



SOUTH DAKOTA

Parent Connection

Resources for families of children with disabilities.

Fall 2015

September

October

November

Visit Us at www.sdparent.org



www.facebook.com/SDParentConnection

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Circuit is a quarterly printed and electronic publication providing in-depth information around a central theme for each issue.

Circuit

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



What Parents Should Know... About Health Care Coordination

Where is Your Child's Medical Home?

A MEDICAL HOME is the kind of health care we all want and deserve. A MEDICAL HOME is not a place—it is the way care is provided to your child/youth and your family. At the core of a MEDICAL HOME is a knowledgeable, compassionate health care provider and care team chosen by a patient and their family to take care of a child/youth's health needs. National Center for Medical Home Implementation

As a parent of a child with disabilities or chronic health conditions, you know that working and communicating with many doctors, nurses, and other health, education, insurance, and social service professionals can be difficult. In a Medical Home, information and concerns are shared by everyone caring for your child. Needs are addressed in a coordinated way, with a primary healthcare provider and their staff serving as a coordinator of your child's Medical Home team.

A Medical Home means your Health Care Team...

- Knows the health history of your child/youth and treats your child/youth with compassion and an understanding of his/her strengths;
- Creates a trusted partnership with you and your child/youth by listening to concerns and needs, and sharing decision making;
- Communicates with and coordinates care with other health care providers your child receives care from when needed;
- Connects with community resources to make sure medical and non-medical needs of your child/youth and family are met to

(Continued on page 2)

Where is Your Child's Medical Home?

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promote health and quality of life for the child and family;

- Respects and honors your culture and traditions;
- Develops a care plan with you and your child/youth when needed;

and You and Your Child/Youth...

- Are comfortable sharing concerns and questions with your health care team and other providers;
- Routinely communicate your child/youth's needs and family priorities to your team;
- Remember to tell your team about any care received between visits (eg, emergency room visits, urgent care clinics).

The benefits to your child and family from a family-centered, teamwork approach to care – a Medical Home – include:

- More organized care
- More efficient communication – families don't have to repeat information to multiple caregivers;
- Support from a team of caregivers
- Exams scheduled in a coordinated, efficient way without duplicated services
- Improved health care for your child

Let your care provider know how important these issues are to you your family. Learn more about the Medical Home approach to care, what to expect, and how to make the most of it, by visiting www.MedicalHomeInfo.org. You'll find information videos, webinars and tools and resources for families and providers.

"The Medical Home recognizes families as Constants in the life of their child, Experts in the individual strengths and needs of their child, Supervisors of those who coordinate their child's care, and Visionaries who see the "big picture" for their child and his or her future.

Medical Home: Families and Providers Working Together. Washington Medical Home Leadership Network. www.medicalhome.org/leadership/brochures.cfm

Supporting Lives Across the Lifespan Resource Available

Supporting Real Lives Across the Lifespan – Charting the Life Course: A guide for Individuals, Families and Professionals is a resource developed by the Department of Human Services, Division of Developmental Disabilities, in partnership with the Missouri Family to Family Resource Center and other state agencies and organizations. The core belief is that all people and their families have the right to live, love, work, play and pursue their life aspirations just as others in their community do. The tool is designed to assist families in creating a vision of the future for their children with disabilities and special health needs. It is designed to help families' think about the questions to ask as well as the choices and options to consider as they "plot a course" for a full and meaningful life for their children. It is a starting point no matter where a family or individual might be in their life journey.

The goal of supporting families is recognizing that individuals live within the context of a family where: the individual will achieve self-determination, interdependence, productivity, integration and inclusion in all facets of community life; and families will be supported in ways that maximize their capacity, strengths and unique abilities to best nurture, love and support the individual to achieve their goal.

The resource provides information and tools to assist families and professionals who work in partnership with them to support positive life trajectories (paths to achieve goals and dreams) and prevent negative life events that lead to a "service" life.

The Lifespan folders are available by contacting Katherine Munson, DHS-DDD at (800)265-9684 or Katherine.munson@state.sd.us



What Does Having a Medical Home Mean for Your Child's Care?

Reprinted with Permission of University of Chicago, Division of Specialized Care for Children

Having a Medical Home Means Your Child's Care Is...

