Shadows of Pineland – yesterday, today, and tomorrow

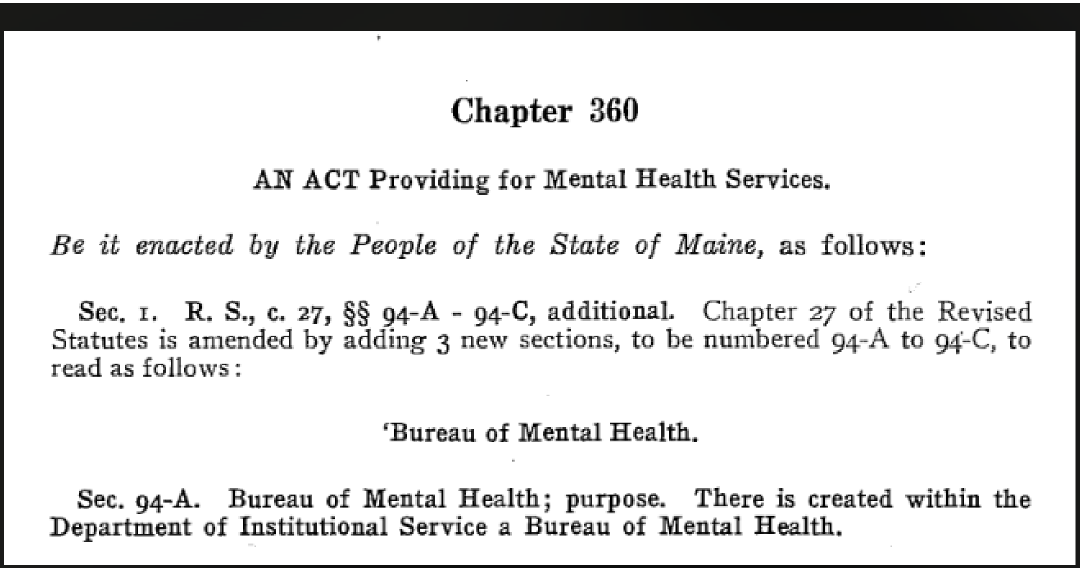
Nancy Cronin

Executive Director
Mane Developmental Disabilities Council

Where did we leave off?

In the 1950s people with Developmental Disabilities were sent to Pineland. For the families who chose to keep their child with Developmental Disabilities there was no system of community supports. Today we will continue the story….

1959 Bureau of Mental Health



Chapter 360

AN ACT Providing for Mental Health Services.

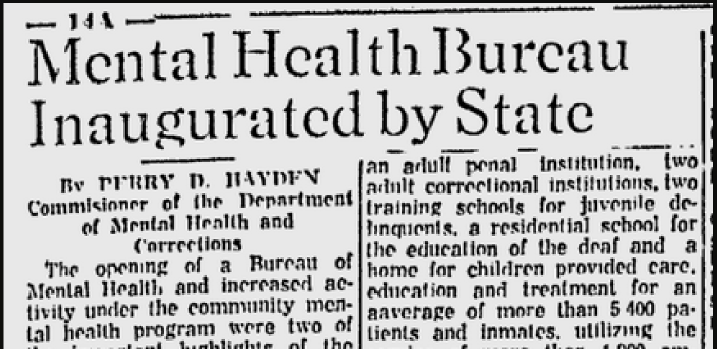
Be it enacted by the People of the State of Maine, as follows:

Sec. 1. R. S., c. 27, §§ 94-A - 94-C, additional. Chapter 27 of the Revised Statutes is amended by adding 3 new sections, to be numbered 94-A to 94-C, to read as follows:

'Bureau of Mental Health.

Sec. 94-A. Bureau of Mental Health; purpose. There is created within the Department of Institutional Service a Bureau of Mental Health.

Public Law 1959 Chapter 360 An Act Providing for Mental Health Services



14A

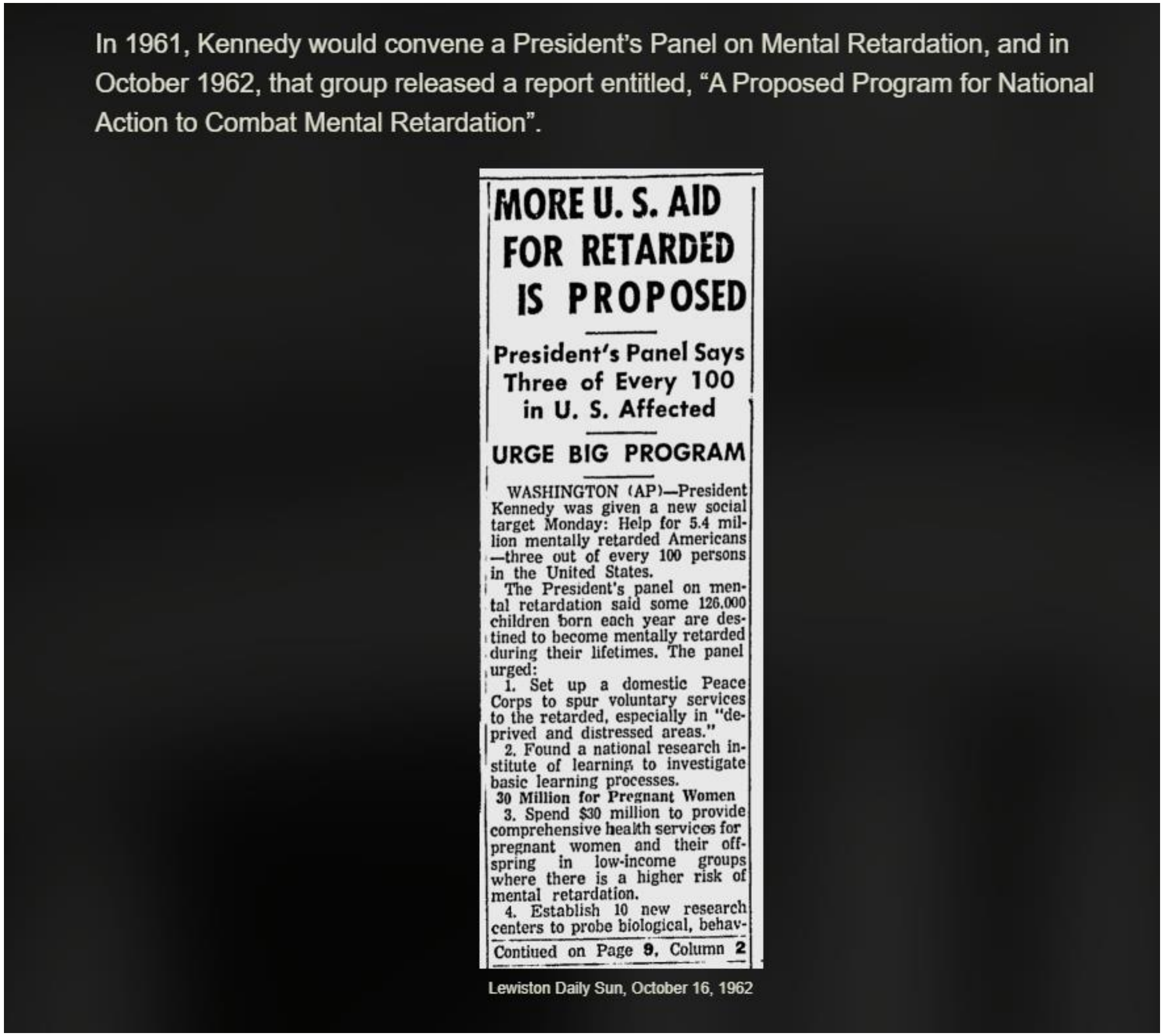
Mental Health Bureau Inaugurated by State

