

Quarterly Independent Expert Compliance Report

United States v. Nebraska, Civ. No. 08-08CV271

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February 9, 2009

Introduction

In June 2008, the United States and the State of Nebraska reached agreement on a remedial Settlement Agreement to address outstanding issues that impact the residents of the Beatrice State Developmental Center (BSDC). On July 2, 2008, the Honorable Richard G. Kopf, US District Judge for the District of Nebraska (Lincoln), entered the parties' Settlement Agreement as an order of the Court.

The Settlement Agreement includes remedial measures in the following areas: safety of residents and protection from harm, placement of residents in the most integrated setting, training in behavioral services and restraints and psychiatric care, and health care and related services including medical care, nursing care, nutritional and physical supports, and therapeutic interventions.

As part of the Settlement Agreement, the parties agreed that I would serve as the Independent Expert (IE) to independently observe, assess, review, and report on the State's implementation of and compliance with the requirements of the Settlement Agreement. As part of my responsibilities, I am to submit to the parties a quarterly compliance report. My specific duties and authority as the IE are clearly set forth in the Settlement Agreement. My past, current, and future activities are dictated by the terms of the Settlement Agreement.

The Beatrice State Developmental Center (BSDC) is a state owned and operated facility for persons with developmental disabilities such as mental retardation, cerebral palsy, Down syndrome, and autism. The number of individuals who were BSDC residents in October 2007 was 356. As of December 1, 2008, the census stands at:

Chart 1: Census

BSDC main campus residents as of 12-1-2008	257	
Bridges—A BSDC service at the Hastings Regional Center	12	
Total BSDC population as of 12-1-2008	269	
Number of persons discharged between 10-27-2007 and 12-1-2008.	74	39 persons went to community homes and 35 went to nursing homes or private ICF/MRs.

Number of deaths between 10-27-2007 and 12-1-2008	13	
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With the BSDC campus population at 257 and its Hastings campus at 12 there were a total of 269 residents as of December 1, 2008. However, in early February 2009 the State further reduced the census by 45 individuals with complex medical needs. This left a population of 224 persons at BSDC.

The State initiated these recent hospitalizations on an emergency basis into Omaha-Lincoln area hospitals. This action was necessary due to the State’s recognition of an increasing deterioration in medical care at BSDC, the need to protect medically fragile individuals from harm, the need to increase opportunities related to active treatment on an on-going basis, and the desire to achieve placements in less restrictive community settings with adequate supports and services.

Consistent with my responsibilities, I am submitting my first quarterly report. I expect to submit similar compliance reports every quarter for the life of the Agreement. I anticipate adhering to a schedule of issuing reports in March, June, September, and December of each year. I should note that I did not submit an earlier report because the parties and I agreed that the September 2008 evaluation visit was an orientation to BSDC for my evaluators so we could determine a process for future evaluations.

In conducting my compliance review this past quarter, I engaged in a number of different activities. I retained a team of expert consultants to assist me in the following areas: protection from harm, community placement, psychology, nutrition, therapeutic care and habilitation, and health care.

My evaluation team and I conducted an on-site review of BSDC from September 15 to September 19, 2008, to become familiar with the BSDC facility, its operations, caregivers, and residents. I provided some preliminary thoughts to the parties about our initial impressions. However, a written report was not issued to give the evaluation team an opportunity to begin to develop a protocol for future evaluations. The parties approved this approach. The team conducted an in-depth review from November 18 to November 21, 2008. This quarterly report is the product of that evaluation period.

We conducted interviews with administrators, clinicians, and staff, spoke and interacted with residents, reviewed medical and other records, reviewed quality assurance and other facility documents, and observed conditions and practices in most of the living units and program areas.

As the IE, I visited BSDC with my evaluation team on: September 15, 16, 17, 18, 19, 2008, and November 18, 19, 20, 21, 2008.

As the IE, I have also visited BSDC without my team on various occasions, including: July 22, 2008, July 23, 2008, July 24, 2008, July 25, 2008, August 12, 2008, August 15, 2008, August 16, 2008, August 17, 2008, August 18, 2008, August 25, 2008, September 5, 2008, November 25, 2008 (Bridges), December 15, 2008, and December 18, 2008.

The State has been very cooperative in enabling me to fulfill my monitoring duties and my on-going review of various provisions in the Settlement Agreement. The BSDC leadership has been open and responsive to me in relation to any questions, issues, or information needs that I presented. The Chief Executive Officer of BSDC has facilitated a cooperative environment. BSDC staff members have cooperated with all my requests. This cooperation has involved many staff members, such as Mr. Brad Wilson, Ms. Sue Spitzer, and Ms. Angela Server.

Besides my central focus on BSDC and its residents, I have also engaged in other compliance activities relevant to the community placement of individuals from BSDC consistent with the mandates in the Settlement Agreement. These activities involved parents, providers, and State officials. Each of these meetings has been related to discussing the major provisions in the Settlement Agreement and how to bring about a cooperative and productive spirit. I have felt that it is important to explain to providers the need for a coordinated effort to carefully place certain individuals in less restrictive settings, but with the needed supports and protections. It has been my hope that parents and guardians might clearly understand the criteria set forth in the Settlement Agreement for on-going habilitation, protection from harm, adequate and appropriate health and other clinical care, and, where appropriate, community placement. I have also felt it necessary to have an on-going dialog with State officials so that I might clearly point out the needs of the citizens who currently reside at BSDC and how to fulfill the State's pledge in the Court-ordered Settlement Agreement to provide the necessary supports, services, and protections to each and every individual there as well as those placed in the community. It is my intention to meet on an on-going basis with individuals or representatives of the various constituencies touched by the Settlement Agreement.

I have met with parents, providers, and government officials on various occasions, including: July 13, 2008, July 22, 2008, July 25, 2008, August 12, 2008, September 5, 2008, September 29, 2008, October 1, 2008, October 2, 2008, October 3, 2008, October 6, 2008, October 10, 2008, October 30, 2008, November 24, 2008, November 25, 2008, December 18, 2008, December 22, 2008, and December 24, 2008.

I recognize the need to review compliance with each and every provision in the Settlement Agreement. Given that my work on this case is at the beginning, I am still engaged in how to best accomplish this. In future evaluations, both at BSDC and in community homes and nursing homes that have received individuals from BSDC, the evaluation team will follow a template that encompasses the particular requirements of the Settlement Agreement. I expect that future reports will include a point-by-point

analysis of the Settlement Agreement. In this report I have focused on certain critical core areas of each section of the Agreement and have provided summary findings with regard to the State's compliance efforts thus far.

I submitted a draft version of my report to the parties on January 4, 2009. The United States provided comments on January 23 and the State of Nebraska on January 29, 2009. The United States shared the concerns I had raised regarding issues related to protection from harm, placements into the least restrictive settings possible with adequate and appropriate supports, and health and behavioral services.

The United States asked that in the future I should more closely tie my compliance reviews with the provisions of the Settlement Agreement. I intend to do that. In future evaluations I hope to provide a more detailed factual summary of relevant data and to more fully describe the State's efforts in fulfilling these concerns.

The State of Nebraska's State's Recent Responses

The State of Nebraska presented the following input for this evaluation report. I am pleased to include it as a significant part of this evaluation:

- The State points out that significant additional funds have been used to recruit and retain employees in order to decrease the excessive and costly mandatory use of overtime. Indeed, the State cites data that in March 2008 total overtime ran over 15,000 hours per month which includes 1,600 hours of mandatory overtime. In December of the same year the State reports a reduction to less than 9,400 hours per month with less than 175 hours of mandatory overtime required. I will continue to look at this issue in the future.
- The State reports that it has hired additional active treatment and other professionals to better serve the habilitation and activity needs of residents. I appreciate these initial efforts and will monitor closely any meaningful impact on residents.
- The State shared my concerns with regard to Dr. Tran and informed me that in December 2008 BSDC discontinued its relationship with him. The State confirmed my finding that he "had been charged for unlawfully selling prescriptions to his private-practice patients."
- The State shared my concerns that many of the medical staff at BSDC "lack specific experience dealing with individuals with developmental disabilities and/or ICF-MR experience." I appreciate that the State and BSDC leadership agree that "action must be taken immediately to address this situation."
- The State also shared my concerns regarding the adequacy of care provided at the Beatrice Community Hospital (BCH). I appreciate that the State has taken some steps in entering into a memorandum of understanding that provides protocols for BSDC staff to accompany residents when they need care at BCH. Nonetheless, the quality of care issue remains outstanding. I agree and remain concerned that the State has concluded that this "quality of care deficiency significantly impairs BSDC's ability to continue to provide care to its medically fragile population." I appreciate that the State has been negotiating with community providers to increase the number of small community-based medical support homes to serve persons with complex medical needs.

