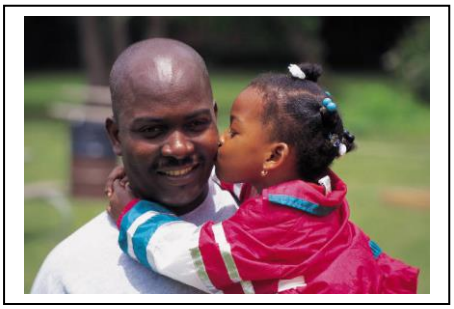
Nevada Early Intervention Services

Father's Welcome Booklet

A GUIDE FOR DADS

OF CHILDREN IN NEVADA EARLY INTERVENTION SERVICES



"I wish this much info was available in one resource booklet when my child was born!"
— A Nevada Father

One out of nine fathers has a child with a developmental or physical disability (Batten & Stowell, 1996; Knitzer & Bernard, 1997). *Being the parent of a child with special needs can bring challenges and stresses that are unique to individual families but still carry common themes that bond fathers of children with disabilities together. Fathers of children with disabilities need access to resources, including other fathers of children with disabilities from whom they can gather vital information, and with whom they can share common experiences. A father who is well informed and has a network of support available to him is able to positively impact the future of his family. Current research suggests that fathers, sometimes more so than mothers, set the tone for their family's attitude regarding how their family perceives and interacts with their child with special needs.*

Father's Welcome Booklet

Adopted with permission from "Fathers Welcome Packet" of
the Fathers Network of Family Connection SC, Inc.

-----Original Message-----
From: WC Hoecke [mailto:wchoecke@familyconnectionsc.org]
Sent: Thursday, January 05, 2006 8:59 AM
To: Daniel Dinnell
Subject: RE: Fathers Booklet

Yes, we are thrilled that the "Fathers Welcome Packet" may be of assistance to fathers in Nevada's Early Intervention programs. **We give** Nevada Early Intervention Services permission to use and adapt the Fathers Welcome Booklet for the purposes of supporting dads in Nevada. **Please use it as you see fit.**

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

Introduction

I am Eric's dad. On Thanksgiving morning, 1989, Eric was born into our family and our world changed. He was one month premature and the doctors at the hospital were not sure of anything other than "something is wrong." He was a shock to everyone, including our family Pediatrician. They kept him in the NICU (Neonatal Intensive Care Unit) for the next two weeks. At the end of the two-weeks they said, "There's nothing more we can do for you. Take him home." The doctors did not expect a long life span and said "Your son might be severely disabled and it's a high probability of severe mental retardation." We were told that we should probably see some early interventionists. Period. No connection to any programs was provided.

Cheryl, Eric, & Dan

So we brought Eric home and called Nevada's Early Intervention program. They filled a badly needed role by providing direction and support. Specialists assessed his strengths and weaknesses, and mapped his progress. They showed us how to work with him. It wasn't always easy. There were many specialists involved, and many appointments to keep. Many operations to go through. There were times when little or no progress was made, and times when new problems were discovered. We were encouraged by caring service providers and other parents who had similar experiences to keep trying, and not give up. We became involved in a parent to parent program that directed us to other resources for information and support. Though we were busy with appointments, doctors, therapists, several operations, filling out paperwork, and paying bills, we learned how important it is for parents to be an active partner in programs that affect our families or children. With every gain we saw a brighter future -- maybe not perfect, but not so imperfect as we first believed.

Almost a year after he was born we were able to get a diagnosis. Eric was born with DeBarsy Syndrome, a rare genetic disorder. There were only 15 known cases in the world and little information. Basically, he has multiple disabilities and will most likely need ongoing supports and supervision for the rest of his life — "endless love" so to speak

Our world has changed now, and as a father I often find it difficult to express my feelings. But there is one little boy in my life where I can feel my emotions constantly being pulled out. That is with my youngest son. He is doing far more than anyone expected, and has helped me do more for others than I had ever dreamed of, and I hope this booklet can do the same. — Dan Dinnell ~ Nevada IDEA Part C Family Support Resource Coordinator

Contact Email: ddinnell@dhhs.nv.gov or ProjectAssist@dhhs.nv.gov

Father's Welcome Booklet

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"I have learned that the 'system' is in place, but there are hurdles, bumps, and sometimes walls. I keep focused on my child having a level playing field. Meeting with other parents, assures me that I/we are not alone in the day to day living." — A Nevada Father

Project ASSIST

Project ASSIST is Nevada's central resource directory for anyone seeking information about organizations, programs or agencies that provide services and supports for children and young adults up to 21 years with disabilities, and their families. Information is available on:

- **parent support groups,**
- **respite care**
- **screening, diagnosis and assessment,**
- **early intervention programs for infants and toddlers,**
- **education, health, and social service agencies,**
- **vocational training,**
- **therapies,**
- **counseling or psychological services,**
- **advocacy organizations,**
- **life planning, financial or legal assistance,**
- **as well as many other services.**

During work days phone calls are answered promptly when staff is available. There is twenty-four hour voice mail as well and calls are returned generally within two to three working days. A search, tailored to the unique needs of the caller, yields information which is provided to the client. There is no cost.

Project ASSIST
1-800-522-0066 or ProjectAssist@dhhs.nv.gov

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

When they arrive in Holland, most people find it very helpful to talk with people who have lived there for a while.

We did not have a Welcome booklet when our child with special needs was born. 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, specific to Nevada, will help you navigate through this journey in developing the best outcome for your child and your family.

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. We encourage you to read this guide thoroughly, to learn this new journey, and take your child and travel as far as you can.