Accessible

- Care is provided in your community.
- The doctor's office accepts your insurance.
- The location meets American Disabilities Act (ADA) accessibility requirements.
- Access to health advice or care is available around the clock, 365 days per year.
- If needed, the office is accessible by public transportation.

Continuous

- The same doctors are available from infancy through adolescence.
- Communication occurs between doctors and specialists to ensure your child's needs are met at any age.
- Assistance is provided to secure a medical home for adolescents transitioning to adult care.

Comprehensive

- Preventive and primary care is provided.
- Growth and development assessments are conducted when appropriate.
- Care coordination is emphasized and exercised between all doctors for your child.
- Referrals to speciality-care services are available and offered when needed.
- Child/family counseling and health education are a part of visits or available upon request.
- Your doctor is knowledgeable about community resources and shares information.

Coordinated

- You and your family are linked to appropriate support, educational and community services.
- Your doctor's office staff communicate and work with all agencies to ensure all your child's needs are met.
- A centralized record containing important information on your child's care will be maintained by you, your doctor and office staff.

Compassionate

- The doctor shows concern for the well being of your child and family as a whole.
- The doctor shows understanding for the variety of emotions because of your child with special health care needs.
- Office staff are flexible and respond to requests and needs.
- Office staff offer privacy when requested.
- Appointment times are scheduled with consideration of your and your family's needs.

Culturally Effective

- Your family's cultural background is recognized, valued and respected.
- Office staff are sensitive to stereotypes and cultural assumptions.
- Multi-language materials and translation services are made available as needed.

Family-Centered

- Office staff recognize that you and your family are the principle caregivers and the center of strength and support for your child.
- Your doctor and family share the responsibility in decision making.

Care Coordination Training Empowers Families

South Dakota Parent Connection was selected to participate in the training, Care Coordination: Empowering Families, a project by Heartland Genetics Services Collaborative and their Partner Region 4 Midwest Genetics Collaborative. Six states from the Midwest had representation at the training that was held in Kansas City, Missouri in May of 2015. South Dakota Parent Connection sent 2 staff members to attend the two-day training that consisted of the training itself and then instruction on how to deliver the training to the families in the state they live in.

The Care Coordination: Empowering Families training curriculum was developed by the Region 4 Midwest Genetics Collaborative. It was created in partnership with representatives from public health, genetic and primary care providers and family members. Often the parent has to work with multiple professionals in order to ensure that the medical and non-medical needs of their child are met. They recognized that even when care coordination is provided within a medical home, the role of the family is an important one and there are few opportunities for formal training for parents on managing these tasks. Parents must learn as they go, often by other parents or by trial and error. It was determined that a need existed for a resource that would provide parents with the knowledge and skills to increase their confidence and competence in coordinating care for their child. With this information, a training curriculum was created to help parents work commensurately with their child's physicians and care providers to better meet the needs of the child and family.

The purpose of the training is to provide parents with the skills, knowledge and resources they need to coordinate care for children with complex needs in partnership with a medical home. Parents will learn:

- How to identify a medical home
- Techniques to organize information and find reliable resources
- Tips to navigate health care and insurance systems
- Skills to increase communication and coordination between multiple providers
- The need to plan early for child's transition
- Ideas for coping with stress and finding support
- Advocacy skills

This one day, interactive training can be provided to up to 25 participants. Participants should be parents of children aged birth to 18 who have been identified as having either a genetic condition or special health care need.

Participants are provided a gift card at the end of the day in recognition of their time investment and childcare costs. Reimbursement for travel from 60 miles to 150 miles is also given. Take-home materials include a participant workbook with additional resources, Region 4 Midwest Genetic Collaborative's Partnering with your Doctor: The Medical Home Approach booklet and a personal journal.

The Care Coordination: Empowering Families training includes a comprehensive evaluation consisting of a pre- and post-training assessment as well as a one-year follow up. Evaluation data to date has demonstrated that participants have shown an increase in key knowledge areas such as care coordination, medical home, transition, advocacy, importance of self-care, evaluating resources, and navigating health insurance.

South Dakota Parent Connection delivered the first training to South Dakota in Sioux Falls on September 12. In the spring of 2016, South Dakota Parent Connection will offer the training in Rapid City, South Dakota. If you are interested in having a Care Coordination training in your area contact tnold@sdparent.org or llarson@sdparent.org.



