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PEOPLE

WITH

DISABILITIES



MAILING ADDRESS  
New Jersey Council on  
Developmental Disabilities  
PO Box 700  
Trenton, NJ 08625-0700

LOCATION  
Mary Roebling Building  
20 West State Street, 7<sup>th</sup> Floor  
Trenton, New Jersey  
Office Hours: 9 a.m. to 5 p.m.,  
Monday through Friday

TELEPHONE 609.292.3745  
TDD 609.777.3238  
FAX 609.292.7114  
EMAIL [njddc@njddc.org](mailto:njddc@njddc.org)  
INTERNET: [www.njddc.org](http://www.njddc.org)

**PEOPLE WITH DISABILITIES**

EXECUTIVE EDITOR  
Ethan B. Ellis

MANAGING EDITOR  
Norman Reim

WRITERS  
Maryann B. Hunsberger  
Jonathan Jaffe

PHOTOGRAPHY  
Rebecca Shavulsky

DESIGN  
Gregory Mizanin

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The New Jersey Council on Developmental Disabilities is an advocacy and systems-change agency composed of 30 members appointed by the governor and subject to the approval of the New Jersey Senate. In keeping with Federal and state statutes, Council membership includes: people with developmental disabilities; parents or guardians of people with disabilities living in institutional or community settings; representatives of local, non-governmental agencies that provide services to people with developmental disabilities and their families; and representatives of the principal state agencies that provide services to people with developmental disabilities and their families. The Council's mission is to help people with developmental disabilities increase their independence, productivity and integration into their communities. To fulfill its mission, the Council develops and monitors a State Plan for Services and administers the federally assisted Basic State Grant Program. The Council employs a staff to perform administrative and clerical functions.

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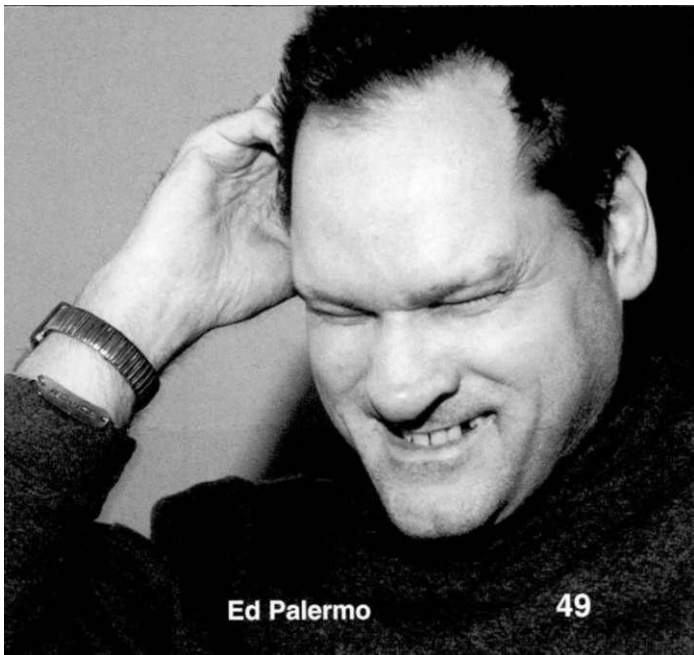
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By Ethan B. Ellis

# Our History

**P**eople with developmental disabilities have lived in New Jersey since its founding and its citizens and governments have supported them from the beginning. Usually those supports reflected society's attitudes about people with developmental disabilities at

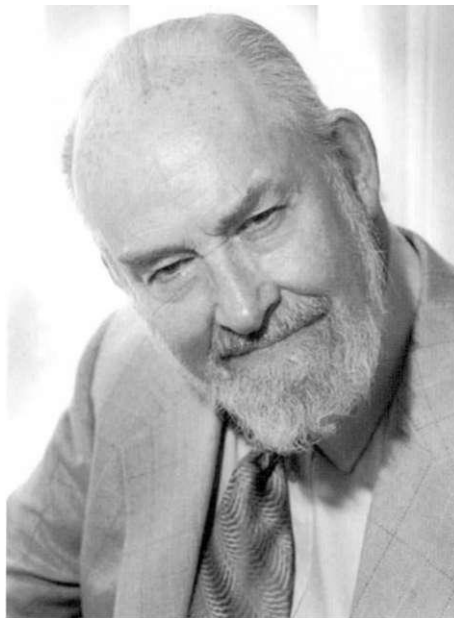
the time. Sometimes those supports improved attitudes; sometimes they lagged behind them and made life worse for the people they were supposed to help.

In this Issue, we sketch the history of supports for people with developmental disabilities in our state. In doing so, we learn that NJ has contributed more than its share to the field—in ideas, practices and leaders.

Most of the ideas and practices have been beneficial; a few have not. Most of our leaders attained national stature. Many had forceful, even colorful personalities. Most advanced the cause; a few set it back.

Here you will meet them and judge their contributions for yourself. Some of their names will be familiar—Elizabeth Boggs, Maury Kott, Eddie Moore, Bob Nicholas. Some may not be—Edouard Seguin, Henry Goddard, Edward Johnstone. James Ells, Dave Rosen. Who you recognize may depend on how long you've been around or how much of a history buff you are.

The early part of our story is, by necessity, told through researching the written-word—books, journals, newspapers. Even the oldest of us



were not around in the beginning. The rest is told through interviews with the people who lived it or knew people who had. In some cases, they take us back 70 years or more.

Mother and Dad were historians so I grew up with an innate, if not genetic, attraction to the subject. Early on, I read about ancient Rome and the American Civil War, choices dictated as much by a love of drama as by a hunger for knowledge.

I never questioned what I read. It was history. It was written down. It was true.

Then Dad gave me a short course

in historiography, how and why history is written. I learned that much of it is subjective, based on who remembered what, and that colored what they thought of the actors, including themselves.

That is true of what we offer here, though we have tried to balance divergent views. Some stories told by people we interviewed don't jibe with my recollections, even though I lived through the same events, but we printed them as told anyway.

You may have the same reaction. You may remember things differently or think we left out events that are important to the history we share. If so, we'd like to hear from you and add your recollections to this growing body of knowledge.

Your contributions are particularly valuable to us all. As I said before, this is just a sketch of our history. It is important that we build it into a panorama. We can only do that by tapping into existing records, artifacts—and memories. We're considering a project to do just that (*see story at the end of the magazine*). If you'd like to be a part of it, please let us know.

*The opinions expressed in this column are those of its author. They do not necessarily represent the opinions of all or a majority of the Council members on all issues. However, they do reflect and actively support all positions the Council has formally adopted.*



*Summarized from Charity and Corrections in New Jersey: A History of State Welfare Institutions by James Leiby; Rutgers University Press, 1967. The original, found at the New Jersey State Library, is a history of the agencies and facilities managing prisons and serving Human Services populations through the early 1960's. We focus on chapters dealing with people with developmental disabilities. The language is archaic, sometimes offensive. We have retained it where appropriate to illustrate changes in attitudes toward people with developmental disabilities. —Ed.*

In the late 1700s, New Jersey was on the frontier. There were no large towns and cities. Hudson County and Trenton were no bigger than the average township today. The same laws covered disruptive and dependent citizens, including people with disabilities.

The poor laws of 1758 and 1774 set up overseers for the poor—elected, paid officials charged with handling the poor, transient and rowdy. They could auction off people to work farms or board them out to be cared for in local homes.

This system was fraught with abuse and graft. But it had two lasting impacts. The law required overseers to provide instruction for children under their care. At the time, all schools charged tuition, so new charity schools had to be created. These

TEXT BY NORMAN REIM

PHOTOGRAPHS OF  
ARCHIVAL MATERIALS  
BY REBECCA SHAVULSKY

IN THE



BEGINNING

charity schools eventually led to free, public education for all children.

Almshouses were created to address the abuses of overseers. Not much better, they were still a step forward and moved the state closer to recognizing its responsibility for vulnerable populations.

Reformers in the early 19<sup>th</sup> Century saw that people with certain disabilities needed something more than sitting in charity schools and almshouses. A few students with hearing, vision and speech impairments were sent to out-of-state schools and efforts began to try to establish in-state schools for these groups.

The first state School for the Deaf and Dumb wasn't founded until 1882; and students with vision loss never had their own schools built, relying instead on a home instruction

system for adults that evolved around 1900 and focused on everyday independence skills. Still, over time there was a growing recognition that people with certain physical disabilities could live independently with some training and support.

Treatment of people with cognitive disabilities was vastly different. Often docile or outrageous behaviors would accompany their disabilities, especially given the depths of misunderstanding and fear surrounding their conditions and the frustrations that caused. It was a world where the person born with a disability was often looked on as either an ill-formed "child of God" or a degenerate "possessed by the Devil."

In 1846, Dr. Eduoard Seguin (see related story) published his treatise "Idiocy," describing the situation for people with developmental disabili-

ties as it appeared to a sympathetic, clinically minded physician.

"Besides 'the confirmed idiot' the doctor recognized much more numerous groups who by degrees approached ordinary, physical, mental and moral powers. The most difficult was the 'imbecile,' who has no muscular or sensory deficiency (unless induced by 'self-abuse'). He lacked the 'gentleness... the timidity, the obedience, the affection' of the confirmed idiot; he was 'self-confident, half-witted, and ready to receive immoral impressions, satisfactory to his intense egotism.' Another type developed outward symptoms of idiocy in later life and then got worse; others suffered a sort of 'incipient insanity.' As outdated and simplistic as these descriptions seem today, they were groundbreaking in the mid-1800s and established a basis for a better understanding of the complexity and variety of cognitive disabilities—as distinguished from mental illnesses and "madness."

But in homes throughout the state and country, most parents had no Dr. Seguin to advise them. When they turned to local doctors, they were told that, while mental illnesses might be treatable, these disabilities were "no business" of theirs.

Reformer Dorothea Dix, instrumental in founding the state's psychiatric hospitals, had sympathy for people with developmental disabilities but, like professionals and public officials, thought their condition hopeless. Educators and advocates for remedial training for people with other kinds of disabilities saw no way to teach the "imbecile ..." "the idiot..." and "the feeble-minded."

It wasn't until the last decades of



**MISUNDERSTANDING AND FEAR**  
**A 1928-publication describes people with cognitive disabilities.**



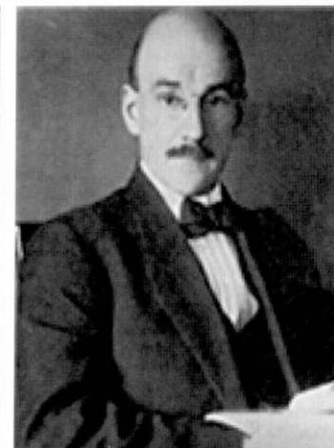
the 19<sup>th</sup> century that significant progress was made in recognizing the plight of "the feeble-minded" and steps were taken to provide some specialized services for them. The Garrison family's efforts led to the creation of the state's first facilities specifically for people with cognitive disabilities.

Father and state Senator Stephen Garrison asked the legislature in 1845 for a training school for "the feeble-minded" even before Dix succeeded in establishing the state's first asylum for people with mental illness. Other priorities were more pressing and the idea was shelved. His son, Stephen Olin Garrison, a Methodist minister from Millville, finally realized that goal, opening his home as a private school in 1887, moving a few months later to a mansion and grounds in nearby Vineland.

Garrison "dreamed of a 'village,' a little community on marginal land where the retarded might live and be made more or less self-sustaining in a world suited to their needs and capabilities. His dream was a humane version of the 'cottage plan' and 'farm colony' that were to dominate thinking about custodial care for



**PIONEERS?**  
**TOP LEFT:**  
 Reformer  
 Dorothea Dix;  
**TOP:** The  
 Research Lab of  
 the Training  
 School at  
 Vineland;  
**RIGHT:** E.R.  
 Johnstone; **FAR**  
**RIGHT:** Henry  
 Goddard.



people with mental retardation in the coming generation."

At the same time there was a groundswell of reform centered on the concept that diminished intelligence was hereditary and led to degenerate behavior. Dr. Richard Dugdale's study of "the Jukes," a "degenerate" family of paupers in rural New York" led to the creation of an experimental asylum for "feeble-minded women" in that state that became a permanent custodial facility in 1885.

Following that model, the founders of the New Jersey State Charities Aid Association helped Garrison set up a companion to the

training school in Vineland in 1888—the Vineland State Institution for Feeble-Minded Women—located across the street.

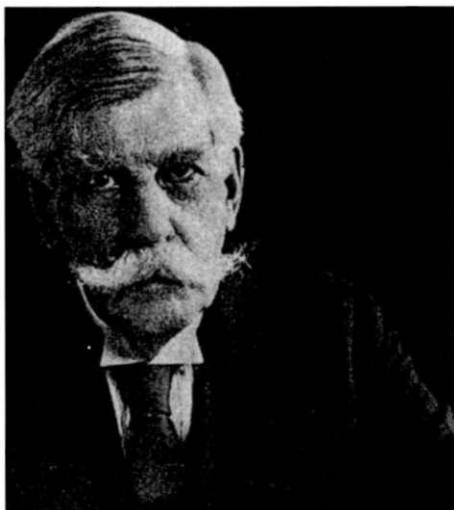
Ten years later the State Village for Epileptics (see related story) was established to get people with that disability out of "lunatic asylums" because their seizures disrupted the other patients. New Jersey's institutional system for people with developmental disabilities was firmly launched and it would dominate public services for them for over a century.

When Rev. Garrison died in 1900, Edward R. Johnstone took over the Vineland facilities. "Johnstone



had a youthful, even childlike, quality, playful, imaginative, full of enthusiastic visions, quick to organize teams and devise expediences. He saw his work as a great challenge and delighted in it. What a wonderful place an institution for the retarded could be, he thought! What a variety of children with problems, what an opportunity to study them, day in and out, with an expert staff to help; how free, relatively, of the belligerent stupidities of normal life! 'Where in all the wide, wide world... is there such a wonderful opportunity within such a small compass, covering such a stretch of time, and directed and practically controlled by one man—the Superintendent!'

To better study his "children" Johnstone brought in Henry Goddard (see related story). Goddard was part of a group Johnstone pulled together that called "itself 'The Feeble-Minded Club'—a characteristic Johnstonian whimsy"—when Johnstone asked him to come to Vineland to spearhead research. Funds were approved and in 1906 the Training School at Vineland launched the most extensive studies yet done on cognitive limitations.



Goddard defined a new level of borderline impairment that he called "moron." His early work—which he later disavowed—bolstered the eugenics movement that sought to eradicate bad genetic lines through forced sterilization.

Johnstone pushed for additional colonies. The first, Menantico—"a colony for its older and stronger boys in a land of scrub oak, knotty pine and thornbush"—became the center of the Training School's agricultural enterprises and experiments. The second was the colony at New Lisbon located in an isolated spot in the wilds of Burlington County, which the state took over in 1916.

Johnstone thus realized the late 19<sup>th</sup> Century ideal of providing a haven for people with developmental disabilities on otherwise useless property, where they could live, be studied and not pollute the surrounding society. The model became known as "waste lands for waste people."

During Gov. Walter Edge's first term (1917-1919) a commission headed by Dwight W. Morrow and Ellis P. Earle recommended re-

forms that led to the creation of the Department of Institutions and Agencies in 1918. In 1926, John Ellis, a protege of Johnstone, became commissioner of the new department and ran it for nearly 20 years.

Ellis' qualifications were not impressive. But he had a genius for working with diverse interests to forge policy through compromise. He had an uncanny knack for managing. In less than 10 years, the department became "a considerable power."

In that decade, the state "maintained an institution for feeble-minded women at Vineland and a 'colony' for men at New Lisbon. It also supported promising trainable boys and girls at the Vineland Training School. In 1921, it established a second colony for low-grade males at Woodbine and in the next few years it developed academic and vocational training for the more promising cases



**S. FEASTS BILATORS BY L. V. L.**

**He's Going to Let Her Baby Die: This Woman Says "It's for Best."**

**DOCTOR TO LET DEFECTIVE BABY EXPIRE UNAIDED**

**Mother Approves Surgeon's Refusal to Prolong Life of Maimed Infant.**

**DOES HUMANITY DEMAND THE SAVING OF DEFECTIVE BABIES?**

**DR. H. F. HANSEN** **MRS. ANNA ROLLINGER**

**FAR LEFT: Justice Oliver Wendell Holmes declared, "Three generations of imbeciles are enough," in an opinion upholding a Virginia sterilization law. LEFT AND ABOVE: Headlines of 1915 report a physician's refusal to treat a "defective" infant.**



at New Lisbon. In 1928, it opened a training school for higher-grade girls at Totowa, near Paterson in North Jersey."

The Woodbine Colony was considered "the most significant institution of the period, as regards mental defect." It was the only facility of its kind -one exclusively for "low grade" male residents. Johnstone secured a sandy piece of land in Cape May. He transferred a number of "very low-grade and multiple-handicapped custodial cases that were complicating the work at the New Lisbon colony and Vineland Training School."

The place was a "hell hole" in its first years. It was home to the most severely disabled residents in the state. The physical plant, including a cow barn that became the dormitory, was old and unsuited to the new residents. The location was remote, especially before cars were common. Help was hard to find and the supports these residents needed were significant—toileting, feeding, bathing, dressing, etc.

Johnstone's son, Edward L.,

asked to put his own ideas into practice at Woodbine. He wanted to teach residents basic self-care. The Depression created a willing workforce.

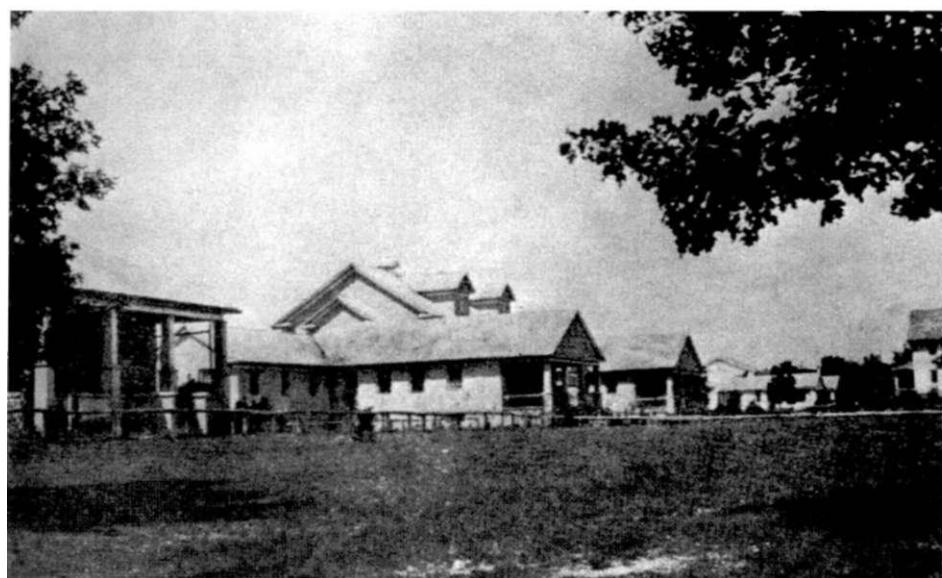
In the late 1930's Frank Walsh, state budget commissioner, paid a routine visit to Woodbine shortly after a similar tour of the Skillman Village for Epileptics. His later comments on those visits show how Woodbine became the exception during those years, due to the spirit of humane care instilled in the place by the younger Johnstone and the staff he put together.

"A tour of the buildings and cottages [of Skillman], the permanent home of innumerable patients... each case more deplorable than the other, was my first shocking realization of the problems of the Department,' he recalled much later. A visit to the dining quarters sent him, he said, 'home to my family counting my blessings but shunning the dinner table.' Then, having partaken of little or nothing for breakfast,' he journeyed to Woodbine. The contrast was striking: the children were happy, the help efficient, the spirit an



inspiration. 'I thought then,' he said, 'that if the Lord did not bless and guide so many wonderful people to dedicated careers... how much graver would be the problems of the Department.'

"By 1940, he (the younger Johnstone) had over half the children in some sort of classes and a teacher training program for public school teachers who were preparing to work with the severely retarded; two-thirds of the children were engaged in some activity. Between 1923 and 1940, the program reduced 'soil cases' from 45 percent to 30 percent, feeding cases from 15 percent to four percent and dressing cases from 47 percent to 27 percent."



#### REFORMS?

**LEFT: The colony for men at New Lisbon, c.1935. ABOVE: John Ellis became New Jersey's Commissioner of Institutions and Agencies in 1926.**

Meanwhile, events and professional opinion were pushing the department away from hereditary theories. A 1933 report called on public schools to help children with cognitive disabilities living at home. Its primary author, Edgar Doll, observed that "by conservative estimate 40 thousand distinctly feeble-minded people lived in the state, but only four thousand of them were in state institutions."

School boards were unwilling to expand services during the depression and most people felt that, "institutions should take care of the retarded." Ellis was caught in a dilemma: "To emphasize hopelessness and the need for custody was to diminish hopefulness and the need for community control and special education—and vice versa."

