

APPENDIX

**IN THE UNITED STATES DISTRICT COURT
EASTERN DISTRICT OF ARKANSAS
WESTERN DIVISION**

UNITED STATES OF AMERICA

PLAINTIFF

v.

Case No. 4:09CV00033 JLH

STATE OF ARKANSAS; MIKE BEEBE,
Governor of the State of Arkansas, in his official
capacity only; JOHN M. SELIG, Director of the
Arkansas Department of Human Services, in his official
capacity only; JAMES C. GREEN, Ph.D., Director
of the Arkansas Division of Developmental
Disabilities Services, in his official capacity only;
and CALVIN PRICE, Superintendent of the
Conway Human Development Center, in his
official capacity only

DEFENDANTS

FINDINGS OF FACT AND CONCLUSIONS OF LAW

Most lawsuits are brought by persons who believe that their rights have been violated. Not this one. The Civil Rights Division of the Department of Justice brings this action on behalf of the United States of America against the State of Arkansas and four state officials in their official capacities alleging that practices at Conway Human Development Center violate the rights of its residents guaranteed by the Fourteenth Amendment, the Americans with Disabilities Act, and the Individuals with Disabilities Education Act. All or nearly all of those residents have parents or guardians who have the power to assert the legal rights of their children or wards. Those parents and guardians, so far as the record shows, oppose the claims of the United States. Thus, the United States is in the odd position of asserting that certain persons' rights have been and are being violated while those persons—through their parents and guardians—disagree.

For its first claim for relief, the plaintiff alleges that patterns and practices at Conway Human Development Center violate the constitutional rights of its residents by failing to provide reasonably safe conditions; by failing to provide the level of habilitation and training necessary to protect the

residents' liberty interests and to ensure their rights and freedom; and by substantially departing from generally accepted standards of care in the medical, psychological, and other services provided by the Center. *Cf. Youngberg v. Romeo*, 457 U.S. 307, 322, 102 S. Ct. 2452, 2461, 73 L. Ed. 2d 28 (1982) (finding that individuals involuntarily committed to a state institution must be assured adequate or reasonable training to ensure safety and freedom from undue restraint). Over the course of a six-week bench trial, the plaintiff examined witness after witness and introduced exhibit after exhibit in an effort to prove that many policies and practices of Conway Human Development Center substantially depart from generally accepted professional standards. *See id.* at 323, 102 S. Ct. at 2462 (recognizing that decisions of professionals are considered valid unless they constitute a substantial departure from accepted professional judgment, practice, or standards). The plaintiff makes allegations of abuse and neglect; takes issue with the Center's use of restraints, psychological services, and medical services; and argues that the procedures used to prevent choking, aspiration pneumonia, fractures, decubitus ulcers, and other injuries are subpar. Finally, the plaintiff alleges that, because of the Center's deficiencies, residents die prematurely. These allegations certainly are serious. They are not, however, supported by the weight of the evidence presented at trial.

For its second claim for relief, the plaintiff alleges that Conway Human Development Center violates the integration mandate of the Americans with Disabilities Act. Under the Act, a public entity must administer services, programs, and activities in the most integrated, least restrictive setting appropriate to the needs of qualified individuals with disabilities. *Olmstead v. L.C.*, 527 U.S. 581, 591-92, 119 S. Ct. 2176, 2183, 144 L. Ed. 2d 540 (1999). In the context of this case, the terms "restrictive" and "integrated" refer to the level of interaction with nondisabled persons. An integrated setting is a "setting that enables individuals with disabilities to interact with nondisabled

persons to the fullest extent possible,” while a restrictive setting is one in which disabled persons have less interaction with nondisabled persons. *See* 28 C.F.R. pt. 35, app. B (Mar. 15, 2011). The plaintiff alleges that Conway Human Development Center is not the most integrated setting appropriate for many of its residents; that the Center’s employees fail to provide parents and guardians with adequate information about other services that the plaintiff considers more integrated; and that the Center’s staff does not exercise professional judgment in determining the most integrated setting appropriate for residents. The weight of the evidence, however, indicates otherwise. The plaintiff has not met its burden under the Americans with Disabilities Act.

For its third claim for relief, the plaintiff alleges that Conway Human Development Center violates the rights of children at the Center under the Individuals with Disability Education Act by failing to provide them with free appropriate public education in the least restrictive environment. *See* 20 U.S.C. § 1412(a) (2006). The plaintiff offers evidence showing that children at the Center do not spend enough time in school; that special education teachers at the Center are not trained on the most advanced teaching methods and tools; that the education plans of the students are inadequate; and that the ratio of teachers to students does not meet state requirements. While the evidence supports the plaintiff’s allegation that Conway Human Development Center does not provide free appropriate public education, the evidence also establishes that the Center has submitted a corrective action plan to the Arkansas Department of Education, which is the state agency responsible for supervising special education programs and monitoring their compliance. At the time of trial, the Department had yet to determine whether the corrective measures proposed in the plan would bring Conway Human Development Center into full compliance with the Individuals with Disabilities Education Act.

The Court conducted its bench trial from September 8, 2010, through October 15, 2010. At the conclusion of the trial, the parties requested that the filing period for post-trial briefs be delayed until completion of the official transcripts. The transcripts have been prepared, and briefs have been filed. Having received all of the evidence, the Court makes the following specific findings and conclusions.

**I.
FINDINGS OF FACT**

A. INTRODUCTORY FINDINGS OF FACT

Conway Human Development Center is a residential facility providing a variety of services for persons with developmental disabilities. It is one of six human development centers operated by the Division of Developmental Disability Services of the Arkansas Department of Human Services. Tr. 749-50, 764 (J. Green). The six human development centers have a total capacity of 1100 persons. Tr. 4332 (T. Kastner). One of the six, Alexander Human Development Center, was in the process of closing at the time of trial. Tr. 751 (J. Green). Alexander Human Development Center had 109 residents. Tr. 4332 (T. Kastner).

Conway Human Development Center is certified by the Centers for Medicare and Medicaid Services as an intermediate care facility for the mentally retarded,¹ Tr. 4044 (T. Kastner), which means that it is eligible for and receives federal funds through Medicaid.² It is licensed by the

¹ See 42 C.F.R. § 440.150 and 42 C.F.R. §§ 483.400-483.480 for the definition of and regulations pertaining to an intermediate care facility for the mentally retarded.

² It is another oddity of this case that the institution at issue is funded and regulated by one department of the executive branch of the federal government while another department of the executive branch contends that its conditions are so deplorable as to violate rights guaranteed to the institution's residents by the United States Constitution. More pointedly, the United States simultaneously funds Conway Human Development Center, certifies it as eligible for those federal funds, and contends that the conditions there are so deplorable as to be unconstitutional.

Arkansas Office of Long-Term Care³ for 539 beds. Tr. 533 (A. Richardson); Tr. 845 (A. Green); Pl.'s Ex. 229. Conway Human Development Center provides medical care, dental care, physical therapy, speech therapy, occupational therapy, special education, habilitation, and recreational services. Tr. 535, 642 (A. Richardson). It employs approximately 1200 persons on a 409-acre campus that includes thirty-two cottages, school buildings, a chapel, a gymnasium, a pool, an infirmary, and other buildings. Tr. 533 (A. Richardson); Pl.'s Ex. 229. The Center serves individuals with a wide range of disabilities through its various programs and has a number of procedures and policies in place to ensure that it is meeting the needs of its residents effectively.

1. The Residents of Conway Human Development Center

Residents of Conway Human Development Center are impaired in a number of ways. The large majority of those residents are classified as profoundly or severely mentally retarded.⁴ Tr. 5810 (K. Walsh). Most of them also have psychiatric disorders as well as additional impairments or disorders. On July 31, 2009, 509 persons ranging in age from seven to seventy-two resided at the Center. Pl.'s Ex. 229. Of those 509 residents, 399 were classified as profoundly mentally retarded; 77 were classified as severely mentally retarded; 25 were classified as moderately mentally retarded; 7 were classified as mildly mentally retarded; and 1 resident, pursuant to a respite, or short-term, admission, was described as functioning at a borderline level. Pl.'s Ex. 229. Fifty-two of the

³ The Office of Long-Term Care is a state agency that, among other things, regulates intermediate care facilities for the mentally retarded.

⁴ Mental retardation is significantly subaverage general intellectual functioning accompanied by significant limitations in adaptive functioning. *Diagnostic and Statistical Manual of Mental Disorders* 39-49 (4th ed. 2000 Text Revision). "Mild mental retardation" refers to an intellectual quotient level of 50-55 to approximately 70; "moderate mental retardation" refers to an intellectual quotient level of 35-40 to 50-55; "severe mental retardation" refers to an intellectual quotient level of 20-25 to 35-40; and "profound mental retardation" refers to an intellectual quotient level below 20 or 25. *Id.* at 42-44.

residents had autism; 171 had aggressive, destructive, or self-injurious behaviors; 319 had dual diagnoses (i.e., developmental disabilities and psychiatric diagnoses); 137 had fragile health; 307 had seizure disorders; 229 had cerebral palsy; 190 were non-ambulatory; 35 were hearing impaired; 21 were deaf; 129 were vision impaired; 36 were blind; 277 of the residents required devices (e.g., wheelchairs, braces, or orthotic devices) to maintain body alignment; and 484 required modified diets. Pl.'s Ex. 229.

Conway Human Development Center is the only human development center operated by the State of Arkansas that provides services to children. Tr. 764-66 (J. Green). In July of 2009, fifty-two of the residents at the Center were school-aged children, Pl.'s Ex. 229, and at the time of trial, forty-eight of the residents were under the age of twenty-one, Tr. 846 (A. Green). Many of these children came to Conway Human Development Center as a result of maladaptive behaviors.⁵ Tr. 846 (A. Green); Tr. 2272 (S. Thibadeau). They previously lived at home, in foster care, in group homes, or in other such settings and may have attended public schools. Unfortunately, their maladaptive behaviors proved to be more than their caregivers and school officials could manage, so their parents or guardians sought to have them admitted to Conway Human Development Center. Tr. 2272 (S. Thibadeau); Tr. 3263-65 (M. Catron); Tr. 4055-57 (T. Kastner); Tr. 5145-49 (D. Nye); Tr. 5607-08 (B. Gale); Tr. 6212 (L. Kraus); Tr. 6616-18 (K. Priest); Tr. 6724-25 (B. Brewer). Some of the children are in the custody of the Division of Child and Family Services due to neglect, physical maltreatment, or sexual maltreatment. Tr. 6724 (B. Brewer).

⁵ Here and in many places in this opinion, the Court uses the terminology commonly used by witnesses at trial.

2. Admission to and Discharge from Conway Human Development Center

Admission to Conway Human Development Center occurs only after certain requirements are met. Generally, a parent or guardian applies for admission to the Center on behalf of the child or ward and retains the right to withdraw the child or ward.⁶ Before a person can be admitted to Conway Human Development Center, a determination must be made that the Center is the least restrictive, most integrated environment in which the services needed by that person can be provided appropriately. Tr. 4310 (T. Kastner); Tr. 5145 (D. Nye); Defs.' Ex. 912, Division of Developmental Disability Services Policy No. 1086 § II(d)1.

In the twenty-six month period between January of 2008 and February of 2010, thirty-seven persons were admitted to Conway Human Development Center. Tr. 4335 (T. Kastner). Also during that time period, forty-four persons entered the Center for respite, or short-term, care rather than admission. Tr. 4336 (T. Kastner). Over a forty-six month period—between July 1, 2006, and March 17, 2010—seventy-two persons were discharged from Conway Human Development Center, which represents an average of almost two discharges per month. Tr. 5981 (K. Walsh). From July of 2009 through mid-October of 2010, six residents of the Center were discharged, as were fifteen persons who had entered for respite care. Tr. 6768 (A. Green). At the time of trial, sixty-five persons were on a waiting list for admission to Conway Human Development Center. Tr. 647

⁶ The Division of Developmental Disability Services has procedures for court-ordered admissions, but no evidence was presented that any resident of Conway Human Development Center has been admitted pursuant to court order. If the Division of Developmental Disability Services or the superintendent of Conway Human Development Center determines that voluntary discharge presents a danger to the individual or others, either may initiate legal proceedings. No evidence was presented that legal proceedings have been instituted to prevent a parent or guardian from removing a child or ward. *Cf. Porter v. Knickrehm*, 457 F.3d 794, 798-99 (8th Cir. 2006) (holding that a guardian's decision to admit the ward, a moderately retarded adult, to a human development center in Arkansas was a "voluntary" admission).

(A. Richardson); Tr. 4310 (T. Kastner); Tr. 5980 (K. Walsh).

3. Parents and Guardians of Residents of Conway Human Development Center

Many, if not most, of the parents and guardians of the residents of Conway Human Development Center keep themselves informed regarding the Center. They have formed the Conway Human Development Center Parents' Association, which is comprised of parents and guardians who are concerned about the Center, its residents, its staff, and what is happening in human development centers around the state. Tr. 5055 (L. Taylor). The association meets quarterly. Tr. 5056 (L. Taylor). Many of the same parents and guardians are also members of a statewide organization, Families and Friends of Care Facility Residents, which is an umbrella group for all of the parent and guardian groups of the human development centers in the State of Arkansas. Some of the members of the statewide group have developmentally disabled family members who receive services in the community rather than in facilities like Conway Human Development Center. Tr. 5058 (L. Taylor). Together, the two parent organizations filed an amicus brief in opposition to the plaintiff's claims in this action.

According to the individual program plans and other evidence introduced at trial, the parents and guardians of residents of Conway Human Development Center are overwhelmingly satisfied with the services there and believe that the Center is the least restrictive, most integrated placement appropriate for their children and wards. Tr. 482 (S. Murphy); Tr. 4328-29 (T. Kastner). Ninety-seven percent of the parents and guardians of residents at Conway Human Development Center who responded to a survey stated that they were satisfied or very satisfied with the services that their children and wards receive. Tr. 4328 (T. Kastner); Tr. 5956-57 (K. Walsh). Six persons who were parents or guardians of residents of Conway Human Development Center testified at trial. Two of

the six were nurses. All six of them testified that they were pleased with the services offered by Conway Human Development Center. Tr. 1502 (A. Fortney); Tr. 3249 (E. Stoddard); Tr. 3273-74 (M. Catron); Tr. 5069-70 (L. Taylor); Tr. 6832-34 (M. Black); Tr. 6850-52 (B. Landen). None of the six had any criticism of Conway Human Development Center.

4. Teams at Conway Human Development Center

The residents of Conway Human Development Center are divided into five “teams,” which are groups of residents assigned to a designated area with a specific group of employees responsible for their training and care. Defs.’ Ex. 910, Conway Human Development Center Policy No. II-A-1. The teams are, in order from the highest functioning residents to the residents with the greatest developmental disabilities, as follows: the Habilitation and Training Team, the Sheltered Living Team, the Individual Assistance Team, the Intensive Training Team, and the Total Care Team.

The Habilitation and Training Team consists of the residents at Conway Human Development Center who function at the highest intellectual level of those admitted to the facility. Their level of intellectual function ranges from the higher profound level of intellectual disability to the moderate level of intellectual disability, with some school-aged children functioning at the mild level. The majority of them are placed at Conway Human Development Center because of maladaptive behaviors. Tr. 1663 (C. Price); Tr. 6723-26 (B. Brewer).

The Sheltered Living Team consists of residents who function at the profound to mild or moderate level of intellectual disability. A large number of them have seizure disorders, issues related to swallowing, and maladaptive behaviors. Tr. 1663 (C. Price).

The Individual Assistance Team consists of residents who function in the lower profound to upper profound level of intellectual disability. Many of them have maladaptive behaviors and

seizure disorders. They have low self-help skills and require manipulation in almost everything that they do. Tr. 1663-64 (C. Price).

The Intensive Training Team consists of residents in the lower profound level of intellectual disability. They have many maladaptive behaviors and seizure disorders. Their skill level is below that of the residents on the Individual Assistance Team. They require total assistance with self-help and daily living skills. Tr. 1664 (C. Price).

The Total Care Team consists of residents who are in the profound level of intellectual disability and have severe medical conditions. They are the most medically fragile residents at Conway Human Development Center. They typically are non-ambulatory. Many of them have major swallowing issues, and most of them are fed by a tube. They require total assistance with everything that they do. Tr. 1664 (C. Price).

Each of the five teams has a manager who is known as the team leader. The team leader is responsible for reviewing, monitoring, and approving programs and supervising the staff that is responsible for the residents on that team. Tr. 6722-23 (B. Brewer); Pl.'s Ex. 279.

5. Interdisciplinary Teams and Individual Program Plans

Each resident at Conway Human Development Center is served by an interdisciplinary team (which should not be confused with the teams into which residents are placed). A resident's interdisciplinary team consists of persons from various disciplines who provide services to that resident. Each interdisciplinary team includes a program specialist⁷ who is a qualified mental

⁷ The current title for this position is "program specialist," but the position was formerly known as "social service worker" or "social worker." Conway Human Development Center employs twelve program specialists.

retardation professional;⁸ the resident's parent or guardian; a member of the direct care staff; the psychological examiner assigned to that resident; and other professionals who provide service for that particular resident, such as a physical therapist, an occupational therapist, a speech language pathologist, or a primary care physician. Tr. 636 (A. Richardson); Tr. 4860, 4901-03 (S. Murphy); Tr. 5017 (G. Miller).

Each resident's interdisciplinary team prepares an individual program plan for that resident describing the resident's needs as well as a program for addressing those needs.⁹ Defs.' Ex. 910, Conway Human Development Center Policy No. II-D-1. An individual program plan includes information submitted by the various professionals and direct care staff who provide services to that resident. The plan includes information about the resident's social history, psychological assessment, medical care, dental care, medications, auditory assessment, nutritional status, dysphagia assessment, speech assessment, physical therapy assessment, occupational therapy assessment, special education, residential assessment, recreational interests, and other assessments as specified by the interdisciplinary team. Tr. 4901-07 (S. Murphy); Defs.' Ex. SM-5; Defs.' Ex. 910, Conway Human Development Center Policy No. II-D-1 at 5. Each individual program plan includes a transition plan and takes into consideration the resident's rights, the strengths of the resident, the needs of the resident, the problems and liabilities of the resident, and the resident's personal, long-

⁸ A qualified mental retardation professional is a person who has at least one year of experience working directly with persons with mental retardation or other developmental disabilities and is either a doctor of medicine or osteopathy, a registered nurse, or a person who holds at least a bachelor's degree in one of several fields identified in the applicable regulation, 42 C.F.R. § 483.430. Those fields include psychology, social work, pathology, special education, and rehabilitation counseling.

⁹ A large number of individual program plans were introduced into evidence. See Pl.'s Exs. 101-1 through 206.

range goals. Pl.'s Ex. 101-1 through 206.

Each resident's interdisciplinary team meets at least annually to review the resident's individual program plan. In addition to the annual meeting, the interdisciplinary team may meet as needed for what Conway Human Development Center calls "special staffing." Tr. 4860, 4866, 4869-70 (S. Murphy). Special staffing occurs when a resident has significant maladaptive behaviors, medical issues, or other indications that some aspect of the individual program plan should be reconsidered.

6. Behavior Plans

In addition to their individual program plans, residents at Conway Human Development Center who have maladaptive behaviors usually have a safety plan, a positive behavior support plan, and a separate description of strategies to be used by staff in dealing with them.¹⁰ A safety plan is a plan for restraints, restrictions, or both. Tr. 5795 (K. Walsh); Defs.' Ex. 910, Conway Human Development Center Policy No. II-D-16. A positive behavior support plan is a plan to identify, develop, and support positive behavior. Tr. 5795-96 (K. Walsh); Tr. 6562 (K. Priest). Strategies direct staff as to how to best work with the residents. Tr. 5795-96 (K. Walsh); Tr. 6561-62 (K. Priest); Defs.' Ex. 910, Conway Human Development Center Policy No. II-D-16. In September of 2009, 99 residents of Conway Human Development Center had safety plans, 33 had positive behavior support plans, and 295 had strategies. Tr. 5803 (K. Walsh).

7. Human Rights Committees

Conway Human Development Center has five human rights committees, one for each team,

¹⁰ Conway Human Development Center policy considers behaviors as "maladaptive" "if they present a danger to self or others, to property, or interfere with habilitation and inclusion in the community." Defs.' Ex. 910, Conway Human Development Center Policy No. II-D-9.

which review and approve specific treatment and behavioral interventions. Tr. 5010 (G. Miller). The human rights committees are comprised of a chairperson; a vice chairperson; center representatives; consumer representatives; and non-affiliated, community representatives. Tr. 5009 (G. Miller); Tr. 5934 (K. Walsh); Defs.' Ex. 910, Conway Human Development Center Policy No. I-F-4. Conway Human Development Center psychological examiners are assigned to each of the human rights committees in a nonvoting role to provide information and consultation to the voting committee members. Tr. 5009 (G. Miller); Tr. 5934 (K. Walsh).

The human rights committees review issues of residents' rights (such as the right to privacy), medical diagnoses, medications, behavior plans, safety plans, and individual program plans. They also review and decide whether to approve behavior plans that involve the use of restrictive or intrusive procedures. Defs.' Ex. 910, Conway Human Development Center Policy No. I-F-4. Prior to submission to a human rights committee, behavior plans are developed as follows: the interdisciplinary team establishes an objective and a plan; the psychological examiner formulates the behavior intervention plan; and the team leader, chief of psychology, and primary care physician review the plan. Then, written and informed consent is obtained from the parent or guardian. Tr. 5849 (K. Walsh). If the human rights committee does not approve a behavior plan, the interdisciplinary team must correct any impediment to approval that is identified. Tr. 5850 (K. Walsh). If the human rights committee approves a behavior plan, it is sent to the superintendent for his approval, and then staff and other Conway Human Development Center personnel are instructed on how to implement the plan. Tr. 5850 (K. Walsh). The psychological examiners train the staff as to how to implement the plan. Tr. 6589-90, 6599-6600 (K. Priest); Tr. 6677-78 (E. Glenn); Defs.' Ex. 910, Conway Human Development Center Policy No. II-D-16 at 4, 11, 14.

8. Incident Review Committees

In addition to the human rights committees, Conway Human Development Center has another group of oversight committees called "incident review committees." Each of the five teams has an incident review committee, and there is also a central incident review committee. Tr. 5936 (K. Walsh). The team incident review committees meet Monday through Friday, Tr. 5014-15 (G. Miller); Tr. 5936 (K. Walsh), while the central incident review committee meets monthly, Tr. 5936 (K. Walsh); Pl.'s Ex. GM-1. The incident review committees review reports of injuries, deaths, disruption of services to clients, patterns and trends, safety concerns, property damage, and workman's compensation-related issues. Pl.'s Ex. GM-1; Defs.' Ex. 910, Conway Human Development Center Policy No. I-F-15.

Conway Human Development Center is required to report to a State of Arkansas database incidents of maltreatment of residents by staff, fractures, cuts and lacerations that require stitches, bruises that require x-rays, client-to-client bites if there is a skin break or if an antibiotic is required, swellings, sprains if there are x-rays, abrasions and burns that require the application of medication or ointment, medication errors that require medical treatment, and certain other types of incidents. Tr. 5938-39, 5943 (K. Walsh); Defs.' Ex. 910, Conway Human Development Center Policy No. I-E-12; Defs.' Ex. 911, Arkansas Department of Human Services Policy Manual §§ 1090 *et seq.*; Defs.' Ex. 912, Division of Developmental Disability Services Policy No. 1027. Minor bumps and bruises are not reportable. Tr. 5938 (K. Walsh). The incident review committees review the incidents that must be reported to the state database. Tr. 5936-37 (K. Walsh).

The central incident review committee at Conway Human Development Center performs a second review of incidents that were reviewed by the team incident review committees. The central

committee also provides oversight review for identifying trends and policy directions. It produces a quarterly incident report summary, which is a statistical report showing all incidents that occurred in the prior quarter. Tr. 5937-38 (K. Walsh).

9. Physical Therapy

Conway Human Development Center employs a staff of physical therapists who are licensed by the State of Arkansas, are assisted by physical therapy aides and assistants, and perform a number of functions at the Center. Tr. 5251-52 (L. Hancock). The physical therapy department performs assessments of new residents upon admission and reassesses them periodically during their residency. Tr. 5251 (L. Hancock). The department also provides wheelchair modifications, power wheelchair training, and wound care. In addition, the department hosts an orthopedic clinic each month. Tr. 5251 (L. Hancock). The department trains direct care staff in proper positioning and lifting and performs spot checks to determine whether direct care staff are complying with the training. Tr. 5254-55 (L. Hancock). The physical therapy department also prepares positioning programs for each resident in need of positioning services. Tr. 5263-64 (L. Hancock). Among other things, the positioning services are designed to avoid decubitus ulcers, also known as pressure ulcers, and to help prevent choking during mealtime. Tr. 5277-81 (L. Hancock).

Conway Human Development Center operates a physical therapy orthotics shop at which it constructs custom-made wheelchairs and other orthotics devices for the residents. Each device is form-fitted to the resident who will use it. Tr. 5265-69 (L. Hancock). Very few residential facilities have on-site orthotics shops. Tr. 3469 (M. Schmeler). A resident at Conway Human Development Center who needs a custom-made wheelchair can have one constructed and properly fitted to that resident's specific needs within approximately two days. Tr. 5269 (L. Hancock). Mark R. Schmeler,

Ph.D., an expert in occupational therapy specializing in assistive technology, described the turnaround rate at Conway Human Development Center's orthotics shop as "lightning speed." Tr. 3474-76 (M. Schmeler). When such a custom-made wheelchair or other device is ordered from a commercial vendor, the process may take four to six months. Tr. 5271 (L. Hancock).

B. FINDINGS OF FACT REGARDING ALLEGED VIOLATIONS OF THE FOURTEENTH AMENDMENT

The plaintiff's first claim for relief is that many of the conditions at Conway Human Development Center violate the constitutional rights of the Center's residents. Specifically, the plaintiff alleges that Conway Human Development Center's efforts to keep its residents safe and free from undue restraint substantially depart from generally accepted practices. The greater weight of the evidence is to the contrary.

1. Allegations that a Pattern and Practice of Abuse and Neglect and a "Culture Of Silence" Exist at Conway Human Development Center

The plaintiff alleges that Conway Human Development Center has a pattern and practice of abusing and neglecting its residents and that a "culture of silence" exists permitting abuse and neglect. That allegation is contrary to the greater weight of the evidence.

Carla Jo Osgood, called as an expert witness for the plaintiff, provided unconvincing testimony that abuse and neglect of residents is rampant at Conway Human Development Center and that a "culture of silence" prevails such that employees over time become reticent to report abuse and neglect. Osgood had no formal education in any field relevant to her testimony,¹¹ nor is it

¹¹ Osgood has a bachelor's degree in political science. She has taken graduate courses at the Cincinnati Bible Seminary and also has studied pastoral counseling. Tr. 41 (C. Osgood). Her curriculum vitae provides no information about her education, thus tacitly admitting that she has no formal education in the field of her purported expertise. Pl.'s Ex. 1-1.

evident that she has any experience that would qualify her to give expert testimony under Rule 702 of the Federal Rules of Evidence. *See* Tr. 37-41, 204-12 (C. Osgood); Pl.'s Ex. 1-1.

In her testimony, Osgood made mention of "generally accepted standards" but did not identify any source where such standards could be found other than the regulations that govern intermediate care facilities for the mentally retarded, which she regarded as outdated. Tr. 279-80 (C. Osgood). She testified that "the standards of practice are fluid over time and could have changed at any time in the last four months, twelve months, what have you." Tr. 222 (C. Osgood). She did not refer to texts, journals, or other sources that would reflect shared knowledge among people who would qualify as experts in a particular field. Her testimony did not seem to connect to any identifiable body of knowledge or any identifiable discipline from which generally accepted standards might be ascertained. She stated that she had toured approximately thirty facilities in fifteen states, but she neither identified the facilities nor gave any description of them from which the Court could determine whether those facilities were comparable to Conway Human Development Center. She also provided no quantitative analysis comparing rates of abuse and neglect at Conway Human Development Center to rates at similar facilities or to any benchmarks. Tr. 269-72 (C. Osgood). Osgood leaped to the conclusion that a "culture of silence" exists at Conway Human Development Center based on the fact that, in a few instances, the staff member reporting maltreatment had worked at the facility less than six months and based on the fact the Center disciplines employees who fail to report maltreatment immediately, as the Center's policy requires. Tr. 156-61, 168, 181, 183 (C. Osgood).

Even disregarding the issues relating to Osgood's credibility, her testimony is contradicted by the greater weight of the evidence, which demonstrates that no pattern and practice of abuse and

neglect exists at Conway Human Development Center.

To begin with, Conway Human Development Center has specific policies in place designed to protect its residents from maltreatment. Defs.' Ex. 910, Conway Human Development Center Policy No. I-E-10. Conway Human Development Center policy defines "maltreatment" as including but not limited to "physical, verbal, psychological, or sexual abuse, neglect, exploitation, misappropriation of property, and violation of rights of individuals requiring services." *Id.* § I.4. Potential employees are screened for a history of maltreatment, and employees are trained on issues relating to maltreatment. Tr. 4872 (S. Murphy); Tr. 4990-94 (G. Miller); Tr. 6534-38 (J. Buck); Defs.' Ex. 910, Conway Human Development Center Policy No. I-E-10 §§ A.1 and A.2. Conway Human Development Center policy requires that employees make an immediate report of any instance of maltreatment to the administration. Defs.' Ex. 910, Conway Human Development Center Policy No. I-E-10 § B. The Center enforces this policy. Tr. 158-59, 179 (C. Osgood); Tr. 4872-73 (S. Murphy).

Conway Human Development Center also adheres to the Arkansas reporting laws, which require that state officials be notified of instances of abuse. If the victim of the alleged abuse is a child, the child abuse hotline¹² is called, and if the victim of the alleged abuse is an adult, the adult abuse hotline is called.¹³ Tr. 4995 (G. Miller); Tr. 6873 (C. Price). The police are notified, as are the Office of Long-Term Care and the Arkansas Attorney General's Office. Tr. 4995 (G. Miller); Tr. 6873 (C. Price).

In addition, Conway Human Development Center has procedures in place for reporting and

¹² See Child Maltreatment Act, Ark. Code Ann. §§ 12-18-101 to 12-18-1108.

¹³ See Adult and Long-Term Care Facility Resident Maltreatment Act, Ark. Code Ann. §§ 12-12-1701 to 12-12-1721.

investigating allegations of maltreatment. Maltreatment incidents are reported to the shift coordinator if they occur after hours or to the team leader if they occur during business hours. Tr. 4994 (G. Miller). When a report is made, the resident who suffered the alleged maltreatment is checked medically, the staff member is suspended, and an investigation is conducted by a person whose sole job is to investigate maltreatment allegations. Tr. 6873 (C. Price). At the time of trial, the investigator at Conway Human Development Center was an attorney. Tr. 4992 (G. Miller). The investigations are thorough and prompt. Tr. 5944-46 (K. Walsh); Tr. 6740 (B. Brewer). After the investigative report is completed, it is forwarded to the superintendent's office for executive review. Tr. 4996 (G. Miller); Tr. 6874 (C. Price). The superintendent makes the final determination of whether credible evidence supports the allegation of maltreatment and forwards that determination to the team, along with written directives for the team to carry out. Tr. 4996 (G. Miller); Tr. 6874 (C. Price). If credible evidence supports the charge of maltreatment, the employee responsible for the maltreatment is immediately terminated. Tr. 232 (C. Osgood); Tr. 6740-42 (B. Brewer); Tr. 6875 (C. Price); Defs.' Ex. 910, Conway Human Development Center Policy No. I-E-10 § F.

The annualized rate of substantiated instances of maltreatment at Conway Human Development Center is .054, which is comparable to published rates for other facilities. Tr. 5948-49 (K. Walsh). This fact supports the finding that there is no pattern and practice of abuse and neglect at the Center.

Moreover, the testimony of parents and guardians of residents at Conway Human Development Center also supports the finding that there is no pattern and practice of abuse and neglect at the Center. When a resident is involved in an incident of aggression, maltreatment, or injury, the Center notifies the parent or guardian unless the parent or guardian has specifically

directed otherwise. Tr. 3236 (E. Stoddard); Tr. 3269, 3282 (M. Catron); Tr. 4868-69 (S. Murphy); Tr. 5033-34 (G. Miller); Tr. 5059 (L. Taylor). Parents and guardians are permitted to visit the Center unannounced. Tr. 3232 (E. Stoddard); Tr. 3270 (M. Catron); Tr. 5059 (L. Taylor). Even though they are permitted to visit unannounced, no parent or guardian of any resident, past or present, testified that he or she had reason to believe that Conway Human Development Center has a pattern or practice of permitting residents to be abused or neglected.

To the contrary, parents and guardians testified that the staff at Conway Human Development Center genuinely care about the residents and immediately report any issues that arise.

The first witness called for the defense was Earline Stoddard, whose forty-four-year-old son is a resident of Conway Human Development Center. Tr. 3230 (E. Stoddard). At the time of trial, Ms. Stoddard was an adjunct instructor for the School of Nursing at Baptist Health. She has worked in the nursing field for more than forty years. Tr. 3230 (E. Stoddard). Ms. Stoddard often makes unannounced visits to the Center to visit her son, and she has never seen anything that would cause her to be alarmed or upset. "I can tell you when he was in a school in Kansas, we were never allowed to go back to the cottage to see him. They always brought him to us. That's one thing I like about Conway [Human Development Center], is you can go see your child any time you want to." Tr. 3233 (E. Stoddard). Ms. Stoddard testified, "[I]t's so important to me to know that the people who are caring for [my son] love him and will take care of him and are held responsible for it." Tr. 3247 (E. Stoddard).

Melissa Catron's son also is a resident of Conway Human Development Center. He was nineteen years old at the time of trial and had been a resident for more than four years. Tr. 3261-62 (M. Catron). Ms. Catron is a registered nurse. She testified that the Center works with her son on

everything she could possibly want. She believes that he is loved there. "I don't feel like anybody is there against their will to work with him. I've just not seen that. Everyone I've seen there that works with him wants to be there, that's what they want to do, and they seem to care about the kids. I'm thrilled." Tr. 3274 (M. Catron).

The defendants also called as a witness Larry Taylor, who is the guardian of his fifty-eight-year-old younger sister. "Tests show that [my sister] functions at about two years and nine months." She was fourteen years old when she was admitted. Tr. 5050 (L. Taylor). Mr. Taylor has lunch with his sister on a weekly basis. "I can rely on them to call me any time there's an injury. And that means a bruise of 2 inches, a scratch, a fall from bed." Mr. Taylor could not recall a time when he noticed that his sister had suffered an injury that he did not already know about. Tr. 5059 (L. Taylor).

