

UNITED STATES DISTRICT COURT

DISTRICT OF OREGON

PORTLAND DIVISION

PAULA LANE, et al.,

Case No. 3:12-cv-00138-ST

on behalf of themselves and all
others similarly situated, and

**UNITED CEREBRAL PALSY OF OREGON AND S.W.
WASHINGTON,**

Plaintiffs,

v.

KATE BROWN, Governor of the State of Oregon; et al.,

all in their official capacities,

Defendants.

UNITED STATES OF AMERICA,

Plaintiff- Intervenor

v.

STATE OF OREGON,

Defendant.

Rebuttal Report of Lyn Rucker

I. Background and Related Experience

Over the course of 46 years, my public service career has enabled me to engage with service systems funded and intended to support people with multiple disabilities from various vantage points: volunteer; service coordinator; provider; state director; national and international consultant; and court monitor. From my experience as a volunteer in a Kansas institution for people with intellectual and developmental disabilities (I/DD) in 1969 to today, I have worked with officials and administrators in 27 states and six countries as they design, develop, improve and manage systems of support for people with disabilities.

Even at the outset of my career, community integration, including supportive employment, was a central component in the array of services for individuals with I/DD. Initially, the adults whom I supported as a case manager in Nebraska in 1972 attended sheltered workshops. However, it rapidly became clear that many of these people were bored and wanted the engagement, respect and money that integrated jobs could offer them. Thus, a colleague and I collaborated on the first "job club" which

enabled adults with I/DD in Lincoln/Lancaster County to examine their interests and skills, their appearance, behaviors and habits, and practice filling out job applications and improving their interview skills while they gained insights into the importance of first impressions and long-term “valued employee” practices.

From 1975 to 1987 I was Nebraska’s Executive Director of Region V Services¹ with the responsibility of overseeing services for more than 700 children and adults with I/DD throughout a 16-county area, including the capital city, Lincoln. Dissatisfaction among the I/DD population with the segregated, custodial care and sub-minimum wage nature of the sheltered workshops in Region V was evident. As a result, I directed multiple initiatives intended to get people real jobs and to promote integration in both their living and work environments. At first, workshops were converted to highly industrialized, technologically sophisticated worksites. While wages improved and the image of the Region at the local level shifted from a “human service agency” to a “community business,” individuals with disabilities continued to be inappropriately segregated. This segregation, with all of its accompanying isolation and demeaning stereotyping implications, was in direct contradiction to our stated values of enabling people with disabilities to participate in and enjoy the same opportunities as other non-disabled citizens.

The community system of support for children and adults in Nebraska in the 1970’s and 1980’s was highly respected and seen as a national model of excellence. Region V’s comprehensive service program in the community of Wahoo was among the first in the nation to be accredited by the Accreditation Council on Services for People with Mental Retardation and Developmental Disabilities (ACMR/DD).²

In 1987 I was recruited by Governor Bruce Babbitt’s team to come to Arizona as the Assistant Director of the Department of Economic Security with the responsibility for services to 4,000 children and adults with I/DD. During my four years as Assistant Director, the program achieved significant milestones that included dramatic growth in the number of persons with I/DD served in our public developmental disability service system, the closure of the largest segregated facility, downsizing of two other large facilities and the expansion of integrated service models in multiple settings (residential, employment, day, and education).

Over the years I also have consulted with many states as they worked to design, implement, evaluate and improve systemic reforms. Three states – Tennessee, New Mexico and Georgia – serve as examples. Beginning in 1996, I worked for the State of Tennessee as it responded to the requirements of two federal class action suits: *People First v. Tennessee* and the *United States v. Tennessee*. This work involved strategic planning and engagement at the individual, provider, regional and systems levels as the state initiated multiple changes and improvements. Particularly relevant is my work developing competency-based Job Coach training materials, providing training, and creating and implementing incentives to advance the construct of “valued days,” including employment, for individuals with I/DD. These were broad-based initiatives which included joining with stakeholders to re-constitute the Tennessee Employment Consortium (TEC). TEC membership included representatives from the intellectual and developmental disabilities state agency, Vocational Rehabilitation, the State Council on Developmental Disabilities, providers, Independent Support Coordination and, at times, people seeking jobs. TEC identified barriers to integrated employment; crafted solutions to those barriers; reported employment numbers by provider, support coordination agency, region and state; set employment

¹ Known as Region V Mental Retardation Services at that time.

² This organization was a part of the Joint Commission (accredited hospitals), then became ACMR/DD and is now known as The Council on Quality and Leadership.

numbers; researched the impact of integrated employment; shared financial and human resources; and provided incentives designed to increase the number of individual class members in integrated jobs.

In New Mexico (1990-1993; 2000-2001; 2002), I assessed statewide resources available and those needed at the individual, provider and state levels to assist in successfully moving people from two state institutions to community settings, which resulted in the closure of all of New Mexico's public institutions for persons with I/DD. Based on this assessment, I assisted the state in developing a strategic Management Plan consistent with court orders (*Jackson v. Los Lunas*) requiring the development of comprehensive community supports for institutionalized people with disabilities, including both residential and employment services. The Management Plan identified complex and inter-related actions needed to ensure people moved safely out of facilities and were supported to live and work successfully in the community.

In addition, I have served (and continue to serve) as a court monitor. Since 2003, I have been the Community Monitor in *Jackson v. Los Lunas*, a case that challenged the segregation and institutionalization of people with severe disabilities, leading to the closure of the two state institutions and the creation of an integrated community system of services statewide. As the Community Monitor, I evaluate the provision of all services provided to class members, including the "meaningful day" and employment services.

