Information and Referral = Knowledge
Knowledge = Power
How to Make It Work for You

by Tim Neyhart

South Dakota Advocacy Services (SDAS) provides many different types of services to the people who call our offices. Callers are usually familiar with the case services SDAS provides, such as attending meetings, doing investigations, researching questions on disability-related topics, legal representation, etc. Another service SDAS provides that many people are unaware of, or do not understand, is Information and Referral Services.

An information and referral is exactly as it sounds. An information and referral call is an opportunity for an individual to call a telephone number and talk to a real person who is trained and motivated to assist you, not an answering machine providing you with a list of choices from a menu. This person will talk with you about your issue and assist you to address it. This person will either provide you with the information that you need, or direct you to someone else who can better assist you. The majority of the callers who contact SDAS are served through information and referral. An information and referral may be as simple as providing a requested phone number. It may be providing the caller with information specific to an issue the caller has, such as information on the caller’s rights or advice on how to proceed at a meeting. It may be referring the caller to another person or agency that can better address the question.

Governor Dennis Daugaard (l) with Partners in Policymaking Year 20

Information and referral is a very simple process. One of the problems is that many people looking for information are unaware that this type of service exists. They do not know how find the initial contact information they need to get started. A good information and referral service is one that anyone can call, know that the call will be kept confidential, and know the person taking the call will work with you to understand the problem. The person taking the call will have sufficient time to listen and provide the information you seek, or refer you to a better source of information. SDAS is not the only agency that provides information and referral services. The demand for this service exceeds the ability of SDAS or any one service provider to meet the requests for assistance.

Information & Referral Services
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Information & Referral Services
(Continued from page 1)

Over the course of the past twenty years or so, there have been several attempts to create a book, or in recent times a data base, to store all of the possible resources needed by callers seeking information. In the last two or three years, there have been several groups of people working to address the idea of creating an appropriate resource data base. Part of the problem with this type of effort is that it difficult to maintain an up-to-date resource directory. It is difficult to maintain an accurate data base because agencies move, change names, change personnel, and/or change or develop new contact information, such as phone numbers and websites. In an effort to address this problem, a group of people working on the state Alliance for Full Participation team came up with the idea of creating a list of agencies that provide information referral services as part of their mission.

The Alliance for Full Participation Work Group is made up of people with disabilities, their family members, and employees of state and private agencies. This group is focused on creating full employment for people with developmental disabilities. Several members of this group also participate in the Core Stake Holders Work Group, which is an advisory body for the Division of Developmental Disabilities. In addition to these members, the group also has representatives from the work group developed by the Special Education Programs office to follow-up on ideas created by the recent review completed by the federal Office of Special Education Programs. These various groups have all targeted information and referral services as part of their work plans. Because there are members of these groups who serve on more than one of them and were aware of the efforts of the other groups, an idea developed to create a “One Page” document identifying ten agencies that provide information and referral services.

The members of the Alliance For Full Participation Work Group each listed the agencies that they call most frequently to seek information for people with developmental disabilities. This list was compiled and it turned out that several of the agencies provide information and referral services for all types of services in addition to those traditionally serving people with developmental disabilities.

After developing the list of providers, discussion took place about how it would be possible to assist people to be more effective in their efforts to gather the information they need. An element of information referral services that is often overlooked is helping the caller to understand what questions to ask and what to do during his or her next call.

The work group decided to add suggestions of questions for callers to ask to a document that would be distributed throughout the service delivery system. This document contains the list of providers that provide information and referral services on the front and the suggestions for questions to ask on the back. Katie Gran, a Vocational Rehabilitation Counselor on the work group, volunteered to put all of this together. The document has come to be known as the “One Pager.” The information contained in the One Pager is included on the next two pages.

As you think about this article, please keep the following quote from Charles Louis de Montesquieu in mind: “Happiness is not the absence of problems but the ability to deal with them.”
### South Dakota Agencies for People with Disabilities

<table>
<thead>
<tr>
<th><strong>South Dakota Agencies for People with Disabilities</strong></th>
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<tbody>
<tr>
<td><strong>Helpline Center</strong></td>
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<tr>
<td><a href="http://www.helplinecenter.org">http://www.helplinecenter.org</a> 211 or 605.339.4357</td>
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<tr>
<td>making lives better by giving support, offering hope and creating connections all day, every day</td>
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<tr>
<td>24-hour information &amp; referral line to community programs for financial assistance, food, clothing, medical assistance, social service programs, government agencies, child care, volunteering opportunities, suicide and crisis support</td>
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| **DSS** |
| [http://dss.sd.gov](http://dss.sd.gov) 605.773.3165 |
| to strengthen and support individuals and families by fostering independence and personal responsibility; protecting people; providing opportunities for individuals to achieve their full potential; and promoting healthy families and safe communities by ensuring quality, cost-effective and comprehensive services are provided in cooperation with our partners |
| Food Stamps; Medicaid; Temporary Assistance for Needy Families; Child Care Assistance; Low Income Energy Assistance; Aging & Disability Resource Connections; Behavioral Health Services and more |

| **Coalition** |
| [http://www.sd-ccd.org](http://www.sd-ccd.org) 800.210.0143 or 605.945.2207 |
| advocates for the full inclusion of individuals of all ages with all types of disabilities |
| provides training on disability related topics; technical assistance on the Americans with Disabilities Act and other disability laws; legislative Enews; and more |

| **Advocacy Services** |
| [http://www.sdadvocacy.com](http://www.sdadvocacy.com) 800.658.4782 / 605.224.8294 |
| to protect and advocate the rights of South Dakotans with disabilities through legal, administrative, and other remedies |
| Client Assistance Program; Protection & Advocacy Developmental Disabilities Program; Protection & Advocacy for Individuals with Mental Illness Program; and more |

| **Freedom to Work** |
| Supports a system of employment services for people with disabilities and helps remove barriers to employment |
| Work Incentives training; Medical Assistance for Workers with Disabilities (MAWD); Personal Assistance Services (PAS); benefits specialist services; Career Development Teams; employment resource materials available |

| **Center for Disabilities** |
| [www.usd.edu/cd](http://www.usd.edu/cd) 605.357.1439 |
| works with others to create opportunities that enhance the lives of people with disabilities & their families through training, services, information, research, & community education |
| Birth to 3 program; Autism Program, Fetal Alcohol Program, and Deaf-Blind Program; trainings available; resource handbooks |

| **Council on Developmental Disabilities** |
| [http://dhs.sd.gov/ddc](http://dhs.sd.gov/ddc) 800.265.9684 or 605.773.6369 |
| to assist people with developmental disabilities and their families in achieving the quality of life they desire |
| Helpful resource to find out about available services; provides financial assistance for advocates and/or families to attend different trainings throughout the state; and more |

| **Transition Services Liaison Project** |
| [http://www.tslp.org](http://www.tslp.org) 605.224.5336 |
| assists students with disabilities, their families, schools, and adult service agencies to make the transition from high school to post-school be a meaningful experience |
| Youth Leadership Forum; Catch the Wave; Transition Tackle-box; transition trainings for special education teachers & parents; and more |

| **Department of Human Services** |
| [http://dhs.sd.gov/drs](http://dhs.sd.gov/drs) 800.265.9679 or 605.367.5330 |
| to assist individuals with disabilities to obtain employment, economic self-sufficiency, personal independence & full inclusion into society |
| Project Skills; Project SEARCH; Assistive Technology assistance; post-secondary and employment training assistance |

| **DHS/Division of Developmental Disabilities** |
| [http://dhs.sd.gov/dd](http://dhs.sd.gov/dd) 605.773.3438 or 800.265.9684 |
| To ensure that people with developmental disabilities have equal opportunities and receive the services and supports they need to live and work in South Dakota communities. |
| Family Support 360; Community Support Provider; Adult Foster Care; Respite Care; Guardianship assistance; and more |
The Secret Questions to Self Advocacy

Here are some sample questions that you can use to learn more about what services are available. Please don’t feel limited to only asking these questions ... these are only to get the conversation started.

Who...
♦ Who is eligible for your services?
♦ Who would be my point of contact?

What...
♦ What type of services does your agency provide?
♦ What is the cost associated with services?
♦ What sort of application/eligibility process is there?
♦ What other agencies can you direct me to for further assistance?
♦ What information do I need to provide to be able to seek assistance?

When...
♦ When will services start?
♦ When will services end?

Where...
♦ Where is the local office located?
♦ Where do services take place ... an office, at school, my home, your agency?

How...
♦ How long will it take for services to begin?
♦ How often do services take place ... daily, weekly, monthly, yearly, or as needed?

Why...
♦ Can you help me understand why you have taken this position?
♦ Why do you believe your interpretation of this material is correct?

[The “One-pager” then contains boxes (not included herein) with questions on the left side and room on the right side to document all contacts between you and any agencies. Your log should include telephone calls, messages, meetings, letters, and notes between you and agency staff. The questions in the log are: Who did I talk with? When did we talk? What did I ask? and What was I told? The log also contains space for additional notes.]

TSA Helpline for Travelers with Disabilities
by Norma Vrondran

There is a Helpline now available to travelers with disabilities and medical conditions. The Transportation Security Administration (TSA) has developed a program called “TSA Cares,” which helps persons with disabilities or medical conditions with questions about screening policies, procedures, and what to expect at the security checkpoint.

