"We all have dreams. But in order to make dreams come into reality, it takes an awful lot of determination, dedication, self-discipline, and effort."

Jesse Owens, Olympic Champion

A Workshop for Families Led by Families

Person Centered Thinking is permeating many systems in South Dakota that support individuals with disabilities. Families Planning Together is the latest addition of training from the Division of Developmental Disabilities for families to gain skills and make a difference in life outcomes for their sons or daughters. A vision for South Dakota is that families understand their role and their power and that they have options in designing their own support system(s).

Families Planning Together sessions are facilitated by a family member. The facilitators are trained in person centered practices to offer one-day workshops for other families. The workshop provides families with tools to create one-page descriptions of their son or daughter with a disability. Some take-aways for families from participation in a workshop are:

- Learn tools that will help them communicate effectively and save time as they develop positive partnerships with those who support their son or daughter.
- Help others see beyond the disability!
- Possibilities for planning the life we want for our children.

Watch for workshops in early 2012!

For more information, contact Brenda Smith: mbsmit@msn.com or 605-770-6098, Katherine Munson: Katherine.munson@state.sd.us, or Elaine Roberts: eroberts@sdparent.org or 800-640-4553.
Navigating the Road to

Nearly a quarter of US households have at least one child with a special health care need, which translates into a need for more services and supports than most families.

This article is intended to give you a map for accessing services your family may need to support your child(ren) with special health care needs or disabilities.

First, every parent with a child with special needs should be aware of the Individuals with Disabilities Education Improvement Act (IDEA) entitling children with disabilities to equal access to a free public education. IDEA provides that children with disabilities receive Free and Appropriate Public Education (FAPE) in the Least Restrictive Environment (LRE). IDEA addresses early intervention services for children birth to age 3, as well as children/youth ages 3-21 being served in early childhood, K-12 or post high school programs. For those students who do not qualify for IDEA protections, civil right protections to FAPE may be accessed through Section 504 of the Rehabilitation Act of 1973. In South Dakota, early intervention services are provided by Birth to 3 Connections (http://doe.sd.gov/oess/Birthto3.asp). Information on early childhood and special education services and Section 504 in South Dakota are available from the Office of Special Education (http://doe.sd.gov/oess/sped.asp) or from SD Parent Connection.

However, there are services beyond the educational experience that families need as their children grow.

It is important to explore what services or supports your child and family may need and investigate what's available. Seek out and apply for all available resources. In other words, don’t wait until you “need it.” The process for obtaining services may be complex and available programs may not be integrated, so families need to be persistent and innovative. Ask for referrals.

A great resource to begin your search for services is the SDPC website, www.sdparent.org, with links to many national, state and regional supports and services. There are links to resources throughout the website, but the best place to start may be Helpful Links where you will find links to information on specific disabilities or disorders and advocacy and support groups. Also be sure to check out the Resource Library page under the How We Help tab and the Parenting page under the Family Life tab. SDPC staff are also available at 1-800-640-4553 to answer specific questions.

Assistance from State Agencies

Families of children with disabilities or special health care needs should investigate the programs available through the South Dakota Departments of Human Services (http://dhs.sd.gov/), Social Services (http://dss.sd.gov/) and Department of Health (http://doh.sd.gov/). SD Connect is an on-line directory for frequently requested services from these departments, (http://www.sdconnect.sd.gov/).

Examples of the services available through these state agencies are Children’s Health Insurance Program (CHIP) (http://dss.sd.gov/medicaleligibility/index.asp); and Medicaid programs (http://dss.sd.gov/medicaleligibility/index.asp) which provide economic assistance to low-income families; Health KiCC (www.sd.children.gov) which provides financial assistance for children with
Here are some tips from parents who have experience accessing services for children with special needs:

- **Be an Active Participant.** You must be an informed and engaged parent. Come to meetings with documents and a plan.

- **Ask Questions.** If you don’t understand something or need clarification, don’t be afraid to ASK.

- **Ask for Help.** You may want to ask a third party to be present when attending meetings.