He settled on a policy of a select number of colonies and schools for "selected problems: lower grades,

multiple handicaps, children beyond school age or from rural districts without special classes." And still the waiting list grew, to 1,127 in 1943, "two-thirds of them low grade."

Ellis' director of the Division of Classification and Education, Dr. Lloyd Yepsen began to explore ways to improve the situation. Yepsen had worked at Vineland from 1921 to 1929. "That association kept him interested in... the retarded... and especially in the need for better community understanding and organization." Although not part of his regular duties, Yepsen arranged an institute at the North Jersey Training School at Totowa, "to enlist the social agencies of the great cities in the cause."

Ellis continued to put more emphasis on home training for pre-school children, foster care instead of institutional care and the problem of coordinating local resources. During World War II, people with developmental disabilities worked for the first time and opened up the public consciousness to their employability.

Despite these positive signs, when Ellis died in 1945, prospects for people with developmental disabilities and their families were still extremely limited. Even though under a clear legal obligation to educate all children, schools refused to take children with IQs of 50 or under, referring them to the state where they faced long waiting lists for the only service available—institutional placement.

For adults who could work the job market was unprepared, uninterested and even hostile. Professionals across the board—doctors, social workers, educators, counselors—rec-

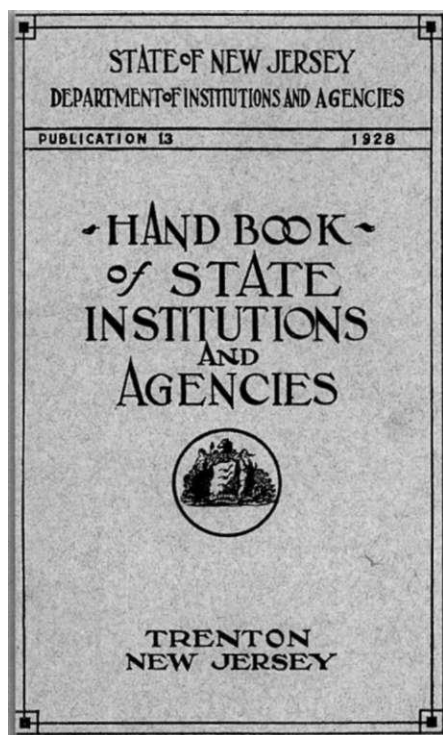
ommended institutional care where overcrowding and understaffing was creating increasingly unacceptable living conditions.

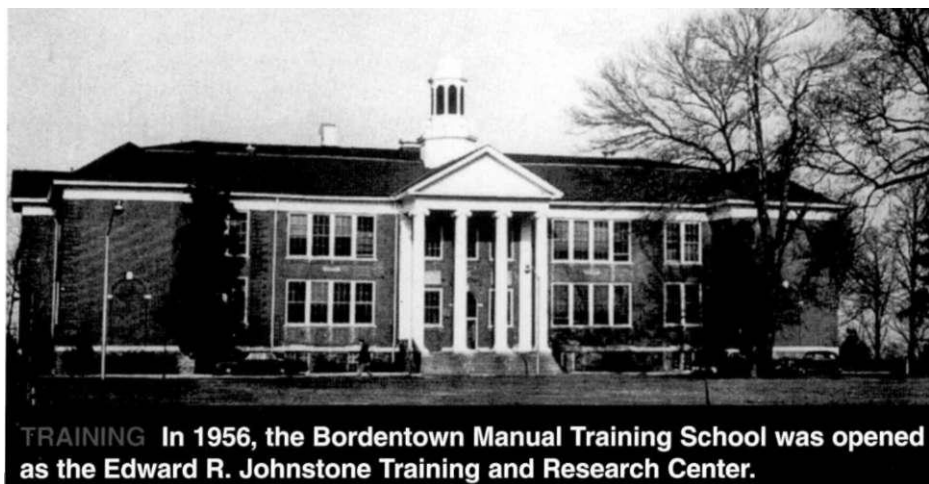
"In October 1946, a letter appeared in the Bergen Evening Record from a woman who had a retarded child and appealed to other parents in her situation to get in touch with her." Ironically, the editor almost didn't use her name (Laura Blossfield). A dozen readers responded and Dr. Yepsen met with them. It was the beginnings of the national parents movement and the Association for Retarded Citizens, originally the Association for Retarded Children, now the Arc.

Groups began across the state and the country. The possibility of a national parents' organization was brought before the American Association for Mental Deficiency (AAMD) at its convention in 1947. With Yepsen's help—he was eager to spread the word and invite parents to AAMD meetings—a national association was established in 1950. Lee Marino, president of the New Jersey Association was chairman of the first national convention and another New Jerseyan, Mrs. Fitzhugh W. (Elizabeth) Boggs (*see related story*), was on the Board of Directors.

The New Jersey group was "well-informed, serious and practical." They convinced leaders to authorize the State Commission to Study the Problems and Needs of the Mentally Deficient in 1950. The report it released in 1954 was "a thorough and critical review of the subject."

Only a third of the report dealt with the institutions. Priority was given to the general questions of public ignorance, research, personnel, and community services, especially education.





Parents and the commission were resolved that children with cognitive disabilities should receive "a free and appropriate education by right."

John Shannon, a Newark school-teacher and assemblyman, who was on the commission, brought a bill to the state legislature in 1953 with this philosophy. It was defeated but the following year New Jersey became the first state in the nation to enact laws upholding public education rights of children with disabilities.

The Beadleston Acts, the most important consequence of the parents groups early advocacy, required the commissioner of the Department of Education to define three classes of students: "the educable, who would receive a special education for more or less independent lives in the community: the trainable, who, although severely retarded, were capable of a degree of training for self-help: and the non-trainable, who could not benefit from classroom instruction." Results were dramatic—by the 1956-57 school year classes for "the educable had increased from 280 to 565, classes for the trainable from seven to 122."

"As for state institutions, the

commission found that only 'devotion and self-sacrifice' had enabled their workers to bear the state's 'policy of low salaries and small staffs.' It recommended more staff and pay increases, as well as policies that offered staff subsidized maintenance instead of salary increases by allowing them to live on grounds.

The commission also applauded the recent creation of the Bureau of Mental Deficiency, to provide much needed central oversight and coordination. Its first director was, Dr. Yepsen.

When Yepsen left shortly thereafter to go to New Lisbon, where he served as superintendent until his death. Dr. Maurice Kott (*see related stories*) took over. He, along with Elizabeth Boggs, dominated public policy in New Jersey for people with developmental disabilities for the next 25 years.

Kott joined the state as a psychologist in 1937. He served at the Annandale correctional facility for women, Trenton Psychiatric Hospital and its Mental Hygiene Bureau, as a cottage supervisor at New Lisbon, as an army psychologist, and as chief psychologist in the central

office. This experience helped form his belief that there were fatal gaps between what central managers and policy makers said and what front-line workers did.

He was also critical of older thinking that "the mentally deficient were unfortunate people who ought first to be kept happy by good-hearted custodians; he believed they were 'people, not pets,' with a right to a joblike performance from the people who served them."

These ideas were supported by the parents movement and in 1955, Kott announced a significant expansion of the bureau's programs. The Edward R. Johnstone Training and Research Center in Bordentown was established in 1956 to develop "intensive training programs for various classes of children, to train cottage workers, teachers, psychologists and social workers, and to be a center for research. "Field services" were reorganized with a large increase in staff to provide case management services for individuals and families.

"There were, of course, many obstacles in working out the new programs, but it seemed to everyone concerned that 1954 and 1955 were a turning point, when the ghost of the Kallikaks (*see story on page 16*) ceased to haunt public policy and airy visions of community care became administrative problems."

That sentence ends the final chapter on people with developmental disabilities in *Charity and Correction in New Jersey*, written 10 years after Kott took over the Bureau of Mental Deficiency (later the Division of Mental Retardation and then the Division of Developmental Disabilities). •

# Survivor of a Hard life

By MARYANN B. HUNSBERGER  
Photos by REBECCA SHAVULSKY



New Jersey's developmental centers were home to Josephine Messina of Cherry Hill for 19 years. At six, she moved to the Vineland State School for Girls (now the Vineland Developmental Center) where she stayed until age 14. She returned home for a bit, then went to live at Johnstone until age 19.

Physicians diagnosed Messina with mental retardation and epilepsy. "My mother sent me to stay in an institution because the doctor said I couldn't take care of myself, feed myself or dress myself since I was retarded. My mother had six children and didn't have much time to take care of me, feed me and train me to do things by myself."

Growing up in an institution wasn't a happy experience. She wanted to be with her family. She was often depressed because nobody took the time to talk with her about her problems. Her father took her home on weekends when he could.

"I was very happy to go home for the weekend. I went roller skating and to some other places like bingo. It bothered me that I couldn't live with my

family. It really hurt me. I used to sit around and rock all day long. That was all I wanted to do is sit around and rock myself back and forth on the floor. They didn't do nothing when I rocked back and forth. They just let me sit on the floor. I used to rock in bed at night in my sleep."

Institutional life deprived Messina of independence. "I was upset a lot and lost my temper. They said I couldn't control myself. If they couldn't handle you, they put you in a strait jacket and they sent you to a clinic. They gave me a needle and when I woke up, I was at a state hospital, tied to the bed. I got shock treatments there every day." According to Messina, she sometimes had to scrub floors as punishment.

Memories of what Messina, 53, did at Vineland Developmental Center are unclear for her, but she does remember Johnstone. She attended academic classes and at 17, she cleaned houses in the community once a week.

When Messina was 19, she left Johnstone. "I finally got out of there and came back and lived with my mother but it still did not work out. My mother was drinking too much and making fun of me. They called me retarded. I didn't stay very long at all."

"My social worker from Trenton found me a boarding home in Trenton. It didn't work out at all. I was beaten with a strap, an iron cord and a belt. The lady that was in charge treated me

very wrong. I didn't stay at the boarding house very long because they closed it down so quick when her daughter-in-law called the cops. She was tying people down the basement so nobody would know she had eight people in that boarding home. The home was not run by the state.

"My mother, my sister and my brothers were looking all over for me and they knocked on the door. She lied to them and said I was not there. She had me upstairs in the bedroom in the closet. Her 11-year-old daughter ran upstairs and told me that my mother was there. I told her to go back down before her mother or sister found her upstairs. I didn't want to see her get beaten. She had a lot of people there. My sister called the cops and got the FBI. That's how they got me out."

While at the boarding home, Messina worked in a workshop. "It was like piecework. It was packing things in boxes to send back to the company and stuff like that."

Messina lived with her mother after that until her social worker located a group home in Woodbury.

She was about 20. "That was a very good home. I was there for one year. I got treated really good there. I had freedom to go out. We learned how to wash clothes and go food shopping. I had an advocate citizen lady go to the store with me. Her name was Marie. She was next door to us. She took me out and I learned how to do the budget. I learned how to grocery shop on my own and about low prices and high prices. She taught me how to cook and wash my clothes and everything. I was very happy to learn all that stuff."

The training paid off. Messina moved to a supervised apartment for a year. Her first solo trip on a bus was to the workshop. "I learned about my name, address, social security number and how to take buses on your own. That was part of my goal. I was pretty scared to learn to do all that. On my way back, I got lost, but I found my way back home. It was part of my goal, and I did okay coming back home late like that. I had my ID card with me, so I was very lucky."

Since 1978, Messina has shared an apartment with her friend Barbara

Coppens, whom she met at the group home in Woodbury.

Messina is happy to have her own apartment, independence and friends on whom she can count. "I did have a very bad life. Yes, I did. I really don't know how I survived everything. I worked it out somehow. I just don't know how I did it. I had a bad life but I went ahead and just did it somehow. The hardest part was being treated very wrong and being away from my family. I didn't know what love was all about or what a home was.

"My mother and my father passed away. My one sister passed away, so I have one sister and three brothers left now. My sister Ruthie takes me home every holiday for Christmas and she'll take me home for my birthday. She lives up in Trenton.

"We are pretty close. She calls me up and then she'll pick me up. If Ruthie passed away, I know I am going to feel very hurt."

Her family never understood that she could be independent. "I didn't go to my father's funeral, because they thought I shouldn't. I finally

went to the graveyard where they buried them. That is the last time I saw my father. I was very hurt and upset about it with tears rolling. It was the same thing when my mother had passed away and died. I finally went over when she got buried. I went to the funeral home. They thought I was going to be scared to see her body, but I wasn't, because I worked in a hospital when people passed away and died."

Her passion for community living led her to join the SWOT Team. "We have meetings once a month. We help other people get out of institutions. I told them that if they get out, they won't be treated wrong, but they will be treated right. I told them they would get help to learn how to do things for themselves.

"One girl that we see once a month thought she would never get out of an institution. We told her that when you first get out, you are going to be scared, but there is nothing for you to be scared of. We told her there will always be staff around 24 hours to help you out so you won't be scared. After that, you are going to learn to do things for yourself.

Messina enjoys her life. She bowls, listens to music, goes to movies, takes walks and visits the mall. She recently went with Coppens to visit her family in New York.

She enjoys advocating for others. "I help a lot of people learn to stick up for themselves. I don't have to prove myself any more because they know I can do it." ■

**Messina and roommate Barbara Coppens share a place in Cherry Hill. (Coppens' story appears on page 54.)**





The Seguin School main building

EDOUARD SEGUIN

# An Unbelievable Way of Thinking

By JONATHAN JAFFE

**O**n a quiet hilltop, overlooking parkland and some of the finest lawns in Essex County, the Seguin Physiological School was a school of choice at the turn of the century for children of "arrested mental development."

The four-acre campus, which promoted pure air, great shade trees and broad stretches of grassy lawn, sat in the City of Orange, at a time when the municipality was nationally regarded for its beauty.

The school was the brainchild of Dr. Edouard Seguin, a pioneering French doctor, who, in the mid-1800s, laid the foundation for modern work with individuals with cognitive disabilities. He led the effort to educate people with mental dis-

abilities, proving that they can learn and thrive.

Dr. Seguin died when the school was in its infancy, never seeing the large campus his wife Elsie later developed in honor of "his genius."

David Goode, a Watchung sociology professor, says Dr. Seguin was a visionary, preaching fundamentals of education that showed a commitment to children with the most severe disabilities. "At a time before the rise in eugenics, Seguin was saying that all children have the capability to learn. It was an unbelievable way of thinking at the time."

Dr. Seguin had a five-point philosophy in teaching children with disabilities:

- Observation of the individual child preceded and was the foundation for the child's education;

- Education dealt with the whole child, and that the things taught must likewise be kept whole;

- Activity was the basis for and the means of learning; sensory learning was included in activity;

- The child learned best and more economically from real things, he remembered in proportion to his opportunity to compare;

- Even the most defective child had some spark of understanding upon which learning could be built.

This was the foundation for every-day living at the Seguin School, where Elsie served as principal for decades after the doctor's death.

The school was designed for three "grades" of children: The very young, those who could not be educated in "ordinary" schools and those whose education "has not brought any practical advantage."

Seguin only saw the seeds of the Orange school, with an enrollment at the time of only three children, taking day classes. Elsie, who married him just months before his death, leased a small house for the school in 1883. The enrollment of six students included two pupils who lived there.

She expanded the school three more times, making it large enough to accept as many students as she thought appropriate. It featured a main building with 25 rooms, which had been built as a mansion. A gymnasium/dormitory was attached in 1896.

The school was for the privileged: It cost \$1,200 for room and board, \$600 for day pupils. Girls under 20 and boys under 15 were admitted. No epileptic or "insane" children were allowed.



## INNOVATORS

"Dr Seguin did not intend to limit the school to the very lowest cases, but to open therein a way for the development of all children who are in any way mentally abnormal," Elsie wrote. "The advantages of special scientific training are of incalculable importance."

In 1906, an \$8,000 cottage was constructed, featuring a model kitchen on the first floor for cooking classes and an infirmary. Another cottage was built for students with contagious illnesses.

Students were strictly supervised. Their sleeping quarters connected to rooms where a teacher or governess lived. Staff watched as they dressed in the morning and undressed at night. Each had a daily bath and a cold spray when needed. It was also of "grave importance" that the governesses supervise the toilet rooms, the school brochure read.

The regimen called for breakfast at 7:30 a.m., dinner at noon, a glass of milk and a graham cracker at 3 p.m., and supper at 6 p.m. A special diet was provided for children who needed it, but "the regular hours, quiet, busy days and pure country air make any more stringent rules" very rare.

Key components of The Seguin School included:

■ **Music** - Dr. Seguin believed that no other science is so good for the general culture of the child as music. Many student recitals were held, with "sufficiently advanced" musicians getting short, unsupervised time periods to practice.

■ **Manual and Industrial Training** - Seguin believed that "the working hand makes strong the working brain." Students learned woodwork-

ing, clay modeling, free-arm black-board drawing, basketry and rug weaving. There was also domestic science for the girls, including cooking and general housekeeping.

■ **Physical Training** - Seguin said, "Our main object - the intellectualization of the muscles." Complete measurements and the weight of each child was recorded three times a year. Studies included the circumference of the head, face and nose, girth of the neck, chest, hips, thigh, knee, calf, ankle, instep, wrist, hand and waist and capacity of the lungs.

■ **Play Time** - Seguin believed if children were left to amuse themselves, their pleasures would be few. The governesses grouped students based on their ability for croquet, tennis, tetherball, and basketball. There were wheelbarrows and horse reins for the boys, dolls and carriages for the girls. There were also walks, pony rides, sledding and trips to New York.

The school was against violence to discipline the children; staff relied on depriving a child of a prized privilege. Children who were incorrigible were expelled.

Seguin taught that the way to the brain, the inner seat of sensation, the throne of reason and judgment, lies through the members of the body to which we have easy access: the hand, the eye and the ear, the brochure stated. The doctor and his staff would train these organs to develop the intellectual faculty to command them.

Elsie wrote that her husband bequeathed the school to her "as a most sacred legacy the care of the children whose darkened intellects had already begun to catch some dim reflection of his own brilliant mind, illumined as it was by a love which

glorified his every thought in connection with them."

Born Jan. 20, 1812 in Clamecy, Seguin went to the College of Auxerre and St. Louis, then studied medicine and surgery under Jean Gaspard Itard. Itard suggested he focus on the training of "idiots," pointing him to a lifelong journey, developing a compassionate and effective solution to idiocy.



Itard

In 1837, Seguin began to treat an idiot boy; two years later he opened the first school for idiots. His training generated remarkable results. In 1844, the Academy of Sciences in Paris concluded that he knew how idiots could be cured and educated.

In 1848, as a growing celebrity, he came to the United States to establish schools here. He settled in Cleveland, and later in Portsmouth, Ohio. In 1860, he moved to Mount Vernon, NY, and received a medical degree from the City University of New York in 1861.

Seguin, more than any other person in his era, showed to what degree the congenital failures of nature can be redeemed and educated to comparative usefulness, states Appletons Encyclopedia.

"The application of physiology to education was the work of my youth, and has been the main object of my thought for 42 years. I give it my last years, with the assistance of my wife, meaning to leave her the young and clear-headed exponent of the method I have scattered, but not exhausted in many books, pamphlets, and living lessons." ■

HENRY GODDARD

# Pariah or Pioneer?

One hundred and twenty years before the University of Southern California had the number one football team in the country, the squad was coached by a young, bookish Quaker who would one day introduce the term "moron" into the English language.

By JONATHAN JAFFE

Then Henry Herbert Goddard was far from reaching his destiny as one of the most prominent, yet controversial, American psychologists of his era - the authority on "feeble-mindedness" of his generation.

Instead, as the first coach of USC, he spent his early days teaching jocks how to block and tackle. Far away, in New Jersey, there was an undiscovered world awaiting him, where research in developmental disabilities was slowly taking shape.

When Goddard hung up his coach's whistle for good in 1888, he began an academic journey that took him back to his alma mater, Haverford College, where he earned a graduate degree in mathematics. Then he became a teacher at an Ohio Quaker science academy, a principal of a Maine seminary and an advanced psychology scholar in Massachusetts.

"Goddard had a missionary sense of himself, as a Quaker,

and had this evangelical calling to help the weak," says Leila Zenderland, professor of American studies at California State University, author of "Measuring Minds: Henry Herbert Goddard and the Origins of American Intelligence Testing."