As the Federal Court Monitor (2007 to 2013) in Massachusetts (*Rolland v. Patrick*), I monitored the implementation of court-ordered active treatment services in a class action case that successfully challenged the institutionalization of individuals with I/DD in nursing facilities. This case resulted in the development of residential and community supports for 1800 people throughout the Commonwealth.

In Georgia (2014 to present), I have had the privilege to consult with the state Department of Behavioral Health and Developmental Disabilities on wide-scale systems reform measures to rectify long-standing deficiencies and identified noncompliance areas (*U.S. v. Georgia*) in the provision of residential and community-based services for individuals in and moving from state hospitals. The Department now is engaging in ambitious, complex and systems-wide change at the individual, provider, region and state levels to ensure a sustainable, self-sufficient and resilient life for people with disabilities in the community.

As described above, these roles have given me the opportunity to understand how to successfully initiate and implement complex systems change, and, perhaps more importantly, the impact and sustainability requirements for effective systems change at the individual, provider, and state/systems levels.

II. Services to People with Developmental Disabilities: Background and Trends

This litigation is informed by and consistent with national trends in the provision of services to people with developmental disabilities.

There exists a major and now long-standing trend toward the provision of services to people with developmental disabilities in integrated living and work settings.

Throughout history, perception and, frequently, economics have determined our method of intervention or treatment goals for people with I/DD. When we, as a society, perceived people with I/DD as deviant (1850 to 1880), often they were separated from society, sold to freak shows, placed in prisons, almshouses or training schools. The goal of the training school was to provide education and training designed to make the person “un-deviant.”

In 1848, Dr. Samuel Gridley Howe founded in South Boston the first public institution for the “feeble minded” in the United States. By the 1880’s, there were similar public institutions in eight states. But only 18 years after the establishment of his school, Dr. Howe strongly opposed the concept of institutionalizing and segregating people.³

As late as the early 1970’s, parents of people with mental retardation/developmental disabilities still had few choices of supports and services for their children. They could keep their family member home and, to the extent of their physical, emotional and financial resources, try to individually or, collectively with other parents, provide supports, or they could send their son or daughter away to a large, segregated, often isolated, congregate care institution. Persons with even borderline or mild mental retardation/developmental disabilities, as well as those with the greatest medical, physical, behavioral and learning challenges, were placed in these segregated settings.

Defendants’ expert Brian Lensink, in the section of his report titled, “History and Its Impact on Current Employment Initiatives,” discusses how people with I/DD have been perceived and treated, especially in regard to their employment potential. He observes that since at least the 1960’s, many people with I/DD and their families have had sheltered workshops as the “valued option.”⁴ I would add that frequently, it was the only option. Again, society’s perception of people with I/DD as un-employable resulted in a service response called sheltered workshops which were and are characterized by segregation, isolation, meaningless and repetitive tasks that they did not choose to do, and poor wages.

By the 1980’s, thanks to the research and applied teaching methods of pioneers such as Marc Gold of California and Thomas Bellamy of Oregon, it became clear that people with I/DD could learn tasks required for successful integrated work in the community. These and other researchers established detailed teaching strategies that enabled the replication of these successful teaching methods that were embraced throughout the country. As David Mank points out in his expert report, “the importance of these teaching breakthroughs cannot be overstated, as they refuted the long held assumption that people with I/DD were incapable of working, or could only work under segregated settings on very simple tasks.”⁵

The systems response to this finding was to create and define “supported employment” as a service option. Supported employment combined paid work in integrated settings with ongoing training and other needed supports. Rather than endless years of training preparation so that people with I/DD could “prove” they were “ready” for employment, the approach shifted and instead promoted placing the individual in integrated work with ongoing support and training to ensure their success.

³ The History of Mental Retardation, Collected papers, Volume 1. Edited by Marvin Rosen, Gerald R. Clark, and Marvin S. Kivitz. University Park Press, 1976.

⁴ Lensink Expert Report, page 5.

⁵ Mank Expert Report, page 3.

About this same time (1984 – 1986), federal funding was made available to states for supported employment. With this financial endorsement, the national trend was set and the march towards integrated employment options for people with intellectual and developmental disabilities began in earnest throughout the country. This included Oregon which, in 1985, enacted legislation “requiring measurement of how employment services enhance social integration, independence and productivity of people with developmental disabilities,”⁶ marking a clear understanding of the benefits of integrated employment for people with IDD. Yet now, 30 years later, Oregon relies on the use of segregated sheltered workshops as the “model” of support for people with I/DD.

III. Values-Based Systems Change: Model Coherency

Mr. Lensink also references the pivotal work of Wolf Wolfensberger, Ph.D., in the I/DD field.⁷ When considering the framework for systems change, Dr. Wolfensberger, the nationally recognized leader in the field of services to people with IDD, challenged IDD leaders to embrace fundamental operating principles, beginning with an expectation of a high degree of individualization, values-based leadership, effective partnering with key stakeholders, internal and external evaluation, integrated data management systems and “model coherency.”⁸

Model coherency is critically relevant as we examine the justifications put forward by the State of Oregon as to why, after 30 years, it continues to rely so heavily on a model of segregated sheltered workshops for adults with I/DD.