TSA strives to provide the highest level of security and ensure that all passengers are treated with dignity and respect. Every person and every item must go through a screening process. TSA Cares serves as a dedicated resource to prepare a passenger with a disability or medical condition who may require specific equipment that needs to be brought through the security checkpoint. TSA works regularly with a coalition of disability and medical condition advocacy groups to help TSA understand individual needs and adapt the screening process.

It is suggested you call TSA toll-free at 1-855-787-2227 approximately 72 hours in advance of travel to allow TSA Cares the opportunity to coordinate the checkpoint support with a TSA Customer Service Manager located at the airport when necessary. Travelers with hearing impairments may call using Relay or use email at TSA-ContactCenter@dhs.gov. Travelers may also go online at http://www.tsa.gov/travelers/airtravel/disabilityandmedicalneeds/index.shtml and click on subjects more specific to their individual situation. These may include mobility, hearing, visual, hidden disabilities, prosthetics, pacemakers, defibrillators, other implanted devices and metal implants, CPAP machines, oxygen/respiratory equipment, diabetic, assistive and mobility aids, casts/body braces, walkers/crutches/canes, augmentation devices, orthopedic shoes/support appliances, dressings, service animals, and children with disabilities. It also includes individuals who have experienced trauma, severely injured military, and other special situations.

All travelers can contact TSA using “Talk To TSA,” a web-based tool that allows passengers to reach-out to an airport Customer Service Manager directly, and the TSA Contact Center at 1-866-289-9673 and TSA-ContactCenter@dhs.gov, where travelers can ask questions, provide suggestions and file complaints.

TSA Cares

(Continued on page 20)
If you are as old as I am, you will remember when a video camera used to be so large it needed to be balanced on a shoulder when filming a home movie, or when a film camera was so big that we couldn’t put it in a pocket, but had to carry it in a bulky carrying case. Because the cameras used film, we all had numerous photo albums packed full of developed pictures. Technology has changed dramatically over the years and now almost everything can fit in a shirt pocket. Today, most people have DVD players, digital cameras, and other media sources to store their information and watch their memories. But, most of us still have the photo albums and VHS tapes, probably in cardboard boxes hidden away in the basement labeled photos or home movies. We would love to watch our home movies or show off our photos, but VHS players are hard to find and not many people want to drag big photo albums with them to show pictures to their friends.

Derek Smith knew that he could help people with this problem. He wanted to help people clean out their cardboard boxes and put their home movies and photos on current technology so that they are more accessible. Derek decided to start his own business, called Derek’s Media Services.

His services include converting VHS tapes to DVD and making slideshows of photos. Derek hopes to offer video editing and web design as services in the near future.

Derek’s Media Services wasn’t born overnight. A lot of time and hard work went into establishing his business. Derek went to high school in Mitchell, South Dakota, and subsequently took computer classes at Dakota Wesleyan University. The high school and college classes taught him how to use computers, how to create slide shows, and other media skills. Derek also worked at various jobs, including County Fair Foods, Mr. Movies, Cabela’s, and Amber Dawn Portrait Plus Designs. Derek participated in the Partners in Policymaking leadership and advocacy training program through South Dakota Advocacy Services. It was during this training that he learned about becoming self-employed. Derek knew he needed the support and guidance of his family and SD Rehabilitation Services in order to get his business up and running. The first thing Derek did was put his ideas down on paper and talked with his vocational rehabilitation counselor. Next, he created a business plan so he had a road map to guide him in the process. Derek knew that it would take time to get through the process and the hardest part was waiting for all the paperwork to be approved. He received his sales tax license and was able to begin helping people with their media needs.

According to Derek, the best thing about owning his own business is that he gets to help his customers with the media services they need. Derek created a website and included information on the services he provides. Derek is a member of the Sioux Falls Chamber of Commerce. His ribbon-cutting reception was a great opportunity for Derek to promote his business and let people know what services he provides.

Derek is also a member of Toastmasters, Life Group, and SD Advocates for Change. He also participates in cooking classes. When Derek has free time, he loves to spend it playing with his niece and nephew. He also likes to spend time with his grandma.

Even though Derek happens to have a disability, he did not let that stop him from accomplishing his goal of being self-employed. Derek knew that with a lot of hard work and perseverance he would be a business owner. He loves to help people and he is ready to transform your cardboard boxes of home movies and old photos! Check out Derek’s website at www.dereksmedia services.com. Congratulations Derek!
87th State Legislative Session Concludes
by Robert J. Kean

The 2012 Legislative Assembly concluded its final regular day on March 2 and the session itself on March 19, which was reserved for consideration of gubernatorial vetoes. Due to successes in the 2010 general election, where the Republicans increased their edge over the Democrats in both legislative houses, the Republican/Democrat membership in the Senate was 30-5 and was 50-19 in the House. Jenna Haggard, Dist. 15, Sioux Falls, Independent, caucus with the Republicans, effectively giving them a 51-19 advantage.

With Republicans holding over 2/3 majority in both Houses, it made for a very challenging environment for Democrats to be heard and propose substantive legislation. For example, since the Appropriations Committee meets most days of the session as a joint committee, it was a challenge for the Democrats to fully participate on it and in the many other committees dealing with the non-budget legislative items. It also made procedural maneuvering more difficult, such as seeking or requiring compromise on issues and positions to get legislation passed.

Before the session began, the prevailing sense was that the state had more fiscal latitude than in the past two years. This, in turn, lead to a feeling that state personnel, programs, and services that were level-funded or received cuts in light of the weakened economy during previous sessions could look for bonuses, increased salaries, and resources in the budget. The Governor’s budget theme was to review initiatives and program activities of the past year (his first as Governor) and propose substantive efforts to move the state forward. The initiatives and activities mentioned included the Infant Mortality Task Force, pine beetle infestation, Better Government Initiative, and growing the economy. Another was the Medicaid Solutions Workgroup, designed to address ongoing issues relating to coverage and costs. Major areas discussed included neonatal care, prescription drug availability, and emergency room usage.

Even though this year’s session had been described by media outlets as a “feel good” session, indicating the state’s situation was “not so dire,” most items of legislative business were again conducted through the prism of the state’s economic health and resource forecasts. The urge for continued spending restraint was used as a caution, and, at times, lead to lower amounts of increased spending and even promoted discussion of a status quo for some programs, services, and new initiatives. These cautions were repeated throughout the final debate on SB 194, the bill that carried the FY 2013 appropriation to Unified Judicial System and revision of filling fees. Line Item Veto on the appropriation portion stating that it was not needed due to the timeframe of the revision of filling fees, veto agreed to; HB 1116, exempt bedding used for agricultural purposes from sales taxes, Bill Veto stating that tax exemptions of this type erodes the state tax base system, veto was overridden; HB 1228, provide tax refunds for certain wind energy projects, Bill Veto stating that the current law requiring a permit is fair and reasonable, veto was sustained; HB 1248, provide for carrying concealed weapon without permit based on valid state drivers license, Bill Veto stating that the current statute prohibiting from banning digital billboards, Bill Veto stating the legislature should not insert itself into an ongoing legal dispute between a city and advertising company, veto was sustained; SB 157, cities prohibited from banning digital billboards, Bill Veto stating the legislature should not insert itself into an ongoing legal dispute between a city and advertising company, veto was sustained; SB 197, provide for sales and property tax refunds for qualified elderly and persons with disabilities, Style and Form Veto recommending that eligibility resource limits be consistent throughout the bill, veto agreed to (style and form changes were made and the bill was signed by the Governor).

The remainder of this article describes select bills that passed during the 2012 session that relate to and/or impact general areas of interest of SDAS. As importantly, bills that were introduced but did not pass are described because often legislative efforts, positive and negative, take several years to pass. It also mentions bills that bear watching in their application to ensure they are not misapplied and become detrimental. References to SDCL and “current law” means a current statute in South Dakota Codified Laws. Bills are numbered sequentially as they are introduced (Senate bills begin with number 1 and House bills with 1001). The SD Legislative Research Council (LRC) provides a wealth of ongoing information on the current and past legislative sessions, summer interim sessions, and other areas of interest. See: http://legis.state.sd.us.

Bills That Passed

**Education Reform:** In his State of the State message, the Governor presented sev-

Martha Anderson, center, received a plaque of appreciation from Dianna Marshall (PAIMI Program Director) and Robert J. Kean (Executive Director) for her years of service on the PAIMI Advisory Council. She served as Council Chair for one year.
eral major areas of reform for the state’s education system. These included a system of merit pay for the best teachers, bonuses for teachers in the fields of math and science, and eliminating the current teacher tenure system. These proposals, in effect, reflected a complete revamping of the relationship teachers have with their school districts and communities. That the proposals stirred a lot of heated debate is an understatement. The ensuing discussion was enormous in terms of volume, quantity, and emotion. When the education reform bill (HB 1234) finally passed by a narrow 36 to 33 margin late in the session, it was vastly different than that originally presented and the vote highlighted the significant number of legislators in disagreement. However, it was pointed out on many occasions that HB 1234 was intended to begin the dialogue on important educational concepts vital to the long-term interests of the state. Key provisions of the bill include:

**Scholarship Program:** A Critical Teaching Needs Scholarship Program will be developed to encourage South Dakota high school graduates to stay in the state to work in a critical need teaching area after obtaining their postsecondary education.

