

Report of the Developmental Disabilities Special Investigative Committee



Senators Steve Lathrop (Chair), John Harms (Vice Chair), Greg Adams,
Abbie Cornett, Tim Gay, Arnie Stuthman and Norm Wallman

December 15, 2008

TABLE OF CONTENTS

INTRODUCTION..... 1

SPECTRUM OF DISABILITIES WITHIN THE DEVELOPMENTALLY DISABLED POPULATION..... 3

OVERVIEW OF SERVICES IN NEBRASKA FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES 4

LEGAL AND REGULATORY FRAMEWORK 7

 Duty Owed to Persons in an Institutional Setting..... 7

 Federal Regulatory Oversight of ICF/MR’s 8

 State Law 10

 Oversight of Community-Based Programs..... 10

HISTORY OF BSDC 11

FAILURES AT BSDC 13

 Department of Justice 13

 Summary Agreement..... 16

 Centers for Medicare and Medicaid Services 18

 History of CMS Involvement at BSDC..... 19

 Results of CMS Surveys..... 19

 CMS Discussions with the Committee..... 21

 Nebraska Advocacy Services, Inc..... 21

 Summary of DOJ, CMS and NAS Investigations..... 22

IDENTIFIED PROBLEMS/CONCERNS 24

 The State’s Strategy for CMS Re-Certification 24

 Staffing Issues..... 27

 BSDC As An Employer 29

 Management..... 30

 Community-Based Programs 31

 Waiting List 33

 Future of Developmental Disability Services in Nebraska..... 35

RECOMMENDATIONS 38

 1. BSDC..... 38

 2. BSDC MANAGERIAL AND STAFFING ISSUES..... 38

 3. COMMUNITY-BASED PROGRAMS..... 39

 4. WAITING LIST 39

 5. APPROPRIATION..... 39

 6. CONTINUED OVERSIGHT 40

 7. PRIVATIZATION OF BSDC 40

 8. VOTE OF NO CONFIDENCE 40

FINAL THOUGHTS 41

INTRODUCTION

The Developmental Disabilities Special Investigative Committee was established by the Legislature in response to reports from the Department of Justice (DOJ) and the Centers for Medicare and Medicaid Services (CMS) which documented repeated episodes of abuse and neglect of residents at the Beatrice State Developmental Center (BSDC). LR 283, passed by the full Legislature, authorized the Committee to conduct its investigation over the interim and provide a report of its findings by December 15, 2008.

The composition of the Committee was established by the Executive Board of the Legislature which appointed Senators Lathrop, Harms, Gay, Cornett, Stuthman, Adams and Wallman to serve. The Committee has been chaired by Senator Steve Lathrop. Senator John Harms has served as Vice Chair.

LR 283 established the scope of the Committee's undertaking. LR 283 provides in relevant part:

“2. The Developmental Disabilities Special Investigative Committee of the Legislature is hereby authorized to study the quality of care and related staffing issues at the Beatrice State Developmental Center. The Committee shall also investigate the placement and quality of care statewide for the developmentally disabled in Nebraska, including the determination of whether adequate funding and capacity exists for persons to be served in the community, options for service provisions for current residents of the Beatrice State Developmental Center at other 24 hour care facilities in the state, and the staffing practices at 24 hour care facilities and the relationship of those practices to the quality of care provided to the developmentally disabled. The Committee shall also study the Department of Health and Human Services with respect to such facilities, including how and why services to the developmentally disabled were permitted to decline to the level as documented by the United States Department of Justice report.” (LR 283)

The work of the Committee necessarily required not only a study of the difficulties at BSDC, but also a comprehensive study of community based programs and the waiting list for those families wishing to receive services for a loved one with developmental disabilities. To fully discharge its duties, the Committee conducted hearings throughout the interim during which representatives from the Nebraska Department of Health and Human Services (HHS) as well as various experts in the field were invited to speak. In addition, employees at BSDC as well as families with loved ones with developmental disabilities addressed the Committee. In some cases, the testimony related to what Nebraska is doing well and too frequently the testimony related to significant problems not only at BSDC but in alternative programs employed by the State in delivery of services.

The Committee received and reviewed volumes of documents related to the provision of services to individuals with developmental disabilities including studies by the Nebraska Advocacy Services, the Department of Justice and the Centers for Medicare and Medicaid

Services. The Committee also conducted informal, unrecorded interviews with representatives from DOJ and CMS.

The Committee believes that a full understanding of the significance of the problems facing the State of Nebraska as a provider of services to individuals with developmental disabilities necessarily requires a working understanding of the population, the legal requirements relative to the care of individuals with developmental disabilities, as well as an overview of community based programs and the systems in place which are intended to provide oversight of these services.

This Committee has undertaken this investigation mindful of the fact that services for individuals with developmental disabilities are delivered by the Nebraska Department of Health and Human Services which, in turn, is an agency of the executive branch. Our goal is not to embarrass or fingerpoint. However, to discharge its responsibility as a check and balance against the Executive branch, the Legislature must necessarily provide a candid and blunt report on the shortcomings of a system which, for most families, is the only available provider of services to a high needs population.

SPECTRUM OF DISABILITIES WITHIN THE DEVELOPMENTALLY DISABLED POPULATION

The phrase “developmental disability” is a legal term. It denotes a disability that occurred during the first 22 years of life, the majority of which occur around birth or sooner.¹ It is, in practice, a phrase most often used to describe the intellectually impaired whose disabilities range from the very mild to profound. The phrase, however, is broad enough to include those who are “health impaired”. A common example of “health impaired” are those individuals with significant orthopedic limitations. Very often this group of health impaired individuals has no intellectual limitation but, rather, face physical limitations which carry with them mobility and communication challenges.

Frequently those who fall within the phrase “developmentally disabled” carry a dual diagnosis. The dual diagnosis often involves cognitive impairments coupled with behavioral health issues and/or other health issues which limit an individual’s ability to ambulate, see, hear, or speak.

Within each of the classifications of impairments, there is a broad spectrum of limitations. Intellectual impairments can range from mild to profound. The profoundly impaired individuals typically have massive brain damage. This group generally functions at a level such that they are unable to do simple life skills. They will need assistance with the very basic activities of daily living such as hygiene, dressing and feeding themselves. This group requires a great deal of care, most of which is directed toward providing for their needs and maximizing their abilities given their profound intellectual limitations.

A majority of those with intellectual disabilities fall in the moderate range. This group is functional. These individuals generally stay in the school system for 21 years and, with proper care and assistance, can transition into an outside setting.

At the mild end of the spectrum are those with mild deficits. With education and socialization, they become very functional. This is the area in which care providers have experienced the greatest success.

Just as individuals with intellectual impairments fit on a broad spectrum so too do those with health and behavioral disabilities. Health impairments can range from mild problems at one end of the spectrum to those who are medically fragile, including those who take nutrition through a G tube and breathe with the benefit of a tracheotomy. Similarly, their behaviors fall on a wide spectrum. At the mild end are those behaviors which, with simple strategies can be corrected and modified. By contrast, there are, at the other end of the spectrum, those whose behavior presents a significant risk of harm to the individual or those around him.²

¹ Dr. Bruce Buehler testimony, June 23, 2008, page 7.

² Dr. Bruce Buehler testimony, June 23, 2008, page 8

OVERVIEW OF SERVICES IN NEBRASKA FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Care for individuals with developmental disabilities is provided in a variety of forms. In the earliest years of life, most services are provided through a child's school district. Federal law mandates that school districts provide for a child's needs as necessary to educate them to their full potential. The school districts in Nebraska have, according to those who appeared before the Committee, done an excellent job in discharging their responsibilities to young Nebraskans with developmental disabilities. Typically, the services provided by school districts continue to a child's 21st birthday, after which time individuals with developmental disabilities turn to the state for services provided in an array of different settings.

The most comprehensive level of care is provided by Intermediate Care Facilities for the Mentally Retarded (ICF/MR). BSDC is a state-run ICF/MR. In addition to the Beatrice State Developmental Center, there are three privately run ICF/MR's which are operated by Mosaic in the communities of Axtell, Grand Island and Beatrice. ICF/MR's provide a full range of services including medical services and therapy, as well as active treatment.

In addition to its responsibilities as an ICF/MR, the Beatrice State Developmental Center also provides three other programs. The first is the Outreach Treatment Services Program (OTS), the purpose of which is to aid community treatment teams in reducing problematic behaviors and improving the quality of life of individuals who are in community placement. This service typically involves a team from BSDC, such as a psychologist, human services treatment specialist, and psychology intern, observing the individual in a residential vocational community and/or educational setting over a three day period. After a review of the individual's file, and following the observation period, the OTS team will provide the community based provider with strategies for addressing the individual's behavior issues.

The second program offered by the BSDC is the Intensive Treatment Services Program (ITS). The ITS program is designed for individuals with behavioral challenges which require attention in a more secure environment. To accomplish this, BSDC offers 90 to 100 day admissions to its ITS program. The ITS program employs a biopsychological approach to assessment, diagnosis, and behavioral stabilization. Treatment modalities include behavior management, individual counseling, psycho-educational groups, recreational therapy, vocational therapy and opportunities for individualized experiential learning. Upon completion of the program, individuals are typically returned to their community setting with recommendations and a discharge plan formulated to aid in the successful transition from the treatment setting back into the community.

The final program offered by BSDC is the Bridges Program. The Bridges Program is operated by BSDC but is located at the Hastings Regional Center campus. The Program specializes in services to individuals with developmental disabilities designed to provide a structured therapeutic environment for persons with the most challenging behavior who pose significant risk to members of the community. This program has a capacity to serve up to 14

adult males. Typically the Bridges Program is utilized only when all other treatment options and less restrictive environments have failed or are unavailable to meet the needs of the individual.³

The Beatrice State Developmental Center is a unique institution for a number of reasons. The most obvious unique characteristic of BSDC is the fact that it stands alone as the only state-run institution for individuals with developmental disabilities. As an ICF/MR, BSDC serves as a residential facility providing a full spectrum of services typically found in an ICF/MR. BSDC is also unique because, unlike the private ICF/MR's run by Mosaic, it has distinguished itself as the only ICF/MR in the state to have been decertified by CMS and found by the DOJ to have violated the civil rights of those who rely upon this institution for care, treatment and rehabilitative services. As of the date of this report, 250 people call BSDC home.

