

Testimony
Department of Human Services
Human Services Interim Committee
Representative Chuck Damschen, Chairman
October 29, 2013

Chairman Damschen, members of the Human Services Interim Committee, I am Susan Wagner, Program Administrator, with the Department of Human Services (DHS), Division of Mental Health and Substance Abuse Services. I oversee the DHS efforts related to traumatic brain injury (TBI) and I appear before you to provide information as requested on services provided by DHS for individuals with TBI and the application process for those services.

DHS contracts for the following services with general funds received in past legislative sessions. There is no cost to the individual for any of these services. None of the services provided would be considered to be evidence-based programs or practices.

- Six contracts for social and recreational services - provided by HIT, Inc. in Bismarck/Mandan, HeartSprings in Fargo, *Onword* Therapy in Fargo, Sanford Health in Fargo, Dakota Center for Independent Living in Bismarck, and University of North Dakota-Center for Rural Health (UND-CRH) in Grand Forks. The goal of the contracts is to provide individuals with TBI the opportunity to become involved in their communities and enjoy appropriate social and recreational activities and interactions with others with similar life challenges. Many of the individuals are no longer able to drive and do not have the financial resources to do things. All of the above-mentioned agencies except for HIT, Inc., facilitate a support group for

individuals with TBI. The addition of the social and recreational services has enhanced the support group experience, increased social connectedness, and provides a real sense of belonging for those participating in the services. There is not a formal application process for the services except at HIT, Inc. The number of participants in the activities varies at each agency for each activity. Twenty-six individuals participated in events and activities during the month of August 2013. The total amount contracted for this service is \$70,000 for the current biennium.

- One contract for pre-vocational skills and mentoring services – provided by Community Options for Residential and Employment Services, Inc. on a statewide level. Once a referral is received or when an individual contacts the agency, the individual meets with an employment specialists to complete an assessment. The results of the assessment along with the skills, interests, and needs of each client are used to develop an individualized plan. As of September 30, 28 individuals are involved in services. The amount of the contract is \$58,344 for the current biennium.
- One contract with UND-CRH for informal supports, peer mentoring, and resource facilitation for individuals with TBI and their family members – the program director at UND-CRH is in the process of hiring three resource facilitators; finalizing the application process and referral packets to send to potential referral sources; establishing a toll-free number for individuals, family members, and referral sources to call; and developing a website. The application process will determine what array of services each individual needs. The program director is currently providing resource facilitation to 10 individuals. The services will be available statewide. The amount of the contract is \$533,494 for the current biennium.

Home and Community-Based Services

Information gathered to date from the data collection tool completed by the county social service Home and Community-Based Services (HCBS) case managers indicates that in August 2013, 50 individuals with TBI from 25 counties are receiving HCBS. The number of individuals may indeed be higher given that only 25 of the 53 counties submitted reports in August. The types of services received include TBI transitional living, case management, TBI residential care, TBI case management-team meeting, non-medical transportation, emergency response situation-lifeline, transportation, homemaker services, respite care, personal care, nurse education care, adult day care, and family home care. The cost of services varies depending on the number of services provided and how many hours of service each client receives. Funding sources include federal and state general fund dollars. Please refer to the Attachment A that Karen handed out for more specific information on the various services.

There are available slots for the HCBS waiver. The need that exists is for these services or a similar array of services to be available for those individuals who do not meet the skilled nursing home level of care. Once eligibility is determined, the individual meets with a HCBS case manager to complete a functional assessment. The results of the assessment guide the planning for individualized services.

Vocational Rehabilitation

Vocational Rehabilitation (VR) provides training and employment services to individuals with TBI to assist them in obtaining and maintaining employment. Services are available on a statewide basis. Once a

referral is made or once an individual contacts VR, they are invited to attend an orientation session or an individual appointment. If VR is an appropriate service and the individual wants to apply, they complete an application that identifies demographics, other services being received, and how their disability impacts their ability to obtain or maintain employment. At this time, there are no suggestions as to how to improve this process. Some of the regional VR offices added the option of an orientation session as a way to educate individuals about VR which has proven to reduce the number of no-shows for the initial appointments. VR counselors determine eligibility, develop an individualized plan of employment, and provide counseling and guidance. In addition, they authorize payment for a variety of services including vocational development/adjustment, supported employment, job referral/placement, diagnosis and evaluation, adaptive aids and equipment, transportation, treatment/restoration, daily living skills training, occupational/vocational schools, colleges, on the job training, and supplies for training. These services are determined by the individualized plan of employment. The costs for the specific services vary and are based on the needs of each individual. VR served 160 individuals with a primary disability of TBI in Federal Fiscal Year 2013. Of those 160 individuals, nine have been employed. At this time, VR is providing services to those individuals with the most serious of disabilities. While they have been under an Order of Selection, it is anticipated that the waiting list for those individuals with less serious disabilities will be resolved by March 2014. We do not anticipate an unmet need in this area. Funds are also available for ongoing employment support once individuals have completed their work with Vocational Rehabilitation and are stabilized in a job. There are six available slots for the service and all slots are taken. Two individuals with

TBI are on a waiting list for the ongoing support. An unmet need does exist in this service area.

