How to Advocate for a Child with Dyslexia

by Tim Neyhart

A group of parents who are struggling with issues related to their children’s reading curriculum contacted me this past January. They asked me to provide them with information about how to advocate for a child who has been identified as having Dyslexia. I agreed to meet with the parents and to assist them in devising a strategy to address their concerns about curriculum-related issues.

Most of the parents in the group have had their children tested by the school and they were found eligible for special education services in the category of Specific Learning Disability (SLD). The problem is that despite meeting the eligibility requirements for special education services and receiving specialized instruction, their children are still not learning to read. The parents believe the issue is the curriculum or methodology the school is using to teach the children. They attempted to address this issue with the schools, but remain dissatisfied. They asked for information about how to better advocate for their children on this issue.

It is important to begin this discussion with a bit of history regarding Dyslexia in South Dakota. In 2008, a group of concerned citizens made an effort to get the South Dakota Legislature to add Dyslexia as separate category of eligibility for special education in state law or rule. This effort was defeated for several reasons, one of which was the argument that this category was already included or covered by the current laws under the category of Specific Learning Disability.

The SD Department of Education created a task force to address this topic, which resulted in creation of “The Dyslexia Handbook For Parents And Teachers in South Dakota.” This handbook is available on the SD Department of Education website at: http://doe.sd.gov/oess/documents/SPED_DyslexiaGuide.pdf. The handbook provides a wealth of information about numerous topics, including definitions, grade- and age-specific suggestions for evaluation and intervention, contacts and other sources for information about advocacy, parent training, and other useful resources. This article will focus on the definitions and the areas to consider when carrying out an evaluation.

Definitions of Dyslexia

Dyslexia is a type of learning disability. Specifically, it is a language-based disorder, characterized by problems learning to read, write, spell, and decode single-words. A person with dyslexia has reading skills significantly below what is expected given his/her intelligence and educational experiences. (National Institute for Literacy)

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Dyslexia is a [learning] disability that is neurological in origin. The condition is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically 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 the growth of vocabulary and background knowledge. (The International Dyslexia Association)

As can be seen from reading these two definitions, they are similar with the second definition providing emphasis on difficulties with accurate and/or fluent word recognition and poor spelling and decoding abilities. These difficulties result from a deficit in the phonological component of language. I have heard this described as the person having a deficit in learning what sound a letter represents when seen in writing.

This is important because one critical element of advocacy is to know what you are asking for and being sure that what you are asking for is what you want. In order to do that when asking for assistance for a child who has been identified as having Dyslexia, it is important to know exactly what issues one is seeking to address.

Evaluations

Each child has a different set of circumstances and the evaluation needs to identify each child’s unique issues. The handbook encourages teams to consider the following areas when evaluating a child (paraphrased from the Dyslexia handbook mentioned above):

♦ Background information: A lot of this information will be provided by the parents, particularly for younger students. It includes information about overall development, family history, developmental milestones, etc. The school will review the types of interventions attempted, the student’s response to interventions, etc.

♦ Oral language skills: Many students with Dyslexia have strong language skills. Counter intuitively, they typically have a deficit in low level language skills. This deficit limits the ability to learn to read and spell using sounds of language.

♦ Word recognition: The ability to read single printed words. It is also called word reading or word identification.

♦ Decoding: The ability to read unfamiliar words by using letter-sound knowledge, spelling patterns, etc. Decoding can also be known as word attack skills.

♦ Spelling: Testing in this area measures the student’s ability to spell words from memory.

South Dakota Advocacy Services (SDAS) is an independent (not a part of state or federal government or any service provider), private, non-profit corporation established in the State of South Dakota and designated by the Governor to provide protection and advocacy services to eligible South Dakotans with disabilities. SDAS is funded in part by the U.S. Department of Health and Human Services, U.S. Department of Education, and Social Security Administration. Articles are intended for informational purposes only and are not intended as legal advice. Comments on SDAS services and priorities are welcome.

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- Phonological processing: Phonology is the sound system of language. Students with Dyslexia have difficulty with identifying, pronouncing, or recalling sounds.
- Automaticity/fluency skills: Students with Dyslexia often have a slow speed of processing visual or auditory information. This can be reflected in naming speed testing and other methods. Students who have both naming speed and phonological processing deficits are considered to have a double deficit.
- Reading comprehension: Typically, students with Dyslexia score lower on reading comprehension than on listening comprehension. It is important to test students for their ability to read and understand long reading assignments.
- Vocabulary knowledge: Vocabulary greatly affects understanding when listening or reading. This skill can be affected by the difficulties students with Dyslexia have had in learning language or with memory deficits.

After completing the testing in these areas, it is important for teachers and parents to understand that the issues identified in this testing are life-long. Many students will report feeling dumb or being called lazy by their teachers and parents. It is also important to understand that there may be emotional issues attached to the difficulties students with Dyslexia have had in learning language or with memory deficits.

The list of questions is not designed to be exhaustive. Rather, it is provided to assist parents in focusing the discussion on the issues related to the student’s specific deficits. The discussion of teaching methodology and curriculum, however, can lead to conflicts between parents and schools. These conflicts are often fueled by the parents’ belief that the school has selected a curriculum that does not incorporate individual instruction or the specific techniques needed to teach their children to read. This conflict is increased when the child is able to adapt and find ways to be successful in school, but is still unable to be a functional reader. Parents report that school staff point to this success as proof their method works and therefore the child does not need additional instruction or an alternative curriculum. This conflict can be contentious and ongoing because parents feel somewhat powerless to impact the educational problems their children are experiencing. This feeling is increased at times by references made by school staff to various court cases, policy letters, and other information that identify the school staff as “educational experts” who have the right to choose methods of instruction and curriculum.

Advocating for a Student with Dyslexia

One may question at this point what any of this has to do with advocating for a student with Dyslexia. It is important to remember that all parties in a meeting are there for one purpose - to address the educational needs of the child. There are times that focus can be lost because of the inability of the participants to communicate. One method that has resolved many issues is to go back and review the purpose of IDEA. In part, 34 C.F.R. § 300.1 reads, “The purposes of this part are: (a) To ensure that all children with disabilities have a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living; (b) To ensure that the rights of children and their parents are protected.” These two identified purposes are the key to the advocacy process in this discussion.

Schools must provide a free appropriate public education to meet each child’s unique needs. Parents rights must be protected. One of the fundamental parental rights is to be fully informed so that they can participate in their child’s educational process. This article points out the suggested areas of evaluation from the State’s Handbook. The “full and individual evaluation” required by IDEA must identify the unique educational needs of the child. Parents can exercise their rights by requesting a complete evaluation of these areas for their child suspected of having Dyslexia or another reading-based learning disability. They can also exercise their rights by seeking more and specific information about the evaluation and services that are being proposed or provided by the school. I suggest a set of well-developed questions be used for this purpose. The following are some examples for consideration:
- Have you evaluated my child (suspected of having Dyslexia) in all of the areas identified in the technical assistance information from the Dyslexia Handbook created by the SD Department of Education?
- What deficits were identified, if any?
- What are the baseline scores identified by the testing?
- What curriculum does the school use to address these concerns?
- Can you show me how this curriculum is designed to improve my child’s specific deficit areas?
- Is there any individualized instruction to address the problems identified by the testing?
- How does this curriculum track the student’s progress?
- What steps can be taken if no progress is being made?

This list of questions is not designed to be exhaustive. Rather, it is provided to assist parents in focusing their discussion on the issues related to the effectiveness of the testing, the proposed services, and ultimately the outcome of those services. Each situation will be different, but the question method helps to focus the discussion and hopefully lead to problem resolution. In addition to the possible improvement of the relationship, these types of questions can also assist parents and schools to determine if the curriculum and services are helping the child to make progress.

“Progress” is a key term in special education. In order for a school to meet the standard of “appropriate” in the term
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free appropriate public education, it must provide services that are calculated to enable the student to make progress toward the goals identified in his or her Individual Education Plan. This is supported by the Federal Regulations at 34 C.F.R § 320.24(b)(1), which states: “(b) Review and revision of IEPs — (1) General. Each public agency must ensure that, subject to paragraphs (b)(2) and (b)(3) of this section, the IEP Team —

(i) Reviews the child’s IEP periodically, but not less than annually, to determine whether the annual goals for the child are being achieved; and

(ii) Revises the IEP, as appropriate, to address —

(A) Any lack of expected progress toward the annual goals described in § 300.320(a)(2), and in the general education curriculum, if appropriate...”

