

# **The PGA/OPEA Vision for the Future of the Northern Oklahoma Resource Center of Enid and the Southern Oklahoma Resource Center**

## *A Safety Net for Oklahoma's Most Vulnerable*

By the Southern Oklahoma Resource Center Parent Guardian Association  
and the Oklahoma Public Employees Association

### **Background and Concerns**

The Northern Oklahoma Resource Center of Enid (NORCE) and the Southern Oklahoma Resource Center of Pauls Valley (SORC) have been home to thousands of Oklahoma's citizens challenged with disabilities since early in the last century. Both facilities are intermediate care facilities for persons with mental retardation (ICFMR) and receive funding from the federal government through the Medicaid program. Currently, the match rate is 64 percent federal and 36 percent state funding.

NORCE was established in 1909 and SORC was converted to an institution for the disabled in 1953. The combined total population of the facilities grew over the years to a total of 2,300 residents, with schools and farming operations. Since the 1960's, the facilities have downsized considerably, as some clients moved into community settings. The 245 residents who currently call NORCE and SORC home are challenged with severe physical and mental disabilities.

### **Client Profiles**

Most of the clients remaining at NORCE and SORC have lived at the facilities for decades. **The average length of stay at NORCE and SORC is 32 years with most of the clients falling within 20 to 50 years of residency.**

	<b>Average length of stay</b>	
	<b>NORCE</b>	<b>SORC</b>
54 to 60 years	3	
51 to 54 years	8	3
41 to 50 years	31	40
31 to 40 years	32	31
21 to 30 years	16	35
10 to 20 years	5	14
Less than ten years	20	12

Both NORCE and SORC have been downsized significantly from the time when they housed thousands of clients. Residents with less significant disabilities have been transitioned to community settings. Those remaining at the facilities are seriously challenged with medical and behavioral disabilities.

**Level of Developmental Disability**

	<b>NORCE</b>	<b>SORC</b>
Profound	89	97
Severe	19	26
Moderate	5	9
Mild	4	3

In addition to developmental challenges, many clients struggle with physical, medical, and behavioral issues that require constant attention, care and therapies.

**Special Needs Profile**

<b>Special Need</b>	<b>Number of Residents</b>	
	<b>NORCE</b>	<b>SORC</b>
Wheelchair	49	64
Walker	2	6
Gastrostomy /Jejunostomy tubes	25	34
Trach	0	6
Oxygen, Oxygen Concentrator, CPAP or BIPAP	5	9
Hill-ROM vest or breathing treatment		16
Vagal nerve stimulator <sup>1</sup>	3	56
Specialized staffing (1:1 or 2:1)	3	5

Additional specialized staffing needed on an emergency basis or community events

**NORCE Profile (additional information)**

<b>Disability</b>	<b>Number of Residents</b>
Blind (little/no useful vision)	10
Deaf (little/no useful hearing)	2
Epilepsy	71
Cerebral palsy	52
Psychiatric disorder	37
Two or more conditions in addition to intellectual disabilities	35
Autism spectrum disorders	11
Receives medication for moods, anxiety or behaviors	45

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<sup>1</sup> According to the Epilepsy Foundation, vagus nerve stimulation (VNS) is a type of treatment in which short bursts of electrical energy are directed into the brain via the vagus nerve, a large nerve in the neck. The energy comes from a battery, about the size of a silver dollar, which is surgically implanted under the skin, usually on the chest. Leads are threaded under the skin and attached to the vagus nerve in the same procedure. The physician programs the device to deliver small electrical stimulation bursts every few minutes.

## Transitioning Issues

The remaining residents at NORCE and SORC are fragile and challenged with severe disabilities. Most have guardians who are actively monitoring their care and well-being and are strongly opposed to them transitioning to community settings. Some have unsuccessfully attempted community settings and returned to NORCE and SORC. **For clients who can be moved to community settings, transitions are complicated and must be implemented with caution. In the past year, only five clients were transitioned into the community from NORCE and SORC.**

**Transitioning fragile clients from their lifetime homes in state facilities to community care can put their lives at risk.** According to a study<sup>2</sup> of 1,878, clients transitioned from California institutions into community homes, mortality rates increased by 47 percent over those remaining in institutions. The study reports 81 died over three years. The mortality rate increased with time. The authors attribute the increase to more fragile clients moving later in the study as the easy transitions were completed.