"A child is a special gift no matter the challenges one will face whether the child is born disabled or not. All children are challenging. Having a child such as ours, who cannot see, sit, stand or walk, I feel blessed that our daughter is alive and that she can smile. It is the little things that inspire me and our family." — A Nevada Father

A Special Perspective on Fatherhood

— WC Hoecke ~ South Carolina

"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 your child will succeed at the thing 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 aspirations? I really do not know and "having to wait and see" for me this 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 goal 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."*

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

Like any parent, when you find out your child has a disability the first thing you look for is information. 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 – but remember that it is vital not to forget the child. 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*** to live longer lives and achieve the best possible future. Talk with parents and professionals about reading materials. Meet with your ***service coordinator***, read the Nevada Early Intervention Service **Parent Handbook**, and don't be afraid to ask lots of questions. There is also a list of internet sites that may be useful towards the end of this booklet.

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.

The Effect of a Disability on the Family

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 may be discouraged from confronting and expressing their feelings.

"Being the father of a child with special needs is very challenging at times. When my wife and I found out about our son, I was very angry. Here is my namesake with special challenges. He won't be able to play basketball or have an athletic or academic career like his dad." — A Nevada Father

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 relationships. Most meetings are during the day when the husband cannot attend them because of work.

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 may be dealing with their child's situation in what they perceive as 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.

"If I could offer any advice to dads is that it's okay to be angry, however, communicate with your spouse. Don't take your anger out on her. Your child's special needs will put a strain on your marriage if you let it. Constant communication is the key!" — A Nevada Father

Parents may have difficulty communicating with each other about their child's disability. One parent may want to share his or her feelings, but the other parent may be unable or unwilling to do so. This difference may set up a communication block and one-sided discussions. Fathers, often at work during appointments or meetings, may have to rely on their partners to relay information from professionals, but the information they need may not be easily 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.

The Three-Legged Stool

As new dads, 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.

I Financial Resources

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?

II Intervention Resources

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 supporting your child's development through your family's daily activities. This can greatly improve a child's outcome later in life.

III 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? Please don't be overwhelmed. Your service coordinator will help you find resources and strategies to approach these situations.

I Financial Resources

Insurance: *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? Only with your permission may your health insurance be used by Nevada Early Intervention Services to assist with service costs, and the early intervention program is responsible for any co-pay or deductible for those services.*

Many families choose to apply for ***Medicaid/Katie Beckett*** 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. Visit www.benefits.gov to locate specific government aid programs and to assist in helping determine eligibility.

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. You have heard the term "HMO" or Health Maintenance Organization. This is the most popular form of managed care. An HMO is an organized health plan that offers care to members through a network of selected doctors, hospitals, and other providers. In this kind of plan, you choose a primary care doctor from the list of doctors available through the plan.

Your primary care doctor is the "gatekeeper" of your health care services. You can choose one doctor who will provide or arrange all of your health care. All these services are provided at a set rate that is often below the regular cost of service.

It is important to choose a primary care doctor that you feel good about. You will want a doctor who is familiar with the needs of children with disabilities and their families. Your doctor should encourage you to form a trusting and respectful relationship with him/her. Remember, your primary care physician decides which services and specialists will be available to you and your child through your Managed Care Plan.

Any new kind of service can be confusing and a little scary. With a little education and information, you will be able to feel comfortable about making the choices that are best for your child.

Supplementary Income: Supplemental Security Income benefits (SSI) is a program that pays monthly benefits to families whose children have certain disabling conditions. To qualify, the family must meet the income eligibility limits. Even if you do not meet income eligibility requirements we recommend you apply here first. This could make it easier for other application processes in other programs. If social security makes these special payments and later decides that your child's disability is not severe enough to qualify for SSI, the benefits DO NOT have to be paid back. For more information call Toll Free 1-800-772-1213 or visit their website at: http://www.ssa.gov/disability/

The disability evaluation and determination process generally takes several months. However the law allows for people (including children) whose condition is so severe that they are presumed to be disabled to receive SSI benefits for six months while the formal disability decision is being made. Some *but not all* of the disability categories in which Social Security will presume the child is disabled and make immediate SSI payments include:

- Blindness
- Deafness (in some cases)
- Cerebral Palsy (in some cases)
- Down Syndrome
- Muscular Dystrophy

The law says that a child will be considered disabled if he or she has a physical or mental condition (or combination of conditions) that results in "marked and severe functional limitations." You will also be asked to describe how your child's disability affects his or her ability to function on a day-to-day basis. Therefore, Social Security may ask you to provide the names of early intervention professionals, child care providers, and other family members who might also spend time with your child, and can share information about your child's abilities and challenges. Your early intervention records might also be helpful and your service coordinator can help you get a copy to take

with you to the interview. Be as specific and complete with your answers as possible. If you do not have all the information, tell the interviewer as much as you know.

When applying for SSI- Bring all documents (not copies) to the Social Security Office. Ask if additional information is needed. They will copy them and return the originals to you. DON'T WAIT TO APPLY- even if you do not have all documents.

These documents are often needed for SSI application:

- 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).

You can find the office nearest you by calling, toll free: 1-800-772-1213 or visit their website at www.ssa.gov. Most of this information comes from Social Security Administration Publication No. 05-10026. Ask your service coordinator to help you with this process.

Note: Most children who qualify for SSI payments will also be eligible for Medicaid, the state program for health care, however this is not automatic and families must apply for Medicaid.

Medicaid: Medicaid is a health insurance program financed and run jointly by the federal and state government that may pay for the health care services for some people with disabilities. The Nevada Department of Health and Human Services offers Medicaid coverage through a number of programs for individuals and families. Some of this coverage is at no cost to families and some requires a sliding fee, based on income. The services provided may include hospital and lab services, doctor visits, prescriptions, dental care, eye exams and glasses, Well-child care-EPSDT (a screening service including immunizations), therapies, and etc. For more information about Medicare, Medicaid and Medigap contact the Centers for Medicare and Medicaid Services at 877-267-2323 or visit the Centers' Web site http://www.cms.hhs.gov/.

Some of the ways a family can receive Medicaid benefits include:

- Medicaid may be provided for the first year of life for any newborn of a Medicaid eligible pregnant woman, regardless of income changes.

- Medicaid coverage for persons who qualify to receive cash assistance (**Temporary Aid to Needy Families — TANF**). Families may choose to receive medical benefits only.