**Incentives:** A math and science incentive program will be developed by the start of the 2014-15 school year. It will provide funds to local districts for the purpose of providing awards to attract certified teachers to teach in math and science areas in middle and high school or who have a math or science special endorsement which they are using for any grade, kindergarten to grade twelve. The monies provided to the teacher are to be used to supplement and not replace amounts the teacher is to receive through a contract with the school.

**Teacher Rewards:** A top teachers reward program will be developed by the start of the 2014-15 school year. The voluntary program is to reward a district’s top teachers. The amounts rewarded are to supplement, not replace amounts the teacher is to receive under a contract with the school district. Up to 20% of a district’s full-time equivalent certified teaching positions shall be eligible to receive the reward. The reward amount will be $5,000. Districts can opt-out of the top teachers reward program by written notice approved by the school board and signed by the board president. A district may choose to create its own local teacher reward plan as a substitute for the top teacher reward program. If substantially in compliance, the local reward plan can use the state funds that would otherwise have been provided through the state’s program.

**Performance Evaluation:** Any public school district seeking state accreditation must evaluate its certified teachers. The school years 2012-13 through 2013-14 can be used to establish the certification methodology to be employed. Certified teachers will be given performance evaluations beginning in the 2014-15 school year. The evaluations will take place every year for certified teachers in the first three years of their contracts and every other year thereafter. The state Board of Education is to establish the certification standards using quantitative and qualitative measures. Every teacher will be placed within a four-tier rating system: distinguished; proficient; basic; and unsatisfactory. Every plan for performance evaluation is to have a program of assistance for teachers who do not meet the required performance standards. Performance standards are not subject of any collective bargaining agreements between school districts and teachers.

**Tenure:** HB 1234 adds a new section to SDCL 13-43. After implementation, teachers will be either tenured or nontenured. A tenured teacher is defined as a teacher who “is in or beyond the fourth consecutive term of employment as a teacher with the school district prior to July 1, 2016.” A nontenured teacher is defined as a teacher who “is not yet in or beyond the fourth consecutive term of employment as a teacher with the school district prior to July 1, 2016.” The 2016 date is two years after the beginning of teacher evaluations. While a district can provide a continuing contract to a nontenured teacher, any nontenured teacher need not acquire continuing contract status by the school district. Teacher contracts are to be made in one-year increments. A nontenured teacher can be fired (a non-renewal) by notice from school superintendent or CEO prior to April 15th without further process (e.g., a hearing by or appeal to the school board) or providing a reason for non-renewal. School boards can refuse to renew a tenured teacher’s contract for a number of reasons, including just cause, gross immorality, and a rating of unsatisfactory on two consecutive performance evaluations.

**Standing Advisory Council:** The South Dakota Educational Reform Advisory Council is established to advise on the implementation of HB 1234 and examine further reform issues.

It is important to note that each of the substantive reform areas in the law is accompanied by implementation activities that must be accomplished before the changes can or will be enacted. Some include advisory bodies that are to meet to establish further implementation steps. The elements dealing with bonuses and teacher rewards require ongoing formulations to finalize the resources available from the state to the local districts for payments. It is also noteworthy that the bill does not specifically reference how the unique aspects of special education are to be considered. For example, how will the challenges of noting progress in a special education curriculum or dealing with behavior be factored into the quantitative and qualitative measures of a teacher’s performance? How are therapists who work in multiple schools and homes to be compared to a teacher in the traditional classroom? These and similar questions need to be monitored during the development of any scheme of review. Knowing that additional changes need to be made, Republican leadership has already scheduled a summer meeting to make further recommendations to the law. In a strong showing of “no confidence,” literally minutes after HB 1234 was signed by the Governor, the South Dakota Education Association announced that petitions were being sent out to recall the law.

**Mental Health Reform:** Part of the reorganization that Governor Daugaard instituted in his Executive Reorganization Order No. 2011-01 included transferring the Divisions of Mental Health and Drug and Alcohol Abuse and the Human Services Center from the Department of Human Services to the Department of Social Services (DSS). In conjunction with the transfer, a Governor’s Behavioral Health Services Workgroup was established. The workgroup was co-chaired by Lt. Governor Michels and the Governor’s Senior Advisor and was composed of various stakeholders, including legislators, providers, associations, advocacy groups, and DSS. The workgroup’s purpose was to develop a strategic plan for the future of behavioral health services in South Dakota and make recommendations to the Governor as to implementation. In addition, the Workgroup reviewed existing mental health statutes. Since the last major revisions were in 1991, the workgroup’s goal was to identify statutes that are outdated and no longer reflect current practice or the current state of behavioral health treatment. The workgroup also considered a better integration of the treatment of behavioral health
conditions, providing an opportunity for a better functioning commitment process that allows the board of mental illness to issue treatment orders at the time of commitment, as well as the ability to issue orders for the commitment and treatment of individuals with co-occurring mental health and alcohol and drug abuse conditions. An overarching goal of the workgroup as it considered statute changes was to remove perceived unnecessary barriers to treatment. After review and discussion, the workgroup prepared a bill (SB 15) that focused on several key areas in the provision of mental health services in the state: Qualified Mental Health Professionals (QMHPs); outpatient commitment process; voluntary admissions process and substituted Informed Consent; integrated commitment process for medication/treatment and co-occurring disorders; treatment; advance directives; and electronic filing. [The South Dakota Report will provide a more detailed description of the proposed changes as the rules are developed that will more fully detail the processes of the legislative changes.]

Special Education Student Allocation: Since the inception of a funding mechanism in 1999 to allocate general funds as dedicated special education funds to local school districts based on levels of disability, the legislature typically adjusts the amounts upwards each year. The figure is based on annually reviewing the local school district tax effort, the applied index factor, and the amounts allocated each year, and adjusting items based on cost data received by the State Department of Education for the past three years. Historically, the figures for most of the categories reflect an ongoing increase in the cost of providing special education services. Students receiving special education services are placed into one of six “levels,” ranging from mild disability (level one) to prolonged assistance (level six). Due to the state economy, no increases occurred the last two sessions despite reported increased costs in serving students receiving special education. This year, SB 8 increased the amounts for some levels for the next school year. The allocation amounts for 2013 will range from $4,525 for level one to $19,993 for level five. However, level three (hearing/vision impairment; deafness; deaf-blind, orthopedic impairment; traumatic brain injury) was reduced from $15,220 to $14,778 and level six (prolonged assistance) was reduced from $8,438 to $7,205.

Bullying in Schools: Following an unsuccessful effort last year to address the growing concern of bullying in schools and the fact that when the session began a number of school districts were still without a policy, Sen. Lederman (R-Dist. 16) reintroduced a bill (SB 130) that would require all school districts to have a policy that dealt with bullying and set out required provisions that all school bullying policies must have. The SD Attorney General introduced a similar bill (SB 44) that “encouraged” school districts to have a policy on bullying, provided a definition of what bullying is, set out a model policy for guidance, provided for a process for acting and reporting on bullying allegations, and required that if a school district did not have a policy, the model policy would be in effect until it adopts its own. As both bills awaited hearing in the Senate Education Committee late in the session, the discussion shifted to whether and to what extent it should be mandatory, the required bullying policy elements, and the processes used for enforcement. At the hearing, “hog house” amendments to each bill were presented. The major change offered in the amended SB 44 was to drop the detail of how a reported incident of bullying was to be dealt with. The amendment to SB 130 included added language requiring school districts without a policy to adopt one and those with one to review it to comply with the bill's provisions. It also provided for a good faith defense if a reported incident was not acted upon by the school. The amended SB 130 prevailed and passed out of committee and the Senate. In the House Education Committee, the amended SB 130 was again hog housed with an amendment that contained much of the language of the previously defeated amendment to SB 44. The amendment passed the committee and the House. In conference committee, the bill was further amended to reconcile the differences between the two bills, resulting in mandatory language of the provisions that must be contained in the school policy. Language was also added stating that no school policy prohibiting bullying, whether existing or adopted pursuant to the act, may contain any protected class. The stated intent of this language was to ensure that all students are protected by a bullying policy, but the extent of the intent is not clear. Nor is it clear if the language will have an unintended consequence in its application to other educational areas, such as special education. It will be important that the implementing rules deal with the potential confusion.

Now that bullying has been addressed, in another area of student vulnerability, South Dakota remains one of only six states that do not have a specific statute that deals with inappropriate seclusion and restraint.

Mandatory Reporting: Two bills were introduced to expand the mandatory reporting requirements in situations of child abuse and neglect. The bills were quite different in scope. SB 154 added language to the existing list of persons who are required to report child abuse and neglect that is set out at SDCL 26-8A-3, adding “employee or volunteer of a child advocacy organization or child welfare service provider.” HB 1264 offered a much broader approach. It deleted the list of specified occupations in SDCL 26-8A-3 and replaced it with the following all-inclusive language: “Any professional, or person who has contact with a child through the performance of services as a support staff member, working within or in conjunction with a hospital, health and wellness or medical clinic, mental health provider, child protection agency, religious function or organization, parole or court services, law enforcement, school or school related organization, registered day care, domestic abuse shelter, chemical dependency center, coroner’s office, or any other business agency, or organization that offers helping services to children.” In committee, concerns were expressed that HB 1264 was too broad and would create confusion when considering to what extent the responsibility extended, especially with phraseology like, “any other business … that offers helping services to children.” HB 1264 was deferred to the 41st day (killed), while SB 154 passed.

