

Establishing a Baseline Rate
of the Use of Restraints and
Psychoactive Medications
with Persons with Developmental
Disabilities in Community-Based
Settings in Nebraska

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Abstract

A study was conducted on the prevalence of the use of restraints and psychoactive medications with people served in Nebraska community-based services for persons with intellectual and developmental disabilities. Data on the use of restraints was collected by surveying the providers of these services and data on the use of psychotropic medications was captured based on claims from the Medicaid Management Information System. The results showed that in the first quarter of 2011, 148 or 3.4% of the population served were restrained at least once. Data revealed that over 53% of the population received at least one psychoactive medication, with over 60% of the persons receiving psychoactive medication prescribed more than one medication and over 28% receiving more than one medication in the same classification of psychotropic medications.

Introduction

The purpose of this paper is to identify current practice with regard to prevalence of use of restraint and the use of psychotropic medications by people supported by community-based developmental disabilities programs the state of Nebraska. This data will provide baseline measures from which to evaluate the effect of practice changes related to the use of physical intervention and psychotropic medications.

What is the prevalence of challenging behaviors?

The use of restraints and psychoactive medications is in response to challenging behaviors. The term challenging behavior is generally attributed to the advocacy group TASH. Emerson (2005) defines challenging behavior as ‘culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities’. In a study of such behaviors, Emerson and Bromley (1995) looked at the form and prevalence of challenging behaviors. They used Qureshi & Alborz’s (1992) criteria for defining challenging behavior. These criteria are 1) the behavior has at some time caused injury to the person themselves or others which has required immediate medical treatment, or destroyed their immediate living or working environment; 2) the behavior occurs at least once a week and requires the intervention of more than one member of staff to control, or places them in danger, or causes damage which could not be rectified by care staff, or causes more than one hour of disruption; or 3) the behavior occurs at least daily and causes more than a few minutes disruption. Using these criteria, they found a rate of eight percent of the population of persons with intellectual disabilities who showed at least one challenging behavior. In a review of population studies, Emerson (2011) provides a data showing that challenging behavior occurs with 10-15% of the population of persons with intellectual disabilities.

In another study of persons with intellectual disabilities (ID) in Ontario, Canada, Deb, Thomas, & Bright (2001) found a psychiatric illness prevalence of 22.2% using the Mini Psychiatric Assessment Schedule for adults with Developmental Disabilities (PAS-ADD) administered by a psychiatrist. However, when using this information to determine diagnoses using the International Classification of Diseases, 10th revision (ICD-10) criteria, the percentage dropped to 14.4%. In another study of the prevalence of mental illness in a population of persons with intellectual disabilities in Scotland, Cooper, et.al. (2007) found rates of psychiatric disorders of 40.9% based on clinical diagnoses, but only 15.7% based on DSM-IV-TR criteria. In reviewing their results, much of the difference was due to clinical diagnoses of problem behavior (22.5%) compared to the DSM-IV-TR diagnosis of problem behavior (0.5%). It should be noted that these are population studies and do not translate directly into the expected prevalence of challenging behaviors or psychiatric disorders in the population served by the community-based developmental disabilities providers in Nebraska. It is likely that the rates are higher in the population referenced in this study, as people funded by the Division of Developmental Disabilities (DDD) likely require

specialized services in contrast to those who live in the community with natural or no supports. It is quite likely that the majority of persons who do not request services funded by the Division have very few challenging behaviors. In addition, the make-up of each population studied varies and the components of that population can influence the overall rate of challenging behaviors or psychiatric disorders. For example, using the Diagnostic Assessment for the Severely Handicapped II (DASH – II), Bradley, et.al.(2004) found a much higher proportion of psychiatric disorders with individuals with severe intellectual disabilities if they also had a diagnosis of autism than if they did not. Thus, if the population served in Nebraska has a greater than expected rate of persons with autism spectrum disorder, there would be an expected increase in the proportion of psychiatric disorders.

Murphy (2009) discusses the effect of challenging behavior on social inclusion and quality of life. Her concern is that persons with ID and challenging behaviors have a poorer quality of life than persons with ID and no challenging behaviors. She points out that in the era of institutions such behaviors may have been a factor in admissions to such settings. But her overall concern is that modern services based in the community, while a vast improvement in terms of quality of life for persons with ID and challenging behavior, are still not good at aiding persons with ID and challenging behavior in developing relationships, becoming gainfully employed or promoting social inclusion.

What is the treatment for challenging behaviors?

In a study of the treatment of challenging behavior between congregate and non-congregate settings, Robertson, et al. (2005) found that having an Individual Program Plan (IPP) with a goal of reducing challenging behavior was most often associated with more severe behaviors. The most common interventions were an individual program plan and the use of psychoactive medications. Their main finding was that very few people actually received behavioral support, while a high number received psychoactive medication. The results showed that the written intervention strategies in either congregate or non-congregate settings were seldom more than reactive management strategies. In their observations of interactions between staff and individuals in service, they also witnessed the use of reactive strategies, including the use of restraint and sedation. Restraint use was reported to be related more to whether staff had been trained in the use of restraints in the last three years than to the nature of the challenging behavior exhibited by individuals.

In another study looking at the types of interventions for challenging behaviors, Feldman, Atkinson, Foti-Gervais, & Condillac (2004) interviewed staff for 625 individuals with challenging behaviors across multiple services in the province of Ontario, Canada. Most (92%) of the individuals received services in community-based settings. Their results showed that informal non-pharmological interventions were slightly more likely to be employed than formal non-pharmological interventions, though restrictive procedures were more likely to be used with formal interventions for dangerous behaviors. Consistency in the interventions used was at 80% for formal procedures versus 50% for informal procedures. There was also a tendency for the informal procedures to employ reactive, intrusive methods to handle behavior problems.

While the use of behavioral interventions and psychoactive medication are not the only treatment options available to address challenging behaviors, the literature has not been supportive of other treatment options. Willner (2005) reviewed the literature on the use of various psychotherapeutic techniques. He did find support for cognitive-behavioral approaches, but did not find them to be superior to behavioral interventions. He does make an argument for the use of cognitive-behavioral approaches with sex offenders, however. As this population generally does not demonstrate their aberrant behavior in situations allowing for the appropriate use of behavioral interventions, the use of a cognitive-behavioral approach may better address the individual's offending behavior. Willner also makes an argument for the use of psychotherapeutic approaches for persons with known emotional problems.

What is restraint and what are the risks?

Tumeinski (2005) defines restraint as 'the use of force to limit another person's movements'. He further defines three forms of restraint: a) physical, using holds or other personal contact to limit movement, b) mechanical, using mechanical devices such as straps to restrict movement, and c) chemical, the use of drugs, either as a one-time use or long-term. The regulations of the Developmental Disabilities Division of the Nebraska Department of Health and Human Services define restraint as:

Restraint means any physical hold, device, or chemical substance that restricts, or is meant to restrict, the movement or normal functioning of an individual. Includes medication used solely to control or alter behavior, physical intervention, or mechanical device used to restrict the movement, normal function of a portion of the person's body or control the behavior of a person receiving services. Devices used to provide support for the achievement of functional body position or proper balance, and devices used for specific medical and surgical (as distinguished from behavioral) treatment are excluded. (From 404 Nebraska Administrative Code, Chapter 2)

Thus the Nebraska definition is similar to the definition found in the literature with the added exclusion of the use of devices for position (which likely do not restrict movement) and the use of restrictive procedures for medical and surgical versus behavioral treatment procedures. It should be noted that the exception for medical procedures is not universally accepted. Newton (2009) argues that dentists' incentive to use medications is to complete treatment versus treat behavior, so they would not be inclined to explore the use of alternative interventions. Therefore, the exception for medical procedures may be due to the need to complete the procedure versus working with the individual to use less restrictive methods.

Multiple issues with the efficacy and risks associated with use of restraint have been discussed in the human services literature. In fact, the Journal of Applied Research in Intellectual Disabilities published a special issue dedicated solely to restrictive behavioral practices in 2009. There has been a general consensus that the use of intrusive procedures should be reduced and eliminated. The concerns have to do with the harm that befalls the person with whom the procedures are used

as well as calling into question whether preventative and treatment strategies have been effectively implemented (Sturmey, 2009).

In another article discussing the need to eliminate the use of restraints, Ferlenger (2008) lists multiple reasons restraint use has been critiqued:

- It has harmful consequences both to staff and clients
- It may reinforce aggressive behavior as a coping mechanism
- It may not be clinically effective
- It may humiliate clients
- It may be counter-therapeutic for individuals with an abuse history
- It has been used for discipline, coercion and convenience
- It may be unethical
- It may be unconstitutional

In addition, the use of such aversive procedures conflicts with the overall benefits of inclusion and self-determination (Amos, 2004). While self-determination has an essential element of increased choice, the individuals for whom these interventions are prescribed often have little choice of procedures to address their behaviors. While informed consent is generally required for the use of restraints or medications, it has been the authors' experience that such consent is received from the individual's legal guardian without consideration for the individual's ability to voice an opinion about the use of the procedure(s). None of the guidelines that have been reviewed specify a need to thoroughly educate the person on all the options for treatment, nor do they specify that the person consent to his or her own treatment. While the DDD regulations state, 'Psychotropic medications used solely for the purpose of modifying behaviors may be used only with the consent of the individual' (404 Nebraska Administrative Code, Chapter 5), there is no clear specification that the consent must also come from the individual if they have a legal guardian. In addition, establishing that a person is truly informed of the procedures to which he or she provides consent may not be possible without carefully applying standards for obtaining informed consent.

Along with an increased emphasis on self-determination has been the evolution of positive behavior supports (PBS.) This approach emphasizes a positive model of supports that incorporates personal competence and environmental integrity, versus the traditional pathology based models (Carr, et al., 2002). Other studies that have shown some effectiveness are those using mindfulness training (Singh, et al., 2006) and person-focused training (Grey & McClean, 2007)

What is the prevalence of use of psychotropic medications and what are their risks?

There is a wide range of literature on the use of psychotropic medications in the population of persons with intellectual disabilities. Courtemanche, Schroeder, & Sheldon (2011) point out that studies suggest that a combination of both psychotropic medication and behavioral interventions are the best option for treating many psychological and behavioral disorders for people with intellectual and developmental disabilities. However, they go on to point out that while there is a

significant amount of literature evaluating one treatment option alone, there is very little literature evaluating drug-behavior interactions.

Brylewski & Duggan (1999) reviewed the literature on the use of anti-psychotic medication. For inclusion in their review, studies were required to consist of unconfounded, randomized controlled trials for adults without mental illness. They only found three studies that met their criteria and the data from those studies were inconclusive regarding the effectiveness of the medications. Their concern is that there are many persons with intellectual disabilities who receive such medications to treat challenging behavior, but there is not research to support the efficacy of such interventions.

A review of the literature by Matson and Neal (2009) found mixed results regarding the effectiveness of the use of psychotropic medication to treat challenging behaviors. They point out that while the literature for decades has not been able to demonstrate the efficacy of the use of psychoactive medications in treating challenging behaviors, there has not been a change in practice noted over that time.

Additionally, several recent articles have found high rates of use of psychotropic medications (Robertson, et al., 2000, Holden & Gitlesen, 2004a, McGillivray & McCabe, 2004) that were not supported by psychiatric diagnoses. A review from the National Core Indicators project (NCI, 2011) indicated that almost 30% of persons without a diagnosis of mental illness receive at least one type of psychotropic medication.

Tsiouris (2010) looked at the literature on aggressive behaviors, their association with psychiatric disorders, other contributing factors, and past and present treatment options for persons with and without intellectual disabilities. In addition, the literature on brain receptors implicated in aggressive behaviors and studies on the anti-aggressive properties of antipsychotics were reviewed. His conclusions were that aggressive behaviors are not directly associated with major psychiatric disorders, the prevalence of psychotic disorders in persons with intellectual disabilities is only 3%, and anti-psychotic medications do not have anti-aggressive properties.

A concern with the use of such medications is the risk related to side effects. Common side effects are weight gain, drowsiness, apathy, agitation, insomnia, excitement, headache, dizziness, confusion and gastrointestinal problems (Fretwell & Fleece, 2007). They also include adverse cardiovascular, central and autonomic nervous system and endocrine function side effects. Matson, Fodstad, Neal, Dempsey, & Rivet (2010) looked at risk factors that could contribute to one of the more severe side effects, tardive dyskinesia (TD). Tardive dyskinesia is a serious neurological disorder that is associated with long term use of neuroleptic drugs. It is characterized by sudden, uncontrollable movements of voluntary muscle groups and is generally a permanent condition. Factors found to be related to the increased likelihood of TD were increasing age, diagnoses of autism spectrum disorder, bipolar disorder or stereotypic movement disorder, and total psychotropic daily dose. The level of intellectual disability was inversely related to TD. Persons with profound intellectual disabilities were more likely to have symptoms of TD than persons with mild or moderate ID. They also found that the risk of TD symptoms was the same regardless of

whether the person was taking the older typical antipsychotics or whether they were taking the more modern atypical antipsychotics.

(Fretwell & Fleece, 2007) looked at staff knowledge of the side effects of antipsychotic medications. In interviews with 25 staff that provided services for persons with intellectual disabilities, five were unable to identify any side effects, seven were able to identify 1-3 side effects, six could identify 4-9 and seven could identify 10-13 side effects. While it is a concern that staff were not readily able to identify many potential side effects, it is noteworthy that in their study only one of the 25 persons interviewed identified tardive dyskinesia as a potential side effect.

McGillivray & McCabe (2006) looked at a group of individuals in Australia in 1993 and 2000 and compared the relative use of psychoactive medications. Their sample was based on 15,300 persons with ID who were registered as being eligible for services in the State of Victoria. There was a slight decrease in the overall use of psychotropic medications from 5.0% to 4.5% with this population across the seven year period. Of the persons who did receive psychotropic medications, there was a decrease in the use of antipsychotic drugs from 98% to 83%. However, there was an increase in the use of antidepressants (from 10.2% to 20.9%) among those taking psychoactive medication. Their primary concern was that the number of individuals taking more than one type of drug increased from around 30% in 1993 to 38% in 2000.

Spreat, Conroy, & Fullerton (2004) studied a large sample of persons with ID in Oklahoma both in 1994 and 2000. They found over 35% of the persons in 2000 were receiving psychotropic medications, similar to the results in 1994. For the persons who were in both samples the use of medications between the two years were compared. While around 20% received antipsychotics in both samples, there was a marked shift toward the newer, atypical antipsychotics and away from the use of the older, more traditional antipsychotics. There was also a marked increase in the use of antidepressants, mainly from the increased use of selective serotonin reuptake inhibitors (SSRIs). They note that the popularity and increase in the use of SSRIs has been recognized in other settings, such that it is not an unexpected result.

In a study of the use of psychoactive medication in North Dakota group homes, Burd, et al. (1997) found that 38% of the persons in these settings received psychoactive medication, including anticonvulsants. This rate was similar to 37% rate found in a similar study in 1991. In their study, over 57% of those who received psychoactive medications did not have a psychiatric diagnosis.

In a study looking at pharmacy records over a 17-month period for 2344 individuals with intellectual and developmental disabilities living in Orange County, California, Lott, et al. (2004) found antipsychotic and anticonvulsant medications were most commonly prescribed, followed by antidepressants. In their study, 60% of the persons received more than one drug during the 17-month period.

What are the causes of challenging behaviors?

Embregts, Didden, Huitink, & Schreuder (2009) looked at contextual variables that effected aggression. Their results showed that receipt of corrective feedback, negative attitudes and communication of direct care staff, failure to have wants or needs satisfied, an overly exciting environment, difficult or new tasks or changes in daily routine were associated with an increased probability of aggressive behavior. These results would suggest that there are multiple environmental variables that can influence the likelihood of challenging behavior.

Wigham, Hatton, & Taylor (2011) reviewed the literature on the effects of traumatizing life events on people with intellectual disabilities. While research can be cited that shows a relationship between such events and the likelihood of mental illness among persons with intellectual disabilities, their concern was with determining if valid case identification of such traumatic events could be identified. If so, the researchers contended, more trauma-focused interventions could be employed. However, their results concluded that none of the studies they reviewed included measures of life events and trauma that had been designed for persons with intellectual disabilities. They point out that some of the effects of trauma relevant to persons with ID are absent from standardized general population measures. These effects include stereotypical behaviors, challenging behaviors and reduced self-care. Thus there is a need for better standardized measurement tools for assessing trauma in the population of persons with ID. Without the ability to clearly specify the trauma people with ID have experienced, it is difficult to understand the relationship of such trauma to the exhibition of challenging behaviors.

Gunsett, Mulick, Fernald, & Martin (1989) discussed the need for medical screening prior to using behavioral interventions. They studied ten individuals referred for behavior management programming at a private intermediate care facility. Medical monitoring was conducted and medical conditions were diagnosed and treated, resulting in decreases in challenging behaviors for eight of the ten individuals. They point out the need for looking beyond the typography of what the individual is doing and looking for the etiology of the behavior. That is, the concern is with looking for the cause of the behavior versus trying to treat the behavior itself.