Michael Black's fourteen-year-old son was admitted to Conway Human Development Center when he was eight or nine. Tr. 6824 (M. Black). "They call if he gets a bruise or a bump or has an incident. They call and let us know that he fell and scraped his knee They call and tell us that he's fine, you know, we put a Band-Aid on it, we gave him a hug and a kiss, and he's back to being a normal little child." Tr. 6833 (M. Black). "All the workers there . . . most of them that we know of have children of their own. . . . We're happy that he's in an environment where we know he's safe and he's going to get good sound medical care while he is there." Tr. 6833-34 (M. Black).

Barry Landen is the guardian of his brother, who is fifty-five years old and has been a resident of Conway Human Development Center for more than forty years. Tr. 6842 (B. Landen). Landen's brother was born blind.

[My brother] is an extraordinarily fragile individual. His balance, as I said, it's just terrible, and it's very easy for him to fall and hurt himself. . . . he doesn't understand

the concept of putting your fingers over the door when you slam will cause you a huge amount of injury. So the fact that nothing serious has happened to [my brother] in 40 years of living there is extraordinarily significant to me.

Tr. 6851 (B. Landon).

The testimony that staff members at Conway Human Development Center genuinely love and care for the residents is inconsistent with the allegation that there is a pattern and practice of abuse and neglect of residents at the Center.

Just as no parent or guardian testified to facts that would indicate a pattern or practice of abuse and neglect at Conway Human Development Center, similarly, no past or present employee offered any testimony indicating that such a pattern or practice of abuse or neglect exists. If a pattern or practice of abuse or neglect exists at Conway Human Development Center, some past or present employee would know of it and would have testified about it. Tr. 4873-74 (S. Murphy). If a “culture of silence” prevails such that present employees are disinclined to report abuse and neglect, some former employee would know of it and would have testified about it. No past or present employee testified that Conway Human Development Center has or has had a pattern or practice of permitting residents to be abused or neglected. No past or present employee testified that a “culture of silence” exists at Conway Human Development Center or that employees of the Center are reluctant to report abuse or neglect.

In fact, Johnny Lee Matson, Ph.D., who was called by the plaintiff as an expert witness in the field of psychology, testified that the psychology staff at Conway Human Development Center consists of “very nice people” who “were trying very hard” and “doing the best they could.” Tr. 1072 (J. Matson). Even though Dr. Matson believes that the technical skills of the psychology staff at the Center are deficient, he did not hesitate to say that they are good people who are doing

their best, an observation that cannot be reconciled with the allegation that a pattern of abuse and neglect prevails.

Other witnesses described the staff at Conway Human Development Center as consisting of people who genuinely care for the residents and exhibit a loving attitude toward them. For example, Louis Kraus, M.D., who testified as an expert in child psychiatry, described the cottage personnel at Conway Human Development Center as follows:

They were amazing. . . . I've seen a lot of different facilities over my professional career. Most of the cottage staff had been there for years, and they were not just there, in my opinion, because it was a job. They truly loved taking care of these kids. They would coddle them, they would hold them. There was a warmth with the staff that I observed during the day and early evening shifts, which I felt was very impressive. They also, I think it's important, they had an understanding of the kids. Like, for example, one child that we talked about, TM, that had the orchiectomy, that staff really knew this child. They knew when people came up to him too quickly, that he'll get anxious. They knew that when he's cold, he shakes, and he likes it when it's warmer out. They knew things about this child. And in each of the cottages and dorms, that's what you found. That's something refreshing, as opposed to people looking at their watches for the end of their shift.

Tr. 6225-26 (L. Kraus). Derek Nye, Ph.D., an expert in special education, testified:

I'm from New Jersey. There seems to be in my experience an edginess that exists all along the shoreline from Boston to Baltimore. And I see that edginess sometimes in our field, and it disappoints me on the east coast where staff have perhaps lost their focus as to why they are doing what they are doing. And I have seen it, quite frankly, in facilities I've worked at And I saw it in some of the developmental centers in New York and New Jersey specifically. And I had a fear that I would . . . see it here, too. Why not? And I was – pleasantly surprised is an understatement. I was overwhelmed by the caring attitude, by the compassion . . . and not just the special educators. People from the boardroom to the washroom, they place these individuals at the center of everything. They understood that they were there because these individuals needed their assistance. And they never violated that trust. My experience is they didn't violate that trust. And it was very impressive. And I saw that throughout in the classroom.

* * *

[T]here was a relationship, there was trust, there were students that were comfortable. Without being able to cite specifics, I believe certainly in my mind it's a given that students who feel they are safe, they are comfortable, that they are loved, are going

to have a greater capacity to learn and to love and to trust back. And I saw that given. People may argue that's an intangible and perhaps it is, but when you've taught and you've been involved in as many places as I have in 36 years, you know it when you see it, and I saw it every day.

Tr. 5120-21 (D. Nye). Even if some of those who testified believe that the technical skills of the staff at Conway Human Development Center are deficient—as Dr. Matson does—it is not plausible to say that employees at the Center genuinely care for the residents and exercise their best efforts to attend to the residents' needs while tolerating a pattern and practice of abuse and neglect about which they remain silent.

The greater weight of the evidence proves that no pattern and practice of abuse, neglect, or maltreatment of residents exists at Conway Human Development Center, and no “culture of silence” exists there. The evidence proves that Conway Human Development Center exercises reasonable care to prevent and to stop abuse, neglect, and maltreatment.

2. Allegations that Conway Human Development Center's Use of Restraints Violates Residents' Rights

Contrary to the plaintiff's allegations, and for the reasons that follow, the Court also finds from the greater weight of the evidence that Conway Human Development Center's use of restraints does not violate the constitutional rights of its residents.

Residents of Conway Human Development Center engage in aggression toward others, self-injurious behavior, tantrums, destruction of property, ingestion of non-edible objects, and the like, which can be dangerous to the resident engaging in the behavior as well as to other residents and staff or property. The Center sometimes uses mechanical restraints including papoose boards, restraint chairs, restraint jackets, mittens, and helmets to contain dangerous behavior. Defs.' Ex. 910, Conway Human Development Center Policy No. II-D-12 at 2-3.

If the use of restraints is to be a part of the program for a resident at Conway Human Development Center, the interdisciplinary team must prepare a safety plan and a positive behavior support plan. Tr. 6652 (K. Priest). Pursuant to the Center's written statement of residents' rights, mechanical restraints may be used when less restrictive interventions have failed and when "absolutely necessary to prevent the individual from injury to himself/herself and to others." Defs.' Ex. 910, Conway Human Development Center Policy No. I-D-5 at 4. Conway Human Development Center's policy on the use of planned restraints provides, "An individual may require the use of emergency or planned restraint . . . to contain behavior that is dangerous to self, others, or property. Unless clinically contraindicated, the use of restraint is a last resort containment measure preceded by less restrictive measures." Defs.' Ex. 910, Conway Human Development Center Policy No. II-D-12 at 1. The policy also provides:

Containment Restraint: Orders for restraint are time limited and shall not exceed one hour and 50 minutes for an adult or one hour for a child or adolescent. The individual is *immobilized* until calm by an approved device or devices which prevent movement of the body or parts of the body and/or normal function, not to exceed 15 minutes without an extension approved and documented by the QMRP¹⁴/designee, preferably after face-to-face attention. Unless otherwise determined by the IDT,¹⁵ QMRP/designee, extensions will be obtained every 15 minutes until the individual is calm. The IDT should define what constitutes calm behavior for this individual when used in a behavior program. Unless determined clinically contraindicated by the QMRP/designee, should time in restraint reach 55 minutes, the individual must be released for five minutes for the opportunity for motion, liquid intake, or toileting. Should time restraint reach 1 hour and 50 minutes, the individual must be released for at least 10 minutes for the previously listed activities. If this 10-minute release is judged to be a danger to the individual and/others, additional staff should be called to ensure safety for all concerned. Constant supervision is required.

Id. at 3 (bold, italics, and underlining in the original). The planned use of mechanical restraints must

¹⁴ Qualified Mental Retardation Professional.

¹⁵ Interdisciplinary Team.

be reviewed and approved by the chief psychologist, the human rights committee, the primary care physician, the superintendent, and the parent or guardian. Tr. 6563-64 (K. Priest); Defs.' Ex. 910, Conway Human Development Center Policy No. I-D-5 at 7.

In addition to the use of mechanical restraints as a part of a safety plan, Conway Human Development Center permits the use of mechanical restraints as an emergency measure to protect the resident or other residents from injury. The incident must be documented, and notice must be given to the interdisciplinary team, the child psychologist, the superintendent, the human rights committee, and others. An individual placed in a mechanical restraint must be monitored at least every fifteen minutes and must be given an opportunity for motion and exercise for at least five minutes during each hour. The unplanned use of mechanical restraints must be reviewed by the chief psychologist, the human rights committee, the primary care physician, the superintendent, and the parent or guardian. Defs.' Ex. 910, Conway Human Development Center Policy No. II-D-13.

While the use of mechanical restraints is troubling, psychologists called by both the plaintiff and the defendants agreed that it is sometimes necessary to use mechanical restraints when providing care for persons with the disabilities and psychiatric disorders found at Conway Human Development Center. Tr. 1180, 1248-49 (J. Matson); Tr. 5565 (B. Gale); Tr. 5855-56 (K. Walsh). The regulations that govern intermediate care facilities for the mentally retarded provide for the use of restraints within certain limits and with specified controls. *See* 42 C.F.R. § 483.420(a)(6) (2011) (requiring facilities to ensure that residents are free from unnecessary restraints and are provided active treatment to reduce the need for physical restraints); 42 C.F.R. § 483.440(f)(3)(iii) (requiring a facility to have a committee consisting of staff, parents and guardians, and unaffiliated persons to review, monitor, and make suggestions regarding the use of physical restraints, among other things);

42 C.F.R. § 483.450(b)(1)(iv)(B) (requiring a facility to adapt and implement policies and procedures regarding the use of physical restraints for the management of inappropriate behavior); *cf.* 42 U.S.C. § 290ii (2006) (governing the use of restraints in facilities that receive federal funds). The policies of Conway Human Development Center comply with these regulations. The Center's use of mechanical restraints is consistent with the regulations that govern intermediate care facilities for the mentally retarded and is not a substantial departure from generally accepted professional standards.¹⁶ Tr. 5565-72 (B. Gale); Tr. 5854-60, 5871 (K. Walsh).

Conway Human Development Center has made and is making a conscientious effort to reduce the use of mechanical restraints. Implementation of a program of safety plans, positive behavior support plans, and strategies is part of that effort. From 2005 until the time of trial, the use of mechanical restraints at the Center declined by sixty-nine percent. Tr. 5798, 5865 (K. Walsh). In September of 2009, sixty-two residents had contingent restraints in their plans, which is approximately twelve percent of the residents. Tr. 5868 (K. Walsh). In other words, eighty-eight percent had no restraints whatsoever in their plans. From July of 2008 through July of 2009, eighty-eight percent of the incidents of restraints involved three individuals. Tr. 5868 (K. Walsh). At the time of trial, restraints had been removed from the plans of two of those three individuals. Tr. 5869

¹⁶ Carla Jo Osgood testified for the plaintiff that the use of restraints at Conway Human Development Center substantially departs from generally accepted standards. As with her testimony regarding abuse and neglect, her testimony regarding the use of restraints was unpersuasive. Osgood performed no quantitative analysis comparing rates of injury at Conway Human Development Center to rates of injury at similar facilities or to any other benchmarks. Tr. 247-48 (C. Osgood). Nor did she provide any evidence that she was qualified to testify as an expert regarding restraint use. More credible testimony criticizing the Center's use of restraints was offered by psychologists called as expert witnesses for the plaintiff, but for the reasons stated in this section and in the succeeding section of these findings, that testimony was insufficient to meet the plaintiff's burden of proof.

(K. Walsh).

Based on the greater weight of the evidence, the Court finds that no pattern and practice exists at Conway Human Development Center of using restraints without sufficient safeguards and supervision to ensure that the safety, welfare, and civil and human rights of residents are adequately protected; and the Court finds that the use of restraints at the Center does not represent a substantial departure from generally accepted standards applicable to intermediate care facilities for the mentally retarded.

3. Allegations that Psychological Services at Conway Human Development Center Substantially Depart from Generally Accepted Standards

Although the plaintiff alleges that the psychological services at Conway Human Development Center substantially depart from generally accepted standards, that allegation was not proven by the greater weight of the evidence.

Johnny Lee Matson, Ph.D., and Ramasamy Manikam, Ph.D., testified for the plaintiff that the psychological services offered at the Center depart substantially from generally accepted standards in a number of ways, but the Court had difficulty in ascertaining to what standards they referred and what they meant when they testified that a practice was a substantial departure from those standards. It appeared that when they used terms such as “departures from generally accepted standards,” they meant that the practices at Conway Human Development Center were not the best. That interpretation of their testimony was confirmed to some extent by Dr. Matson. On cross-examination, Dr. Matson testified that a substantial departure is the same thing as failing to meet best practices. Tr. 1219 (J. Matson). Although he modified that statement on redirect examination, Tr. 1301, 1327 (J. Matson), it still appeared to be an accurate description of the opinions offered by himself and Dr. Manikam, i.e., that the practices at Conway Human Development Center were not

the best practices. For example, at one point Dr. Matson criticized one of the psychological examiners for using bar charts rather than graphs to record behavioral incidents of residents who have behavior plans. Tr. 1145-46 (J. Matson). Dr. Matson also said that something could be a standard even if only ten percent of the professionals in his field were doing it. Dr. Manikam testified, "In this field, [the] standards are fluid. It's not a body that is setting the standard." Tr. 3155 (R. Manikam). In the end, the Court concluded that Drs. Matson and Manikam were correct that the provision of psychology services at Conway Human Development Center could be improved, nor is it likely that anyone would argue to the contrary. The fact that psychology services at Conway Human Development Center could be improved does not mean, however, that the professionals who provide those services have departed so substantially from generally accepted standards that it cannot be said that they are exercising professional judgment.

The Court finds from the greater weight of the evidence that the professionals who are providing psychological services at Conway Human Development Center are exercising professional judgment and that their practices are within the boundaries of generally accepted professional standards. Psychological services are provided at Conway Human Development Center by ten psychological examiners licensed by the State of Arkansas. Tr. 1936-37 (C. Reddig). The chief psychologist, Dr. Carl Reddig, has an Ed.D. in psychology. Tr. 1938-39 (C. Reddig); Pl.'s Ex. 557. The licensed psychological examiners have master's degrees in psychology, Tr. 1937 (C. Reddig); Tr. 6550 (K. Priest); Tr. 6672 (E. Glenn); Tr. 6712 (W. McKindra), and six of them are licensed to practice independently, Tr. 6689 (E. Glenn). Their qualifications meet the standards imposed by the regulations that govern intermediate care facilities for the mentally retarded. *See* 42 C.F.R. § 483.430(b)(5)(v). Conway Human Development Center's practice of hiring master's level,

licensed psychological examiners is within the bounds of generally accepted practice at intermediate care facilities for the mentally retarded. Tr. 5875-76 (K. Walsh).

The evidence established that some and perhaps all of the psychological examiners at Conway Human Development Center lack formal training in applied behavioral analysis. The regulations that govern intermediate care facilities for the mentally retarded, however, do not require psychologists to have formal training in applied behavioral analysis. See 42 C.F.R. § 483.430(b)(5)(v). The evidence fails to show that it is a substantial departure from generally accepted practice for psychological services at such a facility to be provided by psychological examiners who do not have formal training in applied behavioral analysis.

The evidence also fails to prove that the practices followed and procedures used by the psychological examiners at Conway Human Development Center substantially depart from generally accepted professional standards. Much of the testimony at trial focused on functional behavior assessments, which are designed to determine the function that is served by maladaptive behaviors. Tr. 5794 (K. Walsh). The theory is that if the function of a maladaptive behavior can be determined, then that function can be served in another way so that the individual will not feel the need to engage in the maladaptive behavior. Tr. 6563 (K. Priest). These functional behavior assessments are used in formulating positive behavior support plans and strategies. Tr. 6562-63 (K. Priest). The psychological examiners at Conway Human Development Center exercise professional judgment in performing functional behavior assessments and in performing their other duties. Tr. 5828-30, 5836-37 (K. Walsh); Tr. 6566-70 (K. Priest); Tr. 6673-77 (E. Glenn). While it seems likely that Drs. Matson and Manikam could perform functional behavioral assessments and other duties of psychological examiners better than some of Conway Human Development Center's psychological

examiners, the evidence failed to establish that the functional behavior assessments or other work of the psychological examiners at the Center substantially depart from generally accepted professional standards. Tr. 5853-54 (K. Walsh).

4. Allegations that Conway Human Development Center Fails to Provide Adequate Medical Care

Although the plaintiff alleges that Conway Human Development Center has a pattern and practice of providing inadequate medical care to its residents, the greater weight of the evidence disproves that allegation.

At the time of trial, Conway Human Development Center had a staff of four full-time primary care physicians: Denise Thomas, D.O., who serves as the medical director; Patricia Parmley, M.D.; Jarrett Lea, M.D.; and Sam Schultz, M.D. Tr. 1724 (D. Thomas); Tr. 5482 (P. Parmley). Drs. Thomas and Lea are family doctors, and Drs. Parmley and Schultz are pediatricians.¹⁷ Tr. 5449, 5482 (P. Parmley). There was one vacancy on the medical staff at the time of trial. Tr. 6880 (C. Price). After-hours care is provided by another primary care physician, Dr. Gary Stewart, who resides at the facility. Tr. 1725 (D. Thomas). These primary care physicians are available to provide medical care to residents of Conway Human Development Center twenty-four hours per day, 365 days per year. Additional physician services, including those of a neurologist, an epidemiologist, and an infectious disease physician, are provided through a contract with the University of Arkansas for Medical Sciences. Tr. 6880 (C. Price). In addition to its physicians, Conway Human Development Center employs approximately twenty registered nurses and eighty-six licensed practical nurses. Tr. 5382, 5386 (S. Gardner). Not only is the Center sufficiently staffed with

¹⁷ Dr. Parmley has completed a fellowship in developmental behavioral pediatrics. Tr. 5449 (P. Parmley).

medical personnel to meet the needs of its residents, but it also provides psychiatric services in a manner that complies with generally accepted practices, uses and monitors medications appropriately, and provides medical services that are adequate to protect its residents.

In making findings related to medical care, particularly psychiatric care, at Conway Human Development Center, the Court must judge the credibility of the plaintiff's expert witnesses. Jodie Holloway, M.D., and Edwin J. Mikkelsen, M.D., who testified for the plaintiff, are board certified in general psychiatry and in child and adolescent psychiatry. Dr. Holloway is also board certified in forensic psychiatry. Both Drs. Holloway and Mikkelsen are qualified to give expert testimony in the field of psychiatry under Rule 702 of the Federal Rules of Evidence. Both are impressive individuals. Ultimately, however, they were not more believable than the experts called by the defendants, in part because in some notable instances their conclusions went beyond the scope of the support offered for those conclusions.

For instance, Dr. Holloway testified that psychiatric services at Conway Human Development Center are substandard with respect to children because the Center does not employ a psychiatrist who is board certified in child and adolescent psychiatry. Tr. 2514-16 (J. Holloway). In support of that opinion, she cited and read from a policy statement of the American Academy of Child and Adolescent Psychiatry, which was received into evidence as Plaintiff's Exhibit 870. Tr. 2516 (J. Holloway). That policy statement on its face applies to hospitals, not to intermediate care facilities. Tr. 6206-07 (L. Kraus); Pl.'s Ex. 870. Moreover, Dr. Holloway admitted on cross-examination that the American Academy of Child and Adolescent Psychiatry refers to its policy statement as "a voice on the issues" and states that the policy is not intended to define a standard of care. Tr. 2635 (J. Holloway).

Dr. Holloway also testified that Conway Human Development Center does not adequately assess individuals for tardive dyskinesia, a disorder that sometimes develops as a side effect of psychotropic medications. The percentage of individuals at Conway Human Development Center with a diagnosis of tardive dyskinesia is low. Tr. 3979 (T. Kastner). Even though Conway Human Development Center uses the Abnormal Involuntary Movement Scale to assess residents for tardive dyskinesia, Dr. Holloway testified that the incidents of tardive dyskinesia at the Center must be greater than the number of persons who have that diagnosis. Tr. 2606-07 (J. Holloway). She concluded, therefore, that Conway Human Development Center does not adequately assess individuals for tardive dyskinesia as a side effect of the psychotropic medications used there. That the percentage of residents at Conway Human Development Center who have a diagnosis of tardive dyskinesia is low could mean either that the Center fails to identify the individuals with tardive dyskinesia or that the Center manages psychotropic medications in a manner that minimizes side effects such as tardive dyskinesia. The evidence failed to show that any resident at Conway Human Development Center has tardive dyskinesia but has not been diagnosed. Tr. 4701-02 (A. Warren); Tr. 6214-15 (L. Kraus). Nevertheless, Dr. Holloway insisted that the Center does not adequately assess residents for tardive dyskinesia.

Dr. Mikkelsen testified that the overall medical services offered at Conway Human Development Center are substandard and cited as evidence the fact that the average age of death of residents at the Center is lower than the average age of death of residents at certain facilities in Massachusetts and Connecticut. Tr. 3772 (E. Mikkelsen). The evidence established, however, that those facilities serve a substantially older population than does Conway Human Development Center, so the facilities are not comparable as to the average age at which residents might die.

Tr. 3847-48 (E. Mikkelsen); Tr. 4096-97 (T. Kastner). Dr. Mikkelsen also testified that the rate of deaths due to aspiration pneumonia at Conway Human Development Center supports his opinion that medical care at the Center is substandard, Tr. 3776-77, 3918 (E. Mikkelsen), but there is no statistically significant difference between the death rate due to pneumonia at the Center and the rate at the facilities in Massachusetts to which Dr. Mikkelsen was comparing the Center. Tr. 4100-01 (T. Kastner).

Dr. Mikkelsen pointed to several examples of Conway Human Development Center's alleged failure to monitor the side effects of psychotropic medications, one of which concerned CL, a nine-year-old boy who was admitted to the Center with a preexisting prescription for Lithium.¹⁸ Lithium is a psychotropic medication with a narrow therapeutic range and severe toxic consequences. Tr. 5480 (P. Parmley). When CL was admitted into Conway Human Development Center, the medical staff had some doubt as to whether he had received his Lithium consistently. Tr. 5456 (P. Parmley). They drew blood to ascertain the Lithium level and found that the level was 0.5. Tr. 4118 (T. Kastner). Staff at the Center then administered the Lithium in accordance with the prescription that had been written before CL came to the Center. After allowing sufficient time for the Lithium to reach a stable level, another lab test was conducted and the Lithium level was determined to be 1.0, which is within what Dr. Mikkelsen called the therapeutic range. Tr. 4118 (T. Kastner); Tr. 5456-57 (P. Parmley). Over the following month, CL had one incident of difficulty in swallowing, but there was no other record of anything out of the ordinary. Tr. 4119 (T. Kastner). Approximately one month later, staff observed one evening that CL had an altered gait and took him to the infirmary. Tr. 5457 (P. Parmley). At the infirmary it was found that he had some upper

¹⁸ See Tr. 3660-88 for Dr. Mikkelsen's direct testimony regarding CL.

respiratory distress. Dr. Stewart, who provides after-hours care in the infirmary, ordered that a check be taken of the Lithium level. The Lithium level was found to be in excess of 4.0, which is a toxic level. Tr. 4119 (T. Kastner). CL was kept in the infirmary overnight, and on the following morning Dr. Stewart ordered a "trough level" test be taken to determine the level of Lithium. The level again exceeded 4.0, and Dr. Stewart admitted CL to Conway Regional Medical Center. Tr. 4121 (T. Kastner); Tr. 5458 (P. Parmley). At Conway Regional Medical Center, the Lithium level was again determined to be at a toxic level, and CL was transferred to Arkansas Children's Hospital in Little Rock, Arkansas. Tr. 5458 (P. Parmley). His Lithium level was stabilized, and he was found to have pneumonia. Tr. 4123 (T. Kastner). CL was later discharged and has suffered no ongoing effects of Lithium toxicity. Tr. 5459 (P. Parmley). According to Dr. Mikkelsen, CL's Lithium level continued to increase during the month between CL's admission into Conway Human Development Center and the evening when he was first taken to the infirmary. Dr. Mikkelsen believed that the swallowing incident was probably due to nausea and vomiting, which are signs of Lithium toxicity. Tr. 3665-66 (E. Mikkelsen). He also testified that CL necessarily had other symptoms of Lithium toxicity that were not recorded because the staff failed to observe them. Tr. 3678-79 (E. Mikkelsen).

In contrast, Theodore Kastner, M.D., testified that there was no basis for believing that CL had Lithium toxicity during the month between his admission to Conway Human Development Center and the evening when he was taken to the infirmary. Tr. 4125 (T. Kastner). According to Dr. Kastner, the elevation in CL's Lithium level likely was the result of pneumonia and dehydration. Tr. 4123-24 (T. Kastner). Dr. Kastner did not believe that the single incident of difficulty in swallowing was caused by Lithium toxicity, nor did he find any evidence that CL had symptoms of Lithium toxicity during that month. Tr. 4126 (T. Kastner). Dr. Kastner, along with another expert,

Louis Kraus, M.D., concluded that Conway Human Development Center staff carefully monitored potential side effects of the Lithium and saved CL's life by quick response to the sudden onset of Lithium toxicity secondary to pneumonia and dehydration. Tr. 4530 (T. Kastner); Tr. 6218 (L. Kraus). After it was called to Dr. Mikkelsen's attention that CL had pneumonia, he testified that the pneumonia was due to aspiration of fluids during the swallowing incident. Nothing in the medical records indicates that CL aspirated fluids.

Dr. Mikkelsen's opinion regarding CL depends upon findings for which there is no evidence and blames the staff at Conway Human Development Center for failing to record evidence that would have supported those findings. The evidence at trial established that the staff of Conway Human Development Center appropriately monitored CL and responded to changes in his medical condition—they saved his life. Yet, Dr. Mikkelsen criticized the medical care given to CL based on an assumption that CL had Lithium toxicity for a month before anyone noticed, which is an assumption unsupported by evidence.

There were two more examples of a similar nature in the testimony of Dr. Mikkelsen. One of them involved TN, who had a dramatic decrease in his platelet count after having been on Depakote for several years.¹⁹ Dr. Mikkelsen testified that the dramatic decrease in platelets was secondary to Depakote, which had been prescribed for TN by a neurologist as a means of controlling TN's seizures. According to Dr. Mikkelsen, this was another instance in which Conway Human Development Center failed to monitor the side effects of psychotropic medication. The evidence established, however, that the dramatic decrease in platelet count was secondary to an acute infection, and the platelet count rebounded with treatment of the infection and administration of

¹⁹ See Tr. 3736-52 for Dr. Mikkelsen's direct testimony regarding TN.

steroid medication even though TN continued to receive Depakote. Tr. 4179 (T. Kastner). Dr. Mikkelsen recognized that the drop in TN's platelet count could be attributed to the infection but said that whether the dramatic decrease in platelet count "was solely related to the Depakote or the Depakote plus the acute illness would be hard to sort out." Tr. 3752 (E. Mikkelsen). Still, Dr. Mikkelsen admitted that TN's platelet count recovered to its baseline level in the face of ongoing treatment with Depakote. Tr. 3866 (E. Mikkelsen); *cf.* Tr. 4694-95 (A. Warren). TN thereafter continued taking Depakote, and yet he did well. Tr. 4179 (T. Kastner). Common sense suggests that if TN's platelet count recovered to its baseline level and remained stable thereafter while TN was taking Depakote, Depakote was not the cause of the dramatic decrease in the platelet count.

Another example from Dr. Mikkelsen's testimony concerned CJ, a fifty-nine-year-old woman who Dr. Mikkelsen testified died from neuroleptic malignant syndrome caused by an increase in her Haldol prescription.²⁰ Dr. Mikkelsen testified that CJ died from neuroleptic malignant syndrome even though the medical records do not reflect that she had symptoms typical of that syndrome. One of the classic symptoms, as Dr. Mikkelsen admitted, is high fever. Although there are a few instances in the literature of a diagnosis of neuroleptic malignant syndrome without high fever, it is exceedingly rare. Tr. 3874-75 (E. Mikkelsen); Tr. 4199, 4203 (T. Kastner). CJ's temperature was normal or below. Pl.'s Ex. 791-1 to -5. Another symptom is rigidity. Dr. Mikkelsen testified that the fact that CJ had her knees bent meant that her legs were rigid, which is hardly convincing. Tr. 3706-08 (E. Mikkelsen); Tr. 4193 (T. Kastner). Another symptom of neuroleptic malignant syndrome is an oculogyric crisis, which is a spasmodic attack marked by a fixation of the eyes in one position—usually upward. Tr. 3875-76 (E. Mikkelsen). Nothing in the medical records indicated

²⁰ For Dr. Mikkelsen's testimony regarding CJ, see Tr. 3690-3718.

that CJ's eyes were fixated. Tr. 4697 (A. Warren). Dr. Mikkelsen testified that the medical record failed to state that CJ's eyes were fixated because the treating physician failed to look at CJ's eyes. Tr. 3718, 3876 (E. Mikkelsen). Dr. Mikkelsen was not present when the physician examined CJ, so he cannot possibly know whether the physician examined her eyes.

Although Drs. Holloway and Mikkelsen are highly qualified expert psychiatrists, the Court has concluded that their opinions are not as reliable as the contrary opinions offered by experts called by the defendants.

a. *Allegations that Psychiatric Services for Children at Conway Human Development Center Are Inadequate*

The greater weight of the evidence establishes that psychiatric services for children at Conway Human Development Center comply with generally accepted professional standards.

Douglas Callahan, M.D., is the consulting psychiatrist at Conway Human Development Center. Tr. 1729 (D. Thomas). Dr. Callahan is licensed to practice medicine in the State of Arkansas and is board certified in general psychiatry. The core competency of a board-certified psychiatrist includes the care of children. Tr. 4224 (T. Kastner). Dr. Callahan has provided psychiatric services to persons with intellectual and developmental disabilities for more than twenty years. Tr. 5335-36 (D. Callahan). He serves as a consultant to the primary care physicians. The residents at Conway Human Development Center who need psychiatric services are referred to Dr. Callahan, who sees them on campus. Direct care staff and psychological examiners accompany residents when they are seen by Dr. Callahan, and they provide information to him regarding the residents' behavioral symptoms. Tr. 5364-65 (D. Callahan); Tr. 6556-57 (K. Priest). Dr. Callahan makes diagnoses and recommendations regarding medication and other psychiatric care. His diagnoses and recommendations are recorded in progress notes, which are forwarded to the primary

care physicians for review. The primary care physicians then decide whether to implement the recommendations from Dr. Callahan. Tr. 5484 (P. Parmley). Dr. Callahan is on campus approximately two days each week. He has an office in the same suite of offices as the primary care physicians. When he is on campus, he regularly sees the primary care physicians, and when he is not on campus, he is available for consultation by telephone.

There is a shortage of child psychiatrists in the United States and specifically in the State of Arkansas. Tr. 4616-18 (D. Fassler); Tr. 6204-05 (L. Kraus). Moreover, very few child psychiatrists have specific training in dealing with children with developmental disabilities. Tr. 4623-24 (D. Fassler). Psychiatric services are provided to children in the United States most often through pediatricians or general practitioners. Tr. 4621-22 (D. Fassler).

The model of care at Conway Human Development Center by which psychiatric services are provided to children, through the use of a board-certified pediatrician consulting with a physician who is board certified in general psychiatry, is permitted by the regulations that govern intermediate care facilities for the mentally retarded, 42 C.F.R. § 483.430(b)(5), and is within the bounds of generally accepted practice for such facilities. Tr. 4222 (T. Kastner); Tr. 4624-25 (D. Fassler); Tr. 6212 (L. Kraus). Psychiatric services provided to children at Conway Human Development Center are consistent with generally accepted professional standards. Tr. 6212-13 (L. Kraus).

b. *Allegations that Psychotropic Medications Are Inappropriately Prescribed to Control Behavior*

Although the plaintiff alleges that Conway Human Development Center overprescribes psychotropic medications to control behavior, the greater weight of the evidence does not support that allegation. Psychiatric diagnoses generally are made following the criteria of the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders. Those criteria often rely upon patient

reports that persons with mental retardation are unable to give. The reliability of diagnoses of psychiatric disorders in persons with mental retardation, therefore, is in inverse proportion to the level of disability. Tr. 3818-19 (E. Mikkelsen); Tr. 4645-46 (A. Warren). In other words, the greater the level of mental retardation, the less reliable the psychiatric diagnoses. While in general it may be inappropriate to use medication simply to suppress bad behavior, it is not a substantial departure from generally accepted professional standards to use medication to treat specific behavioral symptoms in psychiatric patients with mental retardation, whether or not an identifiable psychiatric diagnosis can be made. Tr. 3828 (E. Mikkelsen); Tr. 4646, 4679, 4682-83, 4693-94 (A. Warren); Tr. 6222-24, 6275 (L. Kraus). The regulations that govern intermediate care facilities for the mentally retarded authorize the use of medication to control inappropriate behavior. 42 C.F.R. § 483.450(e). So far as the evidence showed, the use of psychotropic medications at Conway Human Development Center is consistent with those regulations.²¹ The use of psychotropic medications at Conway Human Development Center is not a substantial departure from generally accepted professional standards. Tr. 4703-04 (A. Warren); Tr. 5450 (P. Parmley); Tr. 6207, 6223-24, 6227 (L. Kraus).

c. *Allegations that Conway Human Development Center Fails to Monitor Side Effects of Psychotropic Medications*

In addition to allegations of overuse, the plaintiff alleges that Conway Human Development Center fails to monitor the side effects of the psychotropic medications it prescribes. The greater weight of the evidence does not support that allegation.

All medications have potential side effects. In the case of psychotropic medications, those

²¹ The caveat to this statement is that no evidence was presented regarding 42 C.F.R. § 483.450(e)(4)(ii).

side effects can be serious. Reasonably careful physicians weigh the risks of the side effects of a particular medication against the benefits that the patient may obtain from the use of that medication. Dr. Callahan testified, and the Court believes, that at Conway Human Development Center the risk versus benefit calculation often is done mentally but not recorded in the practicing physician's notes. Tr. 5349, 5372 (D. Callahan).