- **Document.** In meetings, assign a note taker to document responsibilities for tasks, including deadlines and who will do what. Keep notes and documentation of all types of consultations and meetings. See article on documentation in this issue.

- **Keep it Personal.** Keep the focus on your child. No one knows your child better than you and no one has more at stake than you and your family.

- **Treat Others with Respect.** Be persistent, but courteous. Be firm, but respectful. Remember to never burn bridges.

- **You Are Not Alone.** SD Parent Connection exists to connect families of children and youth with disabilities or special health needs to resources, information and training in an environment of support, respect and hope. SDPC and others are here for you. Call us at 1-800-640-4553.

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**Social Security Benefits**

Families may also want to explore what Social Security benefits may be available. Disability benefit programs include:

- **Supplemental Security Income** (SSI) for people with little or no income and resources. Children applying for SSI may not meet the financial and resource limitation allowance due to required reporting of all household income. When the applicant becomes an adult at age 18, only the income and resources of the applicant are considered, regardless of where they live or with whom.

- **Social Security Disability Insurance** (SSDI) for insured workers. To qualify for benefits, you must first have worked in jobs covered by Social Security. Then you must have a medical condition that meets Social Security’s definition of disability. In general, monthly cash benefits are paid to people who are unable to work for a year or more because of a disability. Benefits usually continue until you are able to work again on a regular basis. There are also a number of special rules, called “work incentives,” that provide continued benefits and health care coverage to help you make the transition back to work.

- **Social Security Childhood Disability Benefits** (CDB) formerly called Disabled Adult Child (SSDAC). An adult with a disability diagnosed before age 22 may be eligible for benefits if a parent is deceased or receiving retirement or disability benefits. Social Security Administration considers this a “child’s” benefit because it is paid on a parent’s Social Security earnings record. SSA makes the disability decision using the disability rules for adults. The “adult child”—including an adopted child, or, in some cases, a stepchild, grandchild, or step grandchild—must be unmarried, age 18 or older, and have a disability diagnosed before age 22.

The Social Security Administration website, www.ssa.gov has a wealth of information. To contact the nearest Social Security Office in your area, look in the Federal Government pages of your local phone directory under Social Security Administration or call 1-800-772-1213. Mike Walling, a national recognized trainer in SSI benefits, has valuable information at an independent website: http://www.benefits-training.com/.

In addition, there are many private entities that provide support and assistance. These include organizations such as Shriner’s, Children’s Miracle Network, Make a Wish and state and national disease or disability specific organizations.

Before applying for a program, understand the operating rules and have an understanding of terminology. If you don’t understand, ask questions until you do. Everything, including notes from conversations, should always be documented in writing.

Remember you always have free help available for navigating systems from SDPC. If you want more information on any of the resources listed here or other specific services needed, be sure to contact SDPC at 1-800-640-4553, e-mail us at sdpc@sdparent.org or visit www.sdparent.org.
Families of sons or daughters with special needs must navigate a variety of systems — education, health care, disability related, service providers, and more. Each system has its own set of rules, guidelines, and eligibility requirements. Also, each system has human beings who interpret the rules, guidelines and eligibility requirements. Often families are told “No, that is not possible,” when in fact, it may be possible if the correct questions are asked or forms are completed. The “no” may be phrased in many ways to delay or deny processes. Some families take “no” as the final answer and don’t ask questions. Other families get angry and burn their bridges with providers by their words and actions. Partnerships with the various systems require that families know and understand their child’s and their rights, be advocates for their children, and be willing to respond to the “no” in factual and positive ways.

At SDPC we believe if “no” is the first response, that is the beginning of dialogue and problem solving. SDPC and SD Advocacy Services are working on a set of possible responses to the various “No” statements that families have heard that often serve to postpone or avoid addressing issues.

The following are just a few examples of statements that families have heard and possible responses to begin the dialogue:

**Evaluation**

**Statement:** Another label would not change how we teach your student.

- On the other hand, another label might change things. If, through evaluation, the school team can recognize that this child has _____ (fill in the blank: sensory processing disorder, specific learning disabilities, autism, hearing loss, vision impairment, auditory processing disorder, Tourette Syndrome, ADD, FASD, ODD, RAD, etc.), then there might be other strategies or technologies that could work better.