- I am pleased that the State agrees with me that there should be zero tolerance of any forms of preventable restraint for BSDC residents. The State reports that restraint usage has decreased. For example, in July 2008 there were 2,313 uses of emergency or programmatic restraint; in December 2008 that number had been reduced to 499 total minutes of use. I appreciate that the State's ultimate goal is to "eliminate all restraint usage." I will continue to monitor this closely.
- I am please that the State is placing increasing importance on the community placement of individuals at BSDC. However, the State has informed us that BSDC has been unable to complete transition plans for all its residents at the present time. I expect the State to remedy this and I will be monitoring this in the future. I am encouraged that the State has begun to develop contracts with providers aimed at creating new community opportunities. I will continue to monitor this and evaluate any placements in relation to the adequacy of needed supports and services based on criteria set forth in the Settlement Agreement.
- The State informs me that community placements will include start up costs for the expansion of services. I endorse this as a worthwhile initiative. I greatly appreciate that the Department of Human Services is desirous of increasing community capacity by developing new medical service units capable of meeting the medical and developmental needs in an adequate, appropriate, and timely manner. I look forward to them developing and implementing these expanded resources promptly in the upcoming months.
- The state also informs me that it will also increase its focus on the development of community living arrangements capable of meeting the needs of individuals with complex behavioral needs in an adequate, appropriate, and timely manner. I look forward to them developing and implementing these expanded resources promptly in the upcoming months.
- I appreciate that the State listened to my concerns regarding the proposed placement of BSDC resident Jake (All names have been changed in this report). I am pleased that the State developed modified supports and services for this individual, especially in regard to enhanced staff to address his needs in the community.
- I appreciate that the State is reluctant to place BSDC residents into nursing home settings. I am encouraged by "the money follows the person" initiative and am hopeful this may prompt the community placement of individuals who had previously been placed in nursing homes or private ICF-MR settings. I share the State's sentiments in that it is "our sincere hope that BSDC clients, even those who have transitioned to nursing homes, will consider placement in these [community] MSUs [Medical Service Units]." Nonetheless, the State needs to take additional steps to address the needs of those BSDC residents who still remain in nursing homes and other segregated settings and move toward inclusive community settings wherever possible. I will monitor this closely in the upcoming months.

Beyond the State's aforementioned financial, structural, and programmatic accomplishments and/or plans yet to be fully implemented, the State analyzed areas where increased State efforts also need to be undertaken. The State has noted the following list of shortcomings:

"Although the Department has taken significant steps towards compliance with the Settlement Agreement, it admittedly still has short comings in many areas. Although

several of these have already been addressed herein, a summary of them is as follows:

- A. BSDC needs to improve the quantity and quality of medical care available to its residents. This includes training and mentoring current medical staff in best practices for treating individuals with developmental disabilities, and recruiting additional staff to provide necessary services. Immediate action is being considered to ensure the safety and welfare of clients at the facility. Meetings are occurring within this week to make determinations in this regard. The department will update you as soon as definitive plans are made.
- B. BSDC needs to recruit additional psychiatric and neurology staff to serve its clients. In particular, BSDC needs to thoroughly assess its clients who suffer from seizure disorders and those clients on psychotropic medications to ensure that they are receiving treatment consistent with best practices.
- C. BSDC needs to continue its efforts to centralize its medical care charts and incident reporting, and to continue its Quality Improvement efforts to ensure it is being proactive with regard to client care and safety.
- D. BSDC needs to focus on its transition efforts and on growing community service providers. Current efforts are headed in the right direction, and the funding proposed by pending legislation will further assist in these areas. BSDC must, however, continue to be diligent in these areas. Clinical Services Management is scheduled to begin assisting BSDC in its efforts [to] update client assessments and to create transition plans for all BSDC clients. It is anticipated that this process will be completed by June 2009.
- E. BSDC needs to continue to reduce its use of restraints. Improvement in medical care (including psychiatric and psychological assessments and care) will assist in this effort. Continued training is essential.
- F. BSDC needs to make serious progress in the area of Active Treatment. Due to staffing difficulties, the facility was delayed in implementing these goals. Now that staff have been employed, there is no reason that this task cannot be accomplished. Active Treatment will also assist with other areas of need, because it should encourage positive behaviors [therefore, not] resulting in the need for restraint and encourage positive health through increased physical activity. Participation in Active Treatment at the facility will also better prepare our clients for community placement.
- G. The Department, through coordination between BSDC and Community-Based Services, must continue its efforts to grow community resources to provide adequate supports to its clients as they transition into the community. BSDC must enhance its ITS program and create other resources (such as Behavioral Health's ACT program, comprehensive training programs, etc.), to provide support to community providers.
- H. The Department must make a commitment to ensuring best practices for all areas of care for the developmentally disabled are implemented at BSDC and in the community."

The State's self-analysis concluded: "Most importantly, the Department through its BSDC leadership and Community-Based Services leadership, needs to develop a detailed action-based comprehensive plan for achieving compliance and maintaining long-term compliance. While many improvements have been accomplished and leadership staff have been put in place to further coordinate efforts, the Department is also working with Clinical Management Services to finalize a comprehensive plan. The Department welcomes direct input from the Independent Expert and his team, and

hopes that CSM and the Department's leadership will be able to communicate and coordinate efforts at the facility and in the community to ensure that BSDC continues towards compliance."

Since the time that I submitted my draft report there has been a significant development that merits comment. During the first week of February 2009, the State recognized that the medically fragile residents at BSDC were not receiving adequate and appropriate health care. This prompted a licensure review by State personnel that limited the State's ability to serve the population of individuals with complex health care needs. In response, the State decided to remove from BSDC approximately 45 medically fragile residents and place them into approximately 5 hospitals in and around the Omaha-Lincoln area. The State has promised that these hospital placements are temporary and designed to assess and stabilize medical needs and hopefully better meet their complex health care needs.

This decision was congruent with the State's pledge in the Settlement Agreement (Section III.A.1): "*The State has declared that the most important concern of the State Department of Health and Human Services is the safety and quality of life of its clients with developmental disabilities....which includes that the State shall: 1) protect residents from abuse and neglect; and 2) take effective steps to minimize or eliminate resident injuries and other significant incidents that may negatively impact their health, safety, and welfare.*" The State had defined these hospitalizations as a necessary means to protect health and well-being given the lack of appropriate and adequate medical care at BSDC.

The State assures me that these hospital placements are temporary and will serve to assess and stabilize the medical needs of this fragile population. The State has made commitments that they have already begun the process, whenever appropriate, to place individuals with these needs into integrated community settings with the necessary supports and services. Indeed, it is my understanding that each person has been assigned a community Service Coordinator. Tangible steps have already begun to be undertaken to implement a community solution for each person. This situation will be closely evaluated in my next report.

As the Independent expert, I have been assured that these vulnerable individuals will not remain in these segregated and isolated hospital settings any longer than is absolutely necessary to assess and stabilize their medical needs. It is recognized that such isolation and segregation can have a devastating impact on each person's health, safety, and welfare. The State has promised that these individuals will have day services arranged in short order to decrease any possible negative impact and provide a modicum of active treatment while hospitalized. This should help alleviate their transition from BSDC and their eventual placement into community settings with adequate and appropriate community services and supports.

I understand that whichever community providers might be selected, the State and its

providers will need to find residential and day program sites, modify them, and assemble and arrange needed supports and services to meet each person's complex needs. This is consistent with the Settlement Agreement.

I strongly encourage the State and community providers to develop and implement the needed community solutions as rapidly as possible. I will continue to monitor this process very closely.

I intend to visit each of the 45 individuals in the various hospital settings in the near future. I pledge to lend my support to any efforts that may be undertaken to better meet the needs of these individuals in the most integrated settings possible.

I also strongly suggest that the State look into encouraging and supporting Nebraska's volunteer and faith-based organizations to step in and provide on-going direct monitoring, advocacy, and companionship for these men and women who are medically fragile during this difficult transition period and beyond.

EVALUATION

Protection from Harm

In the Settlement Agreement (Section III.A.1) the State agreed to the following standard of care, *"The State has declared that the most important concern of the State Department of Health and Human Services is the safety and quality of life of its clients with developmental disabilities.... which includes that the State shall: 1) protect residents from abuse and neglect; and 2) take effective steps to minimize or eliminate resident injuries and other significant incidents that may negatively impact their health, safety, and welfare."*

BSDC has a system for reporting and investigating abuse and neglect and a committee process that assigns remedial actions based on investigation results. In future reports I will include factual data on incidents generally, and provide other descriptive information on abuse and neglect incidents and other serious incidents that have or should prompt an investigation. This will also include among other things comments on the quality assurance system, the soundness of particular investigations, and in each case whether or not remedial measures were recommended and implemented. Furthermore, I intend to provide individual and systemic information on whether or not these processes are impacting resident outcomes and whether or not harm has been reduced.

The chart below lists reported cases of abuse and neglect for the past 5 months.

Chart 2: Abuse and Neglect Cases July 2008 – November 2008

July	9
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August	12
September	8
October	10
November	3

Procedures call for any employee suspected of abuse or neglect to be suspended immediately. The chart below shows the numbers of suspensions for July through November, 2008, with the number of terminations and resignations.

**Chart 3: Employee Suspensions, Terminations, Resignations
July - November 2008**

	Suspensions	Terminations	Resignations
July	8	1	1
August	5	0	0
September	5	1	0
October	12	2	0
November	8	0	1
Total	38	4	2

In the future, we will be following the abuse and neglect reports to detect patterns by living units or shifts and to make recommendations for staff training.

I believe there are still issues related to protection from harm at BSDC and present the following cases as examples.

Allison. According to BSDC records, "Allison had 26 incidents/injuries in the past year. Three incidents resulted in no injuries, six incidents were scratches, seven were discolored areas (bruises), six were just redness, one injury was a blister, and two fractures." She fractured the 4th finger on her right hand because she was wringing her hands. The other was a fracture to her leg when she fell in her bedroom prior to moving to 203 Kennedy. Two fractures and near continuous face slapping certainly contradict an adequate standard of care and equate with a culture of negligence that goes contrary to

the Agreement. In a physician's note on November 18, 2008, her records pointed out a significant increase in her self-harmful behaviors. I observed her on November 19, 2008, and again on December 15, 2008, and she appeared calmer and was not yelling or slapping herself as much, although she appeared very drowsy, perhaps drugged, and her cheeks were still reddened indicating on-going self-injury. On the living units serving individuals such as Allison, harm is sometimes due more to neglect than actual physical attacks. A culture of neglect leads to boredom and boredom leads to developmental stagnation. The end result of neglect is often either harm to self or harm to others. When a person does not possess even rudimentary language or communication skills, screaming and hitting oneself is often the person's "language."