The use of psychotropic medications at Conway Human Development Center typically is initiated by a recommendation from Dr. Callahan (unless a client comes to Conway Human Development Center with preexisting prescriptions for psychotropic medications) and then is forwarded to the primary care physician who writes the order. Before the prescription is filled, the use of the psychotropic medication must be reviewed by the interdisciplinary team and the human rights committee, and it must be approved by the parent or guardian of the resident. The interdisciplinary team, which includes the primary care physician, discusses what the medication is expected to accomplish, what the potential side effects are, and the relationship between the potential risks and the potential benefits. Every resident on psychotropic medication will have taper criteria which the psychological examiners monitor. Tr. 6614 (K. Priest). After all of the consents are in place, the primary care physician orders the drug and establishes a laboratory protocol for monitoring potential problems. Tr. 508-09 (S. Murphy); Tr. 5484-87 (P. Parmley). These safeguards are reasonably prudent safeguards designed to ensure that the risks of psychotropic medications are accurately and adequately assessed and weighed against the potential benefits. Tr. 4163-64 (T. Kastner); Tr. 6221 (L. Kraus).

The potential side effects of each psychotropic medication are listed in the individual program plan for each resident to whom psychotropic medications are administered. Tr. 4925

(S. Murphy). Staff at Conway Human Development Center are trained to watch for symptoms that may be associated with side effects of psychotropic medications. Tr. 509, 4871-72, 4924-25

(S. Murphy). In addition, when psychotropic medications may result in consequences measurable through laboratory analyses, monitoring is conducted through laboratory analyses. Tr. 5486-87 (P. Parmley).

Conway Human Development Center also uses the Abnormal Involuntary Movement Scale to measure involuntary movements known as tardive dyskinesia. The Abnormal Involuntary Movement Scale is the most widely used instrument for the screening of tardive dyskinesia. Tr. 4231 (T. Kastner).

The monitoring of potential side effects of psychotropic medications at the Center complies with generally accepted professional standards. No pattern or practice exists at Conway Human Development Center of failing to monitor for side effects of psychotropic medications. Tr. 4171-73 (T. Kastner).

d. *Allegations Regarding Polypharmacy*

The plaintiff also takes issue with Conway Human Development Center's use of polypharmacy, that is, prescribing two or more psychotropic medications to a resident. Tr. 5342 (D. Callahan). Many of the residents at Conway Human Development Center come to the Center with psychiatric diagnoses and with prescriptions for multiple psychotropic medications. Tr. 5346 (D. Callahan). The practice at Conway Human Development Center is to attempt to reduce the number of psychotropic medications as well as the dosage, but that is not always possible. Tr. 5345-46 (D. Callahan). An effort is made to avoid polypharmacy, but in some instances, in the professional judgment of the physicians at Conway Human Development Center, the benefits of

polypharmacy to individual residents outweigh the risks to those residents, and in those instances polypharmacy is used. Tr. 5346-47 (D. Callahan). In 2010, 278 of the residents at Conway Human Development Center were prescribed psychotropic medications. Forty-three percent of those residents were prescribed one psychotropic medication; 33% were prescribed two psychotropic medications; 17% were prescribed three psychotropic medications; 4.7% were prescribed four psychotropic medications; and 2 residents (fewer than 1%) were prescribed five psychotropic medications. Tr. 4153 (T. Kastner).

The greater weight of the evidence fails to establish that the use of polypharmacy at Conway Human Development Center is excessive and fails to establish a pattern and practice of inappropriate or unreasonable use of polypharmacy at the Center.

e. *Allegations that Inadequate Medical Care Causes Unnecessary Deaths at Conway Human Development Center*

The plaintiff also alleges that many unnecessary deaths have occurred at Conway Human Development Center due to inadequate medical care, but, again, the greater weight of the evidence is to the contrary.

Eldon Schulz, M.D., is the medical director for the Division of Developmental Disability Services for the State of Arkansas. Tr. 6177 (E. Schulz). He is the Rockefeller Professor for Children with Special Healthcare Needs, Director of the Dennis Development Center at the University of Arkansas for Medical Sciences, and a faculty member practicing at Arkansas Children's Hospital. Tr. 6178-79 (E. Schulz). Since 2005 he has served as the physician representative on a committee that reviews all of the deaths of residents of the human development centers in Arkansas. Tr. 6179, 6192 (E. Schulz). As a member of that committee, he reviewed in

depth the records pertaining to each death at Conway Human Development Center between 2005 and the time of trial. In his opinion, which the Court credits and adopts, during that time none of the deaths of residents at Conway Human Development Center was due to medical malpractice. Tr. 6192-93 (E. Schulz).

f. Conclusion as to Adequacy of Medical Care

The greater weight of the evidence establishes that Conway Human Development Center provides adequate medical care, including psychiatric care, to its residents. Tr. 4083-84, 4218 (T. Kastner); Tr. 4649 (A. Warren); Tr. 5456 (P. Parmley). No pattern or practice of medical negligence or inadequate medical care exists at the Center.

5. Allegations that Conway Human Development Center Fails to Exercise Care to Prevent Choking

The plaintiff alleges that Conway Human Development Center fails to take proper steps to prevent choking incidents among its residents. The greater weight of the evidence, however, proves that the Center exercises reasonable care to prevent choking.

First, Conway Human Development Center employs seven speech language pathologists who work full-time at the center. Tr. 5386, 5417 (C. Johnson). The speech language pathologists are licensed by the State of Arkansas and have a number of duties, including providing speech-language therapy services, providing augmentative communication systems, assessing residents for dysphagia, identifying choking risks, and assisting in issues related to swallowing. Tr. 5387, 5391-92, 5417 (C. Johnson).

Second, new employees of Conway Human Development Center are given dysphagia training in which they are taught to observe silent signs of aspiration, to thicken liquids properly, and to use adaptive equipment properly. Tr. 5396 (C. Johnson). New employees are taught that each resident's

eating plan should be reviewed before assisting that resident at mealtime. Tr. 5396 (C. Johnson).

Third, Conway Human Development Center takes a number of steps to avoid choking incidents during mealtime. The Center employs a dietician who is licensed by the State of Arkansas. Tr. 5316-17 (A. Holbrook). Each resident of Conway Human Development Center has a nutritional and eating plan that is designed, among other things, to avoid choking incidents. Tr. 5317-18 (A. Holbrook); Tr. 5393-94 (C. Johnson). The Center also uses food service audits and mealtime monitoring to check for proper positioning, silent aspiration, use of adaptive equipment, and other factors related to choking and aspiration. Tr. 5393-94 (C. Johnson).

Fourth, Conway Human Development Center assesses residents for risk of choking using an assessment tool that has been statistically validated on individuals with developmental disabilities residing in congregate facilities. Tr. 3304 (J. Sheppard). A choking risk assessment is done each year in preparation for the annual meeting of the residents' interdisciplinary teams. Tr. 5407 (C. Johnson). If a resident chokes, that person is reassessed. Tr. 5407 (C. Johnson). In the assessment, the resident is identified as either low risk or high risk for pneumonia and choking. Tr. 6395 (L. Henderson). If a resident scores fifty percent or greater on the assessment for either the choking or the pneumonia risk, that person is placed in a high risk category. Tr. 6395 (L. Henderson). Also, if a resident has a choking history, has x-ray evidence of aspiration, or is fed by a tube, those factors could place the person in a high risk category. Tr. 6395-96 (L. Henderson). The information regarding a resident's risk factors is communicated to the program coordinator so that it can be taken into account on that resident's twenty-four-hour schedule and the individual program plan by the interdisciplinary team. Tr. 6396 (L. Henderson). The information is also placed on the dietary sheet that is used in the living unit and is part of the feeding plan. Tr. 6396 (L. Henderson).

Finally, Conway Human Development Center has a central dysphagia committee, which acts as a consultant and an advisory to the interdisciplinary teams regarding dysphagia and swallowing disorders. Tr. 6389 (L. Henderson). The committee serves to support and make recommendations to the teams as well as the primary care physicians. Tr. 6389 (L. Henderson). The central dysphagia committee reviews all airway events, such as changes in risk factors for choking; choking events;²² difficult swallowing events;²³ and cases that are referred by any member of the committee, the incident review committees, the interdisciplinary teams, or the physicians. Tr. 6389 (L. Henderson). The committee also reviews cases of pneumonia. Tr. 6389 (L. Henderson). The head of the central dysphagia committee is Linda Henderson, R.N., whose title at Conway Human Development Center is "Quality Improvement Nurse." Tr. 6387-89 (L. Henderson). Other members of the committee include a staff development nurse, primary care physicians, four speech therapists, three clinical therapists, a clinic supervisor, an occupational therapist, a physical therapist, a dietician, a human rights committee chairperson, a living unit supervisor representative, an infection control nurse, an administrative representative, Conway Human Development Center's dentist and dental hygienist, a program coordinator representative, and the director of nursing. Tr. 6402 (L. Henderson). The central dysphagia committee meets monthly but will sometimes meet more often than once a month

²² Conway Human Development Center defines "choking" as a partial or complete obstruction of the airway due to a foreign body, such as food or non-edibles. The onset of respiratory distress may be sudden with coughing; there may be agitation in the early stages of airway obstruction. The signs of respiratory distress include labored, ineffectual breathing until a person can no longer breathe; loss of consciousness will occur if the obstruction is not relieved. Tr. 6402 (L. Henderson).

²³ Conway Human Development Center defines a "difficult swallowing event" as an event in which no intervention is required; no acute change in vital signs occurs; and there are no symptoms of airway obstruction, such as change in skin color, eyes protruding, dizziness, change in level of consciousness, or inability to speak or make a sound. Tr. 6390 (L. Henderson).

if necessary. Tr. 6392-93 (L. Henderson).

Prior to a committee meeting, Henderson reviews the clinical record and gathers reportable information that is used by the central dysphagia committee. Tr. 6391 (L. Henderson). The report for any particular resident includes a history of choking events; a history of difficult swallowing events; yearly choking and pneumonia assessment risks; any x-ray studies or diagnoses of swallowing abnormalities; and any types of follow-through studies, such as an esophagogastroduodenoscopy²⁴ or x-rays of the upper gastrointestinal region. Tr. 6391 (L. Henderson). The committee then reviews the resident's respiratory diagnoses, such as asthma or chronic rhinitis, and the resident's history of respiratory disease or distress. Tr. 6391 (L. Henderson). The committee also reviews spinal issues, such as curvature of the spine, rod or metal implants, and the like. Tr. 6391 (L. Henderson). The committee looks at the resident's past history of pneumonia and aspiration; other gastrointestinal and oral disorders, such as gastrointestinal reflux disease or gastritis; esophagitis; constipation; ileus or hiatal hernia; gastric ulcers; or H. pylori infection. Tr. 6391-92 (L. Henderson). The committee also looks for strictures of the esophagus and gingivitis. Tr. 6392 (L. Henderson). It then considers what precautions and interventions are already in place and reviews the resident's food and fluid consistencies and whether the person has altered means of nutrition, such as a feeding tube. Tr. 6392 (L. Henderson). The committee also reviews the resident's oral hygiene care. Tr. 6392 (L. Henderson).

When a difficult swallowing event occurs, the resident is evaluated by a speech therapist, usually at the next meal or the next snack after the swallowing event. Tr. 6393-94 (L. Henderson).

²⁴ An esophagogastroduodenoscopy is an endoscopic examination of the esophagus, stomach, and duodenum. *Dorland's Illustrated Medical Dictionary* 643 (30th ed. 2003).

The speech therapist determines whether it is safe for the resident to eat and, if so, what type of diet is needed and then communicates that information to the dietician. Tr. 6393 (L. Henderson). If the physician, the dietician, or the speech therapist believes that a swallow study is needed, then it is ordered. Tr. 6393 (L. Henderson). In 2009, thirty-three percent of the residents of Conway Human Development Center were referred for a modified barium study, and ninety-one percent of the studies revealed abnormal swallowing. Tr. 3305 (J. Sheppard).

Members of the staff at Conway Human Development Center are trained in methods of clearing a resident's airway when a choking incident does occur. If a choking event occurs, staff will immediately provide first aid and make any necessary dietary changes. Tr. 6397 (L. Henderson). The speech therapist will evaluate and report her findings to the physician as well as to a core meeting of some of the central dysphagia committee members. Tr. 6397-98 (L. Henderson). Sometimes a doctor will be called to the scene of a choking event. At other times, the resident will go to the infirmary after a choking event to be evaluated by a physician. The interdisciplinary team will have a special staffing to make any necessary changes in the resident's twenty-four-hour schedule or treatment plan. The central dysphagia committee will review the incident, and a swallow study may be conducted. A gastrointestinal physician may be consulted to evaluate the case. Reflux precautions may be added if they have not yet been instituted.

Carly Crawford, an expert witness for the plaintiff, testified that members of the staff at Conway Human Development Center do not exercise generally accepted minimum professional judgment regarding choking. Tr. 2756-57 (C. Crawford). The Court, however, is not convinced that Crawford is qualified to testify as an expert regarding professional standards for the prevention of choking by developmentally disabled persons. Crawford is an occupational therapist with an

undergraduate degree in deaf education and a master's degree in occupational therapy. She is licensed as an occupational therapist in the State of Oklahoma. Tr. 2743 (C. Crawford). She described occupational therapy as looking "at how an individual uses their hands for daily activities" and at positions such as sitting or standing for daily activities. Tr. 2741 (C. Crawford). On direct examination, she said that she was qualified to testify about services other than occupational therapy because "I have had education relative to health systems, body systems, understand health risks, and understand anatomy, physiology, and then have been working shoulder to shoulder with speech pathologists and physical therapists." Tr. 2742-43 (C. Crawford). Crawford presented no evidence that convinced the Court that she was qualified to testify as an expert in any area other than occupational therapy.

Apart from her lack of qualifications, Crawford's credibility was called into question by a lack of care in the manner in which she wrote her report. Cross-examination revealed that Crawford's report in this case identified the subject of her report as Beatrice State Development Center, which is the name of a facility in another state about which she had previously written a report. She also referred in her report to sections where recommendations would be made and methodology would be described, but no recommendation section appeared in the report, nor was her methodology described anywhere in the report. Tr. 2905-07 (C. Crawford).

Even if the Court disregarded these discrepancies, Crawford's testimony on choking events at Conway Human Development Center is unpersuasive. She testified that Conway Human Development Center has an excessive number of choking episodes, but the only benchmark that she offered for comparison was that she had recently been to a facility with 250 to 300 residents that had no choking incidents over a six-month period. Tr. 2768 (C. Crawford). During the 2009 calendar

year, Conway Human Development Center had eleven incidents of choking. Tr. 6439-40 (L. Henderson). The fact that one facility, with a population of 250 to 300 persons, had no episodes of choking in a six-month period, while some 500 residents of Conway Human Development Center had eleven episodes of choking in a twelve-month period is insufficient to establish that Conway Human Development Center fails to exercise reasonable care to prevent choking events. Crawford's testimony was inadequate to form the basis for any reliable conclusions.

Other than Crawford's testimony that one facility with 250 to 300 residents had no choking episodes in a six-month period, the plaintiff presented no evidence to establish a benchmark from other facilities across the United States by which one could determine that the rate of choking at Conway Human Development Center was unreasonably or unusually large.

The weight of the evidence suggests that it is not. Cynthia Johnson, a speech language pathologist employed by Conway Human Development Center, calculated that there are approximately 548,000 occasions each year when a resident might have a choking event,²⁵ so the number of choking events is quite small compared to the occasions in which choking is a possibility. Tr. 5446 (C. Johnson). Justine Joan Sheppard, Ph.D., called by the defendants as an expert in speech pathology, testified that in 2009 seventy-four percent of the residents of Conway Human Development Center had a high risk of choking, but only 2.17% experienced a choking event. Tr. 3304 (J. Sheppard).

In the past several years, Conway Human Development Center has had one death as a result of choking. That death occurred in 2008 when a profoundly retarded, fifty-eight-year-old resident

²⁵ The calculation was accomplished by multiplying the number of residents by the number of mealtimes per year and adding one daily medication pass per day per resident.

went unnoticed into the kitchen and stuffed food into her mouth. Tr. 6440-42 (L. Henderson). At 11:30 p.m., members of the direct care staff working the night shift noticed the resident asleep on a couch in the day room, went into the bedrooms to check other residents, and then returned to the day room at 11:35 p.m., by which time the resident had gone into the kitchen and stuffed food into her mouth. Pl.'s Ex. 6-3. Staff attempted to remove the food from the resident's mouth, clear the airway by abdominal thrusts, and administer cardiopulmonary resuscitation. An ambulance arrived at 11:57 p.m. and took the resident to the nearest hospital where she died of aspiration pneumonia several days later. Pl.'s Ex. 6-3. While that incident is certainly tragic, no evidence was presented sufficient to show it is part of a pattern or practice of failing to take precautions to minimize choking risks.

Ultimately, the evidence fails to establish a pattern or practice at Conway Human Development Center of failing to take appropriate and reasonable steps to prevent choking.

6. Allegations that Conway Human Development Center Fails to Exercise Reasonable Care to Prevent Aspiration Pneumonia

Similarly, the plaintiff alleges that Conway Human Development Center fails to exercise reasonable care to prevent aspiration pneumonia, but, yet again, the greater weight of the evidence is to the contrary.

Conway Human Development Center provides preventive care for pneumonia by taking an annual pneumonia risk assessment; by taking reflux precautions, such as keeping residents up for a period of time after they eat and elevating the head of the bed; by providing oral care; and by administering a pneumonia vaccination annually. Tr. 5383 (S. Gardner).

If a resident is suspected of having pneumonia, that person is assessed by a physician who makes a diagnosis. Tr. 5384 (S. Gardner). If a resident is diagnosed with pneumonia, treatment may

include an oral or intravenous antibiotic, updrafts, and breathing treatments. Tr. 5384 (S. Gardner). The resident may be moved into the on-site infirmary or transported to the hospital. Tr. 5385 (S. Gardner).

Data regarding pneumonia is maintained by Conway Human Development Center's infection control nurse, who is a member of the central dysphagia committee. The infection control nurse gives Linda Henderson, the head of the central dysphagia committee, a list of every resident who has had a diagnosis, has had an x-ray, or has been in the infirmary or hospital for pneumonia during that month. Tr. 6413-14 (L. Henderson). The central dysphagia committee reviews cases of pneumonia, acting in an advisory role to the interdisciplinary team. Tr. 6411-13 (L. Henderson). If a resident has a case of pneumonia, the central dysphagia committee will follow up with that resident one to three months after the case of pneumonia to ascertain that resident's respiratory status. Tr. 6414 (L. Henderson).

Dr. Mikkelsen testified that the rate of death from aspiration pneumonia at Conway Human Development Center was excessive compared to facilities in Massachusetts.²⁶ Tr. 3776-77, 3918 (E. Mikkelsen). In 2005, twenty-seven percent of the deaths at Conway Human Development Center were caused by aspiration pneumonia, while twenty-one percent of the deaths in Massachusetts facilities were caused by aspiration pneumonia. Tr. 4101 (T. Kastner). Over a two year period, there were nine deaths at Conway Human Development Center due to aspiration pneumonia and six at the Massachusetts facilities. Tr. 4101 (T. Kastner). Although there was some difference between the

²⁶ Carly Crawford also testified that the number of incidences of aspiration pneumonia at Conway Human Development Center was excessive. However, as mentioned above, Crawford was not qualified to testify as an expert in that field, nor did she offer any benchmarks as evidence from which one could compare Conway Human Development Center with other institutions.

number of deaths due to aspiration pneumonia at Conway Human Development Center and facilities in Massachusetts, the difference between the rates of death is quite small and is not statistically significant. Tr. 4100-01 (T. Kastner).

Conway Human Development Center exercises reasonable care to prevent and to detect pneumonia. Although the plaintiff alleges that the residents of Conway Human Development Center experience a high rate of aspiration pneumonia, the evidence fails to show that the rate of aspiration pneumonia at Conway Human Development Center is statistically higher than the rate in other facilities or among any population with similar risks. Tr. 4079 (T. Kastner). The evidence fails to establish a pattern or practice at Conway Human Development Center of failing to take appropriate and reasonable steps to prevent aspiration pneumonia.

7. Allegations that Conway Human Development Center Fails to Exercise Reasonable Care to Prevent Fractures

The plaintiff alleges that Conway Human Development Center fails to exercise reasonable care to prevent fractures, but the greater weight of the evidence establishes that the Center exercises reasonable care to prevent fractures.

The population at Conway Human Development Center has an increased risk of osteoporosis for a number of reasons. In light of this risk, Conway Human Development Center takes a number of steps to prevent fractures among its residents. The Center uses a DEXA (dual energy x-ray absorption) meter scan for assessing fracture risks. Tr. 6403 (L. Henderson). The DEXA meter has x-ray capability and uses computer software to analyze the lumbar spine and hip, determining bone mineral density and contents. The software compares that information to what would be expected at peak bone age, which is about thirty years of age; compares previous scores and measurements; and then takes all of that information and formulates it into a risk assessment. The resident is then

categorized as not at risk, at increased risk, or at high risk for bone fracture based on the results. The DEXA meter also includes a photographic representation of the scan of the bones, which shows spaces and gaps in the bones. Tr. 6403-05 (L. Henderson). Dr. Steve Kemp, an endocrinologist who consults with Conway Human Development Center, rates these scans and makes the diagnoses of osteoporosis, osteopenia, or normal scan. Tr. 6405, 6438 (L. Henderson). DEXA meter scans are conducted every two years, and the primary care physician reviews the DEXA scan results, as does the interdisciplinary team. Tr. 6405-06 (L. Henderson). Very few intermediate care facilities for the mentally retarded have an on-site DEXA meter. Tr. 4065 (T. Kastner).

Some residents are not susceptible to a DEXA scan because of body shape. For those residents, Conway Human Development Center uses a urine test called an "N-telopeptide," which assesses the rate of bone absorption in the urine. Tr. 6407 (L. Henderson). Conway Human Development Center also may perform other types of testing, such as endocrine testing, testing for Vitamin D, and testing for calcium. Tr. 6407-08 (L. Henderson).

In addition to testing for increased risk of fractures, Conway Human Development Center has procedures in place for treating residents who are at risk. Based on the results of a laboratory analysis of the resident's blood, the treatment protocol usually begins with Vitamin D and calcium treatments. If treatment is required for low bone mineral density, Conway Human Development Center usually starts with bisphosphonates. Boniva and Fosamax are the two most common bisphosphonates used at Conway Human Development Center. Other therapies for low bone mineral density are also used. Tr. 6408 (L. Henderson).

When a resident experiences a fracture at Conway Human Development Center, Linda Henderson does a clinical audit. She assesses the risk of osteoporosis and audits the resident's

medical records to see if bone fractures have occurred before. Henderson then reviews the results of any DEXA scans; examines the types of interventions that have been performed; and reviews any medications related to osteoporosis that the resident receives, including calcium and Vitamin D. She also ascertains whether the resident is having acute back pain, has had any loss of height, or has developed kyphosis. From that information, Henderson then formulates a progress note that the physician will evaluate to see whether additional interventions are needed. Tr. 6410 (L. Henderson).

At Conway Human Development Center, there were twenty-one fractures reported for 2008 (the last year for which data was available at the time of trial), which translates to a rate of approximately four fractures per hundred residents per year. Tr. 4082 (T. Kastner). The only evidence of any benchmarks for comparison was Dr. Kastner's testimony regarding a published study of the annual rates of fractures at four intermediate care facilities for the mentally retarded in New England. At those facilities, the rates of fractures ranged from 13.2 to 15.3 fractures per 100 residents per year. Tr. 4297 (T. Kastner). Thus, the rate of fractures at Conway Human Development Center is substantially lower than the fracture rates at other facilities according to the only benchmark offered for comparison. Tr. 4082 (T. Kastner).²⁷

Conway Human Development Center exercises reasonable care to prevent fractures.

8. Allegations that Conway Human Development Center Fails to Exercise Reasonable Care to Prevent Decubitus Ulcers

The greater weight of the evidence establishes that Conway Human Development Center exercises reasonable care to prevent decubitus ulcers. From June of 2007 until September 16, 2009,

²⁷ Carly Crawford testified that Conway Human Development Center had an excessive number of fractures. However, as mentioned above, Crawford was not qualified to testify as an expert in that field, nor did she offer any benchmarks from which one could compare Conway Human Development Center with other institutions.

the Center recorded seventy-seven incidents of decubitus ulcers for forty-six residents. There were thirty-one instances in 2007, twenty instances in 2008, and twenty-six instances in 2009 through September 16, 2009. The rate of decubitus ulcers at the Center is lower than in comparable facilities in the United States. Tr. 4065, 4081 (T. Kastner). Most of the decubitus ulcers do not go beyond stage two, which involves superficial redness and superficial skin break and is a stage at which the ulcer can be resolved. Tr. 3474 (M. Schmeler). No evidence was offered to show that the occurrence of decubitus ulcers among the residents of Conway Human Development Center is excessive compared to similar populations elsewhere.²⁸ Tr. 3470-71 (M. Schmeler).

9. Allegations that Conway Human Development Center Fails to Exercise Reasonable Care to Protect Residents from Injuries in General

Residents at Conway Human Development Center do not suffer more frequent or more serious injuries than comparable populations in other settings. In 2008 and the first half of 2009, the injury rate at Conway Human Development Center was .41 per person per year. Tr. 5940 (K. Walsh). The per person per year rates of specific injuries at Conway Human Development Center in 2008 and the first half of 2009 were: for cuts, .16; for fractures, .06; for bruises, .06; for bites, .02; for swellings/sprains, .03; for abrasions, .03; for burns, .00; and for other injuries, .05. Tr. 5942 (K. Walsh). Reported injury rates for other institutions range from .36 per person per year to .65 per person per year. Tr. 5941 (K. Walsh). The rate of injury at Conway Human Development Center falls into that range. The greater weight of the evidence establishes that Conway Human Development exercises reasonable care to protect residents from injuries.

²⁸ Carly Crawford also testified that Conway Human Development Center had an excessive number of ulcers. However, as mentioned above, Crawford was not qualified to testify as an expert in that field, nor did she offer any benchmarks from which one could compare Conway Human Development Center with other institutions.

10. Allegations that Residents of Conway Human Development Center Die at an Early Age Due to Poor Conditions in General

Contrary to the plaintiff's allegations, the greater weight of the evidence does not establish that residents of Conway Human Development Center die at an early age because of substandard care.

Over a two-year period, twenty-two residents of Conway Human Development Center died. The average age of death at the Center during those two years was 46.5 years. Tr. 3772 (E. Mikkelsen). Dr. Mikkelsen testified that the average age of death at Conway Human Development Center was lower than the average age of death at facilities in Massachusetts and Connecticut, from which he concluded that residents of Conway Human Development Center die at a young age due to substandard care. Tr. 3917-18 (E. Mikkelsen). Dr. Mikkelsen's reasoning is flawed, however, because the Massachusetts and Connecticut facilities provide services only to an elderly population—the residents at those facilities were older than 46.5 years of age, so of course their average age of death is higher than 46.5. In contrast, Dr. Kastner testified that the mortality rate at the facilities in Massachusetts and Connecticut was higher than the mortality rate in Conway Human Development Center, which also would be expected because those facilities serve an older population. Tr. 3980, 4096-97 (T. Kastner). The facilities in Massachusetts and Connecticut are not comparable to Conway Human Development Center with respect to a critical risk factor for death—age—so these comparisons prove nothing.

The national mortality rate for intermediate care facilities is twenty-two per thousand per year. Tr. 3980, 4089, 4098 (T. Kastner). The mortality rate at Conway Human Development Center is twenty-two per thousand per year. Tr. 3980, 4089, 4098 (T. Kastner). Thus, the mortality rate at Conway Human Development Center coincides with the national average for intermediate care

facilities.

The greater weight of the evidence fails to establish that residents of Conway Human Development Center are exposed to conditions that cause early deaths.

11. Conclusion as to Whether Conway Human Development Center Provides a Reasonably Safe Environment

For all of the reasons that have been stated, the greater weight of the evidence establishes that Conway Human Development Center does not depart from generally accepted practices in its efforts to keep residents safe and free from undue restraint. Conway Human Development Center is a reasonably safe facility that does not use undue restraint.

C. FINDINGS OF FACT REGARDING ALLEGATIONS THAT CONWAY HUMAN DEVELOPMENT CENTER VIOLATES THE INTEGRATION MANDATE OF THE AMERICANS WITH DISABILITIES ACT

The plaintiff's second claim for relief alleges that Conway Human Development Center violates the Americans with Disabilities Act. Specifically, the plaintiff claims that the Center is not the least restrictive, most integrated setting appropriate for its residents; fails to give adequate information to parents and guardians about less restrictive alternatives; and fails to exercise professional judgment in making its determinations as to whether the Center is the least restrictive setting for its residents. The greater weight of the evidence does not support these allegations.

As mentioned above, Conway Human Development Center is certified by the Centers for Medicare and Medicaid as an intermediate care facility for the mentally retarded, which means that it is funded through Medicaid. Medicaid is a program through which the federal government provides financial assistance to states so that they can provide medical care to needy persons.²⁹ In

²⁹ See *Wilder v. Va. Hosp. Ass'n*, 496 U.S. 498, 502, 110 S. Ct. 2510, 2513, 110 L. Ed. 2d 455 (1990).

order to participate, a state must submit a plan that satisfies certain requirements of the Medicaid program. However, the Secretary of the United States Department of Health and Human Services is authorized to waive those requirements so that states can create programs that provide Medicaid-funded services to persons with long-term disabilities in noninstitutional settings. 42 U.S.C. § 1396n(c). Such programs are known as home and community based waiver programs, or simply waiver programs. If a state chooses to offer Medicaid-funded services through a waiver program, the state must apply to the Centers for Medicare and Medicaid Services for a waiver of the requirements of the Medicaid program that otherwise would be imposed.

Arkansas has a Medicaid home and community based waiver program for persons with developmental disabilities. Persons who meet the disability requirements for admission to an intermediate care facility for the mentally retarded and the Medicaid income eligibility requirements may qualify to participate in the waiver program. Tr. 1412-15 (C. Cromer). The waiver program provides an alternative to institutionalization. Defs.' Ex. 410 at 2. Waiver services in Arkansas include case management, supported employment, supported living, specialized medical supplies, adaptive equipment, community transition services, and other services. Tr. 1415-18 (C. Cromer); Defs.' Ex. 410 at 22-38. Providers of waiver services in Arkansas are licensed by the Division of Developmental Disability Services and are compensated according to a daily rate not to exceed \$176 per day for supportive living or \$391.95 per day for persons who require the highest level of care. Tr. 806 (J. Green); Tr. 1418, 1429-30 (C. Cromer).

A state must apply for a certain number of "slots" when it applies for approval for a waiver program. Tr. 750-52 (J. Green). The number of "slots" is determined by the funds available to pay for services. Tr. 752 (J. Green). Arkansas has 4083 "slots," which means that it serves 4083 persons

through its waiver program. Tr. 1426 (C. Cromer). Although the plaintiff alleges that Arkansas promotes institutionalization of persons with developmental disabilities, the number of persons served in the Arkansas waiver program is four times greater than the number of persons served in the Arkansas human development centers.

When a person contacts the Division of Developmental Disability Services to inquire about obtaining services, that person is given a choice of services form that permits the person to apply to receive services from a human development center, through the waiver program, or both. Tr. 1452 (C. Cromer); Tr. 6776 (A. Green). If a person qualifies for services, that person is placed on a waiting list. Tr. 1452 (C. Cromer). In 2007, approximately 700 persons were on a waiting list to obtain services in the Arkansas waiver program. Tr. 778-79 (J. Green). As of April of 2010, approximately 1400 persons were on the waiting list. Tr. 779 (J. Green). At the time of trial, 1600 or 1700 persons were on the waiting list for waiver services in Arkansas. Tr. 779 (J. Green); Tr. 1441 (C. Cromer). Residents of a human development center who seek waiver services are given priority, which is to say that if the parent or guardian of a resident of a human development center seeks placement for the child or ward in waiver services, that resident will go to the top of the waiting list for waiver services.³⁰ Tr. 695 (A. Richardson); Tr. 780 (J. Green); Tr. 4050 (T. Kastner); Tr. 6784 (A. Green).

³⁰ The plaintiff places a sinister interpretation on the fact that residents of human development centers are given priority, contending that it encourages parents and guardians to admit their children and wards to a human development center so as to attain priority on the waiting list for waiver services, but there is no evidence that any parent or guardian has sought to have a child or ward admitted to a human development center in order to receive priority on the waiting list for waiver services. Tr. 4310 (T. Kastner).

1. Allegations that Conway Human Development Center Is Not the Least Restrictive, Most Integrated Placement Alternative Appropriate for its Residents

The plaintiff alleges that residents of Conway Human Development Center are segregated in a restrictive environment where they are deprived of the opportunity to interact with nondisabled persons, whereas, according to the plaintiff, many, if not all of them, could be served in more integrated settings. Much of the presentation at trial discussed this issue in terms that presupposed the outcome: the alternatives were described as “institutionalization” at Conway Human Development Center or “community placement” through waiver services. “Community placement” is a term that implies a more integrated, less restrictive setting than does the term “institution,” but it does not follow from the use of these terms that a resident automatically will have a greater degree of interaction in community placement, i.e., with a waiver provider, than in an institution such as Conway Human Development Center. The evidence establishes that residents of Conway Human Development Center do interact with nondisabled persons—the Center is not a prison with inmates barred from interaction with the outside world; and conversely, the evidence establishes that placement with a waiver provider does not guarantee any amount of interaction with nondisabled persons.

Residents of Conway Human Development Center participate in activities outside of the facility. As of July 31, 2009, eleven residents worked at jobs off campus. Tr. 534 (A. Richardson); Tr. 6731 (B. Brewer); Pl.’s Ex. 229. Some of the residents attend summer programs at the University of Central Arkansas. Tr. 504 (S. Murphy). Many go off campus for recreational activities. Tr. 504 (S. Murphy). Off-campus activities include, but are not limited to, going to the movies, eating out, shopping, bowling, fishing, going to parks, going to the state fair, going to the

library, attending athletic events at a local university, attending church, going on boy scout outings, going to pet therapy, and participating in the Special Olympics. Tr. 5958-59 (K. Walsh); Tr. 6732 (B. Brewer); Tr. 6828 (M. Black); Pl.'s Ex. 230. During the first six months of 2009, residents of Conway Human Development Center participated in 305 off-campus activities sponsored by the Center. Tr. 5958-59 (K. Walsh).

