FACT SHEET ON REFORMS IMPLEMENTED IN THE NEBRASKA DD SYSTEM

United States v. Nebraska, No. 8:08-cv-271 (RGK)

On July 2, 2008, the United States District Court for the District of Nebraska approved a consent decree between the United States and the State of Nebraska that contained remedial provisions to address systemic deficiencies in the State's service system for people with developmental disabilities ("DD").

The decree required the State to address all of the outstanding issues set forth in the United States' findings letter, issued on March 7, 2008. It required the State to remedy health, safety, and welfare issues at the two state-owned and operated institutions – the Beatrice State Developmental Center ("BSDC") and Bridges, a highly-restrictive satellite facility that housed people with behavior problems, who had been involved in serious incidents, typically involving law enforcement. The decree also required the State to significantly expand and enhance community capacity to better serve individuals with DD in integrated settings. It stressed the need to transition institutionalized people with DD *to* the community and to meet their needs *in* the community.

Over the past seven years, the State has developed effective systems to comply with the terms of the decree, and thereby greatly improved the daily lives of thousands of people with DD, including about 5,000 people served in integrated community settings throughout Nebraska. The State has implemented reforms that have transformed its service-delivery system for people with DD, greatly expanded community capacity, minimized reliance on institutional services, and generally improved outcomes for people with DD.

COMMUNITY REFORMS

Since entry of the decree, the State has made a concerted and sustained effort to expand community DD services throughout Nebraska in order to ensure that adequate services are available to meet outstanding needs.

Minimized Reliance on Institutional Services and Decreased Institutional Census in DD System

Beatrice State Developmental Center

- Entry of the decree effectively closed the front door to state-run institutional DD services in Nebraska; the last admission to BSDC was on June 9, 2009.
    - As of July 22, 2015, there were only 116 residents still living at BSDC; this represents about a two-thirds reduction in census size from the time of our investigation in 2007.
    - The State has taken the extraordinary step of physically demolishing at least three of the largest buildings on the campus and it has plans to demolish several others.
    - BSDC is the only state-run DD institution left in Nebraska.
- Since entry of the decree, the State has implemented a number of effective measures to continually engage individuals and guardians about community alternatives. Due to the diligent efforts of State personnel, the State has been successful in convincing a number of guardians who had been opposed to placement to agree to community transition.

Bridges

- By June 2013, the State closed the Bridges institution and placed all of the residents into community settings. In 2011, the Nebraska legislature approved $1.5 million to construct several new homes in a nearby town to enable the residents to live in the community.
- Since the community transition process began, individual outcomes have improved:
    - none of the discharged individuals has had contact with a psychiatric hospital;
    - they are no longer subjected to mechanical or programmatic physical restraints;
    - emergency safety interventions are almost non-existent;
    - they suffer far fewer incidents and injuries;
    - psychotropic medication usage has been reduced significantly; and
    - they have been participating fully in community life – each person spends over five hours per day doing a variety of vocational and volunteer activities in nearby communities, and all but two people are involved in paid work in the community.

Institutional Spending

- The State has been prudently directing DD resources away from institutional services and towards the community. During the life of the decree, overall expenditures at BSDC have decreased. From its peak in FY10, total annual BSDC expenditures have fallen by almost 13 percent; this is almost a $7.5 million reduction in yearly institutional spending.

Significantly Increased Emphasis on Providing Services in the Community

- *Hefty Budget Increases for Community DD Services* - State expenditures on community DD services basically doubled during the life of the decree; this represents an additional $72 million state dollars per year for community-only initiatives than was available before entry of the decree. Given that Nebraska receives about a 50 percent federal match through the Medicaid program, the overall increase in annual community funding has been around $144 million. The increased funding has expanded services, improved their quality, and provided more effective oversight of service-delivery.

- The increased spending in the community has been cost effective. In 2014, the average annual per person cost at the BSDC institution was $393,470; by contrast, the 2014 average annual per person cost of services through the comprehensive community DD waiver was approximately $58,000. Thus, it costs about six times more on average to serve someone at BSDC than in the community.

- *Revised Waiver Rate Methodology* - On July 1, 2014, the State implemented a new rate methodology to ensure all people on the community waiver have access to adequate DD services to meet their individual needs. People with DD now get an individualized budget amount and can spend it flexibly on the services they need and prefer.

- *Reduced Size of the Community DD Waitlist* - During the life of the decree, the State has made a concerted effort to reduce the size of the DD waitlist for community services. For the period July 1, 2009 through December 31, 2012, the State offered DD services to 2,470 people on the waitlist; of those, approximately 1,680 individuals accepted services.

- *Emphasis on Small Community Homes* - Almost 4,000 of the almost 5,000 served through the waiver live in community homes of three or fewer people. The State continues to de-emphasize use of homes of four or more.