In a similar vein, McGuire, Daiy, & Smyth (2010) looked at how caregivers of person with ID reported chronic pain of such individuals. They used a questionnaire sent to the primary caregivers of 250 persons who lived either in their own homes or in community group homes. Their results showed that over 13% of people were reported to experience chronic pain. Further, a relationship between chronic pain and severity of the intellectual disability was revealed. Chronic pain was more likely to be reported with those with a mild intellectual disability than those with a more severe disability. The researchers suggest that chronic pain may be easier to recognize with persons who are better able to communicate their discomfort or that there is a greater perception of pain with that group. Either way, their results suggest that a significant part of the population of persons with intellectual disabilities may be experiencing chronic pain. While they did not discuss the relationship such discomfort could have with challenging behaviors, it would seem plausible that such a relationship would exist.

Discussion of Nebraska's service delivery system for persons with ID

The State of Nebraska's Division of Developmental Disabilities authorizes funding for community-based supports. The State funds Non-specialized services, known as Community Supports, which are services directed by the person or their family/advocate and usually delivered by an independent contractor. According to the State's Applications for 1915c Home and Community-Based Adult Services Waivers, effective January 1, 2011, "self-directed or participant-directed services are intended to give the person more control over the types of services received, as well as control of the providers of those services." Specialized services, on the other hand, are described in the waiver application as "traditional habilitation services that provide residential and day habilitative training that are delivered by certified DD [Developmental Disabilities] agency providers." For the purpose of this study, data was collected only for those individuals who receive specialized services from a certified DD provider. Definitions of specialized services provided by certified providers are summarized below.

Common to all specialized services is the requirement that formal habilitation is provided, no matter the setting. NAC 404 describes habilitation as a formal method of supporting people in the acquisition, retention, or improvement of skills. The State contracts with community-based providers to provide such services, funding the services with a combination of federal and state funds. A complete list of services offered is found in the Department of Health and Human Services (DHHS), Division of Developmental Disabilities (DDD) Specialized Services definitions, Appendix A, to this report.

In general, services offered are differentiated between those provided in or related to the setting where the person lives (Residential Services) and those provided in the person's workplace or related to the acquisition of a job or work skills (Day Services.) In addition, such services may be provided under differential funding rates for people meeting criteria as determined by the Division, such as those identified as requiring "Behavioral Risk Services," "Medical Risk Services, and "Retirement Services." Ancillary support services are also offered in the form of "Respite Services," and "Team Behavioral Services."

Residential habilitation offered as "Group Home Services" includes continuous services delivered in a provider operated or controlled setting, such as a home with 3 or fewer people or a home with four or more people that is licensed by DHHS. Staff must be on-site or within proximity to allow immediate on-site availability at all times. Formalized training and support is provided to assist people to acquire, retain, or improve skills related to living in the community.

"In-Home Services" are residential services that are provided to people living in their own or their family homes. Such services are provided as needed, with staff being intermittently available to deliver habilitative training related to living in the community.

"Companion Home Service" is a residential supported living option, defined as "residential habilitation provided to no more than two other people (3 people, total) in a residence that is under

the control and direction of the individuals who reside there.” Supports may be provided continuously or intermittently (e.g., staff may be on-site and readily available or provide services on an as-needed basis, as defined in the individuals’ plans.)

“Extended Family Home (EFH) Service” is a residential service provided in a single family home setting. Services may be delivered by a person who is acting as an employee of a developmental disabilities provider agency, or by a person who subcontracts with a DD provider agency. The services are provided continuously, as opposed to intermittently, with the EFH provider being on-site and immediately available to the individual receiving the service. This type of service may be considered a supported living option or a provider-operated option, differentiated by a) how many people live in the setting; b) who serves as representative payee; and, c) to whom payment for room and board is made.

The State also serves children under a Home and Community-Based Waiver. Children may receive any of the specialized residential services described above. When a child lives with his or her family, the services are called “in-home supported residential services.” In such instances, community-based developmental disabilities provider agency staff are intermittently available to provide habilitative training and supports to the child and his or her family.

Children living with their families may also be authorized for and receive “Respite” services (an ancillary service described below), or services that are generally considered to be non-specialized services, in that they need not be provided by a certified developmental disabilities services provider. These non-specialized services are not included in the discussion of available services.

There are five types of Adult Day Habilitation Services funded by the State. These services take place in a non-residential setting, separate from the person’s residential living arrangement, during typical working hours.

“Prevocational Workshop Services” provide formalized training for the person to gain or improve self-help, behavioral and adaptive skills. Prevocational supports are delivered continuously for 4 or more hours per day up to 5 days per week. This type of support is intended for people who are not currently seeking to join the workforce but desire habilitation aimed at preparing them to obtain paid or unpaid work. Work completed in such settings is generally paid at less than 50% of the minimum wage. Personal care, health maintenance, and protective oversight and supervision are also considered a part of the habilitation provided under this service type.

“Workstation Services” are delivered continuously and provide paid work experience in a community setting where individuals without disabilities work or meet together. Work experience provided is intended to prepare the person for competitive employment, teaching such concepts as compliance, attendance, task completion, problem solving, and safety, as well as use of public transportation and individualized employment objectives. Personal care, health maintenance, protective oversight, and supervision may also be provided under this type of service.

“Community Inclusion Services” provide habilitation, are generally facility-free, and are provided to people who are not currently seeking to join the general work force or participate in vocational planning services, or to those who prefer an alternative to pre-vocational workshop and/or workstation habilitation services. Supports provided assist people to acquire, retain, or improve skills to display appropriate behavior, increase independence, and to improve personal care, and health, as well as to provide protective oversight and supervision.

“Vocational Planning Services” focus on career planning, job searching, and opportunities for paid or unpaid work experience with the goal of attaining employment in an integrated setting within the community. Habilitation services provided include development of self-awareness, and assessment of skills, abilities and needs for self-identifying career goals and direction, including resume or business plan development for customized home businesses.

“Integrated Community Employment Services” consist of intermittent formalized training and supports to enable a person to acquire and maintain a job or position in the general workforce at or above the State’s minimum wage. The goal of this service is for the person to sustain paid employment. Such services may also be used to assist a person in establishing and maintaining a customized home-based business.

Also included in the services that may be authorized to a child under the Children’s waiver is “Day habilitation,” also known as “specialized disability related child care.” and “Habilitative child care.” Day habilitation is a service for older children normally furnished on a regularly scheduled basis when the child is not receiving educational services, such as on school holidays and during the summer. Day habilitation services are limited to older youth (18-21 year olds) that reside in residential service settings and may not be authorized for youth who receive intermittent in-home supported residential services and reside with their families. “Habilitative child care” is provided only to children residing in their family homes for up to 12 hours per day in the child’s natural home or in a setting approved, registered, or licensed by a DHHS agency. This service is generally not provided by certified specialized community-based developmental disabilities providers.

Other funded services for which a person must meet specific criteria (age or another characteristic) are described as follows:

“Behavioral Risk Services” are provided to individuals with complex behavioral needs that require continuing care and treatment. Such services may be required when the person’s behaviors place them or others at risk of harm, and include continuous services to provide residential and day habilitation, intensive behavioral supports, ongoing supervision for safety, and other supports. The services are provider-operated and are supervised by a mental health practitioner with staffing ratios that are flexible and commensurate to meet the needs of the person. Types of settings in which the residential portion of this service may be provided are not specifically defined. Any type of day habilitation (prevocational workshop, workstation, vocational planning, integrated community employment, or community integration) may be provided under this service. The need for behavioral risk services is determined by designated staff at the DDD central office.

“Medical Risk Services” are provided to individuals with complex medical needs that require continuing care and treatment but are assessed not to need continuous nursing facility level of care. Treatment or interventions to meet complex medical needs are performed by Registered Nurses and require ongoing clinical assessment, professional judgment, and treatment that cannot be delegated to unlicensed persons. The need for medical risk services is determined by designated staff at the DDD central office. Medical Risk services include both day and residential habilitation. Day habilitation is to be provided at a setting away from the residence unless provision of day services at home is prescribed to be medically necessary by the individual’s physician and approved by the DDD central office staff.

“Retirement Services” are available to individuals (generally those who are 62 or older) who have chosen or are no longer able to be involved in employment activities or to participate in day habilitation services. The services may be provided in a home setting or a community day activity setting, and may be provided as a day or residential service. Under this service, active supports are furnished for the purpose of fostering independence, stimulating and supporting participation in activities, increasing awareness of the environment, and maintaining previously learned skills, among other aims. Retirement services may be provided as a continuous or intermittent service, but may not be set up or operated by a DD provider in communities where a community senior center or facility already exists. Any provider-operated retirement setting must be made available to people without disabilities.

Additional services that are authorized by the DDD include two types of support that benefit the individual both directly and indirectly. “Respite” is a service aimed to support a usual unpaid caregiver by providing supervision needed by the person so that the caregiver may have a break. “Team Behavioral Consultation” is a service requested by and provided to a person’s Individual Program Planning (IPP) team so that the individual’s plan can be strengthened by the recommendations provided. Both services are described more fully, below.

“Respite Services” provide temporary, intermittent relief to the usual non-paid caregiver from the continuous support and care of the individual to allow the caregiver to pursue personal, social, and recreational activities. During the provision of respite, a person (either adult or child) is provided supervision, assistance to meet physical and psychological needs and support to take part in social and recreational activities. The amount of respite that may be authorized is based on a maximum number of hours or days per year.

“Team Behavioral Consultation Services” may be requested by a person’s IPP team or directed by the DDD central office for people who are experiencing psychological, behavioral, or emotional instability that has been resistant to other standard habilitative interventions and strategies. An on-site consultation is provided by a team of qualified professionals under the direction of a Licensed Clinical Psychologist. Records reviews and observations are completed, and the Team develops, pilots and evaluates behavioral interventions and makes recommendations for implementation of behavioral support plans to remediate behavior concerns. Other referrals may be made to address

identified needs in areas such as medication review and dental and medical evaluation. Follow-up consultation is provided to ensure treatment integrity and to make additional recommendations.

Nebraska's service system is undergoing significant change, offering new service options with specified guidelines and requirements for the provision of services and documentation of service delivery. New definitions and practices intended to increase opportunities for employment have been introduced and efforts are being made to reduce the use of invasive practices for the purpose of managing behavior. Required use of positive behavior supports is outlined in new regulations. The purpose of this study is to establish baselines of the use of restraints and psychoactive medication for use in evaluating the effectiveness of efforts to eliminate the use of restraints or to modify the usage of psychotropic medications. The experimental questions to be answered include:

- 1) What is the prevalence of use of restraint in community-based developmental disabilities programs;
- 2) What are the curricula used by providers to train staff in the use of restraint;
- 3) What programs and providers utilize restraints and which do not, and what are any relevant correlates;
- 4) What research and initiatives implemented in other states have resulted in restraint reduction and/or elimination;
- 5) What is the prevalence of use of psychotropic medications among people supported by community-based programs;
- 6) What are the current prevailing definitions and understanding of seclusion and time-out as coercive practices

Methodology

Twenty-six providers contracting with the State of Nebraska to provide community-based developmental disabilities services were surveyed for the study. Three providers declined to supply; one of those submitted policies and procedures early in the study but declined to continue participation by providing data. Data on restraint usage was collected from the 23 remaining providers based on provider records from the first quarter of calendar year 2011 (January through March.) Two of the twenty three respondents specified that they did not have policies and procedures specific to the topics being reviewed—restraint and use of psychotropic medications—and so did not submit such policies for review. A number of providers referenced Operations Manuals or additional procedures manuals in the policies and procedures submitted for review. Such documents are referenced as being supplemental to or providing further definition and information about agency practices. Additional definitions and explanation of practice may be found in such documents, but were not reviewed for the purpose of this study.

Study under this grant also polled providers on specific details about the use of restrictive procedures of physical and mechanical restraint and use of time out and seclusion (See Appendix B.) Twenty two providers responded to the questionnaire in full, with one provider giving partial response to questions posed. Some of the information provided in the questionnaire was inconsistent with written policies and procedures that were submitted. It is hypothesized that the difference between policy and procedure and responses in the survey represents the difference between policy and practice. Examples of such differences will be discussed in this report.

To ensure the consistent collection of data for study, an operational definition of restraint was established after input and suggestions were solicited from the workgroup of providers. All providers were invited to submit information in writing, and/or attend a workgroup meeting at which the definitions were discussed. As agreed by the workgroup, the operational definition for use in determining whether an action should be considered a restraint was as follows:

“Restraint (as a physical intervention or mechanical device) for the purposes of the data collected under this grant shall mean: (1) The holding of a person [by another person or persons] in a manner that restricts the person’s movement, and, (2) The use of a mechanical device, material or equipment that immobilizes or reduces the ability of a person to move his or her arms, legs, body, or head freely—or to restrict access to a part of his or her body. The interpretive standards for physical interventions are as follows: Physical escort – to move a person to a desired location. If the person can easily remove or escape the grasp, this would not be considered physical restraint. However, if the person cannot easily remove or escape the grasp, such an escort would be considered physical restraint. Mechanical restraints are devices or materials, including clothing, which is used to prevent self-injury or other forms of self-stimulation.”

Data on the use of psychoactive and anticonvulsant medication was accessed from the Financial and Program Analysis (FAPA) section of the Operations Division of the Nebraska Department of

Health and Human Services. The data was drawn from Nebraska's Medicaid Management Information System (MMIS), which houses all Medicaid transactions. The data was drawn for the four quarters from the second quarter of calendar year 2010 through the first quarter of calendar year 2011. The information was provided with an encrypted unique identifier for each person served to allow the data to be analyzed by individual without compromising any person's confidentiality. The data also included information on whether the person was a child or adult and their gender. With the aid of a Medicaid pharmacist, FAPA pulled all payments for psychoactive and anticonvulsant medication including the service and payment dates and First DataBank (FDB) and Generic Sequence Number (GSN) information for each medication purchased.

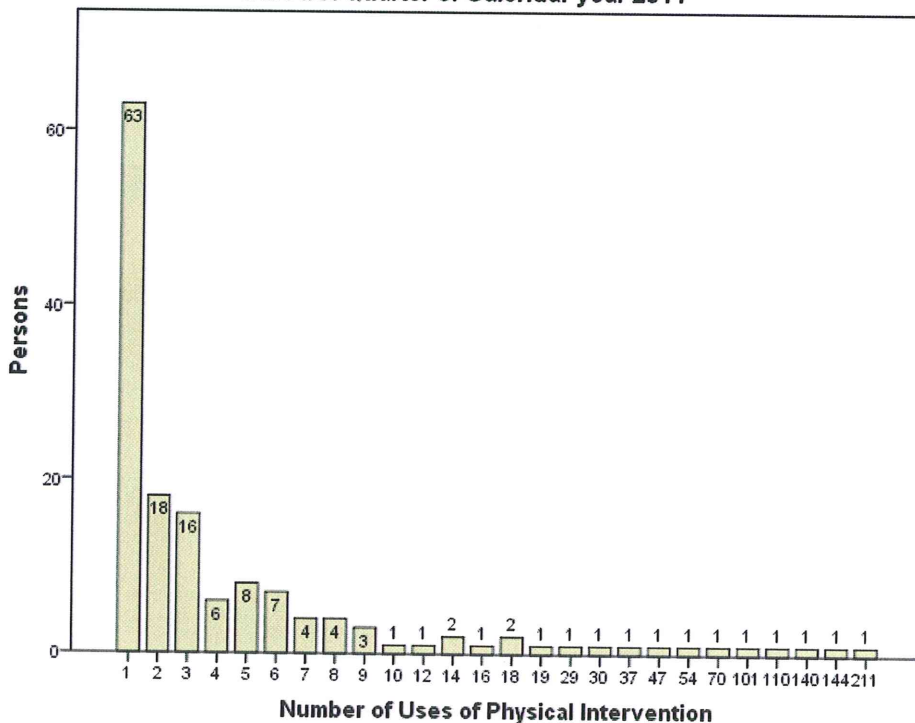
For the purpose of this study, the service dates were used to determine the medications purchased within the first quarter of 2011. As this data includes only purchases made through Medicaid, it does not include any data for any person served by DDD who is not on a Medicaid waiver. For the time period in question, 94% of the persons served by DDD were served under a Medicaid waiver. Therefore, only six percent of those served by DDD during this time period were not included in this data.

The data was provided to the researchers in a password-encrypted Microsoft Excel file and was analyzed using the Statistical Package for Social Sciences (SPSS) software. The data did include corrective entries that negated payments for medications. This data, along with the corresponding entries for the purchase of the medication, was removed from the analysis to avoid counting medications which were not purchased.

Results

For the 26 certified providers who were polled regarding the use of physical and mechanical restraints, three did not provide a response. The relative usage of restraints is reported for the population of persons served in the first quarter of 2011 by the providers who did respond. Eight of the 23 (34.7%) indicated no use of physical intervention during the reporting period. Of those eight, four reported that they prohibit the use of any physical intervention in practice, with one of the four prohibiting restraint in written policies (see discussion below). There were a total of 148 persons with whom physical restraints were used in the first quarter of 2011, which was 3.4% of the persons served by the 23 reporting providers. Physical restraint was used an average of 9.7 times during the quarter for those 148 persons, with a range of one to 211 times. The median usage was two uses, meaning half the persons were physically restrained two or fewer times and the other half were physically restrained two or more times. The modal or most common number of usages was once during the quarter. The graph below shows the distribution of the frequency of the use of physical restraint during the quarter. As can be seen from the graph in Figure 1, there were five persons who had more than one use of restraint per day for the quarter.