October Parent Education Webinar Focusing on Care Coordination

Coordinating your family's medical care can be a stressful, but a very important task in ensuring your families wellbeing. The **What is Care Coordination?** webinar will help participants learn techniques to organize healthcare information, skills to effectively communicate amongst multiple providers, and discover the medical home concept.

SD Parent Connection and the University of South Dakota School of Medicine Center for Disabilities are offering the Parent Education and Support webinar on **Thursday, October 8** as a recorded webinar. Visit www.sdparent.org for the link to the free webinar on October 8. The webinar will also be archived at www.sdparent.org along with other webinars for viewing at any time.

Don't Overlook Child and Dependent Care Tax Credit for Summer

From the U.S. Internal Revenue Service (IRS)

Day camps are common during the summer months. Many parents pay for them for their children while they work or look for work. If this applies to you, your costs may qualify for a federal tax credit that can lower your taxes. Here are the top ten tips to know about the Child and Dependent Care Credit:

- 1. Care for Qualifying Persons.** Your expenses must be for the care of one or more qualifying persons. Your dependent child or children under age 13 usually qualify.
- 2. Work-related Expenses.** Your expenses for care must be work-related. This means that you must pay for the care so you can work or look for work. This rule also applies to your spouse if you file a joint return. Your spouse meets this rule during any month they are a full-time student. They also meet it if they're physically or mentally incapable of self-care.
- 3. Earned Income Required.** You must have earned income, such as from wages, salaries and tips or net earnings from self-employment. Your spouse must also have earned income if you file jointly. One spouse may be considered as having earned income if they were a full-time student or were physically or mentally unable to care for themselves.
- 4. Joint Return if Married.** Generally, married couples must file a joint return. You can still take the credit, however, if you are legally separated or living apart from your spouse.
- 5. Type of Care.** You may qualify for it whether you pay for care at home, at a daycare facility or at a day camp.
- 6. Credit Amount.** The credit is worth between 20 and 35 percent of your allowable expenses. The percentage depends on the amount of your income.
- 7. Expense Limits.** The total expense that you can use in a year is limited. The limit is \$3,000 for one qualifying person or \$6,000 for two or more.
- 8. Certain Care Does Not Qualify.** You may not include the cost of certain types of care for the tax credit, including:
 - Overnight camps or summer school tutoring costs
 - Care provided by your spouse or your child who is under age 19 at the end of the year.
 - Care given by a person you can claim as your dependent.
- 9. Keep Records and Receipts.** Keep all your receipts and records for when you file your tax return next year. You will need the name, address and taxpayer identification number of the care provider. You must report this information when you claim the credit on Form 2441, Child and Dependent Care Expenses.
- 10. Dependent Care Benefits.** Special rules apply if you get dependent care benefits from your employer. See IRS Publication 503 for more on this topic.

Remember that this credit is not just a summer tax benefit. You may be able to claim it for qualifying care that you pay for at any time during the year.

For more about this rule see IRS Publication 503, Child and Dependent Care Expenses available at www.irs.gov.

Thank You SDPC Donors



*Thank You for Helping
Children Like Colton*

South Dakota Parent Connection Honor Roll of Donors

September 1, 2014 - August 31, 2015

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

Thank you to the individuals and business who supported SDPC's mission during the last year and made a difference for children.

\$1 - \$249

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**You Can Support
Our Work by
Making a Donation
at www.sdparent.org
or call 1-800-640-4553!**

Register for Next Sibshops October 17



Sibshops will be Saturday, October 17 from 10 a.m. - 1 p.m. at Here4YOUth, 1721 W. 51st Street, Sioux Falls. Lunch will be provided.

Sibshops is a free program designed specifically for siblings, ages 6-12, with a brother or sister with a special need or disability. Sibshops is a time to meet other with other siblings with a brother or sister with a special need

or disability, build friendships, have fun, do recreational activities, and share feelings with others who really know what it is like to have a sibling with a disability.

Pre-registration is required to attend Sibshops. To register online for the October 17 Sibshops visit www.surveymonkey.com/r/NQP7DZ or call 1-800-640-4553 or 605-361-3171. For more information on Sibshops visit www.sdparent.org (Family Life, Siblings)

Mark your calendar for future Sibshops on Saturday, December 5, Saturday, February 27, and Saturday, April 23. Sibshops is a joint project of South Dakota Parent Connection, Here4YOUth, the University of South Dakota School of Medicine Center for Disabilities and LifeScape.

