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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.

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## **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 special needs child 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.

## **A Special Perspective on Fatherhood**

*WC Hoecke*

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. That's OK. Others may want a coach. Not someone who thinks they're better than them, but rather someone who has played the game before and can share the rules with you. The reality is, coaches know they are usually in the presence of better ball players than themselves but a coach knows the rules and how to work the field to your 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.

The choice is yours. 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 best roads I have ever traveled.

I have talked with hundreds of dads. One thing we all have in common is the sense of loss of the dream we had of what our child may do and be. Yet, 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. But our parents had 20-30 years to discover that their dreams would be re-directed. 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. I can also say that although I am not the engineer my dad wanted me to be, my parents and especially my dad's encouragement has been the most significant factor in realizing the dreams that I have created for myself. **Your role 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 child has made us much better fathers than if we had not experienced this world of disabilities.

Please understand that your child will succeed at 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 these goals.

Will my child reach these goals? I really do not know and "having to wait and see" for me 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 create for themselves. A realistic objective is helping them to walk through all the developmental stages to achieve the dreams they will create for themselves. You have the opportunity to learn and understand all of the developmental stages that it takes to fulfill their dreams. We believe information is power, and you and your child can succeed in whatever endeavor you take on.

WC Hoecke, Karl's Dad

## **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, 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 by saying something like, "You know that dumb thing you just said five minutes ago? I know you're kicking yourself in the head for saying it and it's OK. We are all trying to figure this out and I know this is difficult, but you have no idea how much your friendship and support means during this time."

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/Friends.

## **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. 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 parents of a child with special needs who have been trained by Family Connection to help other parents of children with special needs.)

## **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. Ask your Coach. (See Couples Workshop p.40)

## **The Effect of a Disability on the Family**

- Adapted with permission from "About Special Kids" of Indiana<sup>1</sup>

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, also. 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": That is, 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 crisis, and, in fact, each may define the loss differently. These individual responses or reactions can cause a crisis in itself.

When a parent utilizes his or her own coping skills in the crisis, 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 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 to 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 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 Cohen, also 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. And, it can be quite 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. Do 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.

## **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**

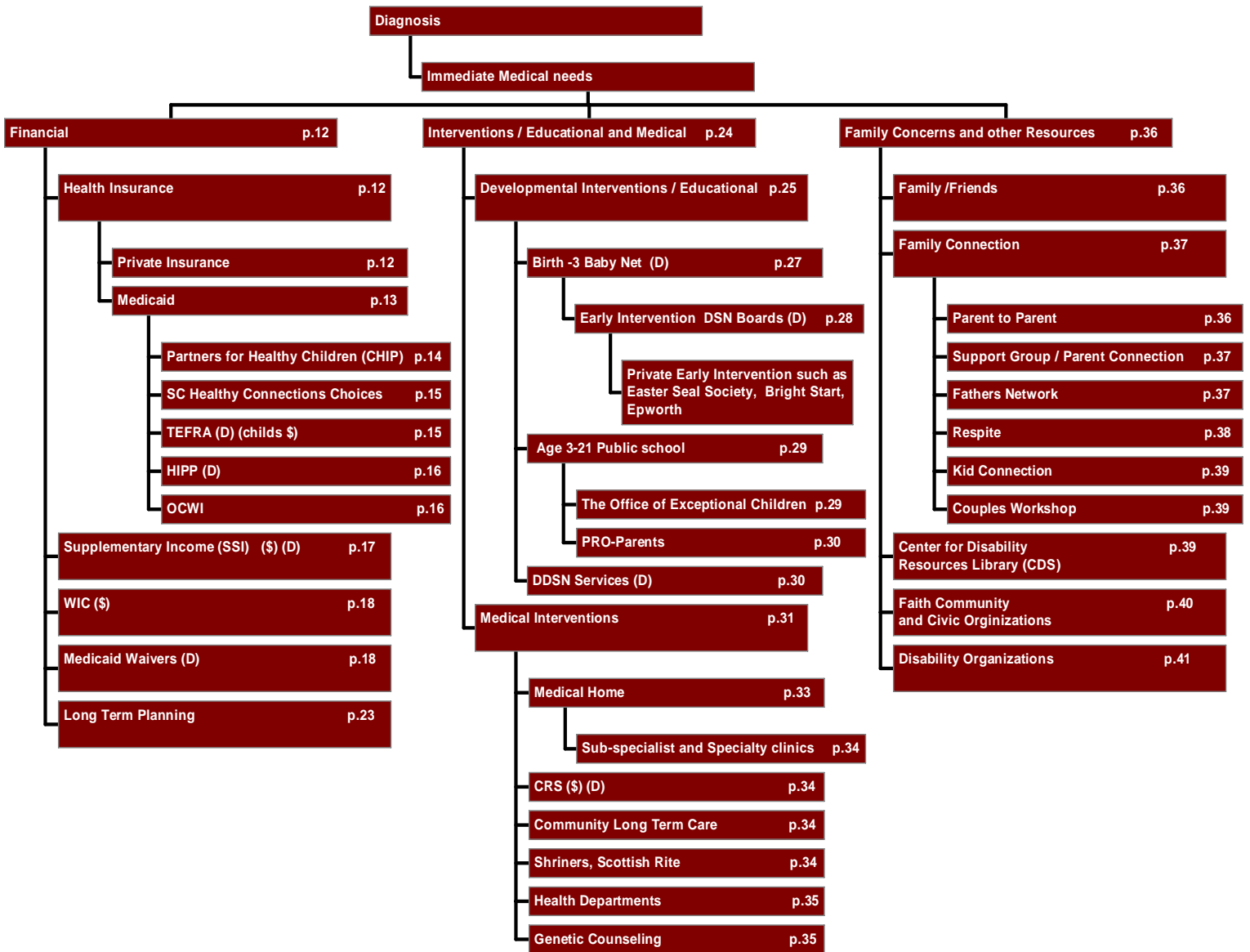
What we mean by intervention is how we can intervene (get involved) in the life of a child with special needs to improve their outcomes. An example is use of specific targeted therapies to help an infant or young child. This can greatly improve a child's outcome later in life.