- TANF medical coverage is available up to three (3) months prior to the TANF application if the child and family received medical services during this time. Eligibility is determined on a month-by-month basis. For more information see the Office of Family Assistance web site at http://www.acf.hhs.gov/programs/ofa/

Medical assistance when TANF ends is available as follows:

- Medicaid assistance continues for up to twelve (12) months for households which become ineligible for TANF assistance due to increased earned income of the caretaker.

- Medicaid assistance continues for up to four (4) months for households which become ineligible for TANF assistance due to child support collected through the agency.

Once determined eligible, Medicaid coverage begins from the date you first apply. It is possible to get coverage for the three months prior to your application date. Ask your Medicaid caseworker about this. For more information talk with your service coordinator.

Medicare: U.S. health insurance program for people age 65 or older, **under age 65 with certain disabilities.** For more health insurance information visit the official Medicare Web site: http://www.medicare.gov/.

Nevada √ Check Up: State Children's Health Insurance Program that provides affordable, comprehensive health care coverage to uninsured children of low-income families who are not covered by private insurance or Medicaid. The goal of *Nevada √ Check Up* is to provide preventive and comprehensive health care coverage for Nevada's uninsured children whose family income is too high for them to qualify for Medicaid. You may request an application by calling 1-800-360-6044 or ask your service coordinator to help you.

Medical Assistance for the Aged, Blind and Disabled (MAABD): A medical services only program. A person can qualify by being eligible for a public assistance program such as Supplemental Security Income (SSI). Other categories of eligible persons are:

- Disabled children who require medical facility care, but can appropriately be cared for at home (see the Katie Beckett Eligibility Option*)

- Aged or physically disabled individuals who require medical facility care, but can appropriately be cared for at home (Home and Community-Based Waivers)

*Certain individuals who have lost SSI eligibility, but would still be eligible if some of their income were disregarded (Public Law Cases)

Child Health Assurance Program (CHAP): Provides Medicaid coverage to pregnant women and children under age six, including unborns, with qualification based on income. These children are also eligible for **"Healthy Kids"** services, a program which provides preventive health care such as immunizations, yearly physicals and referrals for health problems of Medicaid eligible infants, children and young adults. "Healthy Kids" can provide referrals for developmental, dental, vision and/or hearing concerns, as well as family counseling needs. If your family is eligible for "Healthy Kids," you may also be eligible for WIC, a food supplement program for women and children. Ask your service coordinator for more information.

Waivers: A waiver (or Option) is a provision in the federal ***Medicaid*** guidelines, which allows persons who meet specific criteria, the opportunity to receive services and supports that enable them to live in the community or at home with their families.

Julie Beckett

Due to Julie Beckett's unparalleled advocacy for her daughter, Katie, the **"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.

The Katie Beckett Eligibility Option/Waiver

Under 134 of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), 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 parents' income or resources.* This law is commonly referred to as "The Katie Beckett Eligibility Option." See the Medicaid web site previously mentioned or you can get additional information found on the Family Voices web site at http://www.familyvoices.org

In the past, a parent's income or assets disqualified many children from the Medicaid program. Because of the parents assets or income, their child would "fall through the cracks" of the system. If a child is severely disabled and meets specific medical guidelines and standards, the child's income and assets are counted ***and those of the parents may be waived.*** If the child is then eligible, he or she will get Medicaid coverage which may include hospital care (inpatient and outpatient), physician care/services, most physician prescribed drugs, vision and dental care, and other services provided in the home which would normally be provided in a hospital, nursing facility, or Intermediate Care Facility for the Mentally Retarded.

What is my cost?

There is a parental financial responsibility based on the parent's income and resources for those children qualifying under the Katie Beckett Eligibility Option. The amount of money that the parents would be required to pay is determined by the Nevada Division of Welfare and Supportiive Services and is based on a sliding fee schedule.

You apply for this program at your local Medicaid office. Be sure you take medical records, verification of income for you and your child, and some verification of the severity of your child's disability to your appointment. Your service coordinator or Medicaid caseworker can assist you in locating these items if you need help. Like SSI, the Katie Beckett Eligibility Option is retroactive, so apply as soon as you can. Even if you think your child might not be eligible because of income or severity of need — apply. If your application is turned down — start the appeals process. This process can sometimes be successful in overturning a denial. Applying early is important!

How to apply:

— Apply for SSI for the child with the Social Security Administration (SSA)
— Apply for Medicaid for the child with the Division of Welfare and Supportive Services by filling out the Medical Assistance for the Aged, Blind, and Disabled (MAABD) application. Advise the caseworker that you are applying for the Katie Beckett Eligibility Option
— When completing these applications, fill out the applications as if the child is applying him/herself for SSI and Medicaid

— **Do not leave any questions unanswered**, as unanswered questions delay actions on applications. If necessary, print N/A

Note: It is a good idea to write "Katie Beckett Waiver" on the top right hand corner of the application.

Criteria for the Katie Beckett Eligibility Option of Medicaid:

— Costs for the medical coverage cannot exceed the amount that Medicaid would pay if the child were institutionalized.
— The child must be disabled based on Social Security Disability Standards, but not qualify for SSI due to the income or resources of the parent(s).
— The child must require a level of care that is provided in a hospital, nursing facility, or Intermediate Care Facility for the Mentally Retarded
— A physician must validate that it is safe and appropriate for the child to receive necessary services in the home.

If the child is denied Medicaid under the Katie Beckett Eligibility Option, other programs or services might be available for the child.

Women Infant and Children Food Supplement Program (WIC):

Application for ***WIC*** is made available at locations throughout Nevada. To be eligible you must:

- Be a pregnant or recently pregnant woman, infant or child up to age 5.
- Have a moderately low income or be receiving TANF, Medicaid or Food Stamp benefits.
- Must be certified as having a "nutritional risk" at your first WIC Clinic visit.

* Your service coordinator can help find a WIC office near you.