Parents can use the information they have gleaned from the evaluations, and the student’s progress or lack of progress, to advocate for services or different methodology. This position is supported by the legislative history of the IDEA starting in 1997. While it states that methodology does not have to be stated in the IEP, the IEP Team was identified as having a role in the selection of educational methodology. “Teaching and related services methodologies or approaches are an appropriate topic for discussion and consideration by the IEP team during IEP development or annual review.” S. REP. No. 105-17, at 21 (1997).

The 1999 Federal Regulations went further by defining Special Education to mean, in part, specially designed instruction, which the regulations further define as “adapting, as appropriate to the needs of an eligible child under this part, the content, methodology, or delivery of instruction to address the unique needs of the child that result from the child’s disability; and to ensure access of the child to the general curriculum...” The 2006 Federal regulations retained the identical information at 34 C.F.R. §300.39(b)(3)(i).

LRP Publications’ Answer Book on Special Education Law, 5th Edition, page 4:9, provides the following on this topic:

In discussions accompanying the publication of the 1999 regulations, the ED explained that educational methodology will not be an item of special education in each instance when a teacher makes “day-to-day adjustments in instructional methods and approaches.” But when the choice of methodology determines what goals should be adopted and services provided, then the IEP team consideration and approval is required. “It is clear that in developing individual education plans there are circumstances in which the particular teaching methodology that will be used is an integral part of what is ‘individualized’ about a student’s education and, in those circumstances will need to be discussed at the IEP meeting and incorporated into the student’s IEP.” 64 Fed. Reg. 12,552 (1999).

Continuing onto page 4:10, it states:

Who decides when a student’s IEP team must address educational methodology? The IEP team decides, according to the ED. In its discussions accompanying the publication of final regulations, the ED posited cued speech as an educational method that rises to the level of specifically designed instruction. It also stated that “non-traditional instruction methods” to teaching learning-disabled students to read also may be special education.

As with all things in the area of Special Education, this entire discussion is based on a need for process. There are various descriptions of this process available for consideration. For purposes of this article, the following is submitted in an effort to simplify this information and help parents and schools to address the discussions that they will have on these topics.

- All services in special education are based on eligibility.
- Eligibility is based on testing to determine if the student has a disability that affects his or her ability to benefit from educational services such that the student needs special education services.
- Good testing leads to appropriate identification of learning needs.
- Curriculum decisions can be based on learning needs and can be part of the IEP development process.
- Know the student and his or her unique learning needs.
- Ask the school how its program meets these needs.
- Develop questions based on who, what, when, where, why, and how to gain knowledge and help the parent and team to make informed decisions.
- Look for assistance from knowledgeable people to help with this process.

For further information and assistance, interested parties may contact South Dakota Advocacy Services at 1-800-658-4782, and/or South Dakota Parent Connection at 1-800-640-4553.

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**Applications for Year 22 of SD Partners in Policymaking are now Available**

Contact Sandy Stocklin Hook by mail at SD Advocacy Services, 221 S. Central Ave., Ste. 38, Pierre, SD 57501; email hooks@sdadvocacy.com; or phone at 1-800-658-4782; or complete an application on the SDAS website, www.sdadvocacy.com.

The application deadline is September 20, 2013!
This edition of the South Dakota Report highlights three apps, along with information about new assistive technology that can be used with the Kindle eReader. [These reviews are for informational purposes only. No compensation is received and no apps/products reviewed are guaranteed to work for individual situations. What may work for some may not work for all.]

Care for Me
By Damon Taylor; $7.99

Care for Me is an app designed for the iPhone and iPad. This app allows a user to easily record instructions on how to support a person. The user can record information in multiple ways, such as in written form, with pictures, and video format. This would be extremely helpful for a person who has multiple caregivers. Caregivers can review the routines and schedules on the device and know exactly what to do.

Picture Me Calm
By Awesometistic, LLC; $2.99

Picture Me Calm is also designed for the iPhone and iPad. The app is a visual picture schedule for children to use in order to understand what needs to be completed in their day. Each child’s schedule can be personalized with pictures of themselves doing the tasks. Once the task is completed, the child receives stickers for positive support.

Community Sidekick
By AbleLink Technologies, Inc.; $19.99

The Community Sidekick is designed for the iPod Touch, iPhone, and iPad. This app allows the user to keep track of the location of someone who is out in the community on their own. The user receives a notification when a person starts a trip into the community and launches Community Sidekick. Email notifications are sent at 5, 15, 30, or 60 minute intervals to let a caregiver know precisely where the person is located. The app also allows the person who is out on their own to send messages with a touch of a button. The messages read, “I am OK” or “Please contact me.”

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Tech Bytes
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PageBot
By Origin Instruments

A popular way to read a book is by using an electronic book reader, such as the Kindle. Some individuals have a hard time holding the Kindle or pressing the buttons due to motor difficulties. Origin Instruments developed products to enable switches to be used with the Kindle. It is called PageBot. According to Origin Instruments, “PageBot integrates multiple interfaces for adaptive switches that can suit the preferences and abilities of individual users. PageBot is compatible with a wide range of switches.” More information can be found for the PageBot at http://www.orin.com.

There are also a variety of apps that can be used with switches. Switch-accessible apps can be found with an internet search. The apps listed below are for the Apple operating system and can be found in the iTunes App Store.


Lorna Williams
November 12, 1957 - July 7, 2013
by Kim Wienbar and Sandy Stocklin Hook

Lorna Williams, advocate and friend to so many, passed away on July 7, 2013, after a three-year battle with cancer. Lorna worked for South Dakota Advocacy Services (SDAS) for nearly thirteen years before resigning in early spring 2013.

A graduate of T.F. Riggs High School in Pierre, SD, Lorna attended Presentation College in Aberdeen, SD. After college, Lorna returned to Pierre and in 1982 began working for Capitol Area Counseling (CAC), the area’s community mental health center, where she worked for 18 years.

At CAC, Lorna provided numerous services to adults with a mental health diagnosis. During her tenure, she participated in training for Person Centered Planning, then implemented it into the work she did to assist individuals in obtaining personal goals in their living, learning, working, and social environments. Lorna’s commitment included taking many of the individuals she worked with on trips and personal capacity expanding adventures. She was a strong team player, always exemplifying her belief, as she would say often, that there was no “I” in T-E-A-M.

While at CAC, Lorna developed a Person Centered Planning Monograph, which was published in a national disability services information newsletter from the Center for Technical Assistance and Training at the University of Colorado. In addition, she was instrumental in the successful development of the Assertive Community Treatment service model. She was also a past member of the River Cities Transit Board of Directors. Her many contributions while at Capital Area Counseling resulted in her being named Employee of the Month in 1984, 1986, and 1999.

In June of 2000, Lorna joined South Dakota Advocacy Services as an Advocacy Service Representative. Lorna worked in many of the agency’s component programs and was very active in SDAS’ cultural competency efforts through working with clients of the Native American Vocational Rehabilitation 121 Programs. Lorna was a regular presenter to SD Partners in Policymaking. In addition to case work, Lorna further contributed to the agency through her outreach efforts, explaining SDAS’ programs to various groups throughout South Dakota.

Lorna was a gifted and talented advocate for individuals with disabilities throughout the state, always trying to level the playing field for whom she worked. She was a tireless advocate who put the needs of others before her own.

Lorna’s welcoming smile was admired by her co-workers. She always had a warm greeting for everyone each morning and was willing to pitch in to get the job done.

Lorna loved the outdoors, gourmet cooking, and visiting with friends and family. She especially enjoyed sharing these moments with her life-long partner, Jim Osberg.

Lorna’s talents, caring attitude, and warm demeanor will be missed by those she served, her family, friends, and co-workers. Rest in Peace Lorna.
Rhode Island / City of Providence

Found in Violation of ADA / Olmstead

by Elizabeth Overmoe

Twenty-three years following the enactment of the Americans with Disabilities Act (ADA), the State of Rhode Island and the City of Providence allowed their low expectations to create a system that left people with disabilities no choice but to be separated from society in sheltered workshops. The State of Rhode Island and City of Providence were found to have violated the ADA by requiring their students to work manual labor for little pay and having the school act as a “pipeline” to similar programs when students were forced to join once they graduated from high school, specifically Training Thru Placement, Inc. (TTP). The Harold H. Birch Vocational School (Birch), a special education program designated to support students with intellectual and/or developmental disabilities (I/DD), ages 14-21, operated as a “sheltered workshop” for over 25 years, segregating students with intellectual and disabilities from their peers and denying them any opportunity for integrated employment upon graduation.

