living in developing the advocacy skills and interests of South Carolinians with disabilities.

Four core services: These services are provided for people with disabilities:

- Systems and Individual Advocacy
- Independent Living Skills Training
- Peer Counseling
- Systems and Individual Advocacy (retrieved June, 2009 from www.scilconline.org)

Contact Information:

810 Dutch Square Blvd. Suite 214
Columbia, SC 29210
Phone: 803-731-1607

E-Mail: scilc@scilconline.org

Web: www.scilconline.org

SC School for the Deaf and the Blind

A specialized instructional and resource center that provides services statewide for deaf, blind and sensory multi-disabled individuals (both children and adults), their families and professionals: offers programs for preschool, elementary, high school, sensory multi-disabled, vocational and postsecondary students as well as outreach and support services; offers camps for children with hearing or vision disabilities; provides training workshops for parents and professional.

Contact Information:

355 Cedar Springs Road
Spartanburg, SC 29032-4699

Phone: 864-585-7711

Fax: 864-585-3555

Website: www.scsdb.org

SC Vocational Rehabilitation

The SC Vocational Rehabilitation Department is an employment agency for people with disabilities. Many of our clients are highly motivated but need help developing work skills. After eligibility is established, each client participates in an assessment to determine which vocational rehabilitation services are needed to help the client prepare for employment. The SC Vocational Rehabilitation Department serves people who want to work but are hindered from doing so by a physical or mental disability. Information is available at any SCVRD office. When a person with a disability applies for VR services, a team of vocational rehabilitation specialists helps determine eligibility. If VR services could improve that person's prospects of competitive employment, eligibility can be established. Existing records are used in determining eligibility. A VR team helps each new client understand the options available in setting and reaching a vocational goal. SCVRD's informed choice policy makes each client a full partner in the vocational rehabilitation process with access to all the information needed to make necessary decisions.

Contact Information:

1410 Boston Ave

P.O. Box 15

West Columbia, SC 29171-0015

Phone: 800-832-7526

TTY: 803-896-6553

Email: info@scvrd.state.sc.us

Website: www.scvrd.net.net

Shriners Hospital for Children in Greenville

Shriners Hospital for Children in Greenville is dedicated to improving the lives of children by providing pediatric specialty care, innovative research, and outstanding teaching programs for medical professionals. Children up to age 18 with orthopedic conditions, spinal cord injuries, burns, and cleft lip and palate are eligible for care and receive all services in a family-centered environment, regardless of the patients' ability to pay.

Contact Information:

950 West Faris Road

Greenville, SC 29605

Phone: 864-271-3444

Website: www.shrinershq.org

TEFRA (Katie Beckett Waiver)

TEFRA is a category of eligibility for Medicaid coverage for children under age 19 who meet the SSI childhood disability definition and who can more economically be provided home care than in a hospital or community home. Eligibility is based on a child's income resources rather than family income. For further information, please contact Family Connection at: 803-252-0914

WIC (Women, Infant, and Children)

WIC serves to safeguard the health of women, infants, & children up to age 5 who are at nutritional risk by providing nutritious foods to supplement diets, information on healthy eating, and referrals to health care. WIC eligibility is based on financial status. Contact your local health department for more information.

INDEX

	Federation of Families, 37	
A		G
ARC, 34	Genetic Counseling, 25	
Autism Society, 40	Greenwood Genetic Center, 38	
		H
B		
BabyNet, 18	HASCI, 13	
BrightStart, 34	Head and Spinal Cord Injury, 13	
		O
C		
CDR, 33, 34	Office of Exceptional Children, 20, 36	
CDR Library, 33, 35		P
Center For Disability Resources, 33, 34		
CHADD, 35	PRO-Parents, 20, 39	
Children and Adults with Attention Deficit, 35		S
Commission for the Blind, 35, 40	SC Health Insurance Pool, 41	
Community Choices Waiver, 12	SC Healthy Connections Choices, 8	
Community Long Term Care, 35	SC School for the Deaf and the Blind, 42	
Community Long-Term Care Waivers, 12	SCHIP, 41	
Community Parents, 31	SCILC, 41	
Community Supports Waiver, 13	Shriners, 16, 25, 42	
Continuum of Care, 35	Social Security Administration, 40	
Couples Workshop, 32	Specialty Clinics, 23	
	Speech Therapy, 18	
D	SSI, 10, 40	
DDSN Services, 20	Sub-specialist, 23	
Department of Education, 36	Supplementary Income, 10	
Department of Health, 36, 41	Support Groups, 31	
Department of Mental Health, 36, 41		T
Department of Social Services, 36		
Disability Action Center, 37		
		V
E	TEFRA, 8, 43	
Early Intervention, 19	The Office of Exceptional Children, 20	
Easter Seals, 37		W
Epworth, 37		
F	Vocational Rehabilitation, 42	
Family Connection, 37		
Family Partners, 31		
Fathers Network, 31	WIC, 11	
	Women Infant and Children, 11	