Dan. Dan is a BSDC resident who has a history of anti-social behaviors causing harm toward others at BSDC and in community programs. In October 2008, Dan allegedly assaulted Dorie, another BSDC resident. There was press coverage that highlighted the fact that BSDC staff accompanied him to Lincoln where he purchased a pornographic magazine. Some seem to think that his seemingly "minor" desire to buy pornography is a "normal" or "reasonable" choice to allow him to make. The Governor took a strong and praiseworthy public stance against this practice, pointing out the illogic of allowing a person who is being treated for sexual and other anti-social behaviors to purchase and collect pornography. It is common sense for caregivers to prevent anything that might trigger or encourage any form of assault whether Dan is at BSDC or in a community program. Yet, common sense is often the least common of all senses. The State also has the solemn duty to understand the supports that such individuals need to live at BSDC or anywhere else if harm is to be prevented. This pornography magazine story actually points out how attentive, observant, and preventive providers and caregivers have to be. The State needs to be always vigilant. Any such individuals call for close scrutiny and support and protections from experienced providers.

BSDC investigated the sexual assault allegation and concluded, "Both Dan and Dorie have told different versions of what took place to different people. The evidence indicates that the event started off as consensual, but then Dorie changed her mind."

Placement in the Most Integrated Setting

The United States and the State of Nebraska have agreed to, and the Court has ordered, the design and implementation of integrated community settings as delineated in the Settlement Agreement. The Settlement Agreement is clear related to placement into the most integrated setting. Section III.B.23, states, "*In accordance with Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12132, and implementing regulation 28 C.F.R. § 35.130(d), the State shall ensure that each BSDC resident is served in the most integrated setting appropriate to meet each person's individualized needs. To this end, the State shall actively pursue the appropriate discharge of BSDC*

residents from BSDC and provide them with adequate and appropriate protections, supports, and services, consistent with each person's individualized needs, in the most integrated setting in which they can be reasonably accommodated, and where the individual does not object."

The Settlement Agreement (Section III.B.24) outlines a key criteria involved in this order, *"It is the State's determination that all residents of BSDC meet the essential eligibility requirements for placement and habilitation in integrated community settings. All residents can be served in integrated community settings when adequate protections, supports, and other necessary resources are identified as available by service coordination. The State shall ensure that this is clearly set forth in each resident's written interdisciplinary team recommendation contained within each individual's BSDC Personal Plan, or equivalent."*

At the moment, some individuals are being placed out of BSDC into appropriate settings. However, others are placed into nursing homes, perhaps contrary to the Settlement Agreement, and others are placed into the community without sufficient supports and protections. I suggest that everyone take a step back and develop a more systemic approach to community placement under the State's leadership.

To achieve the letter and spirit of this order, the State needs to assume a proactive leadership role, as it has done in the recent protection medically fragile individuals, on an on-going basis to bring key leaders together to assertively develop and implement a plan to effectuate this mandate. This calls for an initiative that brings together, among others, HHS, BSDC, service coordinators, and service providers. It is obvious that, if adequate and appropriate community placement is to occur within the framework and time line of the Settlement Agreement, a significantly more assertive, judicious, and systemic approach needs to be taken. This will require the establishment of new community alternatives with the appropriate supports and protections. The State and its HHS regions must take a significantly more proactive stance in their leadership role. The State of Nebraska has signed and affirmed a hopeful and constructive Settlement Agreement. It is time to make integrated placements, with adequate supports and protections a reality and it is time for the State to enhance its leadership role and create an atmosphere for this transformation to happen. The Settlement Agreement firmly and clearly embraces a world of choice. It requires the interdisciplinary teams at BSDC to develop transition plans for each resident with a clear and concrete description of the "protections, supports, and services that each individual resident will or may need in order to safely and successfully transition." These transition plans should become a covenant between the families and the State. They should be the puzzle pieces that if put together, will bring the residents home and place them in safe and loving hands. The trouble is that the plans, the few that exist, at this point are only cursory documents with no significant power in a laissez-faire bureaucracy. The State has to assume its proper leadership role in bringing this about.

Each resident has a guarantee of a transition plan, yet this is not universally implemented. All the BSDC residents we observed could thrive and succeed in community placement with adequate supports and protections. In the records we examined, service coordinators and other State personnel seemed to take an exceptionally laissez-faire approach toward community placement. If there is a statement about community placement in BSDC records, it is more often than not negative. It appears that the State has not yet seriously approached the question of community placement in a deliberate and assertive manner; however, with recent decisions this seems to be moving in a firmer direction. The State has to continue to take a much more assertive posture to fulfill its agreement related to community placement. Each living unit at BSDC has to make this a top priority and encourage discussions and plans about what each person will need to live in the community. Private providers need to take a similar leadership approach in partnership with the State.

The current average person's cost at BSDC is over \$400.00 per day. A small community home of six individuals funded through Medicaid would have a significantly lower cost. Various funding sources can facilitate the development and implementation of small community homes. In addition to ICF/MR options, the State has the opportunity to use the "waiver" mechanism that would afford many persons more flexibility, choice, and self-determination. The State has already agreed to the following in the Agreement (Section III.B.35), *"The State will develop and implement a systemic plan to develop, through the Home and Community-Based Waiver or otherwise, integrated community alternatives to nursing homes for all residents with unique or more intense and complex health care needs."* This has yet to be aggressively enacted. It is the State of Nebraska alone that can provide the leadership to make such decisions and fulfill the mandates in the Settlement Agreement.

It is reasonable that many parents oppose community placement. Some hang onto the Beatrice or nothing posture; others persevere on the community or nothing posture. Parents rightfully and instinctively want their sons and daughters to be and feel safe and to live their lives in loving and fulfilling places. Since there is a dearth of community alternatives and some alternatives lack adequate and appropriate supports, many parents and families feel that there is little or no choice. The challenge is to bring these alternatives into reality.

The mother of BSDC resident, Allen, informed me that until recently, she was highly opposed to community placement for her son, but now advocates having him in a community home; yet, there is none available. Allen's mother concluded, "Up until my problems, I would have been one of those opposing parents at Beatrice. Now I cannot even take him out. He is on a feeding pump all the time. He just needs treatment." She,

like some other parents, would like such a placement within a reasonable time, but the State will have to initiate a movement to create small community homes that can meet their sons' and daughters' needs as well as enhance family involvement and contact. The solution rests in the State's hands. Allen and many others are waiting. Parents, family members, and guardians need to take a more active role in this entire process.

Procedures for communication between the BSDC interdisciplinary team and community placement teams lack formal structures for sharing critical incidents. If transition plans are to have any useful benefit, they should be prepared and implemented several weeks prior to placement and fully discussed. Preparation for such placements is a necessary step in the process. And, placement should not occur until all factors are adequately covered and adequate supports are guaranteed. The goal is not only community placement of the BSDC residents, but also the guarantee that harm will come to no one and that each person will have active treatment based on his/her personalized needs across their lifespan.

BSDC should be praised for allowing me and my team to have access to all available information. However, the disjointed nature of the information requires significant detective work to develop a somewhat full picture related to needs and risks and, thus, increases the likelihood of harm, especially when community placements are rushed. This is exacerbated now that individuals with histories of anti-social behaviors are being placed into the community with considerable speed, but without well-thought-out full and timely transition planning. The probability of harm is increased considerably. Any placement of individuals with a history of anti-social behaviors requires highly accurate and comprehensive incident reporting and assessments while at BSDC. These become the foundation for transition planning and decision-making. In a similar way, as individuals with complex medical needs are transitioned into community residential living alternatives, it is vital that concrete goals, objectives, and outcomes be carefully delineated for each person in transition plans so that each person receives adequate and appropriate supports based on his/her individualized needs.

BSDC stated that it was not aware of the status of all individuals who have already been discharged from the facility because this does not fall in the facility's domain. According to BSDC authorities, they have no way of tracking these individuals once they are discharged. This is a significant problem. HHS has to set up a mechanism to follow up and report findings to the parties on all discharged BSDC residents in a timely and on-going manner.

I am deeply concerned by the placement of BSDC residents into nursing homes and other settings that might not provide the necessary supports and protections contemplated in the Settlement Agreement. The transfer or placement of BSDC residents into nursing homes or large ICF/MR facilities is quite troubling. The Settlement

Agreement is clear in its mandate for less restrictive placements (Section III.B.35), *“The State will avoid placing residents into nursing homes or other institutional settings whenever possible. The parties recognize that nursing homes are often not well-suited to provide needed habilitation to persons with developmental disabilities. The State will develop and implement a systemic plan to develop, through the Home and Community-Based Waiver or otherwise, integrated community alternatives to nursing homes for all residents with unique or more intense and complex health care needs.”*

Nevertheless, in recent years a large number of individuals has been placed into nursing homes. This is most unfortunate especially since integrated and appropriate care plans could be developed and implemented in community homes. Such placements are most often unnecessary and contra-indicated. This is a harsh practice that can result in people with significant disabilities being moved from the only home many of them have ever known to live and die among strangers who do not understand their limited communication skills or care needs. It slams shut the door of hope to individuals who could be supported in more intimate and personalized community homes.

The next chart shows that although the number of integrated community placements has increased in the past year (38) there are still far too many nursing home or ICF/MR placements (36).