ADA

Title II of the ADA requires that services, programs, and activities provided by public entities (including public schools) be delivered in the most integrated setting appropriate to the needs of persons with disabilities and that no individual with a disability be subjected to discrimination by any such entity. In the opening provisions of the ADA, Congress stated, “Historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem; discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services; and individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, failure to make modifications to existing facilities and practices, and segregation.”

Olmstead v. L.C.

In accordance with Title II, the United States Supreme Court issued a decision on June 22, 1999, namely Olmstead v. L.C., which held that public entities are required to provide community-based services to persons with disabilities when (1) such placement is appropriate, (2) the affected persons do not oppose such placement, and (3) the placement can be reasonably accommodated. In the decision, Justice Ginsburg wrote, “Specifically, we confront the question whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes.”

Justice Ginsburg’s opinion explained what the ramifications of unjustified institutionalization and isolation could be on individuals with disabilities. The Court noted that institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment. The Olmstead decision continues to be a benchmark decision for de-institutionalization of individuals with disabilities.

Subsequent to Olmstead, a plethora of challenges and affirmations circulated throughout the lower courts. One case in particular, Lane v. Kitzhaber, dealt specifically with persons with I/DD who were in, or who had been referred to, sheltered workshops in Oregon. In Lane, the individuals with I/DD alleged the State had failed to provide them with employment and vocational services in the most integrated settings appropriate to their needs. The court found the language of the ADA supports that an integration mandate applies to employment services. Specifically, it noted there is “no statutory or regulatory basis for concluding that the integration mandate to provide services in the most integrated setting appropriate applies only where the plaintiff faces a risk of institutionalization in a residential setting.”

Rhode Island / City of Providence

Taking into consideration the precedent set forth by the ADA, as well as the Olmstead and Lane decisions, the U.S. Department of Justice, Civil Rights Division (DOJ), investigated the Birch School and concluded that the sheltered in-school workshop “put students with I/DD at serious risk of unnecessary placement in segregated adult day activity services programs, including, in particular, the segregated shel-
The DOJ found the structure and function of Birch’s in-school sheltered workshop placed students at serious risk of unnecessary segregation, describing it as “one large classroom, with several communal cafeteria-style tables” and the work being completed included “bagging, labeling, collating and assembling jewelry.” This work is very similar to the work also being performed at TTP. Students at the in-school workshop are supervised by school special education staff that monitor production and ensure the requirements of any private contracts the school has are being met.

The investigation concluded that most students with I/DD spend approximately one-third of their classroom instruction time in the sheltered workshop. However, one former student said she was required to spend a much larger portion of her day in the workshop, sometimes including full days, when the workshop had important production deadlines. Students who earned wages at Birch typically were paid between 50¢ and $2 per hour, no matter the work being performed. Not only were students with I/DD spending a large portion of their school day in the workshop away from similarly aged, non-disabled peers, but they were also being conditioned to have low expectations as a consequence of their low income, making their transition to other adult segregated employment, like TTP, all the more likely.

The DOJ also concluded the lack of appropriate opportunities for integrated experiences and low expectations for Birch students placed them at risk for unnecessary segregation. The investigation found that students were given little choice but to participate in the Birch’s in-school sheltered workshop, in spite of their preference for other transitional work. In some cases, participation in the workshop was a requirement. It also found that some students were paid no wages at all even though they were completing similar work to their paid peers. Students who had previous training and experience in integrated work settings outside the in-school workshop were also given no other options but to work at Birch. The DOJ stated in its letter, “Students with and without disabilities throughout Rhode Island receive integrated services, such as transition work placements with competitive wages, paid internships, and career learning experiences; building resumes; volunteering and acquiring important work-related skills while still in school. However, Birch students generally only learn work tasks that will prepare them for postsecondary placements in segregated work settings.”

Following the investigation and findings of the DOJ, the United States, the State of Rhode Island, and the City of Providence announced a settlement agreement, which vindicated the civil rights complaint brought on behalf of the students at Birch. Under the agreement, the State will help every person at TTP to find, get, keep, and succeed in real jobs with real wages. They will accomplish that by providing “supported employment” services. Over the next year, the State of Rhode Island and City of Providence will also provide integrated transition services at Birch to prepare them to do the same: find, retain, and succeed in real jobs when they leave school. Instead of sheltered workshop experience, students with I/DD will now get exposure to real-world internships, trial work experiences, and other services to ensure that after graduation, they can successfully move into community-based jobs, rather than to segregated settings like TTP.

Also under this agreement, individuals will work, on average, in supported employment for at least 20 hours per week. When individuals are not working, they will have access to integrated day services to be able to enjoy doing the things the rest of America does when not working – recreational, social, educational, cultural, and athletic activities in the community, right alongside people without disabilities. Furthermore, those supported employment and integrated day services will support a 40-hour work week. This means individuals will be offered the opportunity to participate in community-based, integrated activities during the hours they are not working.

For far too long, people with disabilities who can and want to work and engage in all aspects of community life have been underestimated by public service systems that have had limited or no expectations for them. Hopefully this will now change for the students of Providence, RI.

1 Unlike South Dakota, in Rhode Island the schools are run by individual cities.

2 42 U.S.C. §§ 12131-34; 28 C.F.R. § 35.130(d). The ADA, enacted in 1990, is the Federal Government’s most extensive endeavor to address discrimination against persons with disabilities. In the ADA, Congress for the first time referred expressly to “segregation” of persons with disabilities as a “for [m] of discrimination,” and to discrimination that persists in the area of “institutionalization.” §§12101(a)(2), (3), (5). 4 Olmstead v. L.C., 527 U.S. 581, 587 (1999). 6 Id. 7 Id. at 600. Internal citations omitted. 8 Lane v. Kitzhaber, 841 F. Supp. 2d 1199 (D. Or. 2012). 9 Id. 10 Id. 11 Id. at 1206.

12 Letter from U.S. Department of Justice, Civil Rights Division to the City of Providence, June 7, 2013.

13 Id. at 10. 14 Id. 15 Id. at 12. 16 Senior Counselor to the Assistant Attorney General for the Civil Rights Division Eve Hill Delivers Remarks on the Americans with Disabilities Act. Justice News, June 13, 2013.
have you ever been denied coverage for medical equipment, such as a motorized wheelchair, by the South Dakota Medicaid program? If so, you can appeal that decision by requesting an administrative hearing before an administrative law judge (who may also be referred to as a hearing officer or hearing examiner). In order to appeal an action by the Department of Social Services (which administers the Medicaid program in South Dakota), an “individual or individual representing the entity affected must submit a written and signed request for a hearing to” the Office of Administrative Hearings of the South Dakota Department of Social Services. This requirement is set out in the Administrative Rules of South Dakota (hereinafter referred to as “ARSD”) at 67:17:02:03. According to this rule, when making a request for a hearing, the person “requesting the appeal must indicate what department action is being appealed.” There is a time limit to request a hearing on a denial of coverage, such as for a piece of medical equipment. Pursuant to ARSD 67:17:02:04, “[a] request for a fair hearing must be made within . . . (6) Thirty days after notice of the action complained of or of the conference decision or 30 days after action should have been taken by the department as provided by law or rule.”

The administrative law judge may conduct the hearing in-person, by telephone conference, or by electronic or digital means. ARSD 67:17:02:11.01 requires that with “telephonic, electronic, or digital hearings,” all parties are required to submit their proposed exhibits to the hearing examiner and other parties at least five calendar days before date of the hearing. Before the hearing, the South Dakota Department of Social Services is required to send a written notice of the hearing. According to ARSD 67:17:02:12, “Unless waived by all parties, at least 10 days before the hearing the department shall send a written notice of the hearing to the parties involved in the action.” The written notice is required by the regulation to contain “the following information:

1. A statement that the parties must be present at the hearing with their witnesses;
2. A statement that the parties must have all the exhibits and documents intended to be introduced into evidence;
3. A statement that the parties have the right to request the hearing examiner to issue subpoenas for witnesses or documentary evidence;
4. A statement that the parties may represent themselves, may be represented by an attorney, or may be assisted by another person such as a friend or relative;
5. A statement that a corporation must be represented by its attorney;
6. A statement that the department is not responsible for the appellant’s legal fees; and
7. A statement that the department is not responsible for the expenses of any individuals appearing on behalf of the appellant.”