“The results in this and previous studies indicate an increased mortality rate, above that which would be expected,” the report indicates. “The cost savings of deinstitutionalization and social value of integration must be balanced against this increased risk.”

In Nebraska, the Beatrice State Developmental Center was allowed to decline and was decertified by Medicaid. **In February 2009, 47 severely disabled clients were forced to move from the facility. Nine months later, 10 of the transitioned clients had died and five were in the hospital.**<sup>3</sup> Beatrice has since been recertified for Medicaid funding. The state has returned the remaining residents to their homes and is building a medical unit to serve citizens with disabilities across the state.<sup>4</sup>

**With only 245 clients remaining at the NORCE and SORC, those most suited for transition have already been moved. The fragile medical condition of the current residents could put them more at risk than those moved in earlier years.**

From January 2011 until January 2012, only three clients have been transitioned from NORCE and two from SORC. During the transition phase, some clients have returned to the facility for stabilization and others have been returned because of unsuccessful placement. According to the OKDHS plan, 133 of the state's most challenged citizens will be placed in permanent homes by July 2013. This is an unrealistic goal, given that they have lived most of their lives in the facilities.

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<sup>2</sup> Robert Shavelle, David Straus, and Steven Day, “Deinstitutionalization in California: Mortality of Persons with Developmental Disabilities after Transfer into Community Care, 1997-1999,” *Journal of Data Science* 3, 2005, pgs. 371-380.

<sup>3</sup> Nancy Hicks, “10<sup>th</sup> Client Moved from BSDC Dies,” *The Lincoln Journal Star*, November 17, 2009.

<sup>4</sup> Nancy Hicks, “Dark Days at BSDC May be Over,” *The Lincoln Journal Star*, January 14, 2010.

## Safety Net

NORCE and SORC serve as a public safety net for the developmentally disabled service delivery system. In addition, the facilities are a critical part of the full continuum of care in developmental disabilities, from individuals in facilities requiring around the clock medical attention to those in community settings that need minimal in-home support.

Individuals with severe disabilities and medical complications who cannot live in the community reside in the facilities, which serves as either their permanent residence or as a temporary home for monitoring and stabilization before being moved into community homes. When the Health Department closed private ICFsMR, the Choctaw Nursing Home<sup>5</sup> and the Sunnyside Nursing Center of Enid,<sup>6</sup> because of high profile client deaths, NORCE and SORC were the only available options for the residents. Recently, a SORC parent attempted to find a community home for his daughter with serious disabilities. The only place that could safely care for her was a state facility, because she required nursing care and medical oversight.<sup>7</sup>

In February 2010, the *Oklahoman* reported on Health Department surveys of group homes and private intermediate care facilities for the mentally retarded (ICFsMR). The two-day series reported filthy conditions, patient abuse, and failure to provide adequate care.

An Ada provider featured in the story has been the home to several residents who were moved from SORC. According to Health Department records, the Ada facility had 430 deficiencies in the past year, including 21 cases of staff failing to provide appropriate medical care and 13 cases of failing to protect patients' rights. The corporation was fined \$21,465 over the death of a client.<sup>8</sup>

Contrary to statements made by state officials who are proponents of closing NORCE and SORC, other states have not closed their public ICFsMR. As of June 30, 2009, only nine states had closed their state operated residential facilities with 16 or more residents (Alaska, District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia.)

Across the nation, 1,981 people were admitted into state-operated ICFsMR in 2009. The average daily population of persons with disabilities living in state-operated facilities was 660. Oklahoma's average was 289.<sup>9</sup> (OK facilities have 245 residents in 2012.)

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<sup>5</sup> Nolan Clay, "Former Administrator Testifies," *The Oklahoman*, September 16, 2000.

<sup>6</sup> Jim Killackey, "Enid's Sunnyside Home Closing after Medicaid Loss," *The Oklahoman*, December 20, 2002.

<sup>7</sup> Ryan Whitlow, Testimony at the SORC House and Senate Interim Study, August 2010,

<sup>8</sup> "McCall's Chapel School in Ada fined \$21K," *The Oklahoman*, February 22, 2010.