In addition to off-campus activities sponsored by the Center, residents of Conway Human Development Center go off campus for visits with family and friends, sometimes during the day and sometimes overnight or over a weekend or some other extended period of time. Tr. 3232 (E. Stoddard); Tr. 3284 (M. Catron); Tr. 6828 (M. Black); Tr. 6844-45 (B. Landen). These interactions with persons off campus can be beneficial, enriching experiences for the Center's residents. Tr. 3259 (E. Stoddard). More importantly, these interactions render life at Conway Human Development Center less restrictive and more integrated for residents.

Conway Human Development Center also sponsors a panoply of on-campus activities, including but not limited to arts and crafts, bingo, chapel, Connect Four, cookouts, gymnasium activities, movies, miniature golf, and pizza parties. Tr. 5959-60 (K. Walsh). During the first quarter of 2009, there were 592 on-campus activities. Tr. 5959 (K. Walsh). Nondisabled volunteers also come to Conway Human Development Center to visit and work with the residents. Pl.'s Ex. 1227.

The evidence does establish that many, if not all, of the residents of Conway Human Development Center could be served by organizations that provide services through the Arkansas home and community based waiver program. After reviewing approximately forty individual program plans of residents of Conway Human Development Center, the plaintiff's expert Antoinette

Richardson testified that many of them could be considered for the possibility of placement with a provider of waiver services. Tr. 528 (A. Richardson). Similarly, four officers of organizations that provide waiver services in Arkansas reviewed approximately forty-six randomly selected individual program plans of residents of Conway Human Development Center and concluded that many, if not all, of them could be served through the waiver program.³¹ Tr. 868-99 (P. Bland); Tr. 1353-75 (C. Alberding); Tr. 1526-27 (K. Vire); Tr. 1875-76 (J. Lambert).

Although the defense attempted in some measure to discredit this testimony, that some and perhaps all of the residents of Conway Human Development Center could receive services through the waiver program cannot seriously be denied. Indeed, Calvin Price, the superintendent of Conway Human Development Center, when asked how many of the residents of the Center could be served through the waiver program, testified, "Maybe they all could with the proper supports I possibly think that a lot of our individuals could live in the community if they had the appropriate resources." Tr. 1714 (C. Price). That many, if not all, of the residents at Conway Human Development Center could be served by waiver providers does not, however, *ipso facto* establish that a waiver provider is the appropriate placement for a specific resident or that the resident would have a greater degree of interaction with nondisabled persons in the waiver program.

Richardson testified that she toured a small intermediate care facility in Central Arkansas, as well as the Faulkner County Day School, Easter Seals in Little Rock, United Cerebral Palsy in Little Rock, and Pathfinders in Jacksonville. Tr. 576, 590-91 (A. Richardson). She testified that

³¹ Those four persons were Pamela Bland, Executive Director of First Step, Inc.; Cindy Alberding, Executive Director of Independent Case Management; Keith Vire, Ph.D., Chief Executive Officer of Arkansas Support Network; and Jeff Lambert, Assistant Executive Director for programs for Bost Incorporated.

some of these providers could provide services such as those needed by residents of Conway Human Development Center. Tr. 592 (A. Richardson). She did not, however, testify that any of these placement alternatives would be the appropriate placement for any specific resident of Conway Human Development Center, nor did she testify that any specific resident of Conway Human Development Center would have a greater degree of interaction with nondisabled persons if that resident received services at the smaller intermediate care facility for the mentally retarded or through one of the providers of waiver services.

Richardson also visited a former resident of Conway Human Development Center who had been discharged and was living in an apartment with staffing and nursing help available. Tr. 575 (A. Richardson). The former resident required a lift to be transferred from a bed to a chair, as well as special arrangements for bathing and assistance with eating, dressing, and other such necessities of daily life. Tr. 575 (A. Richardson). Richardson's testimony did not compare the extent to which the former resident interacted with nondisabled persons while living alone in an apartment with the extent to which she interacted with nondisabled persons while living at the Center, nor is it obvious that this former resident interacts with nondisabled persons to a greater degree while living alone in an apartment than she did while living at Conway Human Development Center.

Richardson admitted that "some people can be in a fairly restrictive setting even in a community placement." Tr. 693 (A. Richardson). She also admitted that some people have left residential facilities, lived alone in an apartment, and never integrated at all into the community. Tr. 693 (A. Richardson). Richardson acknowledged that each resident should be studied individually in order to determine whether that resident should be placed with a provider of waiver services, and she admitted that she had not performed that type of study. Tr. 700, 708 (A. Richardson). Thus, just

as it is an error to assume that because Conway Human Development Center is an institution its residents have no interaction with nondisabled persons, so too is it an error to assume that a community placement *ipso facto* precludes the possibility of isolation or automatically provides more interaction with nondisabled persons than an institutional setting.

The testimony of some of the parents of Conway Human Development Center residents highlights the importance of making an individualized determination regarding the appropriate placement for a developmentally disabled person. The testimony of the parents also makes clear that it is a mistake to assume that every disabled person would have more interaction with nondisabled persons through the waiver program than at Conway Human Development Center.

Alan Fortney, speaking of his stepdaughter who resides at Conway Human Development Center, testified:

She likes a lot of people interaction . . . a lot of people say community programs, living on your own and all this kind of stuff is the way to go. It would drive her nuts to live either by herself or [with only] one or two people. She likes a lot of people and a lot of interaction. While we were on this waiver program list, we even considered HUD housing and we came to the realization . . . that would drive her nuts. She would not be able to handle that.

Tr. 1501-02 (A. Fortney). It is apparent that the Fortneys have carefully considered the needs of their daughter and have concluded that Conway Human Development Center is the most appropriate place for her. They have also concluded, based on their daughter's individual characteristics, that placement with a waiver provider would not provide their daughter a greater degree of interaction with nondisabled peers.

Another parent, Melissa Catron, testified that her son lived at home and attended public school or a community school until he was fifteen, but "[h]e never was integrated into a regular classroom, except for . . . assemblies or things like that. He didn't tolerate being around normal

children.” Tr. 3263 (M. Catron). As he got older, his behavior problems got worse. Tr. 3263-64 (M. Catron). His violent outbursts eventually reached the point that the Catrons could no longer keep him at home. Tr. 3268-69 (M. Catron). After several years in the waiver program, the Catrons placed their son at Conway Human Development Center, and they have found that he does better with other disabled children than with nondisabled children.³² Tr. 3264-65, 3268-69 (M. Catron). Catron also testified that Conway Human Development Center is the appropriate placement for her son, rather than placement with a waiver provider, in part because

he doesn’t travel well. The fact that all of his classrooms are right there close to where he is, his doctors are right there where he is, the dentist, everything he needs is right there, he handles that transition much better that way than he would in the community. From experience, I just really don’t think that that would be . . . the best option for him.

Tr. 3270 (M. Catron). Thus, the Catrons have determined based on their knowledge of their child that Conway Human Development Center is the appropriate placement for him rather than sending him back to a waiver provider.

Earline Stoddard made the point concisely when asked on cross-examination whether she had found some providers in the community that were not good: “Not where I’d want my son to be. Might be all right for someone else’s child, but not for mine.” Tr. 3255 (E. Stoddard).

As Angela Green of Conway Human Development Center testified, “[E]ach person is [an] individual. They have individual needs, they have their own preferences.” Tr. 6764 (A. Green). Any decision regarding the least restrictive placement appropriate for a developmentally disabled

³² Catron’s experience is not unique. As Price testified, many of the residents of Conway Human Development Center previously received services through a waiver provider but were referred to Conway Human Development Center as a more appropriate placement. Tr. 1714-15 (C. Price); *see also* Tr. 5607-08 (B. Gale).

person must be based on that person's individual needs and individual preferences, as demonstrated by the testimony of the parents, Angela Green, and others.

No evidence was presented that Conway Human Development Center has refused to discharge a resident upon request by the parent or guardian or refused to assist in a placement with a provider of waiver services. If a parent or guardian of a resident of the Center requests placement with a provider of waiver services, staff will attempt to find one. Tr. 618 (A. Richardson). Residents who seek discharge from the Center are discharged without significant delay. Tr. 4049 (T. Kastner). From June of 2007 to July of 2009, eighteen residents were discharged. Seven of those residents were discharged to another human development center. Six were discharged to the care of organizations that provide waiver services. Five were discharged to their homes. Pl.'s Ex. 271. In the two years before trial, eight persons were discharged to waiver services. Tr. 6789-91 (A. Green). Conway Human Development Center does not have a waiting list of residents seeking discharge. Tr. 4049, 4331 (T. Kastner).

That residents of Conway Human Development Center could be served by organizations that provide waiver services does not establish that the residents would have a greater degree of interaction with nondisabled persons if they received services from a waiver provider, nor does it establish that services offered by the waiver provider are the appropriate services for any specific resident. The plaintiff offered no evidence that any specific placement with a provider of waiver services was the appropriate placement for any specific resident of Conway Human Development Center, nor did the plaintiff offer any evidence that any specific resident would have a greater degree of interaction with nondisabled persons if that resident were placed in a particular program of a waiver services provider. The plaintiff failed to prove that Conway Human Development Center is

not the least restrictive, most integrated setting appropriate to the needs of any specific resident.

2. Allegations that Conway Human Development Center Fails to Give Adequate Information to Parents and Guardians Regarding Waiver Services

The plaintiff alleges that Conway Human Development Center does not provide parents and guardians with adequate information regarding waiver services, but the evidence proves that it does.

Before each annual interdisciplinary team meeting, Conway Human Development Center sends to the parent or guardian a brochure explaining services available through Arkansas's waiver program, a list of the providers of waiver services in the State of Arkansas, and a list of waiver providers in the county where the resident's family lives. Tr. 501-02, 4898-99 (S. Murphy); Tr. 3244 (E. Stoddard); Tr. 6776 (A. Green). The per county information describes the services provided by each provider and includes the locations of those services as well as contact information for those services. Tr. 4899 (S. Murphy); Tr. 6776-77 (A. Green). Conway Human Development Center also sends each parent or guardian a choice of services form on which the parent or guardian can choose whether to receive services through the waiver program or from the Center. Tr. 847, 6777-78 (A. Green); Pl.'s Ex. 294; Defs.' Ex. 406.

At the resident's annual interdisciplinary team meeting, staff of the Center discuss whether the Center is the least restrictive, most integrated placement appropriate for serving the needs of the resident. Tr. 6728-29 (B. Brewer). As a part of that discussion, staff members ask the parent or guardian if he or she has received the brochure describing the waiver program and the list of waiver providers. Staff members also ask the parent or guardian if he or she is interested in pursuing waiver services. Tr. 502, 4899 (S. Murphy); Tr. 1476 (B. Brewer). Members of the staff at Conway Human Development Center provide a parent or guardian information to see whether the parent or guardian

is interested in waiver services. Tr. 3244 (E. Stoddard).

Members of the staff at Conway Human Development Center take steps beyond the annual interdisciplinary team meeting to ensure that parents and guardians are informed. Whenever the Center becomes aware that a waiver provider has an opening in a location near the family of one of its residents, the Center notifies the family of that opening. Tr. 529, 556 (A. Richardson); Tr. 840 (A. Green); Pl.'s Ex. 264. In the spring of 2010, the Center invited all of the waiver providers in the State of Arkansas to the campus during a meeting of Friends and Families of Care Facilities Residents, the statewide parent organization, so that the waiver providers could make information about their services available to parents and guardians. Tr. 841, 6777 (A. Green); Tr. 923 (P. Bland); Tr. 1338 (C. Alberding); Tr. 5065-66 (L. Taylor).

Parents and guardians also learn about alternative services through the two parent association groups and through social workers in their counties. Tr. 853 (A. Green). Many of the parents and guardians have looked into alternative services before or during placement at Conway Human Development Center. Tr. 853 (A. Green); Tr. 3239, 3243, 3245 (E. Stoddard). They are well-informed as to the availability of waiver service. Tr. 4050-51 (T. Kastner). Parents and guardians of residents of Conway Human Development Center make informed decisions as to whether residents should be treated at the Center or discharged to an alternative placement. Tr. 853 (A. Green); Tr. 4008 (T. Kastner).

Conway Human Development Center does not prevent any resident from moving to an alternative placement. The Center adequately informs parents and guardians of the nature and scope of the home and community based waiver program in Arkansas, and it provides the parents and guardians with a comprehensive list of waiver providers, including contact information. The greater

weight of the evidence establishes that Conway Human Development Center provides adequate information to parents and guardians to enable them to make informed decisions regarding placement.

3. Allegations that the Staff Members at Conway Human Development Center Fail to Exercise Professional Judgment in Determinations as to the Least Restrictive Placement Alternative

Finally, the greater weight of the evidence establishes that staff members at Conway Human Development Center make professional judgments in determining the least restrictive placement appropriate for each resident. The members of the interdisciplinary teams, including the parents and guardians, typically agree that Conway Human Development Center is the least restrictive placement alternative appropriate for serving the needs of the residents. Tr. 482, 497 (S. Murphy); Tr. 837 (A. Green); Tr. 1464 (L. Brewer); Tr. 6729-30 (B. Brewer). Although the professionals often do not recommend placement with a waiver provider unless requested to do so by the parents or guardians, Tr. 402 (J. Weaver); Tr. 547 (A. Richardson); Tr. 836-37 (A. Green), they frequently encourage guardians to consider placement with waiver providers, Tr. 6785 (A. Green), and they have recommended placement with a waiver provider without a prior request from a parent or guardian, Tr. 4896-97 (S. Murphy); Tr. 6729 (B. Brewer). On at least two occasions, professionals at the Center have recommended community placement when the parent or guardian disagreed. Tr. 855 (A. Green). The professionals exercise professional judgment in determining whether Conway Human Development Center is the least restrictive, most integrated placement alternative appropriate to serve its residents' needs. Tr. 4007-08, 4041, 4086-88, 4329, 4403 (T. Kastner); Tr. 5999-6001 (K. Walsh).

D. ALLEGATIONS THAT CONWAY HUMAN DEVELOPMENT CENTER VIOLATES THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

The plaintiff's third claim for relief is for alleged violations of the Individuals with Disabilities Education Act, which requires certain institutions to provide a free appropriate public education in the least restrictive setting appropriate to school-aged children with disabilities. At the time of trial, Conway Human Development Center had forty-eight school-aged residents and a total of fifty-three children in its special education classes.³³ Tr. 5096 (D. Nye).

The parties presented conflicting expert testimony on the issue of whether Conway Human Development Center complies with the Individuals with Disabilities Education Act. The plaintiff called as an expert witness Susan Thibadeau, Ph.D., while the defendants called Derek Nye, Ph.D., and Bruce Gale, Ph.D. All three were qualified as experts and all three testified credibly.

Dr. Thibadeau's ultimate conclusion was that Conway Human Development Center did not meet its obligation under the Individuals with Disabilities Education Act to provide each child with a free appropriate public education. Tr. 2176 (S. Thibadeau). She testified that many of the children were receiving only ninety minutes per day of special education services, or 450 minutes per week, which she believed was inadequate. Tr. 2176, 2187 (S. Thibadeau). Although the students, according to Dr. Thibadeau, nominally spent more than six hours per day in special education services, much of that time was actually spent in habilitation classes that were neither taught nor supervised by special education teachers. Tr. 2193, 2221-22 (S. Thibadeau). Furthermore, Dr. Thibadeau did not believe that the special education teachers at Conway Human Development Center received adequate supervision or sufficient ongoing training. Tr. 2182-83, 2336-40

³³ Five of the children were at Conway Human Development Center on respite, or short-term, status and were not actually residents of the Center. Tr. 5096 (D. Nye).

(S. Thibadeau).

Dr. Thibadeau also testified that Conway Human Development Center did not educate children in the least restrictive environment, as required by the Individuals with Disabilities Education Act. She testified that several of the children had mild cognitive disabilities and came to Conway Human Development Center because of behavioral problems, but with the improvement of the behavioral problems at the Center, she believed that those children could transition to a less restrictive environment. Tr. 2181, 2304-13 (S. Thibadeau).

In addition, Dr. Thibadeau criticized the assessment test used at Conway Human Development Center and the quality of the individualized education plans, including the transition plans. Tr. 2177, 2818-82, 2222-40 (S. Thibadeau). As a part of her criticism of the transition plans, Dr. Thibadeau testified that there was no indication that adult service agencies participated in transition planning. Tr. 2299 (S. Thibadeau). Dr. Thibadeau also “had concerns” about the “integration of different therapies,” saying that the psychological examiners did not spend enough time in the classrooms. Tr. 2180 (S. Thibadeau). She also “had some concerns” about the students’ “quality of life,” referring specifically to the fact that nineteen of the forty-five children whose records she reviewed were not toilet trained and several were eating chopped or pureed food instead of being taught to eat more slowly. Tr. 2180-81 (S. Thibadeau).

Needless to say, the experts for the defendants disagreed with Dr. Thibadeau’s conclusions. Their ultimate conclusion was that Conway Human Development Center complied with the Individuals with Disabilities Education Act and specifically that it provided a free appropriate public education. Tr. 5097 (D. Nye); Tr. 5585, 5659, 5690 (B. Gale). Contrary to Dr. Thibadeau, they testified that the amount of time spent in special education classes each day was adequate to comply

with the requirements of the Individuals with Disabilities Education Act. Tr. 5100-01, 5152-53 (D. Nye); Tr. 5551-53 (B. Gale). They disagreed that the assessment tool used by the Center was inappropriate. Tr. 5156-57 (D. Nye); Tr. 5587 (B. Gale). Dr. Nye testified that Conway Human Development Center is the least restrictive environment for the children there.³⁴ Tr. 5155 (D. Nye).

The Arkansas Department of Education is charged with monitoring schools in Arkansas and enforcing compliance with the Individuals with Disabilities Education Act. In January of 2010—after Dr. Thibadeau had completed her report—the Arkansas Department of Education officially investigated Conway Human Development Center for compliance with that Act. The Arkansas Department of Education issued its official report on June 16, 2010, in the form of a letter to Calvin Price, Superintendent of the Center. Tr. 2988 (M. Harding); Pl.’s Ex. 1104. The report found that Conway Human Development Center was in substantial compliance with the least restrictive environment requirements of the Individuals with Disabilities Education Act, as well as some of the other significant requirements of the Act, but that there were fifteen areas of noncompliance. Pl.’s Ex. 1104.

Several of the areas of noncompliance involved procedural or technical requirements that readily can be remedied. Tr. 5167 (D. Nye). For example, Conway Human Development Center was found not to be in compliance with the requirement that evaluation procedures be completed and a written report submitted to the Arkansas Department of Education within sixty days from receiving formal consent from a parent or guardian. Pl.’s Ex. 1104 at 1; Tr. 2995 (M. Harding). Another area of noncompliance related to the fact that in its evaluations the Center used categories applicable to the Medicaid program rather than categories applicable to the Individuals with Disabilities Education

³⁴ Dr. Gale was not called as an expert on the least restrictive environment issue.

Act. An example of this type of noncompliance given at trial was that the Center would classify a child as having cerebral palsy, whereas the proper category for special education purposes would be "health impaired" or "multiply disabled." Tr. 2996 (M. Harding).

Not all of the criticisms by the Arkansas Department of Education are merely technical. First, the Arkansas Department of Education found that the individualized education plans at Conway Human Development Center did not sufficiently take into account special factors that impede a child's learning, such as maladaptive behaviors, lack of English proficiency, impaired vision or hearing, and the like; did not adequately address the unique needs of each child; and did not adequately plan for children's transition after secondary school. Pl.'s Ex. 1104 at 2; Tr. 3000-05 (M. Harding). In regard to transition planning, it appeared that representatives of other agencies were not invited to meetings to discuss post-secondary goals and transition services. Tr. 2990-92 (M. Harding); Pl.'s Ex. 1104. Second, the Arkansas Department of Education found that Conway Human Development Center failed to provide a free appropriate public education because it failed to meet the required ratio of teachers to pupils. Tr. 3009-10 (M. Harding). For students whose primary program is special education, the teacher to pupil ratio should be one to fifteen, one to ten, or one to six, depending on how much time, attention, and related services each child needs. Tr. 3010 (M. Harding). Although the record is not as explicit on this point as the Court would like, it appears that for most of the children at Conway Human Development Center the requirement is no more than six pupils to every one teacher; the Center had more than six pupils per teacher. Third, the Arkansas Department of Education found that Conway Human Development Center was not providing a free appropriate public education because children did not spend sufficient time in school receiving special education services. The Arkansas Department of Education seemed to agree

with Dr. Thibadeau that many of the children at Conway Human Development Center were receiving only ninety minutes per day of special education. Tr. 3012-14 (M. Harding); Pl.'s Ex. 1210. Fourth, the Arkansas Department of Education found that Conway Human Development Center failed to provide a free appropriate public education because it failed to adopt "promising educational practices proven effective through research and demonstration for the provision of special education instruction." Tr. 3015 (M. Harding); Pl.'s Ex. 1104 at 15. As explained at trial, this finding means that teachers at Conway Human Development Center were not acquainted with some of the more current types of strategies, interventions, and programs that can be effective with children like those served at the Center, and no system was in place to keep teachers current. Tr. 3017 (M. Harding).

In short, the Arkansas Department of Education found that Conway Human Development Center did not adequately plan special education for each child, did not provide the children with adequate time in special education classes, did not provide an adequate number of teachers, and did not provide for continuing education adequate to enable the teachers to do their job well.

As noted above, the monitoring by the Arkansas Department of Education was conducted after Dr. Thibadeau had submitted her report, and the persons who conducted the monitoring reviewed Dr. Thibadeau's report. Tr. 3033 (M. Harding). It is apparent that the monitors from the Arkansas Department of Education examined the program at Conway Human Development Center with a view toward determining whether the criticisms made by Dr. Thibadeau were accurate or not, and they did so using a process that was systematic and impartial. Tr. 3026-33 (M. Harding). They confirmed many but not all of Dr. Thibadeau's criticisms. After considering all of the evidence, the Court is persuaded that the findings of the Arkansas Department of Education are true. The finding that Conway Human Development Center educates children in the least restrictive environment is

supported not only by the testimony of Dr. Nye but also by the determination of each child's individual education plan team—a team that consists of the persons who are best situated to make that decision regarding that child. The findings that Conway Human Development Center has failed to provide adequate plans and has failed to include other agencies in transition planning is supported by the testimony of Dr. Thibadeau. The finding that children spend too little time in special education classes is supported by the testimony of Dr. Thibadeau. The finding that teachers are not given appropriate continuing education is supported by the testimony of Dr. Thibadeau. Finally, as to the finding that the teacher to pupil ratio was inadequate, it is within the province of the Arkansas Department of Education to set a standard for the teacher to pupil ratio inasmuch as one element of the definition of “free appropriate public education” is compliance with standards of the state educational agency. 20 U.S.C. § 1401(9). The greater weight of the evidence supports the findings of the Arkansas Department of Education, as described above, so those findings are adopted as the findings of this Court.

In response to the letter of noncompliance, Conway Human Development Center was required to submit a corrective action plan. The process of submitting the corrective action plan had begun before trial, Tr. 3037 (M. Harding), but was continuing at the time of trial. Tr. 6503 (J. Buck); Tr. 6881 (C. Price); Defs.’ Ex. JB-2. At the time of trial, the Center had added special education instruction times and developed new pupil schedules. Tr. 2117-18 (S. Milum); Tr. 3047 (M. Harding). Additional special education teachers had been hired. Tr. 3047 (M. Harding). Conway Human Development Center was in the process of hiring additional staff. Defs.’ Ex. JB-2 at 4. The Center was also changing its professional development policies to bring them into compliance. Defs.’ Ex. JB-2 at 4.

When the trial concluded and the record closed, the Arkansas Department of Education had not yet determined whether the corrective action taken by Conway Human Development Center would be sufficient to bring the Center's special education program into compliance with the Individuals with Disabilities Education Act. The process was ongoing and was not scheduled to be completed until sometime after trial. Nonetheless, the evidence was sufficient to show that the Arkansas Department of Education will ensure that the appropriate corrective action is taken to bring the Center's special education program into compliance with the Individuals with Disabilities Education Act. Although the monitors from the Arkansas Department of Education did not review the file of every child at Conway Human Development Center, in the corrective action process, the Center will be required to review the programs for all similarly situated children and correct them. Tr. 3051 (M. Harding). As Marcia Harding testified, "[W]e set out corrective actions, and we go in and assure that it gets corrected." Tr. 3034 (M. Harding). The Court believes her.

II. CONCLUSIONS OF LAW

A. CONCLUSIONS OF LAW REGARDING THE PLAINTIFF'S STANDING

The Civil Rights of Institutionalized Persons Act authorizes the Attorney General to institute a civil action in the name of the United States to obtain "such equitable relief as may be appropriate to insure the minimum corrective measures necessary" to guarantee that institutionalized persons are not deprived of rights, privileges, or immunities secured by the Constitution or the laws of the United States. 42 U.S.C. § 1997a(a) (2006). Conway Human Development Center is an institution as defined in the Civil Rights of Institutionalized Persons Act. 42 U.S.C. § 1997. The United States has standing to bring this action.

B. CONCLUSIONS OF LAW REGARDING THE PLAINTIFF'S FOURTEENTH AMENDMENT CLAIMS

The Supreme Court has held that when a mentally retarded person is involuntarily committed to a state institution, the state has certain obligations under the Fourteenth Amendment. *Youngberg v. Romeo*, 457 U.S. 307, 102 S. Ct. 2452, 73 L. Ed. 2d 28 (1982).³⁵ According to *Youngberg*, a mentally retarded person involuntarily committed to a state institution has the right to minimally adequate or reasonable training to ensure safety and freedom from undue restraint. *Id.* at 319, 102 S. Ct. at 2460. The Court recognized:

Yet these interests [in safety and freedom from restraint] are not absolute; indeed, to some extent they are in conflict. In operating an institution such as [the one at issue in *Youngberg*], there are occasions in which it is necessary for the State to restrain the movement of residents – for example, to protect them as well as others from violence. Similar restraints may also be appropriate in a training program. And an institution cannot protect its residents from all danger of violence if it is to permit them to have any freedom of movement. The question then is not simply whether a liberty interest has been infringed but whether the extent or nature of the restraint or lack of absolute safety is such as to violate due process.

Id. at 319-20, 102 S. Ct. at 2460. Determining whether the rights of a mentally retarded person in a state institution have been violated requires “that the courts make certain that professional judgment in fact was exercised. It is not appropriate for the courts to specify which of several professionally acceptable choices should have been made.” *Id.* at 321, 102 S. Ct. at 2461. A mentally retarded person in a state institution is entitled to “minimally adequate training,” defined as “such training as may be reasonable in light of [the individual’s] liberty interests in safety and

³⁵ The parties agree that *Youngberg* applies in this case, so the Court need not and will not address the issue of whether *Youngberg* is inapplicable because some or all of the residents of Conway Human Development Center are there voluntarily. *Cf. DeShaney v. Winnebago Cnty. Dep’t of Soc. Servs.*, 489 U.S. 189, 109 S. Ct. 998, 103 L. Ed. 2d 249 (1989); *Dorothy J. v. Little Rock Sch. Dist.*, 7 F.3d 729 (8th Cir. 1993).

freedom from unreasonable restraints.” *Id.* at 322, 102 S. Ct. at 2461. Courts “must show deference to the judgment exercised by a qualified professional.” *Id.* The decision by a professional “is presumptively valid; liability may be imposed only when the decision by the professional is such a substantial departure from accepted professional judgment, practice, or standards as to demonstrate that the person responsible actually did not base the decision on such a judgment.” *Id.* at 323, 102 S. Ct. at 2462.

Applying the *Youngberg* standards to this case, the Court concludes that Conway Human Development Center does not violate the mandates of the Fourteenth Amendment. Conway Human Development Center provides minimally adequate training and protects the safety and freedom of its residents in a manner consistent with the standards of *Youngberg*. The professionals at Conway Human Development Center exercise professional judgment. Even if the professional judgment of some or all of the plaintiff’s experts were better than the professional judgment of some or all of the professionals at Conway Human Development Center, the evidence does not prove that decisions of the latter represent such a substantial departure from accepted professional judgment, practice, or standards as to demonstrate that professional judgment was not actually exercised. Conway Human Development Center is in compliance with the Fourteenth Amendment to the Constitution of the United States.

C. **CONCLUSIONS OF LAW REGARDING THE AMERICANS WITH DISABILITIES ACT**

The Americans with Disabilities Act provides, in pertinent part:

Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subject to discrimination by any such entity.

42 U.S.C. § 12132. This prohibition on discrimination

may require placement of persons with developmental disabilities in community settings rather than in institutions when . . . the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account resources available to the State and the needs of others with mental disabilities.

Olmstead v. Zimring, 527 U.S. 581, 587, 119 S. Ct. 2176, 2181, 144 L. Ed. 2d 540 (1999). A public entity must administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. *Id.* at 591-92, 119 S. Ct. at 2183; 28 C.F.R. § 35.130(d) (2010). The most integrated setting appropriate to the needs of a qualified individual with a disability is a setting that enables the individual with a disability to interact with nondisabled persons to the fullest extent possible. *Olmstead*, 527 U.S. at 592, 119 S. Ct. at 2183; 28 C.F.R. pt. 35, app. B (Mar. 15, 2011). The Americans with Disabilities Act prohibits discrimination against qualified individuals, i.e., persons with disabilities who “with or without reasonable modifications to rules, policies, or practices, . . . mee[t] the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.” *Olmstead*, 527 U.S. at 602, 119 S. Ct. at 2188 (quoting 42 U.S.C. § 12131(2)). A state generally may rely on the reasonable assessments of its own professionals in determining whether an individual meets the essential eligibility requirements for habilitation in a community based program. *Id.* There is no requirement that community based treatment be imposed on persons who do not desire it. *Olmstead*, 527 U.S. at 602, 119 S. Ct. at 2188; 28 C.F.R. § 35.130(e)(1).

The plaintiff failed to prove that Conway Human Development Center is in violation of the Americans with Disabilities Act. The plaintiff failed to prove that Conway Human Development Center is not the most integrated setting appropriate to the needs of any specific resident. The

plaintiff failed to prove that any alternative placement would enable any specific resident of Conway Human Development Center to interact with nondisabled persons to a greater extent. The professionals at Conway Human Development Center exercise reasonable professional judgment in making recommendations for placement of the residents there. No person determined by the State's treatment professionals to be appropriate for community placement has been denied community placement. The parents and guardians of the residents at Conway Human Development Center make informed judgments regarding placement. No resident of Conway Human Development Center has been denied community placement when a parent or guardian has requested such a placement.

Conway Human Development Center is not discriminating against persons with disabilities. It is not violating the Americans with Disabilities Act.

D. CONCLUSIONS OF LAW REGARDING THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

The special education program at Conway Human Development Center is subject to the requirements of the Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400 *et seq.* The children at Conway Human Development Center are children with disabilities as defined in 20 U.S.C. § 1401(3). Conway Human Development Center is required to provide each child with a free appropriate public education. 20 U.S.C. § 1412(a)(1) (2006).

The term "free appropriate public education" means special education and related services that --

- (A) have been provided at public expense, under public supervision and direction, and without charge;
- (B) meet the standards of the State educational agency;
- (C) include an appropriate preschool, elementary school, or secondary school education in the State involved; and
- (D) are provided in conformity with the individualized education program required under section 1414(d) of this title.

20 U.S.C. § 1401(9). Conway Human Development Center also has an obligation to educate the

children in the least restrictive environment. Congress has defined that obligation as follows:

To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

20 U.S.C. § 1412(a)(5)(A). To the extent appropriate, with consent of the parents, Conway Human Development Center must invite the agency that likely will be responsible for providing transition services to the individual education plan meeting when a purpose of the meeting will be to consider post-secondary goals and transition services. 34 C.F.R. § 300.321(b)(3) (2007).

Conway Human Development Center educates children in the least restrictive environment, but it has failed to provide children with a free appropriate public education, and it has failed to invite agencies that provide transition services to the meetings at which post-secondary goals and transition services are discussed.

Having concluded that Conway Human Development Center has failed to comply fully with the Individuals with Disabilities Education Act, the issue is whether to enter an injunction. An injunction is an equitable remedy that does not issue as a matter of course. *Weinberger v. Romero-Barcelo*, 456 U.S. 305, 311, 102 S. Ct. 1798, 1803, 72 L. Ed. 2d 91 (1982); *see also Salazar v. Buono*, __ U.S. __, 130 S. Ct. 1803, 1816, 176 L. Ed. 2d 634 (2010). An injunction should issue only when legal remedies are inadequate and irreparable injury will occur without the injunction. *Romero-Barcelo*, 456 U.S. at 312, 102 S. Ct. at 1803. A court should be especially cautious when contemplating relief that implicates public interests. *Salazar v. Buono*, 130 S. Ct. at 1816. In determining whether to exercise the Court's equitable discretion to enter an injunction in a case such as this one, where Congress has provided a regulatory scheme, the Court should consider the

regulatory scheme at issue and the enforcement mechanisms provided therein.

[C]ourt and agency are not to be regarded as wholly independent and unrelated instrumentalities of justice, each acting in the performance of its prescribed statutory duty without regard to the appropriate function of the other in securing the plainly indicated objects of the statute. Court and agency are the means adopted to attain the prescribed end, and so far as their duties are defined by the words of the statute, those words should be construed so as to attain that end through co-ordinated action. Neither body should repeat in this day the mistake made by the courts of law when equity was struggling for recognition as an ameliorating system of justice; neither can rightly be regarded by the other as an alien intruder, to be tolerated if it must be, but never to be encouraged or aided by the other in the attainment of the common aim.

Hecht Co. v. Bowles, 321 U.S. 321, 330-31, 64 S. Ct. 587, 592, 88 L. Ed. 754 (1944) (quoting *United States v. Morgan*, 307 U.S. 183, 191, 59 S. Ct. 795, 799, 83 L. Ed. 1211 (1939)).

The Individuals with Disabilities Education Act imposes a duty for monitoring and supervising compliance with the Individuals with Disabilities Education Act on a state educational agency to be selected by the state:

(11) State educational agency responsible for general supervision

(A) In general

The State educational agency is responsible for ensuring that—

- (i) the requirements of this subchapter are met;
- (ii) all educational programs for children with disabilities in the State, including all such programs administered by any other State agency or local agency --
 - (I) are under the general supervision of individuals in the State who are responsible for educational programs for children with disabilities; and
 - (II) meet the educational standards of the State educational agency[.]