Furthermore, the rule also requires that notice of hearing contain the information required under South Dakota Codified Law (hereinafter referred to as “SDCL”) 1-26-17, which requires the notice to “include:

1. A statement of the time, place, and nature of the hearing;
2. A statement of the legal authority and jurisdiction under which the hearing is to be held;
3. A reference to the particular sections of the statutes and rules involved;
4. A short and plain statement of the matters asserted. If the agency or other party is unable to state the matters in detail at the time the notice is served, the initial notice may be limited to a statement of the issues involved. Thereafter upon application a more definite and detailed statement shall be furnished;
5. A statement of any action authorized by law, which may affect the parties, as a result of any decision made at the hearing, whether it be the revocation of a license, the assessment of a fine or other effect;
6. A statement that the hearing is an adversary hearing and that a party has the right at the hearing, to be present, to be represented by a lawyer, and that these and other due process rights will be forfeited if they are not exercised at the hearing;
7. Except in contested cases before the Public Utilities Commission, a statement that if the amount in controversy exceeds two thousand five hundred dollars or if a property right may be terminated, any party to the contested case may require the agency to use the Office of Hearing Examiners by giving notice of the request to the agency no later than ten days after service of a notice of hearing issued pursuant to § 1-27-17;
8. A statement that the decision based on the hearing may be appealed to the circuit court and State Supreme Court as provided by law.”

The administrative law judge is required to arrange for the testimony to be recorded. Following the hearing, the administrative law judge will issue a proposed decision. Pursuant to ARSD 67:17:02:27, “[b]ased on the transcript or recording of the testimony, the exhibits, and the proposed decision, the secretary or a designee shall enter a final decision accepting, rejecting, or modifying the proposed decision.”

Persons wishing to request a fair hearing for a denial of coverage for medical equipment under the Medicaid program must comply with the requirements set forth by law. However, the success resulting from a request for such a hearing cannot be presumed. The determination whether a person will prevail at their hearing depends on the facts of each case.
In a January 25, 2013, “Dear Colleague” letter from the Acting Assistant Secretary for Civil Rights, the US Department of Education, Office of Civil Rights (DOE, OCR), set out its vision of elementary and secondary schools’ responsibilities under Section 504 of the Rehabilitation Act of 1973 (Sec. 504) regarding extracurricular athletics. The letter continues DOE’s active interest and builds on a previously issued document in August 2011 by DOE providing guidance in the area of participation in physical education (PE) and extracurricular athletics by students with disabilities. These two efforts were in response to a report issued in 2010 after an investigation conducted by the U.S. Government Accountability Office (GAO) calling for more information and guidance in the area. The recent letter also demonstrates DOE’s continuing concern that students with disabilities are not provided consistent opportunities to participate equally in school-sponsored extracurricular athletic activities. This article will discuss the GAO 2010 report, the DOE 2011 report, the OCR Dear Colleague letter, and some initial responses to the OCR letter from representative persons and entities interested in and/or impacted by the discussion.

2010 GAO Report

The GAO, on June 23, 2010, issued a “Report to Congressional Requesters” in response to a request by five legislators to address three areas of interest concerning physical education and extracurricular athletic participation by students with disabilities. GAO was asked to address the following:

1. What is known about the PE opportunities that schools provide to students with disabilities, and how do schools provide these opportunities?
2. What is known about the extracurricular athletic opportunities that schools provide to students with disabilities, and how do schools provide these opportunities? and
3. How Education [DOE] assists states and schools to provide opportunities in PE and extracurricular athletics to students with disabilities?

In responding to the request, GAO conducted a performance audit from June 2009 through June 2010 using a spectrum of methodologies within government auditing standards. GAO stated that it used four nationally representative studies that provided the “most current national survey data available.” The surveys included specific focused inquiries (i.e., school health policies and programs) and longitudinal information (National Longitudinal Transition Study-2 (NLTS2)). GAO conducted on-site visits to five states, which included interviews with officials from state departments of education, state athletic associations, school districts, and schools. GAO staff also interviewed teachers, coaches, parents, and students. Phone interviews were conducted within two additional states that were similar to the on-site visits. In addition to the on-site visits, GAO interviewed representatives from 21 national associations, community organizations, and experts in the areas of disability, health, PE, special education, and athletics. DOE officials were interviewed regarding oversight and assistance efforts.

In the report’s cover letter to the Congressional members requesting the review, the GAO clearly set out the importance of PE and extracurricular athletics for all students and in particular those with disabilities. It noted:

The health and social benefits of physical activity and athletic participation for children are well established. These benefits may be even more important for children with disabilities, including those with cognitive and physical disabilities who have a greater risk of being sedentary and having associated health conditions, such as obesity and reduced cardiovascular fitness. Studies have shown that for students with disabilities, regular physical activity may help control or slow the progression of chronic disease, improve muscular strength, control body weight, and enhance students’ psychological well-being through additional social ties and improved self-confidence and self-esteem.

The report analyzed the applicability of the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973. In reviewing the provisions of IDEA, the report concluded that schools receiving federal assistance are required to “generally provide opportunities for students to participate in regular or general PE classes or in some cases, specially designed PE as determined by the IEP team.” Regarding extracurricular athletics, the report noted that “districts and schools must take steps to provide services to give students with disabilities an opportunity to participate in extracurricular activities which may include athletics, equal to that of other students.”

The same conclusion was reached after analysis of Sec. 504 provisions. The report stated that “similar to IDEA, Education’s Section 504 regulations require that students with disabilities be provided a free appropriate public education and learn alongside students without disabilities to the maximum extent appropriate. These Section 504 regulations also require that students with disabilities must be provided equal opportunities to participate in PE courses and extracurricular athletics.”

In reviewing areas of responsibility to provide PE and extracurricular athletics, the report noted that at the state and district level, several entities may have a role to play in developing, providing, and overseeing these activities. GAO found that the entities may have varying policies on specific content of the PE programs and curriculum areas. It found that extracurricular athletics at the state level are usually governed by an athletic association that is not part of the state departments of education and which, in turn, is a member of a national organization. Each state athletic association develops its own standards and policies for sports competition.

“PLAY BALL” (Continued on page 11)
Based on its review of data and on-site visits, the GAO reported a number of findings. Regarding participation in PE, it noted that schools it visited generally provided students with and without disabilities comparable opportunities to participate in PE. In the detail of the report, GAO shared many situations where the nature of the disability required additional attention, modifications, and accommodations to make the PE experience workable and meaningful for the students with disabilities, which proved challenging. Another challenge to serving students with disabilities in general PE was lack of sufficient training or experience among PE or classroom teachers. It was suggested that the lack of training and experience may result in students with disabilities not actually actively participating in PE or being excused from the PE curriculum altogether. The schools GAO visited also reported budget constraints as a challenge to PE participation. Larger general PE classes reduce the time and opportunity to provide the individual attention that students with disabilities need or certainly would benefit from. Another challenge noted was the continuing shifting of educational emphasis upon academics and away from other curriculums.

Regarding participation in extracurricular athletics, the GAO noted that the national data available did not provide a clear picture of the then-current status as to the extent and scope of participation of students with disabilities. There was no comparison data between students with and without a disability, nor was the national data clear whether the events were sanctioned by the school or state athletic association. The report did provide information that students with disabilities do participate in extracurricular athletic activities, but often through a wide range of different types of teams, partnerships with community programs, and alternative adapted formats. It was also clear that more boys participated in extracurricular athletics than girls. As with PE, budget constraints were noted to be a challenge that prevented schools from providing more athletic opportunities to all students, including students with disabilities. Lack of information was also mentioned by visited schools as being a challenge. Information in this context included training on how to work with students with disabilities. Parents pointed out during interviews that “coaches who do not have such training can be overly focused on winning and fail to fully include students with disabilities.” Another area that was mentioned as needing better information was the establishment of appropriate eligibility criteria and how to conduct competitive events.

In concluding the report, GAO stated that “Education (DOE) has provided little information or guidance.” It noted, “While OSEP (Office of Special Education Programs within the DOE) monitors states’ implementation of IDEA and provides information, resources, and technical assistance to states and schools on teaching students with disabilities, very little of it is related to PE or extracurricular athletics.” It went on to say, “Similarly, OCR has not widely disseminated any detailed guidance or information on schools’ responsibilities to provide opportunities in PE or extracurricular athletics for students with disabilities under Section 504....” In addition, based on its review and interviews, officials from states and districts said that they could benefit from Education (DOE) helping states and schools share relevant information, such as practices or resources regarding PE and extracurricular athletics for students with disabilities.