BSDC also finds itself serving the greatest percentage of the more challenging clients with developmental disabilities. For example, while 50% of the community-based clientele are mildly disabled, only 16% of BSDC's clientele are mildly disabled. Similarly, while 29% of the individuals served in the community fall within the moderate range of disabilities, BSDC's population of moderately disabled is only 11%. Severe disabilities represent 10.6% of the population in the community while 12% of the BSDC population has severe disabilities. Finally, and perhaps most telling, is the disparity found in services provided to individuals with profound developmental disabilities. In a community setting, those with profound disabilities represent only 6.4% while at BSDC they represent 59% of the population.⁴

BSDC also has a disproportionately higher percentage of those with health and behavioral issues. Those with uncontrolled or difficult to control seizure disorder represent 39% of the BSDC population compared to 12% of those in the community. 26% of the population at BSDC have hearing impairments compared to 4.8% in the community. At BSDC 52% of the individuals require a wheelchair for mobility in contrast to less than 10% in the community. Finally, and perhaps most importantly, persons with severe and persistent mental illness in addition to their developmental disabilities represent 66% of the population at BSDC compared to 46.3% in community based programs.⁵

The balance of services provided to individuals with developmental disabilities in Nebraska occurs in what is generally referred to as the "community-based" side. As of June 2008, 4,116 persons received services through the community-based programs. These services include day or vocational services, residential and respite services. Typically, the Division of Developmental Disabilities provides funding for community-based service providers for services specifically designed to meet the needs of persons with developmental disabilities. These services include community supports which are services designed to give the person and his or her family needed assistance. Community support has no requirement of habilitation. Currently there are approximately 3,500 people receiving day or vocational services under this form of service.

³ Testimony of Ron Stegemann, June 23, 2008, p. 74.

⁴ These percentages reflect the current composition of individuals residing at BSDC. As residents from BSDC are moved into community-based settings, the mild disabilities as a percentage of the overall BSDC population will go down and the percentage of profoundly disabled and those with difficult behavioral issues is expected to increase.

⁵ Testimony of Dr. Lee Zlomke, June 23, 2008, page 61.

Community-based programs also include what are known as “day and residential” services. Day and residential services, in turn, are broken down between assisted or supported services. Assisted services are typically provided in a group setting where staff are providing services to more than one individual on an ongoing basis. Assisted residential services are delivered to individuals who require the ongoing presence of providers staffed to meet the residential needs. Assisted residential services may take place in a group home setting or an apartment where two or three individuals live with staff present whenever they are at home. By contrast, supported residential services are delivered to individuals who require the presence of staff only intermittently to meet their residential needs. This is typically found with individuals who are more independent and can live in an apartment or a house without supervision most of the time either because they have natural supports in place or their higher level of functioning lends itself to less supervision.

In both types of residential services the community-based provider is expected to provide habilitative training and supports which typically include teaching skills such as hygiene, socialization, communication and independent living skills such as budgeting and shopping, cooking, housekeeping and laundry. Further, provider staff may also need to support individuals in either setting with transportation and duties such as check writing, handling the mail, medication administration and attending to doctor appointments.

Assisted day services also come under the umbrella of community-based care. Assisted day services are provided to individuals who require the ongoing presence of providers staffed to meet their needs during normal work hours. These services may take place in a sheltered work shop, or during work crew activities such as on a mowing crew or a janitorial crew in a local business. This service also includes work stations in industry where provider staff may operate a work crew in a factory setting.

Specialized respite care is also available through community-based providers. This service provides families with trained staff for short breaks from caring for their loved one. There are currently 480 families receiving this service. Finally, there are community support programs which fall within the category of community-based services. These programs allow family and guardians to hire their own personal provider to meet their needs. This category of supports includes assistive technologies, home modifications and vehicle modifications. There are approximately 60 persons in the community availing themselves of the community support program.⁶

LEGAL AND REGULATORY FRAMEWORK

The legal and regulatory framework which governs the state’s responsibility for care of individuals with developmental disabilities begins with the United States Constitution but also includes federal law, federal regulations and state law.

⁶ Testimony of Karen Kavanaugh, June 23, 2008, pages 88-91.

Duty Owed to Persons in an Institutional Setting

The 14th Amendment to the United States Constitution as well as the Americans with Disabilities Act of 1990 set forth the three paramount duties owed to a person receiving care in an institutional setting. The first, and perhaps most important duty, is the duty of protection. People who reside in an institution such as the Beatrice State Developmental Center have a constitutionally protected liberty interest in safety. The United States Supreme Court in *Youngberg v. Romeo*, 457 U.S. 307 (1982), held that the state has an unquestioned duty to provide reasonable safety for all residents within the institution. This duty of reasonable safety extends to protection from unreasonable restraints which includes both chemical and mechanical. This duty also requires that the state provide appropriate and adequate medical care, food, and shelter. Similarly, this duty requires that the state provide an environment free from verbal abuse and humiliation as well as freedom from physical assault and abuse.⁷ The duty to provide a safe environment is violated when an individual at BSDC is placed in danger of physical or psychological harm as a result of inadequate staffing, inadequately trained staff or inadequate supervision.

The second duty, which also has its origins in the United States Constitution, is the requirement that those individuals who reside at a facility such as BSDC receive training or habilitation. In *Youngberg*, the Court recognized that persons with developmental disabilities have a constitutional right to minimally adequate training. The essence of this requirement is regular systematic provision of activities and programs designed to help develop new skills, and maintain skills that have already been learned. The measure for whether or not the state has met its duty to provide training and habilitation is whether or not the facility's practices substantially comport with generally accepted professional practice. The measure of "generally accepted professional practice" is, in turn, found in the CMS regulations that are discussed below as well as the expert opinions of providers in the field as to the prevailing standards of care.

The third duty owed by the state to individuals receiving care in an institutional setting is the mandate of integration. This duty arises not so much from the Constitution as it does from the Americans with Disabilities Act of 1990 as interpreted in *Olmstead v. L.C.*, 527 U.S. 581 (1989). In *Olmstead*, the U.S. Supreme Court held that undue institutionalization qualifies as prohibited discrimination by reason of disability under the public service portion of the ADA. The Court came to this conclusion for two primary reasons, both of which are important to fully understand the breadth and the limitations of the *Olmstead* decision. First, the Court recognized that the continued institutional placement of persons "who can handle and benefit" from community settings perpetuates unwarranted stigmatizing assumptions that the persons so isolated are incapable or unworthy of participating in community life. Secondly, the Court reasoned that confinement in an institution, such as BSDC, severely diminishes the every day life activities of individuals including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

⁷ Our own state law, Neb. Rev. Stat. §83-1,202(8), recognizes that the first priority of the state to persons with developmental disabilities should be to ensure that such persons have sufficient food, housing, clothing, medical care and protection from abuse or neglect.

Olmstead is very clearly an important decision from the United States Supreme Court as it relates to providing care to individuals with developmental disabilities. Ultimately, *Olmstead* stands for the proposition that professionals must conduct reasonable assessments in determining whether a person residing at a center such as BSDC is either (1) able to handle or (2) can benefit from, community settings. If, based on that assessment, the individual is found to be either able to handle, or benefit from, community settings, that resident is a qualified individual within the meaning of the ADA and the duty to integrate him or her in the community arises. This duty to integrate, however, is not an unqualified mandate for placement in community settings. In fact, the duty to integrate is subject to a qualification found in federal regulations at 28 C.F.R. 35.130(9)(e)(1), 1998 which states that: “Nothing in this part shall be construed to require an individual with a disability to accept an accommodation which such individual chooses not to accept.” The regulations further provide that persons with disabilities must be provided with the option of declining to accept the particular accommodation. “Accommodation” as used in the context of an individual with developmental disabilities in an institution is placement in a community setting.

What is evident from the duty imposed by the ADA, and the qualification of that duty found in the Code of Federal Regulations, is that where an individual is able to handle or can benefit from the community setting, the state has a duty to place them in such a setting rather than leave them in an institution but that duty is subject to the right of the institutionalized person to decline the accommodation, which is to say the individual may decline to be transferred to a community setting.^{8 9}

Federal Regulatory Oversight of ICF/MR’s

Beyond the United States Constitution and the ADA, the primary regulatory process in place for ICF/MR’s is found in the rules and regulations of CMS. Because the State of Nebraska receives well over half of its funding from the federal government for the operation of the ICF/MR’s, including BSDC, CMS was put in place to provide regulatory oversight of such facilities.

The regulatory process employed by CMS involves eight “conditions of participation”. These eight conditions of participation are the overriding principles which govern CMS’s evaluation of the performance of ICF/MR’s across the country. Those eight conditions of participation are:

- (1) Governing body management
- (2) Client protections
- (3) Facility staffing
- (4) Active treatment services

⁸ Testimony of Bruce Mason, June 23, 2008, pages 23-27.

⁹ As the State of Nebraska attempts to reduce the census at Beatrice State Development Center, one can easily imagine an individual who is able to handle or can benefit from a community setting but whose guardian is unwilling to agree to placement outside of BSDC. Witness-attorneys Bruce Mason and Jodi Fenner provided the committee with a thoughtful discussion on a process and procedure which might be employed in those instances where the state believes placement in a community setting is appropriate but is unable to secure the permission of the individual’s guardian. See testimony of Bruce Mason and Jody Fenner, June 23, 2008, pages 22-54.

- (5) Client behavior and facility practices
- (6) Healthcare services
- (7) Physical environment
- (8) Dietetic services.

In addition to the eight conditions of participation, there are 56 standards. These standards provide the measure by which ICF/MR's receiving federal funding are judged.

It is important to note that the duties imposed upon an ICF/MR by virtue of the Constitution and the ADA are separate from the CMS regulations. While the Constitution and the ADA focus on the fundamental rights of the residents of an ICF/MR, the CMS regulations provide the standard of care for how such a facility should be operated.

The process by which ICF/MR's are measured is an inspection of the facility generally referred to as a "survey." Surveys may be conducted by either a state agency or regulators from CMS. The state agency responsible for conducting surveys of ICF/MR's, including BSDC, is the Licensure Unit of the Division of Public Health which, while it is a part of the Nebraska Department of Health and Human Services, stands alone as a separate sub-agency so as to ensure surveys are conducted in an unbiased manner.

The process by which ICF/MR's are surveyed, regardless of whether it's undertaken by the state or CMS, generally involves an onsite visit to the facility, typically over a period of days. The survey will include onsite observations as well as file and record reviews. Once a survey is complete, any deficiencies, or breaches in the standards of care, are presented to the facility, which is then provided an opportunity to respond with a plan of correction. Generally speaking, the plan of correction is provided within 90 days and sets forth the institution's plan to resolve the deficiencies.

In addition to regular surveys, ICF/MR's are subject to two additional surveys. One is what is referred to as an "immediate jeopardy" survey. As the name would suggest, immediate jeopardy surveys are conducted in response to a situation in which a client is found to be in immediate jeopardy of danger or injury. These surveys focus on the condition or situation that presents an immediate danger to a resident. The other type of survey is a follow-up survey. These surveys are typically done to determine whether or not an institution who has provided a plan of correction has actually followed through on that plan of correction and resolved the deficiency found at the time of an annual or immediate jeopardy survey.

State Law

In addition to the requirements of the United States Constitution and the ADA, state law relating to individuals with developmental disabilities is derived from the Developmental Disabilities Services Act which is found at Neb. Rev. Stat. §83-1,201 through 83-1,227.

Oversight of Community-Based Programs

In contrast to regulations that apply to ICF/MR's, community based oversight is characterized by far fewer regulations and much less frequent inspections.