- *Stronger Regulatory Framework* - On July 16, 2011, the State issued new regulations to establish improved review of community providers, to address gaps and weaknesses, to provide information for comprehensive planning and resource-targeting, to investigate complaints, and to follow up on reported incidents.

- *Expanded Number of Community Providers* - To meet the increased demand for community DD services throughout Nebraska, the State focused significant effort on

recruiting new providers to expand DD provider capacity in the community. Prior to 2009, there were 25 specialized providers certified in Nebraska. Since then, the State has certified an additional 35 such providers – well over a 100 percent increase – who operate a total of 87 certified community programs.

- *Service Coordination Focused on Individual Advocacy* - After entry of the decree, the State transformed its old "case management" system into a DD "service coordination" system where personnel now actively advocate for each individual. The State maintains small caseloads for service coordinators, of no more than 25 individuals per coordinator.

Expanded Community Capacity to Address Complex Health Conditions

- *New Accessible Community Homes* - In March 2009, the State entered into a contract with an established community provider to build and operate 11 new accessible community homes across Nebraska with sufficient funding and expertise to be able to meet the needs of dozens of people with DD with the most complex health care issues. The first such home opened in April 2010.

- *Health High-Risk Screening Tool* - Since the entry of the decree, the State has developed and implemented a health high-risk screening tool with a prioritization matrix to identify individuals with DD in the community who have significant medical issues.

- *Traveling Clinical Review Team* - In April 2012, the State created a community clinical review team to expand and enhance community capacity in health care. Individuals are prioritized for visits based on data related to hospital contacts, health outcome criteria, and the results of the health risk screens, with those with the highest risk scores addressed first. Team nurses provide consultation, technical assistance, and/or training for community provider agencies to improve the quality of DD health services.

- *Specialized Training and Services for Physical and Nutritional Support Needs* - By 2014, the State had taken important steps to expand the ability of community providers and clinicians to deliver physical and nutritional supports (PNS). The State contracted with a private entity to provide statewide basic and advanced PNS courses and training to caregivers, and provider staff.

- *Health Care Curriculum and Training for Community Providers* - In 2012, the State engaged a DD physician to develop a video-based health supports curriculum to better equip community staff to recognize and respond to the health care needs of people with DD in the State's system, especially those with complex health conditions. The State made the full curriculum available to all community providers in Nebraska.

- *Tele-Health Network* - The State is utilizing and expanding a tele-health network for underserved areas. Community staff can access the network at many local hospitals and the regional public health clinics across Nebraska.

- *Low Mortality Rate in the Community* – Among the thousands of people with DD in the State's system, in 2014, there was a relatively low death rate of 12.76 in community settings; the rate for 2013 was comparably low at 10.08. By contrast, from 2010 through 2014, the annual mortality rate at BSDC has averaged 20.56.

- *Mortality Reviews* - Per requirements in the decree, the State contracted with a private health care entity to conduct independent mortality investigations. The independent reviews prompt recommendations to reform deficient practices to avoid preventable illnesses and death going forward.

Expanded Community Capacity to Address Complex Behavioral Conditions

- *Intensive Mobile Community Behavioral Services* - The State contracted with a private community DD provider of specialized behavior supports to provide statewide mobile team behavioral consultation services, especially for those individuals with DD with co-occurring complex behavioral/mental health issues. The State has expanded the program to six teams – three in Omaha, two in Lincoln, and one in the geographic middle of the state. The six teams can get to about 95 percent of people in need within one hour.

- *Community-Based Short-Stay Crisis Home* – In conjunction with a private provider, the State operates a crisis stabilization program in a home that is well integrated into the community. This home can serve three individuals at any given time. People placed in this home generally stay a short time before returning to permanent community homes.

- *Intensive Training on Functional Assessments and Behavior Plans* - The State offered several rounds of intensive hands-on training for community providers at various locations across Nebraska to assist them to conduct adequate functional assessments and develop effective behavior plans for several dozen high-risk individuals.

- *Electronic Incident Reporting System* - On January 1, 2014, the State implemented an electronic incident reporting system for all community providers that allows staff to record incidents more quickly, more accurately, and more consistently than was possible before with paper reporting. The electronic system enables the State to take more prompt and more tailored remedial measures to address outstanding concerns. The State's quality improvement committee now utilizes the improved incident data from this electronic system to conduct in-depth analysis of incidents and to track trends.

- *Enhanced Community Services to Prevent Contact with Correctional Facilities* - The State has developed and implemented an effective plan to keep individuals with DD out of jail or prison. In recent years, the State's DD agency has educated county attorneys across Nebraska about DD issues. As a result, these attorneys contact the DD agency to intervene when someone suspected of having DD is implicated in a criminal matter. The DD agency can then assume responsibility going forward and, typically, avoid inappropriate incarceration.