By PERRY D. HAYDEN
Commissioner of the Department
of Mental Health and
Corrections

The opening of a Bureau of Mental Health and increased activity under the community mental health program were two of

an adult penal institution, two adult correctional institutions, two training schools for juvenile delinquents, a residential school for the education of the deaf and a home for children provided care, education and treatment for an aaverage of more than 5 400 patients and inmates, utilizing the

Federal Funding Considered: 1961



In 1961, Kennedy would convene a President's Panel on Mental Retardation, and in October 1962, that group released a report entitled, "A Proposed Program for National Action to Combat Mental Retardation".

MORE U. S. AID FOR RETARDED IS PROPOSED

President's Panel Says Three of Every 100 in U. S. Affected

URGE BIG PROGRAM

WASHINGTON (AP)—President Kennedy was given a new social target Monday: Help for 5.4 million mentally retarded Americans—three out of every 100 persons in the United States.

The President's panel on mental retardation said some 126,000 children born each year are destined to become mentally retarded during their lifetimes. The panel urged:

1. Set up a domestic Peace Corps to spur voluntary services to the retarded, especially in "deprived and distressed areas."

2. Found a national research institute of learning to investigate basic learning processes.

30 Million for Pregnant Women

3. Spend $30 million to provide comprehensive health services for pregnant women and their offspring in low-income groups where there is a higher risk of mental retardation.

4. Establish 10 new research centers to probe biological, behav-

Contiued on Page 9, Column 2

Lewiston Daily Sun, October 16, 1962

1962: Needs More Help

PINELAND
IS AIDING
THE STATE

Dr. Bowman Tells of
Rehabilitation at
Pownal Hospital

NEEDS MORE HELP

1963: Federal Funding Achieved

- Upon President Kennedy’s urging, Congress would pass the **Maternal and Child Health and Mental Retardation Planning Amendments**
  - Provide funding for children with special healthcare needs
  - Directs States to “plan for and take other steps leading to comprehensive State and community action to combat mental retardation”.

- That same year, Congress would pass the **Mental Retardation and Community Mental Health Centers Construction Act of 1963,** providing <u>funding for services</u> in the community for people with developmental disabilities

Civil Rights Act of 1964

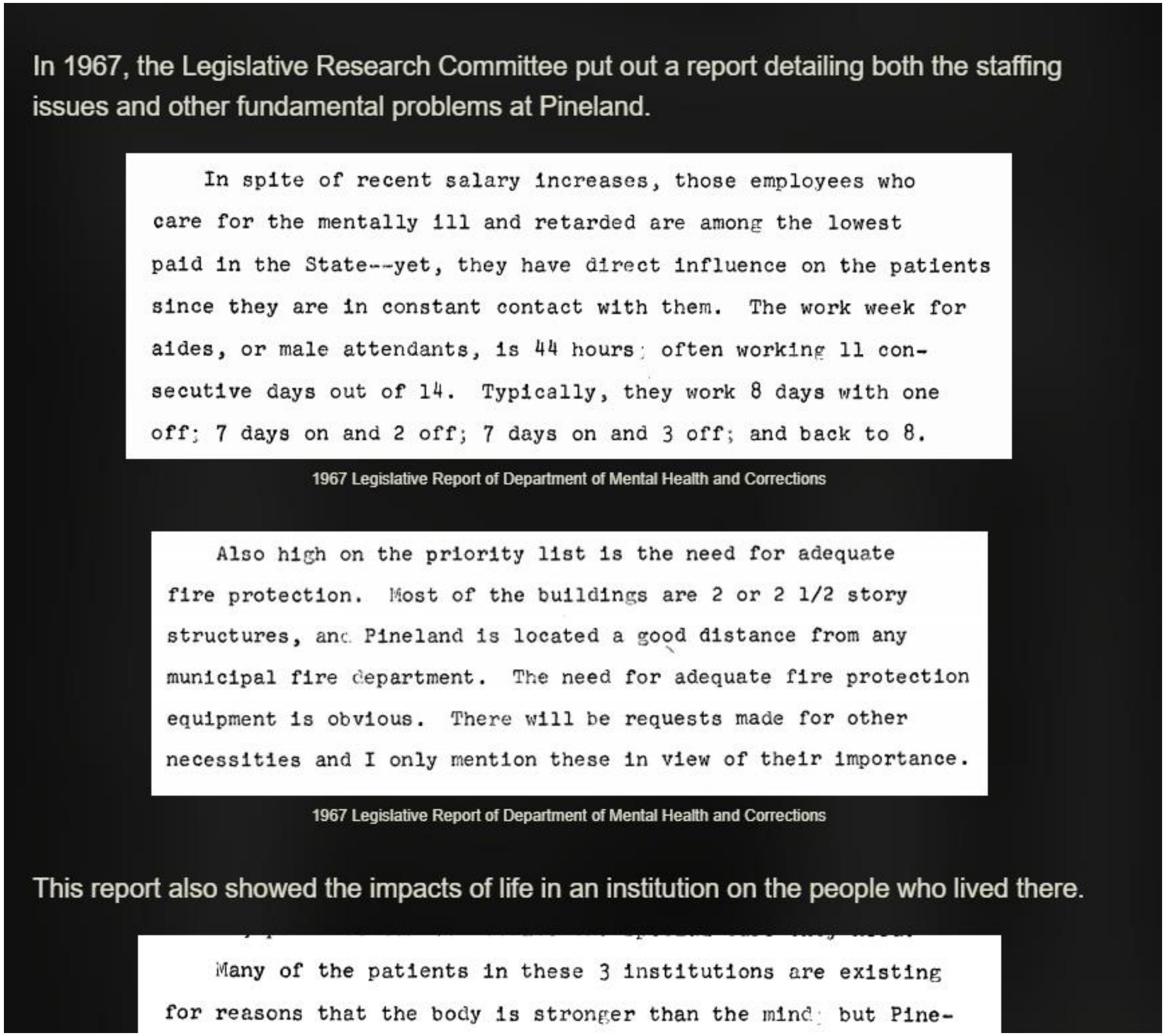
Widely prohibiting discrimination based on race, religion, gender, or nationality. It also made it illegal to discriminate for anything related to employment, voting access, public access, and education.

Note: Disability is not listed here. It is still completely legal to discriminate based on disability.

Social Securities Act of 1965

- Title 19 Established **Medicaid**!
  - Provided healthcare for Elderly and Low-Income Family
  - Provided a federal funding stream for people with disabilities
    - Institutional Bias Starts Here
    - Waivers were not a part of the program. States could either take the money to support people in institutions, or not.

