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**Circuit** is a quarterly  
publication of South  
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**Circuit** is intended to be  
a reference publication  
packed with information  
and is provided  
electronically and in  
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South Dakota Parent  
Connection also produces  
an electronic semi-monthly  
newsletter (weConnect)  
with current events and  
time-sensitive information.

# Circuit

Offering information and assistance to parents and families  
caring for children with a disability or special need.



## What Parents Should Know... About Behavioral Health Supports

## What Families Can Do When a Child May Have a Behavioral Health Condition

*By National Alliance on Mental Illness (NAMI)*

If you are worried about your child's mental health, follow your instincts. Unexplained changes in your child's behavior and/or mood may be the early warning signs of a mental health condition and should never be ignored. There are many different types of mental illness, including anxiety, depression, bipolar disorder, eating disorders, ADHD and autism spectrum disorder, and it isn't easy to simplify the range of challenges children face. One way to begin if you are concerned is to get an evaluation for your child or teen by a licensed mental health professional. Because all children and youth are unique and local mental health services, insurance coverage and school services vary from community to community, it is a challenge to find the right kind of help for your child.

As a parent, there are things that you should be concerned with if you see them, such as:

- A sudden or persistent drop in school performance.
- Persistently aggressive behavior.
- Threats to self or others.
- Substantial mood swings.
- Hallucinations, paranoia or delusions.
- Acting very withdrawn, sad or overly anxious.
- Extreme difficulty interacting with friends and/or siblings.
- Extreme changes in sleeping and eating patterns.
- Increased or persistent use of alcohol or drugs.

*(Continued on page 2)*

# What Families Can Do When a Child May Have a Behavioral Health Condition

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## Several factors contribute to the challenge in getting an accurate diagnosis, including:

- Symptoms, which include difficult behaviors and dramatic changes in behavior and emotions, may change and continue to develop over time. A clinical interview should gather a full history, a “movie,” as well as a “snapshot” in the interview process.
- Diagnoses may co-occur. A teen with an anxiety disorder may be using alcohol extensively. A teen with major depression may also have problematic eating behaviors.
- Children and adolescents undergo rapid developmental changes in their brains and bodies and face multiple social role changes at the same time.
- Younger children may be unable to effectively describe their feelings or thoughts, making it harder to understand their experience. They may “show” distress more than “tell” about their distress. They may be seen frequently in school nurse offices with headaches or stomachaches but may have an undiagnosed psychiatric disorder.
- It is often difficult to access a qualified mental health professional to do a comprehensive evaluation because of the shortage of children’s mental health providers and because some health care providers are reluctant to recognize mental illnesses in children and adolescents.

**21% of youth aged 13-18 live with a behavioral health condition severe enough to cause significant impairment in their day-to-day lives.**

**50% of lifetime cases of behavioral health conditions begin by age 14 and 75% by age 24.**

**Approximately 50% of students over 14 with behavioral health issues drop out of high school, the highest of any disability group.**

**70% of youth in state and local juvenile justice systems have behavioral health conditions with at least 20% experiencing severe symptoms.**

**Only 50% of youth with behavioral health issues receive treatment.**

Despite these challenges, there is plenty families can do to help their child get an accurate diagnosis and receive the most effective treatment, supports and services.

## What Should Parents Do If They Suspect a Behavioral Health Condition?

**Talk with your pediatrician.** Early identification and intervention are important. If you are concerned about your child, start by talking with your pediatrician, share your concerns and ask for a comprehensive check-up. A comprehensive physical examination should be done to rule out other physical health conditions that may be causing a child’s symptoms, such as an endocrine problem, recurrent head injuries in sports or other conditions. If the pediatrician believes your child is exhibiting early signs of a mental health condition, the pediatrician may talk with you about treatment options, may recommend a referral to a mental health professional or may offer to provide some of the services herself.

**Get a referral to a mental health specialist.** If you are referred to a mental health professional, ask your pediatrician to help by calling for you to help get an appointment scheduled for your child. Many mental health professionals have long waiting lists and may not be taking new patients, so a call from your pediatrician can help get an immediate appointment for your child. To find a child psychiatrist,

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[www.sdparent.org](http://www.sdparent.org)

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visit the American Academy of Child and Adolescent Psychiatry website ([www.aacap.org](http://www.aacap.org)) and click on “Child and Adolescent Psychiatrist Finder.”

**Work with the school.** Meet with your child’s teacher or other school officials to request an evaluation for your child for special education services. Work with the school to identify effective interventions that promote positive behaviors, social skill development, academic achievement and prevent challenging behaviors in school. Ask your child’s treating mental health provider to identify interventions that can be used at school and at home to help you and your child cope with challenging behaviors and related issues.

**Connect with other families.** Never underestimate the importance of connecting with and working with other families. There are many seasoned families who have walked the walk and are happy to share their wisdom and experience with you. Contact NAMI at [www.nami.org](http://www.nami.org) to learn how you can connect with other families in your community.