Dr. Wolfensberger’s Model Coherency embodies the idea that all elements of practice in a service should be in harmony with each other and flow from a unifying set of principles. It requires people to think deeply about the identity of the people who are currently or who will be served, what it is that would be required to support people well, who could do the work well, and in what ways the work could be done with consistent, high quality. Model Coherency is a unique and very helpful tool which can be used to both conceptualize positive service designs, and help designers and evaluators of services to develop a framework which increases the likelihood of a coherent match between people’s identities, their most pressing needs, and the supports to actually meet those needs. Any examination or evaluation of practices of states engaged in systems change should include the tenets of model coherency. In a nutshell, this means “the right servers [leaders and providers] should be using the right materials, methods, and language in the right settings [integrated, purposeful, safe] in order to do the right thing for the right recipients who are grouped in the right way.”⁹

⁶ Lensink Expert Report, page 17.

⁷ *Id.*, page 9.

⁸ Wolfensberger, W. (1999). History of Normalization – 1967-1975, In R. Flynn and R. Lemay (Eds), *A Quarter Century of Normalization and Social Role Valorization: Evolution and Impact*, Ottawa, ON: University of Ottawa Press, page 75. The concept of “service specialization,” which eventually became model coherency, evolved from an idea apparently presented in 1959 by Lloyd M. Dunn, chair of the Department of Special Education at George Peabody College for Teachers (since become part of Vanderbilt University) in Nashville, Tennessee, in an advanced graduate course on social and educational aspects of mental retardation which I attended. He proposed that “omnibus” institutions for the mentally retarded be replaced by smaller, more dispersed specialized institutions for specific subgroups of different identities and needs. <http://www.socialrolevalorization.com/articles/journal/1996/srv-vrs-journal-1996-2-part-03.pdf>

⁹ Wolfensberger, W. (2013). *A brief introduction to Social Role Valorization*, 4th Expanded Edition, page 144.

IV. Values-Based Systems Change: Making It Happen

The change that is being sought through this litigation is a change in personal outcomes which result from the supports and services provided by the State of Oregon to people with people with intellectual disabilities. So rather than supports and services which result in segregation, isolation and poor wages, the outcome that is sought is for people to work in paid integrated employment with the supports they need to be successful.

Some of the defendants' experts have tried to provide a rationale for the State's ongoing reliance on segregated sheltered workshops.

For example, Mr. Lensink engages in a lengthy discussion about multiple systems changes, explaining, and implicitly excusing, Oregon's significant decline in the percentage of adults with I/DD who received supported employment because of its increase in residential and new waiver services. Admittedly, as Mr. Lensink repeatedly states, it is difficult to effect systems change in residential services and day programs at the same time and it can be challenging to simultaneously grapple with deinstitutionalization and integrated employment.¹⁰ However, difficult though it may be, and indeed, it is, it must be done – and many states have taken on these challenges and successfully met their obligations to individuals with I/DD who for too long have been segregated in institutions and groups and isolated and devalued in sheltered workshops and enclaves.

Two tenets are at the center of these systems change reforms.

(1) It is not only possible but necessary for a state to concomitantly decrease segregation as it increases integration.

(2) It is not only possible but necessary for a state to manage multiple system reform initiatives at the same time.

Planning for and managing systems change cannot take place in a vacuum. This is especially true for constitutional and statutory requirements like non-discrimination and integration. States are always dealing with what has been created in the past, what is being managed in the present, and what is being planned for the future. This continuous march towards expanding integrated opportunities and improving outcomes for people with I/DD through changes to the supports and services being provided is an ongoing and never ending part of the quality improvement system. As the system becomes smarter, as money shifts, and as external and internal pressures are applied, change occurs at multiple levels and must be thoughtfully anticipated and executed. The results of these changes must also be consistent with the system's purpose and values.

Nebraska

As a part of my work in Nebraska during the 1970's, several major initiatives were in play at the same time, all of which related to and supported integration in multiple settings and through multiple strategies. All of these efforts had one over-arching goal: the integration of children and adults with

¹⁰ Lensink Expert Report, page 7, 11, 12.

IDD into the fabric of the community. All of these efforts depended on the same state legislature. And all of these efforts effectively advanced community integration. These initiatives included:

Creating a regional management structure: Prior to 1975, most of the local private providers of services to people with IDD in Nebraska were established as a result of proactive parents who worked in concert with concerned professionals to create supports. Some youth never went to public schools; instead they were supported by parents and/or professionals in offsite locations such as church basements/annexes or privately donated homes. Youth with disabilities who attended school faced a dilemma when they “aged out.” Their parents desperately sought venues where their adult children to go where they would be engaged, close to home, safe and happy. As a result, there were providers scattered throughout the state receiving funding through a combination of county and state monies, and in some cases, grants.

Through the efforts of many stakeholders – parents and parent organizations, state and local leaders, and nationally respected experts in the field of developmental disabilities such as Dr. Wolfensberger and Dr. Frank Menolascino – plans were developed and legislation was passed which established a regional system of service management. Private providers were brought under the umbrella of Regions with governing boards of county commissioners.

Centralizing support coordination: Nationally, as well as in Nebraska at this time, support coordinators were employees of private providers, the same providers that provided home living and day/work supports. Support coordinators were expected to be advocates for individuals with I/DD and their families. In that role, support coordinators were called upon to monitor the adequacy of the provision of the supports and services being provided by their employers. Obviously, this created a significant conflict of interest. As a result, the Regions took over the hiring and supervision of support coordinators while private providers retained responsibility for home living and day/work supports.