1967 Meanwhile there are problems at Pineland



In 1967, the Legislative Research Committee put out a report detailing both the staffing issues and other fundamental problems at Pineland.

> In spite of recent salary increases, those employees who care for the mentally ill and retarded are among the lowest paid in the State--yet, they have direct influence on the patients since they are in constant contact with them. The work week for aides, or male attendants, is 44 hours; often working 11 consecutive days out of 14. Typically, they work 8 days with one off; 7 days on and 2 off; 7 days on and 3 off; and back to 8.

1967 Legislative Report of Department of Mental Health and Corrections

> Also high on the priority list is the need for adequate fire protection. Most of the buildings are 2 or 2 1/2 story structures, and Pineland is located a good distance from any municipal fire department. The need for adequate fire protection equipment is obvious. There will be requests made for other necessities and I only mention these in view of their importance.

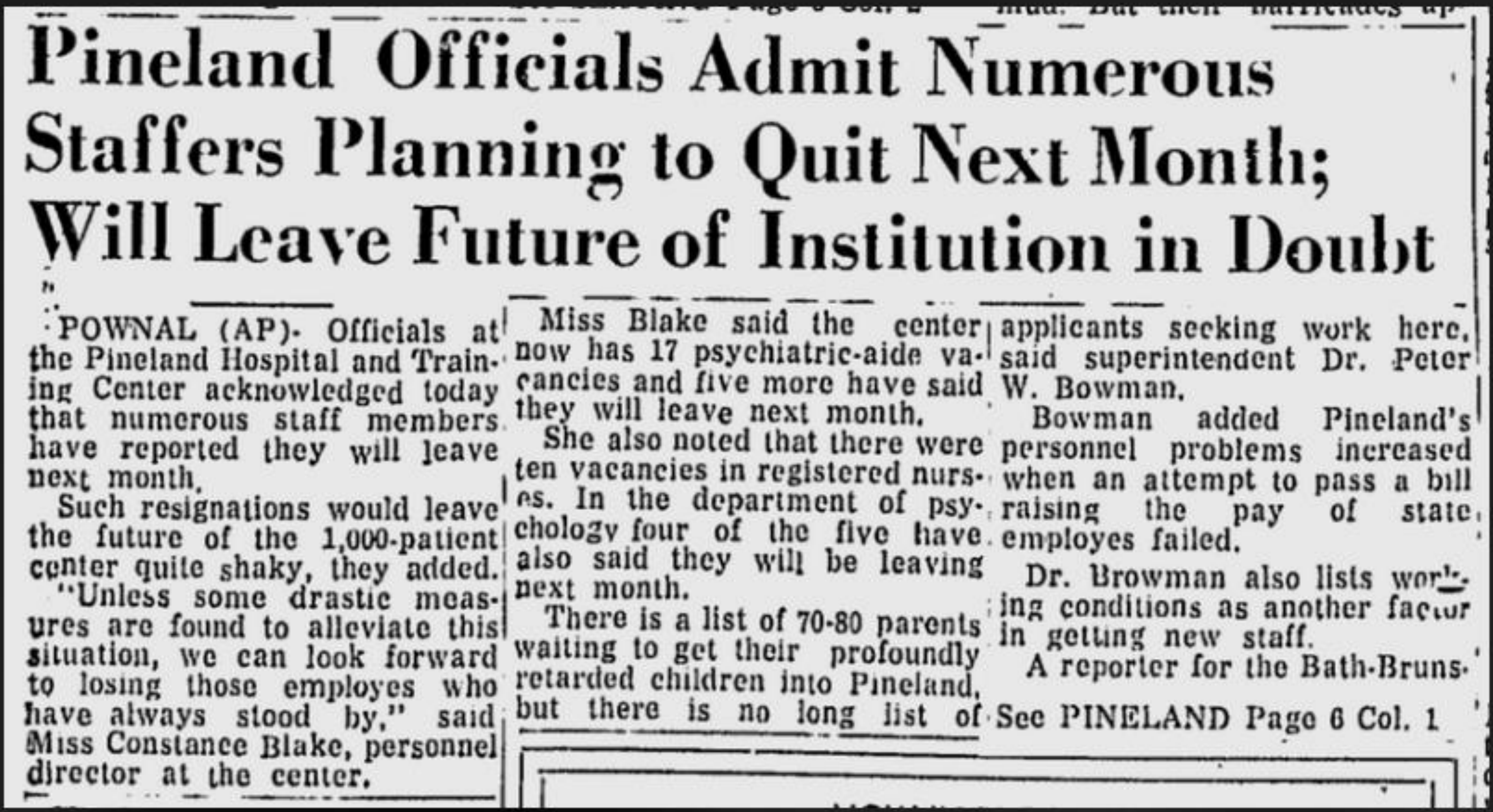
1967 Legislative Report of Department of Mental Health and Corrections

This report also showed the impacts of life in an institution on the people who lived there.

> Many of the patients in these 3 institutions are existing for reasons that the body is stronger than the mind; but Pine-

1967

31, 1967).



Pineland Officials Admit Numerous Staffers Planning to Quit Next Month; Will Leave Future of Institution in Doubt

POWNAL (AP)- Officials at the Pineland Hospital and Training Center acknowledged today that numerous staff members have reported they will leave next month.

Such resignations would leave the future of the 1,000-patient center quite shaky, they added.

"Unless some drastic measures are found to alleviate this situation, we can look forward to losing those employes who have always stood by," said Miss Constance Blake, personnel director at the center.

Miss Blake said the center now has 17 psychiatric-aide vacancies and five more have said they will leave next month.

She also noted that there were ten vacancies in registered nurses. In the department of psychology four of the five have also said they will be leaving next month.

There is a list of 70-80 parents waiting to get their profoundly retarded children into Pineland, but there is no long list of applicants seeking work here, said superintendent Dr. Peter W. Bowman.

Bowman added Pineland's personnel problems increased when an attempt to pass a bill raising the pay of state employes failed.

Dr. Browman also lists working conditions as another factor in getting new staff.