Where ICF/MR's are subject to CMS regulations, community-based programs are subject only to state regulations which are nowhere near as comprehensive as their federal counterpart. Similarly, where ICF/MR's are subject to annual surveys, surveys of community providers which are done by the Nebraska Department of Health and Human Services occur only every four or five years.

Beyond the state's regulatory process, the cornerstone of the oversight of community-based programs is found in three safeguards. The first safeguard is the certification process. Most, but not all,¹⁰ providers must be certified by the Nebraska Department of Health and Human Services before they can provide services to individuals with developmental disabilities. That certification process requires that a provider demonstrate compliance with applicable state standards for the care and treatment of individuals with developmental disabilities.

The second safeguard with respect to community-based care is the monitoring of services by each individual's service coordinator. Those receiving services in the community are provided with a service coordinator. The service coordinator is responsible for ensuring that various services such as residential transportation, medical, dental, etc. are provided to those with a community-based placement. These service coordinators have regular contact with their clients and it is the prevailing view in the industry that service coordinators provide an effective measure of oversight as they carry out their responsibility to those placed in a community setting.

Those in the community-based provider industry also point to an additional safeguard for those with a community-based placement. The industry believes that families and the clients themselves provide a measure of oversight. For those who are placed in residential facilities, many are frequently seen by family members who, when the occasion arises, can express concerns or complaints to service coordinators regarding the level of care or the presence of problems in a particular placement. Similarly, many of those placed in the community are higher level functioning adults. Because of their higher level functioning, many hold jobs and otherwise come into contact with other adults besides their care providers. This affords the client an opportunity to express concerns regarding their placement such as occasions of abuse and neglect that may occur in a residential setting.

¹⁰ Facilities with fewer than 4 beds do not require certification.

HISTORY OF BSDC

The history of Beatrice State Developmental Center generally parallels the prevailing attitudes towards the mentally retarded. When BSDC was established in 1885, it was known as the Nebraska Institution for Feeble-Minded Youth (NIFMY). The purpose of the facility was to provide shelter and protection for those who were generally referred to as “imbecile or feeble-minded.”

In keeping with the then prevailing attitude that individuals with mental retardation should be segregated and warehoused, the Legislature, in 1915, passed three laws touching the lives of those individuals. First was a law which provided for the sterilization of individuals with mental retardation. The second law provided for the civil commitment to NIFMY of individuals with mental retardation. Finally, the legislature mandated that NIFMY accept people who were judicially determined to be “idiot, imbecile or feeble-minded.”

The role of BSDC continued to track prevailing norms for the balance of the 20th Century. By the late 1960’s, 2,300 people lived at BSDC in what were generally dormitory-styled settings which had a capacity for only 800. The overcrowding at BSDC led inevitably to a lack of training and habilitation for residents. Those who were higher functioning often were providing care to the more vulnerable.

BSDC, as did most state facilities around the country, continued to warehouse people with mental retardation with little changing until 1972 when a class action was filed in the United States District Court for Nebraska. (*Horacek v. Exon*, 375 F.Supp. 72 (D. Neb. 1973)). The class action challenged the underlying assumptions that prevailed at BSDC and the operation of the center that reflected assumptions made about the residents.

After three years of litigation, the federal court entered a Consent Decree approving the settlement entered into between the class of private plaintiffs and the State of Nebraska. The *Horacek* Consent Decree recognized the constitutional rights of individuals with mental retardation at BSDC. Their constitutional rights extended to protection from physical and psychological harm as well as their right to habilitation. The Consent Decree also called for the reduction of the population from approximately 1,200 to a “goal” of 250 within three years.

For a time, primarily in the 1990’s, the Beatrice State Developmental Center represented the gold standard of care for those receiving treatment in an institutional setting. By 2001, problems at the Beatrice State Developmental Center began to emerge once again as documented in surveys done by CMS from 2001 through 2007. The shortcomings of the Beatrice State Developmental Center came to a head with the finding by the Department of Justice in 2008 that the civil rights of residents of BSDC were violated as a result of regular instances of abuse and neglect at the facility. In addition to the findings of the Department of Justice, CMS, after providing the State with repeated opportunities to correct the problems of BSDC concluded, following a November 2007 survey, that BSDC was so far out of compliance with the conditions of participation that decertification was an appropriate remedy. As a consequence, the Beatrice State Developmental Center was decertified by CMS on December 5, 2007. As a consequence of the decertification, the State of Nebraska lost over half of the funding to operate BSDC or

approximately \$28.5 million. Finally, the decision by CMS to decertify BSDC has been appealed by the State of Nebraska. A hearing on that appeal was held November 19, 2008 before an Administrative Law Judge who is not expected to provide a decision any sooner than June, 2009.¹¹

¹¹ This brief history of BSDC is a summary of the HISTORICAL ORIGINS OF THE BEATRICE STATE DEVELOPMENT CENTER found in the report An Indictment of Indifference prepared by Nebraska Advocacy Services, Inc., December 5, 2007. For a more thorough treatment of the subject matter, refer to this document found at “E” in the appendix attached to this report.

FAILURES AT BSDC

The Beatrice State Developmental Center has been the subject of two separate federal investigations. While each of the federal investigations have different criteria for evaluating the performance of BSDC, they have, through different approaches, come to the same conclusion: that BSDC has failed the residents at a very fundamental level.

The reports of the DOJ and CMS have been the subject of much discussion and media coverage over the last year. Nevertheless, they provide the most thorough assessment of the Beatrice State Developmental Center and, for that reason, the committee feels that a summary of their findings is appropriately incorporated into this report.

Department of Justice

The Department of Justice initiated an investigation into the Beatrice State Developmental Center pursuant to the Civil Rights of Institutionalized Persons Act (“CRIPA”), 42 U.S.C. §1997. The focus of an investigation pursuant to CRIPA is patterns and practices of conduct that violate the constitution or federal statutory rights of persons with developmental disabilities who are served in public institutions.

From October 15 through 19, 2007, the Department of Justice conducted an in-depth, on-site review of BSDC with the benefit of expert consultants in the areas of protection from harm, training and behavioral services, psychiatry, healthcare, and nutritional and physical management. Their on-site investigation included interviews with administrators, professionals, staff and residents. The investigation also included observations of residents in a variety of settings. The Department of Justice has concluded “that numerous conditions and practices at BSDC violate the constitutional and federal statutory rights of its residents. In particular, [the Department of Justice found] that BSDC fails to provide residents with adequate: (A) protection from harm; (B) training and associated behavioral and mental health services; (C) healthcare, including nutritional and physical management; and (D) discharge planning and placement in the most integrated setting.”¹²

The DOJ Report concluded “BSDC residents are subjected to abuse and neglect and suffer a high number of incidents that often result in injuries or other poor outcomes. We found consistent patterns of staff actions that often subjected residents to repeated preventable injury.” The safety consultant involved in the DOJ investigation concluded that “the nature of many abuse and neglect allegations, and the frequency with which they are made, suggests a “culture undercurrent that betrays human decency at the most fundamental levels...basic human dignities are violated with considerable regularity at BSDC.”¹³

With regard to the risk of harm to residents, the DOJ observed: “Lack of adequate staff supervision, environmental and safety concerns, as well as the failure to provide adequate behavior and mental health supports all contribute to an increased risk of harm for many

¹² Letter from DOJ to the Honorable David Heineman dated March 7, 2008. (p. 2) (hereinafter DOJ Report)

¹³ DOJ Report p. 4.

residents on a day to day basis.”¹⁴ The report detailed an alarming number of fractures and injuries caused by resident to resident aggression as well as a failure to develop and implement safeguards to reduce the frequency of resident falls. Indeed, the report noted “most of the resident injuries appear to occur due to inadequately addressed behaviors – sometimes from self-injury, and sometimes from unchecked aggression of another resident.”¹⁵

The Department of Justice also recognized that many of the residents at BSDC have medical conditions which compromise the ability of the residents to swallow and digest their food and beverages. Notwithstanding these medical conditions, the DOJ found “several instances in which staff failed to adequately protect residents from consuming food or fluids that could cause them serious harm.”¹⁶

The DOJ’s exhaustive report focused a great deal of attention on “staffing concerns.” In relevant part, the report concludes the following with respect to staffing concerns at BSDC:

Many of the deficiencies at BSDC with regard to safety are linked to staffing difficulties. Our safety consultant characterized the BSDC work force as ‘wrought with exhaustion and discontent’. She reported that some employees pleaded for help in order to acquire adequate staffing assistance for the health and welfare of the residents. During our visit, BSDC’s staff expressed concerns about being assigned to work with residents without being trained on how to properly support and care for them. They also told us about their concerns relative to unsafe working conditions due to severe staff shortages, employee exhaustion, and lack of adequate training, and disgruntled co-workers...

During the week of our visit in October 2007, the facility had vacancies in 117 of 411 direct care staff positions. In addition to these, there were vacancies for a physician, six nurses, a nurse supervisor, a physical therapist, two team leaders, and two compliance specialists. Many of these positions have been unfilled for months.

Given a large number of staff vacancies, the facility has relied heavily upon requiring current staff to work overtime. BSDC’s records reveal that direct care staff had been working overtime, sometimes on double shifts, for more than a year now...Overtime is often mandatory for current BSDC staff. We spoke to numerous staff who related their concerns about having to work multiple double shifts (16 consecutive hours) within a single week to provide care to residents....

Needless to say, the demands of current BSDC staffing practices placed both emotional and physical stress on the staff that may lead to an environment that is more conducive to abuse, neglect and mistreatment. At the very least, tired and overworked staff will be less likely to take the initiative and responsibility

¹⁴ DOJ Report p. 9.

¹⁵ DOJ Report p. 11.

¹⁶ DOJ Report p. 11.

necessary to provide residents with the programming, care and treatment they need, especially if the residents have difficult behaviors or complex healthcare needs.”¹⁷

The DOJ Report was also critical of BSDC’s response to client behaviors. The report noted that the programs themselves are typically well-developed but the implementation of the programs in practice is inadequate. The implementation deficiencies, in turn, were attributed to staffing difficulties. The report noted that “the behavior programs at BSDC involve multiple distinct steps or procedures. New staff, temporary staff, “on-call” staff, or staff pulled from other units are often unfamiliar with the particulars of the lengthy and detailed individual behavior programs. This leads to faulty implementation. The report also observes that the difficulties with implementation lead to “a rather consistent reaction to behavioral problems, where staff quickly move from behavior response blocking to physical restraints to mechanical restraints.”

After acknowledging that many of the residents at BSDC have a dual diagnosis of mental illness and developmental disabilities, the report observed there are deficiencies with respect to psychiatric care. BSDC’s reliance upon a part-time psychiatrist who provided care two days per month was simply inadequate given the number of individuals with mental health issues as well as the severity of the problems they present with.

The report also observed that BSDC “too often fails to provide residents with adequate healthcare.”¹⁸ As one might expect, the concerns centered on health risks related to “bowel impactions and obstructions, pneumonia and aspiration pneumonia, skin breakdown, seizures and fractures due to osteoporosis.”¹⁹ The report observed that many of these types of health conditions are preventable with proper care.