20 U.S.C. § 1412(a)(11)(A).

As section 1412(a)(11)(A) makes clear, the state agency's responsibility to supervise special education programs includes not only a duty to monitor but also to enforce. Section 1416(a)(1)(C) provides that the Secretary of Education must "require States to-- (i) monitor implementation of this

subchapter by local educational agencies; and (ii) enforce this subchapter in accordance with paragraph (3) and subsection (e).” Paragraph (3) provides:

(3) Monitoring priorities

The Secretary shall monitor the States, and shall require each State to monitor the local educational agencies located in the State (except the State exercise of general supervisory responsibility), using quantifiable indicators in each of the following priority areas, and using such qualitative indicators as are needed to adequately measure performance in the following priority areas:

(A) Provision of a free appropriate public education in the least restrictive environment.

(B) State exercise of general supervisory authority, including child find, effective monitoring, the use of resolution sessions, mediation, voluntary binding arbitration, and a system of transition services as defined in sections 1401(34) and 1437(a)(9) of this title.

(C) Disproportionate representation of racial and ethnic groups in special education and related services, to the extent the representation is the result of inappropriate identification.

In Arkansas, the state educational agency responsible for monitoring and ensuring compliance with the Individuals with Disabilities Education Act is the Arkansas Department of Education.

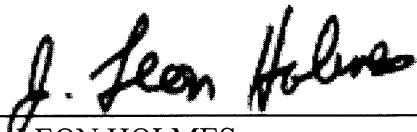
As stated above, the Arkansas Department of Education has required Conway Human Development Center to submit a corrective action plan for bringing its special education program into compliance with the Individuals with Disabilities Education Act. The Arkansas Department of Education will evaluate and determine whether the corrective action plan is appropriate and will ensure that the special education program at Conway Human Development Center complies with the Individuals with Disabilities Education Act. Therefore, it is not necessary for this Court to enter an injunction in order to secure the rights guaranteed by the Individuals with Disabilities Education Act to students at Conway Human Development Center.

CONCLUSION

The Court finds and concludes that Conway Human Development Center complies with all of the requirements of the Fourteenth Amendment and the Americans with Disabilities Act but not all of the requirements of the Individuals with Disabilities Education Act. Because Congress has provided for a state educational agency to enforce compliance with that Act, and because the evidence established that the state educational agency here is enforcing and will enforce compliance, no injunction is necessary or appropriate.

A judgment dismissing this action with prejudice will be entered separately.

IT IS SO ORDERED this 8th day of June, 2011.



J. LEON HOLMES
UNITED STATES DISTRICT JUDGE



Achieve with us.

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**Testimony before the Legislative Panel on
State Psychiatric Hospitals and Developmental Centers
October 17, 2011
Thomas Baffuto, Executive Director**

Good Morning. My name is Thomas Baffuto and I am the Executive Director of The Arc of New Jersey. The Arc of New Jersey is the largest statewide advocacy organization for individuals with intellectual and other developmental disabilities. Thank you for the invitation to speak with you today about the very important issue of developmental center closure in New Jersey. The Arc of New Jersey believes that all individuals with intellectual and developmental disabilities have the right to live, and be fully included, in communities of their choosing. For over thirty years there has been a clear direction in federal and state policy toward community living for individuals with intellectual and other developmental disabilities. However, while the majority of states are actively discussing “when” and “how” to close developmental centers and promote an individual’s right to live in the least restrictive environment, New Jersey continues to debate “if” developmental centers should close at all. In the meantime, we continue to institutionalize more people with intellectual and developmental disabilities than every other state besides Texas. Eleven other states have eliminated their institutions altogether, while another eleven states have only one institution and 27 states plan to close and/or downsize their existing state institutions.

Developmental Centers were created in the 1800s to “treat” individuals with intellectual and other developmental disabilities at a time when there were no services available to them. At that time, they were considered state of the art facilities and there were no other options for families through the 1950s. Much has changed over the past fifty years and now we have a wide range of supports and services available to individuals with intellectual and other developmental disabilities. Current best practice is community-based supports and services that allow individuals with disabilities to be connected and contributing members of their communities in the most integrated settings possible. In this day and age, it is a widely accepted belief that institutions enforce an unnatural, isolated and regimented lifestyle that is neither appropriate nor necessary. Studies show that community living increases the quality of life of individuals with intellectual and developmental disabilities. Including individuals with intellectual and developmental disabilities in our communities certainly better our society as a whole.

The Americans with Disabilities Act (ADA) of 1990 stated that “historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive problem.” Title II regulations under section 504 of the Rehabilitation Act require public entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities” and define “most integrated setting” as one that “enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.” In the 1999 *Olmstead* case, the Supreme Court stated that “confinement to an institution severely diminishes everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and

cultural enrichment.” Currently, the U.S. Department of Justice is stepping up their enforcement efforts and New Jersey must begin taking the civil rights of people with intellectual and other developmental disabilities seriously. Civil rights are a sacred benefit afforded all citizens of the United States, including people with disabilities!

While New Jersey has made some efforts to change the way supports and services are provided to individuals with intellectual and developmental disabilities, there has not yet been a true philosophical or fiscal commitment to eliminating state-operated institutions. Individuals on the state’s waiting list for services do not want to live in institutions. Most people and their families are choosing community-based supports and services, leaving our state institutions well below capacity. While the census of our seven institutions declines, per diem costs rise dramatically. As we continue to reduce our institutional census, we must consolidate our institutions. We simply do not need seven large institutions anymore.

The Arc of New Jersey believes that the time for this change is long overdue, and that we need to move beyond a discussion of “if” and on to the discussion of “how.” The issue isn’t, “can we do it?” We know that we can; we have done it before and are doing it now. To that end, we recommend that the state consider the following as you begin closing our institutions.

1. **A long-term plan to close two centers over the course of four years, followed by one center closure every three years until five have been closed.** This is in line with national timeframes for developmental center closures when the number of residents is taken into account. This will mean closing five institutions over the next 12-15 years, leaving two open for those individuals who want to continue to live in an institution. The two remaining developmental centers should be identified at the outset so that all individuals who want to continue to live in an institution will only have to move once as we begin closing the other five centers. Leaving two developmental centers open will ensure that individuals who have lived in an institutional setting for many years and prefer to remain there, can choose to do so.
2. **A planned order of developmental center closure based, at least in part, on the age and condition of the structure.** In determining which developmental centers to close, the necessity for capital improvements, cost of maintenance, needed repairs and any other foreseeable building or grounds maintenance and repair costs should be considered. Developmental centers with greater repair needs should be considered for closure first to avoid sinking additional money into institutional infrastructure.
3. **The creation of a bridge fund** to cover dual costs that exist prior to actual closure. Additional funding is needed to maintain an institution while at the same time serving individuals from that institution in the community as the institutional population is reduced prior to closure. Advocates believe that dual costs will be approximately \$15 million per year per institution leading up to closure. Once the first two institutions are closed, assuming the savings are reinvested, there should be sufficient funds available to cover the dual costs of the remaining institutional closures.
4. **An individual plan for each developmental center closure.** Every developmental center is different. Therefore, there needs to be an individualized plan of closure for each developmental center. These individualized plans need to take into consideration the residents and their needs, the staff, the services provided by the developmental center, the community where the developmental center is located, the community capacity to serve individuals from the developmental center and the physical structure.

5. **A system for evaluating each closure.** Each developmental center closure should be evaluated systematically and longitudinally as was done with North Princeton Developmental Center. The evaluation of developmental center closures should include the perspectives of residents, families, impacted staff, and the local community. Evaluation should begin at the time closure is announced and continue for at least two years after the last resident has moved. Evaluation and assessment information should be utilized to modify the plan or implementation of other developmental center closures, as appropriate, based on this data.
6. **Well-planned and targeted placements for individuals currently living in institutions.** There must be at least 250 community placements from developmental centers each year. All people eligible for community placement who live in the developmental center closing next should be moved to the community first. If there are not 250 individuals remaining in the developmental center targeted for closure who are eligible for community placement, individuals from one of the two developmental centers that will remain open at the end of the 12-15 year period who are eligible for community placement should be served next. Those not currently eligible for community placement should be transferred to one of the two developmental centers slated to remain open after the 12-15 year closure period. The amount of disruption to individuals' lives should be minimized to the extent possible and no individual should have to move more than once.
7. **A clear individualized plan for each individual who will be moving.** Every person who moves, regardless of where they are moving, has an individualized plan outlining what services they need and how their transition will be supported. Individuals transitioning to the community are assigned a case manager, as required by the Community Care Waiver, to oversee the transition process and ensure that the individual has a plan and is receiving the services and supports they need. If the individual chooses, current developmental center staff serving that individual may be part of the transition plan and process, and should continue to be a regular part of the individual's life for a period of time after they move into the community. As much as it is practicable, resident groups, friends, and staff are kept intact when an individual moves. It is important for the panel to note that the developmental disabilities service system does not use boarding homes for people moving out of developmental centers. Group homes and supported living arrangements that house and serve individuals with developmental disabilities in the community are licensed and highly regulated by the Department of Human Services.
8. **Clear communication with and involvement of families.** This is clearly an important component to a successful transition and the family and/or guardian of the individual should be involved to the degree appropriate. In our communications with Dr. David Braddock about his experiences around institutional closure, he suggests early and frequent communication and connecting families to parents whose children have successfully transitioned from an institution to help reduce anxiety and provide support. Other ways to meaningfully involve families in the process include open houses at community programs, informational sessions at the sending facility, connecting families and parents at the receiving community agency, and having the family/guardian present during the actual move.
9. **Assist developmental center staff in the transition.** Dr. Braddock suggests some personnel guidelines when considering closure, including developing a plan for staffing patterns as individuals are relocated, determining clear personnel policies and engaging employees early in the process. He also suggests terminating one unit at a time, minimizing internal transfers and employee bumping, and adopting as many staff incentives as possible (i.e. early retirement inducements, payment of moving expenses, extended health coverage, staff retraining and a priority interviewing policy at community agencies). Additionally, the establishment of an employee counseling and job placement service, a participatory management approach, an open door policy and early and continued briefings for staff.

To the degree possible, transferring staff along with residents moving from the institution would also allow individuals with close relationships to their staff to bring them into the community and would allow staff to maintain their employment and relationships.

10. **The examination and monitoring of community infrastructure** to ensure the supports and services needed by those transitioning out of developmental centers are available and appropriate. It is critical to ensure that a full array of medical, mental health, behavioral and related services are available to those leaving institutions. We have detailed information on the support needs and preferences of those individuals living in developmental centers. The availability of community services to meet the support needs of those leaving developmental centers is imperative to successful community living for all individuals transitioning out of developmental centers. It is important for the panel to know that community providers are already serving individuals with very significant medical needs successfully in the community. However, the community infrastructure and its ability to support those individuals leaving developmental centers should be consistently monitored to make certain that the development of community supports and services keeps up with the needs of individuals moving to the community. There should be a reassessment of the community infrastructure after each closure to ensure that there is the capacity to continue moving individuals into the community and a plan to create additional capacity in areas where insufficient capacity is anticipated. It is important to note that delaying closure is an impediment to enhancing community infrastructure because as the population in our institutions decreases, the costs increase, consuming more and more of the valuable resources needed to serve people in the community.
11. **Reinvestment of all savings realized from developmental center closure into community-based services for people with intellectual and developmental disabilities.** These funds are desperately needed to expand services to individuals with intellectual and other developmental disabilities and their families. The developmental disabilities community has a wide range of unmet needs due to lack of funding. The overall lack of community-based medical, behavioral and psychiatric supports is a constant impediment to individuals with developmental disabilities in New Jersey being able to move out of large institutions and off long waiting lists. Any savings realized from developmental center closure should be used to strengthen and expand the infrastructure in place to ensure the needs of individuals with intellectual and other developmental disabilities are appropriately met and to develop capacity to serve additional individuals and support future developmental center closures as well as those already living in the community.

These are all issues that we must address regardless of institutional closure and should not be viewed as impediments. We have a great opportunity here to enhance our service system, making community-based supports and services better for everyone and preparing ourselves for future growth. This is our chance to take New Jersey from having some of the highest rates of institutionalization in the country, to becoming leaders in the quality and cost effectiveness of our services while at the same time championing the human and civil rights of individuals with intellectual and other developmental disabilities.

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Testimony of Nancy Thaler

**Executive Director
National Association of State Directors of Developmental Disabilities Services**

Legislative Panel on State Psychiatric Hospitals and Developmental Centers Oct. 17, 2011

Co-Chairs Senator Van Drew and Assemblywoman Huttle, thank you for the opportunity to appear today to discuss the successes and challenges states have experienced in providing community opportunities for individuals with developmental disabilities.

I am the Executive Director of the National Association of State Directors of Developmental Disabilities Services (NASDDDS). I began my career in 1971 working in nonprofit agencies developing community services for children and adults with developmental disabilities. Six years after joining Pennsylvania state government, I was appointed the state's Deputy Secretary for Mental Retardation where, from 1993 to 2003, I managed a system of institutional and community services for over 80,000 individuals. During my tenure as the state director there was significant expansion of community services for Pennsylvanians with disabilities who were on the waiting list for community services, including those living in institutions. During that time, over 2,000 people in institutions were provided with the opportunity for community living, reducing the institutional population by more than 55 percent. From 2003-2005, I served as the Director of Quality Improvement for the U.S. Department of Health and Human Services' Centers for Medicare and Medicaid Services (CMS), Disabled and Elderly Health Programs Group, and was responsible for developing federal oversight of state-operated Medicaid Home and Community-Based Services Waiver programs. My husband and I are adoptive parents of an adult son with developmental disabilities who spent much of his childhood in an institution and now lives and works in the community.

The National Association of State Directors of Developmental Disabilities Services provides an array of services to developmental disability (DD) agencies in the 50 states and the District of Columbia. The NASDDDS mission is to assist member state agencies in building effective, efficient person-centered systems of services and supports for people with developmental disabilities and their families. NASDDDS strives to provide member state agencies with timely analyses of federal statutory and

regulatory policies that affect people with disabilities; to disseminate information on state-of-the-art programs and service delivery practices; to supply technical assistance and support to member states; and to offer a forum for the development of state and national policy initiatives.

A National Comparison of Progress in Supporting People with Developmental Disabilities in the Community:

In 1967, the number of people with what was then called mental retardation living in large state institutions reached its high point, with 228,500 in large state intellectual/developmental disability (I/DD) institutions. Much has changed since 1967. The most recent national data indicates that there were 33,682 people in state I/DD institutions — a drop of 194,768 people (85.3%) since 1967.¹

Between 1967 and the mid-1980s, 5,000 to 10,000 people moved back into the community each year.² Many individuals who learned that they had a right to leave the institution, and had the capacity to do so without special assistance, simply left. The individuals who remained in institutions in the mid 1980s by and large could not leave to live in the community without special assistance.

In 1982, adoption of the Medicaid Home and Community-Based Services (HCBS) Waiver made that assistance available. Allowing funds that were previously reserved for institutional services to be used for community services enabled state DD departments to build systems of community services that initially supported people leaving institutions and soon expanded to those at risk of institutionalization. For the next two decades, the institutional census continued to drop annually by 4,000 to 5,000 people. By 2006, all but one state was spending more for community services than for institutional services.³

Today, 10 states and the District of Columbia have no institutions for people with developmental disabilities and Alabama will bring the number of states to 11 this fall with the closure of Partlow Center.

Sixteen states have less than 250 people still living in large state run facilities — Minnesota with less than 25, Delaware with 75 and Maryland with less than 130. A survey conducted by our association earlier this year found that 67 percent of the states with institutions have plans to downsize or close facilities in the next few years.

Most of the people in state institutions are in 10 states. With over 2700 residents, New Jersey ranks second behind Texas in the total number of people in institutions.

¹ *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009* Lakin, Larson, Salmi, & Scott

² *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009* Lakin, Larson, Salmi, & Scott

³ *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009* Lakin, Larson, Salmi, & Scott

Largest Census

Texas	4,899	New York	1,492
New Jersey	2,703	Ohio	1,423
Illinois	2,300	Mississippi	1,371
California	2,194	Pennsylvania	1,253
North Carolina	1,638	Virginia	1,184

In terms of the number of persons with ID/DD living in state residential facilities (of 15+) per 100,000 of the general population, New Jersey ranks 3rd nationally. Only Mississippi and Arkansas have a higher rate of institutionalization.

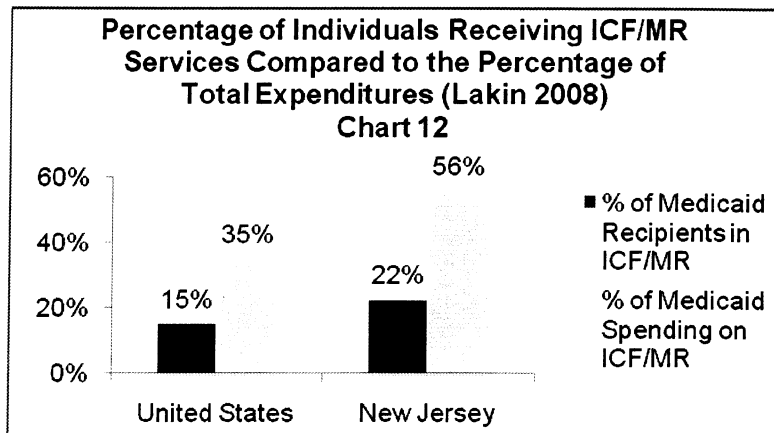
Persons with ID/DD in Large (15+) State Residential Settings per 100,000 of the General Population on June 30, 2009

- Mississippi 45.3
- Arkansas 37.5
- New Jersey 32
- Louisiana 25.9

Investments in ICF/MR and Community Services

In Support of a Sustainable Future: Responding to the Needs of People with Developmental Disabilities in New Jersey, a publication prepared for the New Jersey Council on Developmental Disabilities by the Human Services Research Institute (HSRI), the imbalance of investment in institutions as compared to community is

analyzed. The publication reports that in 2008, New Jersey furnished ICF/MR services to 22 percent of service recipients in the state but allocated 56 percent of funding to these services. Nationally, 15 percent of individuals are served in such settings and 35 percent of the budget is allocated for such services. The high per person cost of ICF/MR programs has contributed significantly to this imbalance.



Key Factors Driving the Development of Community Services

Why has there been such an overwhelming trend toward community services in most state developmental disabilities services systems? There are many reasons and there have been many drivers all coming to push this trend forward.

First and Foremost is the Parent/Advocacy Movement. Outrage at horrific conditions in public institutions in the 1960s and the lack of services for children and adults living with their families in the community fueled simultaneous efforts at: reforming public institutions; establishing a right to education; and creating services for adults living with their families. The thinking quickly evolved – reforming institutions, while important in the short run, was not the final goal. Offering everyone a life in the community became a focus of the advocacy agenda.

By the early 1970s, parents and advocates were experiencing success. Several institutional law suits had been filed resulting in improvements in the institutions as well as expanded opportunities for people to move to the community. Advocacy efforts to achieve the right to education resulted in landmark legislation first in the states, and then at the national level with the adoption of the *Education for All Handicapped Children Act* (Public Law 94-142) in 1975.

The right to education profoundly changed the experiences of children with developmental disabilities and the expectations of parents. Prior to the right to education, parents had two choices: to institutionalize their children – something routinely recommended by medical professionals – or to keep their child at home 24 hours-a-day without support or training. Many parents chose to keep their children at home rather than follow the advice of their doctor. But as their children grew, so too did the stress of being an unsupported care giver. When parents came looking for help, all that states had to offer was the institution. So with grief and often guilt, parents sought admission for their children.

The right to education changed things. When schools opened their doors, admission of children to institutions dropped significantly – and the expectations of families rose just as quickly. If children could live with their families and go to school, then why wouldn't they live their entire life in the community?

Private nonprofit agencies established in the 1970s and 80s were ready and eager to develop community services. Founded by families, faith-based organizations, and community groups, these nonprofits turned a vision into a reality for thousands of people with disabilities. Opening group homes, vocational training programs, and recreational programs, they championed the cause of people with intellectual and developmental disabilities and helped them become part of the community.

And as they did so, they built more and more evidence that community living was, in fact, better for people who were once believed to need institutions. It was better for the person – and also better for their families who could now see them more frequently

because they were providing services in the family's home or in group homes were in the family's community rather than far away in a remote part of the state.

The ADA and Olmstead Decision

The Americans with Disability Act of 1990, which underscored the civil rights of people with disabilities and created the obligation among those entities that provide services to do so in the most integrated setting was reinforced by the Supreme Court's 1999 Olmstead decision which underscored the right of people to receive services in the "most integrated setting". This statute and Supreme Court decision have been instrumental in changing society toward one that is more and more accommodating to individuals with all types of disabilities.

The Department of Justice and Protection and Advocacy agencies also played a significant role in the shift from institutions to the community. Using the Civil Rights of Institutionalized Persons Act, the Department of Justice conducted investigations and litigation to press for improvements in facilities with the most egregious rights violations. Protection and Advocacy organizations, often contacted by families of those living in institutions, conducted investigations, and initiated litigation when conditions did not improve.

The result of these interventions was increased investment in the institutions to improve conditions, along with agreements to decrease the number of people in the institutions – and in many cases agreements to simply close facilities.

Adoption of the Americans with Disabilities Act (ADA), reinforced by the **Olmstead** decision, provided additional tools for organizations to advocate for community services, and it solidified the right of people to live in the community.

Most recently the state of Georgia negotiated a settlement agreement with the U.S. Department of Justice to close all of its state facilities and provide community services for the 700 people remaining in their facilities.

Medicaid Funding and Statutes, regulations, funding, and technical assistance all play an important role in assisting states to make community opportunities available for people in institutions and on waiting lists.

New Medicaid options have enabled states to expand services. While many states already had programs providing community services to individuals with developmental disabilities, usually called "family supports," the advent in 1982 of the 1915(c) Home and Community-Based Services (HCBS) Medicaid waiver program meant the availability of federal funds to support individuals in the community – and this drove rapid expansion of such programs. Allowing states to include a diverse set of non-medical supports and services in their programs gave them the opportunity to innovate and to build systems of support around the specific needs of individuals.

Additional state plan options such as 1915(i) and 1915(k) the Community First Choice Option are additional examples of recent federal initiatives aimed at giving states more opportunities to provide services to individuals in community settings.

Money Follows the Person (MFP) has provide federal funding incentives to provide community options for people in institutions. MFP has made \$2.25 billion grants available to 43 states, including New Jersey, and the District of Columbia to support the movement of people with disabilities out of institutions and into the community.

Most recently, the announcement of the State Balancing Incentive Payment Program (BIPP) makes \$3 Billion available to states to undertake structural reforms to increase access to community services. An incentive payment of a 2% enhanced federal matching on expenditure in the community will be available to all states that currently spend less than 50% of their total funding on community services.

Recognizing the high cost of institutional care for both the elderly and disabled, the federal government, through the Federal Coordinated Health Care Office has funded 15 states to develop and test programs to coordinate care and reduce reliance on institutional services.

A new generation of families with young children who have benefited from early intervention services, public education, medical and clinical advances, and more importantly, have raised their children in a world that is more accepting of people with disabilities, a world that sees the value in diversity, a world that can recognize the gifts that each person brings. They are demanding even more change.

Families of young children not only reject institutions, they also reject community models that segregate or isolate their sons and daughters from typical life. They expect their sons and daughters to graduate from school, to get a job, to have meaningful relationships and to participate in the life of their community.

The cost of institutional services and concerns about system sustainability have also been factors in the transition from institution to community services. While the cost of providing services to each individual differs as systems respond to individual needs, in the aggregate, it is far more cost-effective to customize support that builds on each individual's strengths and the natural supports they have in their family and community, than to create a residential model that provides comprehensive services whether an individual needs them or not. In addition, investment in models of service that do not provide an environment where people grow and achieve positive outcomes is questionable public policy.

States understand that in order to assure that state service systems are affordable and sustainable into the future; they must invest in services that are both cost effective and produce the best outcomes for people.

In regard to cost, there is no refuting that the average cost per person in an institutional based system is much greater than a system that supports families and individuals in integrated community services. The chart provided in this testimony demonstrates the difference in the average cost per person in an ICF/MR at \$128,275 with an average cost of supporting an individual living with their family at \$25,072. While these absolute figures may differ from state to state, the general comparison holds up across the country. For states as New Jersey which reports a waiting list of approximately 8,000 people, the implications of the models chosen are clear.

Type of Service	Cost per Person	People Served with \$5 M
ICF/MR	\$128,275	39
Non-family HCBS	\$70,133	71
Host Family	\$44,122	113
Own Family	\$25,072	200

Source: Lakin, K.C. MSIS and NCI data from 4 states (1,240 Individuals)

The long term implications of the service models chosen become apparent when the costs for 20 years are calculated out. A system built on the most costly models of service will strain the availability of public resources for people waiting.

Type of Service	Cost per Person	20 Year Cost
ICF/MR Institution	\$128,275	\$2,565,6000
HCBS 24 hr staffed	\$70,133	\$1,402,660
Shared Living/Host Home	\$44,122	\$882m440
Supports in Own Home or Family Home	\$25,072	\$502,440

In regard to quality, study after study has proven that people, including and particularly people with the most significant disabilities gain in social skills, cognitive competencies and reduce their dependency on care givers.

Data from our national associations National Core Indicator Project (NCI) has established that those living with their families or in community settings learn more, are happier and are more connected to those they love and who care about them.

NASDDS and the Association of Universities of Excellence published the first in a series of Evidence Policy Briefs titled *The Effects of Community vs. Institutional Living on the Daily Living Skills of Person with Developmental Disabilities*. A review of 36 studies of outcomes over time for nearly 5,000 people with intellectual and developmental disabilities moving from large institutions to community living arrangements found high consistency in positive change in daily living skills for the movers. Altogether 31 studies indicated positive outcomes as compared with five showing negative outcomes. Studies specifically addressing social skill development, language and communication skills development, self-care and domestic skill development and community living skill development likewise overwhelmingly showed positive outcomes associated with leaving large institutions to live in community settings. In all 4 areas the ratio of studies finding positive effects of moving to those finding negative effects was 9 to 1 or greater.⁴

Most importantly, people with intellectual and developmental disabilities themselves have driven the change. An outgrowth of the movement of people from institutions to the community has been the growth of self-advocacy; i.e., people finding their voice and advocating for themselves. Self-advocates have survived indignities and often abuse in institutions and have demonstrated a level of courage, fortitude, and forgiveness that inspires everyone who hears their stories.

Challenges Remain

The barriers to creating community opportunities for people who remain in the institutions are the same barriers that have been with states since the 1980s.

The Availability of State Funding has been and Continues to be a Barrier. While the Medicaid Home and Community-Based Services Waiver program provides significant federal funding for services, it does so only on a matching basis – which requires states to fund up to 50 percent of the cost of services, depending on each state's matching rate. The scope of programs competing for resources within each state's budget include education, transportation, and law enforcement, coupled with a constitutional requirement to balance annual budgets that affects the growth rate of Home and Community-Based Services. The current fiscal crisis, which has meant precipitous drops in state revenue, has recently compounded the problem. States have embraced the Medicaid Waiver program because it provides them with tools to manage growth within the confines of the state's economic conditions.

Opposition from employees has been a factor in downsizing and closing of institutions. An institution may be the primary employer in a geographical area. In fact, some were established in rural areas many years ago precisely for the purpose of providing employment. Employees often enjoy robust wages and benefits that are difficult to replicate in other fields or in the private sector. While the interests of people with disabilities are primary and the core purpose of the program, the interests of

⁴ Evidence Policy Brief on *The Effects of Community vs. Institutional Living on the Daily Living Skills of Person with Developmental Disabilities*. NASDDDS, AUCD March 2011

employees who have provided services for many years must be considered. States have used a combination of strategies such as guaranteeing employment in other state operations or in-state operated community services, providing early retirement options, retraining for new careers, assisting with a transition to private sector employment through job placement and career counseling and in a number of states, state employees have become shared living or host families for people leaving institutions. Each facility closure has been accomplished by employing multiple strategies crafted uniquely for that particular facility and locale.

Opposition from families is another challenge – and the most complex one. What we know from 40 years of experience is that people do better in the community than in institutions. No matter their age, they learn new skills, develop new competencies and appear to be much happier. We know this from research which has established that all individuals make gains but those with the most significant disabilities make the most gains after moving to small community residences.⁵ But just as importantly, the thousands of provider staff, clinicians, and leaders in our field know this – because they have witnessed it.

We know that, regardless of the intensity of the opposition from families, once the person moves to the community the opposition melts and the family sees the benefits of community living. In fact, rarely has any family member requested the return of their son, daughter, sister or brother to the institution.

Opposition can be based on any number of assumptions. One is that the services in the community will be discontinued over time, leaving the family entirely responsible for providing both support and living arrangements. The fact that the Medicaid Waiver is funded with precisely the same funding sources as the institution – and that many agencies providing community service systems are now over 50 years old – can address some of those fears.

Opposition based on the assumption that their family member can't live in the community can be addressed by taking families to visit community services that support people with the same level of needs as their family member. In the past it has been said that for every person living in an institution, there is a twin in the community. Today it would not be an exaggeration to say that for every person living in an institution, there are thousands living in the community.

Opposition based on fear of abuse and neglect requires a frank discussion that acknowledges that abuse and neglect have been serious problems in institutions and can be an equally serious problem in the community. States must explain the processes they have built into community systems to prevent abuse and neglect, to detect it as soon as it occurs, to inform family members and to respond promptly.

⁵ Bradley, V.J., & Conroy, J.W. *The Pennhurst Longitudinal Study Executive Summary* Philadelphia: Temple University Developmental Disabilities Center, 1985.

The institution is often perceived as better able to provide intense and specialized services. It is important to educate families about the impact of environment and experience on learning and that, while the institution may have specialists, the environment and the routines of the institution lack the real life experiences of daily living. Activities as simple as buying weekly groceries and making meals, going to the bank or post office, taking in a movie, or greeting neighbors are the experiences through which people develop competencies and social skills. The availability of medical services may also be a concern, and can be addressed by involving families in establishing a relationship with medical professionals in the community prior to their family member leaving the facility.

The absence of oversight to assure quality is often identified as a weakness in the community system. What is often not recognized is the considerable attention the Federal Centers for Medicare and Medicaid Services has placed on quality assurance. In communicating with families, it is important to describe the protections and oversight in place, facilitate the building of a relationship between families and the leadership of the agency that will be serving their family member and assuring immediate access to an authority that can remedy any weakness or wrong they see.

Lastly, there are those who say that families should have absolute authority to make any decisions that affect their family member, and that any government participation constitutes interference with the family relationship. The central question that should be the primary focus of both family members and state professionals and the basis for any decision making is "what would benefit the person most?" And, it is this question that drives state agency professionals to continue to create community service opportunities for people living in institutions. Having assisted hundreds of people to move from institutions to the community, having witnessed their growth and development and the satisfaction that families inevitably experience, professionals are bound by professional ethics and compelled by their personal commitment to pursue community options for people living in institutions.

It would be a far easier path to simply let the issue go for the 33,000 people still living in institutions, to avoid asking families to reopen the decision they made to institutionalize their family member 30 or even 50 years ago. But knowing what is possible and what is right, professionals working in state agencies cannot do that.

While opposition can be intense, there are also many stories of family groups working hand in hand with states to close institutions and participating actively in the development of community services. The state of Wyoming is a model of what may be one of the best closure processes in the country. The path Wyoming took to respond to litigation filed against the facility was to seize the opportunity to build a robust community service system where there had been none, to serve not only the people from the Wyoming State Training School but also people who were already living in the community with their families and were at risk of institutionalization. The closure of Embreeville Center outside Philadelphia was accomplished in collaboration with families

who made the final decision in choosing the agency that would serve their family member and where they would live.

Preventing Institutionalization: The Waiting List Challenge. The Medicaid statute entitles individuals with developmental disabilities to institutional services. There is no entitlement to Home and Community-Based Services and states are restricted in their capacity to expand services. Therefore waiting lists are a reality in most state developmental disability systems. Few states have achieved enough growth that services can be made available promptly to every eligible applicant upon request. Emergencies and crises become the entry point into Home and Community-Based Services systems for many. The reliable national data on the number of people waiting for services is incomplete but we know that in many states the number is in the thousands and the wait can be as long as 10 years. In New Jersey, it is reported that approximately 8,000 people and their families are waiting.

While states may have institutional capacity to serve additional individuals, families do not want institutional services and they make their preference clear in choosing to wait for years for community services rather than accept institutional placement, including in New Jersey.

Alternatives in New Jersey

Over the past 40 years, the state of New Jersey has lagged behind the vast majority of states in affording people in its institutions the opportunity to move to the community. The New Jersey Department of Human Services website states that “the average age is 51, and a recent survey indicated that more than 80 percent of the residents have lived in a DC since childhood.”⁶ From these facts it is clear that people living in New Jersey’s facilities are there simply because when they were admitted as children when the only option available was the institution and they have simply never left.

New Jersey has built a community service system that can now provide new options. State administrators in the Division and providers have considerable experience in developing services for people with significant disabilities. This commitment and capacity is demonstrated through the state’s many programs and initiatives including: *Returning Home New Jersey* (RHNJ) which is working with individuals who live in out-of-state residential facilities, and their families, to develop community-based residential options, services and supports for them in New Jersey; the *Self-Direction Program* which gives individuals and families greater control over the services they receive, how they receive them and who provides them; the state-wide *Crisis Response Team* which provides on-site crisis intervention services for adults with developmental disabilities; *Pathways to Adult Life* which is preparing students graduating from school for adult life; and finally, *The Path to Progress* which outlines a process for allowing developmental center residents and their families and/or guardians to learn about and choose from among a number of different types of housing and services. DDD has qualified more

⁶ New Jersey Department of Human Services Division of Developmental Disabilities Website

than 100 agencies to provide these services and to meet varying levels of behavioral and medical needs.

The mission of the New Jersey Division of Developmental Disabilities is more robust and specific than most and addresses all of the major issues that concern people with disabilities, their families and the public at large.

Division of Developmental Disabilities' Core Principles

- Ensure Health & Safety while Respecting the Rights of Individuals**
- Serve People In-State**
- Avoid Unnecessary Institutional Placements**
- Expand Community Supports & Services**
- Develop a Presence in Each County**
- Spend State Dollars Responsibly**
- Promote Choice through Individual Budgets**
- Promote Equity and Fairness**
- Ensure Continuous Compliance with Fed. & State Regulations**
- Access Quality, Culturally Competent Services**
- Share Information; Communicate Regularly**
- Collaborate With Other Agencies**
- Conduct Business Ethically and Professionally**

Apologies

In June 2010, Minnesota became the sixth state in the nation to issue an apology to people with developmental disabilities for the years of incarceration, abuse, and neglect in state operated institutions. Such an apology is an indication of a sea change in attitudes. States are apologizing to a group of people who in very recent history were stripped of all rights as citizens, who were denied an education and often medical treatment, who were sterilized without consent and were presumed to have nothing to offer society. These apologies, coupled with the almost complete abandonment of the term "mental retardation" from the names of state agencies, including New Jersey's, are indications that our public systems are about more than providing services; they are about respecting the rights and dignity of people with developmental disabilities and creating opportunities for full participation in community life.