<sup>9</sup> Research and Training Center on Community Living, Institute on Community Integration/UCEDD, College of Education and Human Development, University of Minnesota, *Residential Services for Persons with Developmental Disabilities: Status and Trends through 2009*, 2010.

## State Comparison of Public Safety Net Beds

State	Number of Residents (2009)	Number per 100,000 pop.
Kansas	353	12.5
Missouri	816	14.1
Arkansas	1,083	37.3
Texas	4,629	18.3
Colorado	103	7.6
<b>Oklahoma</b>	<b>289</b>	<b>7.8</b>
<b>National ave.</b>	<b>660</b>	<b>14.8</b>

The OKDHS plan to close beds at SORC and NORCE would place Oklahoma's public safety net for the developmentally disabled dangerously low at **20 percent** of the national average at **3.2 beds per 100,000**.

### Legal

NORCE and SORC are the home of 245 clients by choice. The parents and guardians of clients at SORC have determined the facility to be the best residence for their family members. Many family members live in surrounding communities and visit regularly. Closing these facilities would put an undue hardship on these families to be involved in the care of their loved ones.

In 1999, the United States Supreme Court heard *Olmstead v. L.C.*, which sought to clarify how states implement Title II of the American Disabilities Act. Title II requires states to operate public programs in a “non-discriminatory fashion...appropriate to an individual’s need.”

**The *Olmstead* decision is about choice, not about forcing severely disabled citizens from their homes in institutions. The ruling provides justification for providing a full range of services, both community and institution based, from which individuals and their families may choose.**

A majority of Justices in *Olmstead* recognized an ongoing role for publicly and privately-operated institutions: **“We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.”** 119 S. Ct. at 2187.

Justice Kennedy noted in his concurring opinion, “It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.” 119 S. Ct. at 2191.

As late as 2009, the courts have upheld client and family choice to be the standard. In the *ARC of Virginia vs. Kaine*, ARC of Virginia sued to stop the building of a replacement facility for one of the state's five institutions alleging the clients' right to live in the community was violated by the construction of a new facility. The court rejected this argument and dismissed the case finding that choice was affirmed in *Olmstead*, not deinstitutionalization.

"Thus the argument made by ARC and the United States regarding the risk of institutionalization fails to account for a key principle in the *Olmstead* decision: personal choice," the court found in its decision.

The finding quotes an October 28, 2009 letter from Virginia Secretary Tavener, "individual choice is a hallmark of this entire project [to build a replacement facility]. No one will be forced to transfer to the new homes on the training center campus if they would prefer to live in a community location." In addition, the Court notes more clients had expressed a desire to live in the new facility than beds were available. The hallmark of the Medicaid program that provides significant funding to both the ICF'sMR and home-and-community-based waiver is choice. CMS does not favor one setting over the other, but allows for client selection of the institution or community setting. Possibly the rights of clients who have requested placement at SORC and NORCE could be violated by not allowing new residents this level of service.

### **HB 2184 and the Future of NORCE and SORC**

In the 2011 session, the Oklahoma Legislature passed HB 2184 which states, "The Department of Human Services shall develop a plan which contains targeted dates to change or discontinue the operation of state-administered resource centers. In developing the plan the Department shall consult with the families and guardians of the residents as well as affected employees of the resource centers, and shall take into consideration the recommendations and concerns of the families and guardians of the residents and affected employees."

On December 6, 2011, less than a month before the OKDHS plan for the facilities was required by statute to be submitted to state leaders, OKDHS administration presented a plan to the OKDHS Commission that essentially closed the facilities. The plan would continue the trend of allowing the facilities to deteriorate until they would be closed because the buildings did not comply with federal code and regulations. **The Commission members were told that the legislature would not accept a plan with capital improvements. The legislature, however, communicated their instructions through HB 2184, which did not include any indication that capital improvements are not acceptable.** In the process of formulating a plan for NORCE and SORC, the agency did record the concerns and recommendations of families and employees, obviously the recommendations were not considered when formulating their plan.

The following PGA/OPEA Vision for the Future of NORCE and SORC does consider the concerns and recommendations of the parents and guardians first and foremost. The

employees of both facilities emphasized above all else that they support the parents and guardians in their choices for their loved ones and are gravely concerned with transitioning vulnerable clients from their lifetime homes.