The DOJ Report then went on to make a series of specific recommendations for improvement.

As a consequence of the investigation conducted by the DOJ, the State and the DOJ entered into a summary agreement in order to avoid “protracted and adversarial litigation.” The summary agreement was the basis of a consent judgment, which was signed and entered as an Order and Judgment of the U.S. District Court for the District of Nebraska by Judge Richard G. Kopf on July 2, 2008. That Consent Decree is found in the Appendix at “C”.

Before reviewing the requirements of the Summary Agreement, it is important to note the relationship between the DOJ and the Centers for Medicare and Medicaid (CMS). Though both the DOJ and CMS have ongoing investigations at BSDC, there is in fact and for all practical matters, no relationship between the two entities. Neither the DOJ nor CMS report to the other, share jurisdiction, or coordinate findings or recommendations. The DOJ derives its authorization to act from the Civil Rights of Institutionalized Persons Act (CRIPA), 42 U.S.C. 1997. CMS derives its authority from its appropriations of Medicaid and Medicare funding. Thus, CMS may cause the State to relinquish its Medicare and Medicaid funding while the focus of DOJ is on the protection of the BSDC residents’ civil rights. It is plausible however to suggest that should the

¹⁷ DOJ Report pages 13-14.

¹⁸ DOJ Report page 25.

¹⁹ DOJ Report page 25.

State remedy the deficiencies cited by CMS, the residents' civil rights would be restored. The State is still required though to meet the intent and spirit of the Summary Agreement.

Summary Agreement

The Summary Agreement is a lengthy document divided into three sections: Legal Framework, Office of the Independent Expert and Remedial Measures. Each section sets forth specific requirements the State has agreed to meet.

The legal framework section not only establishes the jurisdiction of the DOJ to act pursuant to CRIPA but it sets out the timeframes for compliance. Throughout, there are specific measures for the State to accomplish. Unless otherwise noted, compliance with these measures is to begin within 90 days of the filing of the Consent Judgment. Furthermore, the Consent Judgment recognizes that both the State and the DOJ anticipate full implementation of all provisions will take four years. The Court will maintain jurisdiction an additional year to ensure maintenance of the changes.

Unique to the DOJ agreement as compared to the CMS investigation is the appointment of an Independent Expert, John J. McGee, Ph.D. Because the DOJ focus is the protection of individuals' civil rights, an independent expert is appointed to assist the State. The Independent Expert reports directly to the Court. He is required to report at least quarterly to the parties regarding the State's implementation efforts and compliance with the Summary Agreement.

The State is required to notify the Independent Expert regarding any death of a resident; serious incidents, including but not limited to, allegations of abuse and/or neglect; incidents producing a serious injury; incidents involving prolonged physical and/or mechanical restraint; and incidents involving law enforcement personnel. The Independent Expert is to be also provided with copies of discharge plans for residents transitioning out of BSDC.

The last section of the Summary Agreement is the most lengthy as it sets out the steps to be taken to correct those violations of the residents' civil rights. The "Remedial Measures" section covers an exhaustive range of care issues. Again, unless otherwise specified, compliance efforts with these measures were to be underway within 90 days of the Consent Judgment being filed.

While the Committee believes the requirements in the Settlement Agreement provide an appropriate road map for improvements within BSDC, it is impossible to verify the current status of each of these requirements as the Independent Expert has not issued a report to date. The Independent Expert was to provide a quarterly report on October 1, 2008 but the Committee has been informed that his first report will not be available until the end of December.

The DOJ investigations focus on the civil rights of those in institutions and the Department's guidelines are considered more of a "baseline" or "floor," while CMS' standards are more specific. As a consequence, even if all of the requirements of the Settlement Agreement are met, it is possible that CMS will still have specific concerns. It is also the Committee's

understanding that even though there are explicit deadlines in the Settlement Agreement, the DOJ realizes that changes of the type envisioned by the Settlement Agreement will take a considerable amount of time.

Centers for Medicare and Medicaid Services

As noted earlier, BSDC is an “intermediate care facility for people with mental retardation” (ICF/MR).²⁰ As an ICF/MR, and in order to qualify for Medicaid reimbursement, BSDC must be certified and maintain compliance with certain federal standards, known as “Conditions of Participation” (CoPs).²¹

The Centers for Medicare & Medicaid Services (CMS) is the federal agency responsible for ICF/MR certification and compliance. To determine whether a provider is complying with a particular “condition of participation” (CoP), CMS surveyors evaluate the manner and degree to which the provider satisfies each of the standards within the condition.²² A “condition level” deficiency (as opposed to a less serious “standard level” deficiency) is one “where the deficiencies are of such character as to substantially limit the provider's or supplier's capacity to furnish adequate care or which adversely affect the health and safety of patients.” The principal focus of the survey is on the “outcome” of the facility’s implementation of ICF/MR active treatment services.²³ In other words, attention is focused on what actually happens to individuals: “whether the facility provides needed services and interventions; whether the facility insures individuals are free from abuse, mistreatment, or neglect; whether individuals, families and guardians participate in identifying and selecting services; whether the facility promotes greater independence, choice, integration and productivity; how competently and effectively the staff interact with individuals; and whether all health needs are being met.”²⁴

There are several components of the “active treatment process”: (1) a comprehensive functional assessment, (2) an individual program plan (IPP), (3) program implementation, (4) program documentation, and (5) program monitoring and change.²⁵ As part of the initial comprehensive functional assessment, the individual’s interdisciplinary team is to identify all of the individual’s:

- Specific developmental strengths, including individual preferences;
- Specific functional and adaptive social skills the individual needs to acquire;
- Presenting disabilities, and when possible their causes; and
- Need for services without regard to their availability.²⁶

²⁰ According to the Centers for Medicare and Medicaid Services, there are currently 7,400 ICF/MR’s in the United States, which serve approximately 129,000 people. Most of the individuals who receive care provided by ICF/MR’s have other disabilities as well as mental retardation. Many of the people who are served by this program are also non-ambulatory, have seizure disorders, behavior problems, mental illness, are visually-impaired or hearing-impaired, or have a combination of these conditions. “Background and Milestones—Intermediate Care Facilities for People with Mental Retardation (ICF/MR)” available at

http://www.cms.hhs.gov/CertificationandCompliance/downloads/ICF/MR_Background.pdf.

²¹ 42 CFR Part 483, Subpart I, Sections 483.400-483.480.

²² These standards are often referred to as “tags.”

²³ State Operations Manual - Appendix J - Guidance to Surveyors: Intermediate Care Facilities for Persons With Mental Retardation. Available at http://www.cms.hhs.gov/manuals/Downloads/som107ap_j_intercare.pdf

²⁴ http://www.cms.hhs.gov/GuidanceForLawsAndRegulations/09_ICF/MR.asp

²⁵ 42 CFR 483.440(c)(3), 42 CFR 483.440(c), 42 CFR 483.440(d), 42 CFR 483.440(e), and 42 CFR 483.440(f).

²⁶ http://www.cms.hhs.gov/manuals/Downloads/som107ap_j_intercare.pdf

The interdisciplinary team is then responsible for preparing an IPP, which includes opportunities for individual choice and self-management, identifies objectives, and includes strategies, supports, and techniques to be employed. The client then receives a continuous active treatment program “consisting of needed interventions and services in sufficient intensity and frequency to support the achievement of IPP objectives,” with a comprehensive functional assessment on an annual basis.²⁷

History of CMS Involvement at BSDC

Both CMS and the Nebraska Department of Health and Human Services (through the Licensure Unit of the Division of Public Health) have conducted surveys at BSDC over the last ten years. In fact, up until 2006, the State of Nebraska completed all of the surveys at BSDC. During 2006 and 2007, CMS used its own surveyors to survey BSDC (except for complaint surveys) and in 2008, CMS again began to partner with the State of Nebraska surveyors when surveying BSDC.

Results of CMS Surveys

There are approximately 2,000 pages of “survey activity” concerning BSDC in the last decade. Since September 2006, BSDC has been surveyed on nine separate occasions, including one full survey, four follow-up surveys to immediate jeopardy situations, three other follow-up surveys, and an incident investigation. BSDC was determined to be out of compliance with seven of the eight CoPs in September 2006, and at all times since, BSDC has remained out of compliance with at least two conditions of participation.

The survey that is the subject of ongoing litigation between BSDC and CMS is the survey with the completion date of November 7, 2007. In this survey, CMS determined that four CoPs were not met and that one deficient standard posed an “immediate jeopardy” (IJ) to client health and safety. The out of compliance CoPs were:

- Governing Body and Management;
- Client Protections;
- Facility Staffing; and
- Active Treatment Services.

As CMS stated, “The facility failed to take appropriate corrective action with substantiated physical abuse cases, with allegations of abuse, neglect and mistreatment, with injuries of unknown source investigations, and with client to client abuse investigations.”²⁸ CMS summed up the situation in this way:

“One begins to see how the various unmet CoPs begin to feed each other: lack of sufficient staff leads to lack of time to train staff, which leads to staff being unfamiliar with the needs of clients, which leads to lack of active treatment programs, which leads to frustrated and disruptive clients, which leads to abuse

²⁷ Id.

²⁸ Respondent’s Pre-Hearing Brief, July 17, 2008.

and mistreatment of clients by staff and by other clients, etc. And it is likely that the staff shortages affected BSDC's unwillingness to adequately discipline staff involved with client mistreatment. BSDC's problems were systemic in nature, which leads to the next, unmet CoP, [Governing Body and Management]."²⁹

CMS notified BSDC that its participation in the Medicaid program would be terminated on March 7, 2008, if the situation was not corrected. A follow-up survey concluding on March 4, 2008 resulted in a determination that five CoPs were not met and that three IJ's existed. A further follow-up survey on March 7, 2008 found that the IJ's had been removed, but that BSDC continued to have condition-level deficiencies (four). CMS then terminated BSDC's Medicaid approval because of its inability to meet the Medicaid CoPs.³⁰

At the June 23, 2008 public hearing, Jodi Fenner, Legal Counsel to the Nebraska Department of Health and Human Services, confirmed an outline of BSDC's recent relationship with CMS:

SENATOR LATHROP: ...[A]s I read the history of our CMS evaluations and the State's response, it looks something like this: CMS comes in and says, these are the problems. The State has responded by saying, we'll do this to fix it. CMS has come in and said, okay, what did you do? And we've said, well, we didn't even get everything done we said we'd do. And they say, you know, you're out of compliance. And then we say, well, we'll do this to get into compliance. And that's been the history since 2001—a series of evaluations, promises by the State followed by more evaluations where we admittedly haven't done what we promised to do and we remain out of compliance.

JODI FENNER: That is correct.

SENATOR LATHROP: And essentially what's happened to us, to us being the State of Nebraska, is that finally CMS said enough is enough. And we had in, I think it was December, we made our last promise and they came in since December and said, we're decertifying you because you've given us promises and you're not fixing the problem. Would that be a fair summary of our relationship with CMS since 2001?