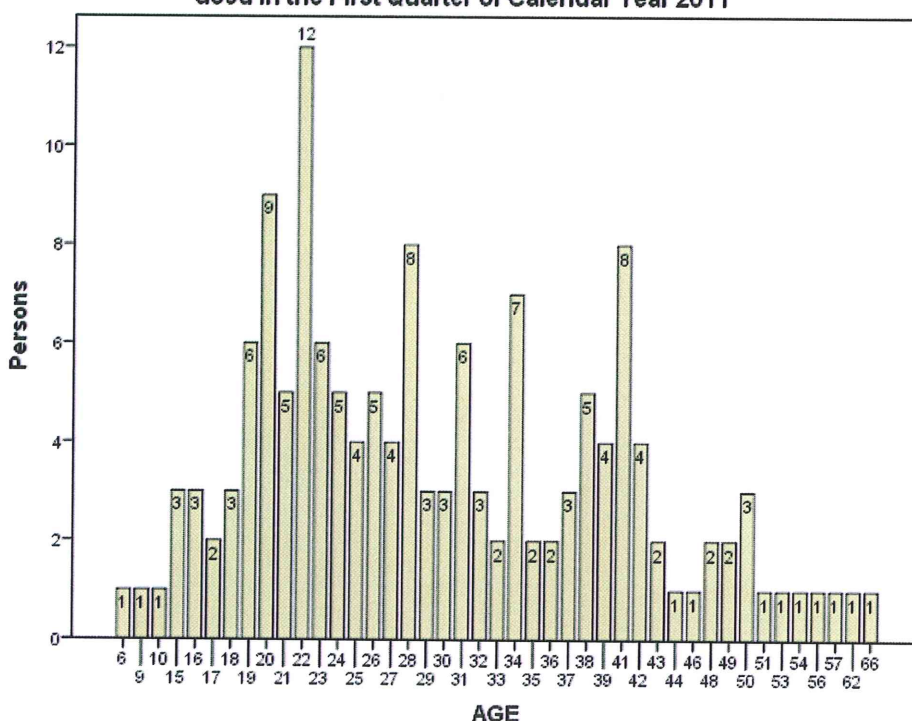
Figure 1: Number of Persons by Frequency of Use of Physical Intervention for the First Quarter of Calendar year 2011



Regarding other supports/interventions in place, 147 of the 148 persons with whom physical restraint was used had a behavior support plan (BSP). 124 of the 147 (84.4%) who had a BSP had physical interventions included in the procedures. Psychoactive medications were used in addition to the other supports by 141 (95.3%) of the persons.

The demographics showed that 101 or 68.2% of those who were physically restrained were male, compared to 57% of the total population of persons served. This equates to 3.9% of the males and 2.5% of the females served in that quarter. The average age of those with whom physical restraint was used was 30.2 years of age. Their ages ranged from 6 to 66 years, with a median age of 28 and a modal age of 22. This is younger than the overall population served at that time. The population served had a mean age of 38.1 years, with a median age of 35 years and a modal age of 27 years. The graph in Figure 2 shows the distribution of ages for the 148 persons.

Figure 2: Distribution of Ages of Persons with whom Physical Intervention was used in the First Quarter of Calendar Year 2011



Mechanical devices, such as restrictive clothing or helmets were reported to be used with 18 persons or 0.4% of the population served by the 23 providers. Eight had daily use of the devices, one was reported to have 61 uses, two had 15 applications, and the remaining seven had one to seven applications. All uses were reported to prevent various types of self-injurious behavior. The average number of days of use of the devices was 46.4, with a median of 38 days and a mode of 90 days.

Seventeen of the 18 had BSPs. Of those 17, 15 (88.2%) had the use of physical intervention written in the BSP. Fifteen of these 18 persons received psychoactive medication.

Thirteen of the 18 (72.2%) were male. The average age was 31.9 years, with a median of 30 years and modes of 28 and 32 years.

Regarding the use of psychoactive medications, 2193 persons of the 4093 persons served who were on Medicaid, or 53.6%, received psychoactive medication during the quarter. An additional 253 persons (6.2%) only received anticonvulsant medication. 233 of the 316 persons served on the Children’s Home and Community Based Waiver, or 73.7% of the children served under that program, received psychoactive medication, with an additional 12 (3.8%) who only received anticonvulsant medication. For the adult population, 1960 of the 3777 served, or 51.9%, received psychoactive medication, with an additional 241 (6.4%) who received only anticonvulsant medication.

Females were as likely to receive psychoactive medications as males, in contrast with use of physical and mechanical restraints, where such use was more likely with males. 960 of the 1759 females (54.6%) received psychoactive medication compared to 1233 of the 2334 males (52.8%). An additional 112 females (6.4%) and 141 males (6.0%) received anticonvulsant medications only. The table in Table 1 below shows the number and percentage of persons receiving each class of medication.

Table 1: Number and Percent of Persons Receiving Medication by Classification for the First Quarter of 2011

	Number	Percent
ANTIDEPRESSANT	1433	35.0%
ANTIPSYCHOTIC	1362	33.3%
ANTICONVULSANT	1304	31.9%
ANTI-ANXIETY	500	12.2%
SEDATIVE-HYPNOTIC	228	5.6%
ADHD	225	5.5%
ANTI-MANIA	108	2.6%
NARCOTIC ANTAGONIST	21	0.5%

As can be seen from the table, antidepressants were most widely used, followed by antipsychotic medications. In looking at the classification of medications by gender (see Table 2 below), females were slightly more likely to receive anti-anxiety and antidepressant medications and males were slightly more likely to receive medications for attention deficit hyperactivity disorder (ADHD) and antipsychotic medications.

Table 2: Number and Percent of Medications taken by Classification and Gender for the First Quarter of 2011

	Number		Percent	
	Gender		Gender	
	Female	Male	Female	Male
ANTI-ANXIETY	251	249	14.3%	10.7%
ANTICONVULSANT	557	747	31.7%	32.0%
ANTIDEPRESSANT	676	757	38.4%	32.4%
ADHD	58	167	3.3%	7.2%
ANTI-MANIA	36	72	2.0%	3.1%
ANTIPSYCHOTIC	524	838	29.8%	35.9%
NARCOTIC ANTAGONIST	9	12	0.5%	0.5%
SEDATIVE-HYPNOTIC	97	131	5.5%	5.6%

The classification of medication by age group is even more pronounced. The children in this study are more likely to receive anticonvulsants, ADHD medications and anti-psychotic medications. Adults are slightly more likely to receive anti-anxiety and sedative-hypnotic medications (see Table 3 below).

Table 3: Number and Percent of Medications taken by Classification and Age Group for the First Quarter of 2011

	Number		Percent	
	Age Group		Age Group	
	Children	Adults	Children	Adults
ANTI-ANXIETY	30	470	9.5%	12.4%
ANTICONVULSANT	145	1159	45.9%	30.7%
ANTIDEPRESSANT	109	1324	34.5%	35.1%
ADHD	89	136	28.2%	3.6%
ANTI-MANIA	16	92	5.1%	2.4%
ANTIPSYCHOTIC	197	1165	62.3%	30.8%
NARCOTIC ANTAGONIST	3	18	0.9%	0.5%
SEDATIVE-HYPNOTIC	8	220	2.5%	5.8%

The number of medications within each classification was also studied. The following table (Table 4) shows the number of persons who only received more than one type of medication within each classification. As can be seen from the table, there were persons who took more than one medication in every classification except for narcotic antagonists.

Table 4: Number and Percent of Persons Receiving More than One Medication within Classification for the First Quarter of 2011

	Number	Total	Percent
ANTI-ANXIETY	36	500	7.2%
ANTICONVULSANT	425	1304	32.6%
ANTIDEPRESSANT	270	1433	18.8%
ADHD	52	225	23.1%
ANTI-MANIA	2	108	1.9%
ANTIPSYCHOTIC	337	1362	24.7%
NARCOTIC ANTAGONIST	0	21	0.0%
SEDATIVE-HYPNOTIC	8	228	3.5%

Overall, the number of persons receiving more than one medication in a classification was 628 or 28.6% of the persons receiving psychoactive medications. If anticonvulsants are also counted, the number increases to 921 or 37.7% of the persons receiving medications. In addition the number of

different psychoactive medications beyond anticonvulsants that were received by each person was calculated for the quarter. The results are shown in Table 5 below.

Table 5: Number and Percent of Persons by Number of Psychoactive Medications Received in the First Quarter of 2011

	Number of Persons	Percent
1	800	36.5%
2	711	32.4%
3	414	18.9%
4	176	8.0%
5	62	2.8%
6	15	0.7%
7	10	0.5%
8	4	0.2%
10	1	0.0%

While not a part of this study, there were 14 individuals who received injectable drugs anywhere from one to ten times during the quarter, two of those individuals did not take any oral psychotropic medications.

As part of the study, providers submitted policies and procedures related to the use of restraint and psychotropic medications for review. The analysis of these documents was completed for the purpose of determining the prevailing definitions and understanding of restraint and other coercive practices. It was determined that establishing common use of terms and definitions will be an important part of understanding and measuring the use of restraint and other coercive practices in the future.

Provider definition of terms

Much of the time, policies reviewed did not include definitions of the terms ‘physical restraint,’ ‘seclusion,’ ‘time-out,’ and ‘mechanical restraint.’ In all, the policies and procedures of 21 providers were reviewed. The table below (Table 6) identifies the number of respondents that provided any definition of each term in policy and procedure.

Table 6: Number of Providers with Definition of Terms

Physical Restraint	Seclusion	Time Out	Mechanical Restraint
5	8	9	5

Prevalence of policies governing the use of restrictive measures

The absence of a standardized definition within and across agencies indicates a possible need for additional study and work in this area. While agencies do not always define these terms, use of such interventions is permitted *or is not specifically prohibited in policy* by the number of agencies outlined in the following table (Table 7):

Table 7: Number of Providers not Specifically Prohibiting Procedures

Physical Restraint	Seclusion	Time Out	Mechanical Restraint
20	0	17	7

As noted previously, just one provider of services specifically prohibits the use of restraint by policy. Three other providers' policies and procedures allow both restraint use and training of staff in the use of restraint but written survey information submitted by the three stated their agencies do not use physical restraint in practice. One of the three agencies indicated it had not used a restraint in 15 years, although it does provide Mandt training, including physical intervention techniques, to its staff. In writing and/or during informal conversations two of the providers indicated that they would be reluctant or unlikely to accept a person with a history of restraint into their services—either because of the nature of supports they provide, or for some other reason. One of the three providers specifically stated that it does not accept or retain in services those who exhibit physical aggression; another stated that the contract under which it provides employment services for people does not allow the employment of people who demonstrate aggressive behavior.

Provider reports of restraint training curricula

Providers were asked to submit information about the curricula used to train staff on restraint techniques. The results of the survey indicated that most providers have taken a curriculum developed and recognized nationally and tailored it to meet their in-house needs. Seven providers use the Mandt curriculum as it is presented by the company that produced the curriculum; five other providers have taken the Mandt curriculum and modified it to include their own philosophies and/or techniques. Three providers use standardized training developed by the National Crisis Prevention Institute, sometimes called CPI (Crisis Prevention and Intervention), with two others reporting that they use a variant of this type of training. Another provider uses the TACT2 (Therapeutic Aggression Control Techniques) curriculum. One provider uses PRAB (Preventing and Resolving Aggressive Behavior), a curriculum developed in Nebraska in the 1990's. The remaining four responding providers indicated they do not train staff in restraint techniques since they do not permit use of restraint.

In addition, the survey asked which staff were trained in use of restraint, whether and how staff competency was tested, and whether restraints are debriefed as a standard of practice. Twelve respondents indicated that all agency staff are trained using the agency's restraint curriculum, with one of those providers indicating that extended family home providers did not receive the training if people served by them had had no restraints in the past year. Another provider noted that staff who are more likely to require use of restraint on their jobs would need and receive more technical training than others. Six other providers indicated that only direct support professionals or only direct line (or client contact) staff receive restraint training. Four others tailor the need for training more specifically, training staff in restraint only if they work with individuals whose programs include such intervention, and/or only on the techniques approved for persons with whom the staff works.

Competency is tested by all providers responding, either by pen and paper testing or by demonstration of skill, or both. Debriefing in some form was reported to be completed by twelve providers, with some of the respondents describing debriefing techniques as being done on a case-by-case basis, based on team requests, and/or by reviewing incident reports documenting restraints.

Historically, restraint curricula in use by contracted providers has been reviewed and approved by the state's developmental disabilities division. Curricula were not submitted by providers for review; most providers consider their in-house curricula to be proprietary. Future activities might include review of curricula, particularly to identify those which are most successful at de-escalating situations so that restraint is not a result.

Regulatory definitions and correlation to provider policy

At the time data was collected for this study regulations defined restraint, in 205 Nebraska Administrative Code, Chapter 2 as:

“Any behavior modifying drug, physical intervention or mechanical device used to restrict the movement or control the behavior of a person receiving services or the movement or normal function of a portion of the person's body. Devices used to provide support for the achievement of functional body position or proper balance, and devices used for specific medical and surgical (as distinguished from behavioral treatment) are excluded.”

In addition to adherence to this definition, providers were required to include the conditions under which a restrictive procedure was permitted for use in an individual's behavior management program including the following provisions:

“205 NAC 4.014.01: The provider shall have policies and procedures to govern the implementation of programs to manage problem behavior. These policies and procedures shall:

- (A) Be directed at maximizing the growth and development of the individual and incorporate methods that emphasize positive, proactive approaches.
- (B) Provide that the methods used should not be employed as punishment, for the convenience of staff, a substitute for habilitation, or reactive in design.
- (C) Include a definition of behavior management which specifies and defines approved intervention procedures, and a description of the mechanism for monitoring its use.
- (D) Specify emergency behavioral intervention procedures to be used to prevent persons served from causing harm to him/herself or others or causing considerable damage to the physical environment, when prior written consent for restrictive procedures has not been obtained;
D1: If these emergency procedures are used three times or more within a six-month period, these procedures must be incorporated as a part of a written behavior management program.

- (E) Prohibit corporal punishment, verbal abuse, physical abuse, psychological abuse, denial of a nutritionally adequate diet, seclusion, and a person receiving services disciplining another person served in the above manner;
- (F) Specify that restrictive procedures can only be used as an integral part of an individual behavior management program that is designed to lead to a less restrictive way of managing the behavior and ultimately to the elimination of the behavior for which the restrictive procedure is used.
F1: Aversive stimuli to manage or change behavior shall not be used unless the IPP team, the behavior management committee, the human and legal rights committee, and a physician concur that to allow the persistent and intractable behavior would probably cause severe and/or irreversible harm to the person receiving services;
- (G) Specify that staff training must be specific to the procedures to be implemented in the individual's program plan and provided prior to implementation of the procedures;
- (H) Specify that for the following behaviors there must be a program or behavioral intervention procedure to meet the needs: 1) Behaviors that are obstacles to an individual becoming more independent; 2) Behaviors that interfere with the person's ability to take part in habilitation or training; 3) Self-injurious behavior; and 4) Behaviors that are a threat to others or are aggressive or destructive."

Nebraska's Home and Community Waiver Services regulations (480 NAC) in force at the time of the survey also permitted the use of physical restraint, requiring providers in 480 NAC 3-003.01(9) to: "define and specify procedures governing facility use of restrictive or intrusive measures such as physical restraints, time out procedures, use of medications to manage maladaptive behaviors, and emergency uses of restrictive measures."

The current Home and Community-Based Children's Waiver application to provide community based services reimbursed under the federal Medicaid program (dated 10/1/10) permits the use of restraints, though it is likely that this waiver reflects previous philosophy, as it was submitted prior to the revision of regulations. In response to the question about how it will establish safeguards concerning the use of each type of restraint (i.e. personal restraints, drugs used as restraint, mechanical restraints, or seclusion) the State provided the following response:

"The use of mechanical restraints and aversive stimuli are not allowable habilitation techniques. Physical restraints and drugs to modify behavior are allowed. Nebraska does not consider time out rooms to be "seclusion." However, safeguards for the use of time out are included in this application to comport with CMS' definition of seclusion.

In Nebraska, "restraint" means any behavior modifying drug or physical intervention used to restrict the movement or control the behavior of a person or the movement or normal function of a portion of the person's body.

A restraint can only be used as an integral part of an individual BMP, except for an emergency. An emergency is defined as an unforeseen combination of circumstances or the resulting state that calls for immediate action.”

The two other Home and Community-Based Waiver applications (Day and Comprehensive waivers for Adults), dated 01/1/11, provide the following response to the question about safeguards concerning the use of each type of restraints;

“In Nebraska, “restraint” means any physical hold, device, or chemical substance that restricts, or is meant to restrict, the movement, normal function of a portion of the person’s body or control the behavior of an individual. Devices used to provide support for the achievement of functional body position or proper balance, and devices used for specific medical and surgical (as distinguished from behavioral) treatment are excluded as a restraint.

The use of mechanical restraints, physical restraints, seclusion, and aversive stimuli are not allowable habilitation techniques and are prohibited. Seclusion means the involuntary confinement of an individual alone in a room or an area from which the individual is physically prevented from having contact with others or leaving. Chemical restraints - drugs, or psychotropic medications used solely for the purpose of modifying behaviors are allowed. PRN psychotropic medications are prohibited.