Voting: Several bills relating to voting were introduced and passed:

SB 58 set out the framework to establish “vote centers” in the state on an ongoing basis. The concept of vote center is to allow for flexibility in establishing places within a jurisdiction where persons who are registered to vote in that jurisdiction can vote. Typically, this would allow for fewer voting places in a jurisdiction than the number of local precincts that now must be open and staffed in most elections. Less voting places should save resources through less cost related to renting/using precinct locations and hiring precinct staff. The bill also authorized an electronic precinct registration list, which can be used in place of the current paper format “poll list” or “poll
book.” This is designed for ease of use and reflects the continuing efforts of the Secretary of State’s office to more fully integrate electronic formats into the voting process. The bill contained an emergency clause, allowing it to go into effect immediately upon passage and approval. This will allow the continuing development of the vote center concept in this year’s voting cycle, which begins in some communities as early as April.

SB 128 dealt with several voting-related procedures and processes. It allows for keeping voter registration information in an electronic format, and states that website voter registration sought from the Secretary of State’s office will be responded to as expeditiously as possible. It also deletes from statute extraneous language and clarifies that the State Board of Elections is to promulgate rules on overseas registration forms.

SB 137 clarified several procedures relating to absentee voting. It clarified that a person wanting an absentee ballot could personally apply at the office as well as to the person in charge of voting. It also clarified that absentee balloting could be used for school district, school bond measure, and municipal elections when conducted pursuant to SDCL 12-19, the section of the law dealing with absentee balloting.

HB 1247 sought to take away the right to vote of a person who is serving a sentence for a felony. Currently, only a person who is convicted of a felony and sentenced to the state penitentiary, including a suspended execution of sentence, is not allowed to vote. Persons who are convicted of a felony, but are on parole or probation status, may vote even though the terms of the felony sentence are not completed. Commentators on the bill claimed that the bill will have a major adverse impact on minorities and lower-income people who are disproportionately represented in our legal system.

Public Assistance Food Distribution: A bill was introduced that focused on the state’s sales tax on food refund program and the mechanics and manner of food distribution to the needy. Several years ago, the state initiated a food tax refund program to address the tax disparity issue. However, in the years since it was initiated, the number of participants has fallen off each year for a number of reasons, including limited time within which to apply. As a result, a sizeable amount of resources has accumulated in the fund created to pay for the tax refund. HB 1206 provided for doing away with the sales tax on food refund program and giving the resources in the fund to a statewide food assistance distribution program. Through a circuitous legislative route that resulted in its passage, the bill offered several occasions to discuss the basis for the need for a food assistance program, the history of programs in the state, the current status of various programs, and ways to better coordinate the efforts. In its final form, the bill repeals sections of SDCL 28-1 dealing with the sales tax refund on food program, transfers the resources currently in the fund to the Department of Social Services (DSS), and authorizes DSS to award emergency food assistance grants. The interest and depth of discussion on the topic indicates that the legislature may take an additional role in this area in future sessions.

Bills That Did Not Pass:

HB 1151: Bill proposed to revise SDCL 13-28-11 dealing with a school district’s financial responsibility when a student from the district is placed into a group home or private child-care center. This area has been subject to litigation between school districts and introduced bills in the past. While the bill was deferred to the 41st legislative day, a summer study group is planned with possible legislation to be presented during the next legislative session.

HB 1174 / HB 1268: Bills proposed to require mandatory drug testing for adult recipients of the TANF (Temporary Aid to Needy Families) and SNAP (Supplemental Nutritional Assistance Program) (HB 1174) programs, and persons receiving Medicaid or financial assistance (HB 1268). These bills have been introduced for the past several sessions. During testimony, it was pointed out that portions of the bills were not permissible under current federal law and program regulations, implementation of the bills would lead to unintended consequences that would be detrimental to the children of the state, and the purpose of the bills were against current state policy. Both bills were deferred to the 41st day.

HB 1175 / HB 1259: Bills proposed to allow for further exemptions from childhood immunizations (HB 1175) and exceptions to vaccination requirements based upon personal beliefs (HB 1259). These bills follow similar ones that have been introduced in the past to allow specific exemptions to immunizations of children by parents or guardians who wish to practice holistic or alternative medicine practices, as well as an exemption for “personal beliefs.” During testimony, the public benefit of immunization requirements in situations where a large number of potentially vulnerable persons congregated was discussed at length and prevailed. Both bills were deferred to the 41st day.

HB 1208: Bill proposed to establish the South Dakota Early Learning Advisory Council. This bill continued a multi-year effort to explore the needs and feasibility of providing early learning educational services to preschool-aged children to better prepare them for the concentrated challenges of regular school. Opponents to the bill expressed a range of concerns from costs to further erosion of parental rights in getting the bill deferred to the 41st legislative day.

HB 1214 / HB 1216: Bills proposed to lower the state sales tax and use tax on certain food items if state economic conditions met certain benchmarks (HB 1214) and increase the rate of sales and use taxation on selected goods and services (HB 1216). These bills intended to address the disparity that food tax imposes upon persons at the lower levels of the economic and resource strata. Persons or families at a subsistence level of living pay a greater percentage of income towards sales tax on necessary food items. Opponents pointed out that the state currently provides a sales tax refund program. Both bills were deferred to the 41st legislative day. [While the sales tax refund program existed as of the date of the committee meeting, HB 1206 later eliminated the sales tax refund program.]

SB 121: Bill proposed to expand Medicaid eligibility to include pregnant women and make an appropriation to pay for the increased costs. This bill continues the effort to provide additional resources to address the issues that may occur during pregnancy to lessen the impact of additional and potentially increased costs of a difficult pregnancy and birth. Opponents argued that due to the still-recovering economy, the resources are not there to support the increased costs. The bill was deferred to the 41st legislative day.

SB 131: Bill proposed to expand the definition of developmental disability that would reduce the number of substantial functional limitations required to be eligible for services from three to one if involving an inability to care for oneself on a daily basis and include a danger to self and danger to others component as a defined limitation. Opponents expressed concerns that the bill, if passed, would add a great deal of cost to the developmental disability program. The bill was deferred to the 41st legislative day.
Gluten, Casein, Celiac Disease, and Autism - Partner Publishes GF/CF Cookbook

by John A. Hamilton

In 2008, I learned a new vocabulary – Celiac Disease, gluten, and gluten-free. Suddenly, I had to stop eating pizza, Chinese food, spaghetti and lasagna, bread, cookies, crackers, and many other things – at least the kind I had been eating. I even had to slightly alter my world-famous salsa. Shortly after speaking at Partners in Policymaking in December, I discovered one of the participants had just published a cookbook of gluten-free (and casein-free) recipes and had quite a story to tell.

Jennifer (Jenny) Jacobson is a Year 20 participant in Partners in Policymaking. She is also the author of “Gluten and Dairy Free Blessings … A collection of Gluten Free / Casein Free recipes from GF/CF families.” Like her participation in Partners, writing the cookbook came as a natural progression from her life experiences.

Jenny and her family’s life became a virtual rollercoaster in 2003, full of many highs, lows, and spirals. Her husband, Barry, was diagnosed with wheat and casein (milk protein) intolerances. Then, at eleven months of age, their son, Kenny, was diagnosed with allergies to wheat, dairy, eggs, bananas, beef, and peanuts. While he outgrew the latter four allergies, he remained unable to eat wheat and dairy products. With the men in her family unable to eat wheat and dairy products, Jenny found shopping for and cooking food they could eat to be a nightmare, describing her cooking as “boring, tasteless and truthfully a lot of work.”

Just two months after Kenny’s food allergies were diagnosed, her second son, Grady, was born with a venous malformation, with three large purple tumors protruding from his left forearm. His arm was stealing his body’s nutrients, resulting in a diagnosis of failure to thrive. He has had fifteen surgical procedures and will require at least two a year, possibly into adulthood. Once Grady’s condition was under control, Jenny began noticing changes in Kenny. At age three-and-a-half, his skills regressed, he became unable to have a conversation, and his sleep pattern changed. He was diagnosed with Autism.

Meanwhile, Barry was experiencing constant fatigue and headaches, and he was losing weight. He was diagnosed with Celiac Disease. Kenny also began losing weight. His skin became pale, he had dark circles under his eyes, and his stomach was bloated. He was also diagnosed with failure to thrive. Jenny found, both through discussions with specialists and her own research, that children with Autism may respond favorably, in terms of behavior and communication, to removal of all gluten and casein from their diets. After removing additional foods from his diet, Kenny began gaining weight. By adhering to a strict gluten-free / casein-free (referred to herein as GF/CF) diet, Barry’s symptoms have improved, both sons are thriving, and Kenny’s Autism symptoms have improved. He did not self-stimulate as much. His conversation improved. His mind overall seemed more clear, as he could think and process information better. Kenny’s tan-trums and sleep pattern also improved.