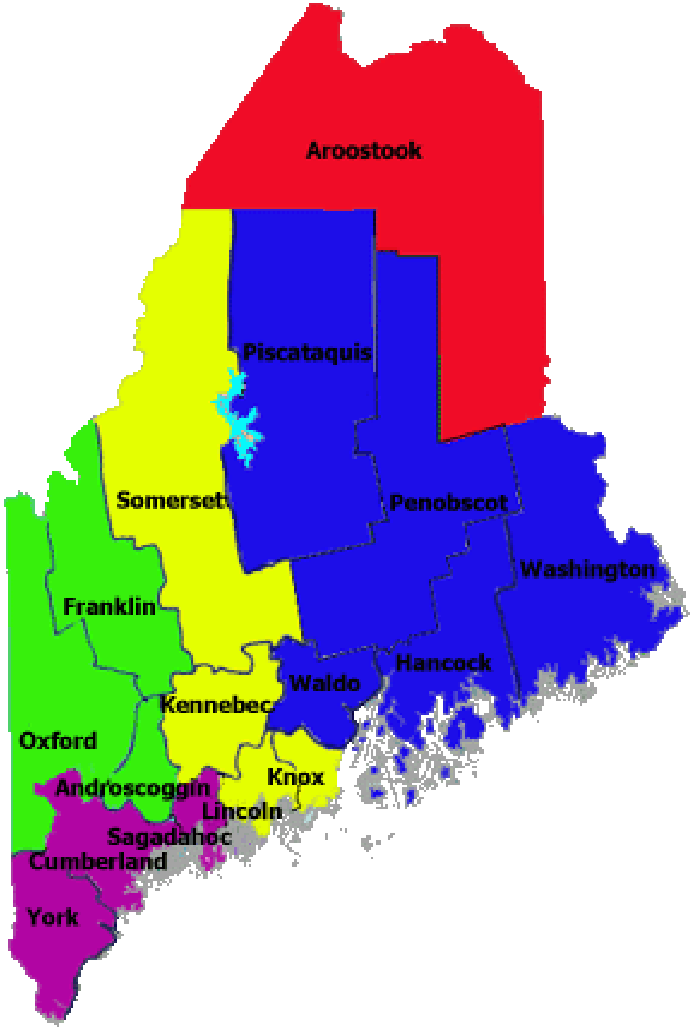
A reporter for the Bath-Bruns-

See PINELAND Page 6 Col. 1

Lewiston Evening Journal, August 14, 1967

1969 Community Services

Bureau of Mental Retardation was created within the Department of Mental Health and Corrections, and the development of a regional system of community services began in 1970.



1969 Rights & Reform

Newspaper stories exposed the worst conditions at Pineland to public view.

1973 The Rehabilitation Act

- Passed the first time in 1972 – and vetoed by President Nixon. Passed again in 1973 – this time President Nixon signed the bill.

- Changed vocational rehabilitation services to “person-centered” focus. Prior to this law people with disabilities were trained in a job. . . . This law changed the service to train people with disabilities in a law that <u>is centered around the persons desires and talents.</u>

Section 504 of the Rehabilitation Act – ACCESSABLE

- “No qualified individual with a disability in the United States shall be excluded from , denied the benefits of, or be subjected to discrimination under” any program or activity that either received Federal funding or is conducted by any Executive Agency or the United States Postal Service.

Section 504

- Schools
  - Provide a Free Appropriate Public Education (FAPE) to qualified students in their jurisdictions with a physical or mental impairment that substantially limits one or more major life activities.
  - Schools must provide reasonable accommodations and supports to allow the child to participate in the general curriculum and program.
- Employment
  - Must provide reasonable accommodations to allow the individual to perform a job as a person without disabilities

Yay! People were protected right?
Nope – But people were done.
Patient No More

- For Years Disability Advocates demanded that rules should be promulgated. It resulted in the longest peaceful sit-in located in a federal building ever.

- If you can – look up Crip Camp – you can see the full length feature here https://www.youtube.com/watch?v=OFS8SpwioZ4

Side Note: 504, New Rule!?!

- The Biden/Haris administration has proposed updated rules to Section 504 which, if enacted, will make it illegal to turn away a person for medical care because the medical provider doesn't know about the disability. Further, it will be illegal to make decisions based on a provider's bias about the person's assumed quality of life.

- https://www.hhs.gov/about/news/2023/09/07/hhs-issues-new-proposed-rule-to-strengthen-prohibitions-against-discrimination-on-basis-of-disability-in-health-care-and-human-services-programs.html

1970s Introduced A Radical Philosophical Change

Principal of Normalization

- Wolf Wolfensberger worked in DD institutions. He discussed how:
  - To have access to what he termed as "the good things in life," one must live a life that includes choices and opportunities that would positively impact a community
  - There are rhythms to lives that people who live in institutions are denied from.
- Wolfensberger presented the principal of normalization. This value how important it is for humans who rely on external systems to have opportunities as culturally normal as possible available to them.
  - This really shaped the field of human services in that it stated that when service systems are being designed, they should be created to allow as many culturally normal opportunities as possible.

Social Role Valorization

- Wolfensbeger noticed that systems of services and marginalized people. People are often forced to remain in undervalued roles that limit opportunities.

- Model of Valued Social Roles transformed the field of human services. He recognized that roles bring a pathway of life which opens opportunity and allows people who are often marginalized to have access to “the good things in life.”

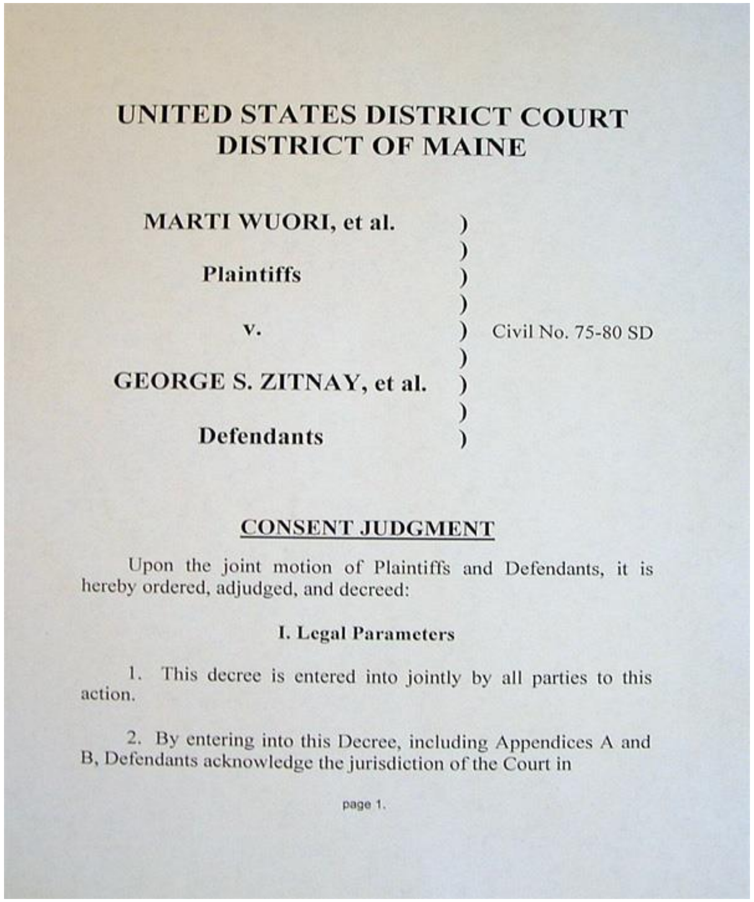
- How could we apply today? Let’s think about Jimmy who loves to bowl and goes with his group home. Why can’t he join a league? Instead of Jimmy being the guy who goes bowling with X he can be a member of XYZ awesome bowling league.

1975 Education for All Handicapped Children

Guaranteed that <u>eligible</u> children and youth with disabilities would have a Free and Appropriate Public Education (FAPE) available to them, designed to meet their unique educational needs.