Restrictive methods used should not be employed as punishment, for the convenience of staff, a substitute for habilitation, or be reactive in design. Drugs cannot be used as a way to deal with understaffing or as a way to deal with ineffective, inappropriate, or other nonfunctional programs or environments. Corporal punishment, verbal abuse, physical abuse, psychological abuse, denial of an adequate diet, and a person in services disciplining another person served, and placing persons in a totally enclosed crib or other barred enclosure are prohibited.

Physical restraint or separation from harmful circumstances or from individuals at risk can only be used as an emergency safety intervention when the person must be kept from harm (i.e., running into traffic, leaving a moving car or other serious, unusual or life-threatening actions by the person). Protocols for the use of physical restraint and separation are written into state regulations and must be included in provider policies, procedures, and practices. An emergency safety intervention which is not used as a behavioral consequence and utilized pursuant to a safety plan is allowed to respond to an emergency safety situation. In instances where the person must be kept from harm, the provider must use their reasonable and best judgment to intervene to keep the person from injuring him/herself or others. This may include the use of separation - hands-on guidance away from harm or to another area or room to safely protect the persons and others from immediate

jeopardy or physical harm. An individual could be physically guided away from an area and staff may block the exit. The individual would always have line of sight supervision and the expectation would be that as soon as the risk of harm is no longer present, then they would no longer be kept away from others. The person would not be put in a room with the door closed and no one watching them. . .”

These two waiver applications also require that the DDD receive notification of use of physical or mechanical restraint immediately upon the provider, participant, or family becoming aware of the incident.

Review of provider policies and procedures indicated that policies 1) may not always conform to regulatory requirements, and 2) may not represent actual practice in everyday use.

Eighteen providers submitted policies that allowed the use of physical restraint in cases when a person’s behavior posed imminent danger to self or others. Six of those also allowed physical restraint in circumstances when the person’s behavior posed a threat of property damage (sometimes qualified as ‘significant’ property damage.) The vast majority of providers has not permitted use of restraint as a standing order, allowing physical intervention only when a person’s behavior posed imminent danger to him or herself, others, or, in some cases, property, and only after efforts to bring about de-escalation have failed. Some providers imposed greater limitations on the use of physical restraint than regulations have required. One provider stated that “physical restraint may be used only when it is the only available immediate procedure for extreme cases of self-abuse.” The provider cites other restrictive measures, such as enforced physical isolation or enforced time out that may be used when the person’s behavior poses immediate danger of physical harm to others.

Another provider defined ‘physical intervention,’ of which *physical restraint* is one type. The provider’s definition of ‘physical intervention’ includes “physically assisting someone against their will in performing daily living activities such as bathing or eating.” Any physical intervention is considered by the agency to be a controversial practice that requires specific review and consent procedures be followed.

One provider stated that “when attempting to gain compliance in order to complete a task, physical restraint is usually unacceptable. The only exceptions for using a physical restraint technique to gain compliance may come about as a result of an external behavioral evaluation (i.e. OATIS) [Outreach and Intensive Treatment Services previously provided by the Beatrice State Developmental Center Team] or an administrative review completed by the Area Director and Chief Executive Officer.”

The failure to maintain adherence to a standard definition of physical restraint in practice posed some difficulty in collection of data, but participating providers did come to a consensus on the definition for the purpose of data collection. Further study and collaboration on a standardized operational definition of the term may be needed to establish consistent definitions for use in

reporting. It is suggested that changes in regulatory definitions since the study occurred may call for additional training on tracking of restraint. The term “Emergency safety intervention” has been adopted, with the new term defined in 404 NAC 2 as: “the use of physical restraint or separation *as an immediate response to an emergency safety situation.*” Further, “Emergency safety situation” is defined, also in 404 NAC 2, as “unanticipated behavior by an individual that places the individual or others in serious threat of violence or injury if no intervention occurs and that requires an emergency safety intervention. “Restraint” and “separation” are now defined together as an intervention that may result when an individual’s unanticipated behavior warrants such action. The term “separation” is not defined in regulation and providers are not required by regulation to define the term in policy. The term “restraint” continues to be defined in regulation as “any physical hold, device, or chemical substance that restricts, or is meant to restrict, the movement or normal functioning of an individual. Includes medication used solely to control or alter behavior, physical intervention, or mechanical device used to restrict the movement normal function of a portion of the person’s body or control the behavior of a person receiving services. Devices used to provide support for the achievement of functional body position or proper balance, and devices used for specific medical and surgical (as distinguished from behavioral) treatments are excluded.” This definition is consistent with the previous definition of the term restraint.

Reporting requirements have not yet been established that will separate data collected on “Emergency Safety Interventions” so that “restraint” and “separation” are reported and data can be analyzed efficiently.

The term ‘seclusion’ was defined in the 205 NAC regulations as: “placement of a person alone in an area which is not under observation and from which exit is prevented.” Title 205 NAC 4-014.01E specifically stated that providers “. . . policies and procedures shall . . . prohibit . . . seclusion.” The Home and Community Waiver Services regulations, at 480 NAC 3-003.01, also prohibited the use of seclusion: “The written and implemented policies and procedures regarding behavior management and emergency procedures for managing inappropriate behavior shall prohibit . . . seclusion. . .”

As noted above, there are no providers that permitted use of seclusion via policies reviewed for this study, although three providers did not specifically prohibit the use of seclusion in policy. One of those providers stated in policy that “mechanical restraints, seclusion techniques, and aversive stimuli may not be used under waiver regulations” leaving a question about whether the provider intended to prohibit such practices only if a person were funded under a waiver. The newly adopted regulations (404 NAC 2) define seclusion as “the involuntary confinement of an individual alone in a room or an area from which the individual is physically prevented from having contact with others or leaving. ‘See emergency safety intervention.’ Seclusion is prohibited. “ It is suggested that this definition is similar to the previously used definition of ‘time-out,’ which is neither specifically defined nor prohibited in the new regulations. Clarification to achieve the

standards set by the Department (including its position on the use of time-out aside from seclusion) may be necessary.

The term 'time out' was defined in 205 NAC as "the removal of an individual from a situation wherein undesired behaviors are exhibited. The individual is isolated but under constant observation and is prevented from leaving the isolated area without staff approval." Both the 205 NAC and 480 NAC regulations in force at the time this study was done required providers to have policies governing the use of time out procedures. Regulations prescribed that terms of use be outlined in policy, including duration, staff monitoring, and environmental specifications (including lock mechanisms on door, lighting, ventilation and absence of objects that may be used to cause bodily harm.)

Analysis of provider policies and procedures indicates that, while 17 providers permit use of some form of time out procedure, just nine of those permitting use of such measures included a definition of the term in policy. In response to the survey completed by providers, 8 of the 17 providers permitting use of time out in policy stated that they do not, in practice, use time-out. Some providers define time-out in ways different from that stated in regulation, ranging from a provision that a person "may go to a quieter placed, but it is not enforced," to "the person removes him/herself and goes to an area where others may be," to "defined as access to staff or other reinforcers." Whether or not time out is permitted or prohibited by regulation in the future, definitions should be standardized so that consistent use and data collection is possible.

Discussion

The current study indicates that approximately one in 30 persons in services was restrained during the first quarter of 2011. As noted by Sturmey, Lott, Laud, & Matson (2005), most of the literature focuses on the use of restraint in institutional populations and there is little information regarding restraint use in community-based settings. The literature that was reviewed did not give a consistent rate of restraint use (though rates of up to 44% in institutional populations were reported), but the data collected for this study appears to indicate that the use of restraint in Nebraska's community-based settings is relatively low. Of note is that only 17 of the 148 persons who were reported to be restrained were restrained at a rate greater than once per week. These 17 persons represent only 0.4% of the persons served at that time. From these results, the task of eliminating the use of physical or mechanical restraints appears to be quite achievable.

However, a concern with this research is that it only reports the restraints used by reporting certified developmental disabilities service providers. Other persons may be involved in responding to challenging behaviors and any restrictive procedures employed by these persons were not captured in this study. Our data does not include any involvement by law enforcement, where the use of at least physical restraint would be likely, nor does it include any data regarding the use of restraints by family members, school staff, or others who provide support to the individual. Thus, while efforts do appear to have been made by providers to reduce or eliminate the use of restraint themselves, the use of law enforcement or others to intervene with individuals exhibiting challenging behavior may have shifted the use of such restrictive procedures from the provider to other sources.

The current regulations specify that, 'Restrains are prohibited, but an emergency safety intervention can be used in a situation where the individual is in danger of immediate jeopardy or harm. If there are disruptive or challenging behaviors displayed by an individual, then a safety and support plan must be developed utilizing the principles of positive behavioral supports' (see 404 NAC 4-005.03). An emergency safety intervention is defined as 'the use of physical restraint or separation as an immediate response to an emergency safety situation.' (See 404 NAC Chapter 2).

Thus, the regulations allow for restraint only as an emergency safety intervention. Research by Williams (2009) concerning the use of emergency versus planned restraint raises issues of safety for those involved. He analyzed data from a facility collected over a twelve month period regarding the use of planned physical, emergency physical, planned mechanical and emergency mechanical restraint. His results showed that for personal restraint, injuries occurred during 5.73% of the episodes when the restraints were used in emergency situations versus 0.25% when their use was planned. Similarly, with mechanical restraints, the rate was 3.60% for emergency use versus 0.42% when the use was planned. This research suggests that planning for the use of restraints for persons who have a history of requiring such interventions may be safer than assuming such interventions will not be needed in the future. Thus, while the authors are in support of efforts to eliminate the use of restraints, in cases where the use of restraint is currently likely it may be best to

ensure that staff know how to utilize such restraint to minimize the likelihood of injury to the individual or others.

In a similar vein, it is recommended that the exception in the DDD regulations allowing for restraint for medical procedures should be reconsidered. With planned or routine dental or medical interventions, there should be training for the individual to minimize the behaviors that require the use of restraint during medical procedures. If restraints are needed during routine medical procedures, then their use should be planned to minimize the likelihood of injury to either the individual or the medical practitioners.

Whether called an ‘emergency safety intervention’ or a ‘restraint’, it is important to continue to collect data on use of any physical or other intrusive interventions with people served by community-based developmental disabilities providers. Standardized definitions of any restrictive and coercive practices are needed, and data must be kept in order to track use of such practices. While reduction or elimination of restraint (or physical intervention used in an emergency) is an aim and efforts to implement positive behavior supports are being made, careful attention must be paid to other practices, such as time-out and other interventions that are punitive and/or reactive. While physical intervention is slated for reduction, attention must be paid to these other restrictive and/or coercive techniques to ensure that such practices do not increase. In addition, the use of psychotropic medications with this population must be monitored in order to ensure that, as utilization of some restrictive measures is reduced, others, such as chemical restraint, are not increased.

Relative to the use of restraints, the utilization of psychotropic medications appears to be quite high. While data of the prevalence is around 35-40% for community-based settings in the literature, the rate in Nebraska is over 50%. It was beyond the scope of this study to try to determine the relative level of mental illness in this population relative to the number of persons who are receiving medications to address challenging behavior. However, from the literature, the high end of prevalence for psychiatric disorders would suggest that there is a fairly high rate of usage of such medications to address challenging behaviors without a diagnosis of mental illness.

Another concern raised by this study is the high level of polypharmacy among people receiving developmental disabilities services. It appears that over 60% of the persons receiving psychoactive medication receive more than one medication. In addition, over 28% of the persons received more than one medication within a classification of psychotropic medication. Both of these figures appear to be quite high relative to the levels reported in the literature. As noted in a technical report from the National Association of State Mental Health Program Directors (2001) the negative consequences of polypharmacy include:

- Multiple medications increase the risk for medication-related adverse events and drug interactions
- Multiple medications creates a more complicated drug regimen for patients, making compliance more difficult

- Multiple medications may confound the effects on one another
- When medications are used to treat the side effects of other medications, polypharmacy potentially creates the need for more medications
- The costs of medications are expensive and the costs of the medication must be borne by the patient or another payer.

Given that medication data was reviewed for individuals receiving services under Medicaid waivers, it can be stated that medications were paid by Nebraska Medicaid. For the first quarter of 2011, the total cost for these medications was over 1.4 million dollars.

Mojtabai & Olfson (2010) looked at trends in psychiatric polypharmacy from 1996 to 2006. Their data was limited to patients seen in office-based psychiatric practices as reported on the National Ambulatory Medical Care Survey (NAMCS). Their results showed an increase in the percentage of persons with two or more psychotropic medications from 42.6% in 1996-1997 to 59.8% in the 2005-2006 period.

This study did not look into the dosages of medication nor did it look at the side effect profile of persons in services. It is recommended that there be a guideline for the use psychotropic medications beyond what is specified in the regulations. These guidelines should include expectations regarding the monitoring of side effects, including tardive dyskinesia. An example of such guidelines from South Carolina's Department of Disabilities and Special Needs is included in Appendix C. In addition, DDD may want to consider establishing a role in educating medical providers and others in the field on issues relative to polypharmacy and the use of psychotropic medications with this population.

Guidelines should also be developed for providing medical screens prior to the implementation of any behavioral or medication based interventions to address challenging behaviors. This should be a part of an initial functional analysis to determine the cause of the behavior. The authors have learned of other states' use of professional Applied Behavioral Analysis consultation paid as a separate service. Another option used in other states is behavioral consultation teams whose make-up includes a medical doctor, in addition to a psychiatrist, psychologist and behavior specialist. The teams provide a comprehensive evaluation of factors that may be affecting an individual's behaviors.

Another concern raised in the literature that should also be considered in Nebraska is whether behavioral interventions are properly and effectively employed. There is currently no provision to require providers who deal with challenging behaviors to employ staff who are trained and credentialed in applied behavior analysis. It is permissible under state regulations to allow Behavior Support Programs to be written and implemented by persons who have minimal training. There are also no activities that provide assurance that procedures are employed effectively or in a consistent manner. If interventions are not developed based on a comprehensive functional analysis and/or not monitored to ensure they are implemented as planned, they are likely to be ineffective (or their effect may only be attributed to serendipity.) While the use of medications is

documented and monitored to ensure the person received what was prescribed, there does not appear to be the same level of monitoring for behavioral interventions.

A concern that appears in the literature is the blending of values-based views with the research literature regarding the efficacy of procedures. While positive behavior support is gaining much support from those that serve individuals with developmental disabilities, there are concerns that it places much more emphasis on values and not enough on the research (Johnston, Foxx, Green, & Mulick, 2006). Research proponents are concerned that values may override decisions regarding questions of efficacy in determining procedures to treat individuals (Van Houten, et al., 1988). Proponents of Positive Behavior Support counter that the applied behavior analysts are too narrow in their view of valid research (Carr, et al., 2002). However, it should be noted that studies of the attitudes of experts in both PBS and ABA have shifted over time away from more intrusive, restrictive procedures (Brown, Michaels, Oliva, & Woolf, 2008)

It would seem more reasonable to avoid having the tug-of-war between the philosophical and empirically-based approaches to services. People with intellectual and developmental disabilities need the best services possible—that should be the expectation of the person who receives the service as well as those who pay for the service with tax dollars. As noted, practitioners of research-based methods have shifted away from more intrusive procedures as changes have occurred in the philosophical milieu surrounding the delivery of services to persons with intellectual disabilities. The two approaches are not incompatible, but merging the various points of view may require some study and effort. The results found by Robertson, et al. (2005) suggests that, at least in the situations they observed, there was not good application of sound behavioral principles. Indeed, a criticism of Positive Behavior Supports has been that it often uses parents and minimally trained staff to develop and implement behavioral interventions (Johnston, Foxx, Green, & Mulick, 2006). Good behavioral interventions need to be developed and overseen by someone who has adequate training and experience in applying such techniques.

A proposal that was developed some years ago between staff at the Division of Developmental Disabilities and the Department of Psychology at Munroe-Meyer Institute could serve as the basis for a program that merges philosophical and empirical-based approaches to effectively serve people with challenging behavior in Nebraska's community-based DD system. The proposal was to utilize Board Certified Behavior Analysts (BCBAs) to work with a small number of individuals as a part of the person's team. The BCBA would conduct the functional behavioral assessment and develop a positive behavior support (PBS) plan. They would also provide training to the staff serving the person and provide oversight of the implementation of the PBS plan, including making any needed revisions. To ensure inclusion of a person-centered approach, the plan would require individual consent. Without such consent, alternatives that have a probability of success, based on research literature, could be presented. The individual would have to select between the viable alternatives presented as a condition of receiving services. Thus, the person would have control and be able to direct their plan within the parameters of receiving services from DDD.

In this manner, empirically proven methods of effective treatment can be blended with the prevailing philosophy of services. The studies by (Singh, et al., 2006) and (Grey & McClean, 2007) demonstrated positive effects of changing the environment for persons receiving services by training staff in person-centered planning. We would hypothesize that the rate of the staff behaviors that could aggravate individuals challenging behavior would be lower than before the training was instituted. It is not enough just to train staff in what they are not supposed to do in working with persons with ID. There must also be training in how to positively interact with the people receiving services. However, it is not possible to determine the effectiveness of such interventions without having a system in place to monitor measure and evaluate the effectiveness of such procedures. This evaluation should include not only the satisfaction of the individual in service, but also the cost relative to the benefits to ensure effective stewardship of the funding for these services. Over time staff supports should decrease as their effectiveness increases.