"Goddard will be remembered as a nice and gullible guy, but an incredibly sloppy scientist," says Dr. Steven

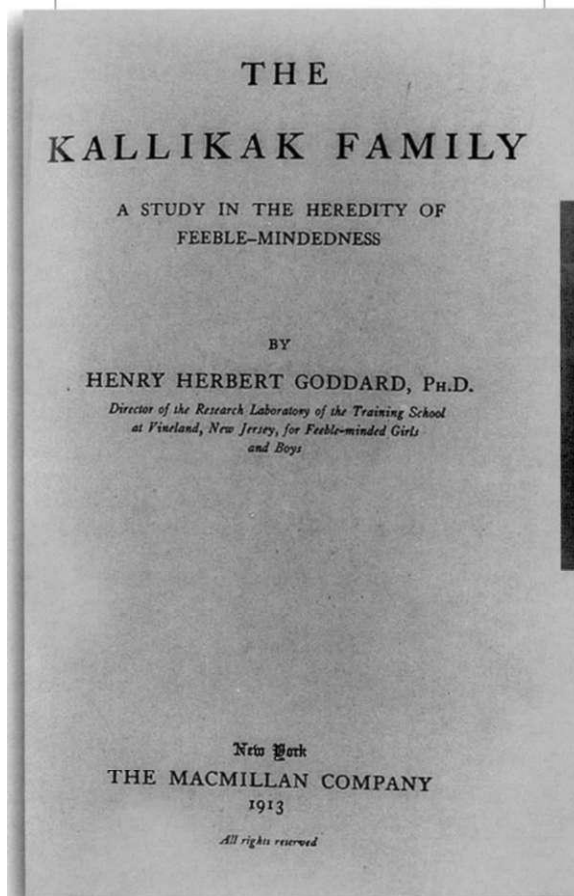
Gelb, education professor at the University of San Diego. "The quality of data that he used was so crazy that he would consider someone feeble-minded if he saw them in a bar or something. He really used gossip to label people, and regretted it so much, later in life."

But in 1899, at 33, he was ready to transform the scientific world.

He became professor of psychology and pedagogy in Pennsylvania for seven years. Then, as research director for the Training School for Feeble-minded Girls and Boys in Vineland, N.J., he was thrust to the forefront of study of developmental disabilities.

"Goddard had the first psychology lab in the United States specially dedicated to feeble-mindedness," says Kevin Walsh, the former assistant director of the Vineland facility. "His research lab at Vineland was very much the same model of what is in the university setting today. Rarely today do you find Goddard's level of research being done at a developmental center."

Working there opened Goddard's eyes to endless possibilities. But in venturing into uncharted territory with



Goddard (above) and his assistants studied more than 300 families, the most famous of which was the "Kallikak" family.



**"Deborah Kallikak" came to Vineland Training School in 1897 at the age of 8; the picture at left of Deborah at 17 appeared in Goddard's study published in 1912; the photo at right was taken in 1962.**

limited knowledge, he took the widely controversial position that people with mental disabilities should be segregated. Goddard also supported the theory of eugenics, in which people are believed to pass on bad genes.

"It would be easy to write an attack of Dr. Goddard in hindsight because many of the things he believed now sound ridiculous," Zenderland says. "Goddard was trying to move the field of psychological science. He was genuinely trying to do psychological research and use the science of the day to help people."

Goddard enjoyed working with the students in Vineland. Through observation, his intellectual interests grew in two areas: the causes of mental deficiency and the methods by which students were taught at the training school.

According to Zenderland, he needed a term to categorize many of the people he was studying. The word imbecile described those with the worst mental deficiencies. People at

the next lowest level of ability were called idiots. Goddard wanted to describe people who were slightly feeble-minded, but not idiots. For them, he coined the term, "moron," meaning both wise and foolish, taken from such words as sophomore and oxymoron.

In 1901, he became a part of a group put together by Edward R. Johnstone, who had recently taken over the Training School at Vineland (see related story). Johnstone realized there were serious gaps in dealing with its population. He asked Goddard to research some of these questions.

As his research took shape, Zenderland says, Goddard became a leader or participant in virtually every significant event occurring during the genesis of American psychometrics—tests to find out what people are like, what they can do, what they know and what interests them.

On a trip to France in 1908, he was able to secure copies of the very

first IQ test, known as the Binet-Simon intelligence scales. These tests were given to students held back one or two years in school. The tests helped judge the children's progress, as compared to their peers and became the measuring stick for those who required remedial education.

Goddard was eager to bring it back to New Jersey. He translated the test into English and began administering it to the children considered mentally deficient in Vineland. The results seemed staggering; he was convinced the test was the

most precise and effective assessment of academic development available.

Goddard distributed 22,000 copies of the Binet-Simon scales and 88,000 answer blanks across the country between 1908 and 1915. He even fought for the tests to become a fixture in public schools.

The fact that Goddard popularized the tests is ironic, Zenderland notes. Alfred Binet, a designer of the Binet-Simon scales and considered the father of intelligence tests, was careful not to attribute test performance to any inherent or unchangeable factors. Goddard, however, staunchly believed that heredity was the primary factor in determining intelligence.

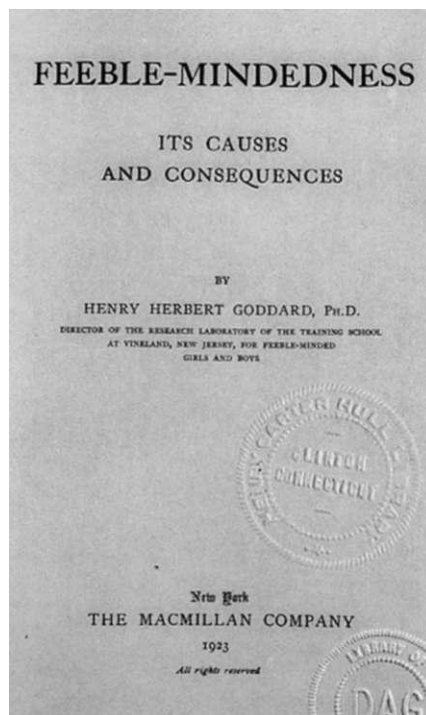
In 1912, he wrote that feeble-mindedness was created by the transmission of a single recessive gene, passed down from generation to generation. In his mind, there was good heredity and bad heredity. And, he concluded, unless bad heredity is removed from society, it would continue to propagate.

He justified his scientific conclusions with a two-year study of two branches of a family tree. Goddard had access to this family through a girl named Deborah, who was sent to the training school when she was eight years old, after being abandoned and found living in an almshouse.

Although Goddard and his assistants studied more than 300 families, the Kallikak family is the most famous. The fictional name "Kallikak" is actually a pseudonym that he coined from the Greek words Kallos (beauty) and Kakos (bad). He separated the Kallikak family into two strains - one "good" and one "bad" - both of which derived from Martin Kallikak, Sr., Zenderland says.

When Kallikak was a young soldier, he had a tryst with an unnamed, feeble-minded tavern girl, Goddard wrote. It culminated in the birth of an illegitimate son, Martin Kallikak, Jr. The bad strain of the Kallikak family descended from this line. Later in life, Martin Kallikak, Sr. married a Quaker woman from a good family. The good line descended from this marriage.

Goddard's study showed that the union with the feeble-minded bar girl created a lineage of "mental defectives" with many social ills, including illegitimacy, prostitution, alcoholism, epilepsy, and lechery.



His study of the other side of the Kallikak family showed the opposite. The marriage of Martin Kallikak, Sr., to the respectable Quaker woman created generations of good citizens. Goddard believed that the striking difference in the two branches of the family was due to the different genes of the two mothers.

"The Kallikak study was a horrible, terrible study by any stretch of the imagination," says David Goode, a sociologist. "Goddard's theory was based on a faulty premise that 'bad' genes can be transferred from generation to generation. It was stupid science. But at the time, it was the only science in this area."

Goddard wrote that feeble-mindedness was a wart on society and must be removed, expressing alarm

that these genetic lemons were "multiplying at twice the rate of the general population" and would "clog the wheels of human progress."

In his 1912 writings, he concluded that such people must be forced to live in segregated "colonies" to protect and preserve society.

"Feeble-mindedness is hereditary and transmitted as surely as any other character," he wrote in *The Kallikak Family: A Study in the Heredity of Feeble-mindedness*. "We cannot successfully cope with these conditions until we recognize feeble-mindedness and its hereditary nature, recognize it early, and take care of it."

Gelb said that Goddard traced the heredity of hundreds of people at Vineland and used complex mathematical equations to prove that mental retardation was a recessive genetic trait. "We all know that is not true, yet Goddard was able to use crazy data that made the math work out precisely," noting that Goddard's 1914 book, *Feeble-mindedness: Its Causes and Consequences*, was hailed at the time as a great text.

With enormous remorse, Goddard reversed many of these opinions on heredity later in life.

During Goddard's time at Vineland, as a steady stream of immigrants flowed through Ellis Island,

**"The Kallikak study was a horrible, terrible study by any stretch of the imagination ... It was stupid science. But at the time, it was the only science in this area." —DAVID GOODE**

**“We cannot successfully cope with these conditions until we recognize feeble-mindedness and its hereditary nature, recognize it early, and take care of it.”—HENRY GODDARD**

there was a growing concern among the American public that many of these people were mentally defective and would be a drag on society.

In 1882, Zenderland says, Congress passed a law banning mentally defective people from entering the country. While the language of the legislation seemed simple enough, enforcing it was a whole different matter.

As many as 5,000 immigrants filed through Ellis Island each day and each needed to be inspected. Desperate for help, immigration officials asked Goddard in 1910 to analyze the screening process and suggest how it could be expedited.

Two years later, he returned to Ellis Island with two trained assistants and a two-pronged strategy. As immigrants moved through the processing center, one visually screened for potential mental defectives; the other administered IQ tests.

Apparently, Goddard's procedure accomplished its objective. "The number of immigrants who were deported increased exponentially as a result of these screenings," Zenderland says.

A reformer of public schools, Goddard had a special interest in the New York school system. He helped draft the first law mandating that schools provide special education, claiming that "normal" children can

benefit from the instructional techniques that had been developed for students with mental disabilities.

"Goddard wrote a book about the special education system in the New York schools," Goode says. "A segregationist, he believed there should be a separate school system for students with mental deficiencies. While such a suggestion today would be controversial, at the time it seemed to be a reasonable interpretation to make."

Although his pro-segregationist beliefs would create an enormous stir today, Zenderland says, Goddard was considered "path breaking." His work became the root of the special education system today.

Goddard helped create a famous summer school in Vineland, in which public school teachers lived with the training school's population. Zenderland says. "They learned how to get along with the children and how to teach them."

Goddard left Vineland in 1918 to join the Ohio State Bureau of Juvenile Research, where he worked until his retirement. He was also a professor of psychology at Ohio State from 1922 to 1938. He died in 1957.

In later years, he became deeply disturbed about the work he had done at Vineland. "People who met Goddard say he was humble, sincere and kind, yet he wrote such horrible

things between 1910 and 1920," Gelb says. "The horrible quality of the science that he had done at Vineland really caught up to him in the 1920s and he was regretful. He refuted eugenics."

Goddard also reversed his claim that people with mental retardation could not be cured, arguing that with a quality education and "a social order that would literally give every man a chance," morons could lead productive lives.

A devout Christian, Gelb says, Goddard looked for humanitarian opportunities later in life. "You think someone like Goddard would be a terrible fascist, but he ended up rescuing a Jewish family from the Nazis and supporting Albert Einstein's group of atomic scientists opposed to use the use of nuclear weapons."

Gelb says Goddard also renounced his earlier belief that he was a great psychologist. "As an old man, he expressed deep shame when confronted with book promotional materials that compared him to...Alfred Binet," Gelb says. Goddard wrote, according to Zenderland, that if such a claim were seen by anyone who knew him, it "would hurt me more than all of my sins."

Goddard fretted about his legacy until his last days. He wrote in his final book that, "honest error is to be pitied, but not ridiculed."



# It Took a Village

By JONATHAN JAFFE

**T**he future of a historic 20-room mansion in Montgomery Township remains unclear. State and municipal officials have been debating it. Once the home of Capt. David C. Voorhees, the Maplewood House is reduced to a rotting reminder of history, with its peeling white paint and porch on the verge of collapse.

The Greek Revival house no longer echoes the grand role it played at the turn of the 20<sup>th</sup> century. In 1899, state officials turned the Maplewood house, its 187-acre property and the neighboring 215-acre Fernwood Farm into the State Village for Epileptics. The property, bought for \$19,500, was considered the ideal refuge for epileptics, then considered

societal outcasts and a drain on state resources.

Now, the Epilepsy Foundation of New Jersey, working with the New Jersey Council on Developmental Disabilities, is pushing for the old house to undergo a million-dollar restoration and become a national museum dedicated to epilepsy. The project would include an access road to two cemeteries where many residents of the village are buried.

Eric Joice, executive director of the foundation, says the plan calls for the Maplewood House to store the artifacts of the Epilepsy Foundation of America, including historical papers, books and articles that preceded the development of the national group in 1968.

"All of the artifacts would be on permanent loan to us, and displayed

in Montgomery," Joice says, noting the new name for the Maplewood house would be "The Disability Heritage Museum at Skillman."

The foundation has made sure the house has been placed on the National Register of Historical Places twice—as a part of the entire village, and as an individual structure—to underscore its tremendous value. The lofty plans to convert the Maplewood home into an education center, however, have been stymied by resistance from the state, which owns the dilapidated structure.

Joice says the state is negotiating with Montgomery Township to purchase the house and about 250 acres of property at the village. If the state sells the house to Montgomery, Joice says, the township could then sell it, as well as four surrounding acres, to the foundation.

Montgomery officials, who hope to renovate some of the village's buildings for civic use, acknowledge





**FAR LEFT: Play hour at the village, c.1927; LEFT: Deterioration of one of the buildings today; ABOVE: One of the obscure graveyards on the grounds.**

that negotiations have been dragged out and want a resolution. "I've been working here for five years and when I first got here, they hoped it would be soon," says Montgomery Township Administrator Donato Nieman.

"Our concern is that the buildings are deteriorating. We want to get the site managed and under control." Nieman says the township has been in "regular contact" with the state regarding the property, but would not divulge the status of negotiations. State officials also had little to say.

"We are not going to negotiate this in the press," says Matt Golden, spokesman for the Department of Treasury, noting he is "marginally aware" of the issue. "We are working to get the most appropriate deal for the taxpayers of this state."

Frustrated, Joice says, his organization had bills submitted to the state Legislature last year (S.837 and A.612), seeking permission for State Treasurer John McCormac to sell the house and surrounding land to the

Epilepsy Foundation of New Jersey. The bill was introduced in both houses; nothing, to date, has happened.

Nieman notes another non-profit organization, Friends of Homeless Animals, was successful in purchasing a piece of village property from the state.

As negotiations continue, Joice questions why the state is blatantly ignoring the long-suffering home - even to the point of leaving its windows open throughout the winter.

"It is disgraceful that the state has done everything it can to frustrate our efforts to move forward on this," Joice says. "We are unable to seek funding to save Maplewood, because the state has the title. In order to attract a significant amount of preservation funding, we need to have ownership."

The village, it appears, has always been a center of controversy.

Before the village opened in 1899, epileptics had been shipped to

asylums and almshouses or jailed in the state penitentiary on charges that were often unclear.

Universally banned from public and private schools, blocked from church services, and barred from work, epileptics were shunned throughout the state - the embarrassment of many families and communities.

By the 1860s, doctors at the State Lunatic Asylum in Trenton decided that people with epilepsy should no longer live in institutions for the insane and feeble-minded. Epileptics easily agitated the mental patients, who, in turn, sparked seizures among the epileptics.

The situation created a nasty circle of unrest, prompting the development of a village to serve about 2,000 people with epilepsy. In authorizing the funding, the state legislature stipulated: The village must be a secluded, self-sustaining farm near a rail line. It must be based in a good climate, as it was believed that epi-

lepsy could be "cured" with exercise and fresh air. The farm must also be large enough to rigidly separate the men from the women, as it was believed that epilepsy was passed through genes.

In the end, medication was the best treatment for epilepsy. In 1938, the drug Dilantin proved to be effective and, along with Luminal became the cocktail for epilepsy control. Then, along with Mesantoin, developed in 1950, most seizures could be controlled.

With medications that controlled seizures, officials began questioning the need to institutionalize epileptics. A 1949 newspaper article reported that many of the residents could be discharged if they took their medication.

The village had outlived its usefulness. But the state had other plans for it. A bond issue funded the construction of three large buildings and, in 1952, the village was recreated as the New Jersey Neuropsychiatric Institute.

It became a research center for the treatment of epilepsy, as well as mental illness, drug addiction and alcoholism. The residential facility operated until June 1998 as the North Princeton Developmental Center.

Bob Nicholas, director of the Division of Developmental Disabilities when the developmental center was closed, says he always envisioned the Maplewood house as a museum.

"It was such a beautiful old mansion, with a big living room," Nicholas recalls. "We used the house for



**An antique wheelchair is now a museum relic.**

community meetings because it was such a comfortable place and it didn't cost the division any money to use it."

Even in the mid-1990s, Nicholas says, the Epilepsy Foundation and other disability advocates were talking about saving the house, which was falling into disrepair.

"There was never any money left over in the capital account to repair the house," Nicholas recalls. "It had been my hope that the house would have been given to someone who had the capability of renovating it, and it could become a landmark."

Today, the village is a virtual ghost town, its stately brick buildings boarded up, steel doors clasped with rusty padlocks. Two village cemeteries sit in the rear of the site, away from the public and difficult to access. The only life on the sprawling

campus is Village Elementary School, a grades K-2 Montgomery Township public school, located in the former multi-purpose facility.

Nieman, the Montgomery administrator, describes the old village buildings and landscaping as stunning, noting the village was designed by a disciple of Frederick Law Olmsted, known as the founder of American landscape architecture.

"If you remove the buildings of the relative recent past, you can visualize the boulevard effect and the attention to detail," Nieman says. "The trees along the boulevard are quite striking. It is almost impossible to conceive that this was a village for epileptics. The beautiful architecture and landscap-

ing does not immediately connect to its purpose at the time."

As the township's farmland is developed, especially along Route 206, the main road in town, the village's real estate value has spiked. Developers eagerly eyeball the land for residential or commercial development. Nieman says the land is not zoned for such uses.

Saving the Maplewood house can serve as a monument to the thousands of people who lived in the village. "Looking back, we know it wasn't right that people with epilepsy were institutionalized," Nicholas says. "By turning the house into a museum, we can remember the past, recall that experience, and properly mark the fact that people with epilepsy have moved on to live normal lives." ■

# Elizabeth

No matter what took place before 1950, one can argue the history of developmental disabilities in New Jersey did not begin until Dr. Elizabeth Monroe Boggs saw a problem and vowed to fix it.

By JONATHAN JAFFE

**E**lizabeth Boggs was insistent that her son, and countless others like him, get effective care. With tenacity and God-given smarts, Boggs launched a 50-year odyssey, which pushed the issue of developmental disabilities to the forefront of the national consciousness, including the Oval Office.

"Elizabeth created the concept of developmental disabilities and guided the creation of the federal Developmental Disabilities Act," says Paul Marchand, director of the Arc and UCP Public Policy Collaboration in Washington.

One of her many accomplishments was helping to shape the modern Social Security system, which



SIMON FULFORD

millions of Americans depend upon today, he adds.

"She developed developmental disabilities councils, whose missions are to bring together state government, advocacy groups and constituents in all 50 states. She created systems that ensure the rights of people with disabilities. She made centers for excellence, which do cutting-edge programming and training for professionals. The combination of those three programs equals \$125 million in federal funding a year. We can thank Elizabeth for that."

She never sought compensation for the thousands of hours she contributed to the movement, coordinating a national effort from her home, which she nicknamed "Delectable Mountain," in Hampton, Hunterdon County.

In fact, Boggs had only one paid position in the disabilities field, albeit brief, when she agreed in 1988 to be the acting director of the New Jersey Office of Prevention of Mental Retardation and Developmental Disabilities, Marchand says. She took the temporary job only because she had lobbied for the position to be created and feared that the job would be eliminated before the right person was found for it.

Boggs, who died from injuries sustained in a car crash in January 1996 at age 82, collected a daunting list of successes in her life, making it hard to pinpoint her greatest contribution to the field.

Her accomplishments span a wide spectrum: earning a doctorate in theoretical chemistry from Cambridge University, serving as vice-chairperson of President Kennedy's Panel on Mental Retardation in 1961-



62, co-founding The Arc of the United States, now with 140,000 members, affiliated through 1,000 chapters nationwide.

Her detailed biography, available at the Elizabeth M. Boggs Center on Developmental Disabilities at UMDNJ in New Brunswick, tells the story of an intriguing woman who gave everything to the cause. Friends and colleagues remember her as being an intimidating person, whose tall frame, extraordinary intellect, and disdain for idle chitchat made it difficult for many to communicate with her.

Boggs had an astonishing memory; such recollection dissuaded some from engaging her in debate or even polite conversation.

"Elizabeth was delightful, but, socially, she was a dud," says Dr. Elsie Helsel, 88, of Ohio, who joined Dr. Boggs as an early pioneer in the 1950s to seek support from Congress

**“Elizabeth was delightful, but, socially, she was a dud. Elizabeth looked at going to a cocktail party as a waste of time. She didn’t like hanging out with people who did not have the same interests that she did. She was a workaholic. She was very serious.”**

**DR. ELSIE HELSEL**

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**DR. ELSIE HELSEL**  
for children with developmental disabilities.

"Elizabeth looked at going to a cocktail party as a waste of time," Helsel recalls. "She didn't like hanging out with people who did not have the same interests that she did. She was a workaholic. She was very serious."

Bob Gettings, the executive director of the National Association of

the message in a human way."

"Elizabeth was a handsome woman, not a beautiful woman," Helsel adds. "She could be a lot of fun, but that side never came through. The business side always came through. She never drank. She never relaxed in a social situation because, she thought, there was just so much to do."