### Getting an Accurate Diagnosis

For some children, having a diagnosis is scary and they may be resistant to accept it. Others are relieved to know that what is happening to them is caused by an illness, that they are not alone, and that there are treatment options that can make them feel and do better. **It is important to find ways to use the strengths and interests of your child to help him or her cope with difficult symptoms.** Benefits are often derived from aerobic exercise, martial arts, music, and art – whatever it takes to provide your child with a therapeutic outlet. The diagnosis is one piece of a much larger puzzle. NAMI offers ten steps for families to getting an accurate diagnosis. These include record keeping; comprehensive physical examination; recording co-occurring conditions; seek specialists in children’s mental health; evaluation based on all aspects of the child’s life; adjust the diagnosis as new symptoms arise or change; make effective interventions and outcomes as needed; work with the school; find service and support options; and never under estimate the importance of working with other families. For more information on these ten steps visit NAMI’s Child & Adolescent Action Center at [www.nami.org/caac](http://www.nami.org/caac).

## NAMI South Dakota Offers Classes, Support

South Dakota’s chapter of NAMI (National Alliance on Mental Health) plans to offer several classes for families and caregivers and/or those living with mental illness this fall.

**Basics** is a new six-week class for parents and caregivers of children and adolescents living with mental illness. Basics provides education on mental illness, treatments, supports, resources, communication and self-care. Locations are being determined. **KidsCope** is a new Saturday workshop for children and teens who have a parent or sibling living with mental illness. Workshops will be piloted in Sioux Falls in Fall 2014.

**Family to Family** is a 12-week class for family members of adults living with mental illness, designed to provide information on mental illness, treatments, supports, resources, communication and self-care. Offered in several of NAMI’s affiliate chapters in the state once or twice a year. **Hope for Recovery** is a Saturday workshop for family members of adults living with mental illness. Contact NAMI to learn more about these classes at 605-271-1871.

Many communities in South Dakota also have NAMI support groups for families and/or those with behavior health issues. Support groups meet in Brookings, Huron, Pierre, Rapid City, Sioux Falls, Watertown and Yankton. For meeting times and locations visit [www.namisouthdakota.org](http://www.namisouthdakota.org). Individuals with other disabilities, such as children with autism spectrum disorders, may also have behavioral health issues. Visit [www.sdparent.org](http://www.sdparent.org) (Helpful Links, Parent Support Groups) for support groups specific to disabilities or special health needs.

# HIPAA and Behavioral Health Records

By Ellen Stevens, SDPC Outreach Coordinator

Parents may have questions about their child's mental health treatment records. Is information about my child and personal family matters released to anyone? Can I have access to records and get an explanation of them? Will information about my child's mental health care harm his or her future opportunities?

HIPAA (Health Insurance Portability and Accountability Act) protects patients' rights related to medical information, and addresses the right to get copies of records, and challenge inaccurate information. Disclosure of mental health information, like all health care information, must comply with both HIPAA and all other federal, state, and local laws that apply. However, there are additional rules that apply to behavioral health records, including stricter access guidelines. **There also are special protections when the patient is a minor** (discussed later in this article).

"Mental health information" means verbal, written, or recorded information. Included is the identity of the patient and references to the diagnosis and treatment course of the individual's mental or emotional condition. In general, a mental health provider may disclose information to the patient or the patient's authorized representative, such as an attorney. The patient or representative may also sign a written release of information allowing disclosure to a third party, such as a pediatrician or school. However, there are certain legal and policy dilemmas concerning mental health records that require specific exceptions (U.S. Department of Health & Human Services, 2014).

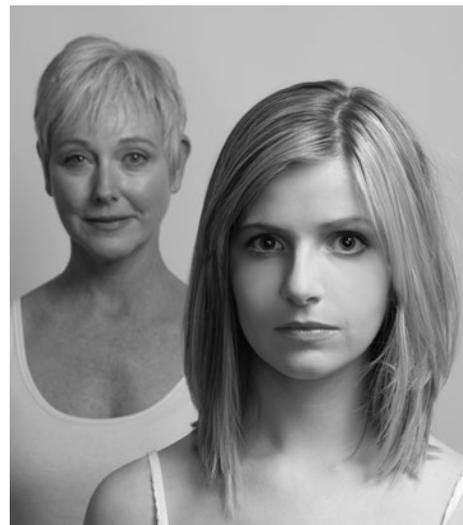
## HIPAA Exceptions

Patients cannot have access to psychotherapy notes, which are personal notes a counselor takes during sessions or conversations with a client. Psychotherapy notes are stored separately from treatment summaries and billing records. Sometimes, these notes are used to hospitalize a person for mental illness, to provide a court-ordered examination, or for the provider to defend himself or herself in a legal or administrative action. In some cases, a provider will allow the notes to be released, if there is a specific authorization (Rose, 2013).

The statutory right for a patient, or a designated representative, to review records is limited when access may cause harm. If the health care provider decides that access is reasonably likely to jeopardize the life or physical safety of the patient or another person, the provider may refuse access. The provider uses clinical judgment in assessing the situation, and may deny review by the patient but permit access to a representative, such as an attorney (Vandenack, 2008).