Residential Services

Residential services are provided by HIT, Inc. and High Soaring Eagle Ranch. HIT, Inc. operates two residential facilities in Mandan, Dakota Pointe (10 beds) and Dakotah Alpha (20 beds). High Soaring Eagle Ranch is located in Valley City (11 beds).

Dakotah Alpha is licensed as a skilled nursing facility (20 beds). As of October 15, 2013, individuals with brain injury occupy 90% or 18 of the 20 beds. Nine of the 20 beds have been designated as long-term beds for those individuals with TBI requiring long-term, possibly life-long care. As of October 15, 2013, there are 11 individuals determined to require long-term care. The increase in the number of individuals with TBI needing long-term care impacts admissions into the facility and the ability of those individuals with long-term needs to transition to Dakota Pointe or another less structured facility.

The daily rate at Dakotah Alpha is \$384 and includes occupational therapy, physical therapy, speech therapy, recreational services, transportation to appointments, independent living skills, and room and board. Psychological and psychiatric services are available at the facility; the costs are not included in the daily rate. If an individual is planning to return to their family home, the occupational and physical therapists visit the home to conduct an evaluation to assist in preparation for discharge.

Approximately 50% of the 83 individuals admitted to Dakotah Alpha since 2009 have a history of substance abuse problems; in some cases, it is

related to the cause of the TBI. The facility does not provide substance abuse services; they refer residents to community providers, most frequently West Central Human Services. While traditional substance abuse treatment services are available; there are no specialized substance abuse treatment services or community-based recovery resources appropriate for those with TBI. In addition, traditional services are based on cognitive concepts and individual motivation for change. The cognitive abilities of individuals with TBI are often impacted thus making it difficult for them to understand treatment components, remember their appointments, control their behavior, or get along with other people. It is imperative to be able to distinguish between the two; otherwise the therapeutic relationship will be compromised. There is an unmet need in North Dakota for specialized substance abuse treatment services.

Dakota Pointe is licensed as basic care. The rate at Dakota Pointe is \$178.73 per day plus a monthly room and board rate of \$460 that the individual is responsible to pay. The program is specialized for brain injured individuals and designed to provide structure and meet the needs of each individual. The ultimate goal is for each individual to move to their own home. For some, this is not possible, so they live at Dakota Pointe on a long-term basis. Those with long-term stays are vulnerable, impulsive, need daily structure, and do not have the cognitive ability to succeed on their own. This can create a backlog in meeting the needs of individuals at Dakotah Alpha or those at any other skilled nursing facility who may be ready to move to a less structured facility.

High Soaring Eagle Ranch is a long-term basic care facility. The daily rate is \$155.97 plus a monthly room and board rate which the individual is

responsible to pay. High Soaring Eagle Ranch provides the day-to-day structure and support that each individual needs to function as independently as possible. Work experience is available through the Eagle's Nest Bookstore, Viking Room Restaurant, and other community options.

Funding sources for residential services include Medicaid, Medicare, private pay, private insurances, and general fund.

Generally, the three facilities are at capacity. Each facility maintains a wait list. There are 20 individuals that have been on the wait list at Dakota Alpha for the past eight months and six at Dakota Pointe who have been on the wait list for at least one year. I was not able to obtain the wait list information about High Soaring Eagle Ranch. The application process involves making a referral or a contact with the facility and submitting background information supporting the need for a placement. The facility completes a screening process to determine if an individual meets the specific level of care.

As of October 23, 2013, there are seven individuals with a TBI residing at the North Dakota State Hospital. One will be discharged to a nursing facility in the very near future. One patient has resided at the hospital since 1996 with only a one week unsuccessful stay in a nursing facility in 2012. They have been long-term patients with serious behavioral, mental health, and substance abuse issues. Due to the complexity of their needs, none of the six individuals have a discharge plan.

Transitional Care

HIT, Inc. and High Soaring Eagle Ranch provide HCBS transitional care.

The daily rate is based on the number of tasks performed for each individual. Tasks provided include bathing, communication, community integration, various personal care services, housework, meal preparation, medication assistance, money management, shopping, social appropriateness, transportation, mobility, and transferring, positioning and turning. Nine individuals utilized this service for a total Medicaid expenditure of \$33,369 between April 1, 2012 and September 25, 2013 (this timeframe is a waiver year). Funding sources include Medicaid, private pay, other insurances, and general fund. The application process involves making a referral or contact with the facility. The facility then completes an assessment to determine if transitional care can meet the needs of the individual.