But even into the later days of her life, she thrived on challenge, even recreationally. She would go snorkeling, white-water rafting and ballooning, as many of her contemporaries, ages 80 and over, were content to sit in the shade and read a book.

Friends likened her to an absent-minded professor. She did not care much about her appearance; she once wore paint-stained shoes to testify before Congress. But when it came to discussing issues that affected her son, David, she was razor sharp and would accept nothing less than perfection.

Perhaps it was her genius that made Boggs so unusual and extraordinary.

Born in Cleveland on April 5, 1915, Boggs was the daughter of Elizabeth McNairy Monroe and Frank Adair Monroe, Jr. Her grandfather was a Confederate soldier and a judge on the Louisiana Supreme Court, her father was an engineer who specialized in developing sugar production facilities, her mother's well-to-do family belonged to Cleveland society. Friends say she was very proud of her family history.

The family relocated from Cleveland to Rye, N.Y. when she was a child. Her parents encouraged her academic potential and sent her to a private boarding school that stressed

achievement of the highest levels. Boggs, in an interview in the early 1990s, recalled her parents wished she also had interest in the "social graces," noting she successfully avoided being a debutante.

In 1935, she graduated from Bryn Mawr College, summa cum laude, with distinction in mathematics. She was intrigued by theoretical chemistry, but no graduate schools in



out. At Cambridge, she engaged in war-related research as Nazism chewed through Europe. Despite pleas from her parents to return home, she was committed to the cause and wanted to continue her work. But as England filled with refugees, it worried about espionage and banned foreigners from war research.

So Boggs returned to the United

**“Her only downfall was really her inability to translate that great energy into a form where she could convey the message in a human way to policymakers. It always took someone else to convey the message in a human way.”**

**BOB GETTINGS**

the United States were eager at the time to accept women into the male-dominant field.

So, funded through a scholarship, she headed overseas to study at Cambridge. Although Cambridge accepted Boggs, she was not entitled to full membership in the university as a woman, and was not permitted to earn the same degree as the men, although she took the same course work.

She had intended to stay in England just briefly, but ended up studying there until World War II broke

States in December 1939, sailing the Atlantic Ocean through full-scale submarine warfare. She then reported to a research project at Cornell University. Her office had been given to a graduate student, Fitzhugh Boggs. They shared the office and ended up sharing their lives, marrying in September 1941.

The newlyweds, both scientists, worked on secret projects for the war effort. Their work was so top secret that they could not even discuss their projects with each other. It was later learned that Mr. Boggs was invent-

ing devices to jam German radar; Elizabeth was peripherally involved in the development of the atomic bomb.

The couple's only child, David, was born in 1945. He ran an extremely high fever when he was 10 days old and suffered profound brain damage. Just weeks earlier, penicillin was only available to soldiers. The medication, suddenly available to the general public, saved David's life.



children, afraid to be blacklisted from the few programs available.

Boggs became increasingly aware of the issues and returned to school to take classes in special education and social work. As an expert on disability issues, she organized classes at her house, social halls, church basements, Boy Scout halls and anywhere else willing to house them. Her goal was to have 50 re-

**“ Elizabeth created the concept of developmental disabilities and guided the creation of the federal Developmental Disabilities Act. ”**

**PAUL MARCHAND**

The couple hoped that David's injuries would be minor, but they discovered that he had an extreme, lifelong developmental disability. Boggs would soon find a cause that would become her life's work.

As they cared for their baby boy, the couple followed Mr. Boggs' career to New Jersey. Elizabeth carefully watched David's progression and was becoming increasingly concerned about his lack of development. She sought the advice of physicians and educators and became frustrated with their answers.

In the late 1940s, there were few programs to assist children with David's severe disability. Boggs saw that other parents of those children were reluctant to advocate for their

tarded children in these classes, with the end result being getting these children prepared enough to enroll in the public school.

Word spread of her efforts, as frustrated parents throughout the country sought similar programs. As a result, she spent more time in Washington, pushing for the establishment of the National Association for Retarded Citizens, founded in 1950 as the National Association of Parents and Friends of Mentally Retarded Children.

Helsel recalls meeting Boggs in Washington in the late 1940s. The pair shared a mutual interest - Helsel's son had cerebral palsy; Bogg's son was mentally retarded. They became a team. "When Eliza-

beth and I got to Washington, we had no resources and didn't know anyone. But both of us had husbands with a good amount of money, which gave us some stature and allowed us to do a lot of advocacy work. We used our own resources to get things going in the beginning, before we had organizations raising money for us."

Helsel says cerebral palsy advocates already had an office in Washington when Boggs arrived. It made sense to share space in the same building, so they set up shop.

"Fortunately, instead of competing, we liked each other and wanted to help each other. Elizabeth knew a lot more people in Washington than I did. But my mother, Nelle Dressier, was a prominent Republican who ran some of Dick Nixon's political campaigns. That helped both of us."

Even then, Boggs had a reputation for being serious. "I remember we both went to South America," Helsel recalls. "Both of us had never been there and I wanted to see what was around. But Elizabeth wasn't interested in sightseeing. To her, that was a waste of time. She was more interested in talking to people about issues."

Although a novice in Beltway politics, Boggs was making a name for herself. She was named a delegate to the White House Conference on Children and Youth in 1950 and the White House Conference on Aging in 1955. Between 1950 and 1963 she served on the Board of Directors for the National Association for Retarded Citizens and was its first female president from 1956-58.

"Elizabeth used her scientific thinking to calculate the numbers of policy, purposes of Social Security



and service needs around disability," says Deborah Spitalnik, executive director of The Boggs Center at UMDNJ. "She also served as a bridge, a translator between the medical and scientific community and the parents' movement."

Spitalnik says President Kennedy appointed Boggs in 1961 to the President's Panel on Mental Retardation and, as co-chair of the subcommittee on human rights, led a fact-finding trip to the Netherlands.

"This trip convinced Boggs of the importance of human rights. She stimulated the focus on the rights of persons with disabilities through the AAMR Consent Handbook. She worked with the International League of Societies on Mental Handicap in developing the "U.N. Declaration of Rights of the Mentally Retarded" (sic) and co-chaired the Congressional Committee on Disabilities, which ultimately led to passage of the ADA."

One of her most important contributions, Dr. Spitalnik says, was to "coin, expand, and popularize" the term "developmental disability" to include mental retardation, cerebral palsy and epilepsy. This characterization highlighted the impact of disabilities that originate early in life and that are persistent and severe.

"Elizabeth had this incredible ability to work on so many levels," Dr. Spitalnik says. "She could work on national Social Security policy, testify in front of Congress and do international work, while also serving the national ARC, the state ARC and her county human services advisory board."

"Elizabeth was very interested in young people. A lot of parents, who



really weren't that close to her, spoke after she died about how she was so personal and personable. She remembered stories of their children and helped them solve problems."

As impressive as Boggs was, Helsel says, she always maintained a modest appearance, noting she never felt the need to get dressed up for a meeting with President Kennedy or President Nixon.

"Elizabeth was a softer person around her husband, and around people with developmental disabilities, but she never really let her hair down," Helsel recalls. "I remember seeing her dance once with her husband. They looked very uncomfortable. That was just not her thing."

From 1964-1968, Boggs served on the advisory council for the Graduate School of Social Work at Rutgers University and was president of the New Jersey Association for Retarded Citizens in 1966 and 1967. She also served on the Joint Committee on Mental Health of Children from 1967-1971.

Gettings met Boggs in 1965 when he joined the National Association for Retarded Citizens, functioning as her assistant on the gov-



ernmental affairs committee, which she chaired. He quickly realized she was an "intellectual powerhouse" and was continually in touch with a range of people, issues, thoughts and ideas.

"Obviously, David was the motivation for how Elizabeth initially became involved, but I think that she would be dedicated to anything she put her mind to. Her dedication was in a way that most of us would find hard to understand. She worked diligently on any cause that interested her."

Gettings says Boggs had "funny quirks," such as responding to one of his documents 15 years after he stopped working for her. "It really didn't matter if you were a lowly parent struggling to raise your child, or somewhere in the world like North Dakota, you still had just as good of a chance to get a 10-page letter response as if you were a U.S. senator. She was so prolific and never stopped working."

From 1968-1971, Boggs served on the Pennsylvania Advisory Council on

Mental Health and Mental Retardation; from 1969-1971, the New Jersey Governor's Task Force on Welfare Management and chaired the National Advisory Council on Services and Facilities for Developmentally Disabled from 1971 to 1974.

Boggs was chairperson of the Advisory Council Graduate School of Social Work at Rutgers University from 1971-1977, chairperson of the New Jersey Developmental Disabilities Council from 1971-1979, chairperson of the Task Group on Implementation of United National Declaration of Rights of Mentally Retarded Persons from 1972-1978 and a member of the President's Commission on Mental Retardation from 1975-1976.

Fitzhugh Boggs died in 1971. Later in life, Boggs said of his unwavering support: "People do sometimes forget about the contribution Fitzhugh made - we worked very closely until his death," she said in an article marking her 80<sup>th</sup> birthday.

Boggs is known for moving legislation in the United States and the United Nations. Her early interest in education widened to include independent living and group homes, the rights of adult-aged people with mental retardation and guardianship for older individuals with mental retardation whose immediate family had died.

"Elizabeth had certain people in Congress she could talk to directly, but she did not have that 'K Street' influence, with contacts and wired into financing of congressional activities," Gettings says. "That was not her strength; her strength was conceptualization.

"She could analyze laws and statutes and regulations with encyclope-

dic knowledge. Her cognitive ability made it possible for her to envision new legislation and administrative initiatives. She was not one to sell an initiative, but she certainly could conceptualize it."

Marchand recalls that she often forgot her briefcase and documents and his job was to make sure she left with everything she came with. He



says she was more interested in policy than trivial matters, such as the location of her belongings.

One day, she showed up before Congress in old, tattered, paint-stained loafers. She explained that she took out the trash that morning and forgot to change her shoes. It was classic Elizabeth.

"So, during her testimony, the chair of the committee and the ranking member start whispering to one another," he says. "She noticed it and she stopped speaking. She didn't say a word until they realized she stopped talking. They looked at her sheepishly and she said, 'May I continue now?' It was a major role reversal."

Gettings says when Boggs testified before Congress, you never knew what to expect. One time, Boggs spoke to the Senate Labor & Human Resources Committee, chaired by the Sen. Lister Hill of Alabama, an old-fashioned Southerner who entered Congress in 1923. "Elizabeth was last on the witness list and there was only 15 minutes left in the hearing. Hill politely asked Elizabeth to give a 10-minute summary. She went on and talked for an hour. He was too much of a gentleman to cut her off, but I overheard him later telling someone he never wanted to see that woman again in his life."

With so many activities, along with hobbies, from gourmet cooking to photography to gardening, it was no surprise that she had a massive home office, which could easily have fit three cars. There were tables around the sides of the room, making it easy for her to pick up one project, then another, then another.

In her later years, she moved into a condominium in Clinton close to the Hunterdon Developmental Center, where her son lived. She died in 1996 when her car slipped on an icy patch and slid into a tree; her son died four years later of pneumonia.

"Her effectiveness as a policymaker was her ability to look at so many fields and draw information from them," Spitalnik says. "When she died in 1996, we were cleaning out her house and found census maps of counties from several states. We didn't know why she had them, but figured maybe she had probably extrapolated from them to talk about Social Security.

"She was always one step in front of us." ■

# Life at Hunterdon

By **MARYANN B. HUNSBERGER**  
Photos by **REBECCA SHAVULSKY**

Gus Wall has seen many changes in his 34 years working in New Jersey's centers for people with developmental disabilities.

"I see many differences from the early days," said Wall, the CEO of Hunterdon Developmental Center. "Our ICF/MR program has gotten very sophisticated. The staffing level is a lot higher. We have probably 300 more staff here than we did in 1987."

*(For a description of the federal Intermediate Care Facilities for the Mentally Retarded Program see related articles later in this issue—Ed.)*

"The image of an institution standing apart from the community is now gone," Wall said. "We consider ourselves a regional center that can serve any developmentally disabled person who needs it. We take great pride in the fact that we have never turned a developmentally disabled person down for service if they call here. That goes from giving haircuts to weighing somebody on a special scale. No one can ever say they called the developmental center from the community or anywhere and say they did not get service."

"I'm not saying that the community is relying on us. I'm just saying that if the cir-

cumstances come and they call us, we offer to serve them. It's an obligation to the community overall, not just the clients here."

Wall also sees differences in how decisions get made. "Many years ago, court decisions were involved. The decisions weren't even made by the MR professionals on issues. All decisions about people are now made with the consumers and their advocates. So, there is a lot more of an interactive communication as opposed to whatever court case it was that said it was up to the MR professionals. Now I would say it is an interaction and a consent."

"Also, clients have a choice at every step of life at every hour here. It starts with their clothes in the morning, the activities, the food, the recreational activities, where they want to go, what they want to do. We have done very well with that aspect. I think it is understood that this is a learning environment as opposed to

an environment of control."

Wall arrived at Hunterdon in 1987. "New Jersey's facilities were more inclined to the institutional way of doing things. It was a less integrative approach for people with disabilities then."

"This year we served 60 community clients in our dental clinic. It is complete service from a filling to oral surgery. We supply daytime respite for clients. Respite is usually a week or two at a time. Sometimes a family is going on vacation. Sometimes a skill sponsor needs a two-week break from the responsibility. Somebody in a group home setting needs a medical evaluation of some sort."

"We have an infirmary and a complete clinic with gynecological care, eye doctor, podiatry, everything. People in the community come for treatment or evaluations occasionally. There are four or five physicians and 25 consultants here."

Hunterdon has 596 residents and 1200 full-time staff. "We have approximately 120 nurses, six therapists, 20 recreation therapists, an education program with 20 certified teachers and about as many teachers' aides. We have occupational therapy and physical therapy departments. We have wheelchair clinics, emergency clinic, 12 full-time EMTs."

The median age of Hunterdon residents is in the late 30s. Three or four are under age 22. Some are around 80. "It's quite a mixture of age population. As for disabilities, 516 clients have profound mental retardation, 53 have severe mental retardation,



Hunterdon Developmental Center CEO  
Gus Wall

seven have moderate mental retardation and 14 have mild mental retardation."

Each resident has an individualized program with goals and objectives. They maintain data on each of those objectives. "Each day, we have three formal zones from 9:00 AM until 3:00 PM with a lunch break in there.

"If the client reaches a goal in a respective zone, he moves on to the

on site or in the community. They work from one to four days a week. "Some work at Shop Rite, at the jewelry store, at the photo shop or at local restaurants. Some work at the greenhouse on the grounds here."

Clients can take part in roller-skating, skiing, field days and horseback riding. Petting zoos visit in the summer. The clients take about 200 community recreational trips each month. "Last year, some clients went

off from the Wizard of Oz. It was so cute. We have our own TV station. It's on 24 hours a day. It goes throughout the buildings and our events are taped. If people can't see it at the specific hour or time, they get to see it on our closed circuit TV."

Hunterdon has two summer camps. The off-site camp is an overnight, weeklong program. At the camp on site, there is a full day of activities, such as horseback riding and arts and crafts. "We have summer employees that are very enthusiastic about the summer program. We can order a picnic lunch or a barbecue, so we can have a barbecue down there any time. Great care has to be taken because two of our clients are on special diets."

Of the three facilities where Wall has worked, Hunterdon has the highest amount of parental involvement. "Approximately 60 percent of our clients have very active family involvement. They are entitled to come any time they want and can go anywhere they want, the bedrooms, the day rooms."

Some people leave Hunterdon to live in the community. "I think we have three people within the next two weeks that are leaving. We work with them and prepare them for life in the community. We have a whole formal plan that the IHP team makes for each individual. It takes a couple of years to train the person to do well in the community.

We teach them the use of phones, pedestrian safety, kitchen use, emergency numbers, cooking, use of the laundry, all those things. The clients that have left and gone to the community have done very well."



**Joann Dellaperute (right) and daughter Karen, who resides at Hunterdon D.C.**



next level. There are recreation zones, bowling zones, a therapy zone. We have our own indoor pool, so the zone could be to go to the swimming pool. We have our own beauty shop and the zone could be that.

"Between those formal zones, we have individualized informal training. In our education department, we have workshops, art programs, all kinds of enriching programs."

Approximately 35 residents are employed in work situations, either

to a dude ranch, some to the Grand Ole Opry. Three years ago, they went to Disney World. They went to Hershey Park. Usually about ten clients at a time go on these trips, with six or seven staff members, almost a one-to-one."

The center has a dramatics department. It incorporates theater, costumes, props, special lighting and sound effects, dramatizing stories, pantomime, improvisation, creative movement, and role-playing. "This year, the play they put on was a take-



L-R: Leo Gold, David Simon  
and Leila Gold

# Certainty is the Fashion of the Moment

By MARYANN B. HUNSBERGER  
Photos by REBECCA SHAVULSKY

Leo Gold remembers when 40 people shared a bedroom in state hospitals early in his career. "There was one bed next to the other," said the 80-year-old clinical psychologist whose stepson David Simon lives at Hunterdon Developmental Center.

"People with developmental disabilities were in state hospitals back then because of misdiagnoses. I was diagnosing autism back in the 1950s,

but they were still calling it schizophrenia then. There were no tranquilizers or other psychiatric medications then. They had introduced shock therapy and were using that. I saw people who had lobotomies, and that made them worse."

Gold also remembers the days when the experts blamed mothers of patients with schizophrenia and autism for their children's illnesses, calling them "schizophrenogenic mothers"

**Leila Gold (right) is a member of the New Jersey Council on Developmental Disabilities.**







and "refrigerator mothers. Fears and superstitions, blaming mothers—these things have changed. The field is only 100 years old and keeps changing. Sixty years from now, things will be totally different."

His stepson has also experienced many changes at Hunterdon. He lives in cottage 18 in a room with furniture from home, wrestling posters and pinups of Anna Kournikova. He shares his room with three others, a far cry from the days Gold remem-

bers. When Simon moved to Hunterdon, eight individuals shared a room. ICF/MR brought changes in how many patients could sleep in one room.

Another positive change is Hunterdon's multi-sensory room. A combination of soft music, colored fiber optic lighting, a heated waterbed, a massage mat, a swing chair, reflexology and aromatherapy makes this a calming place for residents to get hand and foot massages

and just chill out. "That relaxation room is a whole new concept. That atmosphere can cause calming and less behavioral problems. David does well in that room. It makes him very peaceful."

Gold looks forward to changes in years to come. "The world really has changed and it will change again. By modifying subjective environments we can change behaviors, so more changes will come. Certainty is the fashion of the moment." ■



# A Part of History

"Sandra, in her quiet way, did her share of fighting for what her family believes in."

By MARYANN B. HUNSBERGER

Sandra Lapoint, 57, loves to wear jewelry, especially pearls. The day we visited, she wore a pearl necklace and bracelet. Along with her trademark pearls, flowers adorned Lapoint's multi-positional adaptive wheelchair.

Lapoint also wore a generous smile for us. "Everybody knows her for her big smile," said her mother, Helen Peggy Cappeto. Her mother asked Sandra if she likes living at Hunterdon, to which she replied, "yeah." Although she is nonverbal, her mother said she is learning to express herself better and can make clear whether she is happy or unhappy.

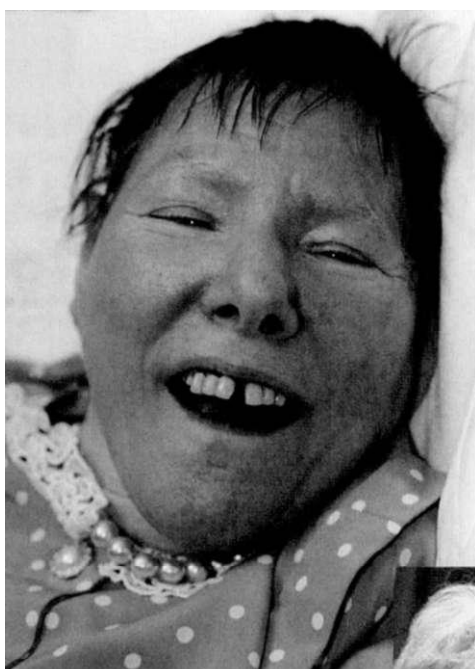
Lapoint lives in the health services residence at Hunterdon, which is equipped for residents with medical needs. She is paralyzed and has lung and heart problems. A feeding tube has nourished her for the past year, since she can no longer swallow food.

Hunterdon has been Lapoint's home for 33 years. She also lived at Vineland Developmental Center for 17 years.

Cappeto said Sandra moved to Vineland at age five "Sandra has cerebral palsy. She wore leg braces and I could not lift her, because I had fractured my ribs." When Lapoint arrived at Vineland, she lived in a large dormitory. At Hunterdon, she shares a

room with two other women. Each woman has a small TV by her bed.

Cappeto described how things have changed. "Originally, if the girls



or boys got into trouble, they automatically were sent to state schools. Many members of that population were the original ones transferred out after ICF/MR. They were sent to glorified old folks' homes out in the country. Now, they go to group homes.