Chart 4: Placements by City and Type October 2007 - November 2008

City	Nursing Home or ICF/MR	Group Home
Auburn		1
Aurora	1	
Axtell	1	2
Beatrice	4	2
Bellevue	1	
David City	1	
Firth	5	
Fullerton	1	
Grand Island	2	1
Hastings		2
Hebron	4	
Holdrege		2
Kearney		2
Lexington		1
Lincoln	1	9
Madison	1	
McCook		1
Merriam	1	
Milford	5	
Milton	1	
Norfolk	1	1
Oakland		1

Omaha	4	8
Papillion	1	
South Sioux City	1	
Wahoo		1
Wayne		1
York		3
	36	38

This chart covers placements from October 2007-November 2008 to establish a categorical and geographical picture of community placements. With 36 placements into settings equally or more restrictive than BSDC, the State had seemingly set a policy where the reduction of the BSDC population is to be partially accomplished by placements into nursing homes. It was surely not the intention of the Settlement Agreement to place individuals into restrictive settings. Thankfully, recent efforts on the part of the State seem to be moving away from nursing home placements.

As it stands, placement into nursing homes further complicates each person’s right to have the opportunity to live in integrated community settings, receive active treatment, and to be free from harm. I fear that such placements often merely open the back door to moving a person from a public institution to a private one, especially when equally or even more severely medically complex individuals can be seen supported in integrated community settings in Nebraska. To make “right sizing” just and decent, it is necessary to follow the criteria set forth in the Settlement Agreement.

The following are descriptions of a few recent community placements.

Bonnie. Bonnie is a young woman who shows that it is quite possible for persons with profound mental retardation and allied chronic medical problems to live fruitful lives in the community in spite of extremely challenging needs.

I visited Bonnie in her bedroom on July 23, 2008, on her living unit for individuals with complex medical needs at BSDC. Much to my surprise, when I entered her room, she looked toward me and with much effort haltingly said, “Go home!” It was difficult to understand her low and quivering voice, but the message was clear. She in her own halting voice wanted to leave BSDC and had a mother who advocated for this.

I asked several staff members on duty who they felt was the most fragile, medically involved person there, and their reply was Bonnie. Her risk factors included conditions related to aspiration, pneumonia, seizures, decubitus ulcers, tube feeding, bowel impaction, fractures, and a range of other medical and developmental disabilities. Delicate care had to be taken to meet her needs.

Thanks to the State's support of the necessary resources and a provider facilitating the placement process and the provider's strong desire to serve those with the most complex needs, and a mother who advocated for her daughter, a few months later she was placed in a community home that has been giving hope to people with developmental disabilities and their parents over many years. This home has well-trained and well-supervised caregivers, as well as 24-hour nursing support. It is located near two major teaching hospitals. The small community home is capable of providing needed medical, nursing, and habilitation support. I visited Bonnie in her day program where she was engaged in a variety of activities. She had a smile on her face. I whispered to her, "So, you went home!" She nodded her head and smiled.

The Settlement Agreement mandate was to avoid placements into nursing homes whenever possible and make placements into integrated community settings a reality. The State achieved this in Bonnie's case. In her case, with much advocacy on the mother's part and the existence of a community program suitable to her needs, the State of Nebraska lived up to its promise in the Settlement Agreement.

The medically oriented living units at BSDC serve individuals with similar or lesser needs, and there seems to be very little habilitation or medical reason as to why they cannot live in a setting similar to Bonnie's. Indeed, the State has determined that individuals at BSDC with similar needs cannot have those needs met at BSDC. These other residents need a home like Bonnie's. It is now time for Bonnie's peers at BSDC to have a similar opportunity to live in the community. The 45 individuals recently transferred out of BSDC with needs similar to Bonnie's merit homes and day programs like hers.

Bonnie was lucky. There was an empty bed in a community home and she moved into a decent and loving home that could meet her needs. She and her mother were fortunate in that a space opened up in an existing home. Others will have to wait for the State to develop the resources to open up several similar homes and for providers to step up to the challenge. The residents who have recently been placed in hospitals and nursing homes will have to wait for the State, its Service Coordinators, BSDC leadership, and providers to come up with integrated community settings that provide active habilitation with the necessary supports and protections to meet individualized needs. There is no time to hesitate. These 45 men and women are waiting for the State's implementation of promises made.

Bonnie's community home and other similar Nebraska homes could serve as a model for several homes that would provide other individuals with the supports and protections that they need in integrated community settings with full habilitation programs. These small, dispersed, and inclusive homes could be managed by the State or private providers. Whoever runs them would have to be assured of long term funding and appropriate agencies would have to guarantee oversight.

Many providers and parents fear that there will be no guaranteed on going funding for such medically intense care homes or other homes that serve complex individuals. The present reality cannot stay at the motionless standstill of the last three decades. It would be most laudable if the State were to facilitate the development and implementation of a plan for such homes dispersed throughout the State so that many others can "Go home!" The State has expressed this intention and has made initial steps toward it; we urge its full implementation.

It should be emphasized again that Bonnie was considered a most medically involved resident and yet she now resides in a community home. She was placed in a significantly more integrated setting than BSDC; the State was capable of providing the resources for her medical, developmental, and habilitation needs in the community. If it is to fulfill the Court's order for more integrated settings, it behooves the State to develop and implement a plan for more homes like Bonnie's. Future homes for medically complex individuals must assure the residents of timely access to adequate medical care.

Bonnie's placement is just a single seedling of hope, but one that bodes well - a mother who advocates for and watches over her daughter, a community program that supports the most marginalized individuals, and a State government that has the courage to enable and facilitate complex community placements. This is a good first step.

Jake. As IE, my highest concern relates to the ill-prepared community placement of individuals with histories related to sexual assaults. The Settlement Agreement is strong in its insistence on the guarantees that any placement should include safeguards to prevent harm from befalling anyone.

Jake is a person with such a history. He is a 29 year-old man who had been living at BSDC due to an apparent history of alleged molestation and sexual assault. He poses worrisome behavioral risks if he fails to receive the supports and protections that he requires. Harm toward him must be prevented, but also all harm toward others. This is a solemn duty of the State.

In Jake's room at BSDC (He has since moved to a home in the country.), there was a picture of a young boy displayed on his dresser; he indicated that it was his nephew. The top drawer of his dresser was ajar and his possession of explicit pornographic material was evident. A picture of any child and the use of pornography, at least in his

case, bring into question the State's understanding of individuals such as this resident and the need to be exceptionally cautious and careful. The fear is that if such seemingly minor transgressions (picture of a child and pornography) in a controlled setting occur, then the risk of harm will increase exponentially in the much more complex world of a community setting.

His most recent risk assessment (June 2008) outlined his history and concluded that he would be "a low risk to reoffend in terms of sexual offending, aggressive behavior, or other illegal activities, under line of sight group supervision." It went on to comment, "Jake is a moderate risk to breach sexual boundaries with vulnerable persons without supervision..." This need for supervision is a safeguard that the State must guarantee and it will likely be needed for the long term.

In a January 2008 risk estimate, the examiner concluded: "Jake's responses indicate some cognitive distortions which he may use to justify sexually and socially inappropriate behavior... He reports being distressed by discussing his abuse and results indicate a moderate degree of involuntary memories and traumatic symptoms... Treatment team decisions should take these issues into careful consideration when determining treatment methods, placement, and unsupervised activities." Moreover, an April 2008 risk estimate stated, "The Nebraska Department of HHS DDS Risk Screen was used and concluded: 'The following behaviors are listed to guide further discussion regarding risk issues: Non-consenting sexual contact/conduct with children or other vulnerable individuals. Comments: Jake has had prior offenses of inappropriate sexual contact with children and in the past some inappropriate sexual contact with other vulnerable people. Assaultive behavior. Comments: Jake can be assaultive with staff and peers. Most recently, he had an assaultive episode with the home manager. Illegal or unsafe social behavior toward others. Comments: Jake will steal from others. In the past, he stole a car... forged checks. He also likes to be around small children and will give them items to promote socialization... History of evading supervision. Comments: Elopement. His treatment team made the following decision, 'Encourage IPP team discussion to determine if there is any current risk...'"

Based on an analysis of Jake's recent behavior at BSDC, the Independent Expert's specialist in community placement noted that there are outstanding issues that merit close and on-going monitoring. For example, he cited the following incidents that require careful monitoring and supervision:

- August 21-08: Personal Plan Review, "The visits that Jake has had to the prospective provider have gone well. He went grocery shopping and went to the vocational site and did some recycling. There were some incidents that their staff would have to watch. When grocery shopping he went walking ahead and weaving through crowds which could possibly have been a precursor to elopement. At the worksite there was another client who was rather childlike and

staff felt that Jake showed an undue interest in her...”

- August 27-08: Progress Notes, “... Swearing- refused active treatment.”

- September 16-08: Progress Notes, “... allowed a peer into bedroom without staff knowledge to watch a video game.”

- November team meeting: “... a number of incidents in past year in which he and another client have been found to be touching each other inappropriately.”

Jake’s recent behaviors at BSDC indicate a defiant attitude and should serve as a red flag for possible danger unless the State provides extremely close and long term supervision wherever he might live, the provider and caregivers receive pre-service and continuing education with on-going monitoring, and careful and on-going monitoring of any future home.

The bottom line is that Jake presents an unknown degree of risk for “breaching [sic] sexual boundaries with vulnerable persons without supervision.” His projected (and now completed) placement mentions the need for and importance of “line of sight group supervision” as an important risk reducer. Since this also means increased costs, there will be tremendous external pressures to eventually reduce staffing and, thereby, increase risks. The State must be dedicated to on-going supervision and increased staffing for the foreseeable future.

