A New Focus: SDAS will begin Monitoring Activities in April

by Tim Neyhart

South Dakota Advocacy Services (SDAS) is celebrating its 40th year of being the designated Protection and Advocacy Agency in South Dakota. Coinciding with that milestone anniversary, based on input from people with disabilities in South Dakota, SDAS has been planning and developing changes to its service delivery model.

Over the course of its history, SDAS has been heavily invested in special education advocacy and, over the past twenty years, provided very successful advocacy in the area of Social Security eligibility. This work was in addition to working with people receiving services in public and private facilities.

There have been developments in the areas of special education advocacy and Social Security in the last few years that have impacted SDAS’ decision to focus the agency’s work in different areas. The Navigator Program through South Dakota Parent Connection and other related programs have impacted the demand for advocacy services in the area of special education. Several private attorneys have expanded their work in providing services to people who are applying for Social Security benefits. These changes, along with the increase in the use of person centered practices in the service delivery system, triggered the planning process for this change. Person centered planning, in part, encourages that the service providers work with the individuals in their facilities to identify what supports the person wants. The providers then work to help make those supports available to the person. This model fits nicely with the SDAS requirement that we represent the expressed desires of the client.

The effort to meet with people directly where they live and work was already part of the service model in one of the programs within SDAS. For the

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past seven years, SDAS had been part of a grant from the Social Security Administration that was designed to evaluate the efficacy of agency-based Protective Payee services. This experience provided SDAS staff with the opportunity to meet with people in their homes and work areas to discuss their opinion of the services that they receive on a day-to-day basis. This experience helped the staff to understand the need for the agency to go to meet directly with people who are receiving services. It became clear that the usual outreach and contact efforts made by SDAS were not effective in helping people receiving services in these facilities to understand the nature and scope of the services provided by SDAS. SDAS decided it was time to meet with people directly and ask them what they needed from the agency. SDAS will use this information to develop direct advocacy-based services.

Over the past year, SDAS has prioritized and planned the development of a monitoring protocol. This protocol included training for the staff and the development of policy and procedure to explain and structure the process for conducting this activity. Staff received training and support from specialists at the National Disability Rights Network. The training was conducted through a series of webinars, culminating with three days of onsite training from the NDRN staff. The NDRN staff observed SDAS staff while they interacted with people in their homes and their work sites. After each interaction at the facility or residence, NDRN staff provided feedback to the training participants about their interview techniques, their approach to people in the particular setting, and suggested questions that could be asked to individuals. NDRN staff provided direct instruction to the SDAS staff about how to improve the monitoring process in future.

What is monitoring? “Monitoring” includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports, and other assistance. Monitoring may take place in an institutional or community setting by: a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; c) observing and evaluating the physical conditions of the setting; and d) accessing and reviewing records, where appropriate, in accordance with applicable federal and state laws. (NDRN Protection and Advocacy Standards, pp. 21-22)

Monitoring is not simply a checklist process; it is much more of an interactive and relationship-building process between SDAS staff and people living in facilities. The process is designed to assist people to identify and address the issues that are affecting them in their day-to-day lives. The initial experiences with this process provided useful information about the settings visited by SDAS staff. The facilities for the most part were neat and clean. The people who lived in the residences or worked in the work settings were satisfied in the sense that they had good food, were clean, and were not mistreated. The one concern identified by SDAS staff was that the people in the facilities were totally dependent on staff schedules. Staff
How Monitoring Works

by Kate Hoekstra

SDAS has shifted its focus to systemic efforts to impact more people with disabilities. This change in focus will not eliminate services to individuals, but may impact the number of individual cases accepted based on staff availability. Part of this shift includes implementing a system of regularly monitoring various facilities in South Dakota that provide services to people with disabilities. SDAS has been preparing for this shift for over a year.

Last spring and summer, SDAS staff received training from National Disability Rights Network (NDRN), an agency that provides legal advice to state protection and advocacy agencies (P&As). NDRN provided training through an online platform, concluding with a face-to-face training. While NDRN staff was onsite, SDAS staff implemented the monitoring skills at a local community service provider while being observed by NDRN. NDRN provided SDAS valuable feedback. Since those trainings, SDAS has developed a comprehensive Monitoring Protocol to direct the monitoring activities. SDAS began implementing this system this spring.

SDAS will monitor facilities where people with disabilities live or receive services to ensure safety, identify and prevent instances of abuse or neglect, maximize independence, and confirm community integration. During monitoring activities, SDAS will:

- Identify, and address to the extent possible, incidents of abuse and neglect;
- Survey the facility for environmental safety;
- Educate people with disabilities about their rights within facilities;
- Determine if appropriate services are provided;
- Evaluate if persons with disabilities are provided opportunities to participate in community activities; and
- Identify people who could live in the community with support.

SDAS will select several facilities to monitor each year, which may include state institutions, mental health facilities and residential programs, community service providers and their residential units, nursing homes, assisted living centers, school settings, and correctional settings. As part of its protocol, SDAS has developed a letter to be sent to guardians and conservators to inform them of the monitoring activity. SDAS will also seek to have a notification form included in all admission packets. During its monitoring activity, SDAS will also ensure the Notification is posted at each facility it is currently monitoring.

How Monitoring Works

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How Monitoring Works
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An initial contact letter will be sent to the facility administrator explaining the monitoring process and SDAS’ authority to conduct monitoring activities. SDAS staff will follow-up with the administrator to schedule the first monitoring activity and request information, such as admissions packets, grievance procedures, discharge policies, staff training policies and checklists, medication policies, and restraint and seclusion policies. SDAS staff will also research the facility’s license or certification, policies, and obtain any survey data available.

SDAS’ general plan is to perform the monitoring activities at each chosen facility on three separate occasions over a three-month period. SDAS’ Monitoring Lead Team may vary the number of visits and the time between visits depending on the circumstances.

At the first monitoring visit, SDAS has three main focuses — environment, residents, and facility policies. SDAS will observe inside and outside the facility, taking note of any concerns. SDAS will look for things such as posting of current licenses, needed repairs, cleanliness, odors, accessibility, and safety concerns. Interviews will be conducted with residents who agree to talk with SDAS. Questions for residents will include everything from what their typical day looks like to future goals, and everything in between. If residents do not feel comfortable answering certain questions, they need not answer and they may also end the conversation at any time. Each individual served at the facility will have an opportunity to speak with SDAS about any personal disability-related concerns. SDAS will address the concern onsite or assist the individual in calling the SDAS Intake Team. The last step of the process will be to interview the facility administrator, asking questions about staff, policies, and resident rights, as well as providing feedback regarding the monitoring visit. SDAS will formalize the conversation in writing and provide it to the facility administrator.

If SDAS staff discovers any issues needing to be addressed during monitoring, those issues will be addressed with the administrator and SDAS will follow-up on them during subsequent monitoring visits to the facility. Depending on the nature of the concern(s), SDAS may offer suggestions for changes or may choose to conduct a more intensive investigation into the issue(s). After the last monitoring visit of the facility, SDAS will send the facility a written report of its findings.

By conducting these monitoring activities, SDAS hopes to enhance its understanding of the issues that may be affecting people who are receiving services in these facilities. SDAS hopes to develop and maintain positive relationships with South Dakota residents with disabilities and the agencies that serve them.
BLACK HILLS ADVOCATE
and
CHAIR LIFT
by Marie McQuay

BLACK HILLS ADVOCATE is an independent patient advocate organization in Rapid City that offers a variety of services that cover a broad spectrum of needs for adults with disabilities, adults who are vulnerable, and the elderly. Black Hills Advocate coordinates all the services necessary to ensure its clients receive the highest standard of quality care and services possible. These services include:

♦ Accompany clients to doctor/hospital visits
♦ Coordination of all health care providers and medical services
♦ Maintain a portfolio of medical history
♦ Research treatment options
♦ Health insurance and financial assistance applications
♦ Implement financial planning strategies
♦ Process monthly bill paying and bank statement reconciliation
♦ Communicate with clients’ accountants, attorneys, and financial planners
♦ Assist with advance directives (Health Care or Financial POA, Living Will, etc.)
♦ Assist with Guardianship applications and Agent designation
♦ Coordinate end-of-life requests and after-care planning
♦ Wellness visits at home or extended care facilities
♦ Advocate for patient’s rights and medical needs
♦ Assist with level of care choices and placement.