Patients also do not receive access to psychological test material. This material is not subject to release to a parent, or even disclosed when there is a subpoena or search warrant. Such information may be released to a psychologist upon written authorization from the patient or the patient's authorized representative (Vandenack, 2008). Other exceptions cover when disclosure may occur, even when a patient objects.

There are recent guidelines from the U.S. Department of Health and Human Services stating when professionals may share information with a patient's family. (*iHealthbeat*, 2014). There are situations when the patient is not present or does not have the capacity to make decisions. A health care provider may share the patient's information with family, friends or others involved in the patient's care or payment for



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care. The professional decisionmaking standard is the best interests of the patient (*Grusz, 2014*).

What happens when a patient is a danger to self or others? A health care provider may warn family members or law enforcement if the threat is “serious and imminent.” The provider uses professional expertise to determine if disclosing information is likely to prevent or reduce the risk of harm (*U.S. Department of Health & Human Services, 2014*). Court orders are another special exception. Health care providers must disclose PHI (Personal Health Information) to comply with a court order. These disclosures must be limited to the PHI specifically authorized by the order (*Vandenack, 2008*). Court-ordered does not mean an attorney-issued subpoena (*Beal, 2010*). The information released also is limited to matters relevant to the specific legal proceeding. The guidelines described above are supplemented by rules related to minors.

## HIPAA and Minors

In general, health care records are released not to the minor but to the parent or other legal representative (*U.S. Department of Health and Human Services, 2014*). However, section 164.502(g) of the HIPAA privacy rule contains several important exceptions to the general rule.

A parent is not treated as a minor child’s personal representative when there is state or other law allowing a minor to receive treatment without parental consent (*Dailard, 2003*). There are times when someone other than a parent, such as a child welfare agency, is authorized to consent for a minor to receive health care services and there are situations in which a parent agrees for a child to have a confidential relationship with his or her counselor (*U.S. Department of Health & Human Services, 2014*).



HIPAA allows release of information without a legal guardian’s permission in child abuse investigations. There are limitations on what can be released. Some states’ laws require courts to determine relevancy of the information before a healthcare provider discloses confidential information during testimony. During an investigation, releasing records to a parent may be denied, due to concerns of jeopardizing the child’s safety (*American Academy of Pediatrics, 2010*).

In situations where a minor patient is being treated for a mental health disorder and a substance abuse disorder, additional laws may be applicable. The Federal confidentiality statute and regulations that apply to federally-funded drug and alcohol abuse treatment programs contain provisions that are more stringent than HIPAA (*U.S. Department of Health and Human Services, 2014*).

Schools also hold some health records, including counseling or psychological records. Student health information generally is subject to the Family Educational Rights and Privacy Act (FERPA), not HIPAA. HHS and the Department of Education have developed guidance clarifying the application of HIPAA and FERPA (*U.S. Department of Health and Human Services, 2014*). Your child’s school will have written policies available.

At South Dakota Parent Connection, we have heard the questions families have, and the actions providers take to ensure HIPAA compliance. Sometimes, one parent wants the child in treatment, the other doesn’t. In another scenario, one ex-spouse may have custody but the other retains certain parental rights. The parent is not always the personal representative; for some children, it may be a state agency, foster parent, or grandparent. The child’s mental health record may contain sensitive information about other persons, such as siblings.

How do behavioral health providers navigate these complex situations and ensure rights are protected? Mental health clinics may consult an agency attorney, or may use weekly staff meetings or individual supervision to examine the appropriateness of disclosing information. Some agencies

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# HIPAA and Behavioral Health Records

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may release only treatment plans, admission and discharge summaries, and/or a narrative of services provided. There are procedures for releasing records after removing information about third parties.

When a family and a mental health provider cannot reach agreement, there are ways to resolve disputes. Agencies have their own internal grievance policy. When problems cannot be resolved at this level, a parent may contact the State Department of Social Services' Division of Behavioral Health or the federal Office of Civil Rights.

Special situations arise when children reach adulthood, but parents continue to be involved in their mental health care. Emergency situations continue to be HIPAA "exceptions." Parents can receive necessary information when their adult child has a mental health emergency that involves serious and imminent threat to health or safety (*U.S. Department of Health & Human Services, 2014*).

HIPAA does not prevent health care providers from listening to concerned family members. If the patient later requests access to the health record, information shared by persons other than health care providers, given under a promise of confidentiality, may be withheld from the patient (if disclosure is reasonably likely to reveal the source of the information). This exception to access gives family members the ability to share important safety information without damaging the family's relationship with the patient (*U.S. Department of Health & Human Services, 2014*).

Some parents are caretakers or advocates for an adult child who has a severe and persistent mental illness. Handling each HIPAA or state law question over multiple episodes of treatment with several different providers may make it more difficult to communicate treatment needs. Families who have questions about Medical Durable Power of Attorney, guardianship, or proxy decisionmaking laws are advised to consult with an attorney to find the best solution for the child and family (*Carnick, undated*).