But it was more than just FAPE (remember Section 504 covered that). Under this law schools had to provide specially designed instruction so that an individual with disability would be able **to achieve an occupation after graduation.**

1978 The Pineland Consent Decree



UNITED STATES DISTRICT COURT
DISTRICT OF MAINE

MARTI WUORI, et al.)
)
Plaintiffs)
)
v.) Civil No. 75-80 SD
)
GEORGE S. ZITNAY, et al.)
)
Defendants)

CONSENT JUDGMENT

Upon the joint motion of Plaintiffs and Defendants, it is hereby ordered, adjudged, and decreed:

I. Legal Parameters

1. This decree is entered into jointly by all parties to this action.

2. By entering into this Decree, including Appendices A and B, Defendants acknowledge the jurisdiction of the Court in

page 1.

In 1975 a lawsuit was filed in Federal District Court in Portland claiming that conditions at Pineland violated the residents' basic constitutional rights as U.S. citizens.

In 1978 a detailed agreement known as the Pineland Consent Decree set standards for Pineland and for former residents living in the community.

1978

The Consent Decree

The Consent Decree brought increased funding, and tremendous efforts were made to create and improve services at Pineland and in the Community.

Residential units at Pineland became smaller and more home-like, with ‘apartments’ of 4-6 people and only 1 or 2 people in a bedroom.

Programs and activities were expanded including regular trips off the grounds.

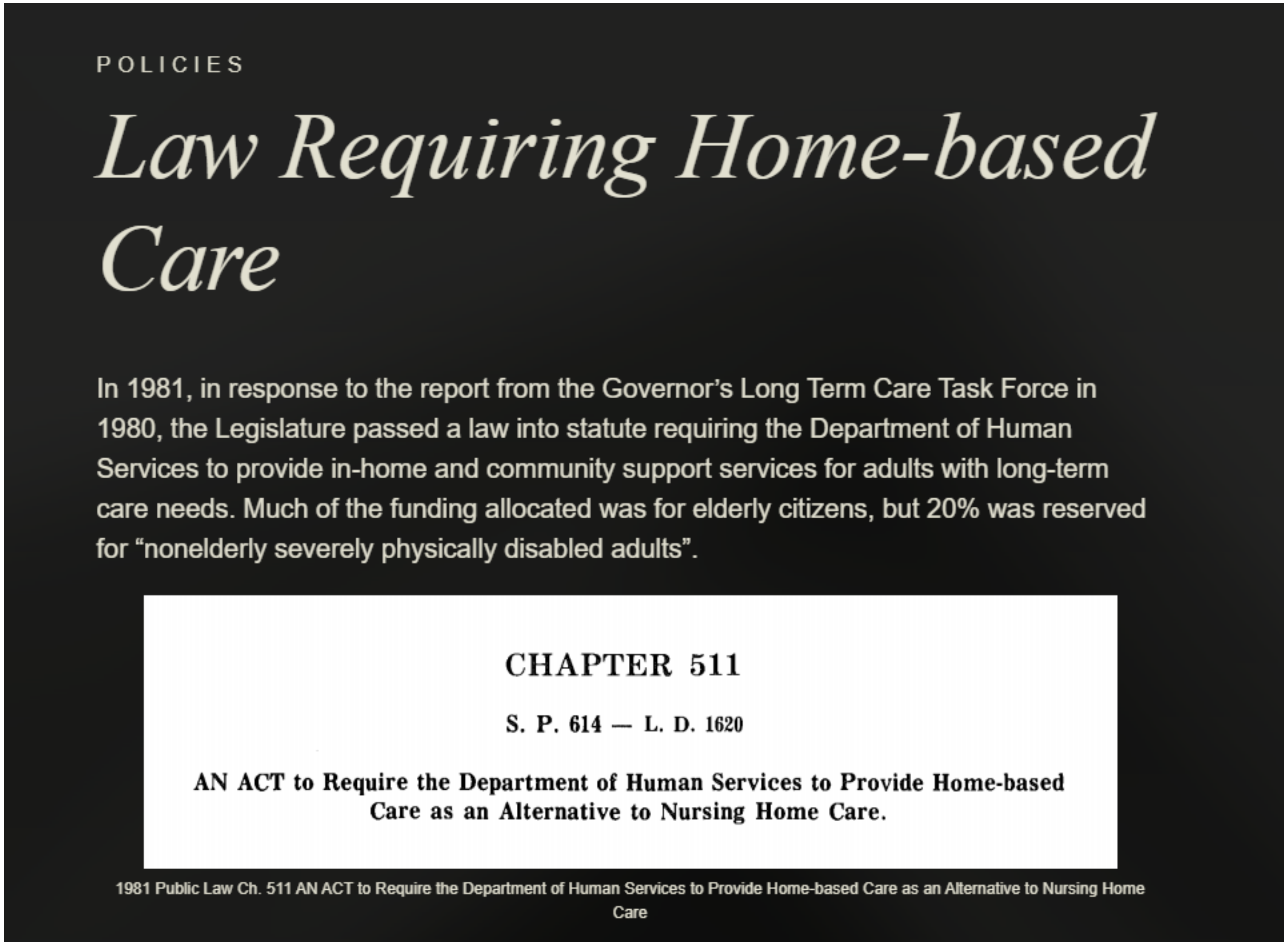
Omnibus Budget Reconciliation Act 1981 (OBRA 81)

- Created the Waiver Program – (we spoke before about how people sign their right to an institutions. The original Medicaid law wasn't amended – only through budget processes – ways to work around it was incorporated.)
- Created the F-Map
- This Changed Everything!

1981 Katie Beckett

- President Reagan created a Medicaid option that allowed children with special health care needs that required institutional level of care could receive that care in the community through Medicaid dollars. As long as it cost less than an institution. This is an Option that States can choose to offer or not. It is not a waiver, but like one in many ways.

Maine was on a similar thought process



POLICIES

Law Requiring Home-based Care

In 1981, in response to the report from the Governor's Long Term Care Task Force in 1980, the Legislature passed a law into statute requiring the Department of Human Services to provide in-home and community support services for adults with long-term care needs. Much of the funding allocated was for elderly citizens, but 20% was reserved for "nonelderly severely physically disabled adults".

CHAPTER 511

S. P. 614 — L. D. 1620

AN ACT to Require the Department of Human Services to Provide Home-based Care as an Alternative to Nursing Home Care.

1981 Public Law Ch. 511 AN ACT to Require the Department of Human Services to Provide Home-based Care as an Alternative to Nursing Home Care

1982 – Maine Hops onto the Waiver Options

nd was better than the alternatives.

Medicaid Funds for Foster Homes Sought

PORTLAND (AP) — Maine officials are expected to ask federal authorities this week for a waiver permitting the use of Medicaid funds to finance community foster homes for the mentally retarded.

Lincoln Clark, the U.S. District Court's special master overseeing improvements at the state's Pineland Center in Pownal, said Monday the waiver "will largely govern the rate of movement (of patients) out of Pineland into the community."

"All residents who would develop better in the community than at Pineland are supposed to be moved out," Clark said. "After all, this is the primary purpose of the original decree, to deinstitutionalize Pineland. Vigorous steps are being taken to get this through the process in Augusta and Washington."

Clark estimated that a waiver would give the state $2.4 million.

In releasing his latest interim report on conditions at Pineland, Clark said he hoped to be able to present a final report to the court on Nov. 14.