Flexible payment schedules are offered, including fees for services based on hourly rates, flat fee for one-time services, discounted monthly rates for clients receiving continuous services, and 10% discount for Veterans. Services are available 24 hours a day, seven days per week. Black Hills Advocate can be reached at (605) 519-5051.

CHAIR LIFT was launched in February 2017 to provide high quality, low cost, wheelchair accessible transportation on a flexible schedule to vulnerable populations of all abilities in Rapid City and the surrounding communities. This program provides well-trained staff to meet the clients’ needs in a compassionate, respectful, and dignified manner, through one-call transportation, no cumbersome forms, personal assistance from living room to check-in desk, and assistance with personal items.

Local hospitals are implementing procedures to utilize Chair Lift to provide transportation for patients discharging from the hospital or emergency room when other transportation services are not appropriate or available. Chair Lift is also developing relationships with other local non-profit agencies (WAVI, TIE, the HOPE Center) to better serve the needs of the community. In addition, Chair Lift partners with the VA to transport veterans to and from Ft. Meade.

Chair Lift is currently pursuing several grant opportunities to subsidize low cost or no cost rides for eligible customers. Chair Lift is a 501(c)(3) organization, and all donations are tax-deductible. Rides can be donated at gochairlift.org.

Hours of operation are M-F, 7:00 am – 8:00 pm, and weekends by appointment. Call Chair Lift at (605) 299-5438.
Each March, the United States observes National Intellectual and Developmental Disabilities (I/DD) and Brain Injury Awareness Month. In recognition of I/DD and Brain Injury Awareness Month, SDAS promotes and participates in the presentation of proclamations in various communities across the state.

National I/DD Awareness Month is an opportunity to promote respect for people with I/DD and to educate others about the abilities of people with I/DD. Some disabilities are visible, such as a person who uses a wheelchair or crutches to ambulate, while other disabilities may not be easily recognized, such as cognitive impairments. It is not always possible to completely understand the effect an injury may have on the way a person speaks, learns, or interacts with others.

Brain Injury Awareness Month was created to acknowledge the causes and consequences of this disability. Promoting Brain Injury Awareness Month helps the general public to understand the need for greater prevention, research, education, and advocacy on behalf of individuals who experience a life-changing brain injury. Brain injuries are a leading cause of death and disability in America. According to the Centers for Disease Control, concussions are one of the most common forms of brain injury, affecting an estimated 1.6 to 3.8 million people each year.
The Importance of Sufficiently Trained Staff in Adult Settings

by John A. Hamilton

This situation frequently became potentially dangerous. Sarah would leave the apartment some nights, sometimes in freezing temperatures with inadequate winter clothing. Since there was only one staff person, the staff person could not leave the other residents to go after Sarah. Again, all the residents required supervision. Sarah, having left the apartment unsupervised and alone, was susceptible to weather, being run over in the street, being picked-up or kidnapped by a stranger, being raped, etc. The facility would call Sarah’s family (who lived many miles away) to ask if they would come to help look for their family member. One could hardly blame Sarah for not wanting to be stuck in the apartment all the time with the residents who were all older than her mother. Sarah’s individual needs were not being met due to inadequate staffing. As a result, when she most needed staff supervision (when she would leave the apartment alone), her needs were neglected. Imagine, as a parent, being called repeatedly by the service provider with which you have entrusted your daughter and being told your daughter is unsupervised somewhere in the community.

It is unknown what each of the residents’ disabilities entailed, but let us assume cognitive impairments and one or two with mental health conditions as well. The assigned staff person varied due to work schedules, as well as turnover. Some staff interacted well with the residents, while others tended to ignore the residents and spend their time on their phones. At one time, the apartment reeked from spoiled food for many days, but none of the residential staff did anything about it. The residential staff that CSPs hire are probably high school graduates, maybe college students or college graduates, but regardless of their education level, the question certainly should be posed as to what type of training the residential staff have received in working with the particular disabilities of the residents.

Case Example 1

“Sarah” has cognitive and other impairments. She lived in a supervised four-person apartment operated by a Community Service Provider (CSP). Due to fiscal limitations or perhaps an inability to hire sufficient staff, the residential setting provided only one staff person. The needs of the four residents differed greatly. There was a large age difference between Sarah and the other residents (at least 30 years). As a result of that age difference, there was certainly a difference in interests, desired activities, and energy level. Sarah wanted to do things young people do, while the older residents did not share those same desires or interests. The residents each required supervision when leaving the apartment. With only one residential staff person, all residents had to agree to, and participate in, an activity outside of the apartment, whether that be bowling, going to the mall, going to a game, going out to eat, etc. Simply, if one decided not to go or was ill, then everybody stayed home.

Because the needs and desires of these residents differed greatly, it is likely that many planned activities never happened. So far, this case example has shown how individual needs were not being met due to inadequate staffing levels. There is also an issue with the appropriateness of the placement, in that Sarah had no age-appropriate peers. Situations like this occur when a need for placement arises and there is only one option available at the time.
successfully live and work at jobs in the community. His behavior was very stable when he aged-out of the public school system and left that setting. Clearly, the public school system, through the IEP Team’s residential placement, did an excellent job of educating Andrew and preparing him for adult services.

Unfortunately, when Andrew moved into the adult services system, he did not fit in well into existing programs or placements due to his severe needs and staffing requirements. Six months after leaving the educational setting, his family found him looking like a “street person.” He had received only one haircut. His basic needs were not being met. He had apparently been wearing the same pair of soiled underwear for weeks. He was expected to independently brush his teeth, which he could not do. He was expected to independently decide if or when he needed to shower, but it would never occur to him to do so. He had been tormented, teased, and injured by another resident. Due to high staff turnover, inadequate staff training in Autism, and the failure to provide consistent and appropriate positive behavioral supports, Andrew regressed. He was engaging in self-injurious behaviors. He was kicking holes in walls and ripping doors off hinges. In less than six months of receiving services in the adult services system, all the gains achieved from the prior six years of services had been destroyed.

During his first four years in the adult system, Andrew was in three residential settings. Each time, the placements ended in crisis and he was moved to another setting. He suffered abuse and neglect in each setting, resulting in physical harm, psychological trauma, and severe behavioral regression. In the last of the three settings, Andrew was kept in a “bedroom” with no air conditioning and no ventilation, where he apparently suffered heatstroke and a heat-induced seizure. Despite holes cut into a Plexiglas window panel on the door, it was reported that during a heat wave, opening his door was like opening an oven door as the hot air rushed out. Due to Andrew’s disability (including deficits in functional communication), he was unable to report any of the abuse, neglect, or injuries he sustained over this four-year period.

The second example demonstrates that for some individuals, the need for sufficiently trained staff does not end when leaving the public school system. In fact, it is at least equally as important, if not more important, to have sufficiently trained staff for adults than it is for students. Instead of services being provided in a single setting, such as a public school or a residential educational facility where other professionals are available to assist, consult, or discuss what is or is not working well, adult services tend to be spread-out into several apartments and other adult living situations. Abuse and neglect can be more easily hidden. There is a lot of staff turnover in adult systems, which translates to less-experienced under-trained staff - staff who do not know what to do when behaviors occur and who, as a result, may instead exacerbate the situation/behaviors.

In Andrew’s situation at the first residential placement, presumably he received only one haircut because he did not ask for one. Andrew does not like to get his hair cut and it would never occur to him to ask for a haircut. Facility staff should have understood that. Andrew would wear the same clothes every day if allowed to do so because he does not understand the need to wear clean clothes and it would not occur to him to wear, for example, clean underwear. Facility staff should have understood that. Andrew needs staff with specific intensive training in Autism and positive behavioral supports. As importantly, he requires staff with an understanding of how his multiple diagnoses uniquely affect him – what his needs are, what triggers maladaptive behavior, and what positive behavioral supports work with Andrew.

Andrew’s placement at the third facility illustrates the issue of staff training. A presumption can be made that the vast majority of people who work in direct care positions do so because they have a caring passion to help other people. Presumably well-meaning staff at the third facility thought it was a good idea to lock Andrew in his bedroom as a way of addressing his significant behaviors. The staff thought it would be a good idea to put a Plexiglas window in the door and cut out air holes, kind of like children do when they place a caterpillar in a jar. For some reason, the staff thought the air holes would create air flow into and out of a non-ventilated room, so it was not necessary to monitor the room temperature. Presumably, these well-meaning staff did not realize the abuse and neglect they were inflicting on Andrew. While intentional acts of abuse and neglect certainly occur, it is much more likely, and more common, that this type of abuse and neglect occurs because staff lacked the specific training needed to work with individuals, then made bad decisions while attempting to improve interventions or controls.