Need Affordable Health Insurance?

Whether you are seeking insurance for the first time or considering changing your coverage, open enrollment in the Marketplace begins November 1, 2015 and continues through January 31, 2016. January 1, 2016 will be the first date 2016 coverage can start.

- If you don't have insurance through a job, Medicare, Medicaid, CHIP, or another source, the Marketplace helps you find and enroll in a plan that fits your budget and meets your needs.
- Most people who apply through the Marketplace qualify for insurance premium tax credits that lower the costs of coverage. Some also qualify for savings on deductibles, copayments, and other costs. All plans cover pre-existing conditions, preventive care and essential health benefits.
- If you don't enroll by January 31, 2016, you can't enroll for 2016 unless you qualify for a Special Enrollment Period due to a life change like marriage, having a baby, or losing health insurance coverage.
- If you don't have health insurance in 2016, you may have to pay a fee. The fee is the higher of these two amounts: 2.5% of your yearly household income or \$695 per person (\$347.50 per child under 18). You'll pay the fee on the federal income tax return you file for the year you don't have coverage.

Families can apply for Medicaid and CHIP any time of year. These programs provide free or low-cost insurance to children and youth in families with limited incomes. Coverage can start immediately.

Get answers to common questions, find local help or enroll in a plan online, by phone or with a paper application by visiting www.healthcare.gov or calling 1-800-318-2596 (TTY: 1-855-889-4325) 24 hours a day, 7 days a week.

Visit www.getcoveredsouthdakota.org to learn about health care and insurance basics; watch videos that answer common questions; find free local help and enrollment events in your area; find out how much help you could qualify for to cover your monthly insurance cost; or use the checklist to prepare items that will speed your application process. Get Covered South Dakota is sponsored by the Community HealthCare Association of the Dakotas (CHAD).



Find free in-person assisters in your area to help you understand your insurance options and enroll in a plan:

Community Health Centers (CHC) - All phone numbers 605 area code

AllPOINTS Health Services

Andrea Nelson
andrea.nelson@allpointshhealth.com
Alcester 934-2122
Serves Union County
Elk Point 356-3317
Serves Union, Yankton Counties
Yankton 260-0310
Serves Yankton County

Aurora County CHC 554-1015 Plankinton
Serves Aurora County

CHC of the Black Hills 721-8939 Rapid City
Serves Pennington County

Falls Community Health 367-8760 Sioux Falls
Serves Brookings, Lake, Lincoln, McCook, Minnehaha, Moody and Turner Counties
Pam Janney pjanney@siouxfalls.org
Mustafa Rashid mrashid@siouxfalls.org

Andy Peterson apeterson@siouxfalls.org

Horizon Health Care Kristen Thompson kthompson@horizonhealthcare.org
Fort Thompson 245-2700 Serves Buffalo County
Howard 772-4525 Serves Hamlin, Kingsbury Counties
Howard Dental 772-4703 Serves Lake, Miner Counties
Lake Preston 847-4484 Serves Kingsbury County
Martin 685-6868 Serves Bennett, Mellette, Todd Counties

James Valley CHC 554-1015 Huron
Serves Beadle, Brown Counties

Jerauld County CHC 554-1015 Wessington Springs
Serves Jerauld County

Prairie Community Health 605-466-2120 Isabel
Kris Johnson kjohnson@pchchc.net
Serves Dewey, Corson, Ziebach, Perkins, Meade Counties

Rural Health Care 223-2200 Ft Pierre
Diana Melvin dianam@ruralhc.net
Serves Potter, Hyde, Hand, Sully, Hughes Counties

Woonsocket CHC 554-1015
Woonsocket Serves Sanborn County

Community Action Partnerships

All phone numbers 605 area code

Grow South Dakota 626-2565 / 419-1966 Aberdeen
Carla Burns carlas@midco.net
Serves Beadle, Brown, Campbell, Day, Edmunds, Faulk, Hand, Hughes, Hyde, Marshall,
McPherson, Potter, Roberts, Spink, Stanley, Sully, Walworth Counties

Inter-Lakes Community Action Partnership

Brookings 692-6391
Kim Jones kjones@interlakescap.com
Serves Brookings County

Watertown 886-7674 x22
Annette Spooner aspooner@interlakescap.com
Serves Clark, Codington, Deuel, Grant, Hamlin, Kingsbury Counties