- In FY14, the State also spent over $1.4 million to provide evaluations and services to people covered by the state Developmental Disabilities Court-Ordered Custody Act ("DDCOCA"), first operationalized a year after entry of the decree. This kept almost a dozen individuals with DD out of a correctional facility. Since the inception of the program in 2009, the State has spent over $4.2 million on this initiative and has diverted about two dozen people with DD. Not only has the State prevented their incarceration, the State has succeeded in providing these individuals with community homes and with services in integrated community settings.

Enhanced Community Capacity to Provide Integrated Day Activities and Supported Employment

- *Supported Employment in the Community* - The State has significantly increased the number of people with DD who are employed in integrated settings, as well as the number of hours they are working there. From 2007 to 2013, the total number of people with DD who worked in integrated settings increased by over 61 percent from 651 people to 1,050 people. As of 2013, the State estimated that over 23 percent of all eligible people with DD in its system were working in an integrated setting. From 2007 to 2013, the number of people working over 10 hours per week in integrated settings increased by 70 percent, and the number of people working over 20 hours per week increased by 77 percent. This is true employment where people with DD are earning minimum wage or above and are being paid directly by the community business, not in sheltered workshops.

- In January 2011, the State revised its two adult waivers to provide greater opportunities for individuals with DD to explore integrated employment. The State offers vocational planning focused on career planning, job exploration, and job skill development to better enable individuals with DD to have a normal and successful job search experience. Once employment is obtained, the State offers integrated community employment services to provide job coaching and supports.

- *Community Volunteer Activities* - The State has made significant strides in involving people with DD in integrated volunteer activities that enable them to explore and experience their community, learn skills that may be transferable to future employment, contribute meaningfully to their community, and build self-esteem. From 2007 to 2013, the total number of people with DD who volunteered in integrated settings increased by 185 percent from 380 people to 1,082 people. During this time, the number volunteering over 10 hours and over 20 hours per week each increased by over 600 percent.

- *Community Recreational Activities* - There has been similar progress with regard to participation in integrated recreational activities. From 2007 to 2013, the total number of people with DD who were engaged in recreational activities in integrated settings increased by over 96 percent from 1,510 individuals to almost 3,000 individuals. The number involved in over 10 hours of community recreation per week increased by over 160 percent and the number involved in over 20 hours of community recreation per week increased by over 223 percent.

- *Reducing Reliance on Sheltered Workshops* – To comply with the new CMS home and community-based services rule, the State is implementing a transition plan that will minimize or eliminate utilization of sheltered workshops over the next five years.

- *Positive Conclusions of the Court Monitor on Community Reforms* – In her final report, the independent court monitor in this case found that the State has taken many steps to "increase community capacity, and improve its oversight of the community system to ensure that individuals the Settlement Agreement covers are provided the protections, supports, and services they require." She reported that the State built "much-needed infrastructure for the community system." She concluded that "[m]any of the pieces necessary for a healthy community system had either been missing or were not operating in a fashion necessary to meet the goals and the requirements of the Settlement Agreement." She reported that "important changes" had been made to improve access to community services for people in need, "particularly individuals with complex medical and behavioral needs." She concluded that the "achievement of these goals has only been possible through strong teamwork and the dedication of many staff." The monitor reported that the implementation of the State's reforms has produced "positive outcomes for individuals"; she provided some examples in her final report:

    - Many individuals "spoke with gratitude" about the work the State had done over the last several years to transition them to more integrated community settings; after placement in the community;

    - The sister of a man transitioned to the community said: "Our family never thought his life would be this full";

    - Men placed into the community from Bridges were thrilled with their new homes and reported that their families now visited them more regularly.

INSTITUTIONAL REFORMS

Since the entry of the decree, the State has implemented effective measures to address outstanding issues at BSDC to meet the individualized needs of residents.

Significantly Increased Community Integration at BSDC

- The State has taken significant efforts to better integrate BSDC residents into the community during the day. In 2014 and the first half of 2015, the State reported that over 90 percent of BSDC residents participated in off-campus activities at least once per week; this is up from 73 percent in early 2013.

- The number and percentage of BSDC residents working in the community continues to increase from year to year. The percentage of eligible BSDC residents who work off campus has increased significantly from less than one percent (one person) at the time of

the United States' findings letter, to seven percent in 2010, to about 25 percent in 2011, to about 33 percent in 2012, and to around 60 percent in 2013 through to today.

Significantly Reduced Restraint Usage at BSDC

- *Mechanical Restraints Eliminated* - One of the most significant accomplishments of the decree is the complete eradication of mechanical restraint usage in the Nebraska DD system – at BSDC, at Bridges, and in the community. In January 2011, the last mechanical restraint was used at Bridges; in December 2011, the last mechanical restraint was used at BSDC; and mechanical restraints have not been used at all in the community since the entry of the decree. This is notable, as at the time of our initial investigation, our psychology consultant had concluded that mechanical restraint usage at BSDC was "the highest in frequency and duration that I have seen in my experience."