**Staff Training Requirements in SD**

South Dakota has statutes and administrative rules addressing staff training requirements in both the developmental disabilities and mental health systems. The following sections detail and discuss those requirements.

**Developmental Disabilities Training Requirements**

SDCL 27B-2-26 requires the secretary of the Department of Human Services to promulgate administrative rules establishing standards for community service providers, South Dakota Developmental Center-Redfield, and other nonpublic facilities, services, and supports for persons with developmental disabilities and for services and supports to be provided or purchased by the Department of Human Services under SDCL Title 27B. It requires administrative rules in the following areas:

1) Staff requirements, to include orientation, continuing staff development, instruction on positive behavioral supports and medication administration;
2) Administration, audit requirements, and record keeping;
3) Services and supports provided;
4) Client rights and safety;
5) Facility fire safety and sanitation requirements;
6) Respite care;
7) Family support;
8) Preadmission Screening/Annual Resident Review (PASARR);
9) Such other standards and requirements as are necessary for federal financial participation; and
10) Any other services and supports necessary to implement this title.

The administrative rule created and adopted addressing staff training is contained at ARSD 46:11:04:15.01, Staff orientation training. It states (all emphasis added):

The provider shall ensure that all employees responsible for providing supports and services to individuals are trained on the minimum requirements necessary to address the individual’s needs. The training and documentation requirements are as follows:
Staff Training in Adult Settings

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(1) Before a new employee, temporary employee, or volunteer performs any duties, the initial orientation requirements are as follows:

(a) Orientation to the community services provider and its policies;
(b) Emergency procedures concerning fire prevention, accident prevention, and response to emergencies;
(c) Techniques of identifying and observing signs of abuse, neglect, and exploitation;
(d) Procedures used in investigating and documenting alleged instances of abuse, neglect, and exploitation; and
(e) Procedures used to report alleged instances of abuse, specifically to whom allegations should be reported, and reporting deadlines;

(2) The following training areas shall be addressed within 30 days of the employee’s start date:

(a) Employee’s specific duties and position; and
(b) Participant’s rights in accordance with state and federal laws;

(3) Employees shall be trained within six months of the employee’s start date regarding the following:

(a) Instruction in the ethical principles related to positive behavior support techniques;
(b) Implementation and development of the ISP;
(c) Training prior to the actual implementation of positive behavior support plan specified in the ISP;
(d) First aid;
(e) Cardiopulmonary resuscitation;
(f) Approved safety intervention techniques;
(g) Disability awareness;
(h) The provider's philosophy and mission; and
(i) Use of adaptive and augmentative devices used to support individuals, as necessary;

(4) The provider shall document in the staff personnel record that training and demonstration of competency were successfully completed. Documentation shall include:

(a) Topic;
(b) Date staff attended training;
(c) Date competencies were verified;
(d) Name of person conducting training; and
(e) Verification of competency signed by a person with education, training, or expertise in the area of the competency.

This rule has several positive aspects. There are numerous specific areas that must be covered for all new direct support staff. Service providers must document when the training occurred and must also verify a new staff person is competent in each area in order to complete the training.

On the other hand, it is disconcerting that new employees can be working for up to a month before learning their job duties or about individuals’ rights. It is even more disconcerting that employees can be working up to six months before receiving training on implementing ISPs, positive behavior supports, safety intervention techniques, and disability awareness. For example, if a new employee is hired as residential staff, presumably the new staff person will actually begin working in the apartment, group home, or other setting long before this training takes place. In Andrew’s situation, it did not take that long to undo all the good work that had been done with him the prior six years.

The first sentence of the rule requires providers to ensure “all employees responsible for providing supports and services to individuals are trained on the minimum requirements necessary to address the individual’s needs.” That language seems to indicate a threshold amount and type of training based on the unique needs of the individual (e.g., for Andrew, the minimum requirements necessary to address his needs entails a high level of specific training in Autism, etc., prior to working with him). However, the rule then defines that phrase by the requirements contained in the rest of the rule. Thus, unless “disability awareness” entails intensive training in specific disabilities and methodologies when needed, the rule fails to account for situations where new staff need, at a minimum, that intensive level of training in order to appropriately support an individual’s unique needs. If “disability awareness” does encompass the intensive training described, staff need this training prior to working with the individual, not up to six months later.

Training is also referred to at ARSD 46:11:05:12, which refers to a behavior support committee. It requires that providers of direct HCB services have a behavior support committee, and this committee’s function is to review “the technical adequacy of and approves all behavior support plans which use any of the highly restrictive procedures listed in § 46:11:05:06.” The behavior support committee “must be provided with training in the effectiveness of behavior support techniques, the mission and philosophy of the provider of direct HCB services, behavior changing medication, and disability awareness.” This rule addresses training only for the behavior review committee, not for direct support staff.

At the South Dakota Developmental Center – Redfield, an administrative rule describes “qualified professional staff to develop, implement, and monitor each person’s ISP” and that these individuals “must participate in ongoing staff development and training; and must be licensed, certified, or registered according to state licensure requirements, if applicable.” ARSD 46:17:04:06. This rule appears to require a higher level of education (“qualified professional staff”) and also requires ongoing training beyond the “staff orientation training” contained at ARSD 46:11:04:15:01.

The foregoing appears to be the extent of South Dakota’s rules on staff training in the developmental disabilities system. None of South Dakota’s administrative rules require staff to receive intensive training in specific disabilities and methodologies when needed to support individual needs. Furthermore, only for staff at the Administrative Developmental Center is there a requirement of “ongoing staff development and training.” There appears to be nothing in the administrative rules on “continuing staff development,” as required in SDCL 27B-2-26, for staff of CSPs. Since the vast majority of individuals with developmental disabilities receive services in the community, the lack of required ongoing training is also a significant deficiency in the developmental disabilities system. Having said that, one must assume CSPs provide ongoing training for direct care staff without a rule requiring them to do so.

Mental Health System Training Requirements

Mental health services differ from services for individuals with developmental disabilities because mental health services are typically overseen by a medical doctor (psychiatrist). SDCL 27A-5-1 requires the Department of Social Services to determine and establish reasonable standards and requirements for the locally operated nonprofit mental health centers in South Dakota in order

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for them to qualify for assistance from the State. “The secretary of social services may adopt reasonable rules in regard to the following standards and requirements:

1. Staff requirements;
2. Administration, audit requirements, and record keeping;
3. Services provided;
4. Patient rights; and
5. Such other standards as are necessary for the safety and health of clients and patients.”

ARSD 67:62:06:03 sets out educational requirements for staff providing direct services and supports to clients. “Staff, hired after December 31, 2010, providing direct mental health services and supports to clients, shall have one of the following qualifications:

1. At least an associate’s degree in the social sciences or human services field to provide:
   a. Intake services;
   b. Case management;
   c. Family education and support;
   d. Liaison services;
   e. Direct assistance;
   f. Psychosocial rehabilitative services; and
   g. Recovery support services;
2. At least a master’s degree in psychology, social work, counseling, or nursing; a social work license as defined in SDCL 36-26-15; or a bachelor’s degree in a human services field and two years of related experience to provide any of the services listed in subdivision (1) or any other mental health services;
3. A licensed physician or psychiatrist, or a resident operating within the Board of Medical and Osteopathic Examiners guidelines, or a licensed physician assistant or licensed certified nurse practitioner practicing within his or her scope of practice, to provide psychiatric services; or
4. A registered nurse or licensed practical nurse to provide psychiatric nursing services.”

The mental health system thus sets the bar much higher when hiring staff. Once a facility hires staff, ARSD 67:62:06:04 sets out staff training requirements. “The center shall provide orientation for all employees, including contracted staff providing direct clinical services, interns, and volunteers within ten working days after employment. The orientation shall be documented and shall include at least the following items:

1. Fire prevention and safety, including the location of all fire extinguishers in the center, instruction in the operation and use of each type of extinguisher, and an explanation of the fire evacuation plan and center’s smoking policy;
2. The confidentiality of all information about clients, including a review of requirements in this article and 45 C.F.R. Parts 160 and 164 (October 7, 2009);
3. The proper maintenance and handling of client case records;
4. The center’s philosophical approach to treatment and the center’s goals;
5. The procedures to follow in the event of a medical emergency or a natural disaster;
6. The specific job descriptions and responsibilities of employees;
7. The center’s policies and procedures are maintained in accordance with § 67:62:05:01; and
8. The center’s procedures regarding the reporting of cases of suspected child abuse or neglect in accordance with SDCL 26-8A-3 and 26-8A-8.”