### **Family Concerns 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, Coach or Support Parent 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 will help you identify the best strategies to approach these tasks.

# Flow chart of how to get started



(\$) = Eligibility is restricted by applicants' income or financial situation.

(D) = Eligibility is restricted to specific disability diagnoses

Family Connection of SC Inc. ©

## **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. (800) 868-2500 ex. 46401.

***Medicaid***

Another way to get health insurance is through public insurance programs. If you meet certain requirements, your child may be eligible for one or more government health insurance programs known as Medicaid and Medicare.

**A Brief History of Medicaid**

The Medicaid program was first enacted in 1965. It was intended to assist those who were uninsured, and had low income, gain access to a medical payment program. Few restrictions were placed on the program initially. The federal government was overwhelmed with thousands of people who needed access to medical care and had no source of payment during the first year of the program. Because it was a joint state and federal matching fund program the cost had skyrocketed to the federal government as well as to the states. In 1966, Congress revisited the issue and decided only the poor needed this kind of protection.

Medicaid was designed as an entitlement program for payment of medical services at no cost to those eligible. In recent years, under 1115 waivers some recipients pay a portion of the cost of services. This will be discussed in depth below. The Medicaid program has broad federal requirements that were designed for its original implementation.

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 mentally retarded;
- 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.dhhs.state.sc.us/dhhsnew/Q&As.asp>

If you need help, please call toll-free: 1-888-549-0820

**Partners for Healthy Children (CHIP)**

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 under the age 19 and families with low income. For example in 2009, a family of four with a monthly income of \$2,757, and an annual income of \$33,084 would be eligible. Coverage is reviewed and renewed annually. For details, call 1-888-549-0820, you can also go to this website and scroll down to find a current income chart for Partners for Healthy Children.

### **Healthy Connections Kids**

The Healthy Connections Kids program provides health insurance coverage to uninsured children in households with income above 150% but less than or equal to 200% of the Federal Poverty Level. Children cannot be covered by any other health insurance. Also, they cannot have had health insurance in the last three months - unless that insurance was cancelled for a reason that was not the family's choice. Individuals who are eligible will receive a health insurance package based on the State Health plan provided to South Carolina State Employees. Dental and Vision services are included in the benefit package.

### **SC Healthy Connections Choices**

South Carolina Healthy Connections Choices is a state 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. Those who are newly eligible for Medicaid or up for annual renewal will receive enrollment packets starting on the date enrollment rollout starts in each region. [www.SCchoices.com](http://www.SCchoices.com).

The first initial enrollment period will be the first 30 days after the packet is mailed, during this time members can choose to stay in regular “fee-for-service” Medicaid or pick from a plan available in the area. In order to stay in regular Medicaid members will have to call Healthy Connections Choices. All other plans available in the area will be specified on the enrollment form in the packet. If the member does not make their choice, Healthy Connections Choices will choose a plan for them. After the initial enrollment period there is a choice period, which is the 90 days after enrolling in a health plan that members can return to regular Medicaid or transfer to another plan for any reason. After the 90-day choice period if a member wants to change plans there must be a special reason and approval will have to be given. To talk with enrollment specialist or to enroll, call 1-877-552-4642 or visit [www.SCchoices.com](http://www.SCchoices.com).