Deinstitutionalization: At this time, there was one large state-operated institution for people with I/DD in Nebraska, two state-operated regional centers that held some individuals with dual diagnosis (intellectual and developmental disabilities¹¹ along with a co-occurring mental health diagnosis), and two private church-operated campus based institutions. Statewide, there was a concerted effort to significantly reduce the numbers of persons served by such institutions and assist them in moving into integrated community settings.

Prevention and diversion: Individuals with complex medical and behavioral challenges were institutionalized in part due to a perception the community was not equipped to support them adequately. The system had to see and accept the challenge of providing real and necessary supports in the community and prevent people from going into segregated settings in the first place. Thus, the state had to expand existing supports and services along with creating new services.

Moving children out of segregated day programs into the public schools: In 1973, two years before the passage of Public Law 94-142 (Education of All Handicapped Children Act, later known as the Individuals with Disabilities Education Act), Nebraska passed a similar law. Many children of all ages, who up to that time were being served by local private I/DD providers, began moving from segregated “I/DD only” day programs to integrated public school classrooms.

¹¹ Mental retardation was the terminology used at that time, now people with intellectual and developmental disabilities.

Expanding integrated employment: Two employment-related initiatives were advanced in the early 1970's. One was an effort at "reverse integration" whereby anyone from the community seeking jobs could apply and become employed at the sheltered workshop. The other initiative was to spin off workshops to employee-owned industries. That three-year initiative was in process when I left Nebraska.

A great deal was happening very fast.

As Chairperson of the Regional Director's Council,¹² I coordinated the development of systemic plans for each of the regions. These plans were, in turn, incorporated into one statewide plan.

There was extensive resistance to centralization efforts from existing providers in Region V. Nevertheless, in collaboration with stakeholders, we designed and implemented an intentional systems-change effort to create more integrated lives for people who were segregated and/or institutionalized. This effort was not focused on moving people from one segregated "institution" to another segregated existing "community" program. Rather, it called for a close and comprehensive examination and critique of the existing community system both within the region and statewide.

For Region V, it was clear that our services needed change and expansion at multiple levels. It was clear that children should not be in our segregated educational centers. Consequently, we entered into a planning process with local school districts that resulted in the transfer of all school-aged children with IDD, qualified teachers and equipment to the public schools. An assessment of the needs of individuals living in both public and private institutions was completed so gaps in existing community services could be identified and addressed. A critical examination of our existing residential, day and employment services was undertaken. It was clear that outdated and in some cases inappropriate services (such as segregated children's programs and segregated day activity centers and workshops) would have to be eliminated and/or modified. We also joined with our colleagues in the public school districts to get an idea of how many students were "aging out" and who they were so that their needs could be appropriately met thus eliminating admission to institutions.

When managing systems change, it is unwise and in some cases dangerous to focus myopically on one or two arenas of change. If a state takes on the challenge of altering or closing one service option, the repercussions vibrate through the system in total. When "closing" or "downsizing" a service, the state has a great opportunity and, one might say, an obligation, to look even more closely at the system in total to determine what other changes might be needed in order to ensure model coherency. Focusing narrowly without controlling for related long-term implications frequently results in unintended and costly to correct results in both fiscal and human terms.

Arizona

My experience in Arizona (1987 to 1991) provides another example of how systems change rarely can or should take place around an isolated issue. When I became the Assistant Director of the Department of Economic Security in charge of I/DD services, I was told my responsibility was to "bring in Medicaid." Yet the agenda for the four years I was there demanded attention to many more inter-related matters including:

¹² Executive Directors of each of the regions sat as a Council for purposes of coordination and consistency.

Deinstitutionalization: Arizona's largest state institution was in the process of closing, and the two other state institutions were downsizing, one under significant protest.

Institutional certification: Since Arizona had never accepted Medicaid dollars, the three institutions for people with I/DD were not certified and did not meet the federal Title XIX standards for Intermediate Care Facilities for People with Intellectual and Developmental Disabilities (ICF/IDD). The inclusion of this optional Medicaid benefit would save the state millions of dollars. Since the Phoenix institution was closed, an all-out effort was initiated to qualify individuals, facilities and services at the two remaining institutions so they would meet Medicaid requirements.

New services were being created in the community: To support individuals with complex health and behavioral needs who were moving from the institution as well as those coming into the system from the community, new supports and services were being created.

Initiation of Early and Periodic Screening, Diagnosis and Treatment (EPSDT): Moving into the Medicaid program included planning for and implementing EPSDT, which is Medicaid's child health component intended to identify, as early as possible, children's disabling conditions and to provide follow-up and treatment as needed. This includes health, mental health and developmental services.

Identifying and relocating individuals with I/DD in nursing facilities: The individuals with I/DD living in nursing facilities were primarily children, prompting an initiative to move them into families in the community.

Re-evaluation of existing reimbursement methodology: With Arizona poised to bring in millions of never before received Medicaid dollars, we could not afford to continue to fund existing segregated services at the same or higher rates. An extensive examination of the existing rates paid to providers was completed. This review identified inequities in provider reimbursements for individuals with the same level of need and also found that existing rates seemed to reward more segregated living and day/employment environments.

Implementing a new rate setting methodology: The effort to equitably reimburse providers offered an opportunity to not only address previous inequalities, but also to use financial incentives to move away from segregated services to integrated residential, day and employment supports. Financial incentives were built into the new rates to pay more for people with the most complex needs (medically and behaviorally) and to pay more for supports and services provided in more integrated environments (personal living vs. group homes; integrated work vs. congregate sites).