The mental health rules require a level of supervision for certain direct service staff. “Any center staff providing direct services to clients, other than those staff who meet the criteria of a clinical supervisor as defined in subdivision 67:62:01:01(8), shall be supervised by a clinical supervisor. The amount and type of supervision shall be based on the center’s staff needs for such supervision and their level of education, training, and experience. Clinical supervisors are also responsible for ensuring center staff who do not meet clinical supervisor criteria are operating within the scope of their education, training, and competencies.” ARSD 67:62:06:05.

The mental health system assumes a certain level of competency by the education level of the staff the mental health facilities hire. The initial orientation training is not on specific mental health conditions. However, the rules require supervision of all direct support staff who do not meet criteria for being a clinical supervisor. Significantly, it requires clinical supervisors to ensure staff the clinical supervisor supervises are not being expected to do more than what is within the particular staff person’s education, training, and competencies. For example, if Andrew had ended up in the mental health system, presumably only those with the necessary “education, training, and competencies” would be allowed to work with him under the mental health rules.

The mental health system also requires mental health centers to provide its staff with “ongoing training and consultation” so that staff and supervisors can “carry out their responsibilities effectively.” ARSD 67:62:06:08.

The mental health rules provide no rules on specific competencies, such as positive behavioral supports, CPR, safety intervention – anything dealing with the residents’ needs or situations that may arise. However, the rules that perhaps address this sufficiently are the requirements that clinical supervisors are to ensure staff do not operate outside of their education, training, and competencies and that staff are to receive ongoing training to enable them to be able to carry out their responsibilities.

The Importance of Specific Staff Training

While Andrew’s needs due to his severe Autism and other impairments are greater than most individuals receiving adult services, his situation provides an excellent example of why staff require training in the specific disabilities they will work with, as well as specific training in methodologies needed to address an individual’s unique needs. For example, Autism entails a spectrum from mild to severe and every individual with Autism is unique. No two Traumatic Brain Injuries are the same in terms of how they affect an individual. Individuals with multiple disabilities present a host of unique needs. There is no cookie-cutter training regimen that will provide staff what they need to appropriately meet each individual’s unique needs. It is not just a matter of receiving training in particular disabilities and methodologies, however, but also regarding how those disabilities affect the individual.

Andrew’s situation provides a good example for this discussion. Beyond intensive training in Autism, methodologies, and positive behavioral supports, staff need additional training to understand...
how to work with him. He needs assistance with personal needs, such as showering, washing his hair, shaving, and brushing his teeth. Andrew does not like doing any of these activities, so staff must understand how to work with him to accomplish these tasks without exacerbating behaviors. Consistency in supports, expectations, and behavioral methodology are all vital, but so is consistency of staff. Thus, it is important to avoid staff turnover to the extent possible and to have a small core group working with him. He is extra sensitive to sounds, requires structure (a schedule) throughout each day, and can become very territorial in residential settings. When he is provided with appropriate programming by trained staff and receives the intensive supports he requires, his behavior can be maintained and he is able to function. Without all the pieces in place, behaviors intensify quickly and he regresses.

Andrew’s situation is certainly more extreme than most, but it shines a bright light on the need for individuals to have sufficiently trained staff working with them in adult settings on an ongoing, lifelong basis. While the situations involving Andrew occurred many years ago in another State, his needs have not changed. He can function only where all staff working with him are sufficiently trained in Autism, methodologies, and positive behavioral supports, are working together so as to provide the needed consistency, and understand his unique needs and how to work with him. While other adults with disabilities may have different disabilities or combinations of disabilities than Andrew, the need for specialized training based on each individual’s needs will often be crucial to the individual’s ability to be successful in the least restrictive setting.

One may wonder how situations like those described herein occur. Are service provider staff supposed to report abuse and neglect? Yes, service provider staff are supposed to report abuse and neglect, but maybe the staff had not been sufficiently trained to recognize it. Maybe the residence was so self-contained that there was no one to report it other than the staff involved. Maybe staff reported it, but nothing was done because no one knew what to do differently or perhaps facility administrators chose not to report it.

Parents/guardians are put in a difficult situation. There may be limited available options (or limited open beds) when it is time for their adult child to transition from the school system to adult services, as well as when seeking a different adult placement. Waiting lists are common. When parents/guardians meet with and tour a community service provider or other placement and their loved one is accepted for admission, there is no doubt they are told that facility staff can meet the individual’s needs. Depending on the proximity to their home and finances, visits may be infrequent. They place their trust in the service provider to do what was promised.

In both of the case examples, the parents have always been very strong advocates for their child. In the first case example, there were no other options residentially, either at the CSP Sarah attended or elsewhere in South Dakota, so short of her parent quitting her job and bringing Sarah home to provide 24-hour supervision, Sarah had no other options. In Andrew’s situation, bringing him home at age 22 was not a good option, again because of the need for 24-hour supervision (which literally meant someone staying awake all night in case Andrew awoke or had a seizure). It is a safe bet that when Andrew’s parents discovered the abuse and neglect in the first facility, they addressed it immediately, which resulted in the second placement. Eventually, Andrew was pulled out of the third placement and placed in an emergency care setting, and when that ended a month later, his family had no other option than to bring him home until an appropriate placement could be located.

The answer to how situations like Andrew’s occur begins and ends with the lack of adequately trained staff, as well as, perhaps, insufficient planning. Staff do not know what to do when they encounter behaviors resulting from disabilities in which they have not been trained. As a result, they may make several bad decisions that cause behaviors to escalate. The end result may be abuse, neglect, possible injuries to self or others, possible property damage, etc.

**What Can Parents/Guardians Do?**

Parents/guardians need to be proactive and need to approach adult services as a long-term planning process. They should research and meet with potential facilities/services providers well in advance of when placement is needed. They should view the residential settings and perhaps speak with the people who live there. When the individual does require staff with specific training in particular disabilities and methodologies, that discussion should be held with the service provider well in advance so that planning can take place. While most parents/guardians would prefer their loved one receive services at the closest facility/service provider, or perhaps in some situations the first one to have an opening, this is a decision that should be governed by quality of care, not convenience.

Once the individual is placed, the parent/guardian should continue to be proactive and participate in all placement decisions and ISP meetings. Especially if their adult child/ward has a disability or multiple disabilities that require additional expertise, parents/guardians should continue to ask many questions, such as:

- Who are the specific staff that will be working with the individual? What specific training in the individual’s disability has each of them had?
- What additional training in the disability and methodologies will they be receiving and when?
- What training has the staff who will be working with the individual had in addressing behaviors, in positive behavioral supports?
- Is there anyone at the service provider who has had specific training in the individual’s disabilities whom the staff can consult with? If not, who does the agency consult with to receive that expertise?
- What are the staffing ratios, both during the day and at night?

These are not intended to be an all-inclusive list of questions, as each situation will undoubtedly generate additional questions. If one does not like the answers to the questions, at that point it would be appropriate to address what the service provider will do to ensure that the individual’s needs can be met. Ideally, everyone involved can work as a team to appropriately address the situation.

**Issues Working Against the Adult System**

Unfortunately, adult services is an area with great staff turnover. It can be stressful and potentially dangerous work, especially when staff are not equipped to work with individuals with significant, or potentially significant, behaviors. New staff may be able to make more money working in unskilled jobs. Statistics provided to the South Dakota Legislature show a Direct Support Professional turnover rate of 44.69% in South Dakota, with an average staff vacancy rate of 17.26%. In November 2016, there were
United States Supreme Court Sets New Standard for FAPE

by John A. Hamilton

For thirty-five years, it has been common for parents of children with disabilities to be told the school district did not have to provide a service because the child “was benefiting from special education without it.” Parents may have been told that all the law requires is “some benefit,” so as long as the proposed IEP was reasonably calculated to provide “some” benefit, the district was not required to provide anything further. In the Tenth Circuit, for example, as long as the proposed IEP was intended for the child to receive “more than de minimis” benefit, that met the standard of appropriateness under IDEA.