For your convenience there are frequently asked questions regarding Medicaid choices on Family Connection of South Carolina’s website [www.familyconnectionSC.org](http://www.familyconnectionSC.org) and Healthy Connections Choices website [www.SCchoices.com](http://www.SCchoices.com).

In addition, Family Connection of South Carolina has a parent on staff that is trained in Medicaid. Please call 1-800-578-8750 or 803-252-0914 if you have any additional questions.

### **TEFRA Coverage also known as Katie Beckett**

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.

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).

**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. (Talk to a Family Connection Family Partner (800-578-8750) if you are denied this resource);
- 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 mentally retarded (ICF/MR),
    - 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 (traditional Medicaid) covered services including doctor visits, specialists, prescriptions and therapies. If you would like to talk to another parent whose child has TEFRA contact Family Connection at 1-800-578-875. You can also learn more about TEFRA through the DHHS website on TEFRA

**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 1-803-933-1825 or 1-888-549-0820.

**(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 2009 level is \$3,400 monthly for a family of four, \$40,793 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

All medical services must be necessary, and some services are limited.

You should apply as soon as you know your significant other is 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.
- If you are pregnant you will need a pregnancy statement signed by a doctor or nurse stating your due date.
- 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.

***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.

Call to make an appointment or to be sent an application, Toll Free 1-800-772-1213, 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.

(WIC) Women Infant and Children Food Supplement Program

### **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*) 1-800-922-4406.

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.

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

- Community Choices,
- HIV/AIDS, and
- Mechanical Ventilator Waivers

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

- Community Supports Waiver (CS)
- Head and Spinal Cord Injury (HASCI)
- Mental Retardation and Related Disabilities (MR/RD), and
- Pervasive Developmental Disorder Program (PDD)

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

- Medically Complex Children’s Waiver

**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.

**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	Adult Day Health Care Nursing
Attendant Care	Case Management
Chore Services (Opt 4 only)	Companion
Environmental Modification	Home Delivered Meals
Institutional Respite Care	Limited Incontinence Supplies
Limited Nutritional Supplements	Nursing Home Transition Services

Personal Care I/II	Personal Emergency Response Systems (PERS)
Respite in a Community Residential Care Facility	

Contact Information: (803) 898-2725

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

Contact Information: (803) 898-2725 or contact the local DHHS Regional Office

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

Contact Information: (803) 898-2725.

**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 Mental Retardation and Related Disabilities (MR/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 & MR/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 1-800-376-4636 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.

**Community Supports Waiver (CS)**

The children cannot be covered by any other health insurance. Also, they cannot have had health insurance in the last three months - unless that insurance was cancelled for a reason that was not the family's choice. The children cannot be covered by any other health insurance. Also, they cannot have had health insurance in the last three months - unless that insurance was cancelled for a reason that was not the family's choice.

**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 65<sup>th</sup> 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 Mentally Retarded (ICF/MR);
- 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:

Behavioral Support Services	Day Habilitation
Environmental Modifications	Health Education for Consumer-Directed Care

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

**Mental Retardation and Related Disabilities (MR/RD) waiver**

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

- Be eligible for MR/RD services (have mental retardation or related disability);
- Be eligible for Medicaid or already covered by Medicaid;
- Meet level of care criteria for Intermediate Care facility for the Mentally Retarded (ICF/MR);
- Have needs that can be met through the provision of MR/RD waiver services; and
- Choose to receive services through the waiver rather than in an ICF/MR 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	Adult Companion Services
Adult Day Health Care Nursing	Adult Dental Services
Adult Vision Services	Audiology services
Behavioral Support Services	Day Habilitation
Environmental modifications*	Nursing Services
Occupational Therapy	Personal-care services
Physical therapy	Prescribed drugs
Prevocational Services	Private vehicle modification**
Psychological services	Residential Habilitation
Respite Care	Speech/language pathology
Supported Employment Services	

\*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>

### **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/Mental Retardation (ICF/MR). 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](http://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>

### **Medically Complex Children's Waiver**

This waiver at DHHS will serve children who meet the Nursing Facility level of care or ICF-MR 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 \$1,962 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 fathers 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 federal organizations include: SC Department of Education, Social Security offices, SC DHEC and County Health Departments, 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 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.

## ***Developmental Interventions / Educational***

### **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 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 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 baby. 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**

BabyNet is South Carolina's Early Intervention Program. The importance of early intervention cannot be stressed enough. Early intervention means parents and professionals working together to ensure that a child grows to reach their greatest potential. Early intervention requires help from professionals, however you can accomplish much of it at home.