Following its conclusions, GAO recommended that the Secretary of Education facilitate information sharing among states and schools on ways to provide opportunities and clarify and communicate schools’ responsibilities under Section 504. This set the framework for Education’s response.

2011 DOE Response

DOE responded in August 2011 with a document entitled, “Creating Equal Opportunities for Children and Youth with Disabilities to Participate in Physical Education and Extracurricular Athletics.” DOE described it as “the initial response to the GAO recommendation” that DOE facilitate information sharing among states and schools on ways to provide opportunities. Interestingly, in the overview portion of the document introducing the topics to be discussed, DOE makes two very clear statements. First, children and youth with disabilities typically are not as active in school-based physical activity and this, combined with “less healthy after school activity and more sedentary amusements,” leads to continued challenges to have an active lifestyle and negative experiences on into adulthood. Second, the current situation, wherein despite clear legislative obligations by states and schools to provide equal access, opportunities for physical activities remain limited for children and youth with disabilities, is described as a “problem.”

The introductory pages of the document review the basis for the obligations relating to physical education and extracurricular athletics, referencing IDEA, Section 504, and Title II of the Americans with Disabilities Act (Title II). The document also reviewed the role and function of the OCR within the U.S. Department of Education, explaining its enforcement activities, including investigations and collaborative efforts with the Office of Special Education and Rehabilitative Services (OSERS) in the areas of policy guidance, technical assistance, and information dissemination.

As a starting point, the DOE document sets out what it calls “Guidelines for Physical Activity,” quoting material from recommendations published by the U.S. Department of Health and Human Services in a 2008 document called the 2008 Activity Guidelines for Americans. The activity guidelines information points out that “children and adolescents with disabilities are more likely to be inactive than those without disabilities” and recommends that “when young people are not able to participate in appropriate physical activities to meet the Guidelines, they should be as active as possible and avoid being inactive.” The DOE document also refers to other efforts to reduce obesity and physical inactivity in youth, such as the national Let’s Move! campaign.

Having set out strong reasons in the initial pages of the document for giving the “problem” attention, DOE then has a section that seems to question some of the rationale provided up to that point for getting children and youth more involved in physical activities, including extracurricular athletics. Entitled, “Limitations in Our Current Knowledge,” the section discusses what it calls a “limited understanding of how the research on children without disabilities can be translated into guidance for physical activity programs for children with disabilities.” It further points out that “there is limited research providing evidence of effective practices and approaches to increase...”
physical activity, to reduce obesity, and to maintain health among children and youth with disabilities.”

Recognizing this, DOE points out the difficult challenge presented to states and schools in developing and implementing practices to increase the participation of children and youth with disabilities in PE and athletics. But, rather than ignoring the issue, the DOE document goes on to state that there is a “growing consensus in the research literature regarding several common barriers to physical activity for children and youth with disabilities.” Among these are inaccessible facilities and equipment, personnel without adequate training, and inadequate, non-compliant, or otherwise inaccessible programs and curricula.

Recognizing that the states and schools do have a role in addressing the challenges, the DOE document then offered “Suggestions to Increase Opportunities,” a narrative of ideas on how to expand the knowledge base of states and schools to increase the potential participation of children and youth with disabilities. The areas discussed are: Accessibility; Equipment; Personnel Preparation; Teaching Style; Management of Behavior; Program Options; Curriculum; and Assessment, Progress, Achievement, and Grading. The discussion in each of the areas is designed to be informative, providing specific examples along with references to studies, reports, regulations, and other source materials as warranted.

The document contains further references to an array of projects involving physical education and athletic activities and three appendices setting out references used in the preparation of the document, an example of state legislation and policy (Maryland), and resources.

2013 OCR “Dear Colleague” Letter

On January 25, 2013, the Office for Civil Rights within the DOE issued a “Dear Colleague” letter to further the discussion and provide further guidance. The letter differs from the DOE document in several important aspects. Whereas DOE’s previous discussion covered the broad range of activities involved with physical education and athletic extracurricular activities, the OCR letter focused upon extracurricular athletics. The letter points out that extracurricular athletics in this context means “club, intramural, or interscholastic (e.g., freshman, junior varsity, varsity) athletics at all education levels.”

The previous discussions in the GAO and DOE documents referred to the IDEA, Section 504, and Title II of the ADA. The OCR letter concentrates on state and school responsibilities under Section 504, the area of the law that is enforced by OCR.

Also, the tone of the letter seems to be different. The DOE document was cast as informational, pointing out that “research and professional opinion support the suggestions for improving opportunities…” and “states and schools can increase opportunities for participation by reducing or eliminating barriers to participation.” In comparison, instead of simply offering suggestions, the OCR letter appears to be more focused and sets out a clear, increasing expectation that states and schools respond to and act on the suggestions being offered by a number of sources. OCR describes the guidance as an “overview of the obligations of public elementary and secondary schools.”

Like the GAO and DOE documents, the OCR letter provides an overview of Section 504 requirements. Importantly, however, the letter’s discussion includes details of what OCR considers “prohibited actions” by school districts. These are:

- Denying a qualified student with a disability the opportunity to participate in or benefit from an aid, benefit, or service;
- Affording a qualified student with a disability an opportunity to participate in or benefit from an aid, benefit, or service that is not equal to that afforded others;
- Providing a qualified student with a disability with an aid, benefit, or service that is not as effective as that provided to others and does not afford that student with an equal opportunity to obtain that same result, gain the same benefit, or reach the same level of achievement in the most integrated setting appropriate to the student’s needs;
- Providing different or separate aids, benefits, or services to students with disabilities or to any class of students with disabilities unless such action is necessary to provide a qualified student with a disability with aids, benefits, or services that are as effective as those provided to others; and
- Otherwise limiting a qualified individual with a disability in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving an aid, benefit, or service.

The letter contains other important caveats in dealing with the subject of extracurricular athletics. For example, Sec. 504 requires that schools provide a free appropriate public education to each qualified person with a disability who is in the school district’s jurisdiction regardless of the nature or severity of the person’s disability. Also, schools must have grievance procedures that incorporate “appropriate due process standards” and provide for “prompt and equitable resolution” of complaints alleging violations of the Sec. 504 regulations. As importantly, the letter takes away any scheme designed to shield a school’s responsibility through membership in an outside sports association or governing body. It states, “Section 504 and the Department’s regulations supersede any rule of any association, organization, club, or league that would render a student ineligible to participate, or limit the eligibility of a student to participate, in any aid, benefit, or service on the basis of disability.”

Throughout the letter, OCR encourages that schools look to the individual student as the best guidance on how to address a question and proceed towards a solution. It warns against generalizations and stereotypes, correctly noting that a student’s ability relative to athletics is dependent upon each individual student and cannot be generalized to a class of students with the same or common disabilities. In this discussion and others, the letter provides clear examples and analysis to frame the discussions. It outlines methods a school can consider to ensure equal opportunity for participation through reasonable modifications without distorting the event and recognizing that all students are not “guaranteed a spot” on a team.

The letter also discusses offering separate or different athletic opportunities. While stating that a school district must ensure that a student with a disability participates with students without disabilities to the maximum extent appropriate to the needs of that student with a disability, OCR acknowledges that there will be occasions where a student with a disability cannot
recently participated in a Work Incentive Seminar Event (WISE) webinar, which explained the Ticket to Work program. If you need a refresher, this article summarizes what the program is and how it can benefit a person with a disability who wants to work.

The Ticket to Work and Work Incentives Improvement Act was signed into law in 1999 (and amended in 2008) to provide supports to people, ages 18-64, who have a disability and receive Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) and who want to work. The goal of the Ticket to Work program is for a Social Security disability beneficiary to achieve becoming self-supporting and eventually going off SSI or SSDI benefits.

An advantage of using the Ticket to Work program is that it has “work incentives” that can allow one to continue receiving benefits while pursuing work. Some of the common work incentives available are:

- **Trial Work Period (TWP)**, which allows SSDI recipients to test their ability to work for up to nine months. The nine months do not need to be consecutive. The recipient will continue receiving their SSDI benefits no matter how much they earn in those months qualifying for the Trial Work Period.