"Life Planning"

Every parent has hopes, dreams, and fears for their children; they want the best things out of life for them. Parents who have children with ***disabilities*** or ***special health care needs*** are no different. Even before your child was born you were probably thinking of music lessons, soccer games, sleepovers, camping trips, holiday celebrations, and even having your child going to school. Then your life changed and you wondered how your child's special needs would change your dreams.

In the first years following a diagnosis, parents begin to ask themselves many questions, such as what will happen when my child is ready for school? Will my child be independent? What about ongoing medical costs? Will my child need financial support for the rest of his/her life? If so, how can I save enough for retirement AND a lifetime of care for my son or daughter? If I die, who will take care of my child?

Parents often get caught up in the day-to-day demands of caring for a child with disabilities and in the process they also push planning for the future to the back burner. Although understandable, postponing this kind of planning can result in a probate court choosing your child's destiny should you die — even if your spouse survives.

Special consideration must be made when planning for the future of a child with special needs and the time to start thinking about it is now! The generosity of family members, friends and organizations giving gifts/monies 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 or other supports. Individuals with special needs are often eligible to receive Medicaid and SSI (Supplemental Social Security Income), however, some state programs have income eligibility restrictions. (Katie Beckett Option/Waiver looks at the needs of a child with disabilities instead of the income of the parents). According to current law, any gift/monies given to individuals with ***disabilities*** or ***special needs*** or assets in his/her name in excess of these limits could make him/her ***ineligible*** for Medicaid services. Currently, gifts/monies given to individuals with disabilities or special needs, in excess of these financial requirements must be "spent down" before one can reapply for Medicaid eligibility. In some cases a two-year waiting period is then enforced. 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.

It is never too late or too early for parents of children with special needs to think about what is possible and to look toward the future. ***Life planning*** impacts family life, community involvement, financial health, special needs trusts and estate planning, guardianship, work and learning, services and supports, government benefits, physical environment/health, and many other areas**.** ***Life planning*** is about one thing - the future life of a family member who is important to you, yet vulnerable without you.

We recommend that you use advisers knowledgeable about ***life planning***, federal and state laws, regulations, benefit programs, Medicaid and SSI, guardianship, estate planning, and other financial issues surrounding the many special considerations that apply to our children with special needs. Special needs planning professionals that have an expertise in their planning approach, should be able to help obtain additional resources and services for families, and provide them with updated information on recent law changes or innovations in the field.

If you would like more information on resources call **Project ASSIST** at **1-800-522-0066 or ProjectAssist@dhhs.nv.gov**

II Intervention Resources

What we mean by intervention is how you can intervene in the life of a child with ***special needs*** to improve their outcomes. To optimize your child's development 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. All intervention should be designed to enhance your family's lives within your daily routines. The more involved your family becomes the better the outcome for your child. Some 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.

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 programs include: Nevada Early Intervention Services, Department of Education, Social Security offices, County Health Departments, Parks and Recreation Departments, recreation centers, and the Nevada Disability Advocacy and Law Centers. 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 or non-profit organizations also provide needed services. These organizations may or may not 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 organizations concerned with ***disability*** issues include the Easter Seals Society, Family TIES of Nevada Lions Club, March of Dimes, Nevada PEP, the Shriners hospitals, and other organizations. Call **Project ASSIST** for more information at **1-800-522-0066**.

What do Community Services Provide?

Community Services can provide special education services for children or instruction for families and 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 grants or 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 service coordinator 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. **Project ASSIST** has a data base of various kinds of services providers and organizations in Nevada and you can call for more information at **1-800-522-0066**.

Important Note: Organize your files and keep your records in good order. Keep everything!

Early Intervention Services

Early Intervention Services may be implemented by service providers who form a partnership with families to work on goals to enhance the child's participation in daily activities. These activities occur within the family's routines in their home and community. Families are supported by a team approach which may consist of team members such as social workers, psychological developmental counselors, pediatricians, speech pathologists,

audiologists, developmental specialists, nutritionists, vision specialists, physical and occupational therapists, public service interns, and language interpreters.

Developmental Interventions

About Therapy and Therapists

So much has been researched and written about the brain in recent years. This research is encouraging to us as fathers 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 an interventionist 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 interventionists, 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 intervention 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 therapists also can make recommendations for equipment or ***orthotics*** (braces to help foot position), which, if needed, may help your baby's development.

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. Because ***gross motor*** skills tend to develop more slowly in our children, early intervention with ***physical therapy*** can and does help. Through appropriate exercises and activities during a routine day around the house, low muscle tone, for instance, can be strengthened. Babies and children may demonstrate improved coordination and balance which, in turn, can assist in the fundamental development of the brain.

Occupational Therapy

The ***occupational therapy*** 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 also apply to occupational and speech therapy.

Speech Therapy

Speech therapy may help in developing feeding, sucking, and language skills for your baby. The focus is 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, etc.

A speech therapist 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 may help decrease frustration and undesirable behaviors in your child, but encourage communication attempts between the child and his/her environment.

Developmental Specialist (DS)

- Professionals called ***Developmental Specialists*** (DS) 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 ***Developmental Specialist*** will come and work in the home (home visit) and help the family monitor the baby's development in all the skill areas (motor, thinking/problem solving, language, self-care).
- They will also teach parents/caregivers ***developmentally*** appropriate activities that they can do to encourage development between home visits.
- The ***Developmental Specialist*** focuses on activities that fit into the child's natural environment and the family's everyday routines and settings.
- The ***Developmental Specialist*** 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.

Nevada Early Intervention Services (NEIS)

http://dhhs.nv.gov/Programs/IDEA/PartC/

NEIS in collaboration with other community organizations is Nevada'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. The goal 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 services mandated by the federal government in ***IDEA***.

NEIS 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, the ***service coordinator***, and other professionals providing services/therapies. When you entered the program you should have received a **Parent Handbook** explaining how the program works and your family's rights. Your service coordinator can help with any questions you have.