Gluten, casein, and Celiac Disease may be unfamiliar terms to most people. They were to me. Before further discussing Jenny’s situation and how that resulted in her publishing a cookbook, this article will discuss gluten, Celiac Disease, casein, gluten-free / casein-free diets, and how such diets may improve communication and behavior in children with Autism Spectrum Disorders.

What is Gluten?

Gluten is a protein found in the seeds of several grains, such as barley, rye, and wheat. Oats do not contain gluten, but often end up containing gluten due to contamination in the milling process. As a result, many foods contain gluten, such as pizza, bread, noodles, crackers, cookies and beer. Gluten is used in providing structure or binding to baked products and is contained in many processed foods, sauces, and mixes as a thickening agent. Wheat, in particular, may be listed as an ingredient under a variety of names (e.g., Triticale X triticosecale, Triticum vulgare).

As with oats, there are a number of gluten-free grains that may become contaminated in the growing, milling, or processing stage. Corn, white and brown rice, wild rice, sorghum, buckwheat, millet, quinoa, amaranth, manioc or cassava, and teff are all gluten-free. One needs to make sure to buy products that have not been mixed or milled with wheat or other unsafe ingredients (which occurs in buckwheat, millet, quinoa, amaranth, manioc or cassava, and teff) or enhanced with gluten-containing ingredients (which may occur in all types of rice, corn, and sorghum).

What is Celiac Disease?

Many people have sensitivity to gluten, while others have what is called Celiac Disease, sometimes referred to as

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Celiac Sprue, Nontropical Sprue, or Gluten-sensitive Enteropathy. Celiac Disease is a digestive disorder (not a food allergy) wherein the body has a toxic reaction to gluten. It is hereditary, chronic (will not ever go away), and autoimmune (causes the body to attack itself). In essence, it is a condition causing malabsorption and malnutrition. Gluten causes the body’s immune system to damage the villi in the lining of the upper small intestine. These villi, when doing their job, absorb many of the nutrients the body requires. Celiac Disease causes these villi to shrink and flatten, preventing the body from absorbing nutrients it needs to survive. It causes persons to become malnourished, no matter how much food they eat.

Celiac Disease is a devious condition, as the nutritional deficiencies caused by the chronic malabsorption can show up with any of a large variety of symptoms and serious health problems. As a result, there is no simple checklist for diagnosis and it can go undiagnosed for years. In the United States, it takes an average of nine to eleven years to diagnose Celiac Disease after the onset of symptoms. As a result, while it is estimated that about three million people, or one in 133, have Celiac Disease, less than five percent of those who have Celiac Disease know it. While it often shows up with gastrointestinal symptoms like diarrhea and bloating, mimicking other gastrointestinal disorders, some people with Celiac Disease have no gastrointestinal discomfort. Signs and symptoms can vary greatly from person-to-person, as Celiac Disease is a multisystem disorder. Some symptoms may be constant, while others are occasional. As a result, doctors frequently mistake Celiac Disease for other conditions. All of these reasons make diagnosis very challenging.

For example, Celiac Disease may present itself with symptoms such as dental and bone disorders (such as osteoporosis), depression, irritability, joint pain, mouth sores, muscle cramps, skin rash, stomach discomfort, and even tingling in the legs and feet (neuropathy). Depending on the degree of malabsorption, the signs and symptoms of Celiac Disease can range from no symptoms, to few or mild signs and symptoms, to many or severe signs and symptoms. Research-inding symptoms can be somewhat frustrating, as no two sources seem to have identical lists. The box on this page includes symptoms combined from a variety of sources, any of which might be an indicator one has Celiac Disease.

In addition, untreated Celiac Disease has been linked with:

- Intestinal cancers;
- Iron deficiency anemia;
- Rheumatoid arthritis;
- Thyroid problems;
- Fibromyalgia; and
- Type 1 Diabetes.

As one can see from the diverse and deceptive symptoms, Celiac Disease may manifest itself in any number of different ways. It can develop at any age. Diagnosis is typically a two-step process – first, a particular blood panel that can rule-out or determine if one is at risk. For those found to be at risk, the second step

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**Possible Indicators of Celiac Disease**

- Abdominal cramps, gas and bloating
- Anemia
- Borborygmi (stomach rumbling)
- Coctaneous bleeding
- Constipation
- Decreased appetite
- Diarrhea (constant or off and on)
- Distension
- Easy bruising
- Epistaxis (nose bleeding)
- Failure to thrive
- Fatigue or general weakness
- Flatulence
- Fluid retention
- Foul-smelling or grayish stools that are often fatty or oily, stools that float, or bloody stools
- Gastrointestinal symptoms
- Gastrointestinal hemorrhage
- Hair loss
- Headaches
- Hematuria (red urine)
- Hypocalcaemia/ hypomagnesaemia
- Infertility
- Iron deficiency anemia
- Itchy skin
- Joint pain
- Lactose intolerance
- Lymphocytic gastritis
- Missed menstrual periods
- Mouth ulcers
- Muscle cramps
- Muscle wasting
- Nausea
- Nosebleeds
- Obesity
- Osteoporosis
- Pallor (unhealthy pale appearance)
- Panic Attacks
- Peripheral neuropathy (nerve damage)
- Reproductive problems (infertility, miscarriages)
- Seizures
- Skin rashes
- Tingling or numbness in hands or feet
- Unexplained short height
- Vertigo
- Vitamin B12 deficiency
- Vitamin D deficiency
- Vitamin K deficiency
- Vomiting
- Voracious appetite
- Unexplained weight loss

**Children with Celiac Disease may also have:**

- Defects in the tooth enamel and changes in tooth color
- Delayed puberty
- Irritable and fussy behavior
- Poor weight gain
- Slowed growth and shorter than normal height for their age

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(Continued from page 10)
is a surgical procedure - a biopsy (called an upper endoscopy) wherein the doctor inserts a tube down the throat, through the stomach, and into the small intestine. There, with a fiber-optic camera and small clip, the doctor views the wall of the small intestine and removes small tissue samples.

While there is no cure for Celiac Disease, fortunately the effects of Celiac Disease are correctable for most through a gluten-free diet. Without the gluten, the body stops attacking itself and the villi will grow back, perhaps even to pre-Celiac Disease state, allowing them to do their job in absorbing nutrients.

Casein

Casein (pronounced Kay-seen) is a protein found in dairy products and other foods containing dairy or lactose. Even foods proclaiming to be dairy-free or lactose-free may contain casein. Because many soy and imitation dairy products also contain casein, it is important to read labels carefully when following a strict casein-free diet. Casein-free diets are often used in combination with a gluten-free diet. Both are referred to as “elimination diets” because particular types of foods are eliminated from meals.

Gluten-free / Casein-free Diets

Going gluten-free is a big change for the entire family. Even if only one family member cannot eat gluten, it still means an adjustment for the rest of the family. Does the person with Celiac Disease eat a separate meal, or does the family eat gluten-free food as well? Either way, whoever does the shopping will need to educate themselves in all the gluten-containing ingredients. Wheat, for example, can be listed under a number of names (in her book, The G Free Diet, Elisabeth Hasselbeck lists 36 different names for types and forms of wheat). Shoppers will need to carefully read the labels of everything purchased for the person with Celiac Disease to eat.

The same goes for persons on casein-free diets. While products containing milk or milk proteins will typically include butter, cheese, yogurt, cream, ice cream, and Pediasure, milk or casein are also contained in many prepared foods.

Reading labels and searching for gluten-free and/or casein-free food is not easy, but becomes easier with time and experience. Jenny described her first experience as follows:

The day after the allergy doctor’s phone call, I drove to the local grocery store with my dairy-free and wheat-free cards in hand. I was completely armed with an arsenal of all the dairy and wheat buzzwords to help me identify what we could and could not eat. Three hours later, I left

Gluten-free/Casein-free Diets and Autism Spectrum Disorders

While research studies are ongoing, and so far not necessarily conclusive due to small study groups, there have been published studies and a great deal of anecdotal evidence from doctors and parents documenting how removing gluten and casein from a child with Autism’s diet has had a significantly positive effect on the child’s functioning. Children with Autism Spectrum Disorders (ASDs) have shown improvements in communication, behavior, concentration, etc.

Children with ASDs tend to have a higher incidence of gastrointestinal problems. The prevailing theory is that a significant number of children with ASDs (as well as ADHD) cannot properly digest gluten and casein proteins. As a result, instead of passing through the digestive system, the proteins break down into endogenous opioids (also referred to as morphine-like peptides, and casomorphines when referring to casein) that leak into the bloodstream. They act like morphine, triggering an opiate-like effect in the brain. In other words, the gluten and casein have a profound effect on the brain, causing the children to appear as if stoned (glazed eyes, dilated pupils, staring, unresponsive, inappropriate behaviors). They also tend to crave foods with gluten and casein, similar to an addict.

Thousands of parents have reported a GF/CF diet has resulted in a mild, moderate, or marked improvement in their children with ASDs. While not all children with ASDs will respond to a GF/CF diet, Dr. Kenneth A. Bock, co-director of the Rhinebeck Health Center in New York and author of Healing the New Childhood Epidemics: Autism, ADHD, Asthma and Allergies, has treated over 2,000 children with ASDs and has seen positive results from a GF/CF diet in 60 percent of those children. It is generally his first step in treatment, although he is quick to point out that each child is different and some require additional dietary changes.