1115 (c) Demonstration Waiver: The creation of a managed care system required the re-engineering of the existing social care network for people with I/DD (educational, residential, day, employment services) as well as the creation of the provision of all health related services through Managed Care Organizations, third party payers and the Indian Health Service. The requisite infrastructure, organizational, social, political and stakeholder changes which took place were mammoth.

The changes Arizona realized during this finite time period were significant. To summarize, the state:

- grew from supporting 4,000 children and adults to over 11,000;
- closed the largest institution for people with I/DD;
- continued relocating individuals from the two remaining institutions to community settings;

- started moving nursing facility residents back to the community;
- brought Medicaid revenue to Arizona for people with I/DD and certified the remaining institutions as ICFs through the Medicaid program; and
- designed and implemented the first managed care system for people with I/DD in the United States which resulted in bundled medical, individualized home and community supports/services to over 11,000 children and adults.

For Arizona, it would have been unthinkable to bring in millions of new federal dollars and not plan comprehensively and act decisively to move the entire system for both children and adults, on and off of reservations, closer to the integrated, person-centered system. In reality, states are responsible for the “big picture” and must know and act to ensure compliance with all laws and to ensure that services are provided consistent with all of an individual’s needs.

Tennessee

Tennessee offers yet another example of a state that turned challenges into opportunities to decrease segregation in both its institutions and in its day services, including sheltered workshops. The state designed, managed and implemented a number of complex system reform projects simultaneously. Some of the initiatives that the state planned and managed during the same time period included:

Planning for and managing change: When I worked in Tennessee (1996 – 2007) I had the opportunity to experience firsthand how energetic state leaders worked to turn the demands of federal lawsuits¹³ into an opportunity to create more integrated, responsive services for people with IDD. Under the direction of state leadership, I coordinated two significant planning initiatives involving approximately 3,000 stakeholders statewide. The resulting two plans were comprehensive and not only addressed what was expected as a part of deinstitutionalization but also addressed and codified the expectations regarding the long-term community system. Part of this enormous undertaking made clear that integrated employment was a priority for adults and as the state also developed integrated residential supports and services.

Improving conditions in the institutions: During the time that the institutions were downsizing and/or closing, concerted efforts were made to improve conditions at each of the facilities that were being monitored by a Federal Court Monitor (West TN) and an appointed Panel (Central/East TN).

Deinstitutionalization: Five institutions were scheduled for closure or downsizing.¹⁴

Expansion of the network of community providers: New providers were recruited and brought into the state to address gaps in services identified during the planning process.

Improving services in the community: Due to inadequacies in the existing community service system the Centers for Medicare and Medicaid placed the State on moratorium, prohibiting it from expanding its waiver. To address these deficiencies, extensive improvements were made and a sustainable Quality Improvement System was re-designed and implemented.

¹³ In 1991 *People First of Tennessee v. Arlington Developmental Center* was filed. In 1994 *U.S. v. Tennessee* was filed.

¹⁴ Arlington Developmental Center in Memphis, Clover Bottom Developmental Center in Nashville, Harold Jordan Center (forensic) in Nashville, Nat T. Winston Developmental Center in Bolivar (dual diagnosis IDD and Mental Health).

Tennessee Employment Consortium (TEC): This statewide consortium dedicated to operationalizing the Employment First! Initiative worked to identify and eliminate barriers to integrated employment at the individual, provider and systems level. Membership included Division of Rehabilitation (VR), Division of Intellectual Disabilities Services (DIDD), the Tennessee Council on Developmental Disabilities, providers, external consultants, and at times employers, Independent Support Coordinators, individuals seeking jobs and parents. Incentives were provided and paid for through a combination of funds from VR, DIDD and the Tennessee Council on DD.

School to Work Pilot: In coordination with a local school district, the East Tennessee TEC initiated, implemented and evaluated a successful Pilot. Recommendations were made and carried forward.

Valued Day Project: Through this West Tennessee project, local providers identified changes needed by work activity centers and sheltered workshop providers to jointly and cooperatively move individuals from segregated centers to integrated competitive employment.

Moving people from the waiting list to services: In 2000, the Tennessee Protection and Advocacy sued on behalf of Medicaid eligible citizens who were either on waiting lists for services provided through the state I/DD agency, or who had been denied the opportunity to apply for services. Several new initiatives were implemented, focusing on enabling individuals to gain the services they needed, both temporarily and for the long term.

Even with multiple and enormously challenging issues – any one of which required immense attention – Tennessee’s coherent approach advanced its goals to simultaneously decrease institutional segregation and increase community integration through expanded residential services and employment services.

Massachusetts

Similarly, Massachusetts effectively tackled community integration issues on multiple fronts as officials simultaneously addressed several class actions and initiatives to expand community-based services for people with I/DD.

Deinstitutionalization: Five class action lawsuits were filed in the 1970’s seeking the expansion of integrated community and day services for residents of five state institutions, leading to the development of home and community-based supports statewide and the gradual closure of four facilities.

Moving thousands off the waiting list for community-based services: In response to another class action challenging a wait list for individuals seeking Medicaid-funded services in the community, the Commonwealth developed integrated home and day services for more than 2000 individuals.

Re-designed and implemented its Home- and Community-Based Services waiver: Recognizing that its efforts to achieve compliance with court orders and/or settlement agreements would be largely advanced through an enhanced waiver, the State substantially reconfigured – and then implemented – a large Home and Community-Based Waiver to support its community integration efforts.