In Nevada, ***NEIS*** falls under the responsibility of the Department of Health and Human Services' Health Division. Children who meet eligibility criteria are served regardless of family income or U.S. citizenship.

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

- Assistive technology devices/services
- Audiology (hearing) services
- Family training, counseling and home visits
- Health services
- Medical services for diagnostic or evaluation purposes
- Nutrition counseling
- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination
- Social work services
- Special instruction
- Speech and language services
- Transportation services
- Vision and orientation and mobility services

There are also private programs that provide support services in Nevada. Check with your ***service coordinator*** if you need to see what services are available in your area.

"In raising a child with special needs, it has brought out a new awareness, compassion & joy for the achievements of my daughter and I realize that it all comes, but at a different level and time. That in itself is what brings inner strength that you were never aware of due to the special needs. Recently she showed me how she could pick up dominoes with her right hand, it was wonderful that she worked at it and did it on her own. In closing, never give up on your dreams for your child and remember challenges only bring solutions." — A Nevada Father

Educational Interventions

Public school and IDEA

There is a federal law known as the Individuals with Disabilities Education [Improvement] Act of 2004, 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, Part B, Part C, and Part D. Part C is the one that is relevant for you and your child involved in early intervention. **Part C:** Infants and Toddlers with Disabilities Early Intervention Services for children under 3 years of age **(**NEIS services are Part C services)

The Individuals with Disabilities Education [Improvement] Act of 2004 (***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 the Educational rights (Part B) are similar to those you have in the ***NEIS*** Program (***IDEA*-Part C**). If you have been receiving services through the ***NEIS*** Program, a transition meeting will be held at least 90 days prior to your child's third birthday to discuss possible future service options and goals.

Medical Interventions

Parent's Record-Keeping [IMPORTANT!!!]

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 such as a notebook or file box.

Many parents find it helpful to put all the information about their child in a notebook. Your child's ***service coordinator***, or ***resource parent*** 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 (Individualized Family Service Plan) 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 a medication is no longer used, 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:

☐ Visits to the dentist regularly starting at age 1

☐ Brushing twice a day
☐ Rinse thoroughly after brushing
☐ Floss at least once a day to remove small food particles that get trapped in 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, who helps you feel comfortable about what you are doing?
- Where does your son or daughter go for routine medical care, physicals, earaches, immunizations, and blood-levels?
- After surgery, who follows your child's care back home?

A *medical home* is not a building, house, or hospital, but rather an approach to providing health care services in a high-quality and cost-effective manner. Children and their families who have a *medical home* receive the care that they need from a pediatrician or physician (pediatric health care professional) whom they trust. The pediatric health care professionals and parents act as partners in a *medical home* to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential - American Academy of Pediatrics at http://www.medicalhomeinfo.org/

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 states that "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.

Health Clinics

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 for Medicaid eligible up to age 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***.

III Family Concerns and other Resources

Family and Friends

One of the tasks of any father is to help their child make connections and build relationships with individuals in their environment. 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.

"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 ~ South Carolina

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.

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

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 may be as high as 80 percent (ARCH 2002). Children who have ***special needs*** are conservatively estimated to suffer twice the rate of abuse and neglect.

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.

"If you have family around keep them in the loop of the situation. They will be key allies because you and your spouse will need to spend quality time together and they can help watch your child." — A Nevada Father

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.

Parent-to-Parent Support Groups

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, and parent support groups can help families recognize and celebrate the potential of that gift. These groups are centered around parent-to-parent networking because families with shared experiences are uniquely qualified to help each other. They also provide valuable input in how programs operate.

"The real important thing is that with a group you learn, in more than one way, that you're not alone. You realize you're having the same problem as someone else. The same problems and issues affect everyone all over the country." — A Father

Family Support Group

For example, in ***Northern*** Nevada's NEIS program the **"Family Support Group"** is sponsored by the non-profit organization Down Syndrome Network of Northern Nevada, and educates families and the community. Meet other

parents who are going through the same issues you face every day as the mother or father of a child with a disability. The Down Syndrome Network of Northern Nevada seeks to connect families and create a strong foundation of support for you and your family. We invite you to visit our meetings. For more information ask your service coordinator or call **(775) 688-1341** and ask about support groups in your area.

Parent-to-Parent Support groups are an invaluable source of support and encouragement because they have faced similar challenges and celebrations. Groups meet regularly and often invite speakers around a variety of issues such as finances, stress, Down syndrome, ADHD, autism, and various other disabilities, chronic illnesses or ***developmental*** delays. Childcare is often provided during these support groups.

Fathers

The majority of the supports and services to families who have children with special health-care needs focus on children and mothers, sometimes 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 have reluctantly shared 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.

Often, because of work fathers are not available to attend or participate during the day 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.

Support Groups for fathers can 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. Such support groups hope 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.

"I've learned that everyone has a disability of some sort, whether it is fear of speaking in front of people, asking for that promotion, fear of what people are thinking about you, fear of doing something wrong and rejection of approval by someone you look up to. I believe that all of us have challenges in life and we all have problems, it is not how mad they make you and stressed out it can become but it is all about how you handle yourself and move through all challenges, problems and issues in our lives." — A Nevada Father

Respite

Respite is temporary relief for caregivers and families, a service in which care is provided to individuals with disabilities and other special needs. Respite can occur in out-of-home and in-home settings for any length of time, depending on the needs of the family and available resources. Check with your Service Coordinator.

Some groups offer parents time away from care giving through respite cooperatives where 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.

Sibshops

This special workshop for siblings of children who have ***special needs*** is offered by NEIS programs on an occasional basis for free. Small groups, ages 8-12, meet to connect with other children who have siblings with special health care needs. Through planned activities, children are encouraged to explore their feelings and learn how to handle situations that may arise. Check with your service coordinator for current information.

Faith Community (church) and Civic Organizations

One of the reasons many individuals attend a faith community (church) 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.