When collaborating with behavioral health providers to ensure good treatment outcomes for children, parents sometimes are overwhelmed by the complex role of advocate. They want to understand what rights their child has and to ask appropriate questions. While HIPAA does not provide complete answers to questions about mental health records, it does support an important role of parents, protecting their child's health information.

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## Insurance, Family Finances and Children's Behavioral Health Care

By Ellen Stevens, SDPC Outreach Coordinator

What do I remember about children's mental health care in 2000? As a provider, I remember incredibly difficult choices parents had to make to get, keep, and pay for care. I remember children whose behaviors went out of control while they stayed on long waiting lists; many landed in the juvenile justice system. I remember families filing bankruptcy when insurance wouldn't cover treatment.

Times are different now, choices don't seem as extreme. But piecing together resources and funding is still a challenge; mental health conditions represent "the most costly health condition among children" according to Sheila Pires with Human Services Collaborative in the 2013 report: *"Customizing Health Homes for Child with Serious Behavioral Health Challenges."* Families without insurance have options. For families with insurance, it's important to understand recent improvements in mental health coverage.

**Private Insurance** -- Families should thoroughly understand their insurance: covered and non-covered services; out-of-pocket costs for deductibles and co-pays (services/treatment, medications, hospitalizations); when pre-approvals are required; and the process for appealing denials (grievance). Families can learn this by reviewing their insurance policies, contacting the insurer directly for consumer assistance; or by contacting Human Resources professionals when insurance is provided through the employer. The SD Division of Insurance may be able to assist when disputes arise.

Changes in insurance due to the Affordable Care Act (ACA) means your children can stay on your plan until age 26. A child through age 18 with a pre-existing condition cannot be denied coverage. Protections against lifetime limits on coverage apply to all health plans, and protections against annual limits apply to most plans. All Marketplace Exchange insurance plans and many private insurance plans are required to provide "parity," meaning costs for mental/behavioral health and substance abuse treatments, including inpatient treatment, must be covered at the same levels as physical health conditions.

Families may wish to apply for insurance through the Marketplace Exchange to determine if they are eligible for subsidies that make insurance affordable for their family. Go to [www.healthcare.gov](http://www.healthcare.gov) or visit [www.interlakescap.com](http://www.interlakescap.com) ("Health Insurance Marketplace" link on left) to find free in-person assisters near you.

**South Dakota Medicaid insurance** covers children in low-income families and does not require monthly premiums (payments). The Children's Health Insurance Program (CHIP) helps families who make more than the maximum income for Medicaid. Even if your child has private insurance, CHIP can help with deductibles, copayments, and services not covered by your insurance. Medicaid/CHIP cover mental/behavioral health services. Apply for Medicaid or CHIP at your local Department of Social Services (DSS) office, visit <http://dss.sd.gov/medicalservices/chip/> or call 1-800-305-3064. In South Dakota, children or youth with a disabling mental/behavioral condition and receiving Supplemental Security Income (SSI) will also receive Medicaid.

**Health Coverage for American Indians/Alaska Natives** — Members of federally recognized tribes have free healthcare services through the Indian Health Service (IHS), tribal programs, or Urban Indian Health, including behavioral health program services. Families are also eligible to purchase private insurance through the Health Insurance Marketplace, providing greater access to behavioral health providers. Subsidies may be available to make the cost of premiums very affordable, and there are no out-of-pocket costs if your income is up to around \$70,650 for a family of 4. Members of federally recognized tribes and Alaska Native shareholders can enroll in Marketplace coverage any time of year.

**Community Mental Health Centers** — South Dakota has 11 Community Mental Health Centers that



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# Community Behavioral Health Centers Provide Services for Children, Adolescents and Families

By Travis Hallock, Assistant Director, South Dakota Division of Behavioral Health

The Division of Behavioral Health (DBH) accredits 11 community mental health centers (CMHCs) and 38 substance abuse agencies that provide quality behavioral health services to children and adolescents across South Dakota. Mental health services provide a comprehensive, child-centered, family-focused, community-based, individualized system of care which delivers services to children with serious emotional disturbances (SED). Adolescent substance abuse services provide a continuum of care including prevention, early intervention, outpatient, intensive outpatient, and inpatient services based on the unique needs of each adolescent.

For more information on accessing services, individuals can contact the Division of Behavioral Health at 605-773-3123 or 1-855-878-6057 or [DSSBH@state.sd.us](mailto:DSSBH@state.sd.us). Information can also be obtained on the division website at: <http://dss.sd.gov/behavioralhealthservices/community/index.asp>.



## Mental Health Services Available:

- **Individual therapy:** Individual therapy is in-person contact between a child or youth and a therapist in which they work towards identifying and achieving treatment goals.

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## Insurance, Family Finances and Children's Behavioral Health Care

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offer a range of services, which may include in-home or intensive services. Most public and private insurances are accepted and fees based on income are available to the uninsured. Visit <http://dss.sd.gov/behavioralhealthservices/community/centers.asp>.

**Private Nonprofits** — Nonprofit counseling programs have limited free or low-cost services, generally for families not eligible for Medicaid or CHIP and without private insurance.