Sioux Falls 334-2808 x212
Tina Andree tandree@interlakescap.com
Serves Lake, Lincoln, McCook, Miner, Minnehaha, Moody, Turner Counties

Rural Office of Community Services

Lake Andes 487-7634
Alexa Raymond araymond@rocsinc.org
Serves Brule, Buffalo, Charles Mix, Douglas, Gregory, Hutchinson, Jones, Lyman, Mellette,
Todd, and Tripp Counties

Mitchell 469-5363
Jennifer Grassrope jgrassrope@rocsinc.org
Serves Aurora, Bon Homme, Clay, Davison, Hanson, Hutchinson, Jerauld, Sanborn,
Union, Yankton Counties

Western South Dakota Community Action

Michael Robeck 348-1460 mrobeck@wsdca.org
Serves Bennett, Butte, Custer, Corson, Dewey, Fall River, Haakon, Harding, Jackson, Lawrence,
Meade, Pennington, Perkins, Oglala Lakota, Ziebach Counties

Great Plains Tribal Chairmen's Health Board -

<http://navigator.gptchb.org/>

Phone: 1-877-209-1215

Email: Navigator@gptchb.org

Helps tribal members find, compare and enroll in the most affordable and highest-quality health insurance. Visit the website or call to learn more, find local enrollment events or free in-person assisters called Navigators. Navigators are experts trained to provide consumers accurate information about eligibility, enrollment and health care options including health insurance, the Health Insurance Marketplace, Medicaid and CHIP, and helps consumers understand new tax credits for premiums, cost-sharing reductions and waivers of copays and deductibles for members of tribes using Indian Health Service (IHS).



NAVIGATOR
PROGRAM

Special Provisions for American Indians

- Enrollment through the Health Insurance Marketplace at any time.
- May be eligible for special Medicaid and CHIP allowances.
- If income below an established level, may not have to pay cost-sharing expenses like copays.
- If receiving services through the IHS or other tribal health program and have health insurance, will not have to pay cost-sharing expenses.
- Depending on income and family size, may be eligible for lower premium costs.

Navigators

Amanda Taylor 605-209-7977 amanda.taylor@gptchb.org
Serves Flandreau, Sisseton, Sioux Falls, Yankton and surrounding areas

Mary Ann McCowan 605-280-8644 mary.mccowan@gptchb.org
Serves Lower Brule, Crow Creek, Pierre and surrounding areas

Nicholas Gibbons 605-407-7932 nick.gibbons@gptchb.org
Serves Pine Ridge, Rosebud, and surrounding areas

Yolanda Villarreal 605-407-0838 yolanda.villarreal@gptchb.org
Serves Chadron, Gordon, and surrounding areas

Elaine Keepseagle 701-329-9139 elaine.keepseagle@gptchb.org
Serves Standing Rock Sioux Tribe, Cheyenne River and surrounding areas

SHOP Marketplace Helps Small Business Provide Coverage

Small businesses can enroll in SHOP (Small Business Health Options Program) coverage any time of year. SHOP Marketplace helps small businesses provide health coverage to their employees and is open to employers with 50 or fewer full-time equivalent employees (FTEs), including non-profit organizations. You can use a licensed insurance agent or broker to provide help or handle your SHOP enrollment. You won't pay more for your coverage if you use a SHOP agent or broker. For questions and help with SHOP coverage, call 1-800-706-7893 (TTY: 711) Monday through Friday, 8 a.m. to 6 p.m. Central Time. Agents and brokers helping small businesses with SHOP coverage can use this number too.

Note: If you're self-employed with no employees, you can get health coverage through the Health Insurance Marketplace for individuals, but not through SHOP.

7 Things You Can Do To Get Ready Now

www.getcoveredsouthdakota.org

1. Learn about different types of health insurance. Choose a health plan that gives you the right balance of costs and coverage.
2. Make a list of questions you have before it's time to choose your health plan. For example, "Can I stay with my current doctor?" or "Will this plan cover my health costs when I'm traveling?"
3. Make sure you understand how insurance works, including deductibles, out-of-pocket maximums, copayments, etc. You'll want to consider these details while you're shopping around.
4. Start gathering basic information about your household income. Most people will qualify to get a break on costs, and you'll need income information to find out how much you're eligible for.
5. Set your budget. There will be different types of health plans to meet a variety of needs and budgets, and breaking them down by cost can help narrow your choices.
6. Find out from your employer whether they plan to offer health insurance, especially if you work for a small business.
7. Explore current options. You may be able to get help with insurance now, through existing programs or changes that are in effect already from the new health care law. Visit www.Health-Care.gov for information about health insurance for adults up to age 26, children in families with limited incomes (CHIP), and Medicare for people who are over 65 or have disabilities.