The goal of early intervention is to increase opportunities for your baby to learn. Your baby may learn exercises to improve muscle tone or new games to improve memory skills. Early Intervention services are based upon the child's needs and may include Special Instruction, physical therapy, occupational therapy, speech therapy, assistive technology or any or all of the sixteen services mandated by the federal government in IDEA.

BabyNet provides services to eligible children (birth to three years of age) and their families based upon an Individualized Family Service Plan (IFSP). This is developed with the family, a family advocate, the service coordinator, and other professionals providing services/therapies.

Children who meet eligibility criteria are served regardless of family income or U.S. citizenship. Children are eligible for BabyNet if they have received a diagnosis of Special needs. BabyNet contracts with the following agencies to provide comprehensive Early Intervention Service: SC Department of Disabilities and Special Needs, SC Department of Education, SC Department of Social Services, SC Department of Mental Health, SC Department of Health and Environmental Control, SC Commission for the Blind, SC School for the Deaf and Blind Outreach Services, and SC Department of Health and Human Services. FCSC also assists families in BabyNet.

In SC, BabyNet falls under the responsibility of The SC Department of Health and Environmental Control (DHEC).

BabyNet is the payer of last resort and will bill your health insurance company for services before paying for them. An E.O.B (explanation of benefits) denying services has to have been issued by your health insurance company before BabyNet will pay the bill. You need to understand that historically BabyNet has insisted on in-home services and would only pay for office visits under special circumstances. Most insurance companies do not cover in-home visits when an office location is available. This may have changed by the time you read this and apply for services. If your child is eligible for BabyNet it is strongly advised that you ask BabyNet and your health insurance provider where services are allowed or required to be performed. BabyNet service providers understand this and expect health insurance companies to deny payment of service. This is where two different types of payment options overlap in a contradiction. Health insurance deals with medically necessary items and services. BabyNet deals with services that help increase educational success.

BabyNet 1-800-868-0404 [www.scdhec.net](http://www.scdhec.net)

### **Early Intervention (EI)**

- Special professionals called Early Interventionists (EI) provide help in Special Instruction (SI) and coordinating therapies. These acronyms are part of the “new language” that is necessary for you to learn
- The Early Interventionist will come and work in the home and help the family monitor the baby’s development in all the skill areas (motor, thinking/problems solving, language, self-care)
- They will also teach parents/caregivers fun developmentally appropriate activities that they can do to encourage development
- The Early Interventionist focuses on activities that fit into the child’s natural environment and the family’s everyday routines and settings.
- The Early Interventionist teaches activities to help the baby reach the outcomes that are identified on the Individualized Family Service Plan.
- Additionally, he/she can be a valuable support and resource to families. By working closely with your family, early intervention professionals make sure that both services and community support groups, including family supports, are brought together to meet the unique needs of each child and their family.

Early Intervention services are provided at no cost to your family and include:

- Hearing Services                      example: fitting for a hearing device

- Vision Services example: prescribing glasses
- Speech Services example: finding out why a child does not talk
- Nursing Services example: tube feeding or bandage changing
- Health Services example: giving prescribed shots at home
- Nutrition Services example: special diets
- Family Training example: learning how to bond with your baby
- Physical Therapy example: working to improve a child's movement
- Evaluations example: checking for a hearing loss
- Occupational Therapy example: teaching a child to use a spoon
- Support Groups example: parents getting together
- Parent to Parent Support example: Family Partners through *FCSC* for emotional and informational support
- Social Work Services example: family counseling
- Transportation example: arranging trip for doctor's appointment
- Special Instruction example: teaching sign language to a mother
- Psychological Services example: information about child behavior
- Service Coordination (case management) example: making a plan (IFSP) to pull services together for the family.

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 1-800-868-0404 [www.scdhec.net](http://www.scdhec.net) (*i.e.* 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.

<http://ed.sc.gov/agency/Standards-and-Learning/Exceptional-Children/>

### **Links to resources for students with disabilities:**

<http://ed.sc.gov/agency/offices/ec/resources/page244.html>

(See page 42 For contact information)

### **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 44 for further contact information) 1-800-759-4776

### **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:

- Mental retardation 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. 1-888-549-0820

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
- 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. 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.

## CRS

### Children's Rehabilitative Services

With the support of federal, state, and other funding, CRS operates a statewide network of children's medical services. By coordinating the efforts of local, regional, and state through FC resources, CRS assures that medical services are available across the state for children with special health care needs. The CRS System of Care provides nursing intervention, social work services, nutrition services, parent-to-parent support, inpatient and outpatient hospitalizations, braces, hearing aids, specialized medical equipment, physical, occupational and speech therapies, and genetic services. Community based care is provided in public health district sites around the state.