"When Sandra lived in Vineland, they used to grow their own food. Many workers came from the population. If they were naughty, they were isolated in a building that the girls called the 'jail.' They had higher level children in those days, because

people came from different sources. We have much more lower-functioning people here now."

Cappeto remembers that when ICF/MR began, the state revamped the health services residence, along with the rest of the campus.

Sandra's picture graced an historic billboard during Governor Whitman's tenure. The state was closing the centers, so the Coalition of Families, an organization made up of families of children with disabilities, decided to fight the closure. "We did not believe in this policy."

The Coalition chose Lapoint to be on a billboard, so Cappeto explained to her daughter that her picture would be on the billboard. Although Cappeto isn't sure how much her daughter understood, she happily complied for the photographer. "Sandra, in her quiet way, did her share of fighting for what her family believes in."



Cappeto said Sandra enjoys life at Hunterdon. "They have dances with a band and Sandra loves being there. She likes rock and roll. They have their activities and their friends. Everything is so well

structured. The workers know the residents. A senior companion regularly visits Sandra. They have a beautiful life here."

**Sandra Lapoint (top), who resides at Hunterdon Developmental Center, and her mother Helen Peggy Cappeto**

# Those Days With Maury

By MARYANN B. HUNSBERGER

In 1953, Dorothy Nelson began working as the secretary for Maury Kott of the Bureau of Mental Deficiency (now known as the Division of Developmental Disabilities), which then fell under the Department of Institutions and Agencies.

The institutions then were New Lisbon State Colony, Woodbine State Colony, Vineland State School and North Jersey Training School.

"That was the division. Kott came in 1952. By the time I joined him, he had his Ph.D. in psychology. In 1955, we became the Division of Mental Deficiency. Bernie White came on at that time. In about 1956, they added Johnstone Training and



Research Center. Maury Kott opened three regional offices and added another six institutions.

"Then we became the Division of Mental Retardation. Later we became the Division of Developmental Disabilities. Kott retired in 1979.

He opened a good number of group homes. He served as president of the New Jersey Psychological Association. He was a member of President Kennedy's Representatives to London.

"Kott was world-renowned. He worked a lot with Elizabeth Boggs. He also served as the Acting Commissioner of the Department of Human Services."

Nelson said that waiting lists were a problem then as now. "We had only four institutions that people were waiting to get into. By 1979, when we had ten institutions, the waiting list was longer, because more people needed placement.

"Life in the division was frantic, because we were growing all the time. More people started to realize that these services existed. The Arc started having meetings and parents became cognizant of what was available.

"Back in 1953, we placed kids in private specialized schools. They needed services other than just teaching, such as padded walls. Then, the educational portion started and we had to make a plan of what would be accomplished with each resident, whether learning to eat with a spoon or go to the bathroom. It was still in Kott's day when we had to bring all our institutions up to a certain level



to get ICF dollars."

"After ICF, they had to have so much space per child," Nelson said. "Each child had to have a dresser for their things. They had to renovate the buildings so that it was a pleasant atmosphere for the children. The number of students-to-staff had to be a certain amount. We had to cut down on the number of children."

The division served only people with mental retardation when Nelson worked there. "If they had other disabilities such as Spina Bifida and cerebral palsy, they didn't have high IQs. They also had mental retardation.

"When I left, they were into developing group homes. Ron Melzer handled all community and Gwen Brown handled residential. Supported apartments, Self-Determination and in-home supports are all new. The Arc and Elizabeth Boggs really started pushing for outside placements that way." ■

# Bernie White Remembers

By MARYANN B. HUNSBERGER

Bernie White was Deputy Director of Institutional Operations at DDD from 1955 until 1987, although the division went by different names throughout those years. He spoke about his history at the division.

**PWD:** What position did you hold at the division?

**BW:** I was the deputy director for institutional operations. Dave Rosen handled community programs. New Jersey was a leader. In the late '40s, legislation said that the public schools must provide classes for the mentally retarded. Until that time, only two or three large cities had classes—Newark, Elizabeth. This law brought about classes for the educable or trainable kids.

**PWD:** Did the day center training start then?

**BW:** Yes, they started in the early '60s helped by federal grants. Under Maury Kott's leadership, whenever we saw a void, we would try to fill it. Some kids were designated as neither educable nor trainable. They could officially exclude them from public programs. We set up our day training program because of that.

This involved the Developmental Disabilities Council. I was the contact with the Council when Cathy Rowan was there. We had to draw up a state plan. The state plan people worked for me. Part of the state plan was that we needed to do something for the neither trainable nor educable group.

Out of that developed Public Law 88-164, which provided construction funds to develop the day training centers in the state. That was our number one priority in the early '60s.

**PWD:** Why were they needed?

**BW:** Some states became interested in getting people out of institutions. There was a feeling that the mentally retarded belonged in the community. You could take two approaches—either take them out of the institutions and try to integrate them back into the community or keep them home, so they don't have to end up in institutions in the first place. We tended toward the latter. We wanted to encourage families to keep their children at home, rather than place them in institutions. That was the main reason for the day training centers.

**PWD:** How did states see that services were needed to keep children at home? Was that during your time?

**BW:** That predated my time. Social workers set up regional offices in the community to assist people leaving the institutions. The next program was kind of like adult foster care, the Family Care program. Mostly higher

level fellows and gals took part. New Lisbon was a place for the higher-level males and Totowa was the place for the higher-level females. We placed them with host families as almost foster children. The state paid for it.

**PWD:** How did that work out?

**BW:** So-so. We established the social workers in three regional offices to keep an eye on things. Like foster parents for kids now, there were abuses. They were taken advantage of. I wouldn't say it was wholesale, but enough to bother us. Ethan [Ellis] was at the advocate's office at that time. They raised some questions about some of the places, and they were right.

**PWD:** Did people go into boarding homes after they got out of the institutions?

**BW:** Some higher level ones did. They arranged it on their own, like anyone else would. If you go back a long time, some people who were in facilities for the mentally retarded were never mentally retarded. In the early 1900s, the term "feeble-minded" was used. We kind of translated feeble-minded into mentally retarded. But, it's not 100 percent accurate. In the early 1900s, it meant people who had weak minds.

One criterion was out-of-wedlock pregnancies. If a girl had a youngster without benefit of marriage, she sometimes got labeled as feeble-minded and ended up in an in-

stitution for the retarded. The concept of feeble-minded meant weak-willed. When I was there in the early 60s, you'd have someone who was barely retarded or possibly not even retarded who spent 40, 50 or 60 years in an institution.

**PWD:** Were there other reasons to institutionalize people who didn't have mental retardation?

**BW:** It was a form of discrimination. There wasn't a similar reaction against males. There were more inappropriate female placements than male placements.

**PWD:** Did juvenile delinquents end up in institutions?

**BW:** Some did, but we tried not to. That was my major responsibility when I came to the division. I was the coordinator of classification. I was a psychologist and I had worked with the mentally retarded from the mid '50s. I worked for the Arc as a clinical psychologist. I was the guardian of the waiting list for institutions. I tried to screen out those who were not mentally retarded. Occasionally, one would sneak through. There were efforts to get more into institutions. I think I can take some credit that most didn't get put in.

**PWD:** When did people start coming out of institutions and getting back into the community?

**BW:** Oh, that goes back. There were always small-scale ones. On a large-scale basis, that was when Kott came on board. He started the Family Care program. That was the first large-scale step.

Earlier, there was a satellite of the Vineland State School, which ac-

quired some property in Red Bank. The girls I identified before, who may or may not have been retarded, went there. Through poor management, it was a dismal failure. For one thing, the community wasn't ready for it. It set the group home movement back a few years.

**PWD:** What was the main reason for starting to put people in the community?

**BW:** It's where they belonged.

**PWD:** How did this get recognized?

**BW:** The community wasn't ready then. Even the girls who weren't really mentally retarded weren't accepted just because they had lived in institutions. That was a handicap. I was very much involved in the first group homes established in New Jersey. It was one hell of a fight. It was the "not in my backyard" syndrome. Now, attitudes have changed tremendously.

**PWD:** How did this come to New Jersey?

**BW:** Wolf Wolfensberger really promoted the idea on a big scale. [Note: Wolf Wolfensberger, a psychologist, coined the term "self-advocacy" in 1973. He believed that people in institutional care needed representation by people in their communities.] People bought the concept that they belonged in the community and started group homes. The same thing happened in many states.

Maury Kott and I wanted to be sure that whatever money the state saved by having federal funds come into the institutions would make funds available to establish community programs. He had enormous respect from the legislature. There was

a kind of state understanding that any federal monies coming into the state had to be disbursed through the treasury. Kott was the first to want the funds that came in to stay with the division and directly benefit the mentally retarded.

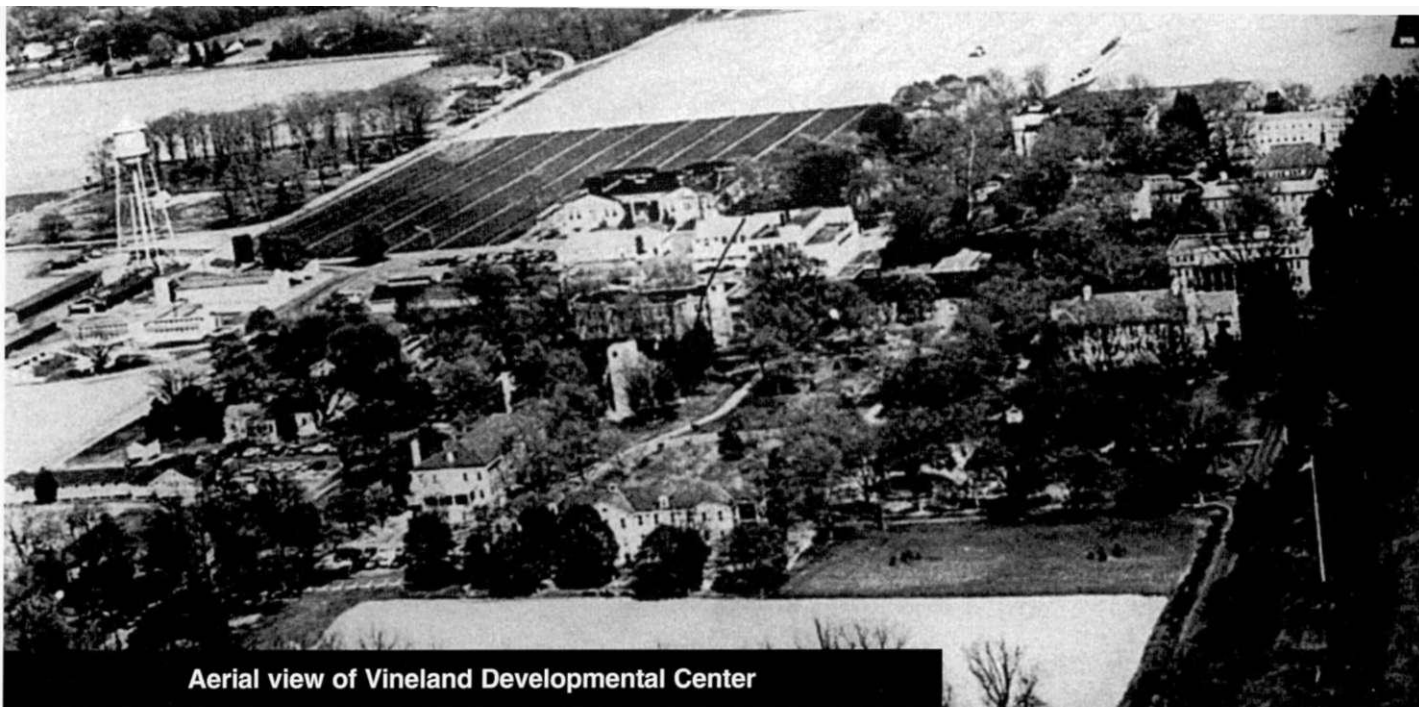
**PWD:** When did the division include other disabilities besides mental retardation?

**BW:** That would be after the name changed from the Division of Mental Retardation to DDD. While I was there, the name changed.

**PWD:** What changes took place then?

**BW:** The background here would be the reluctance of society to keep the mentally retarded at home. Many people, including doctors, had a false impression. It was routine that the standard advice given to a mother was "put him in an institution immediately. He'll never walk, never talk." They painted a dismal picture. As late as 1968, they asked me if we should even allow mothers of Mongoloid [Down syndrome] children to see the child before placing him in an institution.

Without benefit of any legislation, it became a paradox. Things were a heck of a lot more optimistic about their future lives, but without any laws, we just decided we weren't going to accept any more of the Down syndrome children in the nursery. The only facility for very young children was in the nursery at Totowa. If a family was so prejudiced against their youngster that it would do them more harm to stay at home than be in an institution, we'd make an exception. It was a tough job convincing parents to keep their children at home.



Aerial view of Vineland Developmental Center

*"Vineland Developmental Center was founded in the 1880s. There was a philosophy, 'marginal land for marginal people.' In other words, don't use up good real estate for taking care of the mentally retarded."*

The higher-level girls were at the North Jersey Training School in Totowa. Because of the training, they became rather skilled. They were some of the early ones to be sent back into the community. They got jobs working in nursing homes.

**PWD:** Were there any community supports for parents who kept their children at home?

**BW:** I had worked for the Arc at the time they started a day care program. The parents' groups really made a difference. There were also diagnostic services and the day training program. There were nursery programs for younger ones. There were also sheltered workshops.

**PWD:** What about respite care?

**BW:** Respite care was my baby. It came about in a very unusual way. I got a call from a mother whose child was being evaluated for placement in an institution. She wanted to keep her child at home, but she was having open-heart surgery. This goes back a way, because the only place

that was doing it was in Texas. If someone could take care of the child for three or four months until she got home, she was willing to keep her child at home. It started with that one case.

We then realized there were people who wanted to keep their children home if we could provide a kind of backup service. In those days, we didn't have anything like respite workers coming to the house. We had children come to the institutions on a regular basis for respite care. Families would tell us they were dedicated to keeping their child at home, but they wanted to get away for a few weeks during the summer. Other parents, whose children lived in institutions, would take their children home for a few weeks during the summer giving us room for the other children. We kind of swapped beds.

**PWD:** How about skill homes?

**BW:** These were like super foster homes. They were trained to help the child develop needed skills. This started during my time.

**PWD:** How did developmental centers and state schools go from being autonomous to being answerable to the division?

**BW:** That was a long time ago. There was no official action in respect to that change. Each institution had a board of trustees. They were technically responsible for the institutional operation. Over the years, they developed less and less authority.

Vineland Developmental Center was founded in the 1880s. There was a philosophy, "marginal land for marginal people." In other words, don't use up good real estate for taking care of the mentally retarded. So, they were located in places where there was plenty of vacant land. Then there was Woodbine and New Lisbon. The first one that they developed in a metropolitan area was Totowa.

Then we acquired Skillman Village for Epileptics. There was no medicine for them then. Society was prejudiced about seeing people with epilepsy having seizures. We talk about all the ills of society now, but

“After we started taking federal money, there were improvements all over the place. There were physical improvements and we had money to develop community programs. The transition was a smooth one, as far as I remember. We had the best programs for the buck in the country.”

we are a lot more accepting now than then. Then it became the Neuro-Psychiatric Institute. It was a mental hospital, but they kept the people with epilepsy there. They didn't think epilepsy was a mental illness, but it was more a thing of "where are they going to go?"

We poured a lot of money into that facility when we took it over. Johnstone Training and Research Center was a model institution. It was the only one of its kind in the country. That was closed, too, for economic reasons.

We had tremendous pressure to admit people into institutions.

**PWD:** Were you there when Eddie Moore was there?

**BW:** Yes. He misappropriated something like \$20 million. Kott retired and Eddie Moore came in from New York to take the job. He engaged in some practices to which I took exception. We couldn't maintain our institutional integrity with money being drained off without losing federal certification. That happened at two places, NPDC and I think Woodbine.

**PWD:** Did he have accomplishments?

**BW:** Yes. He was very community oriented. But the community isn't the

answer to everything. At Hunterdon, there was a building with people who had severe hydrocephalus. They put some of these people into nursing homes and were crowing that they got people out of institutions. But, you know what happened? They died. They didn't get proper care.

**PWD:** Do you remember about inspections before and after ICF/MR?

**BW:** We had our own inspection team. We ran good institutions. After ICF/MR, dollars could be lost. Once, they couldn't find any good green beans for dinner so they substituted baked beans and got a deficiency report. It was at NPDC and it made the newspapers that they cited the institution for inadequate nutrition.

**PWD:** Do you remember when Geraldo Rivera did the expose on Willowbrook?

**BW:** Oh yes. I saw it on television. They were denying everything and shutting out the parents. After that, a news station called our office and the commissioner's office asking about the conditions of New Jersey institutions. They asked me if anything like this happened at our institutions. I told them if employees don't show up and it's raining outside so you can't take the kids out to play, you

could end up with a situation like this at any institution. I told them to visit one of our institutions without even making an appointment. They did and we never heard anything more from them.

**PWD:** Did that change things for all institutions?

**BW:** It worked to our detriment. It held back the development of community facilities. There was less pressure for community facilities. People were satisfied with the institutions in New Jersey.

**PWD:** I heard that Maury Kott was against taking federal money, but Commissioner Ann Klein decided this would take place.

**BW:** No. Maury felt that if we could get that money to expand programs for the mentally retarded and to get people out of institutions, we wanted it to supplement the state money rather than substitute for it. After we started taking federal money, there were improvements all over the place. There were physical improvements and we had money to develop community programs. The transition was a smooth one, as far as I remember. We had the best programs for the buck in the country.



# The Shift to the Community

An interview with Dave Rosen, the first deputy director of community services for the Division of Developmental Disabilities.

By MARYANN B. HUNSBERGER

**PWD:** Tell us about your background.

**DR:** I got a degree in education from Glassboro College. After that, I got my masters degree in the handicapped child. Glassboro was the first one to give that masters degree.

I started as a public school teacher in 1949. I was placed in a class for the mentally retarded and emotionally disturbed. Before the end of the first year, I started a program of vocational education and work experience for my students. It was the first time it had been done in this country. I did that for about 10 years.

I then worked summers with the Vineland Training School. I was in charge of their summer education and recreation program. I went to the Vineland State School, now called the Vineland Developmental Center, in 1956.

I started the first work-study program for the mentally retarded in this country. I had them in school half the day and got them jobs in the community.

I did this until I was offered the position of superintendent at the Woodbridge State School. I did that for three years until 1968. I taught extension courses at Newark State College on vocational education for the mentally retarded.

**PWD:** What else did you do in New Jersey?

**DR:** I went to Woodbridge and opened a new institution for the severe and profound. It was the first institution for the severe and profound in New Jersey. Five hundred were physically handicapped and 500 were severe and profoundly retarded.

It was quite an experience. We had to hire all new staff and train them. Most of the staff went in one door and came out the other. As we became more experienced, we got better and got national recognition.

**PWD::** What was it like when you started, what kind of changes did you see.

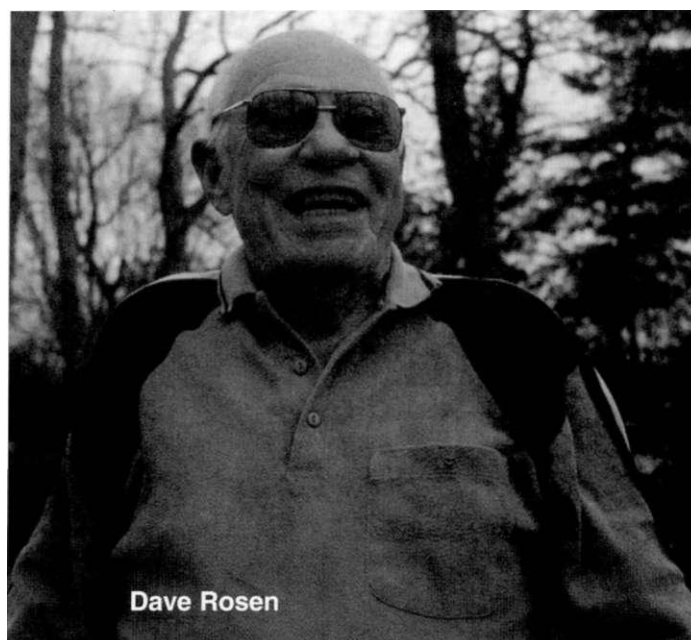
**DR:** My proficiency primarily was in community placement. I was brought into New Jersey to develop and encourage a community placement program in New Jersey. There were one or two group homes in the state. I reorganized the whole group in Trenton. I developed group homes. I had home developers and social workers as part of the team, five groups in different parts of New Jersey. We took responsibility to check out all the group homes and family-care homes.

I was also on the Developmental Disabilities Council.

**PWD:** When you started, had the shift toward community living already begun?

**DR:** The group home process had been barely started. Before that, even when I was back in Vineland, we had family care, and we placed many people in family-care situations who eventually went into independent living. That was the process back in the 50s.