Care Coordination Online Resources

National Center of Medical Home Initiatives for Children with Special Needs:
<https://medicalhomeinfo.aap.org/Pages/default.aspx>

Family Voices:
www.familyvoices.org

Medical Home Portal:
www.medicalhomeportal.org

Center for Medical Home Improvement:
<http://www.medicalhomeimprovement.org/>

Heartland Genetics Collaborative - Region 5 of Midwest Genetics Collaborative
<http://www.heartlandcollaborative.org/>

Three Join SDPC Board of Directors

Three parents are the newest members of the SD Parent Connection Board of Directors. Each will serve a three-year term.

Carrie Geppert of Tea has an eight year old daughter with Down syndrome. Carrie is the Protection and Advocacy Assistive Technology (PAAT) Program Director for SD Advocacy Services. She is a 2015 graduate of Partners in Policymaking and member of a community partnership committee that brings fitness programs to individuals with disabilities, as well as individuals with limited income.

Gina Hale of Dell Rapids is a parent of a teenager with complex special needs and a graduate of the Leadership and Education of Neurodevelopmental Disorders Program (LEND) through the University of South Dakota School of Medicine Center for Disabilities. She has taught in multi-cultural settings, designed curriculum and facilitated learning communities for adults in community education. Gina served as vice chair of the Community Advisory Committee for Special Education for Mount Diablo (CA) Unified School District School Board, and as a facilitator for CARE Parent Network assistive technology resource group in California.

Kerry Larson of Sioux Falls served on the SDPC Board from 2006 to 2012 and was Board President in 2011-2012. She is a Families Planning Together Facilitator, former member of the SD Department of Education Special Education Advisory Board and completed Partners in Policymaking in 2008. She is an advocate for all children and families.

Other SDPC Board members are Brad Bartz, president, Sioux Falls; Chris Bordeaux, Pine Ridge; Deb Docken, Sioux Falls; Rod Domke, Highmore; Carmyn Egge, Sioux Falls; Dr. Wendy Parent-Johnson, Sioux Falls; and Ashlie Richter, Pierre.

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address correction. Thank You.

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*SDPC provides
resources, training
and individual
assistance to families
across South Dakota
at no cost. You can
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SIoux FALLS OFFICE

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RAPID CITY OFFICE

7110 Jordan Drive
Rapid City, SD 57702
605.348.0305

Community of Care (COC)... Healthy Communities that Work

The Community of Care Consortium is a statewide partnership of public and private entities, state agencies, nonprofit and advocacy organizations, health providers, schools, families and self-advocates tasked with creating the organizational relationships (infrastructure) necessary to realize the vision of healthy communities that work for everyone – for children/youth with special health care needs or disabilities and their families, providers, and communities.

As SD Parent Connection enters the final year of the Rural Health Outreach Project which has supported the work of the Community of Care, exciting developments are in progress. In July 2015, a second Summit of the COC was conducted in Oacoma (minutes can be found at www.cocsd.org). Presentations were provided Darryl Millner, Assistant Director, Division of Developmental Disabilities, Department of Human Services; Travis Hallock, Assistant Division Director, Behavioral Health, Department of Social Services; and Dr. Bill Anderson, Dr. Piali De and Mike Charley of Senscio Systems (<http://sensciosystems.com>). Senscio Systems has developed an Ibis Care system that supports individuals with health care needs to maintain independence. Originally developed to support the aging population, Senscio Systems has been working with SD Parent Connection to develop expanded capacity to support families of children/youth with disabilities and/or special health care needs (CYSHCN). A year-long pilot is planned with 30 to 50 families of CYSHCN - - to thoroughly test the virtual document repository, sharing and permission system in which the parent serves as their child's "CEO," ensuring information is shared with the right people at the right time during the child's and family's life journey. Additionally, parents and families will be provided with technology – the Senscio Ibis CareStation – to support activities of daily living which may include prompts, reminders, medication guidance, and monitoring of family psychosocial well-being.