Oral Testimony

October 17, 2011

By Roger A. Monthie

Good morning. My name is Roger Monthie and I am president of Age Plan, Inc. I was asked to speak to you today due in part to my 30 year career as a New York State Employee and my experience in overseeing the operation of New York State institutions. During my career I provided administrative and clinical oversight to three different institutions – Broome Developmental Center, a 480 bed center in Binghamton N.Y.; Letchworth Village Developmental Center, an 1100 bed center in Haverstraw NY; and OD Heck Developmental Center, a 48 bed center specializing in Autism in Schenectady NY.

My state career also involved overseeing the move of over 1,000 individuals from institutional to community support services. I am honored to share my experience with you so that it might aide in the development of successful institutional policies, practices, and decision-making.

There are a number of important issues that should be considered when exploring the institutional care and its cost, as well as, the transition of individuals from institutional to community supported care.

During my career, New York State came to the conclusion that although quality services can be delivered in large institutions, the cost of maintaining these institutions, especially after taking into account the changes in demographics, the actions of advocates and the interest on the part of individuals and their families, made creating services in community a better option. New York State closed 11 developmental centers during my career and significantly downsized the remaining 6 centers.

I will take my limited time before you to draw your attention to five key facets that lead and aided in the implementation of that decision:

First, Fiscal Realities

Fiscal realities significantly dominate the talking points when discussing the ongoing use, function and need for institutions serving individuals with developmental disabilities. This is not a new concern and was a constant source of dynamic tension in our efforts to downsize institutions in New York State.

However, in my tenure, NYS came to the realization (whether on its own or under the strain of pending litigation) that government had a responsibility to support each person in a manner that best allowed them to exercise their personal choices.

Although, the fiscal impact of the care for this vulnerable population may seem like the most important factor to consider for de-institutionalization, especially during difficult economic

times, using only the fiscal lens can be a little like falling down the rabbit hole.

My experience is that the fiscal argument can be used both to support and oppose the de-institutionalization of individuals with disabilities. This is because a fiscal argument depends largely on what factors one puts into the equation. Those supporting continued institutionalization point to the issues of economy of scale for services and supports, the development of specialized expertise and the positive economic impact of the large developmental center. Those supporting deinstitutionalization emphasizes the savings associated with no longer maintaining the infrastructure of a large often old building or campus, duplicative costs at institutions for support services such as security, maintenance, food services, cleaning and laundry, as well as, regulatory mandates in terms of clinical supports.

Relying on the magic bullet of “fiscally advantageous” is foolhardy for two important reasons:

- (1) The analysis of the system of care is too complex and is constantly changing;
- (2) During the process of de-institutionalization it is actually more costly to service individuals with disabilities because you have to fund both the development of a community system and the closing institutional system, until the institution is closed.

Second, Human Resource

There is little question that the clinical supports and services provided in institutions have and in many cases continue to be of high quality. Historically, some of the most important advances in providing services to individuals with developmental disabilities came from center across the United States. However, equally without question the lack of quality care has resulted in increase scrutiny of the institutional model.

In 1992 I became the Associate Director of Letchworth Developmental Center, a New York State Institution with a population that at one point reached over 5,000 individuals. When I began my tenure at this Center there were over 1,000 individuals supported by close to 1,500 employees. The Center was out of compliance in 6 of 8 conditions of participation for continued certification and it was involved in a federal class action consent decree. Since staff at the Center were important, it was critical during our closure process to understand the importance of the relationships between the staff, the individuals, and the families. These relationships many times went beyond the job.

When we looked at the issue of services to individuals with developmental disabilities, we were very cognizant that the public service employees in the state system were dedicated, knowledgeable, valuable and important for the transition of residents to a community supported system of living.

We came to realized that the safe, healthy and successful placement of individuals from the institutional to community model needed to include a transition of this valuable group of staff. That is not to say that one can or should attempt to accomplish a full employment commitment. That was not possible. Instead, New York, during the closing of many of its institutions included a limited number of state operated community homes in the closure plan. By no means was it a guarantee for every individual or employee, but it was critical to ensure the successful closure of the institution. This decision allowed us to successfully transition individuals with the most complex medical, physical and behavioral issues and histories into the community.

Third Political Lens

New York's successful transition from an institutional to a community based support system depended upon the collective effort of all parties agreeing on the long term benefit of integrating individuals into the community of their choice, as well as, understanding the changing political landscape.

In New York managing the many political agenda was significantly aided by several factors including (1) the support of the state legislature and executive branch and (2) cooperative relationships with the State's work force.

With respect to the State Legislature and Executive Branch it was critical that we (1) had a closure plan that was updated

annually that was provided to the State Legislature; (2) the State Legislature passed the Padavan Law in 1978 to ease the resistance of local municipalities and citizens to object to placement of individuals with special needs; and (3) created local and community groups to discuss the use of the center's facilities and grounds after closure.

We also spent great deal of effort working with state and local union leaders to provide a series of options for state employees who were not able to transition into the state operated community based system. This included, transfers to other state positions; retraining to other positions; or connecting employees with private providers.

Clinical, Direct Support and Administrative Services in Institutions

Although, it is possible to deliver quality services in a relatively cost effective manner in institutions, New York State had evidence that the same care could be provided in a cost effective manner in the community.

A limited exception is the direct care oversight, specifically in the night shift, in large institutions. One direct care worker can oversee a greater number of individuals in an institutional model than in a small community based home.

However, in a community setting direct care staff were more willing to work with each other, which enhanced the quality of care and decreased events of unknown origin and overtime. The

smaller environments also lead to fewer behavioral crises, thus reducing the need for clinical interventions and one-to-one supervision.

The shift to a community model had the added benefit of reducing the need for large administrative and support staff to provide security, maintenance of building and grounds, preparation of meals, and cleaning and laundry.

Finally, the introduction of Medicaid Waivers to the states allowed the unbundling of services from the ICF-MR to the individualized design of the community model. No longer did you have services provided based upon a model but rather based upon the needs of the individual. This had the substantial added benefit of the state not incurring a cost for service that the individual did not need.

Fourth Symbolism Lens

Once the decision to close many of the institutions in New York, it was important to take into account the history and culture of years of institutional care provided in New York.

Letchworth Village Developmental Center was more than a facility for individuals with developmental disabilities. It had started as a village, with its own fire department, police department, hospital, school, clinics and culture. Letchworth Village was a place where relatives, sons and daughters, lived and died. When looking at closure, we knew that we weren't just closing a center but were ending an era.

At the closing ceremony, an elderly man came up to me and said he had travelled from California to see the place where he was born and lived until age 5. He told me he had fought in WW II and settled and raised his family in California and came to see his birth place before it was closed.

Looking through the Symbolism lens doesn't tell you how or why to close a facility but it will help to provide a context for that decision an appreciation of its history and lens to look at the future

Thank you again for the opportunity to provide you this information. I have also provided greater details in my written comments but would be happy to answer any questions that you may have.

Testimony De-institutionalization

October 17, 2011

By Roger A. Monthie

The following is the written report to my oral testimony provided on October 17, 2011 to selected legislative members of the State of New Jersey.

I began my career with the State of New York in 1974 as a psychologist responsible for screening and placing individuals from the Willowbrook State School to community placement in upstate New York. This starting point eventually led to my appointment as a Deputy Director of Treatment Services at Broome Developmental Center a 480 bed ICF/MR in Binghamton New York; then Associate Director of the Letchworth Development Center a 1100 bed ICF/MR in Haverstraw New York, where I oversaw the closure and placement of more than a 1,000 individuals with developmental disabilities into community supported living opportunities. I was also responsible for overseeing the day to day operation of over 130 community home, seven day programs and three regional centers supporting over 1,500 individuals with developmental disabilities. Finally, I finished my state career as the Director of the Capital District Developmental Center, a regional state office which covers 10 counties in New York with responsibility for providing residential, clinical and day support services and oversight to over 2,000 individuals receiving supports and services in residential, day, and clinical services.

The vast majority of my 30 year career as a NYS employee and public servant was spent overseeing the day to day clinical, residential and supports services in large ICF/MR and/or a robust community based service delivery system as well as, assisting individuals to move from institutional to those community supported services.

I am honored to share my experience with you so that it might aide in the development of successful policies, practices, and decision-making.

There are a number of important issues that should be considered when exploring the transition of individuals from institutional to community supported care, as well as, the current and future role of large ICF/MR centers in the care and treatment of individuals with developmental disabilities.

The first and foremost is an understanding that change can be traumatic, particularly for vulnerable individuals and their families. Therefore, the process of moving individuals into the community and closing institutions by developing community based opportunities for those individuals needs to be carefully planned and adequately supported.

The de-institutionalization of individuals with disabilities is a highly complex issue with numerous facets. When looking at the issues it may be helpful to look through different lenses to determine a course of action. For this report, I have focused my comments by looking through the following lenses:

1. Fiscal Impact;
2. Human Relationships;
3. Political Pressures;
4. Symbolic Effects.

Fiscal Impact of De-institutionalization

The fiscal pressure on National, State and Local governmental entities is well noted and a constant source of concern for elected officials, public policy makers and citizens. This is not a new concern and was a constant source of dynamic tension in our efforts to de-institutionalize individuals in New York State. However, in my tenure, NYS came to the realization (whether on its own or under the strain of pending or existing litigation) that government had a responsibility to support each person in a manner that best allowed them to exercise their personal choices and in the most integrated setting possible.

Fiscal realities significantly dominate the talking points when discussing the ongoing use, function and need for institutions serving individuals with developmental disabilities. Although, the fiscal impact of the care for this

vulnerable population may seem like the most important factor to consider for de-institutionalization, especially during difficult economic times, using only the fiscal lens can be a little like falling down the rabbit hole.

My experience is that the fiscal argument can be used both to support and oppose the de-institutionalization of individuals with disabilities and the role institutions have in the future system of supports. This is because a fiscal argument depends largely on what factors one puts into the equation. Those supporting continued institutionalization point to the issues of economy of scale for services and supports, the development of specialized expertise and the positive economic impact of the large developmental center. Those supporting deinstitutionalization emphasizes the savings associated with no longer maintaining the infrastructure of a large often old building or campus, duplicative costs at institutions for support services such as security, maintenance, food services, cleaning and laundry, as well as, regulatory mandates in terms of clinical, administrative and direct care supports.

In my experience, using the fiscal lens as the final determinant is difficult at best, since the issues surrounding each institution, as well as, the community support system currently existing or needed to be developed are so different.

For example, the needs of the individuals are complex, each institution has individuals on a continuum of high to low in terms of their need for supports; the physical issues at each institution can be significantly different; the issues surrounding staffing can significantly change the equation and the existing community where an individual moves can be vastly different.

That being accepted, yes, there is an economy of scale in an institution, but does that outweigh the additional cost of providing the ancillary services required in a large institution. Yes, specialty expertise are developed at institutions, in behavioral, medical and allied health, but are those needed as a result of an individual's issues or the result of individuals living in large congregate settings. There are simply too many factors that cannot be quantified to make use of a fiscal discussion in a vacuum.

For example, in New York we repeatedly saw a reduction in the individuals need for services once the person successfully transitioned to a community environment. This reduction in need could not be quantified into an overall fiscal impact statement, yet it resulted in a reduction of the cost of services in the community to individuals with disabilities.

Relying on the magic bullet of “fiscally advantageous” is foolhardy for several important reasons:

- (1) The analysis of the system of care is too complex and is constantly changing;
- (2) During the process of de-institutionalization, it is actually more costly to serve individuals with disabilities because you have to fund both the development of a community system and the closing institutional system, until the institution is closed.
- (3) Only looking at the fiscal bottom line doesn't:
 - a. look at the quality of services
 - b. the emotional effect on staff, individuals and families
 - c. the role of the institution in the community where it resides
 - d. the change in societies attitudes

Human Resources Lens

Letchworth Developmental Center was opened in 1911, as a place individuals would come to learn, live and work. At one point over 5,000 individuals lived at the Center. In 1992, there were over 1,000 individuals supported by more than 1,500 employees. When developing a placement and closure plan, it was critical to understand the importance of the relationships between the staff, the individuals, and the families. These relationships many times went beyond the job. Staff, individuals and families had become interconnected celebrating holiday and lives.

When we looked at the issue of services to individuals with developmental disabilities, we were very cognizant that the public service employees in the state

system were dedicated, knowledgeable, valuable and critical for the successful, safe and healthy transition of residents to a community supported system of living. Looking at the movement of the individuals with developmental disabilities, many of whom had lived most of their lives at Letchworth, it was important to understand the role these dedicated state employees had in ensuring continued quality of care and services. These professional, paraprofessional and support employees understood the needs of the individuals they were serving, ensured their health and safety assisted them in building a life with friends and kept them connected to their own family. Many had dedicated their entire careers to ensuring the health and wellness of the individuals they served¹.

We came to realized that the safe, healthy and successful placement of individuals from the institution to a community model needed to include a transition of this valuable group of staff. That is not to say that one can or should attempt to accomplish a full employment commitment. That was not possible. However, a sensible and appropriate plan needs to be developed that takes into account the years of dedicated and valuable support for the following reasons:

1. The needs of many of the most vulnerable individuals require the understanding of both verbal and non-verbal interpretations not easily transferred to new staff. A sound made by an individual may indicate interest, excitement or pain. The interpretation by knowledgeable staff can be the difference in determining the potential for a significant health event, as well as, minimizing the potential for mortality which can significantly increase during any transition.

During downsizing and closing of the institution, it was going to be necessary to move individuals, not only to a community based system, but

¹ I am confident, having been a monitor of the New Jersey system of care for individuals with disabilities, that the State has an equally well trained and dedicated number of public servants.

also multiple times within the institution as a building was being closed and individuals consolidated. Keeping the staff as stable as possible was critical to minimizing negative effects.

2. Realization that some staff was going to have to be there at to the very end. We needed to have a way to keep the most talented and skilled staff so that the care at the end wasn't seriously affected.
3. The relationship between caregiver and receiver also involves the family. Families count on the continuity of care by staff that over time has become part of their extended family. They share major holidays, significant life events and stories. Families sleep well at night knowing a staff member, who cared for their loved one for years, is there to help, care and protect their child, brother or sister in the future.

Based upon these issues, to name a few, New York during the closing of many of its institutions included a limited number of state operated community homes in the closure plan. By no means was it a guarantee for every individual or employee, but it was critical to ensure the successful closure of the institution.

This decision allowed us to

1. Successfully transition individuals with the most complex medical, physical and behavioral issues and histories into the community.
2. Provide job security to direct care staff who were going to support the last individuals to leave the institution;
3. Gave professional staff reassurance that there was need for their skills in the future
4. Allowed us to continue to recruit talented staff while we were closing, since we could point to the continuation of a public services system in the community

This practice also showed a continual commitment on the part of the State of New York to individuals with developmental disabilities and their families by:

1. Keeping an experienced clinical and professional system of supports;
2. Ensuring that individuals were provided supports and services regardless of the complexity of their needs;
3. Providing an ultimate back up if the private sector was unable to ensure proper care; and
4. Maintaining a system to management for emergency needs.
5. Ensure families member that the state understood their concerns

Political Lens

In New York, we faced a number of issues that I would look at through a political lens.

These included the views of families, associations serving individuals with developmental disabilities; local governments; State executive and legislative members; public unions and legal advocates. Each had their specific purpose, interests and responsibilities.

Successful transition from an institutional to a community based support system depended upon the collective effort of all parties agreeing on the long term benefit of integrating individuals into the community of their choice, as well as, understanding the changing political landscape.

Furthermore, during my tenure many of our state institutions were also faced with the realities of federal court class actions; CMS (Centers for Medicare and Medicaid Services reviews; Department of Justice oversight and every changing federal regulation interpretive guidelines.

To meet or take into account the various political views, it important to understand and mediate the differences between parties with clear expectations that the laws, regulations and mandates are met and followed

In New York managing the many political agenda was significantly aided by the following:

1. Support from the State Legislature and Executive Branch

I am confident that we would not have been able to transition over a 1000 individuals into community placements without the support of the New York State Legislature and Executive branch. These political entities passed critical laws that aided in the placement on individuals into the community including;

- (1) Requiring a closure plan for centers which is updated annually and provided to the State Legislature;
- (2) Passing the Padavan Law in 1978 provided a process for developing community living opportunities by easing the resistance of local municipalities and citizens to object to placement of individuals with special needs into community homes;
- (3) Creating a local community alternate use committee, including local officials and community groups to identify uses for the center facilities and grounds after closure.
- (4) Showing compassion and courage by ensuring that the needs of individual with developmental disabilities, their families; the dedicated staff that served them and the communities that had supported them were taken into account during and after the closure of the institution.

2. Cooperative Relationship with the State's Work Force

As I have previously stated de-institutionalization requires an eye towards the individuals who serve these vulnerable individuals. We spent a great deal of effort working with state and local union leaders to provide a series of options for state employees who were not able to transition into the state operated community based system. This included, transfers to other state positions; retraining to other positions; or connecting employees with private providers. We ensured that employee assistance program was active and available to all staff.

3. Support of State and Legal Advocates

Many of NY's institutions were under investigation by legal advocates or already faced with federal court claims when the State shifted its model of delivery of services to a community based model. The agreement between the state and legal advocates that placement of individual's into a community based support system of small integrated group homes was important and necessary to resolve the class action suits against the institutions. This eventually was confirmed nationally with many states totally closing all of their institutions.

4. Changes in the Services

The services provided and offered to individuals have changed significantly over the last several decades. The introduction of waiver based services has allowed states to offer a variety of services to individuals with developmental disabilities and their families. Special Education services delivered in schools support children in the most integrated system available. All these changes have affected the choices citizens want for their relatives. Based upon these changes institutions that used to be the only option are now often seen as the last and not the most desirable option.

5. Federal Changes

A number of significant changes in Federal Laws and guidelines have supported the movement of individuals into a community support system. These include:

- a. The Rehabilitation Act of 1973
- b. The passage of the Americans with Disabilities Act of 1990
- c. The Supreme Court decision in *Olmstead v. L.C and E.W.*
- d. Executive Order 13217: Community-Based Alternatives for Individuals with Disabilities on June 18, 2001, extended the Supreme Court's decision to all Americans with disabilities, and called upon selected Federal agencies, including U.S. Department of Labor, to help support governors in their implementation of the Olmstead

All of these established a political frame that minimized resistance to change and a belief that placement into community living opportunities was the right thing to do for the individuals living in large state facilities.

Symbolism Lens

Letchworth Village Developmental Center was more than a facility for individuals with developmental disabilities. (This is true with most institutions) It had started as a village, with its own fire department, police department, water treatment plant and reservoirs, power plant supporting 150 building, 29 miles of roads, a school, hospital, clinics and culture.

Over the years, it saw the development of a community center, picturesque grounds, and a swimming pool and became a place where citizens could find help with everything from a complex issue to someone to rake a lawn.

Letchworth Village was a place where relatives, sons and daughters, lived and died. When looking at closure, we knew that we weren't just closing a center but were ending an era and closing a village.

When one looks at closure through the Symbolic lens, one understands the feelings one might experience with the closing of the house where you were born, the town you grew up in, a place that brought you comfort and stress, but is your life and memories.

The passion is understandable and critical to take into account when meeting with those that care.

I would like to leave you with three stories that illustrate the importance of looking at the issues of closure and placement through the lens of symbolism.

First, at the end of a meeting of a group of parents very upset with the decision to close Letchworth, a little elderly woman in her late 80's came up to me and respectfully asked to speak to me. She said that her she was told to place her only son into Letchworth Village over 50 years ago and every Sunday since then she has taken a cab from her home in the Bronx to a bus at the Port Authority to

downtown Haverstraw where staff would pick he up so she could have lunch with her son which she had made and brought from her home. She would sit on a bench outside his cottage every Sunday. How will that happen after you close Letchworth, she asked? I look at this woman and realized that we weren't placing a person. We needed to ensure her that the life she built for herself and her son would remain. Even though, we did close Letchworth, we ensured that she was able to have lunch every Sunday in her son's new home which also included occasionally sitting on a bench in front of her son's old cottage.

Second, after the placement of the last individual from the Letchworth Village Developmental Center, I stood with the direct care and nursing staff who were the last caregivers to the individuals leaving in a van to their new house. As we waved goodbye, a staff member who had worked 40 years at Letchworth and agreed to stay to the end looked up to the name of the last cottage where the individuals lived, pulled down the sign and handed it to me saying, take this so that people in the future will never forget the good we and a lot of others did here. Ironically, the name of the cottage was Omega.

Finally, at the closing ceremony, an elderly man came up to me and said he had travelled from California to see the place where he was born and lived until age 5. He told me he had fought in WW II and settled and raised his family in California and came to see his birth place before it was closed.

Looking through the Symbolism lens doesn't tell you how or why to close an institution but it will help to provide a context for that decision with an appreciation of its history and lens to look at the future.

Conclusion and Recommendations

I leave you these final conclusions and recommendations which are by no means a comprehensive list or in level of importance.

1) Clear Support of the Executive and Legislative Bodies

The Executive and Legislative Branch must provide a clear direction when contemplating closure of an institutional model of care. Without the clear decision of the State that a center will close, with specific timeframes, managing the complex factors on a day to day basis is very difficult if not impossible.

2) Have a Closure Plan

A closure plan with a detailed analysis of the process for transitioning individuals, staff and alternate use of the facility is critical. The plan should be reviewed annually, have facts but also real stories.

3) Acknowledge that the Center is More Than Bricks

Centers are homes not just building. They have history. An understanding and recognition that in some cases the Center is seen as more than a facility serving individuals with developmental disabilities can be critical to assisting everyone to accept and embrace the State plan of closure. Ensure a closing ceremony to celebrate its history

4) Funding the Change

The institution will still need to be supported fiscally until all the individuals are placed and the facility is sold. During this process there will be added costs to care,

oversight and support. Even though the population may be reducing the State has a legal and regulatory obligation to ensure that the institution remains certified to meet Federal and State regulations until the final individual is placed in the community.

5) Make Staff Part of the Transition

Staff provides critical services to the individuals who reside in these Centers. They also have responsibility to themselves and their families. In order to ensure continuity and quality of services to the end, staff members need assurances that they are important and respected with some personal security. Otherwise, they are faced with having to find alternative employment and leave when those options become available. These staff must be utilized as a valuable resource in the successful and safe community placement of individuals with disabilities into the community model.

6) Individuals with complex medical and behavior needs

All individuals can live in a community support system of care. The individuals with the highest needs should be accommodated first so that the institution and its staff are available to ensure the safe and successful transition into the community.

7) Clinical Supports Systems

Consider the availability of a crisis and clinical support system for the individuals moving into the community. Many times success can be improved by supporting the new staff with experienced professional and paraprofessional teams. Consideration should be given to the establishment of state provided regional centers to support individual moving into both private and potentially state operated programs. Developing this system, provides a method of keeping talented

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employees, can also provide expertise to individuals and families living in the region; ensure the State of New Jersey remains committed to services and supports in the future. The region center could become centers of excellence by combining them with region and state colleges and local and national professional.

Follow-up and Feedback

Require follow up with reports to the appropriate legislative and executive committees identifying successes and areas for improvement. This should include an independent satisfaction survey and analysis of individual and their families.

Thank you again for the opportunity to provide you information. Please feel free to contact me in the future if I can be of assistance.

Respectfully Submitted

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October 13, 2011

New Jersey General Assembly and Senate
Attention: Members of the Legislative Review Panel on State
Psychiatric Hospitals and Developmental Centers
c/o Kate McDonnell, Assembly Majority Committee Aide and
Jason Redd, Senator Majority Committee Aide
State House
P.O. Box 098
Trenton, NJ 08625-0098

Re: Written Testimony submitted by VOR for consideration
by the "Legislative Review Panel on State Psychiatric
Hospitals and Developmental Centers."

**Dear Chairman Van Drew, Chairperson Huttle, and Honorable
Members of the Legislative Review Panel on State Psychiatric
Hospitals and Developmental Centers:**

I represent VOR, a national advocacy organization for persons with
intellectual and developmental disabilities (ID/DD) and their families
and legal guardians.

VOR offers this Legislative Review Panel a unique perspective: VOR is
the only national advocacy organization that supports the provision
of a full spectrum of care options for individuals with ID/DD, from
own home and smaller homes to federally-licensed larger residential
homes (ICFs/MR), including New Jersey's Developmental Centers.

VOR's respect for families as experts in their loved ones care also
sets VOR apart from other national groups. The majority of
individuals for whom we advocate that receive ICF/MR care have
profound intellectual disabilities with the cognitive ability of infants
or young toddlers. They rely on their families to ensure they receive
high quality care. Their families know them best and have no ulterior
motives other than their well-being.

As our written testimony will explain in detail, VOR supports the
expansion of desperately needed "community"-based options, but
not at the expense of equally necessary developmental centers
(licensed Intermediate Care Facilities for Persons with Mental
Retardation, ICFs/MR).

To meet the diverse needs of the ID/DD population, one size does
not fit all. New Jersey can and should have it both ways.

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**Correspondence from Dr. Matt Holder,
CEO, Underwood & Lee Clinic (KY), a
community resource center**

I. Summary of VOR Position and Recommendations

The catalysts which support closure are based on faulty assumptions relating to cost, quality and the law.

New Jersey's developmental centers provide cost-effective, specialized services and care not available elsewhere for the State's most disabled citizens. Current census numbers and downsizing do not reflect demand. Individuals who may benefit from developmental center supports are not even presented with the developmental center as service option unless court ordered or referred from another provider who could not handle the individual. When individuals are admitted in these limited situations, the New Jersey Olmstead Initiative requires that the Developmental Center recommend 3 residents for discharge to ensure the center's census does not increase and in fact decreases:

"Additionally, a new initiative has been instituted regarding emergency admissions. When individuals require emergency admission to developmental centers and it is unlikely that they will return to their placements, developmental centers will submit the names of three individuals who meet a similar profile to the agency for consideration to fill existing vacancies." [New Jersey Department of Human Services (DHS), Division of Developmental Disabilities (DDD), "Addendum to the Olmstead Path to Progress: Blueprint for the June 30, 2013 Closure of Vineland Developmental Center," (May 2011)]

True demand and need for developmental center care cannot be known because state policy deflects admissions and requires transfers based on arbitrary quotas which have the net result of reducing census. The emergency placement initiative – requiring 3 people to move out for every one emergency placement – is especially objectionable given that nearly all residents and their families overwhelmingly supported continued developmental center supports and objected to transition from the center.¹ With such a high satisfaction rate, how can an arbitrary quota which requires transitions be reconciled with federal laws regarding resident/guardian choice and **Individual** Habilitation Plans (IHPs)? (See "The Law Requires Residential Choice," p. 6, below).

The lack of community capacity is also well documented. Proposals earlier this year to close Vineland ICF/MR were accompanied by state claims that there was not enough funding to build new homes for the 8,000 people waiting for community-based services. Recent budget cuts have further decimated the community infrastructure, cutting some programs (e.g., the Community Professional Supports and Training program) and making expansion of life-sustaining health care and other specialized supports out of reach.

Recommendations

1. To carry out ACR156's requirement to "examine the feasibility and costs of developing, strengthening, and expanding community-based services," the Legislative Review Panel is strongly urged to arrange for an independent cost comparison of developmental center versus community-based care. Such a study must take into account all costs for each setting², the cost

¹ The survey (December 2010) asked families of developmental center (ICF/MR) residents if they were happy with the current placement of their loved ones or would they prefer community-based care instead. The results were overwhelmingly (96%) in support of continued ICFs/MR placement.

² Although it is often assumed that smaller residential settings cost less, **very** often this comparison is based on the all-inclusive cost of developmental center supports and a community cost figure that excludes significant line items such as room-and-board, transportation, health care, day programming and more. See, "Cost Comparisons of

to develop presently inadequate community programs and infrastructure; consider the impact that closed admissions have had on the cost-effectiveness of developmental centers (which are artificially under-utilized), and take into account the revenues that will be lost with any developmental center closure.

2. The Legislative Review Panel is strongly urged to arrange for an independent outcome study that considers the present well-being of former North Princeton residents. The prior study involving these former residents was discontinued after only 2 years and these early findings were not encouraging. As is contemplated for former residents of psychiatric hospitals (ACR 156 (1)(c)(1)(c)), before displacing current ICF/MR residents, this Panel should consider any lessons learned from the North Princeton closing, as well as the impact on individuals who have more recently been displaced from developmental centers due to downsizing. An outcome study, to focus on individual outcomes, such as mortality, access to health care and other necessary services, trends associated with 911 calls and emergency room utilization, staffing turnover and more, could be built into the required review of community capacity.³
3. **Expand, don't eliminate, service options available to New Jersey residents with ID/DD. 8,000 people are languishing without services.** Some of these individuals would benefit from developmental center supports if provided that option. Given the state's budget crisis, the lack of community infrastructure, current needs, and the likelihood that costs will not be saved, the Legislative Review Panel is urged to embrace a forward-thinking solution that would allow admissions to developmental centers based on individual choice and need, while also making the specialized services at developmental centers available to non-residents. Offering outpatient care to non-residents is a proven model already in place in several states. These "Community Resource Centers" (CRC) have been shown to be a cost-effective way to provide not otherwise available professional services to community-based individuals. Because the CRC model relies on an existing infrastructure, it is cost-effective and helps keep individuals in community-settings well-cared for and out of (more expensive) crisis situations.

II. Rationale and Background

VOR's recommendations are supported by the following background information and rationale.

1. The People Being Served

ICFs/MR are often the best, most cost-effective way to meet the needs of the most vulnerable of the population with intellectual and developmental disabilities.

Residents of ICFs/MR are among the neediest, most fragile and most disabled members of our society. They need support in every aspect of life including walking, communicating, bathing, eating and toileting.

Nationally, nearly 75% (74.5%) of all ICF/MR residents experience severe and profound intellectual disabilities; they also endure multiple disabilities, chronic medical conditions and/or behavioral

Community and Institutional Residential Settings: Historical Review of Selected Research," *Mental Retardation*, Vol. 41, No. 2: 103-122 (April 2003) (detailed on page 4 of this testimony and Attachment A).

³ ACR 156 (1)(c)(2)(b).

challenges. Many also have seizure disorders, behavior problems, mental illness, are visually-impaired or hearing-impaired, or have a combination of these conditions⁴.

In New Jersey, 80% of developmental center residents have severe or profound intellectual disabilities, with 60% having two or more additional disabling conditions such as cerebral palsy, blindness, hearing impairments, seizure disorders, psychiatric disorders, etc.⁵ A significant number of residents cannot communicate "basic desires verbally" (49.4%) and cannot "understand simple verbal requests" (34.3%)⁶. Many developmental center residents also need assistance walking (28.4%), transferring (39.3%), eating (49%), dressing (58%) or toileting (57.4%)⁷.

In New Jersey and nationally residents of ICFs/MR are our most fragile citizens. Compassionate, specialized care provided in ICFs/MR homes – homes specially designed for these complex needs – is a good human and fiscal investment. **Where** will these individuals receive life-sustaining services and **at what cost** are two questions that must be answered before a decision is made to displace ICF/MR residents from their current homes.

VOR Recommendation

1. To carry out ACR156's requirement to "examine the feasibility and costs of developing, strengthening, and expanding community-based services," the Legislative Review Panel is strongly urged to arrange for an independent cost comparison of developmental center v. "community"-based care. Such a study must take into account all costs for each setting, the cost to develop presently inadequate community programs and infrastructure; consider the impact that closed admissions have had on the cost-effectiveness of developmental centers (which are artificially under-utilized), and take into account the revenues that will be lost with any developmental center closure.

2. Costs

a. Developmental Centers provide cost effective care; Conduct accurate, independent cost comparisons

Common-sense says that it is more cost effective to serve individuals with complex, high cost needs in one location than in scattered locations. The care provided in developmental centers is not only cost effective, but also compassionate, consistent, and experienced. In contrast to high turnover of direct care staff in community settings, and the often non-existent professional care, many of the developmental center direct care and professional staff have worked for the developmental centers for many, many years.

The widely-held belief that it always costs less to care for people with intellectual and developmental disabilities in smaller homes rather than in developmental centers **is not true** for people with the most severe disabilities, according to peer-reviewed study published in *Mental Retardation*, a journal by the American Association on Mental Retardation:

"From the studies reviewed here, it is clear that large savings are not possible within the field of developmental disabilities by shifting from institutional to community placements."⁸

⁴ "Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008," Research and Training Center on Community Living Institute on Community Integration/UCEDD, College of Education and Human Development University of Minnesota (2009) (<http://rtc.umn.edu/docs/risp2008.pdf>)

⁵ Id.

⁶ Id.

⁷ Id.

⁸ Kevin K. Walsh, Theodore A. Kastner, and Regina Gentlesk Green, "Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research," *Mental Retardation*, Vol. 41, No. 2: 103-122 (April 2003). An updated summary of this study by the primary researcher is attached (Attachment A).

The study details several cost factors that are often overlooked by policymakers and advocates, including, but not limited to:

- **Level of disability:** The failure to adjust for the different levels of disability of the people included in the studies skews the results. Facility residents are the most needy, most vulnerable and most costly of all Medicaid recipients, regardless of service setting. In New Jersey, 80% of developmental center residents are persons with severe and profound intellectual and other complex disabilities.
- **Aggregate costs and cost shifting:** When individuals are moved from facility-based to community placements, costs shift from the all-encompassing facility care budget to a community services budget that draws from multiple public welfare funding sources for housing, food (e.g., food stamps), transportation, and health care costs. Often only the housing costs are considered in community v. facility cost comparisons. The result is an incomplete look at the true costs of serving the individuals, and a false claim of taxpayer savings.
- **Staffing:** The failure to consider the relevance of lower staffing costs in the community also impacts quality outcomes. If federal initiatives to enhance wages for community-based direct care workers are successful community costs will increase.

The dogmatic belief that placement in the community is always cheaper has resulted in a woefully under-funded community system that is not at all prepared to care for the complex needs of most of the people now residing in larger, specialized facilities, or the thousands of people waiting for services. This study gives state lawmakers the data they need to determine accurate costs.

b. The potential for lost revenues

In addition to the potential loss of federal Medicaid funding, lost state and local revenues is another often-overlooked cost of closure. Consider this testimony (excerpts) by a representative of the Topeka, Kansas Chamber of Commerce:

“We are being told that moving residents out of KNI [a state operated ICF/MR] will save the state money. Yet, we have those who indicate quality housing and services for clients with such significant needs are not currently available. To replicate what now exists at KNI will certainly be very costly.