Advanced active treatment under the ADA through the expansion of integrated community and day services: The State placed over 1800 nursing facility residents with I/DD in integrated settings in the community with community-based supports in an ADA case that also required markedly improved

services for those residents remaining in facilities. As the federal court monitor in this case, I oversaw the transition of 670 facility residents to homes where they enjoyed enhanced community-based supports and day services. The judge, who visited several class members in their new homes, noted:

The community residences in particular, both established and newly minted ones, made clear that many class members were not only able but fortunate enough to live at “home.” The improvements were often subtle: residents having their own rooms, experiencing less stress, sleeping through the night, exercising more independence, and hosting family members in comfortable surroundings.

Rolland v. Patrick, Final Memorandum and Order, May 22, 2013, at 12.

New Mexico

Like the other states discussed above, New Mexico also faced and addressed simultaneous systems changes, leading to the development of an integrated community service system for individuals with I/DD.

Development of Integrated Community Service System: As the defendant in a large class action, *Jackson v. Los Lunas*, New Mexico was required to develop a range of integrated community services. These include residential services, employment services, “meaningful day” programs, as well as assistive technology and supports to address issues regarding behavior, sexuality, and crises.

Closure of all public institutions: At the same time it was developing this community-based system, New Mexico was closing its two state-operated institutions for persons with IDD.

Reconfiguration of Home- and Community-Based Services waiver: In addition, in response to a waiting list lawsuit, the state substantially reconfigured its waiver to enhance and expand its community supports service system.

New Independent Case Management System: To better serve people with disabilities statewide, New Mexico created and implemented an innovative independent case management system, replete with competency-based training, data management systems and infrastructure development.

As noted above in the Introduction, as the *Jackson* Community Monitor, I evaluate the provision of all services provided to class members, including “meaningful day” programming and employment services – crucial components of New Mexico’s integrated community services.

Oregon

Conversely, Oregon has not demonstrated a capacity to phase out institutions, reduce waitlists and expand supported employment.

As Mr. Lensink admits, Oregon, which previously had made significant inroads in employment, “took the focus off of continued growth in employment services” and became pre-occupied with deinstitutionalization matters.¹⁵ Defendants’ Expert Cathy Anderson concurs that the state’s decision

¹⁵ Lensink Expert Report, page 7.

to concentrate on residential placements for people leaving Fairview pushed aside supported employment initiatives. She cites notes from a 2007 department employment strategy work session that state: “Stopped our practice and workshops and non-work ATE [alternatives to employment] sites increased.”¹⁶

The State could have – and should have – capitalized on the creation of community supports as required by the closure of facilities and expanded community integration programs, including supportive employment. This was a missed opportunity, and as Mr. Lensink acknowledged, the “price” for this exclusionary prioritization of deinstitutionalization and the reduction of the waitlist was the continued over-reliance on sheltered workshops/work activity centers.¹⁷ That price was paid by the thousands of people with I/DD funneled into segregated day programs.

V. States Are Able to Expand, Modify or Create Medicaid Waiver Options that Include Advancing and Expanding Supported Employment.

The Centers for Medicaid and Medicare Services (CMS) have a very clear position on the value of work for people with disabilities:

“...[W]ork is a fundamental part of adult life for people with and without disabilities. It provides a sense of purpose, shaping who we are and how we fit into our community. Work has also been associated with positive physical and mental health benefits; meaningful work is also part of building a healthy lifestyle as a contributing member of society. Because it is so essential to people’s economic self-sufficiency, as well as self-esteem and wellbeing, people with disabilities... who want to work should be provided the opportunity and support to work competitively within the general workforce in their pursuit of health, wealth and happiness. All individuals, regardless of disability and age, can work – and work optimally with opportunity, training and support that build on each person’s strengths and interests. Individually tailored and preference based job development, training, and support should recognize each person’s employability and potential contributions to the labor market.

“In conjunction with the administration’s initiative to promote the American with Disabilities Act, the CMS is committed to providing program supports that enable individuals with disabling conditions to live and work in the community. People with disabilities living in the community, who are working, or want to work need the supports and services to ensure that they have the change to fulfill their potential and contribute to our nation. In response, CMS has developed policies and implemented a number of initiatives to help increase employment across America for those who are disabled.”¹⁸

Oregon has long recognized the value of federal assistance to promote supported employment. Over several decades, the state has applied for, received, and benefited from the support that CMS and other federal agencies have made available for promoting and expanding supported employment initiatives. For example, during the past 30 years Oregon has received several federal grants as identified below:

¹⁶ Anderson Expert Report, page 5.

¹⁷ Lensink Expert Report, page 29.

¹⁸ <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Grant-Programs/Employment-Initiatives.html>, accessed April 30, 2015.

- 1985: A 5-year Supported Employment Systems Change Grant from the Office of Special Education and Rehabilitation Services (OSERS);¹⁹
- 1991: A second OSERS System Change Grant for Supported Employment;²⁰
- 2007: A CMS-funded Medicaid Infrastructure Grant for Oregon Competitive Employment Project;²¹
- 2009: A Medicaid Infrastructure Grant Competitive Employment Project for Office of Vocational Rehabilitation Services (OVRs);²² and
- 2012: A contract from the US Department of Labor, Office of Disability Employment Policy (ODEP), to implement Oregon's Employment First Initiative.²³

Contrary to the intent of these grants to promote and expand supported employment, the state has failed to maintain and sustain these initiatives.

Federal grants provide helpful seed money to initiate services and/or to expand learning in identified areas. But grants are time-limited and narrow in focus, and certainly are not a long-term funding source upon which a state could fund significant programmatic and cultural change.