This presumed minimal standard of what constitutes an “appropriate” education under IDEA was the result of the Supreme Court’s decision in *Hendrick Hudson Central School District v. Rowley*, 458 U.S. 176 (1982). The Court was asked to determine essentially “how much is enough” to satisfy the Act’s requirement for a free appropriate public education (FAPE). The lower courts ruled that IDEA (then called the EHA – Education of the Handicapped Act) requires education that allows the child with a disability to achieve her full potential – an equal educational opportunity. *Id.* at 185-86. The school argued IDEA did not create any substantive rights.

**Hendrick Hudson Central Sch. Dist. v. Rowley**

The case involved Amy Rowley, a first grade student with very significant hearing deficits. She received education in the regular classroom, plus spent time with a tutor and speech therapist. The district proposed utilizing an FM hearing aid system. She was able to lip read to some extent. However, due to her disability, she understood considerably less of what went on in the classroom than if she was not deaf. *Id.* at 185. The parents sought an interpreter. However, despite everything Amy missed, she was performing better than the average student in her class and was able to receive passing grades and advance from grade-to-grade.

The Court rejected both parties’ positions and charted a middle ground. The Court held the FAPE requirement is satisfied if the child’s IEP sets out a program “reasonably calculated to enable the child to receive educational benefits.” *Id.* at 207. For children receiving special education in the regular classroom, generally the IEP must be “reasonably calculated to enable the child to achieve passing marks and advance from grade to grade.” *Id.* at 204. The Court determined Amy’s IEP met that standard due to the “substantial” suite of specialized instruction and services the school offered. *Id.* at 202.

The *Rowley* Court stated it was confining its analysis to the case before it – a child who was educated in the regular classroom and who, with the services on her IEP, was able to receive passing grades and advance from grade-to-grade. *Id.* The Court acknowledged that the Act requires schools to educate children with a wide spectrum of disabilities and that “the benefits obtainable by children at one end of the spectrum will differ dramatically from those obtainable by children at the other end.” As a result, the Court stated it declined “to establish any one test for determining the adequacy of educational benefits conferred upon all children covered by the Act.” *Id.*

The Court’s intent was to limit its ruling to the facts before it and decline to establish a test of what is appropriate applicable to all children with disabilities. However, school districts and courts latched onto a particular sentence in the decision wherein the Court stated the Act requires States to provide access to instruction “sufficient to confer some educational benefit.” Often, “some” was interpreted as anything more than none, something more than trivial benefit, something meaningful, or something more than “de minimis” benefit. Court decisions often referred to IDEA’s “modest” requirements, based on the language in *Rowley*.

**Endrew F. v. Douglas County School District**

The United States Supreme Court revisited its *Rowley* decision on March 22, 2017. Endrew F. is a student with Autism. He had received special education services from Douglas County School District in Colorado from preschool through fourth grade. His parents were dissatisfied with his lack of progress. Some behaviors he presented included screaming in class, climbing over furniture and other students, and occasionally running away from school. *Endrew F. v. Douglas County School District*, slip op. at 6 (May 22, 2017). He had severe fears of commonplace things. Endrew’s parents believed his academic and functional progress had stalled, as his IEPs carried over the same goals and objectives from one year to the next, indicating a lack of meaningful progress. For fifth grade, the school proposed an IEP that was essentially the same as his past IEPs. The parents removed him from public school and placed him at Firefly Autism House, a private school specializing in Autism. Endrew did much better at Firefly, as he had a behavior intervention plan and expanded academic goals. His behaviors improved and he was able to make some actual academic progress. *Id.* at 7.

In November 2010, the school presented an IEP similar to prior IEPs. In February 2012, the parents filed for a due process hearing, seeking reimbursement for Endrew’s tuition at Firefly. *Id.* The parents argued the school’s proposed IEPs were not “reasonably calculated to enable [Endrew] to receive educational benefits.” *Id.* at 8. An administrative law judge ruled for the district. The parents appealed to federal district court, which gave “due weight” to the administrative decision and affirmed. The court acknowledged Endrew’s performance did not reveal immense progress, but concluded his IEPs were “sufficient to show a pattern of, at the least, minimal progress.” *Id.* On further appeal, the Tenth Circuit Court of Appeals quoted language from *Rowley* stating the instruction and services must be calculated to confer “some” educational benefit. *Id.* The court noted it “had long interpreted this language to mean that a child’s IEP is adequate as long as it is calculated to confer an educational benefit [that is] merely ... more than de minimis.” Based on that standard, the court held Endrew’s IEP was reasonably calculated to enable him to make some progress and affirmed. *Id.*

The United States Supreme Court granted *certiorari* and, in a unanimous decision, vacated the Tenth Circuit’s decision and remanded the case. Many people were undoubtedly hoping for language renouncing *Rowley* and setting a higher standard of what

*Endrew F. v. Douglas County School District*  
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constitutes an appropriate education based on requirements contained in the 1997 and 2004 amendments to IDEA and requirements of ESSA. That did not happen. Instead, the Court embraced its earlier decision, essentially telling the Nation’s schools and court systems that they had been misinterpreting and misapplying Rowley for the past 35 years. While not overruling Rowley, it would be more accurate to describe the Endrew F. decision as Rowley 2.0.

As it did in Rowley, the Court rejected both parties’ positions and carved out its decision somewhere in the middle. The Court began its analysis by stating the Rowley Court “declined to establish any one test for determining the adequacy of educational benefits conferred upon all children covered by the Act.” Slip Op. at 9 (citing Rowley at 202). The Court first addressed the district’s arguments. The district argued “that Rowley nonetheless established that ‘an IEP need not promise any particular level of benefit,’ so long as it is ‘reasonably calculated’ to provide some benefit, as opposed to none.” Slip Op. at 9. The district relied on several passages from Rowley: “‘Any substantive standard prescribing the level of education to be accorded’ children with disabilities was ‘noticeably absent from the language of the statute.’” Id. (citing Rowley at 189).

“The Court requires States to provide access to instruction ‘sufficient to confer some educational benefit,’ reasoning that any benefit, however minimal, satisfies this mandate.” Id. (quoting Rowley at 200). “The Court conclusively adopted a ‘some educational benefit’ standard when it wrote that ‘the intent of the Act was more to open the door of public education to handicapped children … than to guarantee any particular level of education.’” Id. (citing Rowley at 192).

The Court acknowledged these statements in isolation supported the district’s position, “But the district makes too much of them.” Id. The Court explained that its statement that IDEA imposes no explicit substantive standard must be evaluated alongside its statement that a substantive standard “is implicit in the Act.” Slip Op. at 9-10. It stated, “We find little significance in the Court’s language concerning the requirement that States provide instruction calculated to ‘confer some educational benefit.’” Slip Op. at 10. The Court explained that it had no need to say anything more particular, since Rowley involved a child whose progress demonstrated her IEP was designed to deliver more than adequate educational benefits. Id. It stated its principal concern in Rowley was to correct the lower court decisions (that set out a maximizing standard). “The Court was not concerned with precisely articulating a governing standard for closer cases.” Id. “And the statement that the Act did not ‘guarantee any particular level of education’ simply reflects the unobjectionable proposition that the IDEA cannot and does not promise ‘any particular [educational] outcome.’” Id. (citing Rowley at 192).

The Court found the district’s reading of the isolated statements “runs headlong into several points on which Rowley is crystal clear. For instance – just after saying that the Act requires instruction that is ‘sufficient to confer some educational benefit’ – we noted that ‘[t]he determination of when handicapped children are receiving sufficient educational benefits … presents a … difficult problem.’…” And then we expressly declined ‘to establish any one test for determining the adequacy of educational benefits’ under the Act. … It would not have been ‘difficult’ for us to say when educational benefits are sufficient if we had just said that any educational benefit was enough. And it would have been strange to refuse to set out a test for the adequacy of educational benefits if we had just done exactly that.” Id. at 10-11.