**Statement:** Your student’s IQ is too high/too low to qualify for special education.

- My child's IQ may be high/low, however, IQ alone does not determine if he/she requires special education or related services. Let's do additional testing.
- I suspect my child may have a disability even though he is advancing from grade to grade. This school has a responsibility to locate a child with a disability regardless of the severity of the disability. (34 CFR section 300.111 Child find.)

**Statement:** Your student has to fail our programs before we would consider another option. We need to try all of our programs before we can consider other options.

- I suspect my child may have a disability even though he is advancing from grade to grade.
- Does this policy apply to all children with suspected disabilities? So if a child was involved in some sort of accident over a weekend and became unable to see or hear, would you require the child to try various programs and fail before evaluating the child and providing special education services? If not, then why would you treat a child with a different suspected disability any differently?

**Statement:** Your child’s delays are not significant enough to qualify for special services.

- You have admitted that there are areas of delay. Based on the diagnosis, through an IEP or a 504 Plan, let’s provide supports, including assistive technology, so that my child cannot just survive, but can thrive and succeed, graduate and become a productive citizen.

**Extended School Year – ESY**

**Statement:** Your child qualifies for Extended School Year (ESY) services and we will provide _____, or ESY will be held _____.

- I recall that last year my child received (for example) 20 hours of ESY. This year has been more difficult for him and I feel that he needs more hours.
How did the school determine the amount of hours my child needs? I am of the understanding that we are to discuss this as an IEP team to determine the individual needs of my child.

Statement: Your student does not qualify for ESY.
- How have you arrived at your decision? Do you have documentation?
- ESY services can be based on documented regression and slow recoupment, a likelihood of significant regression and slow recoupment, to capitalize on emerging skills, or to address critical life skills.

Statement: Your student is too old for ESY.
- Show me the regulation that says that.
- There are no age or grade requirements related to ESY. Eligibility is based on the child’s needs.
- Let’s look at the child’s relative progress on various goals and determine which are priorities for this summer.

Individualized Education Plan – IEP

Statement: We don’t have the funds/staff to provide that service.
- My child is entitled to a free public education that is delivered in a way that is he/she can access. My job as a parent is to ensure an appropriate/accessible education is provided to him/her and your job is to figure out the funding and staffing. I understand that budgets are tight and appreciate you have difficult decisions to make.
- All services are based upon a student’s special education and related service needs. Cost is not a valid reason to deny him/her a free appropriate public education (FAPE).

Statement: We don’t need to address that issue.
- This issue directly relates to my child’s education. It is important to discuss, as an IEP Team, to determine if my child needs _____ to benefit from his education. If you are refusing to discuss this issue I will need you to put in writing the reasons why.
- We are members of the team and we consider it an issue. The topic is on the table. Let’s address it, record it and figure out a way to measure it.

Statement: We don’t need to write that into the IEP.
- There may be a substitute in the classroom, and it would be helpful to him/her.
- Maybe you don’t need to, but I am a team member, and I want it written down so that it is not forgotten. If it does not fit under any of your headings, then we can create an old-fashioned section called “Clarifying Comments.”

Statement: We’ll take care of it.
- Thank you. Let’s write it down so I don’t forget.
- Thank you. Please write down the projected date of completion, and let’s plan to review progress on this date ________.

Statements: We don’t need a __________ (staff member with specific training or credentials, such as a nurse, interpreter, behavior specialist, etc.). Our staff are trained to meet your child’s need.
- Please tell me what trainings the staff have participated in which relate to my child’s disability. How extensive was the training (two hours, university course) or what was the extent of the training?
- Is your staff highly qualified in that area?

Parent Tip: Check Teacher 411 on the SD Department of Education website at https://apps.sd.gov/applications/de04public/TeacherLookup/TeacherSearch.aspx to determine if your child’s teacher(s) is(are) highly qualified. They may have a special education certificate but may not have training in the specific content area in which they are teaching your child.