### Eligibility

To participate in the CRS program, a child must be a legal resident of the United States, live in South Carolina, be under 21 years old, be diagnosed with a covered medical condition, and the family must meet certain income guidelines. Financial eligibility for program services is based on family size, income, and federal guidelines that are updated annually. 1-803-898-0784  
[www.scdhec.net](http://www.scdhec.net)

### Covered Conditions and Diagnoses

CRS offers treatment and services for many disabilities, some of which are listed below:

- Bone and joint diseases
- Hearing disorders and ear disease
- Cleft lip and palate and other craniofacial anomalies
- Spina bifida and other congenital anomalies
- Epilepsy (seizures), cerebral palsy and other central nervous system disorders
- Rheumatic fever
- Problems from accidents, burns, and poisoning
- Endocrine disorders
- Hemophilia (children and adults)
- Sickle cell disorders (children and adults)
- Developmental delays such as speech/language, motor and growth abnormalities
- Kidney diseases.

### Covered Services

- Nursing
- Pharmacy
- Durable Medical Equipment
- Physician Services
- Social Work

- Nutrition
- Genetics
- Transition
- Parent-to-Parent Support

**The SC Community Long-Term Care Program**

The SC Community Long-Term Care Program provides services 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 1-803-898-2590.

**Shriners, Scottish Rite**

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](http://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 <http://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.

## **Family Concerns 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. For the second, inform and educate them. Be willing to talk about your child. When you talk about your child be willing to also talk about 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.

### ***Family Connection***

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**

Support Parents provide emotional support and assurance through a careful match to referred parents. The match is made based on the parents greatest concern or need. The Support Parent is encouraged to make at least three contacts with the referred parent, which reflects best practice. Since April 1990, more than 25,000 matches have been made with trained Support Parents. Eighty-four parents completed the 6-hour ***Support Parent*** Training program during 2008, totaling 1056 parents who have completed the program since 1990. When Family Connection was founded, professionals in various disciplines volunteer their services to train Support Parents and to advise as needed. Other family members and friends help with mailings, office work, childcare, and resource development. Support Parents and other special volunteers make up the very fabric of Family Connection.

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.

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, Columbia, Charleston, Florence, and Greenville.

### **Support Groups/ Parent Connections**

Groups organized around specific disabilities or interests meet regularly and often invite speakers. Support groups meet in various South Carolina cities around issues such as Down syndrome, ADHD, autism, asthma and various other disabilities, chronic illnesses or developmental delays. Childcare is provided during these support groups. Family Connection hosted more than 50 support groups statewide. Family Connection supports numerous other groups and workshops around the state by publicizing them in *The Link*, Family Connection's quarterly newsletter mailed to more than 20,000 parents and professionals.

### **Fathers Network**

In 2000, we began hearing more and more from fathers about their needs to become informed and connected. The majority of the supports and services to families who have children with special health-care needs focus on children and mothers, usually leaving fathers out. Often, fathers lack the "knowledge" needed to feel a part of their children's medical and educational decisions. Many fathers of children with special needs are unaware of the significance they have in their children's lives. Some fathers even see the child's mother as the one who is truly "gifted" to help the child. A father is just a "provider/hunter," or someone whose presence is optional. Understanding of how different parenting styles bring balance in child development can be a life-changing discovery.

A father's absence has a significant impact on the family. According to The National Fatherhood Institute, almost 75 percent of America's children who live in single parent families will experience poverty before their 11th birthday (NFI). Many of the fathers who are part of the Midlands Fathers Network reluctantly share their opinion that it is emotionally easier to work long hours rather than deal with stresses that they often find in their homes. In these situations, there are additional effects on siblings.

Beginning in November of 2000, Family Connection established the Fathers Network, where men come together for a meal and informative session on topics of interest to them. Often, fathers are not available to attend or participate in appointments with physicians and hear "news" first hand about their child. This is delegated most often to the mother because of her role in the family. Fathers have responded to an educational format through the Fathers Network because they want

information. After a speaker's presentation, the fathers find themselves talking about issues that are important to them.

Further research of fatherhood programs has shown that less than 12% of all fathers will attend a father's support group setting (*Father Participation in Early Education Programs*: Turbiville, Marquis, 2001). Yet Family Connection has found that many fathers are quite receptive to a one-on-one visit from a veteran father, especially at the time of their child's diagnosis.

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. This is a monumental task that the fathers have embraced with vigor. The Support Parent program of Family Connection has documented its effectiveness. Currently about 500 parents are actively being matched with parents who want to talk with another parent who has "been there." Support Parents offer emotional support and assurance as well as unbiased information on services, programs, and the importance of early intervention with young children so they may reach their potential. More than 95 percent of the Support Parents are mothers, and most matching is with other mothers.