I made sure that the provision was there for adequate supervision because that was always a problem in any type of placement. That was a problem in all



Dave Rosen

the other states. It needed follow up, administration and accountability. If you didn't have accountability, if you didn't have a series of people that would be responsible, you would have problems.

**PWD:** How did community programs expand?

**DR:** We developed more and more group homes so we could reduce the population in the state institutions and they could become accredited.

**PWD:** What was involved in starting them?

**DR:** Red Bank had the first group home. It contained a number of mildly retarded girls from the Vineland State School who worked in the community. Eventually they left, as they became proficient in whatever work they were doing in the community.

It was so successful that after Vineland had been supplying residents to the home for many years, it had to close down because there weren't any more mildly retarded residents to send to their facility. About 25 or so women worked and used it as a boarding house. That was back probably in the early 50s or maybe even before.

**PWD:** What were institutions like then?

**DR:** Maury Kott, who was the director of the division at that time, was a very progressive individual and he encouraged a lot of the programs that we have done.

The women in the state school were placed there and they were expected to stay there for life without returning to the community. A lot of them were very mildly retarded and

had the capability of living in the community.

All of the mildly retarded girls who were there for life were individuals who had been sexually promiscuous. The court had no place to put these girls and they began to put them into institutions for the retarded. Their only problem was that they were promiscuous, but they had no other problems.

After we realized what was going on, we were very anxious to place these girls. Dr. Kott encouraged us to look at our population and see about those who could be placed in the community. We placed hundreds from Vineland, which was the oldest and largest institution in the state.

When these girls were being placed in the community, we wanted to get them prepared, because they had been in the institution for so many years. We started what we called continuation classes. These classes were taught in the evening, because most girls had an assignment during the day. The continuation class taught them social amenities, how to apply for a job, how to get along on the job. We also gave them experiences within the community so that when they went out, they wouldn't be going out cold.

We also had what we called home training. Girls would go there in the evening and learn the domestic things, cooking, etc. They did very well and it increased their appetite to live in the community. We also provided field trips for them to go to local manufacturers, so they could be aware of the kinds of things they could do when they got into the community.

**PWD:** What other types of training did you have?

**DR:** We began to do education with the severe and profoundly retarded. I started the first classes for the people who were not educable, but were trainable, before the public schools did. We had regular classrooms in our school that dealt with these folks. We were very pleased with the progress they made in the school.

We also started a socialization program between the girls and the Woodbine boys. We thought it would be a good idea for them to socialize, because both of them were segregated. The girls didn't know how to act around the boys and the boys didn't know how to act around the girls. We decided to have a dance. I think we started with about ten and worked up to 50 from both Vineland State School and Woodbine.

**PWD:** How did the dances go?

**DR:** It was exciting. I went on the first bus to take the girls to Woodbine. We went to Woodbine because their recreation room was on the second floor. We thought we could supervise the girls and boys more closely to make sure that nothing untoward was happening on the second floor, as opposed to the ground floor at Vineland. That's how much trust we had.

We were very embarrassed when we observed that because of being apart for so long, they were very shy. In fact, we had to match them up to dance and encourage them to do so, because they were too shy to do it.

They had refreshments of ice cream, soda and pretzels. The boys served the girls because they were the hosts.

The boys had to be taught to dance because none of them knew how to. They all learned the same steps and we used to call it the Woodbine Shuffle because they all did exactly the same thing. The girls had been dancing together for years at the state school and every Friday night they had a big blowout in the auditorium.

Coming back from that first party on the bus, the girls were all excited. They were singing and talking about the boys they paired up with. Some of the boys worked in the bakery at Woodbine, so the girls said that they would never have to worry about bread because their boyfriends were bakers.

After that, we increased the number and variety of programs. That developed into other kinds of activities. We had picnics with boys and girls at Vineland.

Some of the old supervisors at Vineland were aghast that the girls would be mixing with boys at Woodbine because they just didn't trust the girls. But, it was a wonderful program. We had no incidents and other institutions in New Jersey began to do it.

**PWD:** What things are much different now from when you started?

**DR:** The rights of the retarded are probably the biggest thing. At all the institutions, each place had a secluded area to place residents when they "acted out." They used it as a threat. It was called the adjustment clinic in Vineland, but actually, it was a small jail. We used to call it the jail. There were actually bars on there. They would throw them in there.

Before that, they would shave their heads if they ran away, which was common, because the mildly re-

tarded didn't want to stay in that kind of environment. They were also put in a cotton ticking dress for a month. It is a very coarse material used to cover pillows or mattresses. It was very embarrassing for them. This was before I arrived, because we didn't allow that.

They also had a reputation for physically manhandling the women. This was true before I got there, and to some degree when I was there, but we stopped it as quickly as we could. The superintendent was a progressive individual, and I didn't want to see any of that stuff going on, so we changed it together.

**PWD:** What first-time events do you remember?

**DR:** There was segregation when I arrived. At Vineland, the state school was made up of the east and west campus. They separated the black

and the white women. All the black women were in the west campus. Most of the employees out there were black, as opposed to the east campus.

They decided to desegregate the institution. They brought over a busload of black women from the colony and had them go into different buildings in the main campus, but it didn't work. They all walked out and went back to the east campus. As time went on, we had a non-segregated facility. Everyone was admitted to the main institution, and gradually we had a good mix.

When I became assistant superintendent, I was the first one to hire a black woman as a supervisor. Previously, they had all been white. Her name was Wilma Irby. She is retired now, but she worked her way up to become the director of Woodbridge after I left there. ■

## ICF/MR History

According to the Centers for Medicaid and Medicare Services, the ICF/MR Program was established in 1971. It allowed states to receive federal matching funds for institutional services that had been funded by state or local government.

To qualify for reimbursement, ICFs/MR have to comply with Federal standards in eight areas: management, client protection, facility staffing, active treatment services, client behavior and facility practices, health care services, physical environment and dietetic services.

Some landmarks in the ICF/MR program are:

1971 .....	Legislation authorizing the Medicaid ICF/MR benefit
1977 .....	40 States participating; private ICF/MR facilities covered
1978-80 .....	States expend nearly \$1 billion to obtain ICF/MR certification for large facilities.
1981 .....	Guidelines issued for ICF/MR facilities serving 15 or less
1988 .....	Outcome-based ICF/MR standards issued
1993 .....	Majority of ICF/MR beneficiaries served in private facilities
1995 .....	Updated guidelines published.
1996 .....	ICF/MR National Satellite Training Broadcasts

—MARYANN B. HUNSBERGER

# A New Era

## ICF/MR and the Community Care Waiver

By JONATHAN JAFFE



INSIDE THE WILLOWbrook State School on Staten Island, an undercover news camera reaches into cold, darkened corners; the eyes of forgotten children peer back. As the tape rolls, a solemn-sounding journalist reports:

"There was one attendant for perhaps 50 severely and profoundly retarded children. Lying on the floor, naked and smeared with their own feces, they were making a pitiful sound, a kind of mournful wail that it is impossible for me to forget. This is what it looked like, this is what it sounded like but how can I tell you about the way it smelled? It smelled of filth, it smelled of disease, and it smelled of death." The film cuts to a Willowbrook doctor. The reporter asks, "We've just seen something that's probably the most horrible thing I've ever seen in my life. Is that typical of ward life?"

The doctor replies: "Yes, there are 5,300 patients at Willowbrook, which is the largest institution for the mentally retarded in the world. The ones that we saw were the most severely and profoundly retarded. There are thousands there like that, not going to school, sitting on the ward all day, not being talked to by anyone, only one or two or three

people to take care of 70 people on the ward."

This infamous report by Geraldo Rivera in 1972 sent chills through the public. Policy questions quickly emerged. Had institutions for people with developmental disabilities gotten this bad? Wasn't there a more humane way to serve them?

The broadcast was a sharp contrast to national policy to upgrade America's institutions through the use of federal dollars and strict guidelines.

The federal program is commonly known as ICF/MR, enacted in 1971. Through an infusion of federal money, states finally had resources to upgrade their antiquated institutions and, in following its guidelines, discharge residents to community care.

New Jersey leveraged ICF/MR funds to upgrade the nine developmental centers that existed at the time, while using federal community care waivers to relocate their residents to group homes.

"The ICF/MR program was the first major federal funding of operational services for people with developmental disabilities in history," says Bob Gettings, executive director of The National Association of State Directors of Developmental Disabilities Services. "Before this program was enacted, the federal government had funded research, some training, some construction. But this is the first

time, through the Medicaid program, that the federal government underwrote a share of the cost of a particular set of programs for this population."

Providing that level of care to the elderly and people with disabilities began in 1965, enactment of "Medical Assistance, Title XIX of the Social Security Act" - commonly known as Medicaid. The program provided federal matching funds from 50 percent to 82 percent for medical assistance, including the admission of people into nursing homes.

Government officials quickly saw a swell in the number of patients admitted to skilled nursing facilities, as people with developmental disabilities met the income guidelines to qualify. Many of them ended up receiving far more medical care than they needed, because half or more of their care was funded through Medicaid.

"People with mental retardation were ending up in medical nursing homes, staffed with plenty of doctors and nurses," says Bob Prouty, co-director of the National Residential Information Systems Project at the University of Minnesota. "A lot of the people didn't need all this medical care, just supervision, training and care."

Government officials needed to revamp the program. And quick. In

1967, government officials created a new, less expensive program, offering an "Intermediate Care Facility" (ICF) to serve elderly and disabled adults through Medicaid.

"The ICFs were an alternative to hospitalization; an intermediate step that still had the Medicaid funding," Prouty says.

In 1971, federal policy makers returned yet again to the drawing board to figure out how this program could be modified to better serve people with developmental disabilities. Intermediate Care Facilities for the Mentally Retarded (ICF/MR) - provided substantial federal aid for states to upgrade their institutions, also known as developmental centers.

"The whole idea behind ICF/MR was for the federal government to increase the quality of care in institutions, which at the time were very sad places. The federal government shared in the cost of institutions that met certain standards."

ICF/MR was considered the ideal way for the federal government to assist states with the rapidly-increasing institutional costs, which averaged 14 percent annually in the five years before the legislation was enacted.

The result of the program was dramatic. With billions in additional federal dollars now available, officials in states across the nation spent the 1970s turning their old, sagging institutions into new ICF/MR facilities.

Not everyone was pleased the



U.S. Treasury was making institutions such a priority. "Many believed that upgrading the institutions is not where the money should go," Prouty says. "People asked why the money wasn't going to support community alternatives for these people.

"Advocates wanted people living in normal environments; institutions were not normal environments," he adds.

Critics charged the ICF/MR program was:

- Creating financial incentives for maintaining people in large state facilities.
- Diverting funds that could have been used to develop community programs.
- Promoting individual dependency

by offering a single standard of care for ICF/MR residents.

These arguments, and the growing desire to provide community residential programs, spawned the development of community ICFs/MR, delivered in 4-15 person group homes, funded by Medicaid.

Senator John Chaffey, a Rhode Island Republican, pushed for a Medicaid waiver to serve as an alternative, an individual response to individual needs. (In 1981,) "Chaffey and others were able to pass legislation that allowed people to stay in their own homes, some with their families; others were able to live in adult or child foster or group homes not certified as ICFs/MR."

There are now three times as many people with Medicaid waivers than those living in ICF/MR facilities. "ICF/MR institutions are history," Prouty says. "People want to live among friends and family and have social activities; the waiver provides that option. The waiver is no more costly than an institution. If both options are the same cost, why would someone want to live in an institution if he or she can live in the community?"

In the early 1970s, when the ICF/MR program began, there were 365 institutions in America. Today, there are 186.

When Claire Mahon joined the Division of Mental Retardation in 1976, its institutions were awful. "There were as many as 40 people in a ward. The staff lined the beds up next to each other. It was not condu-

cive for personal growth, no matter how dedicated the staff had been. The institutions were like Army barracks, no personality. There was not even a night table for personal effects - just a bed in wards segregating men and women."

Mahon joined the division to plan one of the most massive undertakings in this history of developmental disabilities in New Jersey: to upgrade the institutions to ICF/MR standards, thus forcing their de-population, moving thousands of people into group homes. More than \$100 million would be spent in capital expenditures through 1982.

Her first task was to propose a capital grant program to develop group homes and plan a strategy to convert the institutions in a way that would "force a de-population," she says. "In order to change New Jersey's institutions from large wards to four beds per room required massive capital renovation and a loss of bed space. We used Medicaid funding to place the people in the community."

State officials began developing the ICF/MR program in 1976; the federal government earmarked the money three years later. The project began immediately, affecting 9,000 resident in nine institutions. The state hired about 3,000 new workers to coordinate the transition, as part of the ICF/MR stipulations.

Bringing the institutions through the ICF/MR process was like managing a war, Mahon recalls, noting state employees had to relocate hundreds of people to renovate buildings.

"This was something not one or two employees handled," Mahon says. It required an entire state divi-

sion. Not before or since has the state taken on such a major renovation and expansion of residential facilities."

To comply with ICF/MR guidelines, developmental centers lost about 2,000 beds. At the time, officials believed between 2,500 and 4,000 people in the institutions were ready to live in the community and worked to relocate them, Mahon says.

With the conversion completed three years and eight months after it began, the additional Medicaid revenue was dedicated to the development of community resources to place people in group homes. ICF/MR forced New Jersey to consider them an alternative to institutions.

"It was really the kick start to the current day," Mahon says. "If you look at the division's budgets until the mid-1990s, all the funding for community-based services came from Medicaid funding. It was a deliberate political decision of the state Legislature and Governor. There had to be a zero-sum game; these community-based programs could not cost the state more money."

"The state got a great deal. And people who care about developmental disabilities saw this as a commitment from government toward our agenda of community inclusion."

Even with the ICF/MR funding, the institutions could never match the benefits of the community care waivers. When she was CEO of Woodbine later in her career, she recalls: "It was June, we were in the Pine Barrens, and I thought my consumers should have strawberries. I remember the food service supervisor was very upset about how much that would cost in overtime to provide.

Strawberries had to be plucked, etc.

"In institutions, the decisions you make, such as if people should get fresh strawberries in June, does not take into consideration a person's life. Life really changes for a person who leaves an institution. It's the things that you take for granted, which these people can finally have when they move to a group home."

Bob Nicholas, who was an aide to Department of Human Services Commissioner Anne Klein under the Byrne Administration, recalls that New Jersey remained a firm supporter of institutions at the time the Geraldo Rivera story hit. Maury Kott believed that institutions were the best way to care for people with developmental disabilities, although Klein thought there must be a better way to handle this population.

When Kott retired in the early 1980s, the department selected Eddie C. Moore to run the DDD. "Eddie brought in the community care waiver and got the developmental centers to comply with ICF/MR standards," Nicholas says.

Under Moore, the division lowered the staff-to-consumer ratio, reduced the overall institution population and gave the people remaining some much-welcomed breathing room.

"The residents who then left the developmental centers to facilitate the ICF/MR certification got reimbursements through the community care waiver," Nicholas explains. "They were able to finally have some independence. ICF/MR will be remembered as the first major step in the New Jersey community system for people with mental retardation."



# "I did it and I'd do it again"

By JONATHAN JAFFE

Inside the auditorium at Vineland Developmental Center, before a packed house on April 3, 1989, there was a mix of anticipation and dread. Members of the Assembly Appropriations Committee appeared surprised as they stared at the proposed budget the Department of Human Services (DHS) earmarked for fiscal 1989.

The group, chaired by Assemblyman Rodney Frelinghuysen, couldn't comprehend the budget numbers before them. How could the Division of Developmental Disabilities (DDD) possibly overspend its budget by \$32 million? How could its officials spend money they knew they didn't have? Most important, who was responsible for this mess, the largest budget overage in state history?

The eyes of the legislators fell on Commissioner Drew Altman, his deputies and their budget team. They must have an answer. Instead, these officials turned to the first row of the audience. After an awkward silence, Eddie C. Moore, the director of DDD, stood up.

"Eddie told them, 'I did it and I'd do it again,'" recalls Robert Nicholas, then deputy DHS commissioner.

"He said he was 'proud' to have spent the money."

"I had a heart attack. It was like a bomb dropped in my lap," recalls Mary Kay Risi, the young, inexperienced press spokesperson for the DHS at the time. "Eddie just stepped

turned into an overnight media sensation. As the press furiously worked the story, day after day, the public became increasingly enamored with Moore.

Who is this guy? How could he overspend \$32 million of our money?

And: Why?

"It was a hellish whirlwind for me," Risi recalls. "I was told to tell the press that what Eddie Moore did was wrong and that we can't understand why he did it. The official position was it was extremely improper and a very serious matter because he didn't have authorization to spend state money improperly."

Jim Hooker, then a statehouse reporter for The Trenton Times, says there was a feeling among the press that Altman and Risi were not giving them the full story. Their question was: How could the DHS allow this to happen?

"Altman and Risi were telling me everything was okay, but then I'm finding out from my sources that it was not the case," says Hooker, who won an investigative reporting award in 1990 from the Society of Professional Journalists for his coverage of the story.

"It got my journalistic blood going. If someone tells you one thing



**Governor Tom Kean (left) congratulates Eddie Moore on the signing of legislation creating a new Division of Developmental Disabilities.**

up and said he spent all that money. It was such a defiant measure."

It was known that Moore, 40, had submitted his resignation and was finishing out his days as a state employee. It was also known by some that he was dying of cancer.

By admitting he was responsible for enormous cost overruns to help people with disabilities, Moore

and you find out it is something else, then you are going to go after the story that much harder.”

When the story of Moore’s cancer fight broke, it created another furor. In the sunset of his life, was Moore a modern day Robin Hood? Was he intentionally funding programs for the disabled, even though he knew it would force the state to find money elsewhere?

It was possible. Moore was known in the department for his commitment to people with mental retardation. He often spoke about how this population could be better served, and often challenged his peers to find ways to make the state funding stretch further.

“There are very few people like Eddie Moore in government,” Altman says. “There are not a lot of people who will say ‘Damn the torpedoes,’ and do what they think is

right.”

Moore, who earned \$74,000, lived with his wife, Corona, in Manhattan. He began his career 20 years earlier, as an activities therapist coordinator for New York psychiatric programs, according to *The Trenton Times*. In 1973, he earned a graduate degree in psychology from Fordham University.

In 1979, Moore became the youngest associate commissioner of Mental Retardation and Developmental Disabilities for New York and Long Island. He then replaced Maurice Kott as the DDD director in 1981.

Elizabeth Boggs told the *Star-Ledger* in 1991 that when Moore came to New Jersey in 1981, the field of mental retardation was in the throes of change. He “hit the ground running and leaped into the saddle of a bucking horse, delighted to be carried forward by its momentum and to apply the spur and bridle to produce his own style of horsemanship.”

According to *The Trenton Times*, there was a tremendous shift away from institutional care. The number of community-based group homes and supervised apartments in the state had ballooned from seven to 300.

In 1980, just before Moore took over, about 50 people the DHS served were living outside institutions. When he resigned as division director in January 1989, the number had swelled to 1,800-2,000 people enjoying independent living. DDD’s budget also doubled, as the

state rode robust economic times.

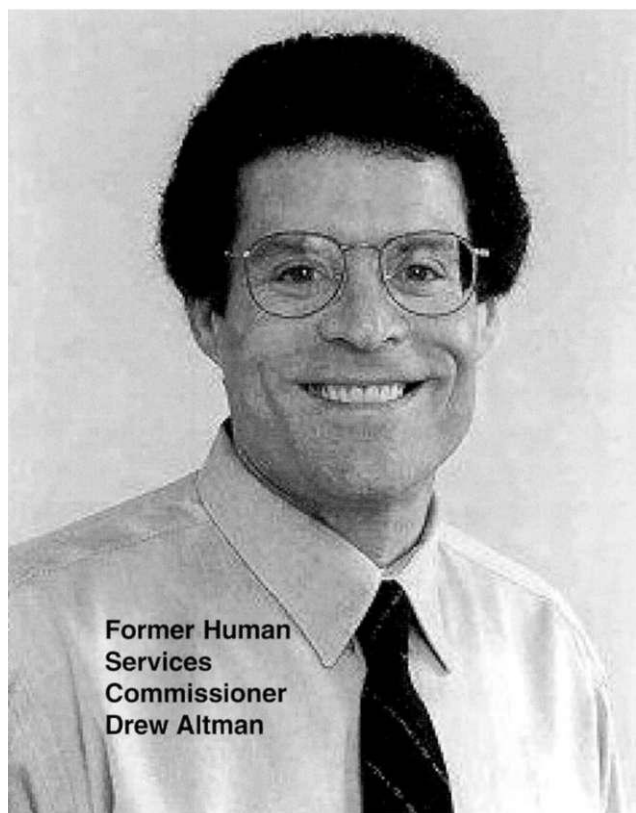
When Governor Kean appointed George Albanese as DHS commissioner in 1982, Moore had already won over a large majority of the constituents the division served. “When I joined the department, I interviewed the top 40 people in the department and made judgments on whether they would stay,” Albanese recalls. “When I met Eddie, he definitely had the support of the mental retardation constituents. He was dedicated to helping people in need.”