(Continued on page 6)
Delays and Denials: Dare to Dialogue  
(Continued from page 5)

- **Statements:** Your student has to fail our programs before we would consider another option. We need to try all of our programs before we can consider other options.
- Please show me your policy on that or provide me a copy.
- That may be your pattern, but that is not a federal regulation.
- Do you know what it feels like to fail something? Let’s work together to help this child succeed and reach the goals we have agreed on.

**Statements:** Our school can only offer these options for your student and nothing more. Our school has these options and is not required to do anything else.

- Fortunately, IDEA is not a “one size fits all” program. Every decision must be based on a child’s unique needs so let’s figure out what my child needs and what services will be provided by the school district.

**Statement:** If we provide this to your student, we will have to provide it to every student.

- All IEP services are based on this student’s unique needs. Not all students need this and it isn’t required for them.
- This is an INDIVIDUAL education program. Other students will have different needs and may not need this.
- That’s like saying if a doctor prescribes _____ for one patient, she has to prescribe it for all patients.
- Providing for this individualized program does NOT commit the school to providing the service to other students.

**Statement:** We don’t have/need to address transition until age 16.

- Transition must be addressed and initially written into the IEP by the 16th birthday, so that means during the year that the child is 15 years old.
- The regulations allow transition to be addressed earlier, as a team decision, and we parents are members of the team. We suggest the following wording _____.

**Statement:** Your student tested “proficient” on the Dakota Step. If you made him do his homework, he wouldn’t be failing.

- This student can pick up the knowledge and can spit back the information to pass a test, yet he does not do daily work in the traditional manner. Is that the only way to grade this child, or can we make some accommodations?
- What strategies have you been using at school that might help us at home?
- An expected part of (ADHD, Executive Function Disorder, etc.) is an inability to organize and prioritize. He has documented deficits in that area. That’s why we have an IEP or 504 Plan. Let’s update the list of accommodations.

**Statement:** You need to have realistic expectations for your child.

- We think it is realistic for our child to teach her peers something about persistence, patience, courage, faith and love, and that’s why we want him/her attending the local school with his/her same-age peers, neighbors and friends.
- You have touched on our biggest heartache. We have realistic expectations, and we also hold onto hopes and dreams. Let’s find some common ground for proceeding.
- We think it is realistic for our child to learn this subject area. We just haven’t yet found the right strategy yet. If my child never has the opportunity to try, he/she will never have the opportunity to succeed.

Please contact SDPC for further information, training and support as you work with professionals to meet your child’s unique needs at sdpc@sdparent.org or call 800-640-4553.

**Family Network Leaders Provide Outreach for SDPC**

Part of the strength of SD Parent Connection is parents advocating with other parents. SDPC was founded by parents for parents. That philosophy is strengthened by Family Network Leaders, who are outreach people for SDPC.

South Dakota has a large geographic territory and it is difficult for the small SDPC staff to personally visit all areas of the state on a regular basis. Family Network Leaders help to fill the gap by working with parents in outlying areas.

SDPC currently has two Family Network Leaders. Rita Jacobs works from the Pierre area and Carolee Little works from the Watertown area. Both are parents and have experience in special education. If you are interested in being a Family Network Leader contact sdpc@sdparent.org.
“When talking with parents in preparation for a meeting at their child’s school it is common for me to ask questions such as ‘what are the exact words on the IEP document?’ and ‘what does it say in the recommendations at the end of the evaluation report?’” notes Nate Anderson, coordinator of the SDPC Navigator Program.

“I’m sure I have that paper in a pile around here somewhere,” may be the response. This brings to light the need to organize documentation, and have a system for retaining records.

First, it is important to keep a communications log. In a notebook or on a calendar, keep track of your communications with schools, medical personnel and other service providers.