The long-term and stable funding source for long term, ongoing services comes from the federal and state government. Across the nation, states rely on the Home and Community Based Medicaid Waiver program for the majority of their long-term funding.

Mr. Lensink rightfully describes the creation of the 2000 supports service waiver and the subsequent K-Plan in 2012 as major system events that posed new challenges and required dedicated focus, energy and resources.²⁴ However, the development of new waiver programs, while demanding and time-intensive, are also opportunities – opportunities to promote integration and achieve desired outcomes. And Oregon failed not once, but twice, to seize such opportunities.

The 1915c waiver created in 2000 by the State of Oregon to develop community services for individuals on the wait list did not advance supported employment opportunities. In fact, little changed for individuals with I/DD waiting to get and maintain a job.

The 1915c supports service waiver involved several thousands of individuals already living in the community who, as Mr. Lensink notes, “wanted integrated services, self-determination, supports provided in the family home, and many wanted employment.”²⁵ Many were young, just transitioning out of school and already were engaged to some degree in integrated living. As Mr. Lensink said, they and their families “saw the world differently.” The opportunity was self-evident: Oregon could have built upon the work it initiated in the 1980s and 90s and created a set of supports for these young adults that would highlight and prioritize work. But Oregon did not do that. Oregon did increase the number of people on the waiver, but not for supported employment services. Rather, the individuals on the 1915c supports waiver ended up in segregated day programs, including sheltered workshops, just like in the days when people did not “see the world differently.”

¹⁹ Lensink Expert Report, page 17.

²⁰ *Id.*, page 18.

²¹ *Id.*, page 32.

²² *Id.*, page 20,

²³ *Id.*, page 22.

²⁴ *Id.*, pages 12-14.

²⁵ *Id.*, page 13.

The K Plan, also known as the Community First Choice Option, is another Medicaid initiative to provide enhanced federal match for people already on waivers. This recent initiative (2012) provided Oregon with a second major opportunity to prioritize supported employment as a waiver funded service. Under the K-Plan, waiver funds were freed up as services including activities of daily living and instrumental activities of daily living were moved out of waivers to the Medicaid State Plan. (See Anderson Report, page 9). The K Plan, in essence, created an entitlement to a number of services provided under waivers, but supported employment was not one of them. There was (and is) enhanced federal participation for services billed under this initiative, but no action was taken to promote or prioritize supported employment services.

The failure to capitalize on the deinstitutionalization and community integration mandate, coupled with the failure to capitalize on the two new Medicaid programs it created, represent three critical missed opportunities to target, prioritize or expand supported employment over a dozen years from 2000-2012.

Unlike Oregon, other states, including Arizona, New Mexico and Massachusetts, seized such opportunities.

As previously discussed, Arizona's new Medicaid program bundled health and social care and added federal financing to augment the state's I/DD budget. As a result, thousands of individuals received supports and services for the first time, and others were able to have the supports and services they were receiving changed or expanded. For people seeking employment, this meant they had real work opportunities and the ongoing supports necessary to sustain employment successfully. This massive systems change, while complex to manage, was necessary and essential to addressing the segregation and lack of meaningful opportunities in the community.

New Mexico, based on median household income, ranks as one of the 10 poorest states in the Union. Consequently, financial resources have been and are very limited. New Mexico joined the Medicaid Waiver program in 1988 and has modified its Waiver and Waiver Standards multiple times. New Mexico, along with other states, joined the Supported Employment Leadership Network (SELN) in an effort to improve integrated supported employment outcomes for those in their Waiver.

New Mexico also faced challenges of institutional litigation²⁶ which required improvements in their two state operated institutions, the creation of community-based alternatives, the initiation of Independent Case Management System, development of competency based training, data and infrastructure development and more. Nevertheless, in 1991, when New Mexico issued its plan to close both of its state operated institutions and design and implement a comprehensive community system, it did not envision allocating resources to one group of individuals while adversely impacting services for others. Integrated residential, day and employment services were incorporated into plans, the Medicaid Waiver and the Medicaid Standards.

Massachusetts reconfigured its waiver into mini-waivers and included a supported employment plan for individuals with disabilities. Many states have taken similar actions; after all, they have to in order to

²⁶ *Jackson v. Los Lunas*, 1987.

honor CMS' commitment to provide "program supports that enable individuals with disabling conditions to live and work in the community."²⁷

VI. Providing Supported Employment Services Will Not Fundamentally Alter Oregon's Social Service System

States commonly provide new or expanded services to one group without cutting services to others. States are able to implement an *Olmstead* initiative in a way that does not negatively impact or unfairly take resources away from other citizens. Contrary to the assertions of Lilia Tennity, Director of Oregon's Office of Developmental Disabilities Services, states have implemented *Olmstead* reforms and treated other state residents with an even hand, without depriving them of their services and supports. Oregon can do the same.

There are documented cost savings from transitioning people into integrated settings. Costs associated with *Olmstead* rulings generally are spread out over several years as courts do not envision or expect overnight transformation of the social service system. Furthermore, the Rhode Island Decree sets forth a "stair-step" approach wherein a specified number of individuals in sheltered workshops get integrated job placements each year over a finite number of years. This allows for orderly implementation as well as managing and controlling costs. In fact, this same approach is mirrored in both of Oregon's Executive Orders on Supported Employment. The Executive Order contemplates that the move away from reliance on Sheltered workshops to the eventual reliance on and provision of supported employment services is a staggered process with definite goals over a period of years.