Adult Day Care

HIT, Inc. provides adult day care. Services include socialization group, exercise, social and recreational activities, and lunch. Funding sources include Medicaid, private pay, other insurances, and general fund. As of October 17, 2013, no one with a TBI has been referred for this service for about four years. As of March 2010, the rate was \$32.29 per half day.

Money Follows the Person

Since the inception of the Money Follows the Person program, 15 of the 90 transitions from nursing facilities and the Life Skills and Transition Center have been accomplished with individuals with TBI.

TBI Screening at the regional human service centers

Based on information collected from the TBI screening completed at the human service centers from October 27, 2012 – June 30, 2013, 1,840 individuals of 6,772 screened reported a history of TBIs, scoring from

mild – severe. An additional 724 individuals reported having an injury or injuries resulting in a possible TBI. It is important to note that this information cannot be generalized to the entire population served or the North Dakota population, but does provide a snapshot of those seeking services and the incidence of TBI that they reported. As a side note, when I presented information to the Long Term Care Interim Committee in 2010, data from the human service center electronic health record indicated 229 individuals with possible TBI. As you can see, implementing the screening process has been successful in assisting in better identification of those with TBI. The types of services the individuals reporting mild – severe TBI are receiving at the regional human service centers are:

- 866 individuals are receiving mental health services such as psychiatric and psychological services, case management, individual therapy, and nursing services.
- 392 individuals are receiving substance abuse services such as case management, addiction evaluations, group therapy, and aftercare services.
- 582 individuals are receiving both mental health and substance abuse services inclusive of the above examples.

Of the 724 individuals reporting a possible TBI:

- 382 are receiving mental health services.
- 156 are receiving substance abuse services.
- 183 are receiving both mental health and substance abuse services.
- Three are receiving other services not identified in the report.

Some of the individuals included in the above-mentioned data are involved in the Integrated Dual Disorder Treatment (IDDT) and Supported Employment (SEP) evidence-based programs. Some individuals are

involved in both programs. The following is a breakdown of the specific screening data for those two programs:

- IDDT - WCHSC - 16 individuals, 8 with TBI
BLHSC - 12 individuals, 2 with TBI
NWHSC - 4 individuals, 2 with TBI
NCHSC - 14 individuals, 5 with TBI
LRHSC - 13 individuals, 4 with TBI
NEHSC - 7 individuals, 6 with TBI
SEHSC - team 1: 40 individuals, 28 with TBI and
team 2: 43 individuals, 30 with TBI
SCHSC - 20 individuals, 12 with TBI
- SEP - WCHSC- 14 individuals, 7 with TBI
SEHSC - team 1: 14 individuals, 14 with TBI and
team 2: 17 individuals, 11 with TBI
SCHSC -7 individuals, 7 with TBI

Case management and clinical services are available at the regional human service centers. In regards to unmet needs, some of our regional human service centers are experiencing a workforce shortage particularly in the area of substance abuse and psychiatry. Depending on where the individual lives, there may be a wait period for some services because of this. Training on what TBI is, how it occurs, impact of injury, and some general information about how to work with individuals has been provided to staff but there is a need to provide ongoing more intensive training.

The application process involves completing admission paperwork which determines the fee for service, if any, obtains demographic information, and then an intake with the most appropriate staff person at the human service center. The application process has been streamlined over time

so there are no suggestions to improve it at this time. The cost of services at the regional human service centers are provided based on a sliding fee schedule for those individuals whose care is not covered by federal or state general funds. The cost of employment services for those individuals involved in SEP are covered by state general fund dollars.

Research

TBI is the leading cause of death and disability across all age groups in the United States. TBI must be considered as a chronic health condition that must be managed over the life span. Research is being conducted in the following areas:

- cumulative effect of multiple injuries.
- the frequency of TBI as a co-morbid condition with post-traumatic stress disorder and other mental health disorders.
- post concussive syndrome.
- substance use disorders, behavior control issues, and chronic pain.
- effects of early TBI on adult behavior and co-morbidity.
- the increasing frequency of falls in older adults.
- the frequency with which individuals with TBI become involved in the criminal justice system and homelessness.

Some recent findings include:

- individuals hospitalized with TBI before the age of six are three times more likely to have a diagnosis of either alcohol or drug dependence by age 25.
- having a childhood TBI doubles the likelihood of having a psychiatric disorder by early adulthood.

Research on the individuals in the TBI model systems studies is now looking at them five years post injury and has found that one on four die within five years of the TBI. Of those that live beyond five years, 57.8% have a moderate to severe disability and 38.8% have a reduction in previously achieved outcomes after the first five years post-injury and generally lower quality of life. Oftentimes, TBI is a barrier to effective treatment and it may worsen another condition, just as another condition may worsen a TBI.

I would be happy to answer any questions you might have at this time.