When the IE’s evaluator reviewed Jake’s placement plan and his proposed placement site, we were not satisfied that the Department of Health and Human Services had yet developed adequate safeguards to address these risks. The selected provider’s initial set of recommendations for his community placement seemed to downplay the risks that Jake presented to the community without adequate supports and protections. This is exceptionally worrisome since there is no room for error. His original treatment plan contained projected goals and objectives such as limiting aggression to no greater than 5 incidents per month, elopement to no greater than 5 incidents per month, inappropriate social/physical boundaries to no greater than 2 incidents per month, and manipulation/lying to no greater than 10 incidents per month. As IE, I was aghast at these laissez-faire goals and objectives that almost seemed to accept the likely possibility of anti-social behaviors and disregarded the potentially horrendous impact of breaching “inappropriate social/physical boundaries.” This must never occur. In the future any such placements must be carefully and assiduously analyzed, prepared, and monitored. It must be recognized that costs for well trained and supervised staffing will be long term and any budget must recognize this investment.

I asked the State to postpone his community placement until such time that the State and its service provider had adequately addressed all outstanding safety risks. In response, the State, much to its credit, developed an alternative site far from an urban center with enhanced safeguards. I also stressed that any provider for a resident such

as Jake must have adequate experience with individuals with similar needs and his need for well trained staffing would be long term.

Hopefully, the new site will balance Jake's ability to live in the community with the common good. The common good can be protected if the State pays sharp attention to its duty to provide the necessary supports and protections to Jake and others with similar needs. The guiding rule must be "Harm comes to no one."

Rule 1 in Jake's placement must be to prevent any harm whatsoever. Rule 2 should focus on a long-term effort to teach him decent and respectful pro-social skills. For example, there should be evidence and verification that he is enrolled in a systematic cognitive behavioral therapy program as recommended in the June 3, 2008 Risk Assessment. There should be a schedule for this therapy, a designation of who will implement the therapy, and a clear list of outcomes. These outcomes should be periodically examined. The provider must guarantee zero harm to vulnerable individuals. Rule 3 should be to institute a statewide on-going education process to ensure that providers and caregivers have adequate skills in serving these complex individuals in the community. Rule 4 should be for the State to be willing to finance this long-term habilitation process.

Transition plans cannot consist of cut-and-paste recommendations. They must be highly person-centered and provide all the supports and protections that a person needs and will require in any placement setting. In Jake's case, his plan must be centered on the core of his emotional disorder and the guarantee of adequate supervision. A central issue in any such placement swirls around the provider and future caregivers. The less experienced the provider, the higher the risk. The often-repeated "line of sight supervision" is vital and cannot allow for one misstep. Each person's freedom must also be balanced with the common good. If he or those with similar needs are to live outside of large congregate care facilities, the State and its private providers must guarantee that harm will not befall anyone.

BSDC residents placed into the community deserve experienced, well-trained, and well-monitored providers and caregivers. It is risky to place this grave responsibility in the hands of inexperienced caregivers without on-going supervision and mentoring. The State lacks any statewide curriculum or training vehicle for the adequate and on-going training for providers and caregivers of individuals similar to Jake. Regarding Jake, his community staff should receive repeated training related to the "line of sight" supervision requirements and frequent monitoring.

Jake is an example of the high-risk nature of a small minority of BSDC individuals with documented histories of sexual abuse. Although it is most laudable that the State has recognized the need to place such complex individuals into the community, several warning signs call for a more deliberate and judicious placement process and one that underscores the absolute need to ensure that harm comes to no one. I urge the State to

reconsider the proposed placements of residents with a history of alleged sexual assaults until such time that a more prudent and judicious approach can be taken that will ensure the safety of all and the prevention on any harm. This should not diminish the need and goodness of community placement, but it points out what must be done now and in similar cases in the future. Hopefully, the State can learn from this placement and ensure that harm will come to no one.

Behaviors, Restraints, and Psychiatric Care

Section III.C.72 states, *“The State shall ensure that all residents are free from unreasonable restraint.” The State shall develop and implement effective measures to minimize significantly or eliminate entirely the use of mechanical, physical, and chemical restraints on BSDC residents. The State shall ensure that restraints are not used as punishment, in lieu of habilitation, skills training and behavior support plans, or for the convenience of staff. Any restraint used will be the least restrictive form of restraint.”*

The Settlement Agreement recognized the right of each resident to be free from unreasonable bodily restraint and to have the necessary psychiatric supports for their mental health and behavioral needs. The residents at BSDC are still not free from the threat of unreasonable physical (i.e., staff physically subduing a resident), mechanical (i.e., staff using a device such as leather straps to subdue a resident), and chemical (i.e., staff using a drug, generally injected, to subdue a resident) restraint. BSDC has been tracking the use of restraints and I have been informed that the overall number is greatly reduced. Some restraint is planned and part of a person’s program; other restraint is unplanned and provoked by an unexpected situation. The State should be applauded for the reduction as evidenced by the following chart:

Chart 5: Facility Wide Restraint Usage in Minutes.

2008	EMERGENCY USE		PROGRAMATIC USE		Total
	Physical	Mechanical	Physical	Mechanical	
July	0	0	288	2025	2313
August	4	13	261	1069	1347
September	0	229	175	678	1082
October	15	0	205	698	918
November	0	0	66	352	418
December	1	74	82	342	499

It is laudable that the State intends to continue this movement to decrease the use of physical management and mechanical restraint. It should eventually be eliminated. The eventual goal should be zero tolerance for any forms of such control that could be prevented through increased and improved staff training, the writing and implementation

of positive behavioral support plans that prevent behavioral outbursts, improved hands-on supervision and mentoring of direct caregivers, and the presence of pro-active and on-going psychiatric services.

As placements occur, individuals moving into the community should only go to providers who avoid physical management and train and mentor their staff in positive behavioral support.

BSDC is in the process of recruiting a psychiatrist who should also be a resource for community providers.

Following are a few stories about BSDC residents who are subjected to restraints.

Carley. Carley is a 23-year-old woman living at BSDC. She has lived a life filled with violence toward herself. In recent months has been subjected to frequent physical management and mechanical restraint and involved in behavioral incidents and injuries to herself. Her records relate a litany of suffering. I have provided a list of some of her notable restraints to the State. At least eight of these restraint incidents involved the use of a mechanical restraint for over an hour. A couple of these restraint incidents involved the use of mechanical restraint for over three hours. It is of concern that many of the restraints were not recorded in an incident report.

She was open about the main reason she is at BSDC: "I explode every now and then. When I explode, I feel like people are rude and mean. They are supposed to help me work on my problems." She described her behavior when she is mad in this way: "I try to hurt staff and myself. I bang my head on the walls. I kick them, spit at them in the face. They don't like my loogies." Carley described her feelings in this way: "They say I'm depressed. I was happy when I was not here."

This woman, abused as a child, has been placed in mechanical restraints at least eleven times in the past year for a total time of 16 hours and 53 minutes. Her life history would seem to contraindicate any further expression of humiliation to her body. There is very limited information available in the record regarding the incidents that resulted in her being placed in mechanical restraints, nor the rationale for using them. Almost 17 total hours tied to a chair or bed should be considered as counter-productive in terms of person-centered planning and the use of positive behavioral supports. This calls for an immediate halt.

Carley has been injured at least three times in recent months while being restrained. She stated that she broke her wrist prior to being admitted to BSDC and this makes the use of wrist restraints very painful. Three physical injuries during these bouts is a strong testament to violence begetting violence. If any physical hold or use of mechanical restraint is to be used, BSDC should ensure that it causes no physical and/or emotional harm to the person.

We asked Carley how she felt when she was tied up and she looked down and said, "When they tie you it feels like I'm a prisoner. My wrists hurt 'cause the straps are so tight. I start to wish I wasn't here. I wish I didn't have the anger problems I have 'cause I am not loved. I want to go to someplace where I can have a little bit of freedom, watch sports, go to school, and see a boyfriend. I am not your typical average girl 'cause I'm kind of a Tom-Boy. I graduated high school. I just want someone in my life who really cares about me."

Physical injuries are mere shadows of the emotional damage that likely occurs, especially for a resident who already suffers from a profound sense of detachment, lack of self-worth and self-esteem, and a history of assaults on her body since early childhood.

Some other BSDC residents subjected to restraints are:

- Frank had five instances of mechanical restraint reported between August 7 and October 10, 2008. These involved using three- and four-point mechanical restraint from 40 to 120 minutes in duration.
- Harry has been physically and mechanically restrained at BSDC with four to five reported instances from July 28, 2008 to September 10, 2008. He was injured on August 21, 2008, while restraints were being applied. His restraint data are mixed-up and incomplete. Harry was also subjected to chemical restraint on August 22, 2008.
- Between July and October, Ellie was subjected to physical and mechanical restraint 11 times with four of these not recorded with any specific information. Ellie has a recent history of multiple injuries: 21 injuries over the past year; 11 related to behavioral issues (five from restraint usage, six from self-injury) and eight due to falls.
- Irwin has been subjected to restraints six times from early July to early November 2008. He also has a standing order for chemical restraint.
- Dorie has been subjected to physical and mechanical restraint six times since early July.
- Frannie was physically or mechanically restrained 11 times from July through August, 2008. She is also suffering from the obvious side effects from psychotropic drugs: tremors of hands when anxious, frequent blinking, and an on-going tongue tremor.
- Eddie's last behavioral plan was well over a year ago. On October 19, 2008, his psychologist reported positive data all year and no mechanical restraint since June 2008. However, a standing PRN order for the use of an emergency medication had been used five times in recent months.

The continued decrease of the use of negative control methods and punishment-based behavioral supports is interconnected with the need for adequate and timely psychiatric

supports and services. The State has agreed to the implementation of a comprehensive psychiatric support system for each individual. To date, this agreement has barely been initiated and certain residents are suffering the consequences. I look forward to the initiation of systematic psychiatric support for those who require it.