Clark has credited the Legislature for passing three acts to improve Maine's mental retardation system: "To permit and regulate the location of group homes in residential districts, to improve due process protection relating to sterilization, and to amend the certification process for admission into public mental retardation institutions."

The report released Monday is the latest in a series since the state and attorneys for Pineland residents entered into a consent decree four years ago.

Lewiston Daily Sun, August 31, 1982

1983

Consumer Advisory Board (Precursor to the Oversight Advisory Board) was created

Several pieces were in place to ensure persons with developmental disabilities – at Pineland and in the community – received appropriate services, lived in appropriate conditions, and were able to exercise other rights outlined in the consent decree.

A nine-member Consumer Advisory Board made up of parents or relatives of residents, community leaders, the Pineland advocate and chaplain, and residents or former residents – was charged with "evaluation of dehumanizing practices, promotion of normalization, and examination of violations of individual rights."

Their Goal: To Join Society

By JOE O'CONNOR
Sun Staff Writer

They could be anybody's sons, anybody's brothers.

Peter is the oldest, a small cheerful man in his 50s who talks in short guttural bursts. Richard, 20, is the youngest, painfully shy, with eyes that seem almost lost behind thick glasses.

Roland is the most articulate; he will probably be the next to move out on his own. Roger, 37, tall and watchful, has to struggle to force out a sound that vaguely resembles his name.

Skip is a gregarious redhead, full of laughter and friendly gestures. Jimmy is a roly-poly bundle of charm, with the slightly oriental features that once led to Down's Syndrome victims being called mongoloid.

Not too long ago, these men would have spent their lives at the Pineland Center, an institutional world bounded by corridors and cell-like rooms and days spent sitting on hard benches, watching television reruns in the day room.

Instead, they live in a house much like

mother.

It is a full-time job for both of them. The "guys" are friendly and eager to please; they are able to shave themselves and bathe — but they do need constant supervision.

While guidance and training are constant, there is no air of discipline at the home. "I figure it's their house — they've been here longer than we have," Scott says.

On a living-room wall, there is a chore chart. Each of the men has chores such as dusting and vacuuming, or loading and unloading the dishwasher. They rotate the chores weekly, and each week one of them is named "Man of the Week," which means he gets the easiest job, setting and clearing the dinner table.

Four of the residents have family who take them home for weekends and holidays; the other two will be spending Thanksgiving with Scott and Gloria at her mother's home.

Wake-up time is 6:30 a.m. during the week. The men all make their beds in the morning, and it is here, Gloria says, that

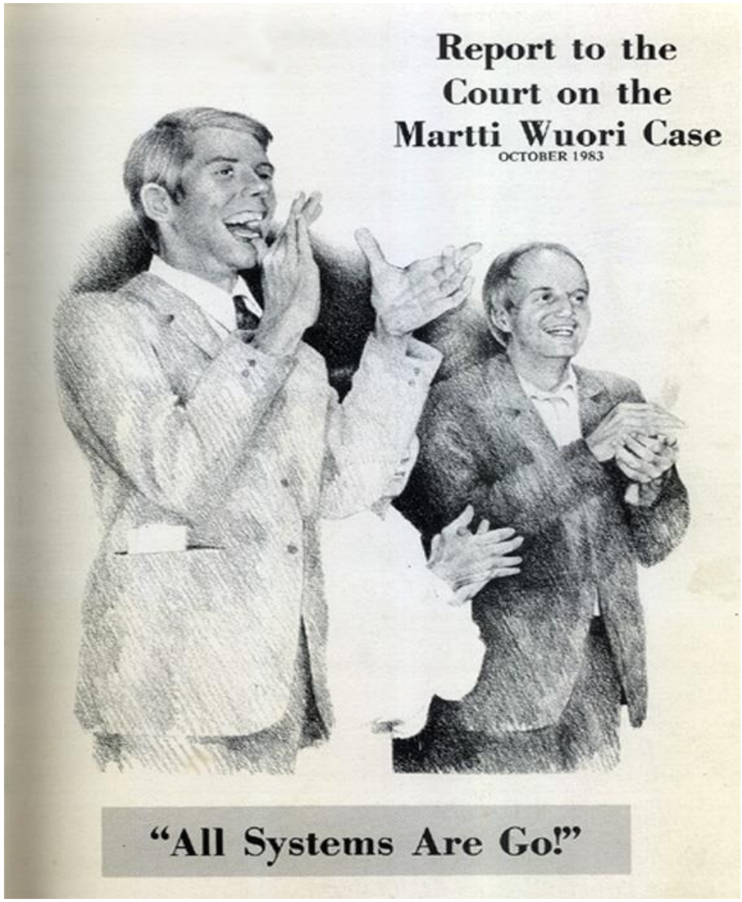
Jimmy McGuigan, left, exercises while at right Skip Farrington, left, and Roger Raymond check out a telescope

Lewiston Daily Sun, November 19, 1983

Each Pineland resident and person in the community had a correspondent – family member or an unrelated trained volunteer – to meet with them at least once a year, attend team meetings about their care and treatment, and report any problems to the Consumer Advisory Board.

A resident advocate at Pineland and advocates in each service region of the state were available to help with individuals' concerns or issues and also try to assure their rights were not violated.

1983
Standards Met!...?



Report to the
Court on the
Martti Wuori Case
OCTOBER 1983

"All Systems Are Go!"

In 1981 the Court Master declared that Pineland had met the standards of the Consent Decree, and Pineland became the first institution in the country to be released from court supervision.

In 1983 the court ended its supervision of community services. While the court's jurisdiction ended, the standards of the decree had become incorporated into the services and systems at Pineland and in the community .

1990 Individuals with Disabilities Education Act (IDEA)

- Replaced the EHA and changed the focus from what a student would be able to do after they left school to a focus on the **individualized education** that the child would need **to benefit from their education**.

- This attention to education, as opposed to basic employment, was aiming to ensure that a student's educational needs were met, and the student progressed in their education as close to their peers who did not have disability as possible.