The PGA/OPEA Vision for the Future of NORCE and SORC phases in the rebuilding of the campuses over the next five years with state or local bonds to be repaid over 20 years with state and federal funds and other funding options. According to information from OKDHS, the facilities need \$34 million in repairs to obsolete buildings. The PGA/OPEA plan does not repair the old buildings, but it does revitalize the facilities with new energy efficient homes. In addition, the plan provides for an acute care unit on each campus, which will house the most medically fragile clients. The acute care unit can also be used for hospital step-down and respite for clients in community settings.

Eventually, each facility will have 10 eight-bed units and 20 acute care beds in a separate unit. Both NORCE and SORC currently have more than 100 clients. Existing structures can be utilized temporarily. If the population remains constant and more beds are still needed, additional eight-bed units can be constructed.

### **Area Offices and Continuum of Care**

The DDS Area Offices should be relocated to the facilities, saving on rental expenses and fostering more cooperation and communication between facility and community staff. Eventually, some of the functions of the two divisions can be consolidated, such as payroll or administrative support staff.

SORC and NORCE should be allowed to admit clients, as space is available, both temporarily, for respite and stabilization, and for permanent residency, according to the needs of the client and the families' wishes. In other states, resource centers are being used to provide dental services, advise providers, stabilize clients and provide respite to family caregivers.

According to the OKDHS website, the resource centers serve, "As a community resource, licensed professionals working at NORCE also provide a variety of services to individuals with developmental disabilities who do not live on campus. Families and other community agencies bring individuals to the center for vocational services, dental services, and therapeutic services such as speech, occupational and physical therapies." SORC and NORCE have been used as a safety net, hospital step-down, and stabilization center for community providers in the past. Recently, these services have been limited by the OKDHS DDS division. With the needs of the waiting list, community services should be continued and enhanced at the centers.

Currently, parents and guardians call the facilities inquiring about services and admission for their loved ones. However, NORCE and SORC personnel are instructed to direct inquiries to the Area Office. The Area Offices in both locations are directed by OKDHS not to consider placement at NORCE and SORC.

## The PGA/OPEA Vision for the Future

In order for the state of Oklahoma to provide a full continuum of care for Oklahoma's most vulnerable, disabled citizens and have a safety net for the system, NORCE and SORC must rebuild the with smaller, energy efficient buildings that provide the residents with safe, comfortable homes. The PGA/OPEA proposal downsizes the sprawling campuses and uses revenue from the sale of the excess land to help pay off bonds. The new residences would be built on existing state land, saving the cost to retrofit homes in the community and subjecting the clients and families to the whims of landlords. In addition, the PGA, as a non-profit organization, can pursue public/private partnerships to help finance the revitalization. However, with the timelines in the OKDHS proposal, there is little time to explore options to preserve this critical service. With only five clients moving from the facilities in 2011, the transitioning of clients in the plan is hasty and irresponsible. The legislature should move the plan implementation date to March 2013 or later.

The PGA/OPEA Vision for the Future of SORC and NORCE is for each to have small campuses of ten eight-bed home-like units and a 20-bed acute care medical unit. The administrative offices would also house the area OKDHS DDS office. Area and facility case management would be seamless, finding placements and continuing to monitor clients as they move between settings. The facilities would be the central hub for therapy and respite services for disabled clients in surrounding communities. Some buildings may be still useful at both facilities and the cost could be minimized. However, this plan is a new vision and includes revitalization of both campuses using home-like residential settings.

The construction projects would cost about \$20 million in general obligation or revenue bonds. **Over the bond payment period of 20 years, the project would be repaid with a mix of state and public/private partnership funds combined with Federal Medicaid Match. The total cost of the project, including interest would be \$28,784,838 (\$8,784,838.93 interest).** During the bond payment period the public/private partnership would provide more than half of the bond service payments with FMAP supplying approximately 40 percent. After Federal depreciation of assets over 40 years, and the accompanying FMAP payments, the total cost of the project will be 64 percent Federal and 36 percent public/private partnership.

An infusion of capital could restore the facilities to efficient, effective state of the art condition to care for Oklahoma's most vulnerable citizens and ensure a full continuum of care for future clients. This infusion, **estimated at a modest \$20 million is less than 10 percent of what is being discussed to renovate the Capitol.**

## The OPEA/PGA Plan for the Future of NORCE and SORC

Although all the bonds are calculated in one year, the proposal could be implemented in phases as outlined in below.