**Prescription Assistance** — There may be help paying for medication. Some drug companies have prescription assistance programs. Partnership for Prescription Assistance can help qualifying patients without prescription drug coverage get the medicines they need through the program that is right for them. Visit [www.pparx.org/](http://www.pparx.org/) or call 1-888-477-2669. NeedyMeds, Inc. [www.needymeds.org/](http://www.needymeds.org/) maintains current information about health cost assistance.

**Hospitals and or private providers** should be asked about reduced rates for low income and/or uninsured individuals; payment plan options; and balance or debt forgiveness policies.

**Crime victims** can get special assistance. The South Dakota Crime Victim's Compensation Program, run by the Department of Social Services, assists with costs of mental health counseling and other services. There is a \$15,000 maximum.

**The School System** — Your child's condition may be considered a disability that interferes with learning and requires an Individualized Education Plan (IEP). The IEP can include positive behavioral supports developed by a psychologist, and/or counseling services. For children who require an intensive or residential setting as the least restrictive environment that meets their individualized need, the school will fund the school portion of residential treatment if part of the IEP and public or private insurance

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- **Family education/support/therapy:** Family education/therapy is in-person contact between one or more family members and a therapist in which education relating to the child or youth's psychiatric condition, and support devices are provided to develop coping skills for parents and family members.
- **Crisis Intervention:** Community Mental Health Centers utilize an on-call system to provide an immediate therapeutic response for children, youth, or families in acute distress that may consist of a phone call or in-person contact.
- **Case Management:** Services that assist and support children, youth, and families in gaining access to and building relationships with family members, caretakers, medical, social, educational, community resources, and other services. Case management may be either in-person or by phone with the child/youth, the family, and other service providers.
- **Assessment and Evaluation:** A face-to-face meeting between or under the supervision of a clinical supervisor and the child/family, resulting in a written evaluation of a set of symptoms.
- **Psychological Evaluation:** Evaluation services provided by or under the supervision of a licensed psychologist.
- **Group Therapy:** Children and/or youth who are treated at the same time and focuses on the mental health needs of the group.

### Substance Abuse Services Available:

- **Prevention:** Prevention is dedicated to promoting safe and healthy families, schools and communities. The objective of substance abuse prevention is to promote the personal and social growth of individuals in order to avoid alcohol, tobacco and other drug related problems.
- **Early Intervention:** Is a non-residential facility providing client contacts, community information, and liaison services. It also provides counseling services and assessments to those affected by alcohol or drugs and who have been determined to not need more intensive services.
- **Outpatient Services:** Provide planned counseling services and information to clients and families affected by alcohol or drugs. The program may provide group or individual services.
- **Intensive Outpatient Treatment:** Provide individuals a clearly defined, structured, intensive treatment program on a scheduled basis.
- **Inpatient Treatment:** Intensive inpatient programs provide structured treatment for alcohol and drug abuse to individuals who require close supervision due to the severity of their chemical addiction. For adolescents this is also known as Psychiatric Residential Treatment Facility (PRTF). This level of care must be approved by the Division of Behavioral Health.

## Insurance, Family Finances and Children's Behavioral Health Care

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typically funds the remainder of the cost. For children without an IEP, or when disputes with schools arise regarding school costs of residential treatment, SD Advocacy Services, 1-800-658-4782, may offer free legal assistance to protect the rights of children/youth.

**Other Resources** — Other supports include medical schools with interns serving at reduced rates under supervision; hotlines (for emergencies) and warm lines (to provide support and referrals); support groups at various locations, and even on-line. You can locate a group by contacting The American Self-Help Group Clearinghouse (<http://www.mentalhelp.net/selfhelp/>) or 973-989-1122. National Helpline at 1-800-662-HELP (4357). Faith communities sometimes offer counseling. Regardless of financial situation, emergency care is available.

**Emergency Services** — Whether free or paid, emergency services will see your child immediately and can offer expert assessment. The Avera McKennan Assessment Team (1-800-691-4336) is available to children in imminent danger of hurting themselves or another person. There is a South Dakota Suicide Crisis Line: 1-800-273-8255 (TALK) or 211 in Sioux Falls and Northern Hills areas and Sioux Falls has the HELPLINE Center at 605-339-4357. In Aberdeen, call 605-229-1000.

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Connecting families of children with disabilities or special health care needs to information and resources in an environment of support, hope and respect is at the heart of SDPC's work.

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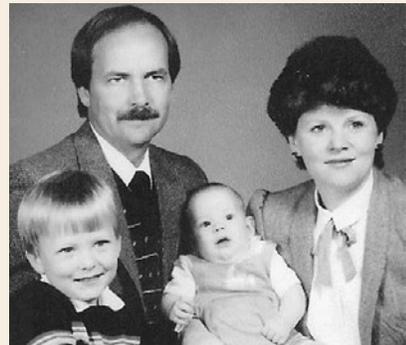
**To Support the Work of SDPC Make a Donation at [www.sdparent.org](http://www.sdparent.org)!**

## 30 Years of Empowering Families

South Dakota Parent Connection (SDPC) begins 30 years of service to South Dakota families caring for children/youth with disabilities or special health needs on October 1, 2014. SDPC has grown from an informal meeting on December 10, 1984 with Dr. George Levin, SD Director of Special Education, parents and professionals in general and special education and other educational groups to a respected, state-wide parent organization. Among the initial group were Elaine Roberts, current SDPC Executive Director and Judie Roberts, current SDPC Information Specialist and Peer Navigator Consultant.