Most caregivers at BSDC have been presented with the task of caring for and about individuals with both mental retardation and mental illness. They have been doing this without the benefit of promised psychiatric care capable of providing the residents with thorough annual psychiatric evaluations and adequate follow along. I strongly suggest that a full-time psychiatrist, experienced in the field of mental illness and developmental disabilities, is urgently needed.

It appears that medications are sometimes used simply to tranquilize the people and dampen their “behaviors” with no relationship to any specific psychiatric diagnosis. PRN medications continue to be used and this is contrary to Section III.C.80 of the Settlement Agreement. They are too often used just to stop “behaviors” and often do not do a good job at this.

The majority (149) of BSDC residents takes psychotropic medications, but many lack an annual comprehensive psychiatric evaluation or a differential diagnosis of a mental illness. Without such a diagnosis, whoever prescribes the medications is often shooting in the dark. These medications then become mere chemical restraints, the equivalent of a modern straitjacket.

The range of “psychiatric diagnoses” or “descriptors” at BSDC are shown in the following chart:

Chart 6: Psychiatric Diagnoses*

Anxiety Disorder	6	Organic Affective Syndrome	4
Autism	5	Organic Hallucinoses Syndrome	1
Bipolar	6	Organic Mental Disorder	1
Borderline Personality	6	Organic Personality Syndrome	7
Compulsive Disorder	1	Other Suspected Mental Condition	114
Conduct Disorder	3	Pedophilia	3
Depressive Disorder	8	Persistent Sleep Disorder	1
Disintegrative Psychosis	1	Pica	3
Early Childhood Psychoses	9	Psychogenic Rumination	1
Fetishism	1	Psychosexual Disorder	2
Impulsive Control Disorder	5	Schizophrenia	14
Intermittent Explosive Disorder	14	Unspecified Psychoses	25
Manic-Depressive Psychosis	4	Unspecified Personality Disorders	2
Obsessive-Compulsive Disorder	8	None Noted	3

***Many individuals have multiple diagnoses**

In the list above, 114 residents have “other suspected mental conditions.” Such a description is a far cry from a useful diagnosis. It is essentially meaningless and unfair to the residents so “diagnosed.” Other diagnoses that are unhelpful from a treatment standpoint are: “unspecified psychoses” (25), “unspecified personality disorders” (2), or even “none noted” (3). Such vague and poorly analyzed “diagnoses” can mislead direct care staff, lead to the use of chemical and physical restraint, and cause emotional and even physical harm. It is vitally important and urgent to formulate clear differential diagnoses for residents taking psychotropic medications to determine whether ordered treatments are, in fact, necessary and working to address the resident’s underlying mental illness.

Habilitation

Most work and evening activities appear to be in residential settings for some and on-campus for most. Very little activity occurs in the community. Many of these events should be in the community as stated in the Settlement Agreement (Section III.C.57) “... *a minimum of five hours per day of off-residence skills training, in the community whenever appropriate, derived from the resident’s skills training and habilitation support plan, to meet the individualized needs of each resident.*”

Participation in work and community events should not be contingent on behavior, but used as a basic mechanism for learning to live respectfully in the confluence of community life. Since such activities cannot be contingent on behavior, this should also preclude the withdrawal of work privileges as a punishment. However, it might then require increased staffing.

For BSDC residents with profound mental retardation, special care must be given to ensure their habilitation and on-going developmental growth. Because they most often do not speak and have complex medical needs, they can be overlooked. They can easily be forgotten. Sitting in wheelchairs and grouped in a semi-circle in front of a television set that is on with no sound day after day with very little staff interaction is not active treatment; its chronic meaningless monotony and boredom that breeds a sense of hopelessness.

Following are a few examples to illustrate my concerns about the current levels of habilitation.

Allison. When we approached Allison, she was in her bedroom yelling and slapping her face. She was alone. She was rocking back and forth in a wheelchair. Both cheeks were red from the slapping. A male staff person came into her bedroom a few minutes after we had entered. He told us, “Her caregiver is X, I don’t know why he left her in here alone without even the TV on.” He turned the television on and left. Allison did not look at it and showed no interest in it. She continued to scream and hit herself. A while later the same caregiver took her out of the bedroom. He placed her in a semi-circle of ten other residents who sat in their wheelchairs before a large screen television set that had “The Price Is Right” show playing. No one was watching it and the sound was off. Allison continued to scream and hit herself. The other ten men and women were just sitting - some were slumped over, others were rocking back and forth, some were staring at the ceiling, and some were asleep, oblivious to the world around them.

Her records described her preferences and desires as follows: “Allison prefers a home with lots of open areas.” Yet, during our shift long observation, she was in bed or in or near a semi-circle of eight to eleven other individuals in wheelchairs, most often without any caregiver with the group. Occasionally one or two caregivers approached the group and spent a few moments. “She prefers a quiet environment as loud and congested

areas increase her anxiety level.” She was seated in a crowded and loud area almost the entire shift. She was either in bed screaming and slapping herself or in or near a semi-circle of other individuals in wheelchairs, most often with a single caregiver or two at the most overseeing the entire group of people. It was far from a quiet and roomy setting. “Allison enjoys being outside and she would like to explore more outdoor activities as the opportunities occur.” Yet, the entire shift she sat inside with noises, crowdedness, and nothing to do. “Allison enjoys those who indulge her with attention and interaction, especially teasing.” During our observation of the few care-giving interactions, attention was fleeting with no warm loving attention.

Although she had a few habilitation goals and objectives, practically speaking, she lived in a habilitation wasteland with almost no structure to her day, no purpose, and no habilitation. Her written records did not match her reality. During our lengthy observation that spread over a two-day period, she did not leave the living area. On subsequent visits she was observed leaving the area once; otherwise she was always seated in her wheelchair in a semi-circle. BSDC has established a policy on active habilitation and person-centered planning; however, in her case, the written policy does not translate into reality. This young woman appeared almost totally abandoned to the confusion of her screaming and slapping. There was virtually no active habilitation, no five hours off the living unit or outside the building, no community engagement, no meaningful habilitation plan, no functional learning in real-life contexts, and no transition plan. One caregiver tried to help her for a few moments on two or three occasions, but she had many other duties to perform. Allison just sat in the ward and hit herself with almost no one even approaching her.

The actual, hands-on staffing ratios present among the residents in the living unit permitted no more than custodial care. This does not necessarily mean that there are not enough staff. It means that there are poorly supervised staff members who work in an unstructured environment. Her written habilitation plan has little practicality or functionality. It would be wiser to write plans that could be structured into the flow of the day for all caregivers to implement on and off the living unit. We had the sense that there were potentially enough employees on the living unit if there had been a structure to the day, an expectation of hands-on interactions, and a locus of authority to guide staff and caregivers throughout the day. It would be more fruitful for clinicians and supervisors to spend their time on the living units, classrooms, and in the community teaching and mentoring caregivers in how to write and carry out meaningful programs.

Ina. As in the case of Allison, Ina's care was custodial. Mealtime seemed to be just a chore to be done with no sense of family or community. Five women were listlessly sitting in wheelchairs in front of a TV. Ina sat off to the side of the semi-circle. No staff attended to any of these women. The TV was on but there was no sound. Four of the women did not bother to look at anything in particular. During our observations of Ina, we noted no programming or active habilitation on the living unit where she spent the vast majority of her time.

Helen. We visited Helen in the same living unit as Ina on November 18, 2008. She was still in her bedroom alone at mid-morning. She was on a waterbed with no staff supervision. Her eyes were half-closed and she was rolling back and forth. Her diaper was soaking wet and she had bruises on her backside from her rolling and banging onto a wooden bed frame. No one paid hardly any attention to her all morning. No one intervened and she was drooling all day. The fact is we observed her much of the day and saw no programs whatsoever. Helen's program of pushing herself in her wheelchair was virtually an impossible task due to her size and the wheelchair's poor adaptation to her body. Her wheelchair needs to be adapted to her particular needs. Helen's "money activity" program was also somewhat meaningless due to her lack of opportunity to use money.

No one whom we observed was involved in any habilitation program. Sitting in a semi-circle in front of a TV was the only activity. No one was receiving any significant active habilitation on the living unit. This is an integral part of the Agreement. The failure to receive active habilitation is developmentally and emotionally destructive to the residents. The "programs" we examined were generally irrelevant, not implemented, and lacking any consistent data. These residents spent almost no time off the living unit as ordered in the Agreement.

Allen. The mother of BSDC resident Allen discussed earlier in this report, expressed concern about the lack of adequate supervision and habilitation at BSDC, "Last Friday my daughter and I went to visit Allen. Every staff person was watching TV. Allen was in his room and his feeding tube was out. Staff members were still watching TV. Every time I looked, staff were just watching TV, every time."

Quincy. Quincy is 42-years-old and has been at BSDC since he was 6-years-old. His plan states that he would like to spend his days laughing, close to those around him, and that he likes swimming, being outdoors, playing interactive games and going for walks. I did not see him outside during my visits nor did I observe or see documentation of any of the activities he supposedly enjoys.

Health Care

I was disappointed and saddened to learn of the arrest of a part-time BSDC physician for allegedly selling prescriptions for narcotics to his private patients in the Lincoln area. The following story appeared in the December 19, 2008, Lincoln Journal Star: “A 71-year-old doctor has been arrested on suspicion of illegally selling prescription drugs. In September, the Lincoln Police Department’s narcotics unit received information that Hai H. Tran of Omaha had been illegally prescribing narcotics for money, said Officer Katie Flood...”

When BSDC learned of his arrest his services were discontinued. BSDC immediately confirmed that its physicians have no access to prescription medications at the facility. BSDC also reviewed Dr. Tran’s records to ensure that client health and safety had not been compromised.