“But, it was clear that Eddie needed to be controlled,” the former commissioner adds, noting he ran the department with a more hands-on management style than Altman.

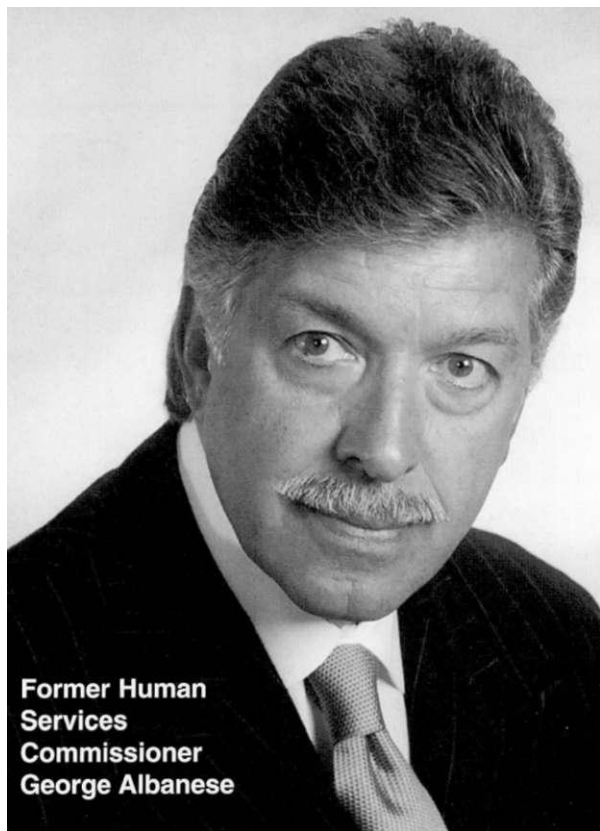
Albanese says the greatest victory he shared with Moore was to ask Kean to change the Division of Mental Retardation to the Division of Developmental Disabilities. “Eddie and I went to Governor Kean’s office and petitioned for the change. It had a tremendous impact.”

When Altman took over as commissioner in 1986, he was in his 30s, an outsider to state government, and some considered him a young hotshot who Kean had brought in for his pet project – welfare reform. Before becoming commissioner, Altman was vice president of the Robert Wood Johnson Foundation for five years and, prior to that, served in the Health Care Financing Administration for President Carter.

“Welfare reform was a huge national issue at the time, and Altman had been big on welfare reform,” Risi says. “He was also an incredibly young, bright guy. Altman was not an insider and he had a lot of trouble with the Legislature and the bureau-



**Former Human  
Services  
Commissioner  
Drew Altman**



**Former Human  
Services  
Commissioner  
George Albanese**

cracy. His missteps were in miscalculating politically how to get things done."

She says Altman's efforts to bring in welfare reform drained money from community-based programs. Moore was not happy.

It is still unclear why Moore overspent the \$32 million. Did he intentionally spend the money, or was he just not watching the books as closely as he should have?

Altman, now head of the Kaiser Family Foundation, believes Moore acted intentionally. "Eddie was upset that I imposed centralized control and a lot of other division directors also bristled at that. The root of it all was that Eddie wanted to be independent and we were there to impose overall fiscal and policy control for the Governor.

"As with every division in the department, the need in Eddie's division far exceeded the resources. Eddie saw it as his job to get every penny he could by following the rules and sometimes not following the

rules. That was the heart of it."

In his response to the Assembly Appropriations Committee, Moore spoke as if the overspending was intentional. "I think we have a responsibility to solve complex problems. The easy thing for me to do as director would be to say, 'We have no money, you have to go to the Legislature.'

"I think it was a very proactive way to behave," Moore added,

noting he actually saved the state money because he expected the extra funds would eliminate potential lawsuits from clients.

According to DHS officials, the Eddie Moore legend is a bit different. Some say it was neglect, not heroism, which caused the deficit.

"It is obvious his remarks before the appropriations committee indicated that Eddie was aware, but subsequent inquiries would indicate he did not know the full extent of the deficit that was created," Nicholas says. "He was unaware of some of the contracts that had been signed."

DHS leaders knew about the deficit weeks before, but figured Moore should explain it to the lawmakers and the public. An article in *The Trenton Times* before the Vineland hearing reported Moore's missteps.

Prior to the hearing, Altman met separately with Kean's staff and Frelinghuysen to lay out the problem. He also gave Hooker an interview about it before hearing took place.

But many attending, said the Assembly Appropriations Committee still appeared shocked that such a huge amount of money could be spent without anyone catching it. "I think some of the committee members were still unaware of the overspending before the hearing," says Hooker, now a correspondent for NJN.

Hooker said Frelinghuysen told the crowd, "someone must have been asleep at the switch."

In later years at DDD, Moore was known to take side jobs. To some, it was obvious he was not putting in a full week as director.

One outside, unpaid consulting gig in 1986 had been approved by the DHS, because it called for Moore to spend three weeks in the Virgin Islands with York Associates, a New Jersey-based consulting firm, to write a housing plan for the government there. York Associates was run by Clarence York, the former chairman of the New Jersey Developmental Disabilities Council.

But there was other part-time work Moore had, with money attached, such as serving as a \$500-a-day court monitor for the U.S. Federal Court in the District of Connecticut. There was also speculation that he spent work-time gambling in Atlantic City.

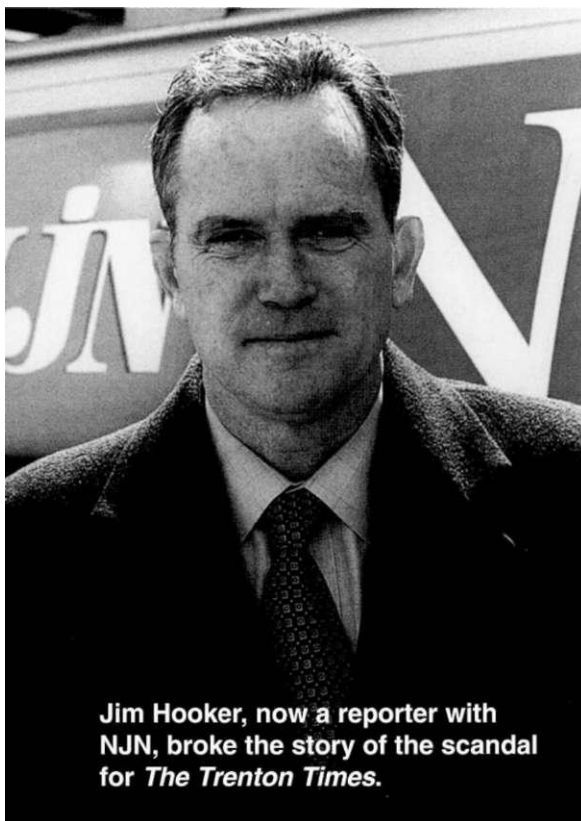
When Hooker asked about his absentee style of management, Moore responded, "You've got to get out. You can't sit in your office. People don't know you if you sit in an office."

Because of his tight schedule, Ronald Melzer, deputy DDD director, often ran the day-to-day operations. He is believed to have found the massive deficits and reported

them to DHS officials – prior to the hearing in Vineland.

When confronted, Moore was initially vague. It was not until the hearing that he offered a full disclosure before an outraged appropriations committee.

As DHS officials delved further,



**Jim Hooker, now a reporter with NJN, broke the story of the scandal for *The Trenton Times*.**

have worked all those days out-of-state, and still have his hands on the rudder in Trenton? It turned out he didn't."

Moore had issued \$21 million in contracts without the funds to back them up; the \$11 million balance was an operational deficit. He later told a reporter that some of the contracts were never signed and others had a 30-day window to be cancelled.

Officials believed Melzer was as responsible as Moore because Melzer did not fully understand the budgeting process and signed off on the contracts. Moore, not around much, was accused of disregarding his duties.

In turn, Altman fired Melzer and brought Nicholas in to pick up the pieces at DDD. Surprisingly, Moore was not asked to leave and was allowed to remain until his resignation was effective April 28, 1989.

"Kean didn't want me to fire Eddie," Altman says. "I think the Governor knew he was terminally ill. I never talked to Kean about it. It is just speculation.

Also, Eddie had a lot of friends in the state Legislature and in the developmentally disabled community. In retrospect, if I had been able to do what I wanted to do, I would have fired him. It would have ended a lot of the fallout."

Following Moore's public announcement, it was up to DHS officials to fill a gaping budget deficit in a division that employed 10,000 workers, or one-sixth of the state's entire workforce.

Altman describes what happened as a "minor miracle." DHS officials

were able to find \$14 million in federal money to fill the deficit. Also, \$18 million in surplus was shifted to DDD from other divisions. In the end, the crisis had little effect on state taxpayers.

In the days following the April 3 announcement, Altman recalls, Moore approached him and asked for time off to care for his wife, who Moore said, was dying of cancer. "I said, 'Of course. Sure'," Altman says. "But it wasn't his wife with cancer; it was him. I think that explains a lot about what he did."

In 1990, Moore was indicted for official misconduct, performing out-of-state consulting work and gambling in Atlantic City on state time. "Eddie was a good guy, who got caught up in a lifestyle that he could not maintain without taking the contract in Connecticut," Hooker says. "And there was the gambling in Atlantic City. Bally's was his place."

Moore pleaded innocent to the criminal charges, applied to a pre-trial intervention program to avoid trial and a decision was pending when he died Jan. 12, 1991 of cancer at age 41.

"What happened with Eddie Moore certainly led to much tighter control of DHS contracts," says Nicholas, now a consultant in Tennessee. "Unfortunately, the overspending overshadowed how committed the people at DDD were to people with disabilities. Unfortunately, the commitment was shown by not properly allocating funds, which is sad. But it should not cover up the overall message that Eddie Moore was a popular person, committed to the needs of the community he served." ■

REBECCA SHAVULSKY



## FEATURE STORY

once he became friendly with staff members.

In 1991, DDD announced plans to close Johnstone. Palermo said he was "up in arms" about the idea. He wrote to the governor asking him to keep Johnstone open. "We fought to save it. We didn't know what it was going to be like to live on the outside. I was scared and so were my friends. My mother had died and a lot of the staff told us scary things about the community.

"I thought other people might have needed it to stay open. We had a rally that they showed on television. I couldn't go that day because I was working in a workshop, but they closed Johnstone and now I am glad."

Palermo moved into a group home for a few months, then moved into a supported apartment in October 1992. He was happy with the change. "It's good here. I like it better than Johnstone. The staff is nice here. I have more independence. Once, I did volunteer work at Robert Wood Johnson Hospital folding menus. I go to wrestling events, restaurants, Star Trek functions and baseball games."

Baseball is his passion. He enjoys kicking back with friends and a few beers to listen to a game. He represented Community Options at a Trenton Thunder game, where its name was in lights. At a Phillies game, they announced his birthday, which was a thrill to him.

Personal care attendants come to Palermo's apartment each day. They assure that he gets to doctors' appointments, stores and activities. When he travels, they take him to bus stations and airports. They also cook,

# The Community is Calling Your Name

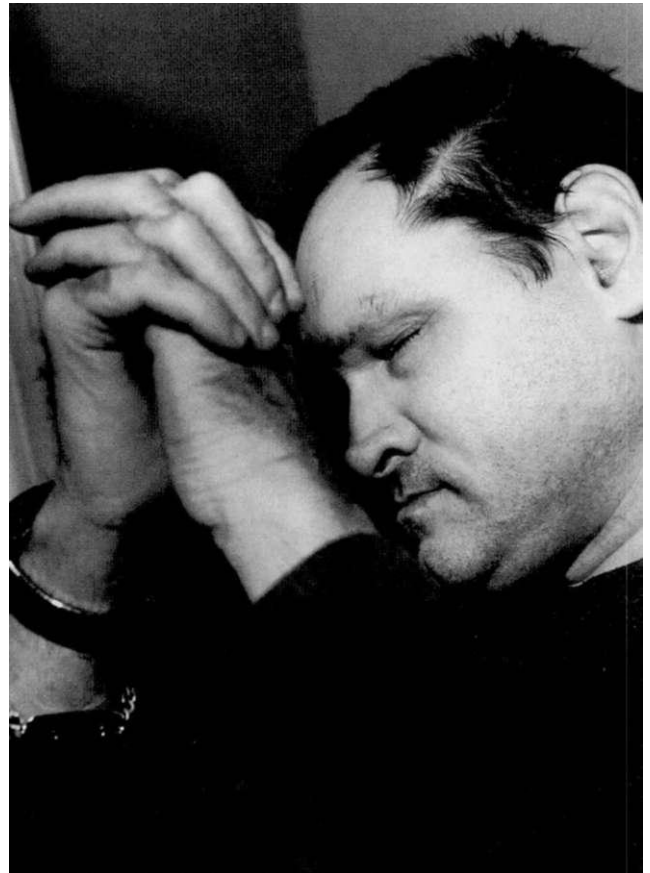
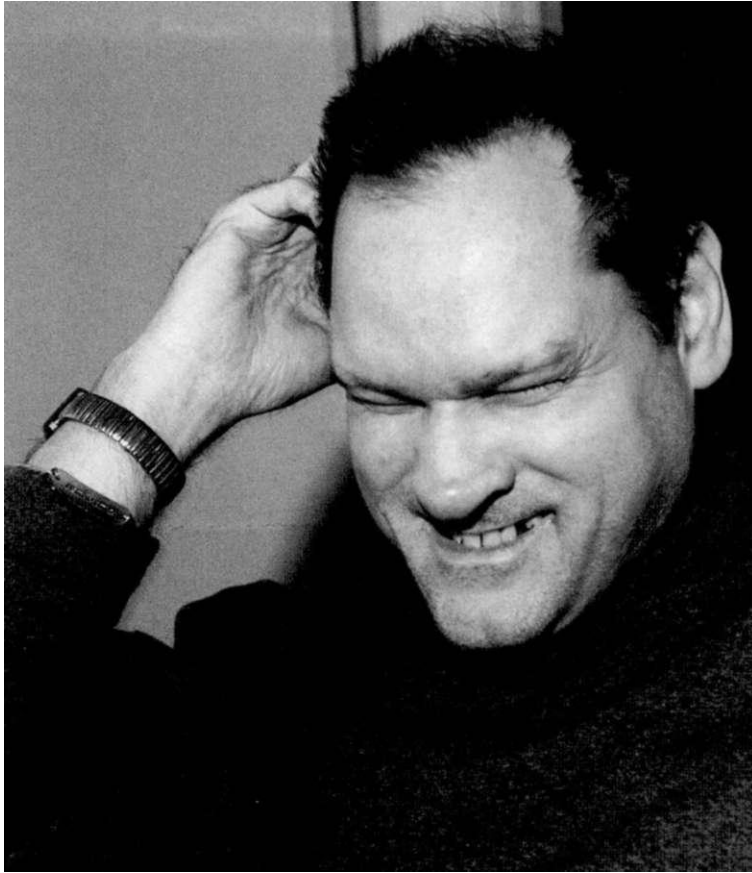
By MARYANN B. HUNSBERGER  
Photos by REBECCA SHAVULSKY

**E**d Palermo is itching to put someone in handcuffs. The Robbinsville resident, 49, wants to accompany his bounty-hunter brother on a job assignment. "He goes after people who jump bail. I want to put the handcuffs on."

Palermo could never have imagined doing that in the 35 years he

lived in institutions. "In the institution, you couldn't say how you felt about things. You had to do what they told you and you couldn't speak up."

He went to the Matheny School at four, because he uses a wheelchair and is blind. "My mother didn't know what it was like in an institution. I missed my family," he said. At age 16, he moved to E.R. Johnstone Training and Research Center. He didn't like it at first, but he adjusted



clean and do laundry.

Palermo travels quite a bit now. He has been to Florida, North Carolina, Hawaii and Jamaica for vacation. He often visits family in Detroit and Boston. He wants to see his 6-month-old niece in Detroit soon, as he enjoys being around babies. Palermo enjoys taking in a baseball game when he travels. "I love to travel and visit new places. I liked going to Tiger Stadium in Detroit. I saw the Tigers play Baltimore. I loved it!"

Palermo relishes living in his condo with a housemate. "I have good support people to help me. I work, I make my own decisions, I vote and I worship."

His outlook on community life led him to join the SWOT (Seeking Ways Out Together) Team. He didn't

know what to expect when he left Johnstone and he feels that most people leaving developmental centers are afraid of the unknown.

"We go to various institutions and tell them how their lives would be better if they were out. Some are pretty scared. We assure them that there is nothing to be scared of and that their lives will be better. We tell them to not worry about it, because they will make more friends like we did. It is a lot better in the community. I tell them, 'Come on. The community is calling your name.'"

Advocacy is his passion now. "In 2001, I testified in Washington, D.C. at the New Freedom Initiative Hearings. This past January I testified at our State House against restraints and aversive treatment for institutionalized children and adults."

The best part of living in the community is going to work and being with friends. He once tried telemarketing and didn't like it but is happy at his current job, working in Princeton at the Daily Plan It, an office, conference and copy center owned by Community Options. "I help make coffee, answer phones, deliver faxes, clean the windows. I work all over the building and like it better than when I worked in a workshop."

Palermo also likes setting his own schedule. "I don't have set bedtimes. I can go to bed whenever I want. I can stay up as late as I want, eat whatever I want and watch whatever I want on TV."

"I would never put a member of my family in an institution. I will never go back."



## RETROSPECTIVE

# Revisiting the Man in the White Hat

By JONATHAN JAFFE

When Robert B. Nicholas stepped in as director of DDD in May 1989, there were a number of critical challenges awaiting him. It had only been four years since the division changed its name from the Division of Mental Retardation—greatly expanding its service base—and staff members were still adjusting to serving the added clientele.

"Prior to 1985, you needed to have mental retardation to receive services from the division," Nicholas says. "By changing the name to the DDD, many other people became eligible. Suddenly, we had to integrate our services for other communities with disabilities, such as cere-

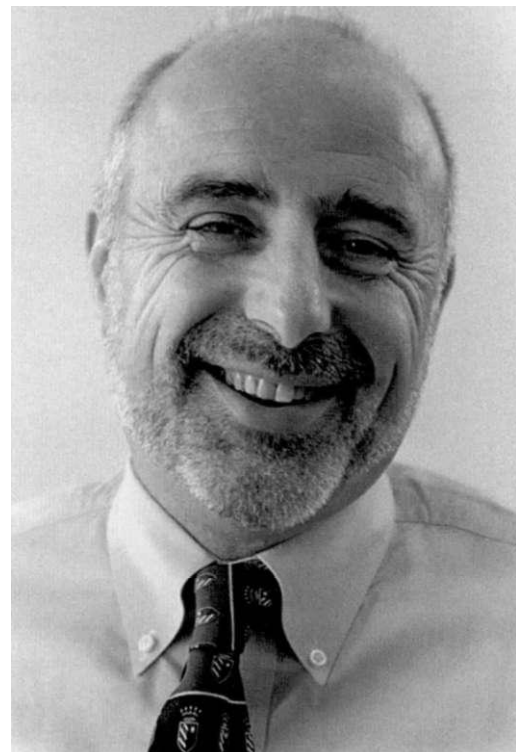
bral palsy, autism and Spina Bifida.

"When I took over, there hadn't been a great deal of programs that fully integrated with these other communities. Each had their own associations. They all believed the statute behind the name change was not fulfilled. They were looking for more aggressive action on our part."

In response, he formed the New Populations Committee, comprising advocates from the groups who became eligible for DDD services. Jane Horowitz, executive director of the Spina Bifida Association, recalls a thorny issue the committee wrestled with from the outset: How was DDD to accommodate these new populations without more funding?



Nicholas receives a plaque from Mary Kay Weber and Jeff Bruce



SIMON FULFORD

Former DDD chief Bob Nicholas

"We were trying to work together to figure out what we can do under these fiscal restrictions. The top levels of DDD began to understand what the needs are of the different populations, but it was difficult to get to the front line workers, who had been dealing with mental retardation for so many years and did not have the training for these new disabilities."

Horowitz still believes DDD employees need to be more educated about caring for the consumers. "Many people with complex physical disabilities still don't have appropriate services. And there still hasn't been sufficient money made available to provide a whole host of services that are needed for this population."

Nicholas says there was "nothing groundbreaking" about the New Populations Committee, but it did ensure that all populations the DDD serves had vocal and active representation.

When Nicholas first took the reigns of DDD, its focus was still on institutionalization. "If you looked at the field of mental retardation in

REBECCA SHAVULSKY



SIMON FULFORD

**Former Commissioner Bill Waldman and Nicholas congratulate each other on the closing of North Princeton Developmental Center.**

1989, New Jersey was ranked 48<sup>th</sup> out of the 50 states in the number of beds operated at developmental centers. We were among the biggest at a time when the whole evolution of services was going away from institutions, to providing programs in the community where people can live and work. We were behind the rest of the country."

There had been no push to close the institutions because it was considered a political hot potato. Family members wanted the institutions to remain open, as did the state labor unions representing the thousands of employees who worked in the facilities.