The Court then discussed the definition of special education, the requirements for what must be in an IEP, and the expectation that most children with disabilities will be educated in the regular classroom and will progress in the general curriculum. The Court arrived at the following: “To meet its substantive obligation under the IDEA, a school must offer an IEP reasonably calculated to enable a child to make progress appropriate in light of the child’s circumstances.” Id. at 11. The court stated, “The IEP must aim to enable the child to make progress. After all, the essential function of an IEP is to set out a plan for pursuing academic and functional advancement. … A substantive standard not focused on student progress would do little to remedy the pervasive and tragic academic stagnation that prompted Congress to act.” Id. The Court added: “That the progress contemplated by the IEP must be appropriate in light of the child’s circumstances should come as no surprise. A focus on the particular child is at the core of the IDEA. The instruction must be ‘specially designed’ to meet a child’s ‘unique needs’ through an ‘individualized education program.’” Id. at 11-12.

The Court essentially divided children with disabilities into two groups – the type of situation presented in Rowley and all other situations. “When a child is fully integrated in the regular classroom, as the Act prefers, what that typically means is providing a level of instruction reasonably calculated to permit advancement through the general curriculum.” Id. at 13-14.

If that is not a reasonable prospect for a child, his IEP need not aim for grade-level advancement. But his educational program must be appropriately ambitious in light of his circumstances, just as advancement from grade to grade is appropriately ambitious for most children in the regular classroom. The goals may differ, but every child should have the chance to meet challenging objectives. Of course this describes a general standard, not a formula. But whatever else can be said about it, this standard is markedly more demanding than the ‘merely more than de minimis’ test applied by the Tenth Circuit. It cannot be the case that the Act typically aims for grade-level advancement for children with disabilities who can be educated in the regular classroom, but is satisfied with barely more than de minimis progress for those who cannot.

When all is said and done, a student offered an educational program providing ‘merely more than de minimis’ progress from year to year can hardly be said to have been offered an education at all. … The IDEA demands more. It requires an educational program reasonably calculated to enable a child to make progress appropriate in light of the child’s circumstances. Id. at 14-15.

The Court refused to adopt the parents’ argument that “appropriate” means “an education that aims to provide a child with a disability opportunities to achieve academic success, attain self-sufficiency, and contribute to society that are substantially equal to the opportunities afforded to children without disabilities.” Id. at 15. The Court believed that standard was similar to what the Court had rejected in Rowley and declined to interpret FAPE in such a manner because Congress had not changed the statutory definition of FAPE since Rowley was decided. Id.

The Court concluded by stating it will not attempt to elaborate on what “appropriate” progress will look like from case to case because the nature of the Act resists such a standard. “The adequacy of a given IEP turns on the unique circumstances of the child for whom it was created.” Id. at 15-16.

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Staff Training in Adult Settings  
(Continued from page 11)

465 open direct care positions statewide. As these statistics demonstrate, most, if not all, CSPs continually have job openings. Constant job openings means two things: First, there is a constant flow of untrained staff working in various CSP settings. Second, because of the constant nature of needing to train new staff, yet still having many positions unfilled, existing staff may be stretched too thin.

From the CSP standpoint, the main “fix” to address turnover is to be able to provide a more competitive wage. The average starting salary at CSPs for direct care staff in South Dakota is $10.83 per hour. This compares unfavorably to Home Health Aides ($12.74), Retail Salespersons ($13.37), Janitors and Cleaners ($11.47), and Stock Clerks and Order Fillers ($11.40). It also compares unfavorably to what the State pays direct care staff at state facilities. The statistics show that state facility direct care staff earn $7,051 more per year than their counterparts at CSPs. The average starting salary at a CSP in South Dakota is $22,526, which, for a family of four, is nearly $2,000 below the poverty line. It is no wonder the turnover rate is 44.69 percent.

Lack of sufficiently trained staff is one issue, but lack of sufficient staff can be just as detrimental to effective programming, including providing sufficient supervision. When there is not enough staff to go around, individual needs become neglected. When individual needs become neglected, it is not uncommon to see individuals who require supervision leaving residences unsupervised. It is not uncommon to see an increase in behaviors because staffing ratios are not what they need to be for an individual. Depending on the intensity of an individual’s needs, a shortage of sufficiently trained staff can become problematic very quickly.

Based on the statistics described above, much of the problem in this system comes down to funding. In other words, it is likely that CSPs would like to hire a second or third staff person in residential settings to provide additional supervision, would like to be able to provide additional specialized staff training, would like to pay their staff more to decrease turnover, and would like to make more slots available because demand is outpacing supply, but they lack the funds to do so.

Conclusion

The need for highly trained staff does not start and stop within the public school systems. For many individuals with disabilities, the need for staff to be highly trained in areas such as specific disabilities, methodologies, and positive behavioral supports is a life-long need. When adult service providers have staff with insufficient training prior to working with adults with disabilities, as well as insufficient staff, the individual becomes more easily susceptible to abuse and neglect, or, at the very least, poor quality services and outcomes.

SDAS has made facility/service provider abuse and neglect monitoring a much greater priority in its work going forward, as discussed in other articles in this newsletter. Given how crucial staff training is to the success of many adults with disabilities, one area SDAS will be reviewing while engaging in monitoring activities is the sufficiency of staff training. It is SDAS’ hope that through its monitoring activities, common areas of concern can lead to positive systemic change.

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Analysis

The Court made it clear that all Rowley did was address the standard of appropriateness for a student who was being educated in the regular classroom and who was advancing from grade to grade. The decision was intended to go no further. It repeatedly referred to its statement in Rowley that it declined “to establish any one test for determining the adequacy of educational benefits conferred upon all children covered by the Act.” While Rowley clearly contained that language, it has gone ignored by schools and courts for the past 35 years. Instead, they incorrectly honed-in on the “some benefit” language to the detriment of children with disabilities ever since. The Court was very clear that such reliance was flat-out wrong. It issued a strong statement that if one had read the entirety of the Rowley decision, it should have been clear that Rowley was not setting a “some benefit, as opposed to none” standard of appropriateness.

The expectation by many was that Endrew F. would overturn Rowley with a new standard of what constitutes an “appropriate” education. Perhaps it is surprising, then, that instead of overruling Rowley based on language in the 1997 and 2004 amendments to IDEA and application of NCLB/ESSA to all students, the Court instead embraced and quoted Rowley throughout the Endrew F. decision. The Court made its position clear that there was nothing wrong with the Rowley decision - what was wrong was how courts and districts had misinterpreted and misapplied it.

Endrew F. is not a reaffirmance of Rowley. Endrew F. not only explains how Rowley should have been interpreted, but it takes the half-full glass set out in Rowley and fills it to the brim. In other words, Rowley set a standard of appropriateness only for children being educated in the regular classroom; Endrew F. sets the standard of appropriateness for all other children with disabilities.

Conclusion

It remains to be seen how Endrew F. will be administered by schools and interpreted by lower courts. “Appropriate” still does not mean “the best.” However, some of the Court’s language is very helpful. The Court stated the IEP “must be appropriately ambitious” and all children “should have the chance to meet challenging objectives.” The Court described the standard it set out as “markedly more demanding” than the Tenth Circuit’s interpretation.

Addendum

One Court has already weighed-in. In M.C. v. Antelope Valley Union High School District, 2017 WL 1131821 (9th Cir. March 27, 2017), the Ninth Circuit Court of Appeals stated: “Recently, the Supreme Court clarified Rowley and provided a more precise standard for evaluating whether a school district has complied substantively with the IDEA: ‘To meet its substantive obligation under the IDEA, a school must offer an IEP reasonably calculated to enable a child to make progress appropriate in light of the child’s circumstances.’ Endrew F., slip op. at 11. In other words, the school must implement an IEP that is reasonably calculated to remediate and, if appropriate, accommodate the child’s disabilities so that the child can ‘make progress in the general education curriculum,’ id. at 3 (citation omitted), commensurate with his non-disabled peers, taking into account the child’s potential. We remand so the district court can consider plaintiffs’ claims in light of this new guidance from the Supreme Court.” Id. at *6 (emphasis added). So far, so good.
Required Notice to Parents and Guardians of Monitoring Activity

by Dianna L. Marshall

In conjunction with other articles discussing South Dakota Advocacy Services’ (SDAS) facility and service provider monitoring activities, this article will focus on the specific requirement of notifying parents of minors and guardians of individuals that SDAS will be monitoring facilities.