This significant event leaves the residents at BSDC with two less hands to care for those with medical needs. His arrest and the State’s subsequent suspension and dismissal of the physician have left BSDC short-handed and likely less capable of meeting the quotidian medical needs of its residents. The Medical Director, Dr. Harrington, is acting as the facility physician while recruitment proceeds for a physician and two internists.

The question of the health care provided to BSDC residents is quite worrisome. Although the facility has a number of nurses, it has a high rate of visits and admissions to the local hospital, Beatrice Community Hospital (“BCH”). I recognize the need for emergency care and hospitalizations. However, there is concern regarding the quality of care and its timeliness.

I have serious concerns about BCH’s role in providing emergency medical care to some BSDC residents, especially given the many subsequent transfers to hospitals in the Lincoln-Omaha areas where there are specialized medical supports. BSDC residents with a very serious injury or illness are often transferred to hospitals in Lincoln or Omaha, because BCH apparently cannot handle some complex cases, thus, adequate and timely medical care for BSDC residents is questionable. When emergency cases have to be transported far away from the BSDC area, time can be of the essence. From July to November 2008, there were 73 visits to BCH from BSDC. Of these, 7 (10%) were then treated in or admitted to hospitals in the Lincoln and Omaha area when BCH was unable to meet urgent medical needs. Two of these transferred admissions resulted in death. There are even a few complaints by some BSDC staff that some professionals at BCH might resent having to treat BSDC residents.

Our concerns about BCH are shared by CMS who notified BCH that it is “out of compliance with the Responsibilities of Medicare Participating Hospitals in Emergency Cases”. A proposed November 2008 termination date has been extended to January 29,

2009. In light of this situation, BSDC is negotiating with ENCOR to expand its Medical Services Unit to provide services to medically fragile residents transitioning from BSDC. The State should be applauded for this intention and I await its fulfillment.

Following are a few illustrative stories regarding health care.

BSDC resident Bill was taken to BCH after a fall and sent back with just a bandage on his head. In fact, he had a broken neck, awoke paralyzed the next day, and subsequently died. Dr. Sheridan, who was contracted to perform chart reviews by BSDC, concluded that “While {Bill} eventually died from complications directly related to his fall, the complications resulted from a missed diagnosis by the ED physician at Beatrice Community Hospital.”

Allen is a resident who was admitted to BSDC in 2002. Allen has recently had pneumonia and a collapsed lung. Allen is also an insulin dependent diabetic. In recent months he quit eating for unknown reasons. His mother is deeply concerned about his physical and emotional well-being because he is now fed via a G-tube. There was ample evidence that Allen was uncomfortable with the tube and wanted it out. Since having to use a tube, he has tried many times to pull it, sometimes successfully.

Allen’s mother feels that he almost died August 28, 2008, due to inadequate medical care at BSDC and the local hospital. She claims a series of “medical errors and abuse” occurred. Specifically, Allen’s mother stated that BCH botched an emergency room visit after he had pulled a feeding tube out at BSDC. The BCH ER doctor assumed it was a mature site and apparently did not re-insert it correctly. During this procedure, the doctor also allegedly allowed security guards to handcuff Allen to the gurney. Allen’s mother claimed, “They [BCH] physically assaulted him, handcuffed him to a gurney, and reinserted the tube in an unhealed opening causing him great pain to the point of his screaming. The ER then sent him back to BSDC and the staff were not aware of the protocol.” She stated, “BCH should have known that he should have stayed more time in the hospital. Upon his return to BSDC, he showed clear signs of shock: paleness, sweating, vomiting, and was doubled up in pain. He was crying out, ‘Hurt! Hurt!’” This plea apparently went unheeded. His mother reported this to the BSDC physician, Dr. Tran, whom she claims said to staff, “Give him a food tray and if he does not eat, tube feed him.” She also claimed that a BSDC staff member said the G-tube was not necessary, “They are doing it for convenience.”

BSDC has a memorandum of understanding with BCH regarding transfers, but in several instances it does not seem to have been followed or effective. One significant policy is a requirement for BSDC staff to accompany residents to the hospital. It can be a frightening experience for a resident to be whisked away from the facility without a familiar caregiver at the person’s side. It is extremely sad when a person has to be hospitalized without the comfort of a familiar person. It is tragic when a person dies surrounded by strangers. It is not just the emotional support that might be given. There

were incidents that could have been avoided if a knowledgeable staff member had been present to share information and comfort the resident. For example, when Allen was taken to BCH for a G-tube replacement, no comprehensive medical file was taken with him.

The chart below shows the frequency of hospital visits by month, numbers of transfers and in-hospital deaths.

Chart 7: Hospital Admissions, Transfers and Deaths in Hospitals

Month	Number	Transfers	Deaths
July	13	0	
August	23	3	1
September	12	2	
October	16	1	1
November	9	1	
Total	73	7	2

The primary reasons for hospital and emergency room admissions are listed in the following chart.

Chart 8: Reasons for Beatrice Community Hospital-ER Visits in the Past Year

Abdomen Distention/ileus	6	Fever	4	Nose Bleed	1
Arm Pain	1	Fracture	5	Pneumonia	27
Baclofen Pump Placement	1	G-Tube	6	Rectal Bleeding	2
Bleeding From Penis	2	Hemicolectomy	1	Renal Bx	1
Body Check	4	Hiatal Hernia/URI	1	Seizure Activity	11
Bowel Obstruction	4	Hypoglycemia	1	Sexual Activity	6
Bronchitis	1	Hypoxia	4	Slurred Speech	1
Change In Sensorium	1	Ileus	3	Sprain Evaluations	8
Check For Rectal Probe	1	Influenza	1	TURP	1
Chest Pain	1	Ingestion-foreign body	6	Unable To Move Extremities	1
Cyst Jaw Area	1	J-Tube	30	Uncontrollable Diabetes	1
Cystoscopy	1	Laceration	1	Unknown Pain	1
Decreased Mobility	1	Lap Cholecystectomy	2	Unresponsive	5
Edema 3rd Finger	1	Lethargy	3		
EGD: Unable To Swallow	1	Liver Function Evaluation	1		
Emesis	3	Low Sodium	1		
Evaluation Port-A-Cath	1	Lower Back Pain	1		
Fall	9	Non-Weight Bearing	1		

The chart above includes data for an entire year as we wanted a comprehensive understanding of the range of medical conditions and emergencies. The most common hospital visits were related to pneumonia, 27 cases, and adjustments and/or reinsertions of J-tube and G-tube feeding devices, 36 cases. Seizures comprised the next highest frequency reason, 11 cases.

Most residents have incomplete therapeutic assessments or no assessments at all. There is very little documentation of the need for equipment. This results in incomplete

and inconsistent treatment and intervention plans, disconnected in-service training, and staff members that often mean well, but do not possess the necessary skills to do well. There are at least 46 people at BSDC who are fed with G-tubes, yet there is no obvious staff expertise in carrying out this procedure. The following case examples illustrate the types of harm that can befall vulnerable people when those who are charged with their care seemingly fail to offer adequate and appropriate services.

- Charles fell ill and apparently had a heart attack. One BSDC staff person was either late or did not show up for the shift. His caregivers did not follow procedures either in trying to resuscitate him or in calling for medical backup. No one will ever know what the outcome would have been for Charles if the staff had up-to-date CPR training and if they had not panicked when Charles fell ill.

- We visited Wesley on November 19, 2008. Upon entering the unit, we asked a nurse where he was. He stated that he had been pulled off his regular job elsewhere and assigned to the unit and would have to have someone identify Wesley for us. We were deeply concerned that Wesley's nurse was unable to identify him. It would be especially tragic if an emergency were to occur and the unit nurse did not know basic information regarding this or any other resident. Anyone who serves as a temporary substitute must have basic information on each person and personal needs and protocols. The lack of this basic information is frighteningly dangerous and must be corrected.

- Helen is 33 years old and has been at BSDC since age 9. She uses a wheelchair but can take steps with assistance. Her wheelchair footrests are too low for her and her feet are unsupported. She feeds herself, but I found no feeding guidelines available. When I visited, she had a sore/infected eye that she kept rubbing and staff report it has been going on for months. Helen should be on an ambulation program if she can take steps. Helen's body and feet need to be stabilized so that she can move her wheelchair. Her chair was not adapted to her body. Her seating was upright, but she seems too drugged to carry out such a program. She needs a thorough neurological/psychiatric assessment for medications as she appeared to be too drugged. She spent half the day in bed and the other half sleeping in her wheelchair. Her buttocks had bruises on both sides due to banging caused by rolling back and forth on her bed and possibly from seizures. She had a red swollen area on her right side eye lid.

- Glinda is 15 years old and has been at BSDC for 11 years. The utility of her custom molded chair is questionable. A body jacket typically provides the support and not a customized chair. Nothing in the records adequately addressed the body jacket. Her staff reported that she wears the body jacket all day until bedtime.

- Quincy's use of shoes and braces is questionable as they can be painful. This young man cannot and will not ever walk.

Supervisory and Direct Care Staff Recruitment and Training

The State has reported on its recruitment efforts of new staff and training all staff. These efforts are meritorious. A comprehensive plan to increase recruitment and retention was implemented at BSDC and has proven successful. Mandatory overtime has been reduced and incentives are in place for anniversary increases and referrals. Legislation is pending that would prohibit mandatory overtime in state owned 24-hour care facilities.