"I am very committed to my faith and asked God a number of times what my wife and I did wrong. I then realized from counsel with my Bishop that my wife and I did nothing wrong. My son will have his own testimony and he will have his own walk in life." — A Nevada Father

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. 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.

For more information about some of the available programs in Nevada call **Project ASSIST** at **1-800-522-0066**

Important Safety Issues

TRAVELING WITH CHILDREN

- Everybody needs an appropriate and approved child safety seat, booster seat, or safety belt! It's also the law!
- There must be one safety belt for each person. Buckling two people, even children, into one belt could injure both.
- People who are not buckled up can be thrown from the car or around inside the car, and seriously hurt themselves or others.
- Never hold a child on your lap! You could crush him/her in a crash, or the child may be torn from your arms.
- Never ride in the cargo area of a station wagon, van, or pickup! Anyone riding in the cargo area could be thrown out and severely injured and/or killed.
- No one seat is 'best'. The 'best' child safety seat is the one that fits your child and can be installed correctly.
- Children age 12 and under should ride properly restrained in the back seat.

A Basic To Do List

At the Birth (or when notified of possible disability)

- ❑ Apply for your Child's Social Security card.
- ❑ Apply for ***Nevada Early Intervention Services (NEIS)*** to begin early intervention services if the child is eligible.
- ❑ Complete medical evaluation with a pediatric/sub-specialists as needed
- ❑ Ask the physician if genetic testing or geneticist/genetic ***counseling*** is in order.
- ❑ Verify the newborn hearing screening has been completed and referred to a hearing specialist if there is any concern.
- ❑ Any additional tests the hospital staff or your physician may deem necessary.

When You Get Home

- ❑ Enjoy your baby! Remember he/she is your child *first*! He/she has ***Special needs*** *second*!
- ❑ Visit pediatric geneticist/genetic counselor for genetic ***counseling*** and overview if recommended.
- ❑ Work with ***your NEIS service coordinator*** to develop an Individualized Family Service Plan and start ***developmental*** interventions especially if therapy is recommended.
- ❑ Read your NEIS program's Parent Handbook.
- ❑ Meet with your *program's resource parent*. They may have additional resources about your child's diagnoses.

In The First Six Months

- ❑ If you have any visual concerns, visit pediatric ophthalmologist (children's eye doctor) by 6 months

- ❑ Visit pediatrician/family doctor at regular visits
  - Get all vaccines at typical times
  - Check for otitis media (middle ear infection) and refer to ear specialist for the consideration of myringotomy tubes (eardrum tubes) that allow for drainage and prevent infections
  - Search for medical checklists for your child's medical needs. Specific disability organizations have published checklists you can bring to your physician i.e., Downs syndrome.
- ❑ Advise your service coordinator to insure you are on the mailing list for activities and information you can use.

"Fathers love your child unconditionally and I promise you that will make all the difference in the world. My son and I have a great relationship. He understands some simple requests and he and I have fun together. FATHERS, NO MATTER WHAT, LOVE YOUR CHILD." — A Nevada Father

Should you decide to get more involved…

There are many ways that you and your family can get involved with Early Intervention Services beyond the services and support activities specifically designed for you. When you are involved, you gain experience in communication and leadership and it helps you to get useful information and answers to questions you may have. Actively participating and interacting with others, you can choose to make a difference in the lives of many young children with special needs and their families. One voice can make a dramatic difference!

"The highest reward for a person's toil is not what they get for it, but what they become by it." - John Ruskin

Below are some of the opportunities in Nevada to…

- Provide valuable input from a parent's perspective,
- Assist in the development of program policies, and
- Help shape and create a better system for all children receiving Early Intervention Services!

Parent Advisory Committees

Sometimes Parent Advisory Committees (PAC) are established by early intervention programs to share concerns and provide input to program policies and procedures that guide services for young children with disabilities and their families. They may conduct surveys, collect information for parents, create resource libraries, serve as community liaison for disability awareness and inclusion. They advise, teach, and support their program, families and communities.

If you are interested in participating on your regional committee, call **Project ASSIST** at 1-800-522-0066 for more information.

Nevada's Early Intervention INTERAGENCY COORDINATING COUNCIL or ICC

The Interagency Coordinating Council (ICC) was established by Nevada's Governor in 1987 pursuant to the requirements of Public Law 99-457, the Individuals with Disabilities Education Act (IDEA). The Council's primary mission is to advise and assist the Nevada Department of Health and Human Services in the development of and implementation of a statewide system of early intervention services for young children with developmental delays or disabilities and their families. The ICC members include parents of children with special needs. The parents on the ICC bring their real life experience to the table and those who provide the services provide expertise on how systems work and how to accomplish the tasks of the ICC. Working together as a team makes the ICC an asset in the planning and advocacy for a statewide coordinated and comprehensive system of services and supports in early intervention. More information may be requested by calling Nevada's **Project ASSIST** at 1-800-522-0066.

ICC Family Support Resource Subcommittee

Nevada's Interagency Coordinating Council (ICC) established a *"Family Support Resource Subcommittee"* made up of parents of young children with special needs and others interested in supporting Early Intervention. They support ICC activities and help ensure the ICC responds to issues important to families,

strengthen and broaden family involvement at all policy and service levels, increase ICC communication with families, provide public awareness support, and identify and support efforts to improve early intervention services and programs within communities.