Under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), the Protection and Advocacy for Individuals with Mental Illness Act (PAIMI Act), and the Protection and Advocacy for Individual Rights Act (PAIR Act), broad access authority is given to Protection & Advocacy Systems (P&As), such as SDAS, to access individuals, records, and facilities or service providers in order to investigate allegations of abuse and neglect. The access provisions of both the DD Act and PAIMI Act (the PAIR Act incorporates access provisions of the DD Act) also authorize the P&A System to have access to individuals during monitoring activities.

Specifically, the DD Act allows SDAS: “unaccompanied access to all residents of a facility at reasonable times, which at a minimum include normal working hours and visiting hours, for the purpose of ... [monitoring] compliance with respect to the rights and safety of service recipients.”

The PAIMI regulations similarly provide that SDAS shall: “have reasonable unaccompanied access to facilities including all areas which are used by residents, are accessible to residents, and to programs and their residents at reasonable times, which at a minimum shall include normal working hours and visiting hours.”

When monitoring a facility or service provider, SDAS does not need permission from a parent or guardian to talk with individuals. The PAIMI regulations, however, do require that parents of minors and guardians of individuals be informed that SDAS will be conducting facility monitoring activities: “The P&A shall make every effort to ensure that the parents of minors or guardians of individuals in the care of a facility are informed that the P&A will be monitoring activities at the facility and may in the course of such monitoring have access to the minor or adult with legal guardian.”

In order to adhere to this requirement, SDAS will inform the parent or guardian of its monitoring activity in a letter. SDAS will have the facility send the letter to the parent or guardian informing them that monitoring will be occurring at the facility. The letter will include the following information:

- Monitoring will include observing the facility environment.
- It includes conducting formal interviews with residents of the facility.
- The monitoring activity will be conducted to minimize any interference with the individual’s treatment or programming.
- If an individual’s records at the facility need to be reviewed as part of its monitoring activity, then SDAS will contact the parent or guardian for permission, which would require a release of information to be signed by the parent or guardian.
- SDAS will not take any formal action on behalf of the individual or initiate a formal legal services relationship without the parent or guardian’s consent, except in an emergency situation of imminent danger.

Contact information for SDAS will be included in the letter should the parent or guardian have any questions or concerns regarding the monitoring of a facility. SDAS will use this same process regardless of the type of facility/service provider it will be monitoring.

Because facility monitoring activities is a fairly new priority for SDAS, we have not had any challenges involving the notification requirement. But, in a recent case out of New York, the New York P&A System, Disability Rights-New York (DRNY), was challenged by a school district that DRNY did not comply with the PAIMI requirement of informing parents of students that DRNY was accessing the school. The court determined that the DRNY was not using its monitoring authority, but rather was investigating a complaint of abuse or neglect in the classroom. The court’s ruling confirmed that the school is a “facility” or “service provider” under the P&A’s access authority. The court held that DRNY can pursue monitoring activities at the school, or other locations used by individuals with disabilities, as long as parents of minors or legal guardians of adults are informed of the monitoring activity.

If parents or guardians have any questions about SDAS’ authority to monitor facilities, please contact SDAS at 1-800-658-4782.

1 “Facility” includes any public or private residential setting that provides overnight care accompanied by treatment services. Facilities include, but are not limited to the following: general and psychiatric hospitals, nursing homes, board and care homes, community housing, juvenile detention facilities, homeless shelters, and jails and prisons, including all general areas as well as special mental health or forensic units. 42 C.F.R. § 51.2.


3 45 C.F.R. § 1386.22(g)(2).

4 42 C.F.R. § 51.42(c)(2).

5 42 C.F.R. § 51.42(e).

PARTNERS CELEBRATES 25 YEARS
by Sandy Stocklin Hook

SDAS is celebrating its 25th year of facilitating and coordinating Partners in Policymaking in South Dakota. The self-advocacy, empowerment, leadership course has over 580 graduates statewide. Year 25 of SD Partners in Policymaking has completed five of six sessions and will be bringing forth the next set of leaders in South Dakota at graduation on April 22, 2017. Partners in Policymaking develops leaders who will challenge the status quo, leaders who will research and leave no stone unturned, leaders who will not accept “no” for an answer, and leaders who change the attitudinal barriers facing individuals with disabilities.

Over the past five months, the 22 committed and motivated individuals making up Year 25 have been learning how to be self-advocates, leaders, and to empower themselves and others. The class has chosen as its graduation theme, HOPE: Helping Others Promote Equality.

JANUARY TRAINING

David Hancox, a lobbyist from Golden Valley, MN, spoke of the legislative process. “Don’t be afraid to talk to your legislators. They are regular people. They are your neighbors. Always remember they work for you.” He explained how constituents are a resource to legislators on all levels. “What you bring to the table is important.” Hancox shared pointers on effective testimony and above all to always tell the truth. “If you don’t know the answer to a question, don’t fake it, admit you don’t know and offer to find the answer,” said Hancox.

He also demonstrated using the internet to follow the SD Legislature and bills being considered.

FEBRUARY TRAINING

Continuing with the governmental theme, this session opened with a panel comprised of representatives from city (Tom Farnsworth, Pierre), county (Kevin Hipple, Hughes County Administrator), school (Cari Leidholt, Pierre School Board), and tribal (David Reiss, staff member of the Tribal Liaison Program from Pierre) governments. The panel members described the similarities and differences in their governmental bodies. They discussed how individuals can be placed on the agenda and be heard.

Partners in Policymaking
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Partners in Policymaking
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Tim Neyhart, SDAS Executive Director, presented on Social Security. He explained who qualifies and why, and what happens if you return to work.

Jim Kellar of Freeman discussed how to have effective meetings, how to be in control of the meeting without being aggressive, and how time management can make the difference between a successful or out-of-control meeting. He shared the importance of including everyone in the meeting, how to listen to ideas, how to effectively summarize what you heard, and how to get a group to work as a team. He spoke of self-advocacy skills and the importance of knowing who you are and what you want. Kellar said, “It is important your voice be heard. You need to learn the importance of negotiating. This is a skill that will last a lifetime and create allies, not adversaries.”

Kellar also introduced the Talking Circle. The basis of the Talking Circle is to give everyone an equal opportunity to speak without interruptions or judgment.

A talking piece is shared among the participants and a person can only speak when in possession of the talking piece. When finished speaking, the piece is passed to the next person in the circle. When not speaking, the participants are taught to listen with open ears and open hearts. Kellar stressed the importance of effective listening skills. “Listening is an art and sometimes listening is a lost art. You need to listen and respect others as they speak. If you are a good listener, you can help affect attitudes, lives, changes, and personalities.”

Pat Czerny of DakotaLink in Rapid City discussed and demonstrated assistive technology devices and how assistive technology can make the difference from being dependent to becoming independent. Czerny brought several examples of technology and gave a “hands-on” demonstration of how they work and can make things simpler and easier for all people.

MARCH TRAINING

Tim Neyhart continued the Social Security training by discussing who qualifies and why, and what happens when a Social Security recipient returns to work.

Dr. Wayne Duehn of Arlington, TX, made his 19th trip to South Dakota to present to Partners in Policymaking. Dr. Duehn explained how to detect abuse and neglect, both physical and sexual. He discussed where, how, and to whom it should be reported, the profile of the perpetrator, and how abuse and neglect occurs everywhere, “yes, even in South Dakota.” He went on to say, “Sexual and physical abuse of our elderly, children, and individuals with disabilities is on the rise and you need to know the signs and how to stop it.”

Duehn provided an overview on human sexuality issues, including suggestions of what and how to educate young children of all abilities on the importance of “it is your body and it is private.” He told the group, “no is no and teach your children to say NO.”

Dennis Hook, Pierre, a Senior Master 4th degree black belt in Tae Kwon Do, taught Tai Chi and self-defense moves that can be used by everyone, including individuals with limited movement and mobility. He also gave a Child Abduction Prevention Seminar with assistance from Gabby Thompson, a member of the Pierre Tae Kwon Do Club.

Desiray Nelson of Onida, a Year 20 graduate of Partners in Policymaking, and Angela Lisburg of Pierre spoke about the Child Advocacy Centers in South Dakota (CACSD). CACSD is an organization that promotes the development, cultural awareness, growth, and continuation of child advocacy centers in the state of South Dakota through education and training, mentoring, collaboration, advocacy, development of child advocacy centers, and legislation.

The sixth and final session of Year 25 will be held April 21-22, 2017, at the Ramkota Hotel in Sioux Falls. The weekend includes continuing education, Common Grounds, and the graduation banquet and ceremony.