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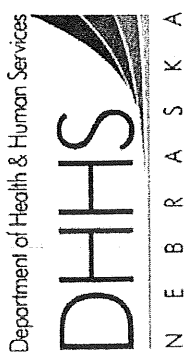
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Appendix A

DDD Specialized Service Definitions



DDD Specialized Services

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} These new service definitions are effective January 1, 2011 with the approval of the CMS waivers. }

Behavioral Risk Services

Note:

This subcategory falls under Provider Operated – Residential Services in 404 NAC

NFOCUS Service Code:

5034

Rate:

\$346.93/day

Definition:

Behavioral risk services are provided to individuals with complex behavioral needs that require continuing care and treatment. Behavioral risk services may be required when behaviors place the individual and/or others at risk of harm and may include actual, attempted, or threatened physical harm to oneself and/or others. This includes implicit threats, which is defined as statements and/or acts that reasonably induce fear of physical harm to others. Additionally, examples of behaviors placing oneself and/or others at risk of harm include self-directed actions intended to cause tissue damage, medication non-compliance, destruction of other people's belongings, elopement, and contact with the legal system for the previously mentioned behaviors, as well as other law-breaking behaviors (e.g., stealing, vandalism).

Behavioral risk services are provider-operated services, considered to be continuous (24/7) services, and include residential habilitation, day habilitation, intensive behavioral supports, ongoing safety supervision, and ongoing supports. The provision of behavioral risk services will be under the direction of a supervising mental health practitioner. Behavioral risk services are furnished as specified in the individual program plan. Staffing ratios are flexible and commensurate to meeting the needs of the individuals.

Intensive behavioral intervention strategies and supports require ongoing assessment, professional judgment, and treatment based on ongoing assessment. The provider must have a licensed independent mental health practitioner on staff to oversee the delivery of behavioral risk services by unlicensed direct support professionals.

Residential habilitation is formalized training and staff supports for the acquisition, retention, or improvement in skills related to living in the community. Formalized training, intensive behavioral supports, and staff supports include adaptive skill development of daily living activities, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, community inclusion, transportation, and the social and leisure skill development necessary to enable the individual to live in the most integrated setting appropriate to his/her needs.

Day habilitation is formalized training and staff supports which focus on the acquisition of work skills and appropriate work behavior. Behavioral risk day habilitation also includes intensive behavioral supports that focus on the behavioral and adaptive skills necessary to enable the individual to attain or maintain his or her maximum integration, inclusion, and personal accomplishment in the working community. Day habilitation services, such as prevocational workshops, workstations, vocational planning services, integrated community employment, or community integration supports are provided away from the home, in a non-residential setting, during typical working hours. Discreet habilitation in preparation for leaving the residential setting during typical working hours is allowed.

Intervention strategies for the delivery of residential habilitation, day habilitation, intensive behavioral supports, ongoing safety supervision, and ongoing supports are determined by the IPP team in conjunction with the supervising mental health practitioner and must be documented in the IPP. Interventions will be based on the individual's assessed needs and, as applicable, will include the following: staff objectives/ safety plans for preventing and/or stopping behaviors that are harmful to the individual or others; habilitation to address acceptable communication of needs and preferences, coping, social, and

problem-solving skills; residential and vocational settings, environmental and architectural factors, and location of service delivery; collaboration with behavioral health efforts to meet mental health needs (e.g., counseling, individual/ group psychotherapy, psychotropic medications); and supervision and monitoring strategies, including the type and amount of supervision, law enforcement contacts, provider monitoring responsibilities, and service coordination responsibilities. Restrictive interventions to ensure the safety of the individual and others must be reviewed at every IPP meeting. When applicable, a plan to reduce/eliminate the restriction must be developed, documented in the IPP, and upon request provided to DDD central office.

When determined appropriate by the IPP team and supervising practitioner, a plan to reduce the intensity of Behavioral Risk Services must be developed and upon request, provided to DDD central office.

Staff that provides a service for which a license, certification, or registration, or other credential is required must hold the license, certification, registration, or credential in accordance with applicable state laws.

Approval Process:

The need for behavioral risk services will be determined by designated staff at Division of Developmental Disabilities (DDD) central office. A risk screen is completed by the individual's IPP team to assist the team in planning, as a guide in giving adequate consideration to risk factors, or at the request of DDD central office. If the risk screen indicates an individual may present a risk of harm to oneself and/or others, the individual may be referred to DD central office for a formal risk assessment.

A risk assessment identifies, evaluates, and prioritizes interventions to implement or attempt to manage/reduce risk. The risk assessment will include the following: description, likelihood, frequency, duration, intensity, imminence, and incapacitation. Additionally, it includes an examination of the function of violence, for example, perceptual distortions, antisocial attitudes, irrational beliefs, labile affect, or interpersonal stressors. A risk assessment will also evaluate "buffering" conditions that reduce the likelihood of risk, for example, residential and day habilitation services, non-DD therapeutic services, an individual's personal strengths (e.g., motivation), support system (e.g., family and friends), ability to establish pro-social judgment, and history of adverse life events. If DDD central office staff concludes an individual presents a moderate to high risk of harm to oneself and/or others, the individual will be eligible for behavioral risk services. Should an individual present with a dual diagnosis of DD and MI and their risk is a result of issues stemming from Axis I, primary diagnosis of severe persistent mental illness, then the individual will be referred for behavioral health services. Behavioral risk services are not intended to supplant other behavioral health services such as, but not limited to psychiatry, counseling, or individual or group therapy.

Limits on the Amount, Frequency, or Duration of Behavioral Risk Services:

Behavioral risk services are not participant directed. The amount of authorized services for behavioral risk services may not be determined using the objective assessment process.

Payments for behavioral risk services are not made for room and board, the cost of facility maintenance, upkeep, and improvement.

Payment for behavioral risk services does not include payments made, directly or indirectly, to members of the individual's immediate family. Immediate family is defined as a parent (biological, step, or adoptive), spouse, or child (biological, step, or adopted) of the waiver participant. Payments will not be made for the routine care and supervision which would be expected to be provided by a family or group home provider, or for activities or supervision for which a payment is made by a source other than Medicaid.

The provision of behavioral risk services cannot overlap or supplant other state or federally funded services such as, but not limited, to respite services, Vocational Rehabilitation services, or Medicaid State Plan services. Behavioral risk services will not duplicate other services provided through this waiver.

Day Habilitation – Community Inclusion

Note:
This subcategory falls under Provider Operated – Residential Services in 404 NAC

Rate:
\$20.07/hour

NFOCUS Service Code:
2620

Definition:

Community inclusion day habilitation service is formalized training and staff supports for the acquisition, retention, or improvement in self-help, and behavioral, socialization, and adaptive skills which take place in the community during typical working hours, in a non-residential setting, separate from the individual's private residence or other residential living arrangement. Community inclusion day habilitation services are generally facility-free services and are provided to persons not currently seeking to join the general work force, participate in vocational planning services or prefer an alternative to prevocational workshop and/or workstation habilitation services. Habilitation activities and environments are designed to assist individuals in acquiring, retaining and improving skills, appropriate behavior, greater independence, and personal choice necessary to successfully integrate into his/her community. Habilitation services also include personal care, health maintenance activities, and protective oversight when applicable to the individual, as well as supervision.

Health maintenance activities, such as medication administration and treatments that are routine, stable, and predictable may be provided by medication aides and other unlicensed direct support professionals and require nurse or medical practitioner oversight of delegated activities to the extent permitted under applicable State laws. Health maintenance activities, supervision, and assistance with personal needs are provided when identified as a need and documented in the IPP. The habilitative services, supports, and strategies are documented in the IPP and delivered based on the IPP.

Transportation may be provided between the individual's place of residence and the site of the habilitation services or between habilitation sites (in cases where the individual receives habilitation services in more than one place) as a component part of habilitation services. The cost of this transportation is included in the rate paid to providers of the appropriate type of habilitation services.

Limits on the Amount, Frequency, or Duration of this Service:

The amount of authorized services is subject to the objective assessment process and is provided based on the individual's preferences to the extent possible, and as documented in the IPP.

The provision of this service cannot overlap with or supplant other state or federally funded services such as, but not limited to, respite services, Vocational Rehabilitation services, residential habilitation, or Medicaid State Plan services. This service will not duplicate other services provided through this waiver.

Day Habilitation – Integrated Community Employment

Note:
This subcategory falls under Individual Support Options – Day Services in 404 NAC

Rate:
\$37.21/hour

NFOCUS Service Code:
6581

Definition:

Integrated community employment (ICE) service is intermittent formalized training and staff supports - needed by an individual to acquire and maintain a job/position in the general workforce at or above the state's minimum wage. The outcome of this service is sustained paid employment in an integrated setting in the general workforce that meets personal and career goals, as documented in the individual program plan. ICE services are person-centered and team supported to address the individual's particular needs for ongoing or intermittent habilitation, throughout stabilization services and extended integrated community employment services and supports.

ICE services include habilitation that is outcome based and focused to sustain paid work by individuals and is designed to obtain, maintain or advance employment. Intensive direct habilitation will be designed to provide the individual with face to face instruction necessary to learn explicit work-related responsibilities and skills, as well as appropriate work behavior.

ICE services enable individuals, for whom competitive employment at or above the minimum wage is unlikely absent the provision of supports, and who, because of their disabilities, need supports, to perform in a regular work setting. Support may involve assisting the individual in accessing an Employment Network, the Nebraska Work Incentive Network (WIN), Ticket to Work services, Work Incentive Planning and Assistance (WIPA) services, or other qualified service programs that provide benefits planning.

ICE services are primarily provided away from the home, in a non-residential setting, during typical working hours and conducted in a variety of work settings, particularly work sites where persons without disabilities are employed. Discreet habilitation in preparation for leaving the residential setting during working hours is allowed. Intermittent face to face individualized habilitation is provided to assist the individual in maintaining employment. Habilitation goals and strategies must be identified in the individual plan and specify in a measurable manner, the services to be provided to meet the preferences and needs of the individual.

ICE services may include a customized home-based business. Habilitation services may be delivered in a customized home based businesses in participant directed companion homes.

ICE services do not include employment in group settings such as workstations or enclaves, classroom settings, or prevocational workshops. In addition, it does not include services provided in provider-controlled residential environments such as group homes or extended family homes. When integrated community employment services are provided at a work site where persons without disabilities are employed, payment is made to the provider only for the supervision and training required by individuals receiving waiver services as a result of their disabilities but does not include payment for the employer's supervisory activities rendered as a normal part of the business setting.

Stabilization is ongoing habilitation services needed to support and maintain an individual in an integrated competitive employment site or customized home-based employment. Stabilization supports are provided when the staff intervention time required at the job site is 20% - 50% of the individual's total work hours. Staff intervention includes regular contacts with the individual or on behalf of the individual to determine needs, as well as to offer encouragement and advice. Staff is intermittently available as needed to the individual during employment hours. Goals and strategies needed for the individual to maintain employment must be identified in the individual plan.

Extended ICE services are provided to persons who need ongoing intermittent support to maintain employment and when the staff intervention time required at the job site is less than 20% of the individual's total work hours. The provision of extended ICE is limited to the work site, including home-based business sites. Staff supports must include at a minimum, twice monthly monitoring at the work site. Extended ICE services must identify the services and supports needed to meet the needs of the individual in the IPP.

Prior to learning to access transportation independently, transportation between the individual's place of residence and the employment site is a component of vocational planning habilitation services and the cost of this transportation is included in the rate paid to providers.

Transportation may be provided between the individual's place of residence and the site of the habilitation services or between habilitation sites (in cases where the individual receives habilitation services in more than one place) as a component part of habilitation services. The cost of this transportation is included in the rate paid to providers of the appropriate type of habilitation services.

Limits on the Amount, Frequency, or Duration of this Service:

This service is not available under a program funded under section 110 of the Rehabilitation Act of 1973 or the Individuals with Disabilities Education Act (20 U.S.C. 1401 et seq.).

Payment does not include coverage of incentive payments, subsidies, or unrelated vocational training expenses such as the following:

- Incentive payments made to an employer to encourage or subsidize the employer's participation in a supported employment program;
- Payments that are passed through to users of supported employment programs; or
- Payments for training that is not directly related to an individual's integrated community employment services

The amount of authorized services is subject to the objective assessment process and is provided based on the individual's preferences and career goals as documented in the IPP.

The provision of this service cannot overlap with or supplant other state or federally funded services such as, but not limited to, respite services, Vocational Rehabilitation services, residential habilitation, or Medicaid State Plan services. This service will not duplicate other services provided through this waiver. ICE stabilization services require at least 40 hours of work per month paid at minimum wage or a wage consistent with that earned by the general working population, whichever is higher. DHHS will continue reimbursement at the ICE rate as long as the minimum total number of hours worked for the last three months (including the current month) is more than 120 hours of work (or an average of 40 or more hours per month for those three months). Multiple jobs that meet the wage requirements may be worked to reach 40 hours of employment per month.

Extended ICE services are time limited. Extended integrated community employment services require at least 80 hours of work per month paid at minimum wage or a wage consistent with that earned by the general working population, whichever is higher. DHHS will continue payment for the extended ICE services as long as the minimum total number of hours worked for the last three months (including the current month) is more than 240 hours of work (or an average of 80 or more hours per month for those three months). Multiple jobs that meet the wage requirements may be worked to reach 80 hours of employment per month. The provider may claim extended integrated community employment services for up to 24 months in order for the individual to meet their personal and career goals.

Income from customized home-based businesses may not be commensurate with minimum wage requirements with other employment. No more than two individuals may participate in a home-based business at the same participant-directed companion home.

Note:

This subcategory falls under Provider Operated – Day Services in 404 NAC

Rate:

\$25.09/hour, unless day and residential services by a single provider then a day rate is used.

NFOCUS Service Code:

6862

Day Habilitation – Prevocational Workshop Services

Definition:

Prevocational workshop habilitation services are formalized training and staff supports for the acquisition, retention, or improvement in self-help, behavioral, and adaptive skills which take place during typical working hours, in a non-residential provider-operated facility, separate from the individual's private residence or other residential living arrangement. Prevocational workshop habilitation services are provided to persons not currently seeking to join the general work force or participate in vocational planning services. Habilitation activities and environments are designed to assist individuals in acquiring, retaining and improving skills, appropriate behavior, greater independence, and personal choice necessary to reside successfully in the community. The habilitative services, supports, and strategies are documented in the IPP and delivered based on the IPP.

Prevocational workshop habilitation services prepare an individual for paid or unpaid work experiences and competitive employment. When compensated, individuals are generally paid at less than 50 percent of the minimum wage. Habilitation may include teaching such concepts as compliance, attendance, task completion, problem solving and safety. Services are generally not job-task oriented but instead are directed at underlying habilitative goals, such as attention span and motor skills, and not explicit employment objectives.

Prevocational workshop habilitation services will focus on enabling the individual to attain or maintain his or her maximum functional level and must be coordinated with but may not supplant any physical, occupational, or speech therapies listed in the IPP. In addition, habilitation services may reinforce skills taught in therapy, counseling sessions, or other settings. Habilitation also includes personal care, health maintenance activities, and protective oversight when applicable to the individual, as well as supervision.

Health maintenance activities, such as medication administration and treatments that are routine, stable, and predictable may be provided by medication aides and other unlicensed direct support professionals and require nurse or medical practitioner oversight of delegated activities to the extent permitted under applicable State laws. Health maintenance activities, supervision, and assistance with personal needs are provided when identified as a need and documented in the IPP.

Prevocational workshop habilitation services are delivered continuously and are normally furnished 4 or more hours per day on a regularly scheduled basis, for 1 or more days per week unless provided as an adjunct to other day activities included in the IPP.

Meals provided as part of these services do not constitute a full nutritional regimen and as applicable, physical nutritional management plans must be implemented as documented in the IPP.

Transportation may be provided between the individual's place of residence and the site of the habilitation services or between habilitation sites (in cases where the individual receives habilitation services in more than one place) as a component part of habilitation services. The cost of this transportation is included in the rate paid to providers of the appropriate type of habilitation services.

Limits on the Amount, Frequency, or Duration of this Service:

This service is not available under a program funded under section 110 of the Rehabilitation Act of 1973 or the Individuals with Disabilities Education Act (20 U.S.C. 1401 et seq.).

The amount of authorized services is subject to the objective assessment process and is provided based on the individual's preferences to the extent possible, and as documented in the IPP.