There are also other opportunities for participation on various subcommittees, ad hoc committees, task forces, and work groups. More information may be requested by calling Nevada's **Project ASSIST** at 1-800-522-0066. Or email Dan Dinnell at ddinnell@dhhs.nv.gov / ProjectAssist@dhhs.nv.gov

"We are proud parents of five children. Our only son was born in 1999 with Down Syndrome. This experience has opened the door for many opportunities to learn and to help others with disabilities. My wife attended ***Partners in Policymaking****, a fantastic eight month leadership and advocacy training program. We have been Volunteer Visiting Parents, and members of a Down Syndrome Support Group.*

Now as members of the ICC we are more aware of the ins-and-outs of the governmental system including early intervention and the school system. Being involved with policies and procedures has prepared us and given us an advantage in dealing with programs and systems change. We believe the time commitment is well worth the information we get, and we receive great satisfaction representing and advocating for parents with children in Nevada's early intervention programs. We encourage everyone to take advantage of any opportunity to be involved in programs that affect them." — A Nevada Father

Useful Nevada Resources

A Central Resource Directory

Project ASSIST is Nevada's Central Resource Directory for anyone seeking information about organizations, programs or agencies that provide services and supports for children and young adults with disabilities, and their families – **1-800-522-0066 or ProjectAssist@dhhs.nv.gov**

http://dhhs.nv.gov/Programs/IDEA/PartC/

Nevada's Early Intervention Services (NEIS) mission is to identify infants and toddlers who are at-risk for, or who have developmental delays; provide services and supports to families to meet the individualized developmental needs of their child; and facilitate the child's learning and participation in family and community life through the partnerships of families, caregivers and service providers – **1-800-522-0066 or ProjectAssist@dhhs.nv.gov**

http://www.familytiesnv.org/

Family TIES of Nevada – ***T****raining,* ***I****nformation, &* ***E****motional* ***S****upport* for all families affected by disabilities and/or special health care needs in Nevada. Toll Free Phone Number is **1-866-326-8467**

http://www.ndalc.org/

Nevada Disability Advocacy & Law Center provides legal and advocacy supports for all individuals with disabilities. Toll Free in Southern Nevada is **1-888-349-3843** and in Northern Nevada is **1-800-992-5715**

http://www.nvpep.org/

Nevada PEP (**P**arents **E**ncouraging **P**arents) – A Parent Training & Information center for families who have children with disabilities and the professionals who support them. Toll Free Phone Number: **1-800-216-5188**

Useful National Resources

http://www.fathersnetwork.org/

The Fathers Network provides up-to-date information and resources for fathers of children with disabilities or special needs.

http://ectacenter.org/families.asp
The **Early Childhood Center Technical Assistance Center** is the national center for Improving Systems, Practices and Outcomes (ECTA Center) — **Welcome, families!** We have designed this page to help families understand their rights under the Individuals with Disabilities Education Act (IDEA), connect with other families, and find high-quality resources related to caring for infants, toddlers and young children with disabilities

http://www.eifamilyalliance.org
The **EARLY INTERVENTION FAMILY ALLIANCE (EIFA)** is a national parent leadership organization dedicated to improving outcomes for infants and toddlers with disabilities and their families, **open to all**. Members receive email alerts and updates on key early intervention topics and participate in active discussions and share experiences.

http://www.familyvoices.org/
Family Voices advocates for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs. Includes a wide variety of resources and information.

https//www.disability.gov
Federal government's disability-related information & resources web site.

http://www.ssa.gov/disability/
The Social Security and Supplemental Security Income disability programs are the Federal programs that provide assistance to children and adults with disabilities.

Useful Books

"Uncommon Fathers: Reflections on Raising a Child With a Disability"
Donald J. Meyer (1995), ISBN 0-933149-68-9
(A collection of numerous fathers' essays)

"Special Children, Challenged Parents"
Robert A. Naseef, Ph.D. (1997), ISBN 1-55972-377-7
(Dr. Robert A. Naseef, a psychologist and father of a son with autism, details the daily blessings and challenges of raising a child with disabilities, offering sensitive, real-world advice along the way.)

"My Son, My Gentile Son"
Robert Greenwald (2001), ISBN: 0595174264
(The special relationship that develops between this father and his son embraces so many of the themes and issues common to parents of special children.)

"The Man Who Would Be Dad"
Hogan Hilling (2002), ISBN: 1892123959
(Hogan Hilling, whose son Wesley is disabled, wrote this: "I try to view life with Wesley as an opportunity for growth.... So, instead of grieving over what will never be, I do my best to accept what is. Instead of agonizing over Wesley's disability, I make the best of whatever life we have together.")

- Many books are available from the Early Childhood Special Education Library. Ask your service coordinator for more information or call **Project ASSIST** at: **1-800-522-0066 or email at ddinnell@dhhs.nv.gov or ProjectAssist@dhhs.nv.gov**

"Just how many of us fathers, with children with special needs, are out there? I don't know, but it is nice to meet them from time to time. It's a great experience!" — A Nevada Father

Glossary of some Terms in Early Intervention

Advocate
Someone who takes action to help someone else; also, to take action on someone's behalf.

apnea monitor
A machine connected to a child that will alert others if that child stops breathing.

assessment
Collecting and bringing together of information about a child's needs, which may include social, psychological or medical evaluations used to determine assignment to special programs or services; a process using observation, testing and test analysis to determine a child's strengths and needs to plan his or her early intervention services.

Assistive Technology Device
Any device, piece of equipment, or product system, that is used to increase, maintain, or improve functional capacities of individuals with disabilities. It can help children and adults learn, compete in the work environment, achieve independence, or improve quality of life.

Assistive Technology Service
Any service that helps an individual select, acquire or learn how to use an assistive technology device.

at risk
A term used with children who have, or could have, problems with their development that may affect later learning.

audiologist
A professional trained to diagnose hearing loss and fit hearing aids.

auditory brainstem-evoked response testing
A sensory test for hearing that can be done within days after birth.

case management / service coordination
The activities carried out by a service coordinator to assist and enable a child and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under the State's early intervention program. See the Parent Handbook for more information.

cleft lip or palate/open palate
A split or opening in the upper lip or an opening in the roof of the mouth.

confidentiality
Information is private and not to be shared with others unless the family is notified and agrees in writing to allow information to be shared.

cognitive
A term that describes the process people use for remembering, reasoning, understanding and using judgment.

cranial/facial anomalies
A malformation of the cranium or face such as cleft lip/cleft palate.