Phase I: Install sprinkler systems in the residential buildings at SORC; Junior and Multiple Unit North and South and Chickasaw at NORCE, by July 1, 2013.  
(Minor cost at NORCE and existing funds in the oil royalty account at SORC)

Phase II: Contract to build two eight-bed units at NORCE and SORC by January 1, 2013  
\$800,000 (per facility) \$1.6 million total

Phase III: Contract to build two eight-bed units at NORCE and SORC by  
January 1, 2014 \$800, 000 (per facility) \$1.6 million total

Phase IV: Contract to build an eight-bed unit at SORC and a 20-bed acute care unit at  
NORCE and SORC by January 1, 2015 \$4.4 million for acute care  
\$800,000 for SORC units  
(NORCE has two eight-bed units completed in 2009)

Phase V: Contract to build two eight-bed units at NORCE and SORC by January 1, 2016  
\$800,000 (per facility) \$1.6 million total

Phase VI: Contract to build two eight-bed units at NORCE and SORC by  
January 1, 2016 \$800,000 (per facility) \$1.6 million total

\$2.4 million is added to the bond issue in Phases II-VI to cover the cost of demolition of the obsolete buildings and pay for any other needed construction. After a thorough evaluation of the campuses is complete, some of the existing buildings could be used for respite or other services.

## **Funding**

**Phase I:** OKDHS will use a existing funds in the SORC oil royalty account to install sprinkler systems at SORC. The cost of the NORCE system is minimal and would require that NORCE proceeds from the pharmacy or other funding stream could be identified.

### **Phases II-VI Funding**

#### **Bonding Options**

A bond issue for NORCE and SORC could be part of a larger state general obligation bond issue, using one or more of the following options;

- A state revenue bond issue backed by appropriations and/or revenue anticipation notes;
- Local revenue bond issue backed by state appropriations and/or revenue anticipation notes; and

- Local revenue bond Issue backed with a mix of local revenues and state and federal revenues,

### **Other Funding Options**

- Pursue public/private partnerships to enhance state funding, including corporations and philanthropic organizations, helping to lower the base amount of the bonds;
- Use oil royalty revenue proceeds from NORCE and SORC land;
- Sell excess land at both facilities, which would net \$1.75 million (approximately 850 acres at SORC and 320 at NORCE at the modest rate of \$1,500 per year). Mineral rights would be maintained by the state;
- Other cost reductions such as donated or low cost labor using CareerTech;
- Energy efficiency through wind power, CNG and energy efficient construction;
- Sale of old building materials; and
- Local government assistance on water and sewer costs and infrastructure improvements.

### **Conclusion**

In presenting the SORCPGA/OPEA Vision for the Future of NORCE and SORC, the families and employees bring an alternative forward for discussion to continue the operation of the critical safety net for Oklahoma's most vulnerable citizens. More importantly, the plan allows beloved clients and family members to remain in their lifetime homes. The vision also provides the opportunity for others to benefit from the decades of experience and care provided at the facilities.

The first step to accomplish this goal is for the OKDHS Commission to support the consideration of alternatives and for state leaders to give the families and employees time to develop their plan by delaying the implementation date of HB 2184. Already several bills have been filed to facilitate the development of alternatives to the plan that dramatically downsizes the NORCE and SORC. Sen. Susan Paddack has filed SB 1129 to delay the implementation date and allow time for planning. In addition, Paddack has filed SB 1136 to install the sprinkler systems in residential buildings and allow much needed time to find a solution. Rep. Lisa Billy has filed legislation to fund the construction phases at both facilities.

The infrastructure at NORCE and SORC has been neglected for decades. It is time for a new vision to provide modern, efficient homes for Oklahoma's most vulnerable citizens. If funding can be found to refurbish the Capitol building, certainly state leaders can

provide for a modest bond issue to house our citizens who are challenged with serious disabilities.

## **Appendices**

Bond amortization schedule provided by House staff

SB 1129 (Sen. Susan Paddack)

SB 1136 (Sen. Susan Paddack)

Drawing of proposed eight-bed unit (approximately \$350,000 to \$400,000)