JODI FENNER: I think that's correct.

²⁹ Id. at 10.

³⁰ Because BSDC filed an appeal prior to the termination date, "CMS has held the termination in abeyance, pursuant to Section 1910(b)(2) of the Social Security Act, which provides that a Medicaid provider agreement with any [ICF/MR] that is dissatisfied with the Secretary's determination that the ICF/MR does not qualify for Medicaid participation and that has requested a hearing, will continue in effect until a hearing decision is issued by the Secretary." Id. at 2.

CMS' Discussions with the Committee

The Committee also met with representatives from CMS in an unrecorded meeting. Based on this meeting, it is the understanding of the Committee that on average five percent of facilities are out of compliance with one or more of the eight CoPs nationwide. The Committee also understands that the only other facility that did not meet seven out of the eight CoPs was in Illinois, five years ago. There has been only one facility besides Nebraska that has had its funding terminated.

As mentioned above, at the time of the September 2006 survey, BSDC was found to be out of compliance in seven of the eight CoPs. As a result, CMS recommended consultation because the methods that BSDC were using were outdated. BSDC reacted slowly to this recommendation but eventually brought in a consultant. In the end however, the facility was unable to make necessary changes and the November 2007 survey found that BSDC still remained out of compliance with four of the CoPs. As a result, CMS began the termination process.

One of the main concerns expressed by CMS was, though there appeared to be a will to make changes, there was little or no follow-through. CMS provided BSDC with many opportunities to make necessary changes but even during its most recent survey in April 2008, BSDC remained out of compliance with three CoPs. In most cases where a facility is found to be out of compliance with a CoP, it is given 90 days to show improvements. In the case of BSDC, it has been given over 500 days by CMS. While CMS indicated that the plans of correction have improved, they were still not satisfied with the changes at the facility.

Nebraska Advocacy Services, Inc.

In December 2007, Nebraska Advocacy Services, Inc. (NAS) issued a report concerning its own ongoing investigation of BSDC.³¹ NAS is "federally mandated to provide legal and other advocacy services on behalf of persons with disabilities, including persons with developmental disabilities and persons with mental illness." It is further authorized to investigate potential abuse or neglect, as well as the health and safety of individuals with developmental disabilities in both institutional and community settings.³²

NAS has reviewed the CMS surveys dating back to 2001, and since November 2006, its legal advocacy staff has visited BSDC twice a month to conduct inspections and on-site reviews. While NAS documented a history of problems at BSDC in its report, it provided extensive details of BSDC's most recent and relevant failures in 2006-2007.³³

31 The NAS report, "An Indictment of Indifference--A Report of the Investigation of the Beatrice State Developmental Center By Nebraska Advocacy Services, Inc.," is attached.

32 Federal statutes, including the Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. Sect. 15001 et. seq.

33 The chronology of NAS's investigation is contained on pages 21-24 of its report.

In its report, NAS incorporates the CMS findings and conclusions from 2006-2007, confirming the CMS findings from its own ongoing observations, analyses, inspections, record reviews, and consultations. In sum, the practices at BSDC have, according to NAS, “substantially departed from accepted professional standards of care” in violation of federal law and regulations. “The evidence is clear that Nebraska state officials failed and continue to fail to provide adequate active treatment/habilitation for residents at BSDC; rather, staff convenience necessitated by chronic understaffing drives habilitation.”³⁴

Summary of DOJ, CMS and NAS Investigations

While the Committee has provided a summary of the DOJ, CMS and NAS findings, it is important to remember that these summaries are supported by very troubling instances of abuse and neglect at BSDC. A few examples of how those instances of abuse and neglect impact the lives of the residents at BSDC are set forth below. These are merely examples. Unfortunately, the CMS, DOJ and NAS reports are replete with equally appalling instances of abuse and neglect visited upon the residents at BSDC as a consequence of the systemic failures at the BSDC:

BSDC investigators substantiated mental abuse of resident WC after concluding that staff engaged WC in a “game” of what could be called “canine catch” in August 2007. This involved staff tossing WC’s pop bottle across the room, instructing the resident to retrieve or “fetch” the bottle, and then return it. After repeating this “game” at least twice, a staffer was observed hiding the bottle behind her back while motioning WC across the room to find the bottle. Not realizing that the staffer had the bottle, WC ran around the room aimlessly searching for it.

BSDC investigators substantiated both mental and physical abuse of resident UA, who requires enhanced staffing to meet his needs. In June 2007, a direct care staff worker began to taunt and upset UA while playing a board game. After the resident reached out in frustration, the staffer retaliated by shoving UA and knocking him to the floor, causing a purple bruise to the resident’s right elbow.

BSDC investigators substantiated both mental and physical abuse where, in April 2007, a male staff worker “slammed” resident TW into a wall for pretending to take a female staff worker’s lunch item. After the push, TW became sad, went to the bathroom, and cried. TW said the altercation “knocked the wind out” of him. BSDC confirmed three prior allegations of physical abuse of this resident by the same staff worker in the prior nine months.

BSDC investigators substantiated both verbal and physical abuse by a staff worker against resident SV, who uses a wheelchair. In April 2007, the staff worker observed SV start to spit out medicine she had given to him. The staff worker used demeaning names to address the resident and then held the resident’s head against the headrest on his wheelchair, forcing a spoon into his mouth; after that, she

³⁴ Page 3.

forcibly held a washcloth across SV's mouth, trying to make him swallow. According to an eyewitness, this situation continued for 10 minutes.

BSDC investigators substantiated verbal abuse of resident RU by a staffer in June 2007. While taking a resident's blood sugar reading nearby, a nurse overheard a staffer talking to RU in the adjacent bathroom. The nurse reported that the staff worker verbally abused RU while he was bathing, saying: "God damn it, don't you know how to take a bath?" As the resident began to cry, the staffer then said: "So now you think you are going to cry like a b__ch and that is not going to help you out one bit. Let's get this done."

BSDC investigators substantiated neglect by a direct care worker who, in August 2007, failed to bathe, check, change diapers, or re-position six residents assigned to her care; instead, BSDC investigators found that the staffer watched television and slept during her work shift.

BSDC investigators substantiated neglect where, in August 2007, four staff workers in one unit failed to check or change resident OR for four-and-a-half hours. During that time, none of the staff re-positioned the resident, interacted with him, completed his treatments, or conducted his programs. The staff of the next shift discovered OR to be soiled and completely soaked in urine, through his clothes.

BSDC investigators substantiated neglect where, in July 2007, two staffers had placed resident NQ in her bed for a nap and then left with four other residents for a trip to a softball game. The resident, who should have been checked and changed every two hours by staff on duty, was discovered five hours later still in her bed in the same attire as before, with her clothes and bedding soaked in urine."³⁵

³⁵ DOJ Report pages 4-6.

IDENTIFIED PROBLEMS/CONCERNS

Needless to say, the reports from DOJ, CMS and NAS document a horrible state of affairs at BSDC. These reports also document the fact that the problems at BSDC did not develop overnight.

The Committee heard repeatedly how BSDC represented the gold standard in providing care to those with developmental disabilities in the 1990's.³⁶ By contrast, the surveys which began in 2001 as well as the reports of the DOJ and NAS chronicle the deteriorating conditions from 2001 through 2007 culminating in an intervention by the United States Department of Justice, which concluded that care at Beatrice State Developmental Center violated the constitutional rights of the residents, as well as the conclusions of CMS which led to the decertification of BSDC as an ICF/MR and the loss of over \$28,000,000 in funding.

These reports also document that little, if anything, was done to interrupt the development of this crisis before the intervention by the Department of Justice and the decertification by CMS. Since that time, the administration has stepped up its efforts to address the deficiencies of BSDC. It is the considered opinion of the Committee that the attempts by the administration to “clean up” the “Beatrice problem” are, in many instances, too little too late. Indeed, many of the efforts to correct the problem are misguided and are most certainly doomed to failure.

As an overall observation, there is a philosophical failure in the State's approach to resolving the issues that plague BSDC. We believe the proper approach to the resolution of the deficiencies at Beatrice State Developmental Center begins with the recognition that our goal should be to return the State's system of delivering services to individuals with developmental disabilities to the place of prominence it enjoyed in the 1990's. By contrast, the approach by the State might best be characterized as “what's-the-least-amount-we-have-to-do-to-get-by”. For reasons more specifically set forth in the discussion which follows, we believe this approach sets Nebraska on a course that will not satisfy CMS nor provide the services individuals with developmental disabilities deserve.

In the discussion that follows, the Committee more specifically sets forth specific findings and concerns with respect to the delivery of services to individuals with developmental disabilities in the State of Nebraska. As indicated in the introduction, our investigation necessarily involved a review of the waiting list and services provided in the community setting. For that reason, our findings and concerns will likewise address these two important subjects.

The State's Strategy for CMS Re-Certification

As a consequence of the CMS survey completed November 7, 2007, the Centers for Medicare and Medicaid Services decertified BSDC. The result was a loss of over \$28,000,000 in funding annually for an institution with a budget of just over \$50,000,000. The State's approach

³⁶ Testimony of Dr. Lee Zlomke: “Well, when I felt we were at our very best, when other facilities across the country came here to see how we did active treatment and psychological services, was in the early to mid 90's.” (Testimony of Dr. Lee Zlomke, June 23, 2008, page 64). See also, testimony of Ron Stegemann, June 23, 2008, p. 80, as well as the testimony of Joan O'Meara, August 21, 2008, page 5.

in the wake of the CMS decertification is what may fairly be described as the “recertification strategy”. That approach may be summarized in this way:

- (1) Appeal the decision of CMS to decertify. The appeal will allow federal funding to continue pending a decision. It also permits the state to “buy time” which will allow more time to resolve the problems at BSDC.
- (2) “Right size” BSDC. The hallmark of this element is to reduce the population of BSDC to a point where the once understaffed facility has enough employees to serve the smaller population of residents.
- (3) While the CMS appeal is pending, apply to CMS to have BSDC recertified.

The state’s recertification strategy is troubling in a number of respects which are evident as the particular consequences of this approach are examined.

The state has appealed the decision of CMS to decertify BSDC. During the pendency of the appeal, CMS funding will continue. The appeal, which was argued November 19 and 20, 2008 before an Administrative Law Judge, is not expected to result in a decision until sometime in the summer of 2009.

It is the collective judgment of the Committee that the State’s prospects for prevailing in this appeal are dim. The nature of the appeal is such that the only question for the Administrative Law Judge to decide is whether or not the State was in “substantial compliance” at the time of the November 7, 2007 survey. As a consequence of the State’s track record leading up to the November 7, 2007 survey as well as the fact that the State was out of compliance with four out of eight conditions of participation, it is unlikely that an Administrative Law Judge will conclude that the BSDC was in “substantial compliance” at the time of the November 7, 2007 survey.