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Balancing Support with Independence

by Cole Uecker

It is the long-standing and guiding principle of South Dakota Advocacy Services that people with disabilities should live in the most appropriate, least restrictive environment available to them. It is the societal and social norm for people to be productive, contributing members of their respective communities. Unfortunately, a recent U.S. Department of Justice investigation found that the State of South Dakota was not doing everything that it could to promote a system which would encourage these outcomes. *Justice Department Finds South Dakota Unnecessarily Relies On Nursing Facilities To Provide Services To People With Disabilities*, DOJ 16-517. The result of this investigation was a mandate by the Federal Government that the State take steps, wherever possible and appropriate, to facilitate reintegration into the community for those who were inappropriately placed in institutional settings. This is a matter of more than a simple geographic change. The question becomes: what services and supports are necessary for each particular individual to be successful when the current institutional structures and restrictions are not present?

Guardianship

One simple solution is to seek to have a court appoint a guardian for the person. For some, a guardian may be a perfect fit for their needs. A guardian can protect the person from being exploited, can safeguard him or her from risks, and can make decisions that may well be in the person’s best interest. However, while having a guardian can have its advantages, it may not be the least restrictive option that is available. In fact, this construct is quite restrictive in effect. In order to have a guardian appointed by the court, it must be shown that the individual lacks the capacity to make his or her own decisions regarding consequential issues. Once this status has been confirmed, the court will appoint an appropriate party - perhaps a family member, a trusted associate, or the State - as the person’s guardian. Make no mistake; a guardianship substantially limits the protected person’s rights.

Conservatorship

When you think of a conservatorship, think of money (specifically that money and income held in an estate). The person who manages a conservatorship is appropriately called a “conservator.” The process for appointing a conservator is, for all intents and purposes, the same as that for a guardian, and should utilize the services of a licensed attorney. However, unlike a guardian, a conservator has authority only over the individual’s financial affairs. A conservator must make accountings to the court per SDCL § 29A-05-408, typically on an annual basis, to demonstrate that the conservator is fulfilling his or her role as a fiduciary. South Dakota law states:

A guardian of a protected person shall make decisions regarding the protected person’s support, care, health, habilitation, therapeutic treatment, and, if not inconsistent with an order of commitment or custody, shall determine the protected person’s residence. A guardian shall maintain sufficient contact with the protected person to know of the protected person’s capabilities, limitations, needs, and opportunities.

A guardian shall exercise authority only to the extent necessitated by the protected person’s limitations, and if feasible, shall encourage the protected person to participate in decisions, to act on his own behalf, and to develop or regain the capacity to manage personal affairs. A guardian shall, to the extent known, consider the express desires and personal values of the protected person when making decisions, and shall otherwise act in the protected person’s best interests and exercise reasonable care, diligence, and prudence.

SDCL § 29A-5-402. The law requires only that the guardian consider the protected person’s expressed wishes. The limitations on a protected person’s freedom are a serious matter, which is why this process must be overseen by the court. It is also why this option should be entertained as a last resort, rather than the first. Guardians must provide written reports to the court per SDCL § 29A-05-403, typically annually, to document activities of the guardian and provide updated information on the protected person.

An alternative to a “full” guardianship is that of a “limited guardianship.” A limited guardianship is just as it sounds; the court will designate the areas(s) where a guardian can exercise control over the legal rights of the protected person. While this can still be somewhat restrictive, it is much more measured and targeted to help individuals in the areas where they need assistance, while retaining as many rights as appropriate with the individual. This more narrowly-tailored option is more likely the less restrictive, and therefore more appropriate, alternative available in many cases.

The legal implications of guardianship are substantial. In order to obtain guardianship for an individual, the prospective guardian should contact an attorney and discuss the process and responsibilities. The services of a licensed attorney will certainly be necessary to establish this status.

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A conservator, when making distributions, shall exercise authority only to the extent necessitated by the protected person’s limitations, and shall, if feasible, encourage the protected person to participate in decisions, to act on his own behalf, and to develop or regain the capacity to manage the estate and his financial affairs. A conservator shall also consider the size of the estate, the probable duration of the conservatorship, the protected person’s accustomed

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New Director of Finance and Administration

Annette July began her duties as Director of Finance and Administration for SDAS on January 3, 2017. Annette grew up in Hebron, North Dakota, and moved to Pierre in 1973. She began her work in the non-profit world when she accepted a position with Easter Seals in the early 1980s. Since then, she has been employed with ARC/SD, the Governor’s Planning Council on Developmental Disabilities, and OAHE, Inc. from 1989 to 1991 and again from 1993 until 2011. Prior to coming to SDAS, Annette was the Business Manager for Kelly’s Retirement Homes in Pierre. Annette has four grown sons and three grandchildren. She enjoys reading, walking with her dog, and spending time with family.

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One of the priorities for the PADD (Protection and Advocacy Developmental Disabilities) Program for FY 2017 is for staff to conduct rights trainings at Community Service Providers to educate individuals and professionals about disability rights. For a participant (person with a developmental disability receiving services or supports) the following are rights guaranteed under the Constitution and laws of the United States and the State of South Dakota:

1. To be free from abuse, neglect, and exploitation;
2. To have privacy, dignity, confidentiality, and humane care;
3. To be able to communicate in private;
4. To be able to communicate in the participant’s primary language or primary mode of communication;
5. To be free from retaliation for making a complaint, voicing a grievance, recommending changes in policies, or exercising a legal right;
6. To be able to maintain contact with family and friends, unless contact has been legally restricted;
7. To be able to refuse or discontinue services;
8. To have access to, read, and challenge any information contained in the participant’s record;
9. To have access to an advocate as defined in subdivision 46:11:01:02(1) or an employee of the state’s designated protection and advocacy system;
10. To be provided choice among waiver services and providers;
11. To be informed of the provider’s grievance procedures pursuant to § 46:11:03:06; and
12. To have a written residential lease agreement that meets the requirements of applicable state law contained in SDCL chapter 43-22.

To schedule a rights training event at your facility, please contact Carrie Geppert at geppertc@sdadvocacy.com or call 605-361-7438.

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Durable Power of Attorney (D-POA)

A Durable Power of Attorney is a very flexible and versatile means of support that can be utilized to assist an individual in an individually-tailored fashion. The individual, not the court, establishes the scope and application of the support. The drafting of the document is often effectuated through the assistance of a licensed attorney. The individual must have the capacity to sign documents/contracts at the time the document is created. Unlike a tradi-
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Empowered to live as independently as they can is to provide them with the information that they need to pursue their goals and desires. Monitoring gives SDAS the opportunity to inform people of the different options available across the spectrum from Supported Decision Making to Guardianship. We can discuss the means of securing these supports where needed and the methods of contesting them where rejected.

Supported Decision Making

A friend, a sage, a trusted family member, a mentor - we all have them. It is natural to seek out help and advice from the people in our lives that we trust and respect. This support costs no money, it requires no judicial authority or oversight, and the individual cedes no legal rights or privileges to receive the support. It is, by far, the least restrictive form of support that can be provided to someone who may or may not require some help living independently. Supported Decision Making is a good option for those who can get by with a little help from their friends.

SDAS and Monitoring

Monitoring is a means for SDAS to reach out to people in the disability community. It provides advocates with the opportunity to discuss individuals’ concerns one-on-one and face-to-face. One of the best ways that people can be empowered to live as independently as they can is to provide them with the information that they need to pursue their goals and desires. Monitoring gives SDAS the opportunity to inform people of the different options available across the spectrum from Supported Decision Making to Guardianship. We can discuss the means of securing these supports where needed and the methods of contesting them where rejected. Monitoring is a powerful tool to promote systems which adhere to the principle (and federal mandate) that people with disabilities should live in the most appropriate, least restrictive environment available to them.

Public Forum Notice
We Want to Hear From You!

On July 11, 12, and 13, 2017, representatives from the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS), Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program will visit South Dakota Advocacy Services in Pierre.

SAMHSA/CMHS invites you to send written comments about the PAIMI Program services and activities conducted by South Dakota Advocacy Services. Please send your comments to SAMHSA/CMHS by e-mail to PAIMI@samhsa.hhs.gov or mail, ATTENTION: The PAIMI Program Coordinator, SAMHSA/CMHS, 1 Choke Cherry Road, Room 2-1105, Rockville, MD 20857.