- *Physical Restraints Minimized* - The decree has prompted significant reduction in the use of physical restraints as well. Programmatic physical restraints are no longer permitted, physical restraints may only be utilized as emergency safety interventions, and the State constantly works towards meeting a target of zero use of physical restraint.

    - In 2008, about 21 percent of BSDC residents were subjected to physical restraints; given the population at the time, this impacted about six dozen people. In the second quarter of 2015, only three individuals (about two percent of the BSDC census) were subjected to physical restraint, a total of 10 times.

    - In 2008, there were 539 instances of physical restraint that totaled 2,660 minutes. In the first two quarters of 2015, there were only 19 instances of physical restraint for a total of 106 minutes. This represents a significant reduction in the use of physical restraints at BSDC from the first year of the decree.

    - The State was able to significantly reduce physical restraints and completely eliminate mechanical restraints at BSDC without increasing the use of psychotropic medications; indeed, the percentage of residents prescribed psychotropic medications has decreased over the past four years.

- *Chemical Restraints Eliminated* - In 2012, the State reports that it has eliminated entirely the use of chemical restraints at BSDC. In 2014, there were only eight instances of emergency use of psychotropic medication at BSDC, even though there were over 90 behavioral crisis episodes. This is a testament to the State employing less onerous practices to deal with crises among residents.

Enhanced Safety and Improved Professional Services at BSDC

- *Abuse and Neglect* - Per the decree, Nebraska maintains a "zero tolerance" policy for abuse and neglect. The State has developed a broad definition of abuse at BSDC that includes verbal abuse and exploitation; the definition of neglect is similarly expansive.

- As a result of the decree, substantiated abuse incidents at BSDC have declined steadily.

    - At the time of our findings letter in 2007, there were over 100 instances of substantiated abuse at BSDC. Based on State reports, in 2011, there were 11 instances; in 2012, there were five instances; in 2013, there were three instances; in 2014, there were only two instances; and there was no substantiated abuse in the first two quarters of 2015.

    - There were only eight reported instances of substantiated neglect at BSDC in 2014, and there was only one instance in the first half of 2015.

    - All this is notable, as in our 2007 findings letter, we had concluded that the nature and frequency of abuse and neglect at BSDC suggested a "cultural undercurrent that betrays human decency at the most fundamental levels … basic human dignities are violated with considerable regularity."

- Since at least 2012, the State has fired every single employee who was found to have committed substantiated abuse or serious neglect. The State even fires employees who fail to report suspected abuse or neglect in a timely manner.

- *Background Checks* - In January 2010, the State implemented a new background check policy requiring a comprehensive set of background checks for new staff and volunteers, and whenever current staff change positions. Starting in October 2011, the State required all staff to undergo an annual background check.

- *Reduced Peer-to-Peer Aggression* - At BSDC, the State has undertaken significant efforts to reduce incidents of aggression between peers; these efforts include better behavior plan design and implementation, more staff training, and thorough root cause analyses of peer-to-peer incidents. In 2014, there were only 21 incidents of peer-to-peer aggression; this represents a 95 percent reduction from the time of our findings letter. No incident of peer aggression in 2014 or 2015 resulted in significant injury.

- *Quality Assurance* - There is now an adequate quality assurance system in place at BSDC on multiple levels; this has had a positive impact on incidents and overall risk of harm.

- *Behavioral Services* - The State now provides adequate behavioral services to all residents, including appropriate functional assessments and properly implemented behavior support plans. The State maintains a list of priority residents with the highest behavioral needs and typically provides them with increased intervention when needed.

- *Psychiatric Care* - There are sufficient psychiatry hours now to meet the mental health needs of those at BSDC, including enough time to complete thorough evaluations, develop carefully considered differential diagnoses, order appropriate treatments, and provide needed follow up. At the outset of this case, there were over 150 BSDC residents

taking at least one psychotropic medication; today, that number has been cut by more than half. The number of residents who are subjected to psychotropic polypharmacy has been decreasing. For the past year, there have been only six residents who were taking two or more psychotropics; this yields a polypharmacy rate of under 15 percent among those taking psychotropic medication, and a rate of about five percent of the total census.

- *Health Care* - Since entry of the decree, the State has implemented a host of improved health care practices to better meet the needs of residents, including those with more involved health conditions. Nursing services at BSDC have improved. The State provides residents with seizures with appropriate neurological care. The State has made significant progress in providing physical and nutritional management services to meet individualized needs at BSDC. As a result, choking incidents are down and the incidence of pneumonias, including aspiration pneumonias, has also decreased.