Chromosomal study
A test to determine chromosomal anomalies, such as Down syndrome.

developmental
Having to do with the steps or stages in growth and development before the age of 18.

developmental disability
Any disorder that prevents normal development in a child.

developmental history
The developmental progress of a child (ages birth to 18 years) in such skills as sitting, walking or talking.

developmental specialist
Someone who specializes in early childhood development, usually having a degree in an area related to early childhood education and/or development.

developmental tests
Standardized tests that measure a child's development as it compares to the development of all other children at that age.

diagnosis and evaluation
The process of examination, testing and analysis of results, used by physicians and other care providers to decide on a cause or a category or signs and symptoms which describe a child's problem.

Disability
The result of any physical or mental condition that affects or prevents one's ability to develop, achieve, and function. Some refer to this as "special needs". An old term was handicap.

due process (procedure)
A Legal action that protects a person's rights, and applies to actions taken to protect the right to early intervention services

early intervention services or program
Programs such as Nevada Early Intervention Services (NEIS) or services designed to identify and treat a developmental problem as early as possible, usually birth to age three. Early Intervention Services may include therapies, aids and devices, speech/hearing/vision services, service coordination and family training.

EPSDT
Early & Periodic Screening Diagnostic & treatment. A screening Service.

eligible
Ability to qualify for a service or program.

evaluation
A way of collecting information about needs, strengths and interests; the evaluation is part of the process of determining whether an infant, toddler (or child) qualifies for special programs and services.

Fine motor
Involving movements of the small muscles of the body, such as the hands, feet, fingers, and toes.

FERPA
Family Educational Rights and Privacy Act (Buckley Amendment): The law that covers rights to confidentiality.

Geneticist/Genetic Counselor
Special health care professional who counsels individuals and families about genetic conditions and birth defects.

Gross motor
Involving movements of the large muscles of the body.

IDEA
The Individuals with Disabilities Education Improvement Act or IDEA. The Individuals with Disabilities Education Improvement Act was signed into law in 2004. This Act strengthens academic expectations and accountability for the nation's children with disabilities and bridges the gap that has too often existed between what children with disabilities learn and what is required in regular curriculum. (More information can be found at: http://idea.ed.gov).

Hypotonia
Low muscle tone. Low tone usually affects all muscles of the body. Your child's muscles appear "floppy" when relaxed.

IFSP or Individualized Family Service Plan
A written statement for an infant or toddler (ages birth through 2 years old) developed jointly by a team of appropriately qualified professionals, and the parents/guardians. It is a plan for providing early intervention services. The IFSP must contain the child's level of development, strengths and needs, major goals or outcomes, expected services needed, date of the next evaluation and the starting date for the present IFSP. See your **Parent Handbook**.

Intellectually Delayed or Intellectual Disability
What used to be called "mental retardation".

Karyotype
Chromosomal study to determine Down syndrome and other genetic disabilities.

LBW
Low Birth Weight: Infants born weighing less than 2500 grams (under two pounds).

Lead Agency
The agency (office) within a state or territory in charge of overseeing and coordinating early childhood programs and services.

Medicaid
A federal program that offers medical assistance (medical insurance) to people who are entitled to receive supplementary security income or who qualify for TEFRA and other state programs.

neonatologist
A medical doctor who specializes in newborn children.

NICU
Neonatal Intensive Care Unit

occupational therapy
A therapy or treatment provided by a person trained to help an individual to develop mental or physical skills that will aid in daily living; it focuses on the use of hands and fingers, coordination of movement and self-help skills such as dressing, eating with a fork and spoon, etc.

Oral motor
Relating to the use of the muscles, in and around the mouth and face. Oral motor skills are important for learning to eat and talk properly.

orthotics
The specialty field of making leg braces and other orthopedic equipment.

Pediatric cardiologist
Children's heart doctor

physical therapy (PT)
Treatment of physical disabilities given by a trained physical therapist that includes the use of massage, exercise, etc. to help the person improve the use of bones, muscles, joints and nerves.

PKU (Phenylketonuric)
Deficiency in the child's ability to break down the protein in food. Special diet often is needed.

private therapist
Any professional (therapist, tutor, psychologist, etc.) not connected with a public agency.

psycho-social (development)
The psychological development of a person in relation to his or her social environment.

psychologist
A specialist in the field of psychology, usually having a Master's degree or Doctoral Degree in psychology.

public agency
An agency, office, or organization supported by public funds and serving the community at large.

respiratory therapist
A licensed therapist who treats breathing problems as prescribed by a physician.

respite care
Short-term care provided by a trained care giver to give the family a break from the extra demands for care that must be given to children with *handicapping* conditions.

Sensory
Information available to use through our senses of sight, hearing, smell, taste, touch, muscle movement, and balance. Sensory activities use senses such as touch and movement to give sensory information.

Sensory integration
The mind's ability to integrate the information of the senses (i.e., sight, hearing, smell, taste, touch, muscle movement, and balance).

services/service delivery
The services (therapies, instruction, treatment) given to a child with special needs.

SIDS
Sudden Infant Death Syndrome

special needs (as in "child with special needs")
A term to describe a child who has a *handicap*, *disability*, or chronic illness and is *at risk* for developing *disabilities* that require special services or treatment in order to progress.

speech/language therapy
A planned program to improve and correct speech and/or language or communication problems in people who are not thought to be able to improve without such help.

NOTES

Nevada Department of Health and Human Services

IDEA Part C Office

Nevada Early Intervention Services

http://dhhs.nv.gov/Programs/IDEA/PartC/

Administrative Office

IDEA Part C Office
4126 Technology Way, Suite 100
Carson City, NV 89706
Phone: (775) 687-0587
FAX: (775) 687-0599
Project ASSIST: 1-800-522-0066
ProjectAssist@dhhs.nv.gov

1-800-522-0066 or ProjectAssist@dhhs.nv.gov

For more information about
organizations, programs or agencies that provide services and supports for children and young adults up to 21 years with disabilities,
and their families.

Brian Sandoval
Governor

Richard Whitley
Interim Director, DHHS

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