- **Extended Period of Eligibility (EPE)** (for SSDI recipients only), which allows a recipient to continue receiving benefits for 36 months after the Trial Work Period. During these 36 months, the recipient cannot earn over the “substantial gainful activity” (SGA) amount or they will not be eligible for benefits in those months. “Substantial gainful activity” is a set amount of earnings that a recipient cannot earn over each month without losing benefits for that month. This figure typically increases each year. SGA for 2013 is $1,040 per month ($1,740 for a person who is blind).

- **Expedited Reinstatement (EXR)** (for SSDI and SSI recipients), which allows a former recipient to resume receiving benefits without having to fill out a new SSA application. The former recipient must have stopped working due to his or her disability.

- **Protection from Medical Continuing Disability Reviews (CDR)** (for SSDI and SSI recipients), a work incentive in which the SSA will postpone any medical reviews of whether a recipient continues to be disabled to qualify for SSDI or SSI benefits. The recipient must participate in the Ticket to Work program to be protected from CDRs.

If a recipient decides to work, he or she can access the Ticket to Work program by contacting the Social Security Administration or contacting the Ticket to Work Help Line to get a better understanding of how the Ticket program works. The first thing the recipient will need to do is to contact an Employment Network (EN) and “assign their Ticket,” which basically means that they have an agreement with an EN to work with them under the Ticket to Work program. An EN is an agency / organization that helps provide employment services and supports (like career counseling or job placement assistance) to help recipients who want to work. ENs must be approved by SSA, and can be a private organization or the state vocational rehabilitation agency. In South Dakota, the state Division of Rehabilitation Services within the Department of Human Services is an EN.

During the WISE webinar, the presenter shared three common myths that may keep a SSDI/SSI recipient from using the Ticket to Work program:

**Myth #1: If I try to go to work, I will automatically lose my Medicare and Medicaid.**

As long as you keep receiving a benefit check of any amount, you will keep your health insurance. If you earn enough that your SSDI benefit checks stop, Medicare can continue for up to 93 months. If you currently receive Medicaid, you should be eligible to continue to receive Medicaid even after you stop receiving SSI benefits due to work. To be eligible, you need to meet certain requirements, which include earnings below a threshold amount set by your state. Even if your earnings exceed the state threshold, you may still be eligible and should talk to your state Medicaid office.

**Myth #2: If I use my Ticket to go to work, Social Security will perform a medical review on me and I will lose my benefits.**

If you use your Ticket to help you go to work, Social Security CANNOT perform what is known as a Continuing Disability Review (CDR) to see whether you still have a disability. Social Security will postpone your medical review when your Ticket is in use and you are making progress toward your work goals, even if you would otherwise be scheduled to have one.

**Myth #3: If I go to work and then have to stop working, I will have to reapply for benefits all over again.** It took me forever to be approved for benefits and I cannot afford to have to wait that long again so I should not try to work.

You will not need to reapply if your benefits ended within the past 5 years due to your earnings and you meet a few other requirements, including that you still have the original medical condition or one related to it that prevents you from working. This is a Work Incentive called Expedited Reinstatement. You may even be able to receive up to 6 months of temporary cash benefits, as well as Medicare or Medicaid coverage, while SSA conducts a medical review to determine if your benefits can be reinstated.

**Where do I go to get more information on the Ticket to Work program?**

You can visit www.socialsecurity.gov/work to find Employment Networks (state and nationwide), and other Ticket to Work and Work Incentives information, including a disability blog, Ticket success stories, and WISE webinars.
participate. The deciding factor will be whether the separate or different opportunity is “unnecessary.” Again, to decide this will require an individualized analysis of the student’s ability to participate with modifications. However, if a student with a disability cannot participate to the maximum extent appropriate, the schools should still provide opportunities to participate in extracurricular athletic activities. This may require the creation of additional opportunities, even those that are separate and different from those offered to students without disabilities. The letter mentions wheelchair teams, such as wheelchair basketball and tennis, as examples.

OCR concludes its letter with a reaffirmation and an invitation. It states that OCR is committed to working with schools, students, families, community and advocacy organizations, athletic associations, and other interested parties to ensure the participation of students with disabilities in extracurricular athletics. It also states that persons who believe that they have been discriminated against may file a complaint with OCR or in court.

Response to OCR’s Letter

OCR’s “Dear Colleague” letter has drawn a sharp response, including some that were anything but collegial. For example, while expressing its support for including students in extracurricular athletic activities, the National School Boards Association issued a strong critique criticizing the letter from several perspectives. It questioned whether schools now have to convene a Section 504 meeting just to consider how a school district operates.

Supporters of the content of the letter are as vocal. National disability rights associations have stated that the letter provides clarity in a complex and dynamic area and OCR was well within the scope of its authority in issuing the guidance letter.

Conclusion

How students with disabilities participate in physical education and extracurricular athletic activities continues to evolve in South Dakota. In light of the OCR guidance letter, it is anticipated that this area of a student’s school experience will become more focused and further explored and questions will be raised as parents fully peruse the meaning of a free appropriate public education.

The reports mentioned in this article can be located at the following sites:

- **OCR**: “Dear Colleague Letter” January 25, 2013, [http://www2.ed.gov/about/offices/list/ocr/letters/colleague-201301-504.html](http://www2.ed.gov/about/offices/list/ocr/letters/colleague-201301-504.html).

Ticket to Work

(Continued from page 13)

You can call the Ticket to Work Help Line at 1-866-968-7842 (voice) or 1-866-833-2967 (TTY); or the SD Division of Rehabilitation Services at (605)773-3195.

You can also contact South Dakota Advocacy Services’ Protection & Advocacy for Beneficiaries of Social Security (PABSS) Program.

**Medicaid Recipients in Central South Dakota – Rides for FREE**

by Lorna Williams, updated by Gail C. Eichstadt

Medicaid recipients in the Pierre - Ft. Pierre area and outlying towns such as Highmore, Miller, Gettysburg, Agar, Onida, and Blunt can ride the River Cities Transit to medical appointments free! River Cities Transit also provides rides to Sioux Falls for medical appointments on Tuesdays and Thursdays and to Rapid City on Mondays and Wednesdays.

River Cities Transit is an approved Medicaid provider. Arranging rides is an easy process. The rider typically calls at least a day before the appointment to schedule the ride and Transit staff will call Medicaid and confirm that the person qualifies. The Transit office or drivers will provide the Medicaid rider with a one-page voucher to complete. Required information includes name, date of birth, date of medical trip, Medicaid number, date and reason for medical trip, and name of medical facility. The treating doctor, nurse, or therapist must sign the form at the visit. On the return trip, the voucher needs to be given to the driver. Transit will request reimbursement from Medicaid.

To find out more information or to catch a free ride to your next doctor appointment, call River Cities Transit at (605) 945-2360. Staff will answer your questions and schedule the ride.
or several years, the concept of “Drop-in Fitness” for people with disabilities has been a goal and dream of Kevin Horner, a physical therapist at Sanford Medical Center in Sioux Falls, SD. Kevin knows how dramatically people’s lives can change from an illness or tragic accident that leaves them hospitalized with a life-altering medical state. Life suddenly changes. Concerns over health, bills, and loss of employment are just a few of the many stressors that people experience when a life-altering event changes their lives and the lives of their family. For many, discharge from a medical or rehabilitation facility to home is a very daunting experience. Services, such as therapies that were provided by professionals in hospitals, will stop at some point, resulting in reduced support to meet one’s physical and emotional needs. The reality is that insurance coverage will cease at some point.

I had the opportunity to learn of Kevin’s dream a few years ago and have now been able to see his vision running “full steam ahead.” The “Accessible Wellness Program” is on the north end of the Van Demark Building, located across the street (north) of Sanford Hospital on west 18th Street. One year ago, Accessible Wellness membership was 12; today it has over 50 members. It has been a positive experience for me, and I am sure others, to hang around the gym and visit with the folks who use this facility. The atmosphere is one of caring, support, and friendship and where the true wellness spirit embodies every person who participates.

The accessible wellness gym offers wheelchair-accessible exercise equipment, knowledgeable staff, and functional and social wellness. Contact Sanford Outpatient Rehabilitation at 605-328-1860 for additional information.

HOW DO I GET STARTED?

All people are evaluated by a therapist, who then develops an individualized wellness program made up of specialized equipment designed for people with disabilities. Fitness machines are designed to isolate and strengthen certain muscle groups and to assist people with disabilities move from a standing or seated position. The machines at Accessible Wellness are designed to accommodate a person who uses a wheelchair and are usually multi-station, which allows ease of transition from one machine to another through the assistance of trainers.