“Most residents have lived in their KNI home for many years and relate to those who care for them as family members. Deliberations to force them from their home, is devastating to their families and guardians. We understand none of the committees reviewing this issue have been provided a list of facilities with available space, appropriate specialized equipment and quality trained staff for KNI residents? We are not convinced such housing is readily available here or throughout the state and believe this proposal will only result in cost shifts to provide what is already existing at KNI, we doubt there will be any cost savings. . . .

“The Topeka Chamber commissioned an economic impact analysis of KNI on Topeka, for the State Closure Commission in 2009. This study was completed by Impact Data Source, Austin, TX. It is attached to my testimony⁹].

⁹ “A Report of the Economic Impact During Fiscal Year 2010 of the Kansas Neurological Institute in Topeka, Kansas” (September 19, 2009), available at http://vor.net/images/KNI_Impact_Report1.pdf.

"KNI had a significant impact on the Topeka area economy during FY 2010. KNI's revenues and expenditures and its employees and their salaries provide direct economic activity. In addition, this activity ripples through the area's economy supporting indirect benefits including sales at local businesses and organizations, as well as indirect jobs and salaries . . . In total the economic impact of KNI in FY 2010 was \$66 million . . .

"If the motive for closing KNI is saving the state dollars, we respectfully ask your very careful consideration of whether there are real cost savings or cost shifts. We ask that you listen to those who know the residents of KNI the best – their families, care-givers and the medical community. The Greater Topeka Chamber of Commerce urges your decision to be that KNI [ICF/MR] and support services continue to serve our State's most needy." (March 2, 2011, Testimony by Christy Caldwell, Vice President Government Relations, Greater Topeka Chamber of Commerce; complete testimony available here: <http://vor.net/images/ChamberTestimonyKNIClosure.pdf>).

See also, **Illinois: Closing center would cost \$47 million, report finds** (*The State Journal-Register*, September 23, 2011 at <http://www.sj-r.com/top-stories/x26164536/Closing-JDC-would-cost-Morgan-County-47-million-report-finds>).

3. The Law Requires Choice

a. The Americans with Disabilities Act (ADA) and *Olmstead*¹⁰

Despite propaganda to the contrary, the law, including the landmark *Olmstead* decision, does not require that *all* people with disabilities be served in community-based settings, nor does *Olmstead* require that ICFs/MR be closed.

Rather, in its *Olmstead* decision, the U.S. Supreme Court considered the ADA's "integration mandate" and very expressly concluded that "integration" (community placement) is only required when an individual's needs can be safely served in a non-ICF/MR setting and when transfer from the ICF/MR is not opposed by the individual (*Olmstead v. L.C.*, 119 S. Ct. 2176, 2181 (1999)).

The Supreme Court even cautioned against taking its holding too far:

"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." *Olmstead v. L.C.*, 119 S. Ct. 2176, 2187 (1999).

Consistently, the plurality opinion noted:

"As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... 'Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution' [quoting VOR's *Amici Curiae* brief]." 119 S. Ct. at 2189 (*plurality opinion*).

¹⁰ The *Olmstead* decision can be found at <http://supct.law.cornell.edu/supct/pdf/98-536P.ZS>; and additional *Olmstead* resources can be found at http://www.vor.net/olmstead_resources.htm.

Federal courts since *Olmstead* have recognized its "Choice Mandate":

"Thus, the argument made by Arc and the United States [*Department of Justice*] who filed regarding the risk of institutionalization fails to account for a key principle in the *Olmstead* decision: personal choice. And here, where more residents desire to remain in institutional care than the new facility can provide for, there is little to no risk of institutionalization for those whose needs do not require it and who do not desire it." *Arc of Virginia v. Kaine* (December 2009)¹¹; see also, *People First of Tennessee v. Clover Bottom Developmental Center* (May 2010) ("The intersection of citizen choice and the ADA was addressed by the Supreme Court in *Olmstead v. L.C.* . . . [T]here is no federal requirement under the ADA that community-based treatment must be imposed on citizens who do not desire it.")¹²

A recent federal court decision further emphasized the importance of the respecting the input of ICF/MR residents and their families as the input that matters most. The court went as to chastise the United States Department of Justice, which brought the lawsuit in its own name, for pursuing a cause without a plaintiff:

"Most lawsuits are brought by persons who believe their rights have been violated. Not this one . . . All or nearly all of those residents have parents or guardians who have the power to assert the legal rights of their children or wards. Those parents and guardians, so far as the record shows, oppose the claims of the United States. Thus, the United States [*Department of Justice*] is in the odd position of asserting that certain persons' rights have been and are being violated while those persons – through their parents and guardians disagree." *United States v. Arkansas* (June 2011)¹³

In New Jersey, a simple survey (December 2010) was conducted to ascertain choice. The result was clear: 96% of respondents supported maintaining current ICF/MR services and we were opposed to transition to the community.

b. Medicaid Law

The receipt of federal Medicaid funding is contingent upon **a state** offering the choice of ICFs/MR or Home and Community Based Services (HCBS) waivers.

A Medicaid HCBS waiver shall not be granted unless the state provides satisfactory assurances that –

"such individuals who are determined to be likely to require the level of care provided in a hospital, nursing facility or intermediate care facility for the mentally retarded are informed of the feasible alternatives, if available under the waiver, at the choice of such individuals, to the provision of inpatient hospital, nursing facility services or services in an intermediate care facility for the mentally retarded." 42 U.S.C. §1396n(c)(2)(C).

When a recipient is determined to be likely to require the level of care provided in an ICF/MR, the recipient or his or her legal representative will be –

"(1) Informed of any feasible alternatives available under the waiver, and (2) Given the choice of either institutional or home and community-based services." 42 C.F.R. §441.302

¹¹ For full decision: <http://www.vor.net/images/SEVTCDecision.pdf>

¹² For full decision: <http://www.vor.net/images/CloverBottomChoiceDecision.pdf>

¹³ For full decision: <http://www.vor.net/images/ArkansasDecision.pdf>

The State agency **must** furnish CMS with sufficient information to support the assurances required by §441.302, including its “plan for informing eligible recipients of the feasible alternatives . . . institutional services or home and community-based services.” 42 C.F.R. §441.303(d).

Likewise, federal law relating to Individual Habilitation Plans (IHPs) for residents of Medicaid Intermediate Care Facilities for Persons with Intellectual Disabilities (ICFs/MR) **requires** individualized plans.

Simply stated, Medicaid law requires that New Jersey’s ICF/MR residents be granted a choice between an ICF/MR and HCBS waiver alternatives.

VOR Recommendation

2. The Legislative Review Panel is strongly urged to arrange for an independent outcome study that considers the present well-being of former North Princeton residents. The prior study involving these former residents was discontinued after only 2 years and these early findings were not encouraging. As is contemplated for former residents of psychiatric hospitals (ACR 156 (1)(c)(1)(c)), before displacing current ICF/MR residents, the Review Panel should consider any lessons learned from the North Princeton closing, as well as the impact on individuals who have more recently been displaced from developmental center care due to downsizing. An outcome study, to focus on individual outcomes, such as mortality, access to health care and other necessary services, trends associated with 911 calls and emergency room utilization, staffing turnover and more, could be built into the required review of community capacity.

4. Quality and Outcomes

Quality care is not a function of where one lives but of the involvement of relatives and guardians, the skills and commitment of the staff and proper oversight.

The cause of documented, compromised quality in community-based settings for people with intellectual and developmental disabilities is generally linked to the rapid expansion of community programs over the past decade; inadequate access to health care; the lack of adequate staff training and competency (attributed to low wages and qualifications); the lack of state and federal oversight; and the lack of adequate funding.

These concerns are widespread. In at least 30 states (including New Jersey¹⁴) and the District of Columbia, reports of **systemic** abuse, neglect and death have appeared in newspapers, state audits, and scholarly journal articles (<http://vor.net/images/AbuseandNeglect.pdf>). Congress, the U.S. Surgeon General, the General Accountability Office and CMS have also cited serious concerns regarding compromised quality in community settings. For example, citing lack of access to necessary health care, the U.S. Surgeon General noted in 2002, “Compared with other populations, adults, adolescents, and children with mental retardation experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care.” Financial exploitation was the subject of a 1993 House Committee on Small Business, released by then-Chair Ron Wyden: “Increasingly, millions of Americans with these life-long handicaps are at risk from poor quality care, questionable and even criminal management practices by service providers, and lackluster monitoring by public health and welfare agencies.”

While similar problems do occur in ICFs/MR, state and federal scrutiny regarding ICF/MR care guards against long-term, systemic problems. CMS holds ICFs/MR to 378 specific standards (“Conditions of Participation”) annually. In contrast, HCBS waiver programs are reviewed only every 3-5

¹⁴ See, “N.J. finds dangers in group homes,” *The Bergen Record* (June 23, 2002) (State inspectors uncovered violations that jeopardize the health and safety of disabled people in more than half of the 86 group homes in Bergen and Passaic counties. Inspection reports reviewed by The Record found dozens of instances where residents were given improper medication or failed to receive prescribed treatments. The 136 reports, which covered a four-year period, also cited homes for lack of care, improper medication, employing untrained staff and failing to keep complete records).

years and are **not** subject to uniform quality assurance standards (**see, Attachment B**). While there are good community programs, there are many others that fail to provide high quality care. The current system of oversight often fails to identify these “bad apples” until tragedy occurs.

VOR Recommendation

3. Expand, don't eliminate, service options available to New Jersey residents with ID/DD. 8,000 people are languishing without services. Some of these individuals would benefit from developmental center supports if provided that option. Given the state's budget crisis, the lack of community infrastructure, current needs, and the likelihood that costs will not be saved, the Legislative Review Panel is urged to embrace a forward-thinking solution that would allow admissions to developmental centers based on individual choice and need, while also making the specialized services at developmental centers available to non-residents. Offering outpatient care to non-residents is a proven model already in place in several states. These “Community Resource Centers” (CRC) have been shown to be a cost-effective way to provide not otherwise available professional services to community-based individuals. Because the CRC model relies on an existing infrastructure, it is cost-effective and helps keep individuals in community-settings well-cared for and out of (more expensive) crisis situations.

5. An Ideal Balance: Admissions and Community Resource Centers

Across the country, individuals with intellectual and developmental disabilities who reside at home or in community-based services face long waits for needed services, such as health care, dental care, OT/PT, and even wheel chair adjustments. New Jersey is no exception: 8,000 individuals await services. Many of these people simply go without.

It doesn't have to be that way.

VOR recommends the expansion of specialty out-patient clinics (Community Resource Centers) situated at New Jersey's existing Developmental Centers, while also allowing admissions to New Jersey's developmental centers for individuals who choose and require this level of care.

Presently, the State's Developmental Centers are an undervalued resource. Closed admissions have resulted in higher-than-necessary waiting lists and artificially higher costs. Developmental centers have extensive, onsite specialized, professional services that are not available in most New Jersey communities (**see Attachment C**).

Allowing admissions **and** making the developmental center's specialized professional supports available to nonresidents, would have the effect of making the developmental centers more cost effective, while also ensuring successful community placements. Costly crises that occur when individuals don't have access to health care (e.g., 911 calls, emergency room visits, dental surgeries v. preventative care) could be avoided by allowing non-residents to access the center's professional services as out-patients.

Community Resource Centers are a proven model in several states.¹⁵ Attached is a compelling letter from the Dr. Matt Holder, Director of a Community Resource Center in Kentucky, the Underwood and Lee Clinic. Situated at Kentucky's Hazelwood ICF/MR, the clinic opened its doors a decade ago and now serves more than 1,000 individuals with intellectual and developmental disabilities from throughout Kentucky. Demand is significant; major expansion is in process and when completed (2012), the clinic's capacity will quadruple (**see, Attachment D**).

New Jersey lawmakers are encouraged to speak directly with Dr. Holder. Another helpful resource is Dr. Mark Diorio, Director of the Northern Virginia Training Center, a state operated ICF/MR that has a long-standing, successful Community Resource Center on site.

¹⁵ Examples of Community Resource Centers can be found in Virginia, Massachusetts, Kentucky, Washington State, Missouri, and Florida. In New Jersey, a component of the model - training - is in place at Hunterdon Developmental Center where students preparing for a career in healthcare (nursing, physicians and dentists) receive onsite training opportunities working with people with disabilities.

III. Conclusion

Thank you for this opportunity to present our recommendations. Community expansion is desperately needed. Community expansion, however, must not take place on the backs of the fragile residents receiving life-sustaining supports in New Jersey developmental centers.

Rather than eliminating developmental centers and displacing people from their *homes*, consider the opportunities that the developmental centers offer to assist in delivering high quality care to more people at less cost.

Thank you for your thoughtful consideration and your compassionate leadership. Please support a full spectrum of services and supports, including New Jersey's Developmental Centers, to meet the diverse needs of all New Jersey citizens with intellectual and developmental disabilities. For more information, please contact VOR's Director of Government Affairs and Advocacy, Tamie Hopp at thopp@vor.net or 877-399-4867.

Sincerely,

A handwritten signature in cursive script that reads "Sandra Reeves". The signature is written in dark ink and is positioned above the printed name and title.

Sandra Reeves
President

ATTACHMENT A

(For a copy of this 2003 study contact thopp@vor.net)

UPDATE

January, 2009

Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research

Kevin K. Walsh, Theodore A. Kastner, and Regina Gentlesk Green
Mental Retardation, Volume 41, Number 2: 103-122, April 2003

In the 2003 article noted above a review of selected literature was undertaken to determine the validity of institutional vs. community cost comparisons. A number of methodological problems were identified in the literature reviewed that compromised much of the earlier research on the topic. Additionally, a number of considerations were outlined – *source of funds*, *cost shifting*, *cost variation*, *staffing*, and *case mix* – that need to be taken into account when such comparisons are undertaken.

The question has arisen whether the conclusion of this 2003 review, that large savings are not possible within the field of developmental disabilities by shifting from institutional to community settings, remains current.

For the reasons explained below, we find that the 2003 article continues to be valid in 2009 and beyond. That is, cost savings at the macro level are relatively minor when institutional settings are closed and, if there are any at all, they are likely due to staffing costs when comparing state and private caregivers.

As such, the study will continue to be useful in policy discussions in states.

Several factors point to why the study's conclusions remain valid in 2009:

Review Article. As a review article, the 2003 publication does not generate new *data*; that is, it reviews previous research. Because of this, the article is more resistant to becoming outdated. Those reading the article, however, would do well to keep in mind that the studies reviewed in the article employ cost figures that existed *at the time the original research articles were published*. Therefore, while the findings and conclusions drawn in Walsh, et al. (2003) will continue to be timely, the actual cost figures may need to be adjusted to current levels.

Stability of the Components. Because the service and support landscape remains, in large part, similar in 2009 to 2003 and before, the conclusions of Walsh, et al. are likely to hold. For the most part comparisons reviewed generally compared congregate ICF/MR settings and community-based residential settings (typically group homes) funded under the Medicaid HCBS waiver. Although many states have been moving toward personal budgets and fee-for-service models, group homes continue to be a primary community residential service setting. In this way also the conclusions of the 2003 article continue to be applicable.

Stability of the Issues. As noted, the 2003 article presented descriptions of various considerations that affect cost comparisons across states. Because the structural components of the issue have remained unchanged (e.g., institutional settings, group homes) and the funding models have remained largely intact (i.e., Medicaid ICF/MR and HCBS waivers), the various factors affecting them, for the most part, remain as presented in Walsh, et al.

That is, there remains a great deal of cost variation from institutional to community settings as described in the article; cost shifting, as described in Walsh, et al., is to some extent likely to be structurally fixed in most states owing to the nature of state governments. That is, when certain costs disappear, when individuals are transferred from ICF/MR settings, it is highly likely that these costs will reappear in other state budgets (such as Medicaid). In nearly all instances, this is almost unavoidable. In short, costs don't just disappear when individuals are moved.

Based on the forgoing, it appears that the conclusions drawn in the 2003 article continue to be valid.

Kevin K. Walsh, January 23, 2009

ATTACHMENT B

Home and Community Based Services Waivers: An overview

The Home and Community-Based Services (HCBS) waiver program was established in 1981 as part of Medicaid in the Social Security Act (1915(c)). Under the HCBS waiver program, states can elect to furnish a broad array of services (excluding room and board) that may or may not be otherwise covered by Medicaid, including case management, homemaker, home health aide, personal care, adult day health care, habilitation, and respite services. States can request permission to offer additional services. The Centers for Medicare & Medicaid Services (CMS) must grant approval of all waiver applications. The intent of the waiver is to give states the flexibility to develop and implement alternatives to institutional care for eligible populations. Eligible populations include Medicaid-eligible elderly and disabled persons, physically disabled, persons with developmental disabilities or mental retardation, or mental illness. Individuals must be shown to be eligible for institutional services (such as an Intermediate Care Facility for Persons with Mental Retardation (ICFs/MR)) to be eligible for HCBS. (Source: Duckett, M.J. & Guy, M.R., *HCBS Waiver*, Health Care Financing Review (Fall 2000). Vol. 22, Number 1, pp 123-125).

Quality Assurance: ICF/MR and HCBS Compared

ICF/MR	HCBS
<p>To be federally certified, ICFs/MR must meet 8 conditions of participation: (CoPs): Management; Client Protections; Facility Staffing; Active Treatment; Client Behavior and Facility Practices; Health Care Services; Physical Environment; and Dietetic Services. The eight CoPs comprise 378 specific standards and elements.</p> <p>State surveyors conduct annual onsite reviews. CMS is currently conducting "look behind" surveys of every state and public ICFs/MR to "double check" the state surveyors' findings. Serious deficiencies must be corrected within 90 days; other deficiencies must be corrected within a year. Failure to correct deficiencies results in loss of certification and loss of Medicaid funding.</p> <p>The Department of Justice (DOJ) also has a role in overseeing public (not private) ICFs/MR. DOJ does not have jurisdiction over community programs.</p>	<p>Although there is no standard HCBS program, all are required to provide CMS with the following assurances, as a condition of waiver approval: health and welfare of waiver participants; plans of care responsive to waiver participant needs; only qualified waiver providers; State eligibility assessment includes need for institutionalization; State Medicaid Agency retains administrative authority; and the State provides financial accountability (the waiver must cost less than the institutional program).</p> <p>HCBS waivers are reviewed every 3-5 years. Earlier this year, CMS refined its method of quality oversight, initiated with the release of <i>The Protocol</i> in 2000. In January 2004, CMS made mandatory the use of the <i>Interim Procedural Guidance</i> as the method for federal waiver review. The <i>Guidance</i> requires CMS staff to solicit evidence from the states as to their quality management strategy and implementation, including evidence that the statutory and regulatory assurance have been met. CMS is also revising the voluntary waiver application template and the annual report form ("372 form") to gather additional information about how states assure and improve quality.</p>

Note of caution: The "flexibility" catch-22

The cornerstone of the HCBS waiver – state flexibility – is also its catch 22 for participants. Every 3-5 years a state has the option to renew, not renew, or change the terms of its waiver program. HCBS services must be delivered pursuant to the development of a plan of care and based upon assessed individual needs. However, because the HCBS program is an optional benefit and states have the flexibility to determine the service package, number of persons to be served, target group, etc., a participant may find themselves cut from the program or with a different mix of services than in prior years. In Mississippi, for example, an approved waiver resulted in 48,000 people being cut from the waiver program. In nearly every state, Governors are considering changes to the Medicaid program.

There is no question that the HCBS waiver program has allowed thousands of individuals to be adequately served in community-based settings. The residents remaining in our nation's ICFs/MR, however, are the most fragile and most in need of consistent, high quality, services. When considering the waiver option, individuals, families and guardians are cautioned to weigh the benefits with the costs.

ATTACHMENT C

The services people receive in licensed Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR)

For More Information

Background and Milestones – ICFs/MR →

http://www.cms.hhs.gov/CertificationandCompliance/downloads/ICFMR_Background.pdf

ICFs/MR: → Meeting the Long Term Care Needs and Maximizing the Potential of Individuals with MR/DD:

<http://www.ihca.com/consumer/ddcare.htm#Meeting>

Characteristics of Residents of Large Facilities: →

<http://rtc.umn.edu/docs/risp2008.pdf> (pages 33-39)

ICFs/MR as Permanent Homes: →

http://vor.net/images/stories/ICFsMR_are_home.pdf

ICFs/MR: A sampling of the comprehensive services provided to residents

Medical	Dental	Behavioral psychology	Clinical social work	Dermatology
ENT	Gastroenterology	Gynecology	Neurology	Nursing
Nutrition	Occupational therapy	Physical therapy	Orthopedics	Ophthalmology
Pharmacology	Psychiatric	Podiatry	Pulmonology	Lab work
Speech/language therapy	Therapeutic recreation (e.g, swimming, equestrians, etc.)	Vocational assessment, training and opportunities (on and off campus)	Wheelchair clinics/Rehab engineering	Assistive technology/communication augments/switch activation
audiology	Respite Services	Habilitation	Staff and Student Training (classroom/on-the-job).	Residential, including dormitory, group homes, private rooms, cottages, apartments.
Direct care for activities of daily living (eating, dressing, bathing/hygiene, toileting, mobility, etc.)	Sensory integration/Stimulation Room	Pet therapy	Respiratory therapist	QMRPs
Family Support and Advocacy Organizations	Active Treatment Services	Transportation	Library	Nutritionist/Dieticians
Religious services/chapel	Human Rights Committee	Cafeteria, private kitchens, Canteens	Restaurants and stores open to public	Other services not noted here

This comprehensive assortment of federally-certified professional therapeutic, dietary, health care, recreational, and residential services is required by the neediest, most fragile, and most disabled members of our society.

Group homes – even those homes that are certified by the Centers for Medicare and Medicaid Services (CMS) – do not provide the same level of programming, with the same assortment of onsite, specialized services, as ICFs/MR.

For many ICF/MR residents, the provision of professional support and health care is required for their very survival.

ATTACHMENT D

October 12, 2011

Dear Chairpersons Van Drew and Huttie and Members of the Review Panel:

My name is Dr. Matthew Holder, I am writing in support of the Community Resource Center model, as recently proposed by VOR, a national advocacy organization for persons with intellectual and developmental disabilities. I am the Chief Executive Officer of what is arguably the most successful patient care, teaching and research model of dental care designed for people with neurodevelopmental disorders (ND) in the United States, the Underwood and Lee Clinic in Louisville, Kentucky. I would like to share with you our experience in starting, maintaining, growing and transforming this clinic over the past decade.

The Community Resource Center Model is not a new concept. It has been around for over a decade. In 1999 our clinic founder, Dr. Henry Hood, first started working on the idea of building an outpatient clinic on the campus of the Hazelwood Intermediate Care Facility for Mental Retardation (ICF/MR) in Louisville. Originally, the concept was to have a medical and dental outpatient clinic focusing exclusively on adults with neurodevelopmental disorders and/or intellectual disabilities (ND/ID) living in the community. One of the benefits of the model was that existing ICF/MR infrastructure could be utilized, thereby reducing the cost of care provided.

As a concept in 1999, the Underwood and Lee clinic met some significant resistance. There was resistance from those in the state who felt that ICF/MR infrastructure was untouchable ground – that people in the community would be so repelled by the thought of setting foot on ICF/MR grounds, that the clinic would be destined to fail. There was resistance from those who had the incredibly misguided notion that community-based healthcare was adequate for this population and that a specialized clinic would only represent redundant care – after all, there were Medicare clinics and Federally Qualified Health Centers (FQHC) who were supposedly taking care of this population. There was resistance from those in the state who only examine finances. Their objection was that the cost of such care simply was not a sensible investment for the state. And of course, there was resistance from within state government itself, because what was being proposed was an unproven and untested concept.

After a lot of negotiating, what started off as a proposal for a medical/dental outpatient clinic (with a proposed operating budget of \$2,000,000 per year) became whittled down to a dental clinic that started with only a \$350,000 annual operating budget. The general consensus among the detractors of the project was that the Underwood and Lee clinic would be lucky to survive more than two years and that surely no more than 300 patients would ever come to the clinic.

I am happy to report that the detractors of the original project, from all areas, have been proven wrong. The Underwood and Lee Clinic now serves over 1,000 patients from 45 counties in the state. Despite the fact that some of our patients drive 4 to 5 hours each way to access care at our clinic, we have a 97.2% patient satisfaction rate (the other 2.8% only rated their opinion of our clinic as just "average" – none ranked it as "below average" or "poor").

The Underwood and Lee Clinic's research program established, early on, that it was not performing redundant care. Frequently, the clinic would see patients who had been unable to access adequate care for over 10 years. Some patients arrived at the clinic with more than a dozen painful dental abscesses in their mouths – a testament to their long-standing inability to find care at any other medical or dental facility in the state.

The teaching program at the clinic has positively affected the entire community of dental providers in the state. Since inception, nearly 500 dental students and dental hygiene students have rotated through the clinic, learning how to care for our special patient population.

Word of the success of the clinic has spread around the nation. The founders of the Underwood and Lee Clinic have been asked to consult with Senator Ted Kennedy, Senator Tom Harkin, the Surgeon General of the United States, the President's Committee on People with Intellectual Disabilities, HRSA, CMS, multiple governors and other government offices, to share their expertise in shaping this unique area of healthcare policy.

The soundness of the clinic as a fiscal investment has been recognized by both public and private insurance entities. In 2003, the clinic received an award from CMS for its innovative approach to patient care, and in 2007 the clinic received the Kentucky Area Health Underwriters award. This award has been historically reserved for the most innovative physicians: Dr. Jarvik for his work on the world's first artificial heart, Drs. Kutz and Kleinert for their work on the world's first hand transplant, and C. Everett Kopp for his work as Surgeon General are some of the previous recipients. 2007 marked the first year ever that this award was given to a dentist. That dentist was Dr. Henry Hood – for his ground breaking work at the Underwood and Lee Clinic.

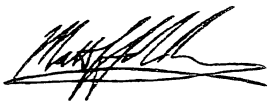
The feedback from patients of the clinic has been so positive that in 2008, the state approved a \$10 million appropriation to help expand the clinic. This is perhaps the most amazing part of the story of the Underwood and Lee Clinic. In these tough economic times, in a political environment of extraordinary budget shortfalls, massive budget cuts, and even a major political shift from a Republican administration to a Democratic administration, the Underwood and Lee Clinic prevailed as one of the few projects worthy of capital investment in the Commonwealth of Kentucky.

By 2012, the Underwood and Lee Clinic will open the doors of its new clinic. At that time, it will have the capacity to serve over 4000 people with ND/ID, in the fields of medicine, dentistry and psychiatry / behavioral care. It will have an annual operating budget of between \$4 - \$5 million.

To be sure, as with any new venture, there is no guarantee of success. Creating a successful Community Resource Center requires the proper vision, funding stream, personnel, knowledge base and management. Over the past 10 years, we have learned many of these lessons through trial and error. Should New Jersey choose to invest its resources into a similar model of care, however, I can assure you through personal experience that with the proper attention to these factors, the CRC model can be successful in New Jersey as well.

If you would like to speak with us in more detail about our experience with the Underwood and Lee Clinic we would be happy to answer any questions. Please feel free to contact us at anytime.

Sincerely,



Matthew Holder, MD, MBA
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Executive Director, American Academy of Development Medicine and Dentistry
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WRITTEN, PUBLIC TESTIMONY SUBMITTED TO:

**NEW JERSEY LEGISLATIVE REVIEW PANEL ON STATE
PSYCHIATRIC HOSPITALS AND DEVELOPMENTAL CENTERS**

**TESTIMONY TOPIC AREA:
DEVELOPMENTAL CENTERS**

**Tuesday, October 17, 2011
Trenton, New Jersey**

Testimony of:

Kevin K. Walsh, Ph.D.
Director of Quality Management and Research
Developmental Disabilities Health Alliance, Inc.

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Attachment/Appendix:

Six Fact Sheets on Developmental Center Closure in New Jersey

FACT SHEET #1: Integration, Olmstead, and the ADA
FACT SHEET #2: "Institution vs. Community?" or "Waiver vs. ICF/MR?"
FACT SHEET #3: Utilization of Institutional Services: Is New Jersey Really 49th in the Nation?
FACT SHEET #4: Mortality After Deinstitutionalization
FACT SHEET #5: Cost Differences: Institution vs. Community
FACT SHEET #6: Direct Care Compensation and Turnover

[Qualifications of above individuals are attached at the end.]

Testimony: 5 pages

Fact Sheets: 10 pages

Witness Qualifications: 2 pages

A. Introduction

There are several sets of facts that are often not fully understood in public debate on the future of developmental centers. These have to do with how centers are funded, potential cost savings if centers are closed, comparisons of New Jersey to other states, and so forth. To clarify some of these important issues we have appended six brief (mostly single-page) fact sheets to this testimony as crucial background information to the more pragmatic testimony that follows. It is critical that legislators or members of their staff review these fact sheets because they elucidate important elements that have a bearing not only the future of developmental centers, but on how best to build a comprehensive system of services and supports for individuals with intellectual and other developmental disabilities (formerly: "people with mental retardation) in New Jersey. In the testimony proper that follows, we will focus on a pragmatic view of the system including services and supports offered under the Medicaid ICF/MR program (that is, in developmental centers) and under the Home and Community-Based Services (HCBS) waiver program, known in New Jersey as the *Community Care Waiver*.

B. The Two Models of DD Services: ICF/MR and HCBS Waiver

ICF/MR and HCBS Waiver. Federal Medicaid funding supplements New Jersey funds in two predominant ways for people with developmental disabilities: (1) the ICF/MR program (DCs) and (2) the HCBS program (community). Medicaid service requirements for these programs are not the same. ICF/MR programs (largely in DCs in NJ) must meet stringent *federal* regulations which are comprised of more than 450 individual “tags” or requirements in order to qualify for federal funding. Waiver programs (i.e., the “Community Care Waiver” or CCW in NJ), on the other hand are individually created by states and approved by the federal Centers for Medicare and Medicaid Services (CMS). Therefore, all ICF/MR programs nationwide meet the same guidelines while waiver programs differ across the states. Similarly, there is more federal oversight of ICF/MR programs (e.g., federal “look behind surveys”) than typically exists in waiver programs. Finally, the federal Medicaid program allows states to “cap” waivers and therefore waiting lists for waived services have grown in every state (including for the CCW in New Jersey).

Service Access Problems in the CCW. In ICF/MR programs clinical professional and active treatment services are *bundled* and must be available to all individuals in the developmental center. Therefore, DCs have on staff, or hire as consultants, physicians, nurses, psychiatrists, psychologists rehabilitation therapists, pharmacists, and other professional practitioners; in contrast, in waiver programs services and supports, including professional clinical services, are *unbundled* – individuals funded by the waiver must locate services in community settings and access them through regular Medicaid programs and providers. For example, now, in New Jersey, health care services for people eligible for DDD services must enroll in Medicaid managed care.

This arrangement has not been problematic for individuals who need few professional, clinical, or behavioral services; however, there have long been barriers in NJ to care for people with developmental disabilities who require additional medical, nursing, rehabilitation, psychology, behavioral or other services. In fact, research (some carried out here in New Jersey) has shown that the lack of access to medical care, psychiatric services and behavioral supports often leads to subsequent institutionalization. In short, many services have *not* been accessible by people living under the CCW. Unfortunately, there have been almost no concerted efforts by DHS in New Jersey over the past two decades to improve the array of professional/clinical services available to individuals in the CCW (e.g., typically referred to as building the “community infrastructure”). Therefore, a gap has grown between services available to individuals in developmental centers (i.e., in ICF/MR settings) and those in the CCW program – it is this gap in services that helps to fuel the resistance to the closure of DCs by family members and guardians of residents.

C. The Needs of Individuals in New Jersey Developmental Centers

Self-Care Levels. In addition to research conducted by the DD Planning Institute at NJIT, the Division of Developmental Disabilities' own Olmstead Plan of May, 2007 (entitled the *Path to Progress*) highlighted the intense levels of need of individuals who currently reside in developmental centers. For example, the state's Olmstead Plan described the basic self-help and self-care needs of all individuals living in New Jersey developmental centers as follows:

- Of the 3,027 individuals living in NJ developmental centers at the time of the plan (2007), 39% (1,171 individuals) were rated as a *Level 4* with respect to **Self-Care**. Level 4 indicates that individuals can often not do anything for themselves; they may be able to eat and drink but are unable to self-toilet or dress; and caregivers must spend most of their time providing basic care and support.
- Another 1,042 individuals (34%) were at *Level 3* with respect to **Self-Care** which is described as: the majority can eat, drink, toilet, and dress themselves; but they need help with activities of daily living (laundry, preparing meals), and cannot shop or count change.

Therefore, taken together, 73% of individuals in developmental centers are rated at the two highest levels of need with respect to self-care.

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Behavior Problems. In addition, many, perhaps as many as 50% to 60% or more, of individuals who currently reside in developmental centers may have psychiatric diagnoses that require treatment with psychiatric medications. Thus, the DDD *Path to Progress* plan also identified the *behavioral* support needs of individuals then living in state developmental centers, with similar findings, as follows:

- There were 1,365 individuals (45%) who were rated as *Level 3* on behavioral support needs, which was the level designated as “**Formal Behavioral Supports Required**” and described as follows: one or more inappropriate/rule violating behavior, self-injurious behavior, aggressive/disruptive behaviors requiring special behavioral support including redirection, additional supervision, personal controls, or formal behavioral plan – behaviors include: tantrums/outbursts, smearing feces, self-injurious behaviors, hitting/kicking others, or property destruction.
- At Level 4, “**Intensive Behavioral Supports Required**,” the state’s plan identified 957 individuals, or 32% of the statewide developmental center population. These individuals were described as often requiring one-to-one staffing, personal controls, and implementation of formal behavioral plans for behaviors such as: sexual predatory behaviors, running away, pica (eating inedible objects), hitting, scratching, biting, choking, kicking, or head-butting.

Once again, taken together, 77% of individuals living in state developmental centers are rated as having one of the two highest levels of behavioral need. Without doubt, these individuals will need specialized mental health and behavioral services in community settings. In fact, New Jersey’s Olmstead Plan recognizes these facts and clearly states: “Reinforcing existing community services and supports and expanding the types of available services will be necessary so that people with greater health, behavioral and mental health needs can move from DC settings to the community...” (*Path to Progress Plan*, p. 9).

RECOMMENDATION #1: NJ/DHS, through DDD, must work to expand the professional clinical services (medical, psychiatric, behavioral, and other services) in community settings that will support individuals who live in the community under the CCW. DHS, through its Medicaid Division, must aggressively monitor the health organizations with whom it contracts to assure that specialized services for individuals with developmental disabilities are available and accessible.