While a GF/CF diet is certainly something parents should strongly consider, the transition may be difficult. In addition to the change parents must make in the food they purchase and prepare, children with ASDs may have difficulties for two reasons. First, children with ASDs may have limited foods they will eat in the first place, so they may initially demonstrate increased behaviors simply because some or all of those foods are taken away and new foods are introduced. Second, it may be precisely the foods the children want that happen to contain gluten and/or casein. Since it is these foods that cause the opioid effect, the children are literally addicted to the foods worsening their condition. For many children, removing these foods may result in actual withdrawal symptoms like one would see when an addict withdraws from a drug. For this reason, some children will have increased behaviors for a few days, such hyperactivity, agitation, or irritability, while others may become lethargic or “spacey.” Dr. Bock describes this “withdrawal” as usually lasting one to three days, but sometimes up to a week. Jenny experienced this when Kenny began his GF/CF diet: “It was like he was coming off a high.”

While some parents will see a change within a week, switching to a GF/CF diet may not produce immediate results. For casein, it may take up to three weeks, while with gluten, it may take up to three months before seeing results. However, for it to work, the GF/CF diet must be strictly followed. Dr. Bock also described that for some children, following the GF/CF diet trial, there may be additional foods the child is sensitive or allergic to that will need to be removed from the child’s diet.
Gluten-free/Casein-free Diets and Autism Spectrum Disorders

the grocery store frustrated and in tears. This was going to be harder than I thought.

I felt the same way. It is initially overwhelming. It is a constant learning experience, but one that opens a door to many foods I had never heard of previously, and foods that are nutritionally superior to all products made with white wheat flour. For example, I recently purchased quinoa (pronounced keen-wah – Inca for “the mother grain”) for the first time and used it with stir-fry.

Jenny Jacobson

Celiac Disease can be looked at as a curse and a blessing. The “curse” is readily apparent – a chronic autoimmune disease where one can no longer eat some of their favorite foods, probably not ever without consequences. You have to ask questions, read labels, discuss, and be aware of everything you eat. It is easy to overlook the “blessing” – you have the ability to make yourself feel better. You have the unique ability to heal yourself, not with medications or invasive surgeries, but with food! Again, many of the replacements are much better for you.

Elimination and Replacement

As mentioned previously, gluten-free and casein-free diets are elimination diets because certain types of foods are completely removed from the diet. While wheat, rye, barley, and possibly oats are removed, there are a number of grains that do not contain gluten that can be used to replace those containing gluten. It is important to make sure that replacement occurs – that one receives ample fiber, vitamins, and minerals. Supplementation can help make-up for the lack of these nutrients when foods containing gluten are eliminated.

Similarly, the major health concern with a casein-free diet is whether the person on the diet will receive adequate nutrition, since a major source of calcium (as well as other nutrients like vitamin D), which is required for strong bones and teeth, is removed. Calcium can be replaced by sources like orange juice, soy milk, and calcium-enriched rice milk. It would be a good idea to talk with one’s doctor or a nutritionist about fortified replacements are much better for you.

Resources

Fortunately, a person new to the gluten-free and/or casein-free world does not have to “reinvent the wheel.” There are a number of resources available at a variety of websites, in books, and from nutritionists. Grocery stores are getting better at helping one find gluten-free and casein-free foods. Some have separate “health food” sections. More health food stores exist today.

Two books I have found extremely helpful are The G Free Diet by Elisabeth Hasselbeck, and The Gluten-free Bible by Jax Peters Lowell. Whether one remembers Elisabeth fondly from Survivor: The Australian Outback, or loves/hates her on The View, her book (234 pages) is very good, covering first-hand all aspects of Celiac Disease and living gluten-free, such as diagnosis and symptoms of Celiac Disease, gluten and its sources, shopping, setting up the kitchen, cross-contamination, cooking (including some recipes), dining out, traveling, children on gluten-free diets, being a guest or having guests, living with someone on a gluten-free diet, the benefits of eating gluten-free for those without Celiac Disease, and the connection to Autism (wherein she also discusses casein / casein-free diet). Finally, she lists several pages of resources: books; cookbooks; online information and resources; grocery stores; and many types of gluten-free products.

The Gluten-free Bible (530 pages) is also written based on the author’s first-hand experiences. She also covers all aspects of Celiac Disease and living gluten-free, includes many recipes, and includes references to a number of resources, including support groups throughout the country, and much, much more.

“Gluten and Dairy Free Blessings”

One of the most recent gluten-free / casein-free cookbooks available is Jenny’s book, Gluten and Dairy Free Blessings... A Collection of Gluten Free/Casein Free recipes from GF/CF families (see back cover below). Jenny began accumulating recipes in 2007, looking for those that both tasted good and could replace foods one would otherwise typically eat. She had friends who had found GF/CF recipes and they began exchanging ideas and recipes. While Jenny’s extended family was supportive of Barry’s and Kenny’s dietary needs, wanting to prepare foods that were safe, she heard from others how their families were not very supportive. They either did not want to take the time to understand, or were simply overwhelmed with the prospect of preparing gluten-free and/or casein-free meals.

Jenny also had many friends who wanted to try a GF/CF diet, but found it overwhelming. Rather than continually asking Jenny if she had a recipe for this or that, her friends suggested that Jenny compile a cookbook. Jenny decided to do so, mainly to help-out her friends, but also to help-out her extended family. She began the project in February 2011, and completed and published her cookbook in December 2011.

GF/CF Cookbook

(Continued on page 15)
Home Health Services Coverage by the South Dakota Medicaid Program

by Chris C. Houlette

The South Dakota Medicaid Program provides for the coverage of “home health services” in certain situations. What are home health services? According to Administrative Rules of South Dakota (“ARSD”) 67:16:05:01, home health services are “skilled nursing services, medical social services, or home health aide services provided by a home health agency.” Medical social services are “those services which contribute to the treatment of a patient’s physical condition and are needed because social problems exist which impede the effective treatment of the patient’s medical condition or the patient’s rate of recovery.” Home health aide services are “nursing-related services not required to be performed by a licensed health professional but prescribed by a licensed physician and provided on an intermittent basis.” A home health agency is “an organization which is primarily engaged in providing skilled nursing, medical social services, or home health aide services and which meets the requirements of a home health agency under 42 C.F.R. §§484.1 to 484.55 inclusive (October 1, 2005). This does not include an agency or organization whose function is primarily the care and treatment of mental illness.”

Pursuant to ARSD 67:16:05:03, home health services are available in the person’s place of residence. To qualify, one must be eligible for medical assistance and the services needed must meet the relevant requirements of the administrative rules.

The types of covered home health care services are limited to those listed in ARSD 67:16:05:05:

(1) Skilled nursing services, which may include visits by a student nurse enrolled in a school of nursing;
(2) Medical social services provided by a licensed social worker who is not an employee of the department;
(3) Medical supplies used incidental to the visit when necessary to administer the attending physician’s prescribed plan of care;
(4) Multiple visits of the same discipline on the same day if the medical necessity for the multiple visits is documented by the attending physician in the individual’s medical record;
(5) Daily visits if the medical necessity for the visits is documented by the attending physician in the individual’s medical record. The daily visits are limited to four weeks but may be extended beyond the four-week period if the attending physician documents the need for the visits in the individual’s medical record;
(6) Therapy services unless restricted by § 67:16:05:05.05; and
(7) Postpartum services meeting the requirements of §67:16:05:05.06.

Therapy services are “physical, respiratory, occupational, and speech therapy services provided by the home health agency either directly or by contract with a qualified therapist acting within the therapist’s scope of practice.” The attending physician is the person’s “personal private physician or a physician assigned to care for the individual in the absence of a personal private physician.” Skilled nursing services are “nursing services defined in SDCL 36-9-3 which are provided on a part-time or intermittent basis.” Postpartum services are “skilled nursing services following a child’s birth.” ARSD 67:16:05:05 also provides, “The covered items and services provided under this chapter for children under the age of 21 are not subject to the limits contained in this section.”

Home health services are required to meet criteria set out in ARSD 67:16:05:05.01:

(1) They must be provided by a home health agency employee who is qualified to perform the required service;
(2) They must be prescribed by the attending physician and contained in the home health agency’s written plan of care;
(3) They must be provided at the individual’s place of residence, which does not include a hospital, penal institution, detention center, school, nursing facility, intermediate care facility for the mentally retarded, or an institution which treats individuals for mental diseases;
(4) They must be provided to an individual who has a medical condition caused by an illness or injury and for whom leaving the home would require a considerable effort and the assistance of another individual or the aid of supportive devices. This provision may be waived for postpartum services or when leaving the home is medically contraindicated by a physician. An individual’s age alone does not qualify the person for home health services; and
(5) They must be provided intermittently but more than once a day and no more frequently than five days a week, except as specified by subdivision 67:16:05:05(4).

If Medicare does not pay for a service due to a lack of medical necessity, one will not be eligible for home health services.