Newly created positions designed to enhance staff performance include:

- (1) Orientation Facilitator
- (3) Mentor/Developmental Technician III
- (30) Developmental Shift Supervisors- (30 more to be hired)

Active Treatment Services

Staffing efforts have also focused on enhancing active treatment supports:

- Active Treatment Program Administrator (starting date January 2009)
- Active Treatment Clinical Services Administrator (starting date February 2009)
- Vocational Activity Specialists
- Recreation Activity Specialists
- Recreation Aides
- Full time Speech Therapist (Guardian Healthcare Provider starting date January 2009)
- Full time Physical Therapist (Guardian Healthcare Provider starting date January 2009)
- Positional and Nutritional Management Team Facilitator- (contract begins January 2009)
- Psychology Services are provided through contracts with Lee Zlomske, PhD and Dr. Rod Koch

Neighborhood Services

Staffing efforts have also focused on enhancing residential living services:

- Neighborhood Services Administrator (starting date September 2008). Responsible for allocation of staffing resources to maintain safety and active treatment.
- Training: Person Centered Thinking with Michael Smull and Amanda George. This was held for QMRPs, HSTs and Direct Care Staff.

Quality Improvement

Staffing efforts have also focused on enhancing on-going quality assurance efforts:

- Quality Improvement Director (starting date October 2008)
- Investigations Administrator/Lead Investigator

Medical Services

Staffing efforts have also focused on enhancing medical supports:

- Medical Director- Dr. Alfred Harrington (start date July 2008)
- Psychiatric/Family Practice Nurse Practitioner
- Registered Nurses
- Medical Chart Review contract with Liberty Health Care and Dr. Daniel Sheridan
- Expanded clinic hours contract with Dr. George Wolcott for Neurology Services while seeking additional resources
- Psychiatric Services contracts with Dr. Todd Stull and Dr. Susan Howard
- Negotiating a contract with Columbus Organization for physician consulting services
- Clinical Services Management for on-going support needs

Community Placement

Staffing efforts have also focused on community placement supports:

- Negotiating a contract with Clinical Service Management to do assessments, individualized plans, and transition plans for all residents - expected completion in May or June 2009
- Money Follows the Person Waiver in process to move people from nursing homes to the community.

RECOMMENDATIONS

Based on this evaluation, I strongly urge the State to consider the following recommendations:

- I ask that the State consider each deficiency and/or recommendation in this report.

Hospitalized Individuals

- If those who are hospitalized in the current emergency cannot stay in the hospital beyond their medical care and treatment, I urge the State to ensure that each person receive adequate and appropriate care in a community setting or other adequate setting while waiting for their eventual placement.
- The State, while being rightfully applauded for its noble efforts to protect BSDC's medically fragile men and women, now must develop transitions plans for each person, individualized active treatment plans while temporarily hospitalized, a protocol for each related to their active treatment while temporarily hospitalized, and a protocol for their daily support while temporarily hospitalized.
- With all due haste, the State must also develop contracts with providers for the placement of each of these individuals in small, inclusive group homes with full day programs outside of these homes. These homes should meet all Settlement Agreement requirements including adequate and appropriate developmental and therapeutic supports, community recreational activities, and a full day program for active treatment apart from the homes.
- Services Coordinators should forward a weekly progress note to the IE related to each hospitalized person.
- The State, perhaps in conjunction with parent advocates, should keep family members and guardians abreast on all issues related to the medical care and active treatment of their protégés.
- It is also vital that each hospitalized person have a personal advocate to visit him/her while hospitalized and provide emotional support that enables the person to feel safe and loved while hospitalized and beyond.
- The State should consider the establishment of a parents-helping-parents project in which parents experienced in community placement help parents struggling through the maze of rules, regulations, and financing. This has been successful in other States. This project has taken on increased urgency with the recent placement of medically fragile persons in the Omaha-Lincoln area.
- The IE's evaluation team will focus on these individuals in the next quarterly evaluation visit and will report on their impressions and will make recommendations.

Transition Planning

- There is a critical need for meaningful transition plans. These plans should be virtual contracts that fully describe what is needed before placement, during placement, and in the long-term.
- These plans should be developed through the facilitation of each person's Support Coordinator with the active participation of BSDC staff and future providers along with each person's family members.
- A protocol should be developed for potential community placements that delineates what records should be provided to community service providers to ensure that a complete and accurate picture is presented.
- Transition plans should be completed and begin to be implemented prior to any placement.
- Any residents who have guardianship approval for community placement should immediately possess a transition plan with a targeted date for placement. This must include adequate time for the involvement and input of community providers. The resident should be expected to return to community living with the use of positive behavioral support, adequate psychiatric back-up, and the avoidance of punishment and any form of restraint. Providers and caregivers must have the skills to effectuate such a placement. The State needs to support a statewide training initiative for providers and caregivers.
- Among many other factors, the State must ensure that residents considered for community placement, should have: adequate and appropriate financing sufficient to comply with the factors in the Settlement Agreement; flexibility in placements such that any provider placing a high-risk individual will be able to support the person for a time with adequate start-up support without other residents in the house; certified caregivers and providers, credentialed through a State training and certification mechanism; transition planning, established far in advance of any actual placement with the resources available to meet all transition criteria, including the active involvement and input of the provider, Service Coordinator, and others.
- Prior to community placement for individuals with anti-social behaviors, BSDC should prepare a clear and comprehensive packet of information and provide guidance in the development of a transition plan that will ensure the acquisition of pro-social skills and also ways to prevent harm.
- Communications between BSDC and providers should be improved so that important incidents at BSDC and during any trial visits are reported, thoroughly discussed, and acted on.

Community Placement

- In terms of systemic needs, it is absolutely vital that the State take a cautious and prudent approach toward placements from BSDC into community programs for those

residents with a history of anti-social behaviors. Since individuals with these needs tend to have more skills, they are often perceived as needing less staffing and supervision. The fact is these individuals generally need more staffing in order to prevent harm and intense staffing tends to be needed for longer periods of time. Providers for these individuals should be experienced, well-trained, and well supported.

- While integrated community alternatives are being established, the State should reconsider its rate of placements into nursing homes and establish placement practices congruent with the Settlement Agreement.
- BSDC residents who have been placed in the community or in nursing homes since October 2007 should be followed along by HHS, with full disclosure of deaths with autopsies, causes, symptoms leading up to death, and any systemic changes recommended due to these deaths.

Provider and Caregiver Training

- Residents require providers and caregivers who have specific skills and training. A statewide training curriculum should be established for all supervisory, clinical, and direct care staff in Nebraska.
- The State should develop a statewide training curriculum to teach the skills and strategies necessary to serve individuals through positive behavioral supports and without the use of restraint and punishment, approaches for working with individuals who are medically fragile, who have behavioral issues, and who have an allied mental illness.
- The curriculum should also include outcomes related to human and civil rights, medical interventions such as First Aid and CPR, and adapted to particular sub-populations.

BSDC

- All caregivers, supervisors, and clinicians need to develop skills related to the development and implementation of meaningful person-centered-plans, transition plans, and positive behavioral support.
- BSDC should establish an intense mentoring program for old and new staff that provides direct caregivers with adequate supervision and hands-on training so that they learn to carry out programs in a meaningful manner.
- Settings focused on individuals with behavioral problems should consist of smaller groups living together. These environments are prime for altercations given the challenges each person has. I would advocate “softening” up each environment, making them more home-like, and making the groups smaller. These changes might help decrease behavior problems and enhance the opportunity to teach pro-social behaviors.

- BSDC should establish a protocol for mealtime so that it might become more of a social and interactive experience rather than simply a feeding experience.
- All injuries caused by or attributed to any form of physical management should be thoroughly analyzed and related revised training provided to all caregivers.
- The entire question of physical management should be re-analyzed to determine its usefulness and to identify alternate ways to prevent behavioral outbursts.
- All reports on the use of physical management and mechanical restraint should be more closely defined and examined for the purpose of continuing to decrease its use. There needs to be more information about what led up to any behaviors, who were present, what the particular trigger might have been, and how it could be prevented. The central focus should be on prevention, not correction.
- The use of physical and mechanical restraint should be more thoroughly and accurately recorded in all instances.
- Behavioral plans need to be made more precise and focused on interpersonal relationships and, of course, must be positive. The more precise and concrete the plans, the more likely direct caregivers and others can follow them.

Medical Care

- The quality of BCH's emergency room and inpatient care should be examined including an analysis of any complaints related to BSDC residents' care, the identification of any possible resentment to the care of BSDC residents, the specific reasons for the need for the transfer of residents to out of town hospitals, and any negative impact on residents' physical well being.
- Since pneumonia and the replacement or adjustment of tube feeding devices are the two highest reasons for seeking care at BCH, BSDC should re-analyze its training curriculum in these areas, ensure continuing education and direct supervision related to the prevention of medical problems based on these causes, and ensure supervisory staff are mentoring direct caregivers in areas related to pneumonia and feeding devices.
- BSDC should strictly enforce the memorandum of understanding with BCH, especially the section on familiar staff accompanying residents to the BCH emergency room to share BSDC charts related to medical needs, reduce any possible trauma, and offer comfort.
- Each person must have a comprehensive psychiatric evaluation along with on-going medication reviews. No resident should be subjected to psychotropic medications for behavior problems. The psychiatrist must present a differential diagnosis.
- Those who are on psychotropic and neurological medications must have comprehensive evaluations by both disciplines.
- All standing orders for PRNs for behavioral issues should be removed, as well as any other prescribed use of chemical restraints.

- The use of poly-pharmacy should be halted wherever possible and appropriate.

As the Independent Expert monitoring the Settlement Agreement, I would like to thank the State for its recent bold and courageous actions to defend the well being of Nebraska's most medically fragile and vulnerable citizens. The State's recent actions bode well for the coming years. This emergency action is but the first step in the need to fulfill the Settlement Agreement. It is my hope that by working together we will be able to give the least among us equality as full citizens and the supports and services that they merit as citizens of Nebraska and the United States. We are just at the beginning, but the beginning is good. I am thankful for this. Now the challenge is to ensure each person adequate, appropriate care, services, and supports.