### Help Us Celebrate

During the next year we will celebrate this milestone in several ways. To help us celebrate, we are inviting families who have received assistance or resources from SDPC during the last 30 years to share their stories along with then and now photos. Families that submit a story will receive a canvas briefcase suitable for holding the FILE or other important papers. Stories and photos may be emailed to [sdpc@sdparent.org](mailto:sdpc@sdparent.org) or mailed to SDPC 3701 W. 49th Street, Suite 102, Sioux Falls, SD 57106. If you wish to submit your story anonymously or change names to protect your privacy, we will honor your request.



*Derek's (above center as baby) family came to SDPC 27 years ago seeking resources to help them "navigate" special education services and supports to include Derek in school and envision a positive future focused on his strengths. Today, Derek (with his dad and mom) has his own business, is active in his church, Toastmasters and other community activities.*



The Community of Care consortium's vision is to guide the development of **Healthy Communities that Work** for South Dakota's children, youth and young adults with special health care needs; families; providers; and employers.

South Dakota Parent Connection has been awarded a grant to guide a Community of Care (COC) initiative, a statewide consortium to support a system of care that promotes optimal health, functioning, and full participation in all aspects of life for South Dakota children, youth, and young adults with special health care needs (CYSHCN) and their families. SDPC is excited by the interest in the Community of Care and pleased to announce the membership of the Steering Committee. These generous individuals, with the support of their organizations, have volunteered to lead efforts to better serve children, youth and young adults with special health care needs and their families across South Dakota.

**The Steering Committee roster includes: Phyllis Arends, Executive Director, Sioux Falls National Alliance on Mental Illness; Rebekah Craddock, Vice President SD Association of Health Care Organizations; Terry Dosch, Executive Director, SD Council of Mental Health Centers; Deb Fischer-Clemens, Senior Vice President Public Policy, Avera; Travis Hallock, Assistant Director, Community Behavioral Health, SD Department of Social Services; Connie Halverson, Vice President Public Benefit, Delta Dental; John Johnson, Associate Director of Research, Center for Disabilities; Ann Larsen, Division Director, Department of Education – Division of Educational Services and Supports; Darryl Millner, Assistant Director, Division of Developmental Disabilities, SD Department of Human Services; Bill Molseed, Workforce Training Director, Department of Labor and Regulation; Linda Ross, Executive Director, Community Health Association of the Dakotas (CHAD); Ellen Stevens, Outreach Coordinator, South Dakota Parent Connection; Tony Tiefenthaler, Health Strategy Officer, Sanford Health; Shanon Waldner, Director of Women and Children's Services, Regional Health; and Barb Hemmelman, Director of Children and Youth with Special Health Care Needs, SD Department of Health.**

Developing a Community of Care, a comprehensive system of services for children and youth with special health care needs, cannot be addressed by a single program, but it can be accomplished through the concerted and coordinated efforts of people like YOU - families, providers, advocates, consumers, administrators, and professionals from the public and private service systems - dedicated to improving systems of care for South Dakota children and their families. **The kick-off meeting of the COC consortium will take place on September 25 and all interested individuals are invited to attend.** Visit [www.cocsd.org](http://www.cocsd.org) to learn more.

## Links to Information on Behavioral Health

Behavior Suite – Resources for Behavior Assessment, Plans, and Positive Supports; Behavior at Home; and Behavior at School — <http://www.parentcenterhub.org/repository/behavior/>

Center on Social Emotional Intervention for Young Children – [www.challengingbehavior.org](http://www.challengingbehavior.org)

Dr. Mac's Behavior Management Site – [www.behavioradvisor.com](http://www.behavioradvisor.com)

Positive Behavioral Interventions and Supports – [www.pbis.org](http://www.pbis.org)

Positive Environments, Network of Trainers – [www.pent.ca.gov](http://www.pent.ca.gov)

What Works Clearinghouse – <http://ies.ed.gov/ncee/wwc/>

National Institute of Mental Health – [www.nimh.nih.gov/index.shtml](http://www.nimh.nih.gov/index.shtml)

NAMI South Dakota – [www.namisouthdakota.org](http://www.namisouthdakota.org)

SD Kids Mental Health – <http://sdkidsmentalhealth.org/>  
Includes: A Parent's Guide to Children's Mental Health Services in South Dakota, Directory of SD Mental Health Clinicians, SD Community Mental Health Centers, Helpful Books, other resources.

Sioux Falls Mental Health Resource Guide – <http://helplinecenter.org/2-1-1-community-resources/resources-guides/>

Black Hills Mental Health Resource Guide – <http://helplinecenter.org/2-1-1-community-resources/resources-guides/>

SD Suicide Prevention – [www.sdsuicideprevention.org/](http://www.sdsuicideprevention.org/)

SDPC frequently posts stories and links at [www.sdparent.org](http://www.sdparent.org) /Our Resources (Virtual Library).