<p>The provision of this service cannot overlap or supplant with other state or federally funded services such as, but not limited to, respite services, Vocational Rehabilitation services, residential habilitation, or Medicaid State Plan services. This service will not duplicate other services provided through this waiver.</p>	<p>Note: This subcategory falls under Individual Support Options – Supported Day and Provider Operated – Day Services (3 or less person workstation) in 404 NAC</p>	<p>Rate: \$29.72/hour</p>	<p>NFOCUS Service Code: 6474</p>
<p>Day Habilitation – Vocational Planning Services</p>			
<p>Definition: Vocational planning habilitation services focus on enabling the individual to attain work experience through career planning, job searching, and paid and unpaid work experience with the goal or outcome of vocational planning being integrated community employment. Services are furnished as specified in the individual’s program plan. Vocational planning habilitation services are formalized training and staff supports which take place during typical working hours, in a non-residential setting, separate from the individual’s private residence or other residential living arrangement, such as within a business or a community setting where individuals without disabilities work or meet together. Discreet habilitation focused on job searching or in preparation for leaving the residential setting during typical working hours is allowed. Direct training and supports will be designed to provide the individual with face to face instruction necessary to learn work-related responsibilities, work skills, and appropriate work behavior. Vocational planning services focus on the acquisition of work skills, appropriate work behavior, and the behavioral and adaptive skills necessary to enable the individual to attain or maintain his or her maximum inclusion, inclusion, and personal accomplishment in the working community. Habilitation may include teaching such concepts as compliance, attendance, task completion, problem solving and safety as well as accessing transportation independently and explicit employment objectives. Vocational planning habilitation services also include personal care and protective oversight and supervision when applicable to the individual. The habilitative services, supports, and strategies are documented in the IPP and delivered based on the IPP. Vocational planning habilitation services may include career planning that is person-centered and team supported to address the individual’s particular needs to prepare for, obtain, maintain or advance employment. Habilitation services with focus on career planning includes development of self-awareness and assessment of skills, abilities, and needs for self-identifying career goals and direction, including resume or business plan development for customized home businesses. Assessment of skills, abilities, and needs is a person-centered team responsibility that engages all team members to support an individual in identifying a career direction and developing a plan for achieving integrated community employment at or above the state’s minimum wage. The outcome is documentation of the individual’s stated career goals and career direction and strategies for the acquisition of skills and abilities needed for work experience in preparation for integrated community employment. Establishment of career goals may not take place at the same time as other vocational planning activities. Habilitation services with focus on career planning and strategies for implementing career goals may involve assisting the individual in accessing an Employment Network, the Nebraska Work Incentive Network (WIN), Ticket to Work services, Work Incentive Planning and Assistance (WIPA) services, or other qualified service programs that provide benefits planning.</p>			

Vocational planning habilitation services may include job searching designed to assist the individual or on behalf of the individual to locate a job or development of a work experience on behalf of the individual. Job searching may take place in the individual's private residence, in integrated community settings, or in provider staff office areas. Job searching may not take place in a fixed-site sheltered workshop facility in the areas where other individuals are receiving prevocational workshop habilitation services. Job searching with the individual will be provided on a one to one basis to achieve the outcome of this service.

Vocational planning habilitation services may include work experiences that are paid part-time employment, workstations or enclaves, or unpaid experience such as volunteering, apprenticing, interning, job shadowing, etc. A work experience takes place during typical working hours, in a non-residential setting, separate from the individual's private residence or other residential living arrangement, with the focus on attaining the outcome of integrated community employment. Habilitation provided during a work experience may include teaching such concepts as compliance, attendance, task completion, problem solving, and safety as well as accessing transportation independently and explicit employment objectives.

Prior to learning to access transportation independently, transportation between the individual's place of residence and the employment site is a component of vocational planning habilitation services and the cost of this transportation is included in the rate paid to providers.

Transportation may be provided between the individual's place of residence and the site of the habilitation services or between habilitation sites (in cases where the individual receives habilitation services in more than one place) as a component part of habilitation services.

Vocational planning habilitation services may take place in conjunction with integrated community employment services, workstation habilitation services, community inclusion day habilitation or other day activities.

Limits on the Amount, Frequency, or Duration of this Service:

This service is not available under a program funded under section 110 of the Rehabilitation Act of 1973 or the Individuals with Disabilities Education Act (20 U.S.C. 1401 et seq.).

The amount of authorized services is subject to the objective assessment process and is provided based on the individual's preferences to the extent possible, and as documented in the IPP.

The provision of this service cannot overlap with or supplant other state or federally funded services such as, but not limited to, respite services, Vocational Rehabilitation services, residential habilitation, or Medicaid State Plan services. This service will not duplicate other services provided through this waiver. Some components of vocational planning habilitation services are time-limited. Establishment of career goals through career planning may not exceed three months. If the outcome of career planning is not reached within three months, a team meeting must be held to change the service plan. Unpaid work experiences must lead to paid employment and are therefore time-limited. Work experiences for which the general population is paid to perform may not last beyond six months. Volunteering to provide services and supports in an integrated community setting for which the general population does not get paid to perform are not considered to be a work experience and are not time-limited.

No more than three individuals may participate in the same paid or unpaid work experience at the same time.

Day Habilitation – Workstation Services

Note:
This subcategory falls under Provider Operated – Residential Services in 404 NAC

Rate:
\$25.09/hour, unless day and residential services by a single provider then a day rate is used.

NFOCUS Service Code:
8997

Definition:

Workstation habilitation services are formalized training and staff supports for the acquisition, retention, or improvement in self-help, behavioral, and adaptive skills which takes place during typical working hours, in a non-residential setting, separate from the individual’s private residence or other residential living arrangement, such as within a business or a community setting where individuals without disabilities work or meet together. Discreet habilitation in preparation for leaving the residential setting during typical working hours is allowed.

Workstation habilitation services focus on the acquisition of work skills, appropriate work behavior, and the behavioral and adaptive skills necessary to enable the individual to attain or maintain his or her maximum inclusion, inclusion, and personal accomplishment in the working community. This day habilitation service also includes personal care, health maintenance activities, and protective oversight when applicable to the individual, as well as supervision.

Health maintenance activities, such as medication administration and treatments that are routine, stable, and predictable may be provided by medication aides and other unlicensed direct support professionals and require nurse or medical practitioner oversight of delegated activities to the extent permitted under applicable State laws. Health maintenance activities, supervision, and assistance with personal needs are provided when identified as a need and documented in the IPP. The habilitative services, supports, and strategies are documented in the IPP and delivered based on the IPP.

Workstation habilitation services are delivered continuously and provide paid work experiences in preparation for competitive employment. Habilitation may include teaching such concepts as compliance, attendance, task completion, problem solving, and safety as well as accessing transportation independently and explicit employment objectives.

Transportation may be provided between the individual’s place of residence and the site of the habilitation services or between habilitation sites (in cases where the individual receives habilitation services in more than one place) as a component part of habilitation services. The cost of this transportation is included in the rate paid to providers of the appropriate type of habilitation services.

Limits on the Amount, Frequency, or Duration of this Service:

This service is not available under a program funded under section 110 of the Rehabilitation Act of 1973 or the Individuals with Disabilities Education Act (20 U.S.C. 1401 et seq.).

The amount of authorized services is subject to the objective assessment process and is provided based on the individual’s preferences to the extent possible, and as documented in the IPP.

The provision of this service cannot overlap with or supplant other state or federally funded services such as, but not limited to, respite services, Vocational

Rehabilitation services, residential habilitation, or Medicaid State Plan services. This service will not duplicate other services provided through this waiver.		Note: This subcategory falls under Provider Operated – Day and Residential Services in 404 NAC	Rate: \$437.42/day	NFOCUS Service Code: 5578
<h2 style="text-align: center;">Medical Risk Services</h2>				
<p>Definition:</p> <p>Medical risk services are provided to individuals with complex medical needs that require continuing care and treatment but are not assessed to need continuous nursing facility level of care. Complex medical needs may result from the diagnoses of some types of diabetes or seizures or may result from use of g-tubes, g-buttons, j-tubes, tracheotomies, ventilators, or a combination of the above. Treatment or interventions to meet complex medical needs require ongoing clinical assessment, professional judgment, and treatment based on ongoing assessment and cannot be delegated to unlicensed direct support professionals.</p> <p>Medical risk services are also available to individuals who have a degenerative/regressive condition diagnosed by the individual’s medical practitioner and that make further growth or development unlikely. The degenerative/regressive condition requires continuing care and treatment, <u>and</u> significantly impedes independent completion of activities of daily living, <u>and</u> impedes self-directing others to perform activities of daily living. Degenerative or regressive conditions that affect all areas of daily living activities may include cerebral palsy, muscular dystrophy, multiple sclerosis, post-polio syndrome, dementia, Parkinson’s disease, Huntington’s disease, Alzheimer’s, or other neurological impairments.</p> <p>Medical risk services are provided 24/7, considered to be continuous services, and include residential habilitation, day habilitation, health maintenance activities, routine complex medical treatments, ongoing health and safety supervision, and ongoing supports. Physical nutritional management plans must be implemented as applicable.</p> <p>Residential habilitation services are formalized training and staff supports for the acquisition, retention, or improvement in skills related to living in the community. Formalized training and staff supports include adaptive skill development of daily living activities, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, community inclusion, transportation, and the social and leisure skill development necessary to enable the individual to live in the most integrated setting appropriate to his/her needs. Residential habilitation also includes personal care and protective oversight when applicable as well as supervision.</p> <p>Day habilitation services, such as prevocational workshops, workstations, vocational planning services, integrated community employment, or community inclusion are provided away from the home unless prescribed to be medically necessary by the individual’s physician and approved by DDD central office, and are provided during typical working hours to increase the person’s independence, integration, inclusion, personal accomplishment, and employment objectives, as applicable. Day habilitation services are formalized training and supports, which focus on enabling the individual to attain or maintain his or her maximum functional level and must be coordinated with but may not supplant any physical, occupational, or speech therapies in the IPP. The habilitative training and supports may include workplace training, increasing socialization and recreational skills and abilities in the community, and skills to assist in access to and integration in their community. Day habilitation also includes personal care and protective oversight when applicable as well as supervision.</p> <p>Health maintenance activities, such as medication administration and treatments that are routine, stable, and predictable may be provided by medication aides and other unlicensed direct support professionals and require nurse or medical practitioner oversight of delegated activities to the extent permitted under applicable State laws. Health maintenance activities, supervision, and assistance with personal needs are not an exclusive component of medical risk services and are provided when identified as a need and documented in the IPP.</p>				

Assistance with personal needs may include toileting, transfer and ambulation, skin care, bathing, dressing, grooming, meal preparation, eating, extension of therapies and exercise, and routine care of adaptive equipment primarily involving cleaning as needed.

Treatments or interventions to meet complex medical needs or address degenerative conditions are outlined in a nursing plan and included in the person's IPP. Health and safety factors including the type and amount of supervision, environmental conditions, weather conditions, architectural conditions, special diets, and safe evacuation plans are included in the IPP as applicable to the individual.

Medical risk providers must have a sufficient number of Registered Nurses on staff or under contract to develop nursing plans, provide complex medical treatments, train unlicensed direct support professionals, and oversee delegation of health maintenance activities to the extent permitted under applicable state laws.

Staff that provides a service for which a license, certification, or registration, or other credential is required must hold the license, certification, registration, or credential in accordance with applicable state laws.

Approval Process:

The need for medical risk services will be determined by designated staff at Division of Developmental Disabilities (DDD) central office. A referral is completed by the individual's IPP team to assist the team in planning, as a guide in giving adequate consideration to health and medical factors, or at the request of DDD central office. When the team, which may include the individual's physician, believes that the individual's needs require medical risk services, the individual may be referred to DD central office for a formal health assessment.

Limits on the Amount, Frequency, or Duration of this Service:

Medical risk services are not participant directed. The amount of authorized services for medical risk services may not be determined using the objective assessment process.

Complex medical treatments require ongoing assessment, professional judgment, and treatment based on ongoing assessment and can only be delegated to unlicensed direct support professionals to the extent permitted under Neb. Rev. Statute § 71-1, 132.30.

Payments for medical risk services are not made for room and board, the cost of facility maintenance, upkeep, and improvement.

Payment for medical risk services does not include DDD payments made, directly or indirectly, to members of the individual's immediate family. Immediate family is defined as a parent (biological, step, or adoptive), spouse, or child (biological, step, or adopted) of the waiver participant. Payments will not be made for the routine care and supervision which would be expected to be provided by a family or group home provider, or for activities or supervision for which a payment is made by a source other than Medicaid.

The provision of medical risk services cannot overlap with or supplant other state or federally funded services such as, but not limited to respite services, Vocational Rehabilitation services, or Medicaid State Plan services. Medical risk services will not duplicate other services provided through this waiver.

Residential Habilitation – Extended Family Home Services

Note: This subcategory falls under Individual Support Options – Supported Living and Provider Operated – Residential Services in 404 NAC and CDD in 175 NAC	NFOCUS Service Code: 4824
Rate: \$26.77/hour, unless individual Daily Rate when day and residential services by a single provider	NFOCUS Service Code: 4824

Definition:

Extended family home residential habilitation service is formalized training and staff supports for the acquisition, retention, or improvement in skills related to living in the community. Formalized training and staff supports include adaptive skill development of daily living activities, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, community inclusion, transportation, and the social and leisure skill development necessary to enable the individual to live in the most integrated setting appropriate to his/her needs. Residential habilitation also includes personal care and protective oversight as applicable to the individual as well as supervision.

Health maintenance activities, such as medication administration and treatments that are routine, stable, and predictable may be provided by medication aides and other unlicensed direct support professionals and require nurse or medical practitioner oversight of delegated activities to the extent permitted under applicable State laws. Health maintenance activities, supervision, and assistance with personal needs are provided when identified as a need and documented in the IPP.

Residential Habilitation services provided in a single family home setting are called extended family home (EFH) residential habilitation services. EFH residential habilitation services are delivered as an employee of the DD provider agency or under a subcontract with a DD provider agency and are continuous services.

EFH residential habilitation services are services provided in a setting where the individual and the EFH provider resides and the EFH provider is on-site and immediately available at all times to the individual receiving services, including during the individual's sleep time. The EFH provider must be present and awake during the times the individual is present and awake. Eight hours of overnight staffing are not billable. The EFH provider may be sleeping, unless awake overnight supervision or assistance is required as documented in the individual's program plan, and must be present to respond immediately to individuals' needs and emergencies. Overnight staffing may or may not provide formal training or intervention when the person awakens during the night. The need for formal training or interventions during overnight hours is based on the individual's assessed needs, and how the needs will be addressed, which may include explicit formal training or interventions, assistance with personal needs, and/or health maintenance activities must be documented in the Individual Program Plan.

Limits on the Amount, Frequency, or Duration of this Service:

An EFH may qualify as a supported living option. For a supporting living option, it must be a residence for no more than two individuals with DD, owned or leased by the subcontractor providing supports. The individual is his/her own payee or representative payee and pays room and board directly to the EFH provider. The agency must not own the residence when the EFH provider is engaged as a subcontractor or employee of the agency.

An EFH may also qualify as a provider operation option. For the provider operation option more than two individuals with DD may live in the residence.

Payments for residential habilitation are not made for room and board, the cost of facility maintenance, upkeep and improvement. Payment for residential habilitation does not include payments made, directly or indirectly to members of the individual's immediate family, defined as parent (biological, step, or adoptive), spouse, or child (biological, step, or adopted). Payments will not be made for the routine care and supervision which would be expected to be provided by a family or group home provider, or for activities or supervision for which a payment is made by a source other than Medicaid. The amount of authorized services is subject to the objective assessment process and is provided based on the individual's preferences to the extent possible, and as documented in the IPP.

The provision of residential habilitation cannot overlap with or supplant other state or federally funded services such as, but not limited to respite services, Vocational Rehabilitation services, day habilitation, or Medicaid State Plan services. Residential habilitation services will not duplicate other services provided through this waiver.

Residential Habilitation – Group Home Services

Note:
This subcategory falls under Provider Operation - Residential Services in 404 NAC and CDDs in 175 NAC

Rate:
\$26.77/hour, unless Individual Daily Rate when residential services by a single provider

NFOCUS Service Code:
2026

Definition:

Group home residential habilitation services are formalized training and staff supports for the acquisition, retention, or improvement in skills related to living in the community. Formalized training and staff supports include adaptive skill development of daily living activities, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, community inclusion, transportation, and the social and leisure skill development necessary to enable the individual to live in the most integrated setting appropriate to his/her needs. Residential habilitation also includes personal care, health maintenance activities, and protective oversight when applicable to the individual, as well as supervision.

Health maintenance activities, such as medication administration and treatments that are routine, stable, and predictable may be provided by medication aides and other unlicensed direct support professionals and require nurse or medical practitioner oversight of delegated activities to the extent permitted under applicable State laws. Health maintenance activities, supervision, and assistance with personal needs are provided when identified as a need and documented in the IPP.

Group home residential habilitation services are continuous services and are delivered in provider operated or controlled settings, such as a home with three or less individuals with DD, or a licensed Center for persons with Developmental Disabilities (CDD) with four or more individuals with DD. Rental agreements with and payment for room and board to a DD provider must be treated as landlord-tenant agreements and all applicable state and local laws must be followed.

Continuous group home residential habilitation services are services provided in a provider operated setting where there are DD provider staff on-site or within proximity to allow immediate on-site availability at all times to the individual receiving services, including during the individual's sleep time. Staff must be

present and awake during the times that individuals are present and awake. Eight hours of overnight staffing are not billable. Staff may be sleeping, unless awake overnight supervision or assistance is required as documented in the individual's program plan, and must be present to respond immediately to individuals' needs and emergencies. Overnight staffing may or may not provide formal training or intervention when the person awakens during the night. The need for formal training or interventions during overnight hours is based on the individual's assessed needs, and how the needs will be addressed, which may include explicit formal training or interventions, assistance with personal needs, and/or health maintenance activities must be documented in the Individual Program Plan.