DDD was still operating a significant number of beds in the Woodbine and Vineland developmental centers that did not comply with ICF/MR standards and, thus, were not eligible for federal reimbursements.

"I determined that we could take these beds out, and use the money to get people out of institutions," Nicholas recalls. "We closed 250 non-certified, non-ICF/MR beds in Vineland. Then, in 1992, we closed

100 beds at Woodbine, transferring the people out into the community."

But the big push did not take place until 1993, when the Florio Administration mandated that DDD slash millions of dollars from its operating budget. Rather than eliminating services, the division decided to

close Johnstone and use additional federal revenue to place the consumers in the community.

"At that point, we had never closed a large developmental center. There was a whole range of issues that needed to be addressed as far as planning who would live in the community and who would be assigned to another developmental center. Families also needed to be addressed."

Nicholas recalls it took 14-15 months to close Johnstone and relocate 230 people, adding most families regarded it as an "acceptable operation." When Christie Whitman replaced Jim Florio as Governor in

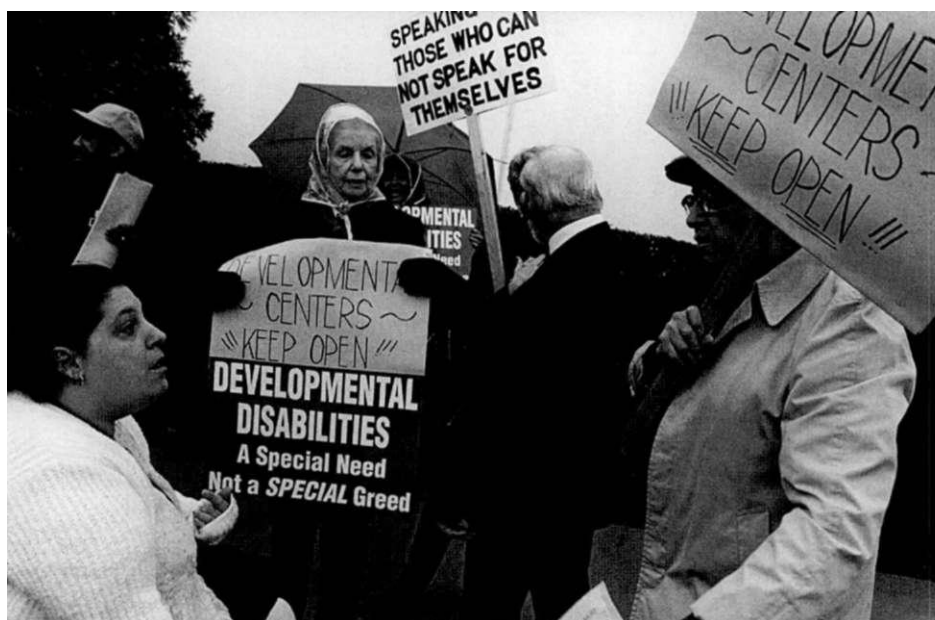
1993, she pressured the DDD to close more institutions.

"We then targeted North Princeton, which was much larger with about 500 people there. The goal was to make sure as many people as possible went into the community. To help smooth the process, the Developmental Disabilities Council launched the "SWOT" (Seeking Ways Out Together) team, made up of former institutional residents who volunteered to help current residents prepare for life in the community.

"There was a round of controversy involved with the closing of North Princeton because it was such a large undertaking. Many families did not support it. But national research shows that when institutions are targeting for closing, people who live there oppose it. But a year later, the research found, they support their new living arrangements. We knew that going in and we braced ourselves for it."

Besides the SWOT team, the Council also undertook a support project, conducting small group meetings with family members and effectively providing them with information about day-to-day community living for their loved ones. North Princeton closed in 1998.

**Family members protest the closing of developmental centers.**



SIMON FULFORD

Leila Gold of West Orange, whose 39-year-old son lives at the Hunterdon Developmental Center, recalls that many parents wanted to keep the institutions open. "Johnstone and North Princeton were run down, but I know that many people liked them. When they closed, lots of people were happy in the community setting, but I know that some did not make it and had to go back into a developmental center."

While DDD moved more consumers into the community, division officials were also trying to reduce the growing waiting list for services. With the many new populations eligible for services, the number of people waiting for services consistently mounted without a solution in sight.

The vast majority of the people were waiting to be placed in community residential services. By 1989, when Nicholas took over, there was already a pile of pending lawsuits from people who were eligible for DDD services, but were not getting any. The waiting list was approaching nearly 3,000 people. Through Nicholas' tenure from 1989-1998, the numbers continued to grow because DDD was not given enough funds to serve them.

"One key problem is that people who receive DDD services keep receiving them for their entire lives. So, if we are spending \$40,000 a year to serve an individual, those funds will be tied up for decades. People living in community programs weren't passing on, and there wasn't a great deal of turnover to reduce the waiting list."

To help get some control over the waiting list, advocates passed the \$84.25 million Capital Bond Act of



**Harry Randall, family member of a North Princeton Developmental Center resident, protests the closing.**

1994. for the purchase of group homes. Nicholas says the program was well intentioned, but did little to reduce the numbers on the waiting list.

"When families went to the state Legislature and said we needed community residential programs, the easy answer was to build more buildings. But that wasn't going to get people services. It doesn't make sense to build a building if you don't have the money to staff it."

In 1997, the Legislature called for the development of a waiting list committee, comprising members of the developmental disabilities community and other constituents. A 10-year plan - to end the waiting list by 2008 - was developed, in which Whitman committed 500 new residential placements annually to pare down the list.

The last 500-person initiative was in fiscal 2002. State officials say DDD is now moving in new directions to provide people with in-home care, making group homes less of a focus.

"Every year, for the last three

years I was there, we got money for the 500-person initiative," Nicholas says. "After two years, the waiting list did not get any smaller. Lots of people who did not get on the list, because they figured it was a waste of time, suddenly saw people getting services and came out of the woodwork."

Nicholas says that when he retired May 29, 1998, the waiting list had not gone down.

Gold says the DDD is still trying to figure out how to pare the list down. "It is very difficult to reduce it. The waiting list just grows so rapidly."

Today, there are 2,842 individuals living at home waiting for funds to become available for community placement. In addition, there are 7,200 individuals who are waiting to transfer from one service to another, or living with family and not ready for a community placement, according to Pam Ronan, a DHS spokesperson.

"In fiscal 2001, the DDD received \$11 million in state funds for 144 individuals to be relocated from four developmental centers to the community. The following fiscal year, the state spent \$20 million for 200 additional consumers to be relocated into the community and off the waiting list. Another 25 were also relocated that year through DDD efforts," Ronan added.

"We always said Bob should have been a judge," Ronan recalls. "He would weigh everyone's concerns and would analyze issues objectively. The outcome of any decision was always heartfelt. There was always the person with the disability at the heart of his decision." ■

# Working Her Way Up

Most people wouldn't describe a former developmental center resident as ambitious, determined and zealous. Yet, those words describe Barbara Coppens of Cherry Hill.



By MARYANN B. HUNSBERGER  
Photos by REBECCA SHAVULSKY

**B**arbara Coppens, 46, lived in Vineland Developmental Center from age 5 until age 21. She worked her way up from an assembly job in a workshop to a desk job in competitive industry. Throughout everything, she remains cheerful and enthusiastic about life.

Coppens was sent to an institution because she had some behavior problems as a small child, so her doctors thought she had a cognitive disability. "When I first went there, it was a little scary and kind of difficult for me. I didn't know what was going on. After a while, I got used to it. I would go home on holidays to

be with my family in Bergen County and they'd come to see me. The best part was going home and the worst part was coming back. I would cry a lot when I would go back because I missed my family.

"When I lived there, I was unable to make my own choices. We had no self-advocacy back then. But they were nice people there and they treated me well. We did some fun things, like going on day trips and overnight trips."

Vineland educated Coppens until age 16, when she attended high school. "I learned a lot in the classes at Vineland. The kids at the high school knew where I lived because of where I got on and off the bus. The first time, they laughed, made fun of me and called me retarded. It made

me not feel good at all. I was scared, but I made quite a few friends at high school, anyway. I got a diploma."

Coppens graduated high school at 20. Her IHP showed she was ready for community life, so she left Vineland in 1979 at 21. She moved to a group home in Woodbury. "I was a little bit scared to move out of Vineland, but I loved it at the group home once I got adjusted. I learned to cook, clean and do laundry. I learned to get around by myself.

"I needed a little help learning how to make choices, since I had never made any. I learned to decide what meal I wanted to eat and which clothes I wanted to wear. I had never gotten to do that at the institution. My favorite thing was that I could learn how to find my own job with competitive pay."

In high school, Coppens was in a cooperative education program where she got credit for doing janitorial work in the afternoons. After she graduated, she did piecework at the workshop. Once she moved to a group home, she began searching the want ads for work. She filled out a number of applications and found a job cleaning at a motel in Mt. Ephraim in 1980. "I rode my bike from the group home to my job and loved it. I was making better money than I did at the workshop."

She moved into a supervised apartment where she stayed for two years. She now has her own apartment with a roommate and has lived in Cherry Hill for 23 years.

Coppens has had a variety of jobs, doing housekeeping, laundry and food service at nursing homes. Her current job is at Maximus Inc., which runs welfare-to-work pro-

grams for a dozen states and manages public health care programs for local governments. She has been there three years. "I knew about Maximus through the self-advocacy project, since they once did a presentation."

Coppens is a health benefits coordinator. "I outreach the special populations and handle people who call. I've learned to use a computer at work. I enjoy being out in the field and going out to meetings. I like it a lot."

Maria Evangelista, field health benefits coordinator, is Coppens' supervisor. "Barbara is a hard-working individual, committed to everything she does. She takes her job very seriously. She's always on time and doesn't like to take days off."

"Just to see the kind of effort she puts into her day-to-day work is amazing. She gets on her bike at 6:00 AM, and rides to the train. Then, she takes her bike on the train and gets to work an hour early. Having lived in an institution must have been hard for her but she doesn't show it. She never complains and is an inspiration. She's always willing to help. She gets along with everyone."

The struggle to arrive at her current position was difficult. "It was frustrating, but I stuck it out for a long time. I worked my way from the bottom to the top. I feel like I finally climbed up to right where I wanted to be."

"Now I go back to Vineland on business. I'm on the human rights committee there and I work on the SWOT Team helping 40 people getting ready to leave there."

Coppens gives community living classes to residents preparing to leave. "We tell them what it's like living out there and what's different

about it compared to an institution. About a month ago, we did an open house at Vineland Developmental Center. We showed videos, talked, had refreshments. When the people

get out of institutions, I see some of them again at self-advocacy conferences."

She said society treats people with disabilities differently now. "Things have gotten better. They're not being locked in. They are getting more freedom. They get to make more of their own choices. They get to come and go as they want."

"At Vineland, things have changed. People there go on more field trips and go to dances. They have a self-advocacy group now so they get to speak up for accessibility. They get many more choices when it comes to going out, choosing meals and clothes and decorating their rooms. The people there are mostly older now. The ones I've interviewed have been there since they were kids. A lot of people who I know have left, and more are getting ready to go."

Coppens sees some areas that have not improved enough. "Transportation for people with disabilities has a long way to go. Better transportation is one main change I'd like to see. Accessibility is another. Half the curbs don't even have curb cuts."

Asked if she wishes she were born later to take advantage of society's better attitude, she doesn't



**Maria Evangelista oversees Coppens' work at Maximus.**

know. Although she has no regrets, she knows some things would have been different. For instance, she has never learned how to drive. She feels she would have if she had grown up at home the way younger people with disabilities do today.

Family is important. Her family loves her a great deal and she loves them. Her parents live in Florida, her sisters in New York and her brother in Vermont. She is close to them and sees them often. They are proud of her and even travel to see her receive awards.

Coppens serves on many boards. Besides being active in the disability community, she enjoys going to movies and bowling.

Coppens said that in some ways, she feels she had a bad life because of living in an institution. In other ways, she was happy. "The bad part was not having choices and not liking the meals. Everything looked the same in the dormitory and we had no choice in what we wore. Back then, I didn't know that other people had choices. As I got older, I looked forward to making those choices on my own when I got out. I make all my own choices now. I have a good job and am happy about all I have achieved." ■

# Preserving the Records

As New Jersey's rich contribution to the field of developmental disabilities folds quietly into history, there is a push to save as many artifacts as possible before they disappear.

**D**avid Goode of Watchung, a sociology professor, is launching the New Jersey Disability Heritage Project, designed to locate, link and list as many of these historical materials as possible.

To pinpoint as much information as possible, Goode is banking on help from the State Archivist, the New Jersey Council on Developmental Disabilities, the state Division of Developmental Disabilities, the State Historian, the State Historical Society, colleges and universities and disability advocates statewide.

"It is important that this history, both good and bad, become part of the historical record," says Goode, who teaches at the College of Staten Island. "There are many individuals, governmental and private organizations that have materials unorganized and perhaps in danger of being lost through improper storage and conservation. These should be located, collected and conserved."

The end goal of the project is to create a database that can be accessible to the public. In it, people can learn about how the nation's history of development disabilities is rooted, in part, in New Jersey through the 19<sup>th</sup> and early 20<sup>th</sup> centuries.

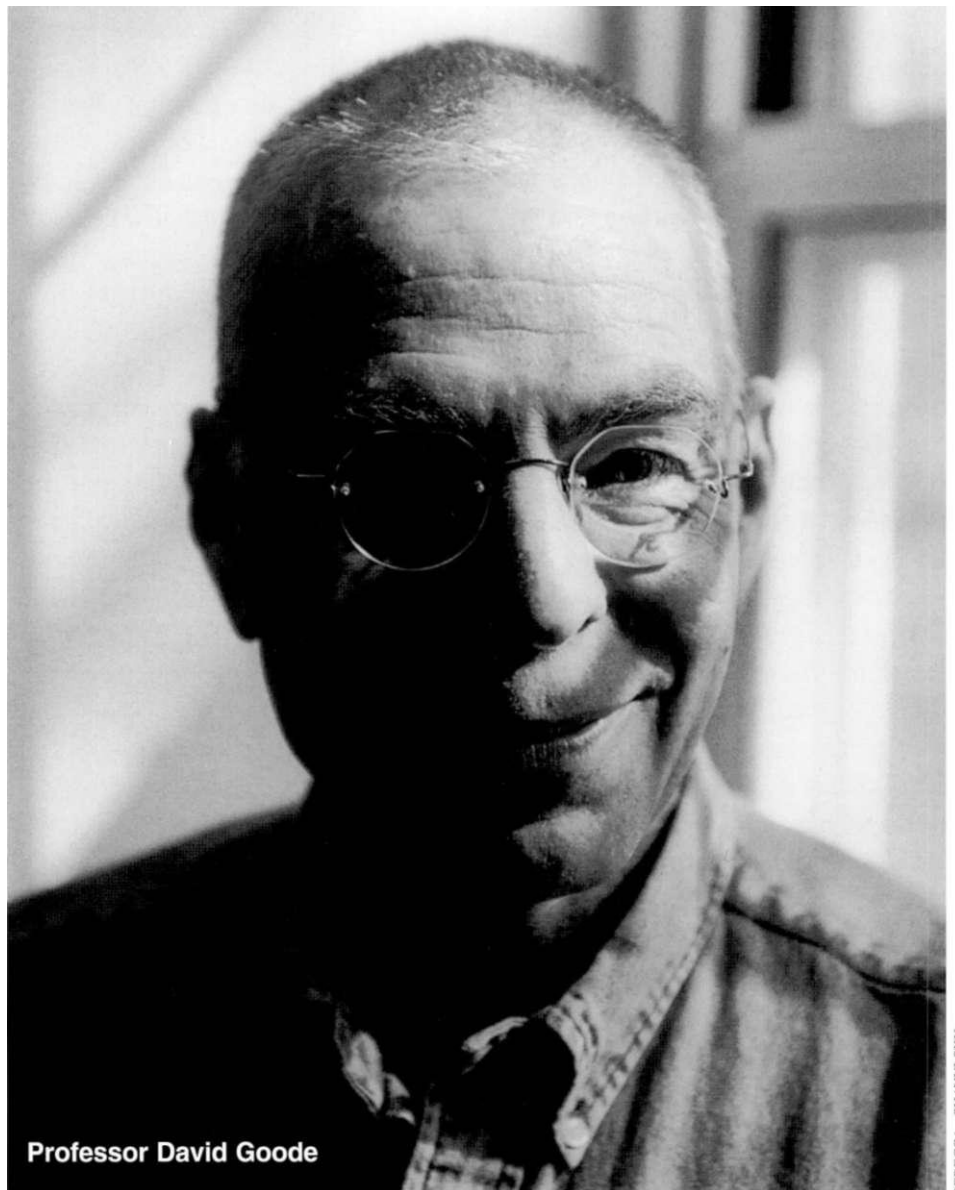
For example, New Jersey was home to the Elwyn Institute, one of the earliest schools caring for persons

who were at the time considered "feeble-minded." The Training School at Vineland was also an important research center, led by Henry

Goddard and Edward Johnstone. The Seguin School, located in West Orange, was the last school ever headed by Edouard Seguin, the author of the important approach to care known as "moral treatment."

Goode notes a key component of the project is to collect the many artifacts that have migrated outside of New Jersey over the years, such as the personal papers of the late Elizabeth M. Boggs, a leading advocate in the field of developmental disabilities. ■

—By JONATHAN JAFFE



Professor David Goode

REBECCA SHAVULSKY



## LETTERS

WHEN PRESIDENT GEORGE W. BUSH made his State of the Union speech he did not talk about his disability policy. More people want to hear more about his disability policy. We want to hear more about how much is in his federal budget for people with disabilities. We want to know what his plans are to educate people and advocates with disabilities, and to support local, state, national and international organizations that help support the needs of people with disabilities.

GREG FELZENBERG  
*Hillside, NJ*

I AM WRITING TO MAKE THE PUBLIC aware of how disabled clientele are being treated in group homes and apartments. I want to get a bill passed called "Disabled Care Act for Group Homes and Apartments." This bill will require new certification procedures for all group homes and apartments in the state for people with disabilities. Current certification requires staff to have a high school diploma and have a background check. If it's a licensed group home, funding goes through the state Division of Developmental Disabilities. If the home is not certified by DDD, they need home health certification. For both types of homes, staff members need CPR, first aid and medication training. There is usually a 90-day probationary period.

This bill will help educate staff members at the group homes and apartments to communicate better with residents regarding their needs. I am a student at Georgian Court University in Lakewood, NJ. I have been interning working with people with disabilities on a daily basis and hear many horrors

that are swept under the carpet.

Residents have trouble receiving assistance with their daily activities. They are told to wait to go to the bathroom or are forced to use a bedpan for the staff's convenience. They worry about speaking up due to staff holding grudges.

Residents also worry about losing staff members, even bad ones. They worry about not having someone to replace them. Staff doesn't receive adequate information regarding the residents' disabilities, making it hard to understand their needs.

Nancy Seigle wrote ("A world of Similarities" PWD October 2003), "It's a 24-7 job and a lot of the staff are young, so if you have a young person staffing a home where a 58-year-old begins wetting himself at night, they might not think about the possibilities of a prostate problem." Maryann Hunsberger wrote ("Direct Care Workers: An amazing group of people" PWD Oct. 2003), "(T)here was a \$1-an-hour pay raise for community-based direct-care workers that Governor Whitman included in this year's state budget. The average pay was 18,000 a year, about \$8.75 an hour. Now, staff can earn approximately \$20,000." This figure still seems pretty meager to me when you consider all of the responsibilities staff has.

The public needs to be aware of what is happening in today's society. People with disabilities get overlooked. Some may think, "Hey, the state is taking care of them!" When hearing some of these problems, is the state doing the best? This bill, if passed, can help educate staff concerning the needs of clientele. It would provide a safer, nur-

turing environment to those in need.

If the public advocates for people with disabilities, better care will become a priority.

Express your concerns by writing or calling (U.S.) Senator Jon Corzine or (State) Senator Robert Singer. Ask about the disabled care act for group homes and apartments. Help stop the abuse! Let's get this bill passed before more suffer.

What requirements should be in the bill:

Classes to educate staff members to:

- 1) Communicate with residents
- 2) Understand residents needs
- 3) Ensure residents privacy
- 4) Help residents with ADLs (Activities of Daily Living)
- 5) Advocate for residents
- 6) Teach staff more about medications given to residents/ what they are (blood pressure, cardiac, seizure and anxiety meds) and possible side affects
- 7) Teach staff more pertaining to the disabilities residents have
- 8) Sensitivity training (role playing, staff can play the part of client and vice versa to see what it's like to be disabled)
- 9) Help residents be assertive
- 10) Show respect towards residents
- 11) Teach staff to be trustworthy
- 12) Teach why confidentiality is so important
- 13) Help residents fit into society

These steps must be included into the certification procedures for all group homes and apartments in New Jersey. A new policy procedures manual needs to be made or old ones may be updated.

MELISSA MITCHELL  
*Lakewood, NJ*

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# I M A G E S & I D E A S

THE HISTORY OF DEVELOPMENTAL DISABILITIES



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