# Overcoming Negative Attitudes, Stigma

Adapted with permission from the MayoClinic.com article "Mental health: Overcoming the stigma of mental illness" [www.mayoclinic.org/diseases-conditions/mental-illness/in-depth/mental-health/art-20046477](http://www.mayoclinic.org/diseases-conditions/mental-illness/in-depth/mental-health/art-20046477) © Mayo Foundation for Medical Education and Research. All rights reserved

Stigma is when someone views you in a negative way because you have a distinguishing characteristic or personal trait that's thought to be, or actually is, a disadvantage (a negative stereotype). Unfortunately, negative attitudes and beliefs toward people who have a behavioral health condition are common. Stigma can lead to discrimination. Discrimination may be obvious and direct, such as someone making a negative remark, or subtle, such as someone avoiding you or your child because the person assumes the person could be unstable, violent or dangerous due to the condition.

- 57% of all adults believe that people are caring and sympathetic to persons with behavioral health issues.
- Only 25% of adults with behavioral health believe that people are caring and sympathetic to person with behavioral health conditions.

These statistics highlight the need to educate the public how to support persons with behavioral health issues and the need to reduce barriers for those seeking or receiving treatment for behavioral health.

*Source: Centers for Disease Control and Prevention*

## Some of the harmful effects of stigma include:

- Reluctance to seek help or treatment
- Lack of understanding by family, friends, co-workers or others you know
- Fewer opportunities for work, school or social activities or trouble finding housing
- Bullying, physical violence or harassment
- Health insurance that doesn't adequately cover mental illness treatment
- The belief that your child will never be able to succeed at certain challenges or that you can't improve your situation

## Here are some ways you can deal with stigma:

**Get treatment.** Don't let the fear of being labeled prevent you from seeking help. Treatment can provide relief by identifying what's wrong and reducing symptoms.

**Don't let stigma create self-doubt and shame.** Stigma doesn't just come from others. You may mistakenly believe that your child's condition is a sign of personal weakness or that you should be able to control it without help. Seeking psychological counseling, educating yourself about behavioral health conditions and connecting with others with mental health conditions can help you gain self-esteem and overcome destructive self-judgment.

**Don't isolate yourself or your child.** You may be reluctant to tell anyone about a behavioral health condition. Your family, friends, clergy or members of your community can offer you support if they know about it. Reach out to people you trust for the compassion, support and understanding you need.

**Don't equate your child with the behavioral health issue.** You or your child is not an illness. So instead of saying "My child is bipolar," say "My child has bipolar disorder." Instead of calling yourself or your child "a schizophrenic," say "My child has schizophrenia."

**Join a support group.** Some local and national groups, such as the National Alliance on Mental Illness (NAMI), offer local programs and Internet resources that help reduce stigma by educating people with behavioral health conditions, their families and the general public. Some state and federal agencies and programs offer support for people with mental health conditions.

*(Continued on page 14)*



## Join the Fun on Saturday, November 8

Sibshops will be Saturday, November 8 from 10 a.m. - 1 p.m. at Here4YOUth, 1721 W. 51st Street, Sioux Falls. Lunch will be provided.

Sibshops is a free program designed specifically for brothers and sisters, ages 6-12, of children with special needs or disabilities. Sibshops is a time to meet other brothers and sisters of children with special needs, build friendships, have fun, do recreational activities, and share feelings with others who really know what it is like to have a sibling with a disability.

Pre-registration is required to attend Sibshops. To register online for the November 8 Sibshops visit [www.surveymonkey.com/s/ZF6T37G](http://www.surveymonkey.com/s/ZF6T37G) or call 1-800-640-4553 or 605-361-3171. For more information on Sibshops visit [www.sdparent.org](http://www.sdparent.org) (Family Life, Siblings)

Mark your calendar for future Sibshops on Saturday, January 17 and Saturday, April 25. An additional Sibshops will be held in February on a date and at a location yet to be determined.

Sibshops is a joint project of South Dakota Parent Connection, Here4YOUth and LifeScape.



*Sibshops participants enjoy a game of Twister at recent event. Siblings of children with special needs or disabilities enjoy activities and sharing.*

## Overcoming Negative Attitudes, Stigma

(Continued from page 13)



**Get help at school.** If your child's behavioral health affects learning, find out what plans and programs might help. Discrimination against students because of a behavioral health condition is against the law, and educators at primary, secondary and college levels are required to accommodate students as best they can. Talk to teachers, professors or administrators about the best approach and resources. If a teacher doesn't know about a student's disability, it can lead to discrimination, barriers to learning and poor grades.

**Speak out against stigma.** Consider expressing your opinions at events, in letters to the editor or on the Internet. It can help instill courage in others facing similar challenges

and educate the public about mental illness.

Others' judgments almost always stem from a lack of understanding rather than information based on the facts. Learning to accept your child's condition and recognize what you need to do to treat it, seeking support, and helping educate others can make a big difference.