Perhaps because the State has come to the very same realization as the Committee, the State’s strategy includes a fallback position. The State’s position, as it anticipates an adverse decision from the Administrative Law Judge, is to make various staff and managerial changes at BSDC and attempt to secure CMS recertification at some point before an adverse decision by the Administrative Law Judge. The problem with the “recertification strategy” is the approach taken by the State is not likely to result in recertification by CMS.

The State’s approach to resolving the “problems” at BSDC in anticipation of recertification is to reduce the number of people living at BSDC from just over 300 as of the spring of 2008 to 200 by the end of December 2008.³⁷ To reduce the population at BSDC, the State will offer BSDC residents an opportunity for “community placement.” Community placement has led to the placement of many residents in nursing homes. The balance have been or will be offered opportunities to live in a residential facility operated by community-based providers.

³⁷ The current census at BSDC is 250.

The task of moving residents from BSDC to the community on a voluntary basis ultimately results in a process by which community-based providers sort through the BSDC population for patients for whom care can be provided within the financial limitations imposed by the State's formula for reimbursement of providers. The consequence to the population at BSDC is that the patients with the fewest needs and the less injurious behaviors are moved to the community first. The other side of that equation is that when the State reaches its goal of reducing the BSDC population to 200, those who remain will be those with the most profound health and developmental disabilities and those with the most difficult behaviors. Ultimately, this sorting out process may help BSDC to limit its services to those for whom services should be provided at an ICF/MR, but the process results in an unintended consequence. By reducing the population to 200 of the more difficult cases, the State has made the prospects of recertification in a future survey more difficult. When CMS returns to conduct a survey for recertification, it will be observing care provided to patients with the most difficult behaviors and the most profound disabilities. Similarly, file reviews which will be conducted as part of the survey will involve the files of the State's most problematic individuals with developmental disabilities.

The problem with a strategy that involves reducing the population and seeking recertification was best described by a Kentucky official involved in implementing a similar strategy following decertification by CMS. This official indicated that once a state run ICF/MR has been decertified, and the decision has been made to seek CMS recertification, several things are important to understand. First, because the facility has been decertified, recertification by CMS will necessarily involve a survey which will be conducted at a higher level of scrutiny. The apparent CMS logic behind this heightened level of scrutiny is that if a state run ICF/MR has been decertified, it has been found to be out of compliance on conditions of participation on multiple occasions and tendered plans of correction have not been implemented as promised. Thus, the history of failures justifies the heightened level of scrutiny.

In addition to the higher level of scrutiny by CMS in the recertification process, recertification will now involve observations of care provided to a more difficult cohort of patients. Thus, the combination of a higher level of scrutiny at a time when care is provided to a more challenging population make this strategy questionable at best.

The Kentucky official offered two other observations relative to the recertification process. First, CMS will not pass a state ICF/MR with a "gentleman's C." In other words, recertification will not happen because BSDC was found to be "good enough." Recertification will only happen if fundamental changes occur which address the shortcomings at BSDC as measured by the CMS standards.

The second observation made by the Kentucky official is that recertification will not happen without a substantial commitment of resources. The problems that lead to decertification are deep, substantial and systemic. These types of problems will not be rectified by rearranging staff and offering more excuses for failures to meet CMS standards.

It is the committee's observation that the necessary commitment of resources has not been made by the State of Nebraska. Rather, the State has adopted an approach, with only a few

exceptions, in which changes are made at BSDC only when they can be made without the expenditure of anything greater than nominal resources.

In summary, we believe the “recertification strategy” is not likely to succeed. This strategy has inherent flaws in its reasoning that diminish the chances of success. The strategy has at its foundation the assumption that the State is able to resolve the CMS deficiencies by the time the recertification process is undertaken. The Committee has grave doubts about the State’s ability to resolve all of the issues facing BSDC, particularly the staffing issues which are central to the greatest share of problems identified by CMS and the DOJ. Because resolution of the staffing issues is central to the success of the State’s attempts at recertification, those issues will be addressed in more detail in the following section.

Staffing Issues

Both the DOJ and CMS identified staffing problems as central to the problems at BSDC. As the DOJ observed, “the facility had vacancies in 117 of 411 direct care staff positions. In addition to these, there were vacancies for a physician, six nurses, a nurse supervisor, a physical therapist, two team leaders and two compliance specialists.”³⁸ These vacancies were in addition to the direct care staff positions whose numerous vacancies led to the well-documented overtime hours at BSDC. The numerous vacancies, in turn, resulted in the failure of the state to meet the CMS conditions of participation and were, according to the DOJ, a significantly contributing circumstance to the numerous cases of abuse and neglect.

The Committee appreciates the fact that the administration has filled a good number of management and professional care positions over the course of the last twelve months. Indeed, the state has filled the following managerial and professional staff positions since the November 7, 2007 survey:

- One Orientation Facilitator
- One Medical Director
- One Nurse Practitioner
- Speech Pathology*
- Physical Therapy*
- Psychology*
- Neurology*
- Psychiatry*
- Nutritional Management*
- Medical Chart Reviews*
- Neighborhood Services Administrator*
- QI Director*
- Active Treatment Administrator*
- Investigations Administrator*

* Filled by contract worker.

³⁸ DOJ Report page 13.

Nevertheless, the following managerial and professional staff positions remain unfilled:

- Two Activity Specialists
- Four HSS Treatment Team Leaders
- Two Human Service Treatment Specialists I
- Two Human Service Treatment Specialists II
- Three Licensed Practical Nurses II
- Four Nurses II
- One Nurse Supervisor
- One Physical Therapist II
- Two Psychologists/Clinical
- One Security Chief
- One Social Worker II
- One Speech Pathologist II³⁹

Notwithstanding the improvements at the managerial and staff level, shortages at the direct care staff positions continue. As measured by all overtime hours, BSDC still continues to use 11,000 hours of overtime as of September 2008.⁴⁰

The ongoing problems with staffing are particularly frustrating for the Committee. In the 2008 legislative session, Senator Kent Rogert introduced, and the legislature passed AM 2451 to LB 959 which provided for \$1.5 million to be used for recruitment and retention at BSDC. Notwithstanding the specific purpose to which this money was appropriated, only \$123,000 has been spent on recruitment and retention. Over \$688,000 has been spent on temporary help.

The failure to use the appropriated funds for recruitment and retention is particularly concerning given that shortages of direct care staff persist. These direct care staff are the individuals with face to face, day to day contact with the residents of BSDC. The failure to have sufficient numbers of direct care staff is at the core of the issues identified by the DOJ and CMS. The requirement of mandatory overtime as a substitute for sufficient staffing has been identified as the principal reason for abuse and neglect of residents, failure to provide active treatment to the residents, and appears as the principal reason for failure to provide adequate staff development at BSDC.

To be sure, there are challenges hiring people to serve a community of individuals with high needs and behaviors. The problems are compounded by the fact that BSDC is situated in a smaller community. Nevertheless, these staffing issues have been identified as problems in surveys and investigations conducted well over a year ago and there is simply no excuse for the fact that they persist.

The difficulties with staffing at BSDC are not limited to the nature of the work and the small town setting in which BSDC finds itself. There are many issues which persist which

³⁹ More detailed information on these positions can be found in the October 8, 2008 Settlement Letter that is found in the Appendix to this Report at "G".

⁴⁰ HHS information supplied to the fiscal office.

contribute to the difficulty in fully staffing BSDC. Some of those problems are identified in the section which follows.

BSDC As An Employer

The Committee had occasion to conduct hearings at BSDC. Employees at all levels were encouraged to provide input about BSDC. In addition to employee input at hearings that were conducted at BSDC, direct-care employees were provided surveys by the Committee. The purpose of the surveys was to provide the Committee with a sense of employee perceptions of the work place at BSDC. The results of the survey can be found in the Appendix at "I".

The input from employees at BSDC provided important insight into the difficulties management experiences filling vacancies at BSDC. Employees told us time and again that at one time BSDC was regarded in the Beatrice community as a good place to work. Indeed, we heard many stories of generations of family members serving individuals with developmental disabilities at BSDC. Witnesses spoke frequently of the former reputation of BSDC as a good job for members of the Beatrice community.

The change in this perception in Beatrice is a significant contributing circumstance to the difficulties BSDC faces in filling vacancies. Concerns expressed by employees relate to a change in the "culture" at BSDC. Employees more often than not feel left out of the process. Several employees testified that questions, concerns and suggestions went up the organizational chart but no response or feedback was ever provided by management.

Interestingly, most employees, and the employee union representative, indicated that the rate of pay was not the most significant issue to employees at BSDC. The biggest impediment to job satisfaction related to the issues of culture, the absence of an engaged management and management's abuse of mandatory overtime.

Employees repeatedly expressed concern regarding disciplinary practices at BSDC as affecting their job satisfaction. To be sure, BSDC must necessarily employ a zero tolerance policy for abuse and neglect. On the other hand, the circumstances in which employees find themselves in what is generally referred to as a "west Texas vacation" is problematic. In each instance in which a resident makes an allegation of abuse or neglect, an employee is suspended pending an investigation. During the first six days of suspension, the employee is not paid by BSDC. They are paid for subsequent days until the investigation is complete. If they are exonerated, they do receive back pay for the first six days.⁴¹ In the meantime, the employee has had their stream of income interrupted while at the same time they have been instructed to wait by the phone for the results of the investigation into the allegations of abuse and neglect.

While BSDC certainly has a duty, consistent with its zero tolerance policy, to separate the accuser from the accused during the pendency of the investigation, nothing prevents the employees from being reassigned to administrative positions pending the completion of the investigation. This would, in the Committee's judgment, appear to be a better course of practice from the point of view of employee morale as well as a cost saving measure.

⁴¹ Information provided to the Committee by Director Wyvill.

An additional problem, the perception in the community that the State of Nebraska has not made a commitment to keep BSDC open into the future, was identified by the employees at BSDC as a contributing circumstance to the difficulties this institution faces in hiring workers in the Beatrice community. When asked about BSDC as an employer in the Beatrice, a number of individuals expressed that members of the Beatrice community regard the future of BSDC as uncertain. This uncertainty has led to a reluctance to make a commitment to work at BSDC when there has been no clear indication by the State of Nebraska that the institution will remain open.

Management

In many ways, the issues regarding management are a mirror image of the concerns expressed by the employees of BSDC. This is certainly true with respect to middle management at BSDC.

The bigger concern, however, for the Committee is not with BSDC middle management. Rather, the greatest concern regarding management of BSDC is with the CEO of the Department of Health and Human Services, the Director of the Division of Developmental Disabilities and the CEO of the Beatrice State Developmental Center.