D. A Heterogeneous Population Requires an Array of Service Models

People with intellectual and other developmental disabilities span the range of human diversity. Individuals in this group vary more than the general population – more than most people understand or realize – ranging from individuals little different from the general population to individuals who need constant care.

Mild Disabilities. People with mild intellectual disabilities who need only minimal supports to live in community settings are barely distinguishable in the general population. The vast majority of such individuals, if not all of them, who are often thought of as having mild intellectual disabilities, already live in community settings. They are our co-workers, friends and neighbors and need only minimal services and supports to succeed in community settings. In the past, many of these individuals were inappropriately placed in state institutions; for the most part, unless they have associated mental health or behavioral problems or were placed in such settings by court order following criminal behavior, these individuals are *no longer residing* in developmental centers.

Severe and Profound Disabilities. However, people with severe and profound disabilities are far different in their needs. These individuals are quite noticeable in the general population, and often have few or no self-help or adaptive skills. They require personal assistance for all areas of their life, have associated multiple disabling medical conditions, and are often quite fragile and in need of constant and pervasive services and supports (that is, round-the-clock care). These are the individuals who, by far, make up the bulk of individuals in larger congregate care facilities in America and in New Jersey (cf. *NJ DDD Path to Progress*, May 2, 2007; this is the NJ/DHS and NJ/DDD Olmstead Plan).

Conclusion. For the most part, the guardians of people with severe and profound disabilities believe that their family members do better in developmental centers (i.e., under the ICF/MR model of services) while

the families and guardians (and the individuals themselves) of those with mild and moderate disabilities typically prefer waiver services in community-based settings under the CCW. Current surveys of developmental centers family members in nearly all states consistently find them supportive of DCs. A recent survey in New Jersey found that 96% of respondents preferred that their family member remain in the DC. At the same time, the majority of individuals in the DDD population (i.e., the larger numbers of mildly and moderately disabled) are able to thrive in community settings and clearly prefers such arrangements.

RECOMMENDATION #2: New Jersey must continue to provide *both* ICF/MR level services in developmental centers (or create new private ICF/MR capacity) *and*, at the same time, continue to provide HCBS waiver services and supports under its current CCW.

E. Potential DC Efficiencies – Consolidation and Closure

At present, through DDD, the NJ/DHS operates seven (7) developmental centers with substantially reduced numbers of residents at all centers compared to historical numbers. That is, as the census at the developmental centers has declined, the number of institutions has remained relatively constant. The last closure was the North Princeton Developmental Center, which was closed in 1998. It is reasonable to search for efficiencies within developmental centers through consolidation (i.e., moving individuals from one DC to another) and through closure of centers.

Consolidation. The availability of ICF/MR-certified (or certifiable) beds across the developmental center system should be assessed and analyzed in comparison to the number of current residents in all developmental centers. Similarly, any specific expertise (e.g., behavioral programming, aging services, forensic units, etc.) should be taken into account prior to making any consolidation or closure decisions. If consolidation is possible, movement of individuals should be *carefully* conducted and minimized to the extent possible. Movement should be avoided for the most disabled and medically fragile. All residents and their families should be fully prepared for consolidation before it takes place; residents, family members and staff should make visits and meet the staff members of other settings. In addition, because the average population of developmental centers is aging there will be a natural downsizing that takes place which will help to support such consolidation.

Closure. A single developmental center (the smallest) should be initially targeted for closure while consolidation takes place. Time frames should be ample to avoid negative impact on the quality of life of individuals served by developmental centers. Despite recent public debate over the closure of the Vineland Developmental Center, it does not seem reasonable that it should be the first to be targeted because: (1) it serves a large number of very disabled individuals (at the highest risk of negative outcomes, including death, following movement to community settings); (2) it has an admirable record with respect to federal authorities (CMS and DOJ) inasmuch as other New Jersey DCs have been threatened with the loss of federal financial participation for quality problems and continue to operate under consent decrees with the US Department of Justice, (3) there are too few health care, behavioral, and other specialized ancillary services in southern New Jersey to care for the high proportion of VDC residents that have indicated a desire to remain in southern NJ when leaving the DC and (4) VDC is an economic necessity in its region (located in the county with the highest unemployment rate statewide). Thus, it seems reasonable to look to close other facilities first.

RECOMMENDATION #3: Analyze current DC capacity and performance in order to consolidate capacity. Consolidate residents statewide to produce efficiencies in both capacity as well as specialty care and/or facility expertise.

RECOMMENDATION #4: Identify one smaller DC for closure and move residents either to other DCs or to community settings as they choose. When one DC has been successfully closed and outcomes assessed, then target a second for

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closure and initiate long-term planning. At the point of selecting the second DC for closure, consider balancing closures statewide, i.e., close one in the north and one in the south.

F. The Need for Community Infrastructure

When New Jersey last closed a developmental center (the North Princeton facility in 1998), the Department and the Division clearly recognized the need for specialized services and supports in the community that would be accessible for individuals with developmental disabilities. In addition to providing funds to NJIT to follow and study the effects of the closure, the Department took direct steps to enhance the professional services infrastructure in the community. Among other things, the state took the following steps to provide specialized services by developing:

- **ISDT Services:** Developed the ISDT (Integrated Service Delivery Team) program at Trinitas Hospital which has now been expanded, beyond Trinitas, and is offered by other providers in northern and north-central DDD regions.
- **Health/Mental Health Services:** Provided funding to support a community-based, specialized health and mental health care office in Hamilton.
- **Dental Services:** Developed a community-based dental clinic with a practitioner who had worked with individuals who had resided in North Princeton. [This clinic has since closed.]
- **Therapeutic Services (Behavioral Supports, OT, PT, and Speech Therapy supports):** Maintained an active therapeutic network (called the ITN program – *Integrated Therapeutic Network*; a name later changed to the CPST – *Community Professional Supports and Training* program) that provided, as part of the Division's Community Care Waiver, professional services to individuals living in community settings. [This program has since been, inexplicably, discontinued by DDD.]

Unfortunately, more recent discussions of DC closure (e.g., around VDC) has not, to date, given rise to similar, community-based programmatic efforts. This is particularly problematic because it is even more difficult for individuals with intellectual and other developmental disabilities to access health care, mental health, and behavioral services in the southern part of the state. For the most part, existing specialized services (e.g., ISDT) are *only* available in the northern parts of the state. We believe that services for people with developmental disabilities *must* include the development of community-based infrastructure in the areas of health, mental health, ancillary therapies, and behavioral supports. These services will no longer be available to former DC residents once they leave the developmental center.

RECOMMENDATION #5: When there is developmental center closure there must also be concurrent development of health, mental health, and behavioral support components (i.e., "community infrastructure"), especially in community settings in the *southern* part of the state.

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DEVELOPMENTAL CENTER CLOSURES IN NEW JERSEY

▶▶ 6 FACT SHEETS ◀◀

- FACT SHEET #1: **Integration, Olmstead, and the ADA**
- FACT SHEET #2: **“Institution vs. Community?” or
“Waiver vs. ICF/MR?”**
- FACT SHEET #3: **Utilization of Institutional Services: Is New
Jersey Really 49th in the Nation?**
- FACT SHEET #4: **Mortality After Deinstitutionalization**
- FACT SHEET #5: **Cost Differences: Institution vs. Community**
- FACT SHEET #6: **Direct Care Compensation and Turnover**

►► FACT SHEET #1 ◀◀

INTEGRATION, OLMSTEAD, AND THE ADA

1. **The “Integration Mandate”** – The “integration mandate” referred to appears in Section 504 of the Rehabilitation Act, in the Americans with Disabilities Act (ADA) and in the Code of Federal Regulations (CFR) and holds that people need to live in the least restrictive setting *that is appropriate to their needs*. In this way it is a *qualified* mandate.¹
2. **Clarification of the Olmstead Decision** – The Supreme Court’s decision in the Olmstead case (Olmstead v. L.C.) interpreted the nature of segregation under Title II of the ADA. The decision concluded that states are required to provide treatment in a less restrictive setting when:
 - a) **The state’s treatment professionals determine that it is appropriate for the person**
 - b) **The person (or his/her legal guardian) does not oppose such placement**
 - c) **The placement can be accommodated given the resources of the state.**²

Thus, the Olmstead Decision also sets up a *qualified* mandate; in the end, it is clear that the decision to move to a less restrictive setting is vested in the persons served and/or their legal guardians and depends on whether the community is *appropriate* to the needs of the person. Regardless, individuals may elect to remain in a more restrictive setting.

3. **Olmstead Recognizes that Some People Need Institutional Settings.** The Supreme Court recognized that for some individuals “no placement outside the institution may ever be appropriate.” (Olmstead Decision p. 20). Furthermore, the Court noted that “...the ADA is not reasonably read to impel States to phase out institutions.” (Olmstead Decision p. 20).
4. **New Jersey’s Approach is Not Consistent with the Olmstead Decision.** The Department of Human Services has stated that it will rely upon three decisions in determining who is to move from the VDC: (1) the treating professionals; (2) the legal guardian’s; and (3) the residents themselves. Because nearly all of the VDC residents have been determined to be in need of a legal guardian, they may not have the legal right to consent to treatment in the Home and Community-Based Services (HCBS) waiver. As noted in #2b above the legal guardian makes the final determination. It would be inappropriate for New Jersey to, for example, place someone in a community setting based on their decision if that person is not their own guardian.
5. **CONCLUSION:** Individuals are *not* discriminated against simply because they live in an institution; states only discriminate against such individuals when they remain in an institution despite (1) the State’s treatment professionals determine that the community is appropriate for the person, AND (2) the person (or their guardian) does not oppose such placement, AND (3) such a placement can be reasonably accommodated given state resources. In such a case, if the state does *not* place the person in a community-based setting then, according to the Supreme Court’s Olmstead decision, the state would be discriminating against the individual.

¹ “A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 CFR §35.130(d) (1998).

² “...under Title II of the ADA, State States are required to provide community based treatment for persons with mental disabilities when the State’s treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.” (Olmstead Decision p. 22)

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►► FACT SHEET #2 ◀◀

“INSTITUTION VS. COMMUNITY?” OR “ICF/MR VS. WAIVER”

1. **Medicaid Models.** The language of the institutional closure debate (“institution vs. community”) masks important differences in the two major Medicaid programs. Federal payments are received by New Jersey for both community-based and institutional settings – but under two separate Medicaid programs: (1) the Intermediate Care Facilities/Mental Retardation (ICF/MR program) for developmental centers and (2) the Home and Community Based Services (HCBS) waiver, which in NJ/DDD is known as the *Community Care Waiver*. These programs offer fundamentally different models of treatment.
2. **ICF/MR** – The Medicaid ICF/MR funding model provides federal matching funds for individuals residing in institutional settings. The ICF/MR program model requires comprehensive interdisciplinary planning and treatment services as well as *active treatment* according to federal guidelines. “Active Treatment” is a specific program of interdisciplinary training/treatment interventions delivered on site by licensed professionals according to ICF/MR federal guidelines. Continued federal funding is contingent on the facility meeting the ICF/MR guidelines.
3. **HCBS Waiver** – The Medicaid Home and Community-Based Services waiver program provides community-based care to individuals who would otherwise need institutional-level care. In this program certain requirements of the ICF/MR model are *waived*; under the waiver the services are *unbundled* such that the agency that provides residential services may not necessarily be the same agencies or professionals providing health care, behavioral supports, nursing, and other therapies. Instead, services must be accessed through various existing funding mechanisms (e.g., Medicaid for health care) that are generally accessible by other citizens of the state as well. Thus, for example, physicians must be accessed in the community and payment comes from Medicaid (through managed care). There is no body of federal service guidelines because each state’s HCBS waiver program is different; thus providers must meet quality guidelines established by the state.
4. **Choice Between ICF/MR and Waiver Services.** When someone becomes eligible for long-term care services, Medicaid regulations, as well as the federally-approved New Jersey Community Care Waiver require that the person be given a choice between receiving services in an institutional or community setting. If the state offers ICF/MR services, such services rise to the level of an entitlement and must be provided immediately; although services in community settings funded under the waiver are permitted to have a waiting list. This is what has given rise to the large waiting lists for services in states, including New Jersey.
5. **CONCLUSIONS:** Neither the ICF/MR nor the waiver model is necessarily inherently superior to the other. The best model is the one which best meets the needs of the individual. Decisions about which to choose must be made on an individual basis by the person and/or his/her family/guardian. People who have lived in developmental centers, and who have extensive and multiple disabilities often prefer the ICF/MR model because of the assured access to a wide-range of professional services and supports. Individuals with fewer service needs often find that the flexibility of the HCBS waiver suits them better. In short, *where* one lives and *which* model of services is best for a person is an *individual decision*, a decision that has been guaranteed to all individuals served, by both the Medicaid rules as well as the Supreme Court Olmstead decision.

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►► FACT SHEET #3 ◀◀

UTILIZATION OF INSTITUTIONAL SERVICES: IS NEW JERSEY REALLY 49TH IN THE NATION?

The claim that New Jersey has more institutional beds than all but one state (Texas) has been repeatedly voiced by advocates for institutional closure. Although true in absolute terms, it is not the case on a *per capita* basis. Additionally, when states have closed state-operated ICF/MR developmental centers, they have often relied on privately-operated ICF/MR facilities at the same time. New Jersey, in contrast, has not increased the number of private ICF/MR beds in more than 25 years. Thus, many states have been able to close public institutions by using private institutions. To compare New Jersey's developmental center system to other states, a more reasonable approach is to examine the size of facilities on a per capita basis and to include consideration of both public and private ICF/MR facilities.

According to researchers at the University of Minnesota, 42 states, including New Jersey, fund privately-run ICF/MR facilities serving between 21 individuals (in Colorado) and 6,841 (in California).³ As of 2009, New Jersey had only 2 privately-operated ICF/MR facilities serving only 80 individuals – well below the national average. Indeed, despite its large population, New Jersey ranked 34th of 50 states and the District of Columbia in the total number of individuals living in any type of ICF/MR (public or private). Thus, 17 states have *more* individuals, per 100,000 population, in public and private ICF/MR facilities than New Jersey has (see table on next page).

By June 30, 2009 eight states and the District of Columbia no longer operated public institutions of 16+ beds for this population (AK, DC, HI, ME, NH, NM, RI, VT, and WV).⁴ However, three of these states continue to fund public or private ICF/MR facilities of 16+ beds, and six of them fund private ICF/MR facilities of up to 15 beds, thereby affording their residents continued access to ICF/MR services. Alaska and Michigan are the only states that do not offer ICF/MR services.

Nationwide there are 401 *private* ICF/MR facilities of 16 or more beds. Several states have *very* large numbers of such private 16+ bed facilities (Florida has 55; Illinois has 46; Iowa has 30; New York has 82; Ohio has 83; Pennsylvania has 36; and Texas has 30) while New Jersey has only two private ICF/MR facilities.

Therefore, by moving people from *public* institutions to *private* institutions several states have been able to close their state-run developmental centers. Because New Jersey only has two private ICF/MR facilities, it needs to continue to support some of its developmental centers. Substantial reduction of developmental center capacity may require New Jersey to increase its capacity to provide

³ Lakin, K.C. Larson, S.A., Salmi, P. & Webster, A. (2010). *Residential services for persons with developmental disabilities: Status and trends through 2009*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute of Community Integration.

⁴ Ibid.

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Rank	State	Pop Est. 2,009	All ICF/MR Residents 2009	ICF/MR Residents Per 100,000
1	Alaska	698,473	-	0
2	Michigan	9,969,727	-	0
3	Oregon	3,825,657	22	1
4	Vermont	621,760	6	1
5	New Hampshire	1,324,575	25	2
6	Maryland	5,699,478	129	2
7	Colorado	5,024,748	115	2
8	Arizona	6,595,778	200	3
9	Rhode Island	1,053,209	38	4
10	Nevada	2,643,085	100	4
11	Alabama	4,708,708	233	5
12	Montana	974,989	52	5
13	Hawaii	1,295,178	91	7
14	Georgia	9,829,211	761	8
15	Washington	6,664,195	760	11
16	New Mexico	2,009,671	231	11
17	Missouri	5,987,580	785	13
18	Massachusetts	6,593,587	866	13
19	Delaware	885,122	120	14
20	Maine	1,318,301	183	14
21	Kentucky	4,314,113	623	14
22	Florida	18,537,969	3,100	17
23	Tennessee	6,296,254	1,089	17
24	South Dakota	812,383	146	18
25	Kansas	2,818,747	521	18
26	Virginia	7,882,590	1,606	20
27	Nebraska	1,796,619	427	24
28	California	36,961,664	9,293	25
29	West Virginia	1,819,777	477	26
30	Utah	2,784,572	780	28
31	Connecticut	3,518,288	1,080	31
32	Pennsylvania	12,604,767	3,939	31
33	South Carolina	4,561,242	1,445	32
34	New Jersey	8,707,739	2,865	33
35	Minnesota	5,266,214	1,747	33
36	Idaho	1,545,801	535	35
37	New York	19,541,453	7,664	39
38	North Carolina	9,380,884	3,854	41
39	Texas	24,782,302	10,792	44
40	Oklahoma	3,687,050	1,616	44
41	Ohio	11,542,645	6,136	53
42	Arkansas	2,889,450	1,598	55
43	Indiana	6,423,113	4,129	64
44	Illinois	12,910,409	8,525	66
45	Iowa	3,007,856	2,056	68
46	District of Columbia	599,657	443	74
47	Mississippi	2,951,996	2,644	90
48	North Dakota	646,844	584	90
49	Louisiana	4,492,076	4,988	111
50	Wisconsin	5,654,774	18,271	323
51	Wyoming	544,270	2,181	401
United States		307,006,550	90,348	29

ICF/MR services through contracts with private organizations, if access to ICF/MR level services is to be maintained. It is clear that, historically, New Jersey has elected to retain state-run developmental centers rather than invest heavily in private institutions.

At the same time, some states have also shifted state institution beds to *nursing homes* in the same way. For most individuals with developmental disabilities, this is not an ideal practice. Nonetheless, moving residents to nursing homes has allowed some states to claim reductions in developmental centers, at the expense of less appropriate services for many individuals with developmental disabilities who are moved to nursing homes.

An analysis of states' utilization of nursing homes for individuals with developmental disabilities shows that NJ ranks 24th nationwide; that is, there are 27 states that have placed more individuals in nursing home facilities than has New Jersey. In fact, New Jersey's utilization of nursing homes for this group (8.5 persons per 100,000 of population) is below the national average (11 individuals per 100,000).⁵

Finally, another reason that large, densely populated states (such as New Jersey, Pennsylvania, Illinois, Florida, California, New York) may continue to have more institutional capacity than smaller states is simply that they had *more* facilities to begin with. The fact that there are still seven developmental centers in New Jersey is, in part, the result of a long history of commitment to this population – with the state opening institutions in the late 1800's and early 1900's. In 1991, when New Hampshire became the first state to have no state-run institutions, it did so by closing its single, facility (Laconia State School and Training Center) and moving the most disabled individuals to private institutional placements.⁶

CONCLUSION. Because as late as 2009 New Jersey has 9 ICF/MR settings larger than 16 beds – the 7 state-run developmental centers and two private ICF/MR facilities – and because 17 states have more state and private ICF/MR institutional facilities than New Jersey, the allegation that New Jersey ranks 49th rings hollow.⁷ In fact, many other states have a rather large number of intermediate-sized private institutions. Furthermore, when New Jersey is compared to other states on a *per capita* basis and including all types of institutions, it is not “49th in the nation.” Therefore, this oft-stated statistic is not a very useful comparison, especially given the proliferation of private ICF/MR institutional settings across the nation.

⁵ Data from: Braddock, D., Hemp, R., & Rizzolo, M.C. (2008). *The State of the States in Developmental Disabilities*. Boulder, CO: Coleman Institute for Cognitive Disabilities, Department of Psychiatry, University of Colorado.

⁶ Note that with regard to individuals who have intellectual disabilities, New Jersey has six and a half times as many people than New Hampshire and therefore will have six and a half times as many individuals with disabilities.

⁷ After 2009, one of the private ICFs/MR discontinued participation in that program leaving only 1 private ICF/MR facility in NJ (of 48 beds).

▶▶ FACT SHEET #4 ◀◀

MORTALITY AFTER DEINSTITUTIONALIZATION

Mortality Research. People with intellectual and developmental disabilities often have co-occurring medical, behavioral, and adaptive behavior problems that increase their risk of death – for people in public ICF/MR settings (typically developmental centers), this risk is three times higher than the general population. As individuals have moved from these centers to community-based waiver-funded programs, questions have persisted about whether these individuals die at an increased rate compared to those who remain in the developmental centers. A very large study conducted in California in the mid-1990s found that the risk of mortality did increase when individuals were transferred to the community (compared to large publicly-operated ICF/MR settings).⁸

New Jersey Study. A more recent New Jersey report, from the Developmental Disabilities Planning Institute at the New Jersey Institute of Technology (DDPI-NJIT), studied individuals who moved from the North Princeton Developmental Center (NPDC).⁹ This study is important because it followed two matched groups during an actual developmental center closure. Two groups – 150 “movers” (individuals who moved to the community from NPDC) and 150 “stayers” (individuals who lived in other developmental centers) were matched according to characteristics known to be associated with an increased risk of mortality. This study followed both groups of subjects for a period of only 27 months.

Findings from the North Princeton Closure. During the study period there were 22 deaths for “movers” but only 13 for “stayers” (see chart below). The rate of mortality of the two groups was different; 14.7% of the community group died compared with 8.7% of the institutional group. When

Deaths documented by Lerman, et al. (2003)

Follow-up (months)	MOVERS	STAYERS	Deaths
4 months	4 (44%)	5 (56%)	9
15 months	9 (64%)	5 (36%)	14
27 months	9 (75%)	3 (25%)	12
Totals	22 (63%)	13 (37%)	35

the study ended, the number of deaths reported between the two groups was diverging. During the last measurement interval (months 15 to 27) 75% of the deaths (9 of 12) occurred in the community (that

⁸ Dr. Ted Kastner, a New Jersey practitioner and national leader in health care for people with developmental disabilities was a co-author on this study which found in a study of over 22,000 individuals a risk-adjusted mortality rate that was 72% higher in the community than in the institution. [Strauss, D., Kastner, T., & Shavelle, R. (1998). Mortality of adults with developmental disabilities living in California institutions and community care, 1985-1994. *Mental Retardation*, 36, 360-371.]

⁹ One of the authors of this study was Dawn Apgar, now the Assistant Commissioner responsible for DDD (Lerman, P., Apgar, D.H., Jordan, T., & Taylor, S.J. (2003). Deinstitutionalization and mortality: Findings of a controlled research design in New Jersey, *Mental Retardation*, 41, 225-236.

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is, the "movers" group). The difference in the numbers of deaths between the two groups, however, was not "statistically significant" although it was nearly so (it would have been statistically significant had there been one more death among movers and one fewer death among stayers, or perhaps if there had been a larger sample).

It is, therefore, not at all unlikely that if the study had been continued for a longer period, the difference in the number of deaths in these two groups would have reached statistical significance, suggesting increased mortality risk associated with community placement as previous studies had reported. Although extensions of this study have been suggested, the Department has not carried one out.

CONCLUSION: Previous very large-scale studies have found mortality differences; the small New Jersey mortality study of the North Princeton Developmental Center closure was truncated at 27 months although there appeared to be mortality differences that were developing in the two groups. This study should be extended beyond 27 months to determine if there actually are any differences between the two groups studied.¹⁰

¹⁰ This study would not be difficult to conduct; all that would be needed are the names of the 300 subjects and a determination if they are still alive and, if not, the date on which they died.

►► FACT SHEET #5 ◀◀

COST DIFFERENCES: INSTITUTION VS. COMMUNITY

Will funds be “liberated” by DC closures? In its *Blueprint* for the VDC closure, DHS reinforced this perception by implying that per capita costs would be reduced from \$310,000 (incorporating “interdepartmental” costs) in the institution to \$160,000 in community settings. This striking difference begs the questions (1) how were these cost estimates made? and (2) what services costs could possibly account for the \$150,000 difference that is claimed?

Cost Comparison Research. Published research in this area is equivocal – with both community and institutional advocates claiming studies that support their own positions. Overall, the research has been criticized with respect to methodology because, among other things, it often doesn’t take into account differences in the groups studied (referred to as *case mix*) resulting in apples-to-oranges comparisons.¹¹

Comparisons between institutions and community are more comparable if individuals from the institution are *followed* to the community while tracking costs. A study of the Hissom Memorial Center, an Oklahoma institution, did just this and found that, on average, when the individuals from the center were placed in community settings they cost \$34,000 more per person than other Oklahoma community-based residents and required staffing ratios that were often 2.5 times as high.¹²

Cost Shifting. Furthermore, the issue of *cost shifting* is often ignored. Costs in ICFs/MR are for comprehensive, or *bundled*, services – that is, the facility provides residential staff, psychologists, social workers, rehabilitation therapists, physicians, nurses and other specialized personnel. Additionally, the facility provides transportation, and safety and security officers. In community settings, many of these costs are *shifted* elsewhere, to other Divisions or Departments or to municipalities. For example, health care costs (physicians and nurses) are *included* in the institutional costs for a person. However, in the community, health care costs are paid, not by DDD, but by DMAHS (Medicaid) and therefore go off the DDD budget. While this may be a “cost savings” from the perspective of a DDD administrator; it is *not* a cost savings from the perspective of a legislator or the Governor, or taxpayers – that is, costs are just shifted.

Even when savings in the community are found, they are reported to be between 5 and 30 percent – and are more than offset by the difference in salaries and benefits between state-employed staff and employees of private providers in the community. Thus, it may be that any cost savings between the two settings is borne by the workers in the community setting – not necessarily a strong argument for institutional closure when considering that the individuals requiring care are among the most disabled in society.

CONCLUSION: Claims about cost savings need to be carefully examined; *case mix* and *cost-shifting* affect any comparison offered. Cost savings claimed by the NJ *Blueprint* for the VDC closure are 48 percent! This is a striking figure that is far higher than published literature in the field typically reports.¹³

¹¹ Walsh, K.K., Kastner, T.A. & Green, R.G. (2003). Cost comparisons of community and institutional residential settings: Historical review of selected research. *Mental Retardation*, 41, 103-122.

¹² Jones, J., Conroy, J.W., & Sprent, S. (1999, June). *Costs of support for the former residents of Hissom Memorial Center* (Rep. No. 8 in the Oklahoma Outcome Series). Center for Outcome Studies, Rosemont, PA.

¹³ Stancliffe, R.J., Lakin, K.C., Shea, J.R., Prouty, R.W., Coucouvanis, K. (2005). The economics of deinstitutionalization. In R.J. Stancliffe and K. C. Lakin (Eds). *Costs and outcomes of community services for people with intellectual disabilities*. Baltimore: Brookes.

►► FACT SHEET #6 ◀◀

DIRECT CARE COMPENSATION AND TURNOVER

1. The stability of direct care staff is an important predictor of quality of care for persons with developmental disabilities.¹⁴
2. Research has shown that the most important predictor of turnover in staff members is wages. In the past, studies have reported that direct care staff turnover rates in New Jersey are higher in community settings (67.8%) when compared to public ICF/MR settings (20.3%).¹⁵
3. Direct care staff salaries in community settings in New Jersey have not kept up with inflation while those of state employees have. The gap between public and private employee compensation has grown in the past 12 years with community provider agencies receiving, taken together, about 11% cost-of-living increases overall; however, until very recently public employees have had routine salary and benefit increases that have kept pace with inflation.
4. The result is that the difference in direct care staff compensation has resulted in increased turnover in community settings as compared to public ICF/MR settings over the past 15 years.
5. Community providers have vigorously advocated around the "cost-of-living" issue over the past years showing that wage and compensation needs to increase for community direct care staff in order to prevent a widening of the direct care turnover gap between public and private providers.
6. Without the necessary investments in community direct care staff compensation, any potential savings associated with developmental center closure will likely be due to decreases in direct care staff compensation, a long-standing finding in the cost-comparison literature (Walsh, Kastner & Green, 2003).¹⁶
7. **CONCLUSION.** Individuals with intellectual and other developmental disabilities benefit from stable direct care staffing relationships. Going as far back as 1994, the rate of direct care staff member turnover in New Jersey was *more than three time higher* in community settings compared to developmental centers. It is likely that this turnover gap has widened in the past 15 years as the wage gap has widened.

¹⁴ Test, D.W., Flowers, C., Hewitt, A. & Solow, J. (2033). Statewide study of the direct support staff workforce. *Mental Retardation*, 41, 276-285.

¹⁵ Mitchell, D. & Braddock, D. (1994). Compensation and turnover of direct care staff in developmental disabilities residential facilities in the United States II: Turnover. *Mental Retardation*, 32, 34-42.

¹⁶ Walsh, K.K., Kastner, T.A. & Green, R.G. (2003). Cost comparisons of community and institutional residential settings: Historical review of selected research. *Mental Retardation*, 41, 103-122,

EXPERT QUALIFICATIONS

- I hold Masters (1978) and Ph.D. (1982) degrees in life-span developmental psychology, with an emphasis in intellectual and developmental disabilities, from The University of Akron. I have provided expert testimony or expert level consultation with respect to developmental disabilities and/or community and institutional services in eleven states (OH, CT, FL, ME, MD, MA, PA, AR, NJ, NE & WA).
- My entire career, pre-professional (i.e., direct care) and professional, has been in the area of developmental disabilities beginning with direct care work and including professional behavioral services and psychology. In addition, I have served as an executive-level administrator of both institutional and community residential, day, and professional services.
- I am a published author with 50 peer-reviewed publications in the field, on 36 of which I appear as either the first or second author. Additionally, I currently serve as one of 14 Associate Editors of the journal *Intellectual and Developmental Disabilities* published by the American Association on Intellectual and Developmental Disabilities (AAIDD, formerly AAMR). During my career, I have served as a regional president of that organization (AAMR, Region IX, Mid-eastern states) and also served two terms on the national AAIDD Board of Directors.
- Currently, I am the Director of Quality Management and Research of the Developmental Disabilities *Health Alliance, Inc.* a provider of primary care and mental health services, health care management, and behavioral supports to persons who have developmental disabilities. During 2005 and early 2006, I was the lead DDHA consultant on a contract providing technical assistance and training in quality improvement to the New Jersey Department of Human Services. In 2009 I managed a project that produced an independent interdisciplinary assessment of 229 residents of an ICF/MR facility in Nebraska. In 2010-2011 I was a member of the management consulting team that closed the Alexander Human Development Center in Arkansas. At present I am an active consultant to the Arkansas Department of Human Services, Division of Developmental Disabilities Services.
- Additionally, I have served since 1991 on the Board of Directors of the Arc of Cumberland County, New Jersey (serving most of that that period as President) an Arc-affiliated advocacy organization and a state-contracted service provider of family support, supported living, supported work, and other services and programs. I also am an at-large member of the Arc of New Jersey Board of Directors Executive Committee, having served five two-year terms as Southern Regional Vice President to the state Arc board and its Executive Committee.
- I also serve or served on the following state-level developmental disability policy or oversight groups within the New Jersey Division of Developmental Disabilities (DDD) and the New Jersey Department of Human Services (DHS):
 - * Statewide Interdisciplinary Research Committee (DDD), past chair; current member
 - * Statewide Behavior Management Policy Review Committee (DDD); current member
 - * Statewide Dual-Diagnosis Task Force – Adult Care Subcommittee (2007-2008)
 - * State Level Quality Improvement Steering Committee (DDD); past member (2000-2002)
 - * Statewide Olmstead Task Force – Outcomes Subcommittee (2007-2008)
 - * Medicaid Managed Care Working Group (DHS); past member (1998-2003)
 - * Shared Responsibilities Work Group (combined Mental Health and MR/DD task force) 1999-2006
 - * Long-Term Care Exploration Group (DDD, 1997-98)
 - * Aging Task Force (DDD, 1999-2000)
- Additionally, I have served on the Health Care Committee of the NJ Developmental Disabilities Council and currently serve on the Advisory Board of the Mainstreaming Medical Care Project of the Arc/NJ.

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EXPERT QUALIFICATIONS

- My entire career, pre-professional (i.e., direct care) and professional, has been in the area of developmental disabilities beginning with direct care work in 1976 and including professional health care services. In addition, I have served as an executive-level administrator of both hospital and community and professional services.
- Currently, I am the President of the Developmental Disabilities *Health Alliance, Inc.* a provider of primary care and mental health services, health care management, and behavioral supports with a variety of contracts. Our work has been recognized by the US Surgeon General, among others, as a national model.
- I hold the degrees of M.D. (University of Connecticut School of Medicine, 1981) and M.S. (University of Wisconsin School of Medicine, 1997). I am board certified in four specialties: Pediatrics; Developmental and Behavioral Pediatrics; Neurodevelopmental Disabilities; and Medical Management. I have provided expert testimony or expert level consultation with respect to MR/DD and/or community and institutional services in nineteen states including (AR, AZ, CT, FL, IL, IO, LA, MA, MD, OH, NJ, NE, NY, PA, SC, TN, TX, VA, WI & the District of Columbia), Canada and Israel.
- I hold appointments at the Associate Professor level in the Department of Pediatrics, New Jersey Medical School and Department of Internal Medicine, Robert Wood Johnson Medical School, both schools being in the University of Medicine and Dentistry of New Jersey. In addition, DDHA has served as a clinical training site for social workers and nurse practitioners from five universities.
- I am a published author with 68 peer-reviewed publications in the field and another 48 which were not subject to peer-review. Additionally, since 1993 I have served as one of 14 Associate Editors of the journal *Intellectual and Developmental Disabilities* published by the American Association on Intellectual and Developmental Disabilities (AAIDD, formerly AAMR). I have made more than 150 presentations at local, state, and national forums.
- During my career, I have served as the National President of AAMR Medicine Division, The Founder and National President of AAMR Special Interest Group on Health Promotion, The President of AAMR's New Jersey Chapter, and a board member of Region IX, Mid-eastern states. I served two terms on the national AAIDD (then AAMR) Board of Directors and was a member of AAMR's Legislative and Social Issues Committee. I have also served on the board of the New Jersey Chapter of the American Academy of Pediatrics and was a member of the national Committee on Children with Disabilities where I drafted national policies related to the health care needs of persons with developmental disabilities.
- I have been recognized for my work at a local, state, and national level, having received the Elizabeth Boggs Award (NJ UCP), The Health Care Provider of the Year (NJ ARC), the prestigious Ann Klein Advocacy Award (Community Health Law Project) in NJ and the National Leadership Award (National AMA).

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