ARSD 67:16:05:05.6 provides further limitations for postpartum services, stating:

Postpartum services are limited to one visit each day, may not be for more than four consecutive weeks following the child’s birth, and are subject to the provisions of this chapter. The home health agency must receive approval from the department before providing additional visits. One of the following risk factors must be present and must be documented in the physician’s written orders and the home health agency’s plan of care:

(1) The mother has a documented prenatal or postpartum medical condition which threatens the mother’s health or the health of the baby;
(2) The infant has a documented medical condition which requires skilled nursing intervention;

Home Health Services
(Continued on page 15)
While the cookbook contains sections on appetizers and beverages, soups and salads, vegetables and side dishes, main dishes, breads and rolls, desserts, cookies and candy, and finally “this and that,” it contains pages on substitutions to use in recipes for dairy items and wheat flour. It also provides lists of items that contain gluten and dairy, as well as items that *may* contain gluten and dairy.

In discussing her cookbook, Jenny emphasized that she wanted to make sure the recipes in the book were actually something people would like to eat and that she has tried nearly all the recipes in the cookbook. Jenny’s cookbook works well for those in communities without ready access to specialty food stores because most ingredients are typically available everywhere.

The cookbooks are hard covered with a plastic binding. They cost $15.00 ($20.00 if mailing is necessary). All proceeds from the sale of Jenny’s cookbook go towards paying for Grady’s surgical procedures in New York City and Jenny’s Autism therapies. For information on contacting Jenny to purchase a cookbook, go to [http://www.facebook.com/pages/Gluten-and-Dairy-Free-Blessings-cookbook/291307627586512](http://www.facebook.com/pages/Gluten-and-Dairy-Free-Blessings-cookbook/291307627586512). Copies are also available at Parham Chiropractic at 2500 W. 46th St., Suite 100, Sioux Falls, SD 57105, and Autism Behavioral Consulting, 6009 W. 41st St., Suite 4, Sioux Falls, SD 57106.

Jenny has also just started a blog at [http://glutendairyfreeblessings.com/](http://glutendairyfreeblessings.com/). “The blog will feature the cookbook but will also focus on my family’s GF/CF Diet among other things. There is a spot where you can follow my blog by adding your email address so then you can get automatic notices whenever I add a post. It is in its infancy right now but follow me or check back often for updates.”

**Sources:**


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Copy is also available at Parham Chiropractic at 2500 W. 46th St., Suite 100, Sioux Falls, SD 57105, and Autism Behavioral Consulting, 6009 W. 41st St., Suite 4, Sioux Falls, SD 57106.

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**In Memoriam – Jim Johnson**

Former SD Advocacy Services employee, James “Jim” Johnson, passed away at age 69 on November 19, 2011. Jim worked half-time for SDAS from January 1 through October 31, 1992, as an advocate in what was then our new Protection and Advocacy for Individual Rights (PAIR) Program.

Jim was always an active participant in whatever he did. Prior to sustaining a spinal cord injury from a diving accident at age 35, Jim coached Teener Baseball for ten years, winning two state titles, and was a member of the City Council and the Volunteer Fire Department in Brandon. Following his injury, Jim’s life took an entirely new direction. He went back to school to get degrees in Business Administration and Computer Science from Augustana College. He worked as a Program Development Coordinator for Prairie Freedom Center in Sioux Falls before moving to Pierre to work for the State in 1989. Jim was co-founder of the South Dakota Coalition of Citizens with Disabilities and later was its Board President. He actively promoted adoption of uniform disabled parking policies on State-owned or leased property. He participated in and promoted Ski for Light and Fishing Has No Boundaries. He helped reestablish what was then called the Mayor’s Advisory Committee for the Handicapped in Pierre. After leaving SDAS, Jim worked for DakotaLink for several years.

Jim was an advocate in every sense. Rather than allow his disability to deter him, instead it seemed to empower him to become even more involved, wherein he specifically focused his energy toward helping other individuals with disabilities.
For the past five months, 27 committed and motivated individuals have been learning how to be self-advocates and leaders, and how to empower themselves and others. These 27 individuals are the dedicated members of Year 20 of South Dakota Partners in Policymaking. The class has chosen the theme, “Like Minds, Like Hearts … One United Voice.”

DECEMBER TRAINING:

Katherine Munson from Pierre and Brenda Smith of Sioux Falls (Year 5 graduate), opened the session teaching all about one-page profiles, focusing on the person, relationship maps, and much more during their presentation on Person Centered Thinking.

What are my rights and how do I get what my child needs? John A. Hamilton, SDAS Legal Affairs Director, presented on IDEA and “How to be a Superhero for Your Child’s Education.” He explained that many of the “Superhero” discussion points apply equally to self-advocates and guardians seeking services from adult service agencies. “One must speak up, as you are your child’s best, and often only, advocate at IEP Team meetings. Silence is NOT Golden.”

Dr. Patrick Schwarz from Skokie, IL, provided valuable insight and actual experience for successful inclusion in education. “Inclusion means everyone belongs everywhere in our schools and community.” He stressed how successful school inclusion leads to successful community inclusion, and starting as early as possible is best. Schwarz also highlighted the 12 components of inclusion.

Tim Neyhart, PADD Program Director for SDAS, Pierre, ended the session discussing transition and how it is never too early to start thinking about it and talking to your child about what he/she wants. He stressed including the student in all IEP meetings addressing transition services.

JANUARY TRAINING

David Hancox, a lobbyist from Golden Valley, MN, spoke of the legislative process. “Don’t be afraid to talk to your legislators. They are regular people just like you! And, always remember, they work for you!” He explained how the class is a resource to legislators on all levels and “What you bring to the table is important.” He shared pointers on effective testimony - always tell the truth and if you do not know the answer, say so. He also discussed campaigns and coalition building and using the media effectively.

Participants used their newly-acquired skills by providing mock testimony on current bills before the South Dakota Legislature. Helping as “bill coaches” were Tom Scheinost, Dennis Hook, Dan Rounds, Dawn Nagel, Arlene Poncelet, and Neyhart, all of Pierre, and Roger and Vikki Day of Highmore, Year 10 and 16 graduates, respectively. Mock testimony panel members included District 24 Representative Tad Perry of Ft. Pierre; District 4 Representative & Speaker of the House Val Rausch of Big Stone City; District 26A Representative Larry Lucas of Mission; and District 13 Representative Susy Blake of Sioux Falls. Lt. Governor, Matt Michels, chaired the panel. The class also viewed the House and Senate in action and met with Governor Dennis Daugaard for a photo on the Rotunda steps.

Robert J. Kean, Executive Director of SDAS, and Shelly Pfaff, Director of the South Dakota Coalition of Citizens with Disabilities, presented on the Americans with Disabilities Act. Kean also demon-
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strated using the internet to follow the SD Legislature and bills being considered.

FEBRUARY TRAINING

Continuing on with the governmental theme, this session opened with a panel comprised of representatives of city, county, tribal, and school government. Pierre Mayor Laurie Gill (who is also the Secretary of the Dept. of Human Services) spoke on behalf of city government. Kevin Hipple and Cari Leidholt, both of Pierre, represented counties and school boards, respectively. Year 1 graduate, Stacey LaCompte of Ft. Pierre, represented the tribal nations. Each described the similarities and differences in their governmental bodies and how individuals are invited to attend meetings, get on the agenda, and be heard.

Jim Kellar of Sioux Falls discussed the importance of listening skills and how to develop those skills. He used a Talking Circle to help the class learn how to listen. In this circle, each participant is given a chance to talk, without judgment or interruption, when in possession of the talking piece. When finished, the talking piece is passed to another member of the group. Kellar explained, “Listening is an art and sometimes listening to others is a lost art. You need to listen, respect, and HEAR others as they speak, and if you are a good listener you can help affect attitudes, life changes, and personalities.”

Pat Czerny of DakotaLink in Rapid City discussed assistive technology devices, explaining how even the simplest device can make the difference in being dependent or independent. He brought several devices, giving a “hands on” demonstration on how they work and can make things simpler for everyone.

Kellar ended the session discussing meeting management and the importance of being in control, but not aggressive. He showed how to be sure to include everyone in the meeting, listen to all ideas, summarize what you heard, and work as a team and get everyone involved.

MARCH TRAINING

This session began with Kean and Neyhart presenting on Social Security, explaining who qualifies and why and what happens if you return to work.

Dr. Wayne Duehn of Arlington, TX, made his thirteenth trip to South Dakota to teach Partners how to detect abuse and neglect. He discussed where, how, and to whom it should be reported, the profile of perpetrator, and how abuse and neglect occurs anywhere, including South Dakota. “Sexual and physical abuse of our elderly, children, and individuals with disabilities is on the rise and you need to know the signs and how to stop it.” He also provided an overview on human sexuality issues, including suggestions of what and how to educate young children of all abilities on the importance of “it is your body and it is private.”

Dennis Hook (pictured right), a Sr. Master 4th degree black belt in Tae Kwon Do from Pierre, taught Tai Chi, self-defense moves that can be used by everyone (including persons with limited movement and mobility), and with assistance from Jamison Smith of Pierre, provided a seminar on child abduction prevention.

The sixth and final session of Year 20 will be held April 27-28, 2012, at the Ramada Inn & Suites in Sioux Falls. The weekend also includes continuing education, Common Grounds, and the graduation banquet and ceremony.
A
fter listening to a three-hour presentation by Susan Barton, an internationally recognized expert, I realized just how much I did not know about dyslexia. Most people do not know what dyslexia is, what the warning signs are, where it comes from, how to get help, and what does and does not work for people who have dyslexia.