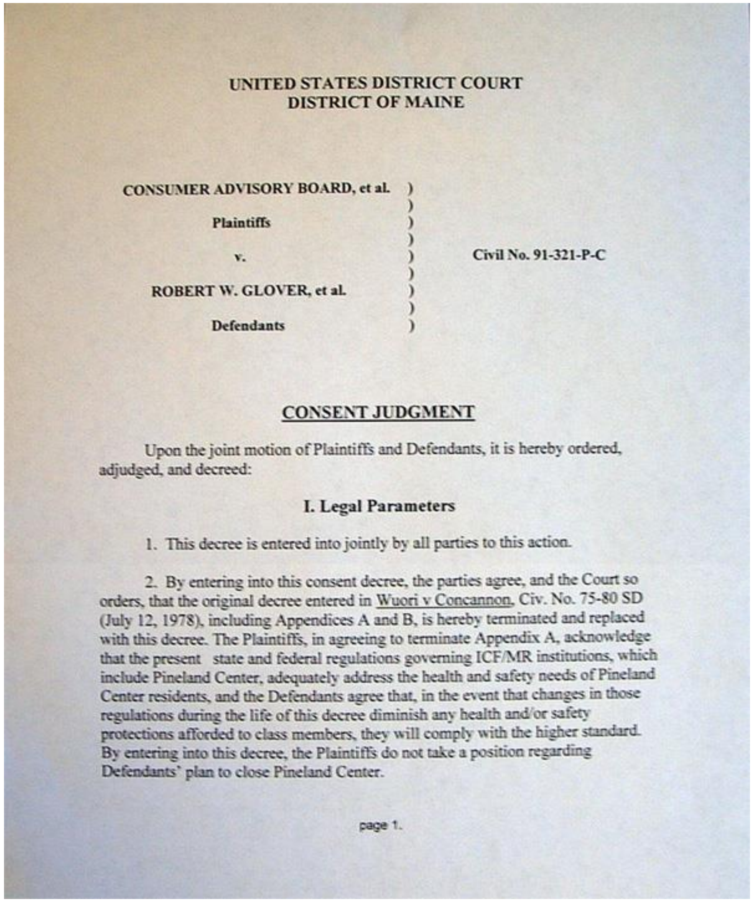
1990 Americans with Disabilities Act

Public Law 101-336 [42 USC 12101]

- Not just Access – Civil Rights!
- Judith Heumann call this bill the "*people with disabilities Emancipation Proclamation*"? This bill required civil rights for people with developmental disabilities making it illegal to discriminate on the basis of disabilities.

1994

The *Community* Consent Decree



UNITED STATES DISTRICT COURT
DISTRICT OF MAINE

CONSUMER ADVISORY BOARD, et al.)
)
Plaintiffs)
)
v.) Civil No. 91-321-P-C
)
ROBERT W. GLOVER, et al.)
)
Defendants)

CONSENT JUDGMENT

Upon the joint motion of Plaintiffs and Defendants, it is hereby ordered, adjudged, and decreed:

I. Legal Parameters

1. This decree is entered into jointly by all parties to this action.

2. By entering into this consent decree, the parties agree, and the Court so orders, that the original decree entered in Wuori v Concannon, Civ. No. 75-80 SD (July 12, 1978), including Appendices A and B, is hereby terminated and replaced with this decree. The Plaintiffs, in agreeing to terminate Appendix A, acknowledge that the present state and federal regulations governing ICF/MR institutions, which include Pineland Center, adequately address the health and safety needs of Pineland Center residents, and the Defendants agree that, in the event that changes in those regulations during the life of this decree diminish any health and/or safety protections afforded to class members, they will comply with the higher standard. By entering into this decree, the Plaintiffs do not take a position regarding Defendants' plan to close Pineland Center.

page 1.

In the early 1990s the Consumer Advisory Board, which had been created to monitor compliance with the Pineland Consent Decree, initiated a new lawsuit asserting that Maine's mental retardation services fell short of the standards of the original decree.

In 1994 a new agreement, known as the community consent decree, was signed in Federal Court, setting new standards.

The Community Consent Decree

The new decree took no position on the closing of Pineland, yet the declining population of the center, growing anti-institution sentiment and the rising costs of maintaining the aging facility had a large influence.

Many employees, family members and others protested the idea of community placement, citing long-standing personal ties and the stability of the institution.

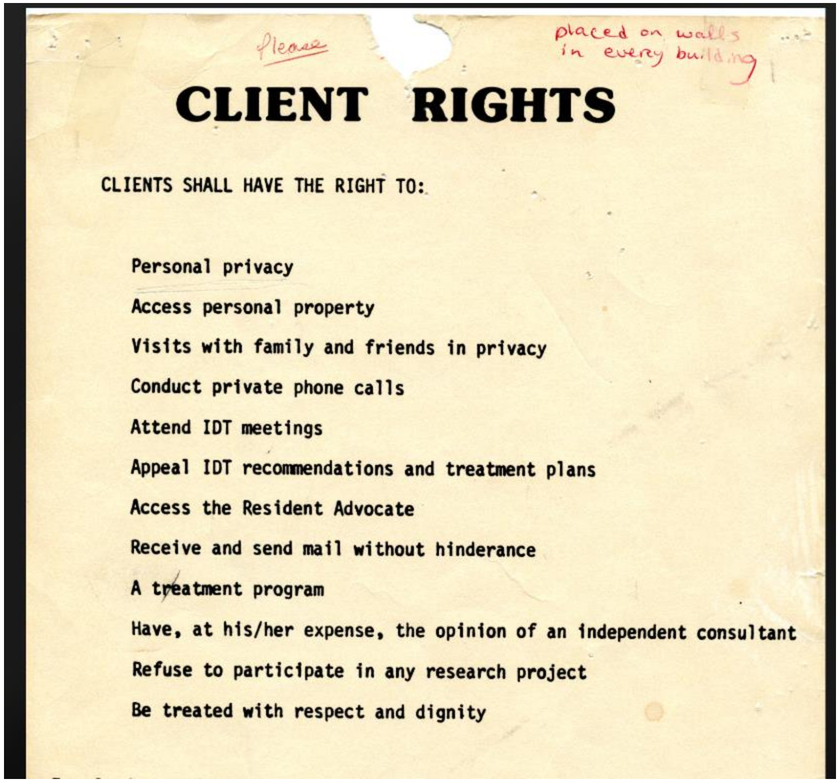
However, the community service system had continued to grow and serve people with significant and multiple disabilities, as well as those with seriously challenging behavior.

1992 Decline and Closing

Admissions to Pineland became fewer, and for shorter periods of time. The 207 residents in 1992 rapidly dwindled to 76 by 1993. The success of community services, the small number of residents and the great cost of maintenance for an aging facility prompted the decision for closure.

In May of 1996 the last resident of the center left and in June of that year ceremonies were held to mark the official closing of the institution that had been known at different times as the Maine State School for the Feebleminded , Pineland State School, Pineland Hospital and Training Center, and finally Pineland Center.

May 31, 1996 Pineland Closes



Please

placed on walls
in every building

CLIENT RIGHTS

CLIENTS SHALL HAVE THE RIGHT TO:

Personal privacy

Access personal property

Visits with family and friends in privacy

Conduct private phone calls

Attend IDT meetings

Appeal IDT recommendations and treatment plans

Access the Resident Advocate

Receive and send mail without hinderance

A treatment program

Have, at his/her expense, the opinion of an independent consultant

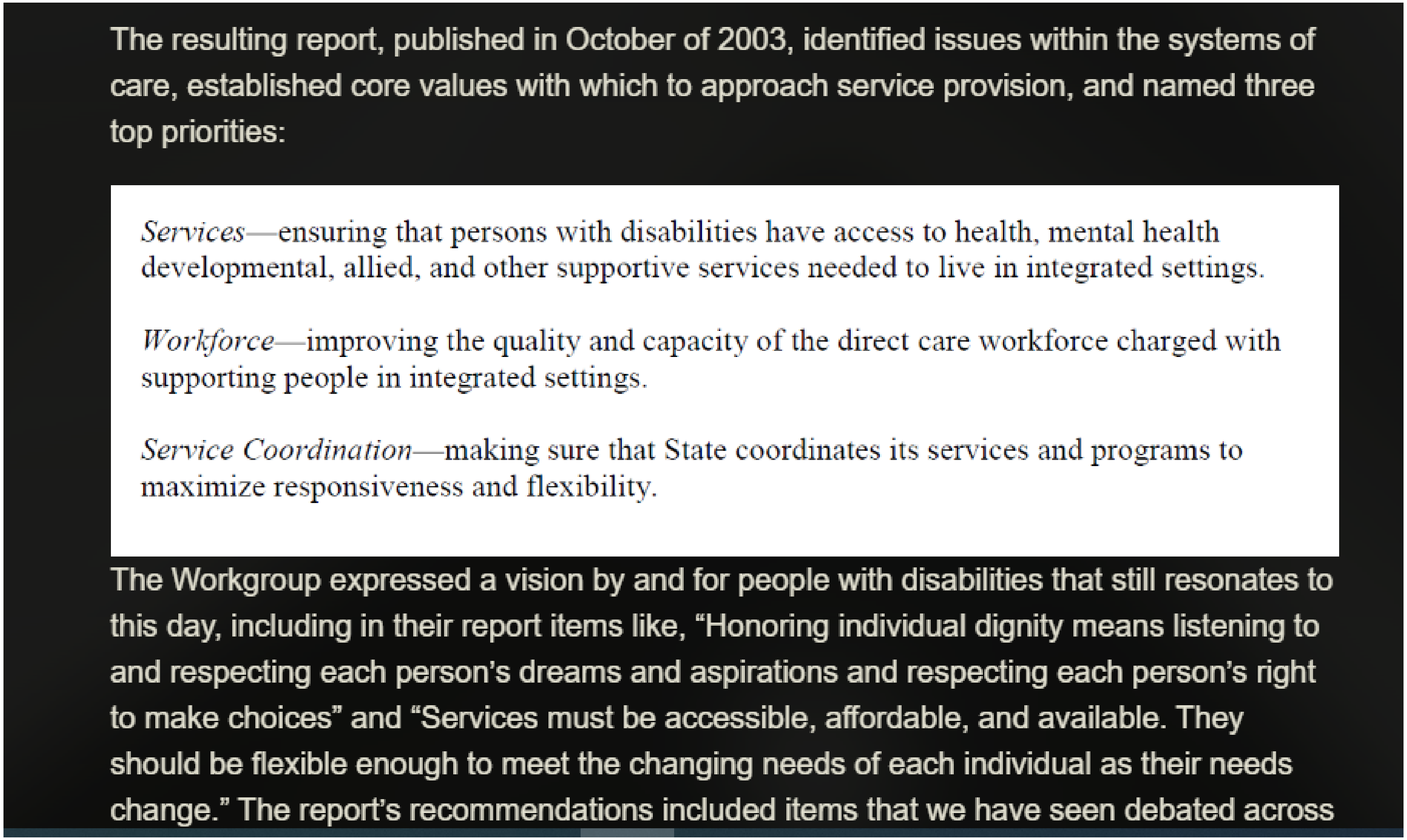
Refuse to participate in any research project

Be treated with respect and dignity

1999 - Olmstead

The story begins with Lois Curtis and Elaine Wilson. Both of these women were institutionalized. They were placed in the institution when they were younger and could not leave, even though many recognized that they COULD live in the community. They sued under the ADA that they were being forced to remain in the institution unnecessarily. This case went all the way to the Supreme Court and in 1999 the Olmstead Decision was made that people with disabilities have the right to live in the least restrictive setting. Lois Curtis and Elaine Wilson were able to move out into the community, into their own home with supports.

2003 Maine Responds



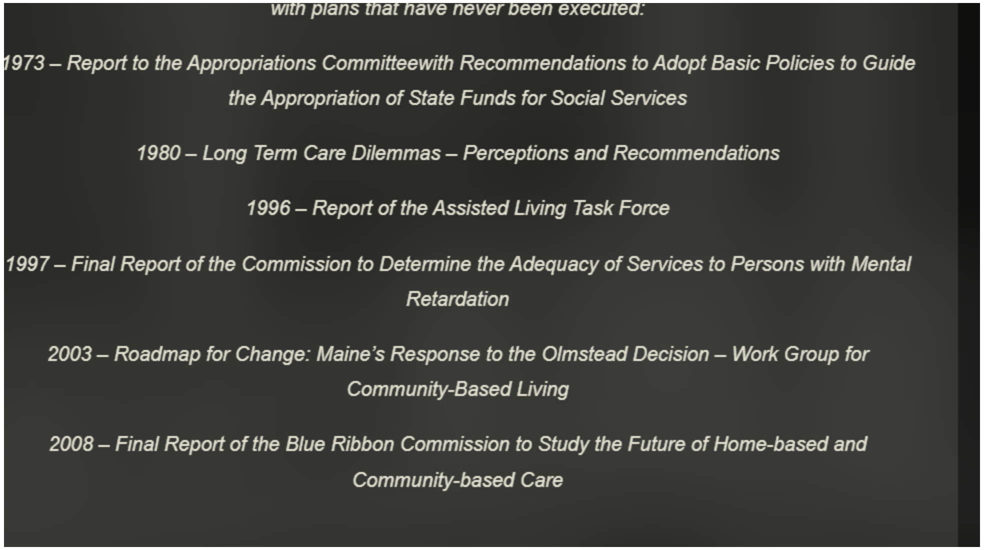
The resulting report, published in October of 2003, identified issues within the systems of care, established core values with which to approach service provision, and named three top priorities:

> *Services*—ensuring that persons with disabilities have access to health, mental health developmental, allied, and other supportive services needed to live in integrated settings.
>
> *Workforce*—improving the quality and capacity of the direct care workforce charged with supporting people in integrated settings.
>
> *Service Coordination*—making sure that State coordinates its services and programs to maximize responsiveness and flexibility.

The Workgroup expressed a vision by and for people with disabilities that still resonates to this day, including in their report items like, “Honoring individual dignity means listening to and respecting each person’s dreams and aspirations and respecting each person’s right to make choices” and “Services must be accessible, affordable, and available. They should be flexible enough to meet the changing needs of each individual as their needs change.” The report’s recommendations included items that we have seen debated across

A few themes throughout history and beyond

- Workforce Crisis
- Money
- Studies instead of action
- Waitlists



with plans that have never been executed:

1973 – Report to the Appropriations Committeewith Recommendations to Adopt Basic Policies to Guide the Appropriation of State Funds for Social Services

1980 – Long Term Care Dilemmas – Perceptions and Recommendations

1996 – Report of the Assisted Living Task Force

1997 – Final Report of the Commission to Determine the Adequacy of Services to Persons with Mental Retardation

2003 – Roadmap for Change: Maine's Response to the Olmstead Decision – Work Group for Community-Based Living

2008 – Final Report of the Blue Ribbon Commission to Study the Future of Home-based and Community-based Care

Will History Repeat Itself?

Must we repeat history, or can we find new solutions?

If we don’t know our history we will think the old is new.

Thank you for giving me this opportunity to speak

Contact me any time

nancy.e.cronin@maine.gov