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.

The mission of the Fathers Network program is to celebrate and support fathers and families raising children who have developmental delays, disabilities, or chronic illness.

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. This mission also includes educating society as a whole to the importance of fathers' involvement in the lives of their children.

### **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.

### **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**

Numerous studies show the benefits to children when two parents are in a loving marriage. While the divorce rate is as high as 40 percent (US Census 2000) in the United States, among parents

who have children with special needs, the rate is reported at 80 percent (ARCH 2002). Children who have special needs are 3.4 times more likely to suffer from abuse and neglect. The additional stress families have and the exhaustion parents experience, mentally and physically, can be detrimental to a marriage and the children unless the couple has the tools to support each other.

The multiple responsibilities, as well as the unrelenting demands for daily care of the child, prove to be very stressful for parents. Parent-reported mental health treatment for stress is 2 to 3 times higher for parents of children with special health care needs versus that reported by parents of well children (The Ontario Child Health Study. Cadman, Rosenbaum, Boyle & Offord, 1991). Families exhibit isolation, depression, loneliness and fatigue, which contribute to possible abuse and neglect situations and which may lead to institutional care for the child. These parental impacts are detrimental in and of themselves, and it is important to note that the parents' response to stress also affects the child. Positive adaptation of the parent and family to the stress of the special health need is a very significant factor in the positive adaptation of the child. Disruption in parenting and family functioning has been found to be one of the primary mechanisms causing further dysfunction in the child.

Parent surveys have supported the need, specifically in the form of a workshop or conference, for marriage enrichment. We see this as a key way that we can strengthen families. In answer to this need, and with funding from a recently expired grant from the United Way Association of South Carolina, Family Connection supported WC and Catherine Hoecke to be trained in the Prevention and Relationship Enhancement Program—P.R.E.P.© This nationally recognized curriculum, with 20 years of research developed at the University of Colorado, addresses the needs of the families who call upon Family Connection and will provide very practical skills for couples to use in marriage. With a generous support from the Lipscomb Family Foundation, Family Connection has piloted its PREP© couple's weekend workshops in the Midlands. The format of a Friday evening, an all day Saturday workshop and two follow-up Monday night sessions has been very well-received. Participants evaluating the entire workshop rated “the benefit of this workshop in its ability to improve our relationship in the future,” at 92 percent.

### ***Center For Disability Resources (CDR) Library***

#### 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. \*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: (803) 733- 1501

E-mail: wilsons@gw.med.sc.edu

Fax: (803) 733-1509

Web site: <http://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've worked on projects with or went to school with. Sharing experiences with others creates relational bonds.

As men, we typically do not want any 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.

## **Disability Organizations**

### **ARC of SC**

P.O. Box 8707

Columbia, SC 29202

(803) 935-5266

1-866-300-9331

Email: [thearcsc@aol.com](mailto:thearcsc@aol.com)

- Advocacy organization that provides information, training and support to people with mental retardation or other lifelong disabilities and their families.

### **Assistive Technology**

SC Assistive Technology Program

At USC

803-935-5263

### **Commission for the Blind**

See "SC Commission for the Blind"

### **School for the Deaf and the Blind**

See "SC School for the Deaf and the Blind"

### **Department of Health and Environmental Control- CareLine**

1-800-868-0484

- Provides information about prenatal care, infant health care, transportation to medical appointments, Family Planning services, well child checkups, immunizations, services for Children with Special Health Care Needs (CSHCN), BabyNet, and Medicaid. Hours of Operation: 8:30-5:00 M-F

### **Department of Education: Office of Exceptional Children**

Suite 808

1429 Senate Street

Columbia, SC 29201

E-mail: [Sdurant@ed.sc.gov](mailto:Sdurant@ed.sc.gov)

803-734-8224

Fax: 803-734-4824

- 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.

### **Department of Mental Health**

Administration Building

2414 Bull Street

Columbia, South Carolina 29202

(803) 898 - 8581

TTY For Deaf Services: (864) 297-5130

- 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.

**Department of Social Services**

P.O. Box 1520

803-898-7462

Columbia, SC 29202-1520

<http://www.state.sc.us/dss/>

- 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](mailto:donna.casteen@dss.sc.gov).

**Easter Seals SC-State Headquarters**

803-256-0735

800-951-4090

- 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.

**Epilepsy Foundation of SC**

652 Bush River Road, Suite 211

(803) 798-8502

Columbia, SC 29210

Fax: (803) 798-8591

Home Page: [www.epilepsysc.org](http://www.epilepsysc.org)

Email: [epilepsysc@mindspring.com](mailto:epilepsysc@mindspring.com)

- Provides advocacy services, self-help groups, information and referrals, educational materials, week-long residential summer camp for children with epilepsy, vocational counseling and individual and family counseling.