Limits on the Amount, Frequency, or Duration of this Service:

Payments for residential habilitation are not made for room and board, the cost of facility maintenance, upkeep and improvement. Payment for residential habilitation does not include payments made, directly or indirectly to members of the individual's immediate family, defined as parent (biological, step, or adoptive), spouse, or child (biological, step, or adopted). Payments will not be made for the routine care and supervision which would be expected to be provided by a family or group home provider, or for activities or supervision for which a payment is made by a source other than Medicaid. The amount of authorized services is subject to the objective assessment process and is provided based on the individual's preferences to the extent possible, and as documented in the IPP.

The provision of residential habilitation cannot overlap with or supplant other state or federally funded services such as, but not limited to respite services, Vocational Rehabilitation services, day habilitation, or Medicaid State Plan services. Residential habilitation services will not duplicate other services provided through this waiver.

Residential Habilitation – In-Home Services

Note:

This subcategory falls under Individual Support Options – Supported Living in 404 NAC

Rate:

\$29.72/hour

NFOCUS Service Code:

6933

Definition:

Residential habilitation is formalized training and staff supports for the acquisition, retention, or improvement in skills related to living in the community. Formalized training and staff supports include adaptive skill development of daily living activities, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, community inclusion, transportation, and the social and leisure skill development necessary to enable the individual to live in the most integrated setting appropriate to his/her needs. Residential habilitation may also include personal care, protective oversight, and supervision as applicable to the individual when provider staff is present.

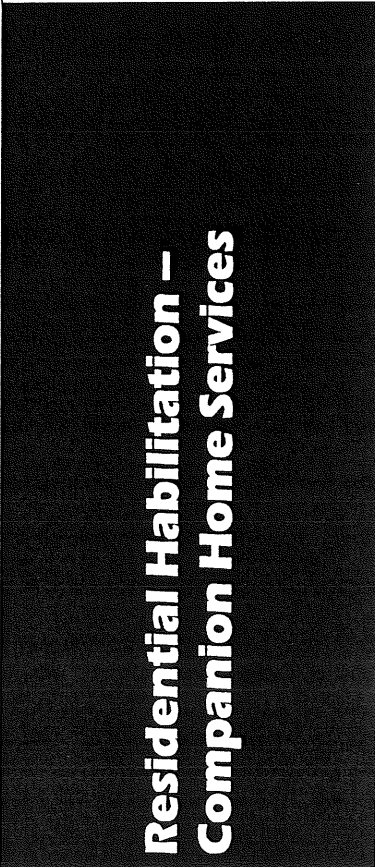
Residential Habilitation services provided to a participant living in his/her family home are called in-home residential habilitation services and are intermittent services. Community based DD provider staff is intermittently available to deliver habilitation to the person receiving services in the family home or in the community. Training and supports are designed to provide the individual with face to face habilitation.

Limits on the Amount, Frequency, or Duration of this Service:

Payments for residential habilitation are not made for room and board, the cost of facility maintenance, upkeep and improvement.

Payment for residential habilitation does not include payments made, directly or indirectly to members of the individual's immediate family, defined as parent (biological, step, or adoptive), spouse, or child (biological, step, or adopted). Payments will not be made for the routine care and supervision which would be expected to be provided by a family or group home provider, or for activities or supervision for which a payment is made by a source other than Medicaid. The amount of authorized services is subject to the objective assessment process and is provided based on the individual's preferences to the extent possible, and as documented in the IPP.

The provision of residential habilitation cannot overlap with or supplant other state or federally funded services such as, but not limited to respite services, Vocational Rehabilitation services, day habilitation, or Medicaid State Plan services. Residential habilitation services will not duplicate other services provided through this waiver.



Residential Habilitation – Companion Home Services

Note:
This subcategory falls under Individual Support Options – Supported Living in 404 NAC

Rate:
\$29.72/hour for Intermittent Service
\$26.77/hour for Continuous Service
Individual Daily Rate if day and residential services by single provider

NFOCUS Service Code:
8244

Definition:

A companion home is a supported living option in Nebraska. Supported living is defined as residential habilitation provided to no more than two other individuals (3 individuals total) in a residence that is under the control and direction of the individual(s).

Companion home services consist of residential habilitation delivered as formalized training and staff supports for the acquisition, retention, or improvement in skills related to living in the community. Formalized training and staff supports include adaptive skill development of daily living activities, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, community inclusion, transportation, and the social and leisure skill development necessary to enable the individual to live in the most integrated setting appropriate to his/her needs. Residential habilitation may also include personal care, protective oversight, and supervision as applicable to the individual when provider staff is present.

Health maintenance activities, such as medication administration and treatments that are routine, stable, and predictable may be provided by medication aides and other unlicensed direct support professionals and require nurse or medical practitioner oversight of delegated activities to the extent permitted under applicable State laws. Health maintenance activities, supervision, and assistance with personal needs are provided when identified as a need and documented in the IPP.

Companion home residential habilitation services may be delivered intermittently or continuously. A companion home may be an apartment, a house, a condominium, or a townhouse which the individual owns or rents. The provider of residential habilitation services in a companion home must be able to document that the individual freely chose their residential setting and housemates and that the lease or mortgage is under the control of the individual. The owner or lessee of the property must be unrelated, directly or indirectly, to the provider of services.

Continuous companion home residential habilitation services are services provided in a setting where the provider staff is on-site and immediately available at all times to the individual receiving services, including during the individual's sleep time to respond immediately to individuals' needs and emergencies. The provider staff must be present and awake during the times that individuals are present and awake. Eight hours of overnight staffing are not billable. The

provider staff may be sleeping, unless awake overnight supervision, health maintenance activities, or assistance with personal needs is required or requested and is documented in the individual's program plan.
 Companion home residential habilitation may be delivered intermittently. Community based DD provider staff is intermittently in the home to deliver face to face habilitation to the person receiving services. Intermittent companion home residential habilitation services are based on the individual's preferences and assessed needs, and must be documented in the Individual Program Plan.

Limits on the Amount, Frequency, or Duration of this Service:

Payments for residential habilitation are not made for room and board, the cost of facility maintenance, upkeep and improvement.

Payment for residential habilitation does not include payments made, directly or indirectly to members of the individual's immediate family, defined as parent (biological, step, or adoptive), spouse, or child (biological, step, or adopted). Payments will not be made for the routine care and supervision which would be expected to be provided by a family or group home provider, or for activities or supervision for which a payment is made by a source other than Medicaid. The amount of authorized services is subject to the objective assessment process and is provided based on the individual's preferences, to the extent possible, as documented in the IPP.

The provision of residential habilitation cannot overlap with or supplant other state or federally funded services such as, but not limited to respite services, Vocational Rehabilitation services, day habilitation, or Medicaid State Plan services. Residential habilitation services will not duplicate other services provided through this waiver.

Respite Services

Note:

This falls under Respite in 404 NAC and can be under Individual Support Options – Supported Living and Provider Operated – Residential Services in 404 NAC

Rate:

\$13.73/hour OR \$109.78 when 8 hours or more in a 24 hour period

NFOCUS Service Code:

3214

Definition:

Respite is the temporary, intermittent relief to the usual non-paid caregiver(s) from the continuous support and care of the individual to allow the caregiver to pursue personal, social, and recreational activities such as personal appointments, shopping, attending support groups, club meetings, and religious services, or going to entertainment or eating venues, and on vacations. Components of the respite service are supervision, tasks related to the individual's physical and psychological needs, and social/recreational activities. Services are provided on a short-term basis because of the absence or need for relief of those unpaid persons who normally provide care for the individual. These services may be provided in the individual's living situation and/or in the community.

Provider Qualifications:

Respite Agency:

- 1) As defined in Neb. Rev. state statutes 71-401 to 71-459.
- 2) Staff or agencies that provide a service for which a license, certification, or registration, or other credential is required must hold the license, certification, registration, or credential in accordance with applicable state laws and regulations.
- 3) 175 NAC 15-000
- 4) All respite provider agencies must meet applicable regulatory requirements.
- 5) All waiver providers must be Medicaid providers as defined in 471 NAC 2-000.

Contract Community Based DD Provider Agency:

Provider staff and/or agencies that provide a service for which a license, certification, or registration, or other credential is required must hold the license,

certification, registration, or credential in accordance with applicable state laws and regulations.

The CBDD provider agency must be a certified and contracted provider.

All providers of waiver services must be a Medicaid provider as specified in Nebraska Administrative Code Title 471. (471 NAC 2-000)

A provider of respite must:

1. Be age 18 or older;
2. Not be a member of the individual's immediate household;
3. Have knowledge of basic first aid skills and of emergency responses;
4. Agree never to leave the individual alone;
5. Prepare and serve any appropriate meals and/or snacks to meet the individual's dietary needs, as explained by the usual caregiver; and
6. Not be the parent, spouse, or child (biological, step, or adopted) of the participant.
7. Be authorized to work in the United States.

When respite is provided in a community based residential setting such as a group home or extended family home, the CBDD provider may not claim for the cost of room and board.

Independent Provider:

Licensing, credentialing, or certification is not a requirement to be a qualified individual respite provider.

All providers of waiver services must be Medicaid providers as described in 471 NAC 2-000.

A provider of Respite must:

1. Be age 18 or older;
2. Not be a member of the individual's immediate household;
3. Have knowledge of basic first aid skills and of emergency responses;
4. Agree never to leave the individual alone;
5. Prepare and serve any appropriate meals and/or snacks to meet the individual's dietary needs, as explained by the usual caregiver; and
6. Not be the parent, spouse, or child (biological, step, or adopted) of the participant.
7. Be authorized to work in the United States.

If Respite is provided outside of the family home, it is recommended that the family visit the facility or home in which the service is to be provided and agree to the provision of services in that location. The provider must ensure that:

1. The home/facility is architecturally designed to accommodate the needs of the individuals being served;
2. An operable phone and emergency phone numbers are available;
3. The home/facility is accessible to the individual, clean, in good repair, free from hazards, and free of rodents and insects;
4. The home/facility is equipped to provide comfortable temperature and ventilation conditions.
5. The toilet facilities are clean and in working order;
6. The eating areas and equipment are clean and in good repair;
7. The home/facility is free from fire hazards;
8. The furnace and water heater are located safely;
9. Firearms are in a locked unit;
10. Medications and poisons are inaccessible; and
11. Household pets have all necessary vaccinations.

All providers of waiver services who have direct contact with the individual receiving services must:

1. Provide services in a manner demonstrating acceptance of, respect for, and a positive attitude toward people who are disabled;
2. Have training or experience in the performance of the service(s) being provided and be able to perform the tasks required for the individual's needs;
3. Obtain adequate information on the supports necessary to meet the medical and personal needs of the individual;
4. Observe and report all changes which affect the individual and/or the individual's plan to the service coordinator, taking action as necessary;
5. Have knowledge and understanding of the needs of individuals with intellectual or developmental disabilities;
6. Exhibit the capacity to:
 - a) Assume responsibility;
 - b) Follow emergency procedures;
 - c) Maintain schedules; and
 - d) Adapt to new situations.
7. Protect the confidentiality of the individual's and family's information;
8. Accept responsibility for the individual's safety and/or property;
9. Exercise universal precautions in the delivery of services, have the physical capability to provide the service, and provide a physician's verification statement, if requested;
10. Continue to meet all applicable service-specific standards; and
11. Operate a drug-free workplace.

When respite is provided in a private residence, the independent provider may not claim for the cost of room and board.

Limits on the Amount, Frequency, or Duration of this Service:

Respite is available only to those individuals who live with their usual non-paid caregiver(s). The term "usual non-paid caregiver" means a person who resides with the individual, is not paid to provide services, and is responsible on a 24-hour per day basis for the care and supervision of the individual. Payment for respite does not include payments made, directly or indirectly to members of the individual's immediate family, defined as parent (biological, step, or adoptive), spouse, or child (biological, step, or adopted).

Respite services cannot be used as adult/child care while the parents work or attend school.

The amount of authorized services for respite services is not determined using the objective assessment process.

Respite cannot be provided by members of the individual's immediate household.

All waiver services and providers must be prior authorized within the following guidelines:

1. The tasks and interventions to be performed to meet the needs of the individual are documented in the IPP.
 2. For respite services, a unit is defined as an hour, or if eight or more hours are provided in a calendar day, a day. Respite cannot exceed 30 days per state fiscal year;
 3. Unused respite hours are not carried over into the next waiver year; and
 4. Respite funding is available from one DHHS program source only.
- Federal financial participation is not claimed for the cost of room and board.

Retirement Services

	<p>Note: This falls under Individual Support Options – Day and Supported Living and Provider Operated Day and Residential in 404 NAC and under CDD in 175 NAC</p>	<p>Rate: \$17.56/hour \$87.80/day Individual Daily Rate when provided as a continuous service by one provider</p>	<p>NFOCUS Service Code: 5207</p>
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Definition:

Retirement services are available to individuals who are usually 62 years or older and who have chosen to end employment or participation in day habilitation services. Retirement services are also available to individuals who are 62 years or older and are no longer able to be employed or participate in day habilitation services due to physical disabilities or stamina. Retirement services are structured services consisting of day activities and residential support. Retirement services are provided in a home setting or community day activity setting and may be provided as a day service or a residential service. Retirement services may be self-directed or provider controlled. The outcome of retirement services is to treat each person with dignity and respect, and to the maximum extent possible maintain skills and abilities, and to keep the person engaged in their environment and community through optimal care and support to facilitate aging within the person’s home and community.

Retirement services and supports are designed to actively stimulate, encourage and enable active participation; develop, maintain, and increase awareness of time, place, weather, persons, and things in the environment; introduce new leisure pursuits, establish new relationships; improve or maintain flexibility, mobility, and strength; develop and maintain the senses; and to maintain and build on previously learned skills.

Active supports must be furnished in a way which fosters the independence of each individual. Strategies for the delivery of active supports must be person centered and person directed to the maximum extent possible and is identified in the IPP.

Retirement services and supports may include personal care, protective oversight, and supervision as applicable to the individual when provider staff is present. Health maintenance activities, such as medication administration and treatments that are routine, stable, and predictable may be provided by medication aides and other unlicensed direct support professionals and require nurse or medical practitioner oversight of delegated activities to the extent permitted under applicable State laws. Health maintenance activities, supervision, and assistance with personal needs are provided when identified as a need and documented in the IPP.

Retirement services may be provided as a continuous or intermittent service. Continuous day service activities are provided for five or more hours per day and delivered in a non-institutional, community setting that may include people without disabilities. Retirement day settings cannot be set up or operated by a DD provider in communities where an existing community senior center or facilities geared for people who are elderly, such as an adult day care center are available. DD provider-operated retirement day settings must be made available to people without disabilities.

Continuous retirement residential supports are provided for five or more hours per day and may be provided in a supported living companion homes or provider operated residences. A supported living companion home has no more than two other individuals with developmental disabilities and is under the control and direction of the individual(s). The home or residence must be in an integrated community setting.

When retirement services are delivered in a provider operated residence, there must be staff on-site or within proximity to allow immediate on-site availability at all times to the individual receiving services, including during the individual's sleep time. Staff must be available to meet scheduled or unpredictable needs in a way that promotes maximum dignity and independence, to provide supervision, safety and security, and to provide activities to keep the person engaged in their environment.

The personal living space and belongings of others must not be utilized by others receiving retirement services. When retirement services are delivered in residences, only shared living spaces such as the living room, kitchen, bathroom, and recreational areas may be utilized, and when retirement services are delivered to two or more individuals, different residences must be utilized on a rotating basis.

Transportation into the community to shop, attend recreational and civic events, go to the senior center, adult day care center, or other community activities is a component of retirement services and is included in the rate to providers. It shall not replace transportation that is already reimbursable under the Medicaid non-emergency medical transportation program. The IPP planning team must also assure the most cost effective means of transportation, which would include public transport where available. Transportation by the provider is not intended to replace generic transportation or to be used merely for convenience.

Limits on the Amount, Frequency, or Duration of this Service:

The amount of authorized services for retirement services may not be determined using the objective assessment process.

Payments for retirement services are not made for room and board, the cost of facility maintenance, upkeep, and improvement.

Meals provided as part of retirement services and supports do not constitute a "full nutritional regimen" (3 meals per day).

Payment for retirement services does not include payments made, directly or indirectly, to members of the individual's immediate family. Immediate family is defined as a parent (biological, step, or adoptive), spouse, or child (biological, step, or adopted) of the waiver participant.

Payments will not be made for the routine care and supervision which would be expected to be provided by a family or group home provider, or for activities or supervision for which a payment is made by a source other than Medicaid.

Retirement day supports cannot duplicate or replace existing natural supports, senior centers, adult day care centers, or other community activity centers in the communities in which the person resides.

The provision of this service cannot overlap with or supplant other state or federally funded services such as, but not limited to, respite services, Vocational Rehabilitation services, residential habilitation, or Medicaid State Plan services. This service will not duplicate other services provided through this waiver.

*Retirement Services cannot be utilized for an individual receiving any habilitation services.