The fitness machines are top-of-the-line and are designed for people with disabilities in mind. Sanford has the Functional Electrical Stimulation (FES) machine. This machine uses low levels of electrical current to stimulate physical or bodily functions lost through the nervous system. FES is applied to peripheral nerves that control specific muscles or muscle groups. One person told me that he was a “runner” before his accident and by using the FES machine he experiences a “runners’ high.” In other words, the electrical stimulation exercises certain muscle groups even though the person cannot.

One person said that having a facility like this is new for a lot of people. Because of their disability, people can begin to see a new world for them. They can come and easily work-out and use...
Red Blanket is 500th Graduate From SD Partners in Policymaking

by Sandy Stocklin Hook

Travis Red Blanket from Huron had the distinct honor of being the 500th graduate from South Dakota Partners in Policymaking. Red Blanket and his classmates, the 21st group to complete the leadership, empowerment, and training program, graduated on April 27, 2013.

The 25 members of Year 21 were comprised of self-advocates, parents and family members of individuals with disabilities, and Partner assistants from all areas of South Dakota. Graduates included: Rockiel Akason, Jason Bruns, and Edward and Timothy Kopp of Rapid City; Elizabeth Avery, Alcester; Jacque Brown, Kevin Hinnners, Ashley Kienow, Bobbie Muilenburg, and Travis Red Blanket of Huron; Estan Douville, Chamberlain; Toni Feist, Deadwood; Emily and Erin Gustaf and Brandon Haug of Sioux Falls; Stephanie Haugen-Brown, Black Hawk; Carrie Jacob, Beresford; Rebecca Lamma, Madison; Julie Lewandowski, Max Merchen, Amethyst Schwender, and Josh Steinhaucer from Spearfish; Ricky Miller, Hot Springs; Jon Vavruska, Tyndall; and Charlotte Walking Eagle of Wanblee. Year 21 was unique in that the class had two sets of twins and nine members of the class were second generation Partners. South Dakota now has 504 graduates of Partners.

Partners in Policymaking training analyzes developmental disability issues and builds skills that consumers, parents, and guardians need to effectively obtain the most appropriate state-of-the-art services for themselves and others and participate in decision-making situations. While attending the six-month training program, participants learned the history of the disability movement, people first language, and how the legislature works, as well as city, county, school, and tribal government. Other topics included resume writing, employment, effective meetings, abuse & neglect, ADA, inclusive education, being a part of a community, and self-advocacy. The class noted as a highlight of the training when they met legislators, gave mock testimony, and met the Governor.

Approximately three-hundred people attended the banquet and commencement ceremonies at the Ramkota in Sioux Falls, including Lt. Governor Matt Michels, who received the 5th Annual Legislative Advocacy Award. This award is given by the Protection and Advocacy Developmental Disabilities (PADD) Advisory Council to an individual who supports disability-related legislation. Carmyn Egge, Sioux Falls, received the 5th Annual Legislative Advocacy Award. This award is given to an individual for exemplary advocacy on behalf of all individuals with disabilities. Trobaugh is the Mayor of the City of Elk Point.

Banquet guests included Lt. Governor Matt and Karen Michels of Yankton; Department of Human Services Secretary, Laurie Gill, and her husband, Bob, of Pierre; former state legislators Dan Ahlers and wife Amy of Dell Rapids; and Suzy Blake and husband Dr. Jerry Blake of Sioux Falls; Elaine Roberts and Lisa Sanderson, Sioux Falls, of SD Parent Connection; Dave Timpe and wife Benita, Sioux Falls, representing Children’s Care Hospital & School; from the Center of Disabilities in Sioux Falls were Heather Stettich, Shelly Grinde, Eileen Van Soest and Sheri Gunderson; Arlene Poncelet, Executive Director of the SD Council on DD from Pierre; friends and supporters of Partners, Jack & Mary Mortensen and Judy Struck from Sioux Falls, and long-time Partners speaker, Jim Kellar, of Freeman; members of the SDAS Governing Board (Chris Beesley, Custer; Roger Bowie & Monica Matt, Sioux Falls; Vikki Day, Highmore; Dillon Haug, Spearfish; Tim Lemke, Bruce); PADD Advisory Council Members (Avery; Michael Grengs of Watertown; Juanita Harrington, Piedmont; Haugen-Brown; Jacob; Brad Konechne, Kimball; Merchen; Connie Lemke, Bruce; Lincoln Waltner, Yankton; Peggy Waltner, Freeman; and Mark Way, Winner); along with 42 others who have been speakers for a Partner training event.

Lt. Governor, Matt Michels

Falls, of Senator Tim Johnson’s office, and Andrew Curley, Sioux Falls, of Representative Kristi Noem’s office, shared letters of congratulations.

Isabel Trobaugh, Year 2, from Elk Point, received the 12th annual Robert J. Kean Advocacy Award sponsored by the SD Advocacy Services’ Board of Directors. This award is given to an individual for exemplary advocacy on behalf of all individuals with disabilities. Trobaugh is the Mayor of the City of Elk Point.

Bank guests included Isabel Trobaugh of Elk Point, received the 12th annual Robert J. Kean Advocacy Award sponsored by the SD Advocacy Services’ Board of Directors. This award is given to an individual for exemplary advocacy on behalf of all individuals with disabilities. Trobaugh is the Mayor of the City of Elk Point.

Dan Ahlers of Dell Rapids was the keynote speaker. Ahlers is a former state legislator and has been a presenter for Partner training events. Ahlers spoke from the heart regarding his personal life experiences and encouraged everyone in attendance to never quit. “Don’t stop; keep working toward your goal. You will have set-backs, disappointments, but you will never feel fulfilled if you quit.”

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Partners in Policymaking (Continued from page 16)

Partners in Policymaking in South Dakota is conducted by South Dakota Advocacy Services (SDAS). “We came of age this year — 21 classes!” commented coordinator Sandy Stocklin Hook, who has led this training course for the past 16 years. “With over 500 graduates throughout South Dakota, our voices graduates, they are not forgotten,” commented Stocklin Hook.

Continuing education started with Common Grounds (a place where everyone is equal) on Friday evening. The Amazing Arthur, Omaha, helped everyone to “chillax,” laugh, and forget about daily obstacles and challenges. He is a juggler, comedian, and magician.

Continuing education classes included:

**It’s All About Respect:** D’Este Chtyka, Year 20, from Lake Andes, spoke about respect for self, others, and Earth.

**A Different Kind of Lifeguard:** Blowing the Whistle on Depression, Self-Injury and Suicide: Jill Furan, Miss South Dakota International 2012, shared insight on a mentally ill mind. Throughout her year, she is traveling the state speaking about her platform. Jill is also a member of the SDAS PAIMI Advisory Council.

**Keeping the Stress Out of the IEP:** Tim Neyhart, SDAS PADD Program Director, Pierre; parents Lori Douville (Year 7) of Chamberlain and Juanita Harrington (Year 19) of Piedmont; general education professional, Sheila Haanen, Chamberlain; and Dennis Hook, Pierre, teacher and an adult with a disability, shared ideas on writing a basic IEP, working as a team, who should set the goals, who should be present, and the roles of the parent, student, educator, and advocate.

**Self-Advocates for Change on Bullying:** Mike Grengs (Yr. 18) and Rick Rust (Yr. 19) from Watertown and Derek Smith (Yr. 16) of Sioux Falls talked about their organization, which is an advocacy group in South Dakota comprised of adult self-advocates, how to join it, what it means to be a self-advocate, and how to recognize bullying and what to do if it happens to you or someone you know.

**Guardianship:** Robert J. Kean, SDAS Executive Director, discussed the history of guardianship statutes, the processes and procedures used to create and maintain a guardianship, how today they are more focused on the person, and situations that will allow or require termination.

**Inclusive Self-Defense for All Ages/Child Abduction Prevention:** Instructor Sr. Master Dennis Hook demonstrated how to defend yourself from attacks and child abduction prevention.

**Humor in Hard Times:** Kati Seymour, Year 10, Murdo, taught how to improve self-esteem and reduce stress through laughter.

**Zumba:** Angie Albonico of Spearfish, Year 19, taught how Zumba is a fun workout regardless of one’s physical capabilities.

**The Plan:** Laurie Gill, Secretary of the SD Department of Human Services, outlined the 2013 DHS Strategic Plan.

**SibShop:** Sponsored by SD Parent Connection, it was for siblings who do not have disabilities, letting them know what an important role they play in the lives of their family member.