# Parent Education Sessions Offered Online and at Center for Disabilities

SD Parent Connection's (SDPC) Free Parent Education Series returns on **Thursday, September 11**. ***The Basics of an IEP and Procedural Safeguards*** will walk participants through the IEP's purpose and the basic steps of developing an IEP. Parents and professionals need information about the rights and responsibilities built into special education law. Learn the procedural safeguards in special education laws, parents and school responsibilities for implementation, and resources to assist in helping children with disabilities or special needs succeed. Paula Souhrada, SDPC Navigator Coordinator, will present. The Navigator Program is a partnership between the SD Department of Education and SDPC, and provides individualized guidance to parents of children and youth with disabilities or special health care needs and school professionals at no cost.

The Parent Education series is held the second Thursday of each month during the school year from 7 - 8:30 p.m. (Central Time) or 6 - 7:30 p.m. (Mountain Time). Sessions are offered online using Adobe Connect with the ability to ask questions through a chat feature. The link to participate online is <https://usdcadobeconnect.com/parenteducationsessions/>. Participants may also attend the presentation each month at the University of South Dakota School of Medicine Center for Disabilities, 1400 W. 22nd Avenue in Sioux Falls (no child care provided). Following the live presentations, the recorded presentations are posted at [www.sdparent.org](http://www.sdparent.org) (Family Life, Parent Education Series) for viewing anytime.

The sessions are appropriate for all parents and those working with or supporting children with special needs. Pre-registration is encouraged, but not required. Register at [www.sdparent.org](http://www.sdparent.org) where you will also find materials which may be provided in advance of the presentation and previously recorded sessions. Call Tana at 605-361-3171 or 1-800-640-4553 if you have questions.

## Parent Education Sessions:

**September 11, *The Basics of an IEP and Procedural Safeguards*** (see description above)

**October 9, *The Ins and Outs of a 504 Plan*** — How is a 504 different from an IEP? This presentation will discuss the requirements of Section 504 of the Rehabilitation Act and Title II of the Americans with Disabilities Act along with the responsibilities of public schools in educating students with disabilities. Join us and learn about the purpose of a 504 plan and how one should be implemented. Presented by Paula Souhrada, SDPC Navigator Coordinator.

**November 13, *A Positive Approach on Parenting Children with Challenging Behaviors*** — This presentation will discuss and teach different ways parents can set behavior expectations and boundaries for their children. The importance of identifying positives in your child and developing a healthy relationship will be highlighted as well as how parenting each child can be different. Presented by Dr. Aimee Deliramich, Licensed Clinical Psychologist, LifeScape.

**December 11, *Bridging the Behavior Intervention Plan From School To Home*** — Behavior Intervention Plans (BIPs) are common place for students who display challenging behavior that impacts learning. The plan may be effective in the educational setting, but what if the home environment isn't seeing the same benefits? What happens when the best laid plans don't translate to a different environment? Presented by Lacy M. Knutson, M.S., BCBA, Training Associate/Board Certified Behavior Analyst at the Center for Disabilities.

2015 Sessions will be held on January 15, February 12, March 12, April 9 and May 14. Watch for more details.



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*Resources for families of children with disabilities.*

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**Visit Us at  
[www.sdparent.org](http://www.sdparent.org)**

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**RAPID CITY  
 OFFICE**

Children's Care  
 7110 Jordan Drive  
 Rapid City, SD 57702  
 605.348.0305

# Partners in Policymaking Can Change Your Life

Partners in Policymaking is a training program designed for parents of children with disabilities, self-advocates, and family members. Over 500 South Dakotans have successfully completed the training and many say it has been life-changing. South Dakota will be starting its 23rd year of Partners in Policymaking in November 2014.

Partners learn about current issues and best practices and become familiar with the policymaking and legislative processes at the local, state, and national levels. The overall goal is to achieve a productive partnership between people needing and using services and those in a position to make policy and law. Partners attend two-day training sessions, six times a year, with each session beginning on Friday morning and concluding mid-afternoon on Saturday. Each session is devoted to specific topics with nationally known presenters.

Applications are due on **September 20**. To receive an application, contact Sandy Stocklin Hook at 1-800-658-4782 or you can apply on line at [www.sdadvocacy.com](http://www.sdadvocacy.com).



***“Partners helped me find a strength I didn’t know I had. I have more ability to stand up and speak for myself.”***

*Leon Adams  
 2013 Partners  
 Graduate*

The contents of this newsletter were developed under a grant from the U.S. Department of Education and U.S. Department of Health and Human Services. However, these contents do not necessarily represent the policies of the Department of Education or Department of Health and Human Services and you should not assume endorsement by the Federal Government. Products and services described herein are not endorsed by South Dakota Parent Connection, the U.S. Department of Education, Department of Health and Human Services or by the Federal Government. The Parent Training and Information Center is funded by the U.S. Department of Education, Office of Special Education Programs (OSEP). The Family-to-Family Health Information Center is funded by a grant through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs. This grant program was established by the Family Opportunity Act of 2005 and amended by the Patient Protection and Affordable Care Act of 2010.