**Federation of Families of SC**

P.O. Box 1266

(803) 799-0402

Columbia, SC 29202

1-866-779-0402

Home Page: <http://www.fedfamsc.org/>

- 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. (retrieved June, 2009 from <http://www.fedfamsc.org/info.html>)

**Muscular Dystrophy Association**

(803) 799-7435  
 Fax: (803) 799-3046  
 Home Page: [mdausa.org](http://mdausa.org)  
 Email: [columbiascservices@mdausa.org](mailto:columbiascservices@mdausa.org)

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

**National Association of Mental Illness (NAMI) of SC**

P.O. Box 1267 (803)733-9593  
 5000 Thurmond Mall Boulevard, Suite 205 1-800-733-9591  
 Columbia, SC 29202 Home Page: [www.namisc.org](http://www.namisc.org)

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

**PRO- Parents**

652 Bush River Road (803) 772-5688  
 Suite 203 1-800-759-4776  
 Columbia, SC 29210 Fax: (803) 772-5341  
 E-mail: [PROParents@proparents.org](mailto:PROParents@proparents.org)

- 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.

Workshops

PRO-Parents provides training to parents of children with disabilities to prepare them to make decisions about their child's education: Regional Education Coordinators conduct free workshops around the state on several topics:

- Parents' rights and responsibilities under the law: An overview of the special education process.
- How to participate successfully in designing the Individualized Education Program (IEP) for your child.
- What does “inclusion” really mean? What constitutes the “least restrictive environment”?
- How to advocate effectively and work collaboratively with professionals.

- The laws: What are they and how do they differ? How do they protect my child with special needs?
- Transition: What help can I expect as my child prepares to leave school?
- Attention Deficit Disorder: Effective educational intervention.

**Protection and Advocacy for People with Disabilities**

3710 Landmark Drive, Suite 208                      1-866.275.7273  
Columbia, SC 29204                                      (TTY) 1.866.232.4525

- Mission: To protect the legal, civil, and human rights of people with disabilities in SC by:
  - Enabling individuals to advocate for themselves
  - Speaking on their behalf when they've been discriminated against or denied a service to which they are entitled
  - Promoting policies and services which respect their choices

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.

**Social Security Administration (SSI)**

Strom Thurmond Fed Bldg.                              1-800-772-1213  
1835 Assembly Street                                      (TTY) (800) 325-0778  
Columbia, SC 29201

- 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.  
(retrieved June, 2009 from <http://www.socialsecurity.gov/pubs/11011.html>)

**SC Autism Society**

806 12<sup>th</sup> Street    1-800-438-4790  
West Columbia, SC 29169                                      803-750-6988

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

**SC Commission for the Blind**

1430 Confederate Avenue                                      800.922.2222  
P. O. Box 2467    Email: [publicinfo@sccb.sc.gov](mailto:publicinfo@sccb.sc.gov)  
Columbia, S.C. 29202

- 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 REQUIREMENTS:** 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.

(retrieved June, 2009 from <http://www.sccb.state.sc.us/index.html>)

**SC Independent Living Council (SCILC)**

810 Dutch Square Blvd., Suite 214  
Columbia, SC 29210

(803) 731-1607

TTY: (803) 731-1400

E-Mail: [scilc@scilconline.org](mailto:scilc@scilconline.org)

- 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:

- Advocacy
- Independent Living Skills
- Peer Counseling
- Information and

(retrieved June, 2009 from <http://www.scilconline.org/>)

**SC School for the Deaf and the Blind**

355 Cedar Springs Road  
Spartanburg, SC 29032-4699

(864) 585-7711

Fax: (864) 585-3555

- A specialized instructional and resource center that provides services statewide for deaf, blind and sensory multidisabled individuals (both children and adults), their families and professionals: offers programs for preschool, elementary, high school, sensory multidisabled, 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. Regional Centers throughout the state.

**SC Vocational Rehabilitation**

1410 Boston Ave., P.O. Box 15  
West Columbia, SC 29171-0015

1-800-832-7526

TTY: (803) 896-6553

Email: [info@scvrd.state.sc.us](mailto:info@scvrd.state.sc.us)

- 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.