Team Behavioral Consultation Services

Note:
CMS approved waiver service

Rate:
\$3,371

NFOCUS Service Code:
TBD

Definition:

Team behavioral consultation is on-site consultation by highly specialized teams with behavioral and psychological expertise when individuals with DD experience psychological, behavioral, or emotional instability which has been resistant to other standard rehabilitative interventions and strategies that have been attempted by the individual's IPP team. Sometimes in rural areas of the state, community resources, such as psychologists or psychiatrists are not readily available to consult with or participate in meetings, or have very little experience with treating individuals with DD. Team behavioral consultation service may be requested by the IPP team or directed by DDD central office and the need for the service is reflected in the IPP.

Team behavioral consultation (TBC) service includes reviewing referral information, an entrance conference, on-site observations, interviews, assessments, training to direct support staff, identification of the need for referral(s) to other services if applicable, an exit conference, report of findings and recommendations, and follow-up.

The TBC team contacts the individual's service coordinator (SC) to schedule a consultation visit and the SC submits informational packet to the TBC team for review prior to the scheduled visit.

The on-site consultation begins with an initial meeting of the IPP team – the individual, legal representative and/or parent, service coordinator, staff from habilitation service components delivered to the person (day services, residential services, or both day and residential services), other professionals serving the person in the community, as well as TBC service staff.

The TBC service is provided under the direction of a Licensed Clinical Psychologist, and may include the following members, depending upon the individual's needs: a Certified Master of Social Work, a Registered nurse, a licensed mental health practitioner, or other qualified professionals. This meeting is designed to further explore the negative behavior and plan the schedule for the on-site consultation.

Observations where the individual lives, and/or takes part in day services or other activities are conducted at any time of the day or night, depending upon when and where the specific negative behaviors are exhibited. IPP team members are interviewed, and assessments are completed. The current interventions are noted and efficacy assessed. Behavioral interventions are developed, piloted, and evaluated, and revised, as necessary. Training is delivered to the IPP team as applicable and requested, such as best practices in intervention strategies, medical and psychological conditions, or environmental impact to service delivery.

Findings and recommendations are written and discussed with the team at the exit conference and a copy is provided to DDD central office. The individual is present for the consultation.

If at any time the TBC team identifies a need for a referral as a result of the review of the individual case file, observations, interviews, and/or completion of

assessments, the TBC will notify the individual's DDD service coordinator to recommend/direct that a referral be made for needs such as, but not limited to a medication review, dental work, medical evaluation, or a physical nutritional evaluation. Such referral recommendations are documented in the TBC report. Follow-up begins after the TBC staff has left the community site. It includes all revisions to the recommendations package, and phone, e-mail, and on-site contact with the individual's IPP team in the community. Weekly contact with the IPP team is conducted by telephone or e-mail to provide support and additional recommendations, as needed. Behavioral data, treatment integrity checklists, or similar performance assessments are reviewed on an on-going basis, with on-site follow-up conducted if problem behaviors continue to be resistant in spite of consistently applied efforts. Continued follow-up is provided after each successive on-site visit. The TBC file is closed when there is agreement to do so by TBC staff and the individual's IPP team.

The recommendations from the TBC service provider for addressing behaviors and intervention strategies must be addressed by the individual's IPP team and changes resulting from the recommendations are documented in the IPP.

Approval Process:

The service begins with submission of a referral to DDD central office to log and forward to the assigned TBC team.

Provider Qualifications and Standards:

Staff or agencies that provide a service for which a license, certification, or registration, or other credential is required must hold the license, certification, registration, or credential in accordance with applicable state laws and regulations.

The provider must meet the following:

1. Be a DDD approved HCBS waiver provider;
2. Be a Nebraska approved Medicaid provider;
3. Be approved by DHHS to provide team behavioral consultation;
4. Offer team behavioral consultation service on a statewide basis;
5. Have inpatient hospital or ICF beds available for use as needed;
6. Have experience offering team behavioral consultation;
7. Not provide TBC in cases where the provider or subcontracted provider is also the habilitation provider; and
8. Have on staff or under contract a psychologist, medical staff, and other professionals as needed.

Scope and Limitations:

Team behavioral consultation is only available to individuals receiving services from a certified DD agency provider.

Team Behavioral consultation is not available for an individual when the Team Behavioral Consultation provider is the only specialized service provider for that individual.

TBC will not be available to individuals that receive behavioral risk services or retirement services.

TBC services will not be furnished to an individual while s/he is an inpatient of a hospital, nursing facility, or ICF. Room and board is not included as a cost that is reimbursed under this service.

To avoid overlap or duplication of service, team behavioral consultation services are limited to those services not already covered under the Medicaid State Plan or which can be procured from other formal or informal resources such as IDEA or Rehab act of 1973. Furthermore, TBC services will not duplicate other services provided through this waiver.

A unit of team behavioral consultation is defined as a day.

The authorized amount of team behavioral consultation is not determined using the objective assessment process.

General Billing Rules

1. Services and supports must be delivered as documented in each individual's person-centered plan, which may also be referred to as a service plan, Individual Program Plan (IPP), or Individual and Family Support Plan (IFSP), hereafter referred to as IPP. The type and amount of service and/or support, the location and schedule for delivery of the services and/or supports, and the person or agency responsible for the delivery of the service and/or support must be documented in the IPP.
2. Services billed must be provided in accordance with all regulatory and contract requirements.
3. Agency staff activities that can be claimed (billable):
 - a. Habilitation training and direct support of ongoing service needs as specified in the person's current IPP;
 - b. Individualized job development and support on behalf of the individual as specified in the person's current IPP;
 - c. Attendance and participation at the person's interdisciplinary team meetings; and
 - d. Documentation of information supporting the agency staffs' performance of activities that are specified in the person's current IPP.
4. Agency Staff activities that cannot be claimed (are not billable):
 - a. Staff meetings, agency-wide staff training, habilitation plan/training program research and development, supervisory/administrative activities, staff paid leave time, ancillary support activities not involving the participation of the individual (e.g. shopping for supplies, building cleaning, maintenance, etc.);
 - b. Any time periods where other paid services (e.g. Personal Assistance Services, Speech Therapy, Physical Therapy, Counseling/Therapy sessions, etc.) are provided concurrently;
 - c. For a child (person under 21 years of age), time periods the child is to be attending school – 8:00 a.m. to 3:00 p.m. or the operational hours of the school;
 - d. Paid staff time providing only general care and supervision to the person during the delivery of Supported services.
5. Provider's need to keep records in accordance with 404 NAC 4-004.09A and any contract requirements.
6. Day Rate must include a minimum of 4 hours per 16 hours of assisted services 7 days a week in order to be billable as one daily unit. The individual must have only one provider for both day and residential services.
7. Residential Services
 - a. Eight hours of overnight staffing are not billable. When continuously awake overnight staff is required the need, rationale, and expectations must be included in the individual's current IPP and DDD central office approval is needed for payment for overnight services.
 - b. The staffing for individuals receiving assisted residential habilitation services must be maintained during the times that the individual is under assigned supervision of the provider, unless the individual's needs justify otherwise, as determined by the individual's team and approved by DDD central office.

Appendix B

Nebraska DD Restraint Survey

Nebraska DD Restraint Survey

Information is being solicited to provide an accurate picture of the use of restraints by community-based providers of services to persons with developmental disabilities. For this survey, information is being solicited on information on training and policies and procedures. The questions regarding training and policies and procedures are on the next sheet entitled 'Training and P&P'. Information regarding the use of restraints is on the sheet named 'Restraint Data'. Specific instructions are provided on those pages.

All information being solicited is for the period from January 1 to March 31, 2011. If you can provide information for this period, leave the responses below as they are. If for some reason you are unable to provide information for this three month period, but are able to provide information for another quarter, please change the response for the Jan to March quarter to no, change the 'other' response to yes and indicate the quarter for which you are providing information.

Yes Jan to March 2011
No Other:

Provider:

The survey can be completed either by printing out the workbook (there are three worksheets in the workbook) and filling it out by hand or by filling out the worksheets and saving the file. If completed by hand, please send it to Carla Lasley at Collaborative Industries, Inc., 5701 Thompson Creek Blvd. Suite 200, Lincoln, NE 68516. If completed electronically, please return it by e-mail to Carla at clasley@cii.us.com.

Please return the survey by May 20, 2011. If that is not possible, please let Carla know when the survey will be returned on or before that date.

If you have any questions or concerns regarding this survey, please contact Carla at (402) 435-2134 Ext. 1011 or clasley@cii.us.com

Training and Policies & Procedures

Below are several questions regarding training and policies and procedures regarding the use of physical intervention and mechanical restraint techniques. Please answer these questions as fully as possible. If you wish to submit additional documentation, that is permissible, but please refer to these documents in your response.

1. Please describe how your staff are trained in the use of physical and mechanical restraints:

2. Do all staff receive training in this techniques? If not, who is trained and how does the agency determine who is trained?

3. How is competency to apply physical intervention techniques/ restraints tested?

No Pen and pencil tests
No Demonstration of skill
No Other (please indicate):

4. Are incidents of physical intervention debriefed (if no, skip to question 6)?

5. Who is involved in the debriefing?

List all persons involved, including whether the individual is involved and what staff are involved:

6. Does your agency collect any other information with regard to restraints, such as injuries that result from the use of restraints?

7. Is restraint data analyzed. If so, how often and how is the data analysis used?

8. Does your agency have a definition of 'time-out'? If so, what is your definition and is this definition used to specify where time-out can be used or to restrict the use of time-out?

9. Does your agency have a definition of 'seclusion'? If so, what is your definition and is this definition used to specify where seclusion can be used or to restrict the use of seclusion?

Name & contact information for person completing this portion of the survey:

Restraint Data

For the first quarter of 2011 (January 1 to March 31), please list the restraint use with each individual in your agency who had any use of restraint during the quarter. Please identify the individual by a unique identifier. This is to be used in case there are additional questions regarding the data and the key of who the identifier refers to is to be kept by the agency and not shared with others to ensure the confidentiality of the individuals whose restraint data is being shared. For each item, use the unique identifier, select the person's gender, and record their age in years. For uses of physical intervention, record the number of times the physical intervention was used in the quarter. For mechanical devices or materials that were used to prevent or restrict the likelihood of a behavior occurring, record the number of days in the quarter the device was used (there were 90 days in the quarter). Then, please indicate if the person had a behavior support plan or formal intervention strategy in place and whether the person receives psychoactive medication. For the purpose of this survey, only persons served by the Division of Developmental Disabilities should be considered.

As agreed to by the workgroup, the operational definition to use to consider whether an action should be considered a restraint is as follows:

Restraint (as a physical intervention or mechanical device) for the purposes of the data collected under the grant shall mean:

- (1) The holding of a person [by another person or persons] in a manner that restricts the person's movement against his or her will and
- (2) The use of a mechanical device, material or equipment that immobilizes or reduces the ability of a person to move his or her arms, legs, body or head freely—or to restrict access to a part of his or body.

The interpretive standards for physical interventions are as follows:

Physical escort—to move a person to a desired location. If the person can easily remove or escape the grasp, this would not be considered physical restraint. However, if the person cannot easily remove or escape the grasp, such an escort would be considered physical restraint.

Mechanical restraints—devices or materials, including clothing, that is used to prevent self-injury or other forms of self-stimulation.

Name & contact information for person completing this portion of the survey:

Appendix C

Psychotropic Medication Guidelines Reference

Psychotropic Medication

Guideline: Psychotropic medication may be used when it has been determined that it is the treatment of choice, when other environmental or psychosocial interventions are not indicated, and in conjunction with behavior support programs. Each person should receive a comprehensive assessment prior to the initiation of medication. The person's response to medication should be carefully monitored during the use and after the discontinuation of the medication.

DEFINITIONS:

Behavioral-pharmacological hypothesis: A hypothesis based on the analysis of the function of the behavior and a medication's known psychopharmacology. A behavioral-pharmacological hypothesis is developed by the psychotropic drug review team.

Individual's record: A permanent legal document that provides comprehensive information about the individual's health care status.

Primary care prescribers: Physicians, nurse practitioners, and physician's assistants who provide primary care services and are authorized to prescribe medications and treatments for people on their assigned caseloads.

Psychiatric diagnosis: A diagnosis based upon DSM-IV criteria.

Psychotropic medication: Any drug prescribed with the intent to stabilize or improve mood, mental status, or behavior.

RATIONALE:

1. Although an interdisciplinary team approach is used in conjunction with the use of psychotropic medication, only the consulting or primary care prescriber has the legal authority to order psychotropic medications.
2. Psychotropic medication should not be used excessively, as punishment, for staff convenience, as a substitute for meaningful psychosocial services, or in quantities that interfere with a person's quality of life.

EXPECTED OUTCOMES:

The following outcomes are consistent with the Guidelines for the Use of Psychotropic Medication developed by the International Consensus Panel on Psychopharmacology - Committee on Standards of Care. Documentation that the following guidelines are being followed should be found in the individual's record according to the documentation procedure identified at each facility.

1. **Coordinated Interdisciplinary Care Plan.** Psychotropic medication should be used within a coordinated interdisciplinary care plan designed to improve the person's quality of life. The psychotropic medication plan should be part of the Single Plan of care. A psychiatric consultation may be obtained when determined necessary by the primary care prescriber and other members of the team. The psychiatric consultation may be considered for the purpose of diagnosis, developing a treatment plan, and/or monitoring progress. Consultation reports should be maintained in the individual's record.
2. **Psychiatric Diagnosis or Behavioral-Pharmacological Hypothesis.** The use of psychotropic medication should be based upon a psychiatric diagnosis or a specific

behavioral-pharmacological hypothesis resulting from a full diagnostic and functional assessment. Supporting documentation should be found in the medical section of the individual's record.

3. **Informed Consent.** Written informed consent should be obtained from the person for whom the medication is being prescribed before the use of any psychotropic medication. If the person is not capable of giving informed consent, the appropriate surrogate consent giver should be contacted to provide consent. Informed consent should be renewed periodically. Informed consent does not have to be obtained before the **emergency** use of psychotropic medication. The informed consent should be obtained and maintained as per facility policy.
4. **Index Behaviors & Quality of Life.** Specific index behaviors and quality of life outcomes should be objectively defined, quantified, analyzed, and tracked using recognized empirical measurement methods in order to monitor psychotropic medication efficacy. A summary of outcome measures and the person's progress should be documented as part of the psychotropic drug review and maintained in the individual's record.
5. **Side Effects Monitoring.** Each person should be monitored for side effects on a regular and systematic basis using accepted methodology that includes a standardized assessment instrument. Presence or absence of side effects may be addressed and documented at the psychotropic drug review and more frequently as needed.
6. **Tardive Dyskinesia Monitoring.** If antipsychotic medication or other drugs capable of inducing tardive dyskinesia are prescribed, the person should be monitored for tardive dyskinesia on a regular and systematic basis using a standardized assessment instrument. Results of tardive dyskinesia screening should be reported and documented as part of the psychotropic drug review. Changes identified through tardive dyskinesia screening should be documented and reported to the consulting or primary care prescriber immediately. *See SCDDSN policy on tardive dyskinesia for further monitoring information.*
7. **Clinical & Data Reviews.** Psychotropic medication usage should be reviewed on a regular and systematic basis.
 - a. Clinical reviews should be conducted and documented on a regular and systematic basis by the consulting or primary care prescriber.
 - b. Data reviews should be conducted and documented at least quarterly by appropriate members of the interdisciplinary team.
 - c. Joint clinical and data review should occur at least every quarter and be documented as part of the psychotropic drug review process.

8. **Lowest “Optimal Effective Dose”.** Psychotropic medication should be reviewed on a periodic and systematic basis to determine if it is still necessary. Psychotropic medication should be prescribed at the lowest “optimal effective dose”. This information should be included as part of the review and documentation process discussed in item 7 above. If the lowest “optimal effective dose” exceeds the recommended dose range, the rationale should be documented by the prescriber.
9. **Frequent Changes.** Frequent drug and dose changes outside of documented titration and care plans should be avoided. Modifications should be consistent with current practice standards.
10. **Polypharmacy.** Psychotropic medication regimes should be kept as simple as possible to enhance compliance and minimize side effects. Intraclass polypharmacy or the use of more than two psychotropic medications from the same therapeutic class at the same time is rarely justified. Interclass polypharmacy or the use of more than two psychotropic medications from different therapeutic classes at the same time should be minimized to the degree possible. This guideline does not apply to brief periods of time when one medication is being substituted for another. If either of these practices is deemed most effective for an individual, the rationale and empirical support for the medication prescribed in this manner should be documented in the individual’s record.
11. The following practices should be minimized as much as possible. If any of these prescribing practices are deemed most effective for an individual, the rationale and empirical data supporting the need for the medication prescribed should be documented in the individual’s record.
 - a. Long-term use of benzodiazepine antianxiety medications such as diazepam
 - b. Use of long-acting sedative-hypnotic medications such as chloral hydrate
 - c. Long-term use of shorter acting sedative-hypnotics such as temazepam
 - d. Anticholinergic use such as benztropine without signs of extra-pyramidal side effects (EPSE)
 - e. Long-term anticholinergic use
 - f. Antipsychotic medication at high doses
 - g. Use of phenytoin, phenobarbital, and primidone as psychotropic medication

REFERENCE

Reiss, S. & Aman, M. (eds.) (1998). Psychotropic medication and developmental disabilities: The international consensus handbook. Columbus, OH: Ohio State Nisonger Center.