Examples of communications to document:
• A record of meetings.
• Dates you requested, sent or received important documents.
• Dates you gave the school important information.
• Dates of suspension or disciplinary action.
• Notes on telephone conversations or e-mails (includes dates, person you talked to and short description of the conversation.) This applies to behavior, disciplinary actions or progress as well as other issues.

Having records in one place will reduce stress and can pay dividends in accessing services and supports for your child. SDPC has a free **Folder of Information and Life Experience** (FILE). The FILE has folders and tabs to help parents stay organized, and includes suggestions on how to manage the volume of information regarding your child (see related story at right).

Here are types of records parents should be sure to keep.
• IEPs and other official service plans (504, etc.)
• Medical records related to disabilities or conditions.
• Evaluation reports and results (medical and educational).
• School records (report cards, progress reports, attendance records, student handbooks and policies).
• Social Security documentation and letters.
• Copies of applications for services or funds; record when and where sent.
• Work and employment history.
• Resumes and letters of recommendations.
• Lists of school and community activities and/or student awards.

Another key to staying on top of the flood of paper is to break large filing tasks into small ones. As you think of new subcategories, make new folders. For example, a sorting pile for Therapies might then be split into three: Occupational Therapy, Physical Therapy, and Speech Therapy. As you run across papers that have no more use, shred those that have confidential information.

“There is a good old saying that relates to preparedness: ‘a place for everything, and everything in its place.’ Then, it is a matter of following the newer Nike philosophy of ‘Just Do It,’” concludes Nate.

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**Organized Records Will Pay Dividends**

**Please Help Provide a FILE to a Family!**

The **FILE** (Folder of Life Experiences) is provided FREE to South Dakota families of children with disabilities or special health care needs to help them organize and track information and life experiences.

The plastic folder and supporting filing system helps families organize and retain needed papers related to family records, developmental history, medical therapies, Individual Education Programs (IEP), respite and child care, transition and legal and life planning.

Through a contribution from the Rapid City Regional Hospital, SDPC is now providing Medication Cards in many of the FILE systems. **SDPC is able to provide the FILE because of gifts from individuals like you.** Each file costs approximately $35. A contribution of less than $50 will make it possible to provide a FILE to a South Dakota family.

In addition, your tax-deductible contribution of any size before the end of year will make you a charter member of the SDPC Trailblazers. Please use the envelope provided in this issue of the **Circuit** to support SDPC with your donation or go to [www.sdparent.org](http://www.sdparent.org).
Meet the Ryder Family

“Many people going through the disability maze will tell you that they go from knowing practically nothing to feeling overwhelmed with the avalanche of information, advice, predictions and choices they have to make for their child,” notes Ryan Ryder who says their family was no exception.

The Ryder family of Black Hawk includes Ryan and Jennifer and their three sons, Liam, Gavin and Corey. Their oldest son, Liam, likes many of the same things as other eight-year-olds, and has a high-functioning autism spectrum disorder. “Liam is great. He has taught us so much,” says his Dad.

Ryan and Jennifer’s first interaction with SDPC was upon referral from the South Dakota Birth-to-Three Program shortly after Liam’s diagnosis at 30 months. The family received the FILE (Folder of Life Information Experiences). The Ryders still use the original folder more than five years later.

“Liam has made GREAT strides from where he was six years ago when we began to tackle this world of “disability,” said Ryan. “I know it’s cliche, but it truly has been a journey from wondering what is wrong, how to fix it, to having the confidence and acceptance of making the changes that we can make, and moving from the “disability” to discovering his “abilities.”

Ryan is a member of the SDPC Board of Directors, a graduate of Partners in Policymaking and active in the Autism Society of the Black Hills. “My wife and I believe that parents are the first and foremost advocates for their child,” says Ryan “There is only so much that others, like teachers and counselors, can do to help a child reach his or her potential. Parents need to ask questions, pursue answers, and use resources that are out there, and made accessible through SDPC.”

“Originally, we looked to SDPC and other groups and organizations for assistance and answers. My experiences have made me more confident in giving advice to others. This includes not only where to reach out for help, but also when and how to advocate for oneself and one’s children or family members,” said Ryan.