## **Abridged Resources Directory by Topics**

### ***Health Medical, Developmental***

SC Autism Society 806 12 <sup>th</sup> Street West Columbia, SC 29169	1-800-438-4790 803-750-6988
SC Assistive Technology Program At USC	803-935-5263
BabyNet <a href="http://www.scdhec.net">www.scdhec.net</a>	1-800-868-0404
Children's Rehabilitative Services (CRS) <a href="http://www.scdhec.net">www.scdhec.net</a>	803-898-0784
Community Long Term Care (CLTC)	803-898-2590
CareLine	1-800-868-0404
Local DSN Boards Please call the SC Department of Disabilities and Special Needs (DDSN) To get the number of your local DSN Board at	1-888-376-4636
Family Connection of South Carolina Inc. 2712 Middleburg Dr. Suite 103-B Columbia SC. 29204 <a href="http://www.familyconnectionsc.org">www.familyconnectionsc.org</a>	800-578-8750 803-252-0914
Greenwood Genetic Center One Gregor Mendel Cr. Greenwood, SC 29646 <a href="http://www.ggc.org">www.ggc.org</a>	864-941-8100 888-442-4363
Shriners Hospital in Greenville <a href="http://www.shrinershq.org">www.shrinershq.org</a>	864-271-3444

SC Children’s AIDS Care System	803-898-0291
SC Department of Disabilities and Special Needs <a href="http://www.state.sc.us/ddsn/">www.state.sc.us/ddsn/</a>	803-898-9600 or 1-888-376-4636
SC Department of Health and Human Services, Premium Payment Project	1-800-933-1825 or 1-888-549-0820
SC School for the Deaf and the Blind	1-877-225-8337
Social Security Office <a href="http://www.ssa.gov">www.ssa.gov</a>	1-800-772-1213
WIC (Women Infant and Children)	1-800-922-4406

***Emotional/Mental Health***

CHADD (Children and Adults with Attention Deficit)	1-800-233-4050
The Continuum of Care for Emotionally Disturbed Children	1-888-539-8863
SC Department of Mental Health	1-800-763-1024
The Federation of Families of SC	1-866-779-0402
NAMI (National Alliance for the Mentally Ill) <a href="http://www.namisc.org">www.namisc.org</a>	1-800-788-5131

***Educational Resources***

Center for Disability Resources Library at USC	1-803-733-3310
Department of Education Office for Exceptional Children	1-800-763-5497
PRO-Parents	1-800-759-4776
Protection and Advocacy for People with Disabilities	1-800-800-6997
Family Connection of South Carolina Inc.	800-578-8750

2712 Middleburg Dr. Suite 103-B 803-252-0914  
 Columbia SC. 29204  
[www.familyconnectionsc.org](http://www.familyconnectionsc.org)  
 Reading materials and Resources

SCAutism Society 1-800-438-4790  
 806 12<sup>th</sup> Street 803-750-6988  
 West Columbia, SC 29169

SC First Steps to School Readiness 1-877-621-0865

**Insurance**

Partners for Health 1-888-549-0820

TEFRA (Katie Beckett Waiver) 1-800-578-8750

Supplemental Security Income (SSI) 1-800-772-1213

SC Health Insurance Pool  
 (SCHIP) 1-800-868-2500 ext.42757

**Services Providers (Early Interventionist and Service Coordination)**

BabyNet  
 Mills Jarrett Complex 803-898-3432  
 PO Box 101106 800-922-1107  
 Columbia, SC 29211 800-868-0404

BrightStart,  
 main office: 1514 Pickens Street  
 Columbia, SC 29201  
 (803) 929-1112; fax (803) 929-1418  
 -serving Richland & Lexington Counties  
 upstate office: 105-G Hunt Street  
 Greer, SC 29650  
 (864) 801-2081; fax (864) 801-2818  
 e-mail address: [brightstart@sc.rr.com](mailto:brightstart@sc.rr.com)

Easter Seals SC-State Headquarters 803-256-0735  
 PO Box 5715 800-951-4090  
 Columbia, SC 29203

Epworth Early Intervention Services 803-212-4757  
 PO Box 50466  
 2900 Millwood Ave  
 Columbia SC, 29250

Play Works Inc.	864-599-9229
555 John B. White, Sr. Blvd.	866-752-9967
Spartanburg, SC 29306	

Local DSN Boards  
Please call the SC Department  
of Disabilities and Special Needs (DDSN)  
To get the number of your local  
DSN Board at 1-888-376-4636

SC School for the Deaf and the Blind	877-225-8337
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“This project is supported by the US Dept of Health and Human Services Grant Program 93.086, from the Office of Family Assistance. The Office of Family Assistance is an office of the Administration for Children and Families-- which, among other things, administer all Temporary Assistance to Needy Families (TANF) programs. Points of view or opinions in this document are those of the staff of Family Connection of South Carolina. As such, they do not represent the official position or policies of the United States Department of Health and Human Services, or its offices.”

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