Year 22 of SD Partners in Policymaking will begin in November 2013. For
Farewell To An Advocacy Matriarch
by Twila Stibrals

Lynne Cain, former South Dakota Advocacy Services (SDAS) employee of 24 years, died Thursday, May 30, 2013, at Avera McKennan Hospital in Sioux Falls. Funeral services were held on Wednesday, June 5, 2013 at St. Peter’s Catholic Church in her hometown of White Lake, SD with burial in the church cemetery.

Lynne was born December 3, 1953, in San Antonio, TX, to Donald and Dorothy (Jira) Gillen. She grew up in White Lake, where she graduated from White Lake High School. She attended Presentation College, receiving an Associate Degree in social work, and received her BA Degree in sociology from Yankton College. In January 1976, Lynne married Lamont C. Cain, Sr. and instantly became a mother of a three-year-old daughter and a nine-year-old son. Lynne worked as an activities director, gerontologist, and enjoyed cooking for the company members at the Black Hills Playhouse.

Lynne started her employment with SDAS on February 14, 1982. She began in a Vista program conducted by SDAS in its effort to develop Citizen Advocacy programs for persons with developmental disabilities throughout South Dakota. In 1987, Lynne began focusing her career in the area of mental health with SDAS’ new component program, Protection and Advocacy for Individuals with Mental Illness (PAIMI). She opened the SDAS Yankton branch office and worked as an Advocacy Services Representative, assisting hundreds of people hospitalized at the South Dakota Human Services Center. Her role at SDAS later expanded to additional SDAS programs. Due to medical complications, Lynne retired from SDAS in 2007.

She immersed herself in a number of activities within and outside her work with SDAS. She enjoyed working with the PAIMI Advisory Council’s Anti-Stigma Committee, Kids on the Block puppets program, Yankton Area Mental Wellness, Inc. Committee, National Disability Employment Awareness Month Committee, Blind and Visually Impaired Peer Support Groups, South Dakota Statewide Independent Living Council, and a variety of agencies and organizations that promote independence and well-being for people with disabilities, as well as writing articles for the South Dakota Report.

Lynne was also affiliated with the American Legion Auxiliary, HAPY of Yankton (Citizen Advocacy), animal rights organizations, and was named Yankton’s Volunteer of the Month by the United Way & Volunteer Services in August 2005.

Lynne was a life-long member of the Phi Theta Kappa (co-ed honors fraternity). She loved theater, both on stage or behind the scenes, and had been involved with the Custer Community Theatre, the Black Hills Playhouse, the Yankton Community Theatre, and the Harmony Notes in Yankton. Lynne enjoyed writing and received journalism awards. She was very proud that every play she wrote had been staged.

She loved gardening, reading, camping, fishing, sewing, photography, collecting dolls, and being in the company of her family and pets.

Based on her own life experiences, providing advocacy services for persons with disabilities presented a very personal challenge and passion for Lynne. SDAS appreciated Lynne’s work and determination in promoting and advocating the rights of persons with disabilities, for encouraging full inclusion and independence of individuals with disabilities in all aspects of society, and for the many activities she had undertaken to reduce mental illness stigma.

Lynne will be deeply missed by SDAS staff, and will be remembered for her teachings to:

✦ Think before you act;
✦ Treat others as you would like to be treated; and
✦ Before you label people, look at their contents.

SDAS applauds Lynne for her legacy of promoting dignity, equality and respect for all.

Partners in Policymaking
(Continued from page 17)

more information about the training or to receive an application, please contact Sandy Stocklin Hook by mail at SD Advocacy Services, 221 S. Central Ave, Suite 38, Pierre, SD 57501; email hooks@sdadvocacy.com; or phone at 1-800-658-4782. You can also access an application on SDAS’ website, www.sdadvocacy.com. Click the training button and follow the links. The webpage also has testimonials from Partners graduates and a video explaining what Partners in Policymaking is all about.

Partners in South Dakota is funded in part by grants from the SD Council on Developmental Disabilities; Center for Disabilities at Sanford School of Medicine at USD; SD Parent Connection; Children’s Care Hospital & School; and the PADD, PAIMI, and PAIR Programs of SD Advocacy Services. Stocklin Hook was assisted by volunteer Year 7 graduate Lori Douville of Chamberlain.
the machines. It really promotes an overall better quality of life.

**MUSCLE TONE**

We cannot discuss a wellness program without explaining “normal” versus “abnormal” muscle tone. Normal muscle tone is when the muscles are in a state of tension or resistance, which is called “resting muscle tone.” In normal tone, when one set of muscles contracts, the opposite set will relax in order for smooth, coordinated movement to occur. Abnormal tone occurs when the messages from the brain are disrupted or incorrect. We see this in conditions such as Cerebral Palsy, TBI (Traumatic Brain Injury), Multiple Sclerosis, and spinal cord injuries, as well as other disorders. Spasticity is a muscle condition characterized by tight or stiff muscles that may interfere with voluntary muscle movements. Kevin noted that many people have been able to stop or reduce the medication that helps keep the tone in check through exercise. This is significant because when the muscle tone is not “normal,” the person not only suffers pain, but also experiences a reduced range of motion.

**WELLNESS**

People with disabilities who participate in a wellness/fitness program are showing us that in general their health improves. For some, it may mean getting to a certain level and then maintaining muscle through a wellness program. Kevin’s group completes an assessment on a regular basis, which provides individuals data on how their body is responding to the fitness program. The fitness program not only works on the affected muscle group, but also expands lung volume, increases circulation, may reduce high blood pressure, etc.

**DISABILITY ENTITLEMENTS**

Many participants may receive SSI/SSDI benefits. The Social Security Disability Insurance and Supplemental Security Income programs are the largest of several federal programs that provide assistance to people with disabilities. While these two programs are different in many ways, both are administered by the Social Security Administration and only individuals who meet medical criteria may qualify as “disabled” and thus eligible for benefits under either program. It is not unusual for people who have been determined eligible for SSI/SSDI to want to seek employment again. If you want to work, but are afraid about what will happen to your state and federal benefits, you should contact South Dakota Advocacy Services (SDAS). Its Protection and Advocacy for Beneficiaries of Social Security (PABSS) Program can provide you with information and a range of services to assist with these issues. Staff will inform you about the different work incentives, such as those that allow you to keep your Medicaid or Medicare benefits while you work. If you are planning on returning to work and are currently using Vocational Rehabilitation Services, the Client Assistance Program (CAP) can provide assistance in working with your provider. There is no cost for these services. Please contact SDAS intake at 1-800-658-4782 for further assistance.

**CONCLUSION**

Accessible Wellness at Sanford was developed by one man’s dream and many grants. Kevin Hornor’s goal was and remains simple: Develop a wellness program that is affordable and offers specially-designed fitness equipment that accommodates people with disabilities and they will come. The hours of operation are Monday thru Friday from 7:00 a.m. – 6:00 p.m. On Monday, Wednesday, and Friday, trainers are available from 2:00 - 6:00 p.m. Membership is $30.00 per month and includes the use of the pools at Sanford Wellness at 49th and Oxbow.
“Access Pass” Widens Vacation Opportunities to Federal Recreation Areas

by Gail C. Eichstadt

The “Access Pass” increases recreation opportunities for individuals of any age with permanent disabilities in America. Instead of paying entrance fees to any of 2000 federal recreation sites, an Access Pass holder is entitled to free lifetime entrance to most of them. A permanent U.S. resident or U.S. citizen with permanent disabilities may request an Access Pass in person at most federal recreation entrance stations without a processing fee while traveling. If one is planning a trip, the Access Pass may be requested in advance by mailing an application, proof of permanent disability and citizenship, and a $10 processing fee to USGS, Box 25286, Denver, CO 80225.

Many people are familiar with the “Golden Access Passport,” the “Golden Eagle” pass, or the “Golden Age” pass. The Golden Eagle and Golden Age passes are still valid, but not sold. The “Golden Access Passport” was the forerunner of the Access Passport. A Golden Access Passport holder may still use that pass for his or her lifetime.

Good news for everyone is that no entrance fees will be charged to anyone on August 25, 2013, the birthday of the National Park Service; September 28, 2013, National Public Lands Day; and on November 9 to 11, 2013, Veterans’ Day weekend.

More information on the Access Pass may be found at http://store.usgs.gov/pass/access.html or by speaking with staff at a federal recreation area.