Ultimately, Beatrice represents a failure of management. Too often the Committee has heard excuses for these failures. Those excuses range from the geographical location of BSDC to past reorganizations of the Nebraska Department of Health and Human Services. In the end, however, these excuses must give way to accountability. Indeed, the Legislature was told that the reason the Nebraska Department of Health and Human Services was reorganized in the first place was to provide accountability. It is the considered judgment of the Committee that accountability of top management must necessarily be measured not by the process employed by management but by the results. Judged by the results, these individuals, however well intentioned, have failed to set BSDC on a proper course. Indeed, the CEO of the Department of Health and Human Services has presided over BSDC at a time when the Department of Justice found that the State violated the civil rights of the residents and CMS decertified the institution and withdrew \$28,000,000 annually in funding. The Director of the Division of Developmental Disabilities and the CEO of the Beatrice State Developmental Center were admittedly not serving in their current capacity at the time of the November 2007 CMS survey and the DOJ inspection. On the other hand, they have been unable to rectify the problems at BSDC notwithstanding the assistance of Liberty Consulting Group, which was paid \$1.5 million to provide a plan for turning BSDC around.

It is not only the failure to properly manage BSDC but the apparent lack of any vision for what BSDC might be for the people of the State of Nebraska in the future. Rather, these individuals who have had frequent contact with the Committee have demonstrated a mentality of “what-do-we-have-to-do-to-get-CMS-off-our-backs” rather than vision and leadership. They have also presided over the deterioration of the culture at BSDC. Witnesses often said that BSDC stood in the 1990’s as an example of a well-run state institution for individuals with developmental disabilities. Witnesses attributed this period during which Nebraska enjoyed a

good reputation nationally to not only a commitment by the State to individuals with developmental disabilities but the presence of management which cared about the residents as well as the staff. This is simply not the case today.⁴²

The Committee does not make this criticism lightly. We are struck by what the necessity of a special investigative legislative committee says about the management of this division of the Department of Health and Human Services. An agency, a department or an institution should operate without the level of dysfunction identified by DOJ and CMS. Indeed, these agencies should not require micromanagement by the legislative branch and the fact that they do demonstrates all too clearly that those in charge are in over their heads.

Those who call BSDC home as well as those who wait in line for services deserve better.

Community-Based Programs

Discussion regarding community-based programs initially presents in the context of moving people from BSDC to community-based programs. The first observation of the Committee with respect to community-based programs relates to the appropriateness of placement of individuals in a community setting. While the United States Supreme Court in *Olmstead* very clearly expressed that the ADA requires placement in the most integrated and least restrictive setting, the admonition calls for the option of placement in a community setting when such a placement is in the best interests of the individual.

It is important to recall that many of the residents at BSDC present a dual diagnosis, which results in significant challenges to appropriate community-based programs. For example, three-fourths of the residents at BSDC have speech and language impairments; almost half are non-ambulatory and two-thirds have a history of seizure disorders, 10% of which are uncontrolled. More significantly, half the residents receive medications to control behavior that would injure themselves or others and 40% have significant behavioral needs requiring behavioral program intervention.⁴³ These statistics demonstrate the challenges with placement in a community setting. It is the opinion of the Committee that the sole criteria for placement into the community is the best interests of the individual and the community to which they will be placed, rather than considerations of cost savings which invite placement where individuals do not receive the services they require or which place the individual or the community at risk with uncontrolled behaviors.

Real issues exist regarding capacity. As the DOJ observed, a barrier to community placements from BSDC is “the lack and/or perceived lack of available community resources, including inadequate community provider expertise and capacity.” The DOJ noted that “the State appears to provide inadequate expertise and support to place individuals and to their providers when behavioral and mental health concerns and crises emerge. The lack of adequate community resources, real or perceived, has the effect of discouraging families and guardians from pursuing community alternatives to BSDC placement.” The result, as expressed by the

⁴² Testimony of Dr. Lee Zlomke, June 23, 2008, page 64, and testimony of Patricia Crawford, August 21, 2008, pages 46 and 47.

⁴³ NAS Report page 15.

DOJ, is that “an unfortunate cycle has been created: community resources are not developed because parents and guardians oppose and the parents and guardians oppose because sufficient community resources have not been developed. The State has not done enough to break this cycle by creating sufficient incentives for community providers to respond to service referral requests and to develop homes and resources to meet the placement needs of BSDC residents.”⁴⁴

The problems with service delivery in the community are more than perception. The DOJ observed: “Problems with service-delivery and monitoring of the community appear to be having a direct, negative impact on the health and welfare of a number of clients with developmental disabilities who live in the Nebraska community system. During our visit, for example, we learned that a number of community clients have experienced significant problems associated with their inadequately addressed behaviors and/or inadequately treated mental illness....It seems clear that the State has not done enough to ensure that adequate behavioral supports and psychiatric care are provided to clients in the community.” The DOJ also observed that the problems in the community-based programs affect BSDC residents: “As referenced above, problems in the community like this have a negative impact on current BSDC residents as well. If the State does not identify and resolve such community problems, certain BSDC residents, who are entitled to adequate and integrated community placements, will not have a viable alternative to ongoing, unduly restrictive care at the BSDC institution.”⁴⁵

To the extent community-based placement is regarded as the panacea for the right sizing of BSDC, identified problems abound. The Committee is aware that there are many competent community-based providers who offer quality services to individuals with developmental disabilities. On the other hand, serious issues relative to capacity and support of community providers exists.

In many ways, the difficulties of BSDC are also present in the community-based provider system. The Committee heard testimony regarding staffing shortages and the lack of properly trained staff with community-based programs. Very clearly, these problems cause difficulties as the State attempts to move people from BSDC to the community. They also present difficulties for those who rely on community-based programs for services and those on the waiting list hoping one day to receive community-based services.

In addition to issues that relate directly to transitioning patients from BSDC to community-based programs, there are deficiencies with oversight in community-based programs that are common to those transitioning from BSDC as well as those currently receiving services in a community-based placement.

Oversight is a two-step process. At first there must be in place proper regulations to govern the providers. Secondly, there must be an adequate number of surveys. In both respects, the State’s community-based provider system falls short.

Where ICF/MR’s are governed by CMS regulations, no corresponding comprehensive regulations govern community-based providers. Certainly no one wants to see regulation for the

⁴⁴ DOJ Report page 35.

⁴⁵ DOJ Report pages 35-36.

sake of regulation. On the other hand, standards such as those employed by CMS are regulations which reflect the standard of care for the treatment of individuals with developmental disabilities.

Not only does Nebraska lack comprehensive regulations for the governance of community-based providers, it also lacks sufficient personnel to inspect or survey the community-based providers. In testimony presented to the Committee (the Licensure Unit of the Division of Public Health of the Nebraska Department of Health and Human Services), which is responsible for surveying community-based providers, indicated that there are four inspectors responsible for surveys of all community-based providers in the State. The consequence of the low number of inspectors means the community-based providers are reviewed once every four or five years rather than annually which is the case for ICF/MR's. This simply is not enough.

Waiting List

While the developmental disability spotlight has most recently been shown on BSDC, a similarly troubling circumstance exists for those on the so-called waiting list. The waiting list is a phrase used to describe those with developmental disabilities who get in line hoping one day the State of Nebraska will provide necessary services. The growing numbers on the waiting list stand as a testament to the consistent neglect shown to the those with developmental disabilities.

Any Nebraskan who has a developmental disability is potentially eligible for services in Nebraska, according to the Developmental Disabilities Services Act. Once their eligibility is determined, a request may be made by the individual or their family and they select a date when they believe services will be necessary for that individual. They are then placed on the Division of Developmental Disabilities Registry. The individual does not go on the waiting list until their date of need has been reached or passed. Individuals on the waiting list were last offered services in 2006.

In contrast to 1997 when Nebraska had only a handful of persons on the waiting list and passed their date of need, as of July 1, 2008, there were 1,865 persons officially waiting for services in Nebraska. Of these, 1,628 were waiting for residential services. In total, there are 2,443 requests for services from these individuals.

Since 2006, there have been two groups of individuals who have received services, those with an emergency need (priority one status) and graduates from Nebraska high schools or those who have turned 21 years of age. Services are authorized on an emergency basis if there is a threat to the health or safety of the individual. If this occurs, the individual is eligible for day or residential services. Those on the waiting list who graduate from a Nebraska high school or turn 21 are currently put at the front of the list and offered day services and service coordination. As a result of a lack of funding, it is rare for an individual in this category to receive residential services. If they have a need for residential services, they are placed on the waiting list.

Nebraska's attrition rate for individuals with developmental disabilities receiving services is approximately 200 per year. The priority one individuals as well as the graduating high school students who received day services annually take up the services vacated by those who leave the

system. The net result is that the number of persons receiving services remains approximately the same while the waiting list grows at a rate of 200 individuals per year.

The waiting list persists notwithstanding the Developmental Disability Services Act which, among other things, provides:

“All persons with developmental disabilities shall receive services and assistance which present opportunities to increase their independent, productivity and integration into the community.”

Neb. Rev. Stat. §83-1,202.01 specifically provides:

“It is the intent of the legislature that the state pursue full funding of community-based developmental disability programs in a reasonable time frame and the legislature commit itself and the state to attaining a goal of providing services to all eligible persons by July 1, 2010.”

In contrast to the stated intent of the Legislature, the goal of providing services to all eligible persons by July 1, 2010 is simply not going to happen. More concerning is that there appears to be no initiative to do anything to address the waiting list other than watch it grow.

The Committee recognizes that LR 156 created a task force specifically assembled to evaluate the waiting list.⁴⁶ In that regard, we appreciate the testimony of Mary Gordon, Director of the Nebraska Planning Council on Developmental Disabilities. Nevertheless, the Committee feels the waiting list issue is so acute and must be part of the State’s priorities as we set a course for providing services to individuals with developmental disabilities that its inclusion in this report was critical.

Future of Developmental Disability Services in Nebraska

In the section which follows, the Committee makes specific recommendations regarding the provision of services to individuals with developmental disabilities by the State of Nebraska. Before providing recommendations, however, the Committee feels compelled to set forth a vision for the future of services to individuals with developmental disabilities in Nebraska.

Very clearly, the current state of Nebraska’s programs for the individuals with developmental disabilities is at a critical point in time. Nevertheless, the Committee feels there are opportunities for Nebraska to return to its place of prominence as a provider of services to individuals with developmental disabilities. This return to prominence will not take place overnight. Nevertheless, a vision for the future of services to individuals with developmental disabilities must necessarily be established so that state government has a roadmap to take us from the place we find ourselves to our return to excellence.

While there are many facets to the problems with delivery of services to the individuals with developmental disabilities, we believe the starting place is with the Beatrice State

⁴⁶ The LR 156 Report has been completed and can be found in the Appendix at “H”.

Developmental Center. The first, and perhaps most simple, step is to recognize that there is a place for BSDC in Nebraska's delivery of services and that a commitment to keep BSDC open must be made both publicly and in reality. In truth, the State of Nebraska does not have an option other than keeping BSDC open. The community-based programs simply lack the capacity and support to absorb the residents at BSDC.

While *Olmstead* very clearly calls for community placement in the appropriate circumstance, the reality is that the needs and behaviors of a certain portion of the population of individuals with developmental disabilities can only be served in an institutional setting. That is certainly the case given the present state of community-based providers. For example, those with serious self-injurious behaviors and those who engage in criminal behavior must necessarily be placed in an institutional setting for the safety of the community as well as the disabled.