Susan Barton is not only an internationally-recognized expert in the field of dyslexia, but also in the field of ADHD (Attention Deficit Hyperactivity Disorder). She has presented at conferences throughout North America and has taught at the graduate and undergraduate level at several leading universities. Susan is trained in seven different Orton-Gillingham influenced system, an Orton-Gillingham influenced system designed specifically for parents, home school parents, and volunteer tutors in literacy programs. The website is www.Bartonreading.com. In 1998, Susan Barton founded Bright Solutions for Dyslexia. The sole mission of Bright Solutions for Dyslexia is to educate parents and teachers about the causes, symptoms, and research-based solutions for children and adults with dyslexia. Her website is www.BrightSolutions.US.

Dyslexia is a language-processing disorder that impacts directionality and the ability to memorize random facts. It is inherited and is neurological in origin. Some of the warning signs of dyslexia can begin to appear as early as one year of age. You can accurately test for dyslexia as early as age five. Dyslexia is very common, as it affects 20% of the population. At least 40% of people with dyslexia also have ADD (Attention Deficit Disorder) or ADHD. Contrary to popular belief, people with dyslexia do not see things backwards. It is not a vision problem. One can sometimes hear dyslexia because people with dyslexia will get sounds out of order. For instance, a person with dyslexia may say “animal” instead of “animal.” They may have a hard time memorizing math facts and telling time. For some, dyslexia will be mild, while others may have a much more severe form. Dyslexia is the most common reason that a child struggles with spelling, writing, and reading. Children with dyslexia CAN read. They have to use different strategies in order to read, but these strategies will fail them by the time they reach the third to fourth grade, and in some cases sooner than that.

The National Institutes of Health has been studying dyslexia for more than 30 years. The research has resulted in the following current definition: Dyslexia is a specific learning disability that is neurological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties usually result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede growth of vocabulary and background knowledge. The reading, spelling and writing failure caused by dyslexia is preventable and fixable by teaching them using an Orton-Gillingham-based system.

According to Susan Barton, if a child has three or more of the following warning signs, they may have dyslexia, and parents should learn more about dyslexia and/or seek out testing.

**WARNING SIGNS**

**Preschool**
- delayed speech;
- mixing up the sounds and syllables in long words;
- chronic ear infections;
- severe reactions to childhood illnesses;
- constant confusion of left versus right;
- late in establishing a dominant hand;
- difficulty learning to tie shoes;
- severe reactions to childhood illnesses;
- dysgraphia (slow, non-automatic handwriting that is difficult to read);
- letter or number reversals continuing past the end of first grade;
- extreme difficulty learning cursive;
- slow, choppy, inaccurate reading--guesses based on shape or context, skips or misreads prepositions (at, to, of), ignores suffixes, can’t sound out unknown words;
- terrible spelling;
- often can’t remember sight words (they, were, does) or homonyms (their, they’re, and there);
- difficulty telling time with a clock with hands;

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Dyslexia

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- trouble with math - memorizing multiplication tables, memorizing a sequence of steps, directionality;
- when speaking, difficulty finding the correct word - lots of “whayamalaciltis” and “thingies,” common sayings come out slightly twisted;
- extremely messy bedroom, backpack, and desk; dreads going to school - complains of stomach aches or headaches;
- may have nightmares about school.

High School

All of the foregoing symptoms plus:

- limited vocabulary;
- extremely poor written expression - large discrepancy between verbal skills and written compositions;
- unable to master a foreign language;
- difficulty reading printed music;
- poor grades in many classes;
- may drop out of high school.

Adults

Education history is similar to high school, plus warning signs in adults include:

- slow reader;
- may have to read a page two or three times to understand it;
- terrible speller;
- difficulty putting thoughts onto paper - dreads writing memos or letters;
- still has difficulty with right versus left;
- often gets lost, even in a familiar city;
- sometimes confuses “b” and “d,” especially when tired or sick.

People with dyslexia have many strengths or gifted areas controlled by the right hemisphere of the brain. Some of them are: fashion; photography; architecture; musical ability; artistic ability; and mechanical ability. They often have great social skills and make friends easily. They may have high intuition, good logic, and 3-D visualization skills. They can be extremely curious with lots of “why” questions and have very vivid imaginations. They can be creative, global thinkers. Many famous people in all walks of life have dyslexia, including several of our United States Presidents.

Things that will not work in teaching a person with dyslexia:

- Reading to someone with dyslexia does not help them to read independently;
- Making them feel they are a disappointment because they cannot read;
- Waiting to get help if you suspect someone has dyslexia will make things worse!

The following programs will not work if used for someone with dyslexia, but they can be used for other disabilities:

- Hooked on Phonics or The Phonics Game;
- Reading Recovery;
- Accelerated Reader;
- Vision Therapy;
- Brain Gym or other neurodevelopmental exercises;
- Special classes;
- Medicine;
- Special diets;
- Most commercial learning center chains, such as Sylvan, Kuman, and Score.

There are certain things that will work in teaching a person with dyslexia. The most well-known Orton-Gillingham based systems that will work are:

- Orton-Gillingham (If auditory processing is too severe, they may not be ready for it). Eighty five percent are ready. Orton-Gillingham teaches reading and spelling at the same time. (781) 934-5548;
- Slingerland – www.Slingerland.org;
- Alphabet Phonics - Texas Scottish Rite Hospital for Children. (214) 559-7800;
- Project Read - www.ProjectRead.com;
- Language! - www.SoprisLearning.com;

If a person with dyslexia is to achieve maximum success, the following must be done:

I. Dyslexia needs to be identified.
   A. Either suspected or diagnosed.
   B. Right type of tutoring needs to be secured.
   C. Hire a tutor or become one yourself.
   D. Classroom accommodations.


   Texas has a dyslexia law that requires screening for dyslexia at no charge. A 504 plan is developed with accommodations, and the child works with a dyslexia specialist on campus with Orton-Gillingham. A handbook published by the Texas Education Agency can be accessed by going to www.BrightSolutions.US and clicking on “How to Get Help” on the top bar, then clicking “States with Dyslexia Laws” on the left, and lastly clicking “Texas.” This information can be very useful in getting legislation enacted in your own state.

   An attempt was made to enact a law during South Dakota’s Legislative Session in 2008. A bill was introduced to amend ARSD 24:05:24:01:01 to include dyslexia as a qualifying disability for special education. The bill passed the House by a narrow margin, but it did not make it through the Senate because it was argued that dyslexia is covered under specific learning disabilities. After the defeat of this bill, a study was completed, a work group established, and an education aid document for teachers and parents was developed. This document is entitled “The Dyslexia Handbook for Teachers and Parents in South Dakota” and is available at http://doc.sd.gov/eoss/sped.asp by clicking “Dyslexia Handbook” on the right-hand side. It was first published in March 2009 and revised in November 2010.
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CHANGE SERVICE REQUESTED

TSA Cares
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This is a good website to visit, as it also goes into detail on what is normally allowed for carry-on, as well as items that are prohibited. You may also download a disability notification card for air travel at http://www.tsa.gov/assets/pdf/disability_notification_cards.pdf. Happy traveling!

Home Health Services
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(4) It is not furnished primarily for the convenience of the recipient or provider; and

(5) There is no other equally effective course of treatment available or suitable for the recipient requesting the service which is more conservative or substantially less costly.

ARSD 67:16:05:02 requires a home health agency to have the physician’s order prescribing the services that are needed before it can provide services to a person. The home health agency is also required to prepare a plan of care for the person based on services prescribed by an attending physician and information the home health agency has received from the person. The attending physician needs to review and sign the plan of care. A plan of care is “the plan developed by the home health agency in response to the attending physician’s written orders to the agency prescribing the needed services and the duration of those services.”

Once active, the attending physician needs to periodically review the plan of care and recertify the need for services. A recertification for medical social work needs to be done “at least every 30 days” following when services began, but for nursing, home health aide, and therapy services, the recertification must be done “at least every 60 days” following service commencement. The home health agency is required to get the recertification.

ARSD 67:16:05:06 lists services that are not covered. Those services are physician’s medical or surgical services; drugs and biologicals; personal comfort items; general housekeeping services; meals or other nutritional items delivered to the person’s home; posthospital benefits which include services by a home health agency operating primarily for the treatment of mental illness; dietician visits; visits solely for the purpose of teaching the person or the person’s caregiver; services which are not medically necessary; custodial care; and mileage.

One’s ability to obtain home health services cannot be presumed and is subject to the requirements set forth by law. Eligibility is on a case-by-case basis.

Calendar

♦ April 27, 2012 - SDAS Board of Directors, 3:30 p.m., Ramada Inn, Sioux Falls
♦ April 27, 2012 - PADD Advisory Council, 3:00 p.m., Ramada Inn, Sioux Falls
♦ April 27-28, 2012 - Partners in Policymaking, Ramada Inn, Sioux Falls
♦ April 28, 2012 - Partners in Policymaking Continuing Education, Graduation, Ramada Inn, Sioux Falls
♦ June 6-7, 2012 - Yankton Area Mental Wellness Conference, Mount Marty College, Yankton
♦ June 10-12, 2012 - Dare to Dream Conference, Holiday Inn, Spearfish