This same approach has been used by other states.

For example, in New Mexico, a financially impoverished state which had constitutional and Rehabilitation Act violations, there were no requirements or expectations that the State would close both of its institutions simultaneously, discharge all residents and create all residential and employment services for each person in one year. Doing so would have exceeded the capacity of the state agencies and would have been prohibitively expensive, irresponsible, unrealistic and reckless. Instead, such efforts must be deliberate and phased in. New Mexico's efforts to address legal violations did not result in cuts in services to other of the state's citizens. The state did, however, prioritize curing long-standing legal violations, like segregated residential and other services.

When downsizing and/or closing five institutions in Tennessee, the state put forward comprehensive multi-year plans which sequentially identified what would need to happen, when, who had to be involved, what would be phased down or out to save expenses as well as projected the need for increased revenue over time. By including thousands of stakeholders in the development of its plans, Tennessee marshaled the resources of its sister state agencies, public and private providers, cities and towns, individuals and families to agree on the vision and share in creating the needed infrastructure and services to successfully attain that future.

Oregon can allocate resources to supported employment initiatives without adversely impacting other services for individuals with I/DD. The same effective implementation strategies used in Arizona, Massachusetts, Rhode Island, Tennessee, New Mexico, and numerous other states are available to

²⁷ www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Grant-Programs/Employment-Initiatives.html, accessed April 30, 2015.

Oregon. Such strategies have allowed these and other states to successfully implement system reforms that complied with *Olmstead* and did not cause harm to their other citizens.

Furthermore, the resources the state has obtained to fund the Executive Order undermines the State's fundamental alteration defense.

Since the *Lane* litigation was filed, Oregon's governor voluntarily issued not one, but two, Executive Orders on Supported Employment that mandate the provision of employment services – as opposed to integrated supported employment services – for individuals with I/DD. Oregon already has obtained substantial funding for implementing the Executive Order that the State believes will allow it to cure long-standing segregation and to come into compliance with *Olmstead*.

In his Opinion Disclosure, Defendants' Expert Ralph Amador sets forth a detailed analysis, based on a series of funding assumptions, of the cost of implementing the most recent Executive Order in comparison to the Rhode Island Consent Decree (the Rhode Island model). He also creates a comprehensive cost model for implementing the Governor's recent Executive Order (the EO 15-01 model). He then compares the costs of both models, and concludes that the Rhode Island model would be significantly more expensive than the EO 15-01 model. But Mr. Amador's cost analysis of what he and his "modeling team" project it would cost Oregon to implement the Rhode Island Consent Decree is based on the erroneous assumption that the *Lane* plaintiffs are seeking the same relief as the Rhode Island case. That is incorrect.

Based on the assumptions and cost models developed by Mr. Amador, Ms. Tennity and Erinn Kelly-Siel, Director of the Department of Human Services, then express the strong view that it would require a fundamental alternation of Oregon's I/DD system if Oregon replicated the commitments in the Rhode Island model.²⁸ But Ms. Kelly-Siel acknowledges that "Oregon DHS has already obtained significant additional funds to carry out Executive Order 13-04" and is pursuing additional funds from the legislature to "support the ongoing implementation of the Employment First policy and 15-01."²⁹ Implicit in Ms. Siel's and Ms. Tennity's Disclosures is an acknowledgement that implementing the Executive Order 15-01 model does not constitute a fundamental alteration.³⁰ I agree. The state's creation, adoption, and endorsement of the EO 15-01 model, coupled with the Legislature's funding of and support for the Executive Order, renders the state's fundamental alteration defense moot. The State cannot raise a fundamental alteration defense based on cost projections for a remedy that is not being sought (Rhode Island model) or a remedy that it developed and affirmed (EO 15-01 model).

It is crucial that every system develop objective, measurable outcomes not only to evaluate changes to the system, but also at the individual level. This is important not only as a way of measuring whether strategies are effective and successful, but also for purposes of accountability.

Most, if not almost all, *Olmstead* remedial orders or settlements include numerical and qualitative compliance standards. For instance, in Georgia, there is an annual plan that specifies the number of individuals leaving institutions annually. The Georgia plan also requires the development of a certain number of integrated community, residential and day services and supports, with caps limiting the

²⁸ Kelley-Siel Disclosure, pages 4-5; Tennity Disclosure, page 3-4.

²⁹ Kelley-Siel Disclosure, page 4.

³⁰ Tennity Disclosure, pages 3-4.

number of persons who can be served in a given setting. This overall deinstitutionalization and service delivery plan extends out five years.³¹

In New Mexico, the state's efforts to close two institutions resulted in plans that called for specific numbers of individuals moving each year, the development of specific numbers of integrated services and supports, limits on the number of individuals who can be served together, expansion of supported and competitive employment and an external annual audit of the services provided to a sample of class members.

In Tennessee, the state established annual targets for the number of integrated community services and supports it would develop and the number of individuals it would help to move out of institutions. Like the other states, Tennessee sets limits on the number of people in each residence.

In Massachusetts, the State committed to moving a certain number of individuals out of segregated nursing facilities each year and to develop a corresponding individualized, small residential and day supports. The State also committed to have the Court monitor evaluate the adequacy of the services and supports that each person received.

States will always face and be expected to competently and effectively address political, resource, infrastructure, paradigm shifts, revenue fluctuations, and administrative changes. That is their obligation and responsibility.

³¹ The Settlement Agreement entered in October 2010 had timelines and target numbers through July 2015.