Because the Committee believes that BSDC must remain open to provide care for the most challenging of the population of individuals with developmental disabilities, the first priority moving forward must be a retooling of the "recertification strategy." Very clearly, Nebraska finds itself with its back against the wall at BSDC and, as a consequence, there are no other options other than the recertification strategy. This strategy, however, must be retooled. In order for the recertification strategy to carry the day, it is, in the judgment of the Committee, critical that new leadership be put in place and that sufficient resources be devoted to the effort to ensure the highest likelihood of success.

The road map out of the quagmire at BSDC has been provided to the administration. Liberty Consulting (which the State paid \$1.5 million) provided the administration a plan. In addition, the Consent Decree entered into between the State of Nebraska and the Department of Justice has provided the administration with, what the Committee believes, is the clearest and most comprehensive course for turning the problems around at BSDC.

Beyond BSDC's role as provider of services to the most challenging population, BSDC with proper leadership, has the potential to serve as a resource center for community-based providers across the state. The DOJ properly pointed out that the OTS and the ITS programs are fine examples of programs which support community-based providers in dealing with challenging behaviors among their clients. It is the Committee's judgment that BSDC has the potential to serve as a resource in other respects as well. Indeed, the failure to provide community-based providers with necessary support represents one of the most significant deficiencies in the community-based programs. These deficiencies, in turn, frustrate efforts to place BSDC residents in the community and otherwise contribute to difficulties with community placement.

The shortcomings with community-based providers is bigger than the problems it presents to placement of BSDC residents into the most integrated setting. The Committee believes that the second priority in repairing the broken system of delivery of services to individuals with developmental disabilities involves addressing important issues that plague community-based programs. Those issues include developing comprehensive and relevant regulations for providers. A measure must be in place by which provider performance is judged. Those regulations need not necessarily be as comprehensive as the CMS regulations governing

ICF/MR's. On the other hand, regulations must be in place to provide for the safety and habilitation of those in the care of community providers.

It is not enough to develop regulations if the resources are not in place to see that they are followed. The Committee believes that improvement of community-based programs necessarily requires that the Licensure Unit of the Division of Public Health be given adequate staff to perform inspections of facilities where residential and day services are provided.

While the spotlight has been on BSDC over the last several years, the Committee is familiar with incidents taking place in community settings which are fairly characterized as abuse and neglect. For that reason, the Committee's second priority is developing a proper system of oversight for community-based providers. Our failure to do so will result in simply taking our problems from one institution and scattering them across the state.

The third priority for the State of Nebraska must be to improve the capacity of the community-based providers to serve individuals with developmental disabilities. *Olmstead* requires that individuals with developmental disabilities be served in the most integrated setting. In order to accommodate the mandate of the ADA and *Olmstead*, assessments must be undertaken of the residents at BSDC to determine their suitability for community-based placement. As this is done, there must be capacity in the community-based programs for those individuals who choose to accept an accommodation by placement in the community. Increasing capacity is likewise important to those who find themselves on the waiting list.

The fourth priority of the State must be to attend to the needs of those who find themselves on the perpetual waiting list. To date, the administration has justified its neglect of the waiting list by pointing out that developmental disability services is not an entitlement. This may or may not be true. Certainly the Developmental Disability Services Act expresses the intent of the Legislature to provide appropriate services to the population of individuals with developmental disabilities and that is simply not being done at the present time.

The Committee recognizes that capacity and oversight issues in the community-based programs must be addressed before meaningful progress can be made on the waiting list. On the other hand, with proper leadership, and an earnest commitment of resources, the waiting list can and should be reduced to a level where those who are nonpriority one status wait no longer than twelve months for appropriate services.

Ultimately, the delivery of services to individuals with developmental disabilities will require commitment to a model which has at its center the Beatrice State Developmental Center. The State must commit the resources to keep BSDC open so that it may serve those individuals for whom community-based placement simply is not appropriate. BSDC has the potential to serve as a hub or a center of excellence for not just the residents of this institution but those who provide services in community-based settings.

Broad-sweeping statements regarding visions of what BSDC might become and what improvements in the community-based programs might look like are all fine and good. In the end, making any vision a reality requires leadership and the commitment of resources. Indeed,

the lives of those who call BSDC home as well as \$28,000,000 annually in funding from CMS are dependent upon it.

RECOMMENDATIONS

Mindful of the identified concerns as well as the stated priorities, the Committee makes the following recommendations:

1. BSDC

- A. The State must make a commitment to keep BSDC open. BSDC serves an important function in the delivery of services to individuals with developmental disabilities. This institution must be available for placement for those individuals whose needs and/or behaviors cannot be accommodated with community placement. Moreover, the ITS, OTS and Bridges programs serve important roles in providing for a particularly segment of the population of individuals with developmental disabilities as well as a necessary resource for community-based providers.
- B. New leadership is needed not only to provide the recertification strategy with the best chance of success, but to return BSDC to its place of prominence nationally as an integral part of the State's delivery of services to individuals with developmental disabilities.
- C. An independent, comprehensive evaluation should be done by April 1, 2009 of each client at BSDC. The evaluation will provide the foundation for individual treatment plans and will also serve to identify those residents who are suitable for placement in the community.
- D. Follow the terms of the Agreement which are incorporated in the DOJ Consent Decree and accomplish each element of the Agreement in a timely manner.

2. BSDC MANAGERIAL AND STAFFING ISSUES

- A. A complete evaluation of all mid-level management and administrative staff must be completed by April 1, 2009 to ensure these individuals have the necessary skills to be successful.
- B. A comprehensive staff development program must be established by April 1, 2009. This staff development program should be developed with the assistance of resources at institutions of higher learning in the State.
- C. Create an apprenticeship, or internship program, with colleges and universities to assist with the shortages at BSDC. This serves the dual purpose of providing a resource for chronic staff shortages and begins the process of creating a pool of qualified individuals to properly staff BSDC into the future.
- D. A program must be developed and implemented by April 1, 2009 that addresses the cultural changes that are so badly needed at BSDC. We specifically

recommend the assistance of outside consultants with the expertise to set out a plan of correction to change the troubled culture at BSDC.

- E. Review of salaries and benefits by July 1, 2009 for all personnel with a goal for establishing a competitive wage rate for direct care staff as well as professional and managerial positions at BSDC.

3. COMMUNITY-BASED PROGRAMS

- A. Assemble (or re-assemble) a task force to develop appropriate regulations for the performance of community-based providers by May 1, 2009. This task force should be composed of experts in the field to include community-based providers. The findings of DOJ Report clearly reflect that more families will be comfortable with transitions from BSDC to the community-based programs as their level of confidence in the programs improves. We believe proper oversight is an important piece in developing confidence in the community-based placement.
- B. Increase the staff at the Licensure Unit of the Division of Public Health sufficient to provide an annual survey of community-based programs providing day and support services by July 1, 2009.
- C. Develop sufficient capacity in the community-based programs to meet the needs of those who are proper candidates to transition from BSDC as well as those on the waiting list whose needs will be addressed as recommended below.
- D. Establish a task force to review the State's reimbursement formula. It is clear that the reimbursement formula presents a barrier to placement in community-based programs for high needs individuals. This should be completed within one year.

4. WAITING LIST

Provide services for the needs of individuals on the waiting list over the course of four years after which time the waiting list (comprised of people at or past their date of need) includes no one waiting for services longer than twelve months.

5. APPROPRIATION

- A. A budget must be developed for the next four years which reflects the cost to the State to correct the problems at BSDC as well as the community-based programs. This should be done with the assistance of the Legislature's fiscal staff.
- B. The Appropriations Committee of the Legislature should set aside \$28.6 million annually in the appropriation process to provide for the continued funding of BSDC in the event the recertification strategy fails.

6. CONTINUED OVERSIGHT

- A. The LR 283 Committee should be reauthorized at the beginning of the next legislative session. This investigative committee should work with the Health and Human Services Committee to ensure that the terms of the DOJ Consent Decree as well as the recommendations herein are implemented in a timely fashion.
- B. The Task Force as well as the Health and Human Services Committee should receive copies of critical incident reports (both at BSDC and the community-based programs) for as long as the Investigative Committee continues to exist. Thereafter, copies of all critical incident reports shall be provided to the Health and Human Services Committee.

7. PRIVATIZATION OF BSDC

The fact that Mosaic operates three ICF/MR's in the State and has not been decertified by CMS has not been lost on the Committee. It is a source of frustration to the Committee that while BSDC has been decertified and properly criticized by the DOJ, three private ICF/MR's have continued to operate in the State of Nebraska without similar problems. Indeed, one private ICF/MR operates in the City of Beatrice, Nebraska. This frustration has led this Committee to recommend a study to determine the viability of having a private provider operate the Beatrice State Developmental Center. This study would at least provide the State with information necessary to evaluate this option.

8. VOTE OF NO CONFIDENCE

The Committee expresses a vote of no confidence for the CEO of the Department of Health and Human Services, the Director of Developmental Disabilities and the CEO of BSDC.

FINAL THOUGHTS

The very nature of the Committee's assignment necessitates that this report focus on the problems with delivering services to individuals with developmental disabilities, particularly at BSDC. On the other hand, the Committee would be remiss if we did not acknowledge the commitment and dedication of many people who provide care across the state to individuals with developmental disabilities. Our hearings regularly included accounts of people who have committed their lives to care for individuals with a developmental disability. Indeed, families with loved ones at BSDC regularly testified to the commitment and loving care provided by the professionals and direct care staff at BSDC. A similar situation prevails in the community-based programs.

There are many community-based programs which are well run and staffed by caring people doing their best. We wish to acknowledge the hard work and dedication of these people.

Those who have committed their lives to this calling should understand that our concerns are at an institutional level and our recitation of the problems facing the State are not intended to diminish their dedicated service.

ACKNOWLEDGMENTS

The Committee wishes to thank all of those who testified and otherwise offered their experiences and insights into the broad subject of services to individuals with developmental disabilities. Our understanding of the subject matter is a direct result of their efforts for which we are grateful. The Committee also wishes to acknowledge the hard work of Doug Koebernick, Matt Boever, Jeni Bohlmeier and many other legislative staff who spent countless hours reviewing tens of thousands of pages of documents and providing valuable assistance in the preparation of this report. Lastly, the Committee would like to thank Beth Otto whose service as Committee Clerk was invaluable to the hearing process.

APPENDIX

- A. Legislative Resolution 283
- B. DOJ Report
- C. DOJ Consent Decree
- D. Liberty Healthcare Report
- E. NAS Report
- F. CMS Summary of Surveys
- G. October 8, 2008 Letter from HHS to CMS
- H. Legislative Resolution 156 Task Force Report
- I. BSDC Employee Survey
- J. Transcripts from LR 283 Public Hearings

For a copy of the items listed in the appendix, you may go to the Unicameral's web site at <http://www.nebraskalegislature.gov/reports/committee.php> or contact Senator Steve Lathrop's office (471-2623) for a CD with each of the items.