## **AFFIDAVIT OF CARROLL MACGOWAN**

- I, Carroll Macgowan, being duly sworn, depose and say:
- 1. My name is Carroll Macgowan. I live in Cumberland, Maine. I make this affidavit on my personal knowledge, information and belief, and to the extent that statements are based on information and belief, I believe them to be true.
- 2. I am currently working as an advocate for the Office of Advocacy within the Maine Department of Health and Human Services and have held that position since 1994. I began working for the state of Maine on December 8, 1975 at the Pineland Center, an institution then managed by the Department of Mental Health and Corrections. The Department of Mental Health and Corrections has gone through a number of name changes and most recently has merged with the Department of Human Services to become part of the current Department of Health and Human Services (the "Department"). I have continued to be employed by the Department since 1975, primarily working with Maine's citizens with mental retardation.
  - 3. I have held the following jobs with the Department:

Direct care aide at Pineland Center; supervising and assisting Pineland residents in all aspects of daily living (two years);

Client Advocate at Pineland, training and assisting individuals in all aspects of patient/client rights and investigating allegations of rights violations, abuse, neglect, and exploitation (two years);

Southern Community Client Advocate, training and assisting individuals living in the 10 southernmost counties in Maine regarding rights related matters and investigating complaints and rights violations (two years);

Acting Chief Advocate and Chief Advocate of the Office of Advocacy, supervising and coordinating a system of advocacy services for: clients of eight state facilities serving individuals with mental health or mental retardation needs, inmates of Maine's correctional facilities, individuals receiving mental health and mental retardation services in the community; and children with special education needs. (seven years);

Project manager of a federally funded demonstration grant for Maine's Autism Project, which provided training, coordination, and the development

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of exemplary collaborative service delivery modalities with schools and service providers in southern Maine (five years);

Regional Advocate since approximately 1991, providing training and assistance on rights issues, and handling grievances and investigations of alleged violation of rights of individuals with mental retardation.

In addition, over the past 34 years I've been a member of the State's Council on Developmental Disabilities, a member of the Consumer Advisory Board and chair of the Board's Pineland Subcommittee as well as a member of, or consultant to, various other boards and committees having a focus on services to persons with mental retardation in Maine.

- 4. On December 7, 1975 I presented myself at the administrative offices of Pineland Center looking for a job. After a brief interview I was told it was likely they could use me, and that I should visit and have a brief tour of Yarmouth Hall, one of the buildings in which I would be working.
- 5. Upon climbing the stairs of Yarmouth Hall and trying the door I discovered that it was locked. I rang the bell and saw a gentleman open the door greeting me with "thank God you're here, I haven't had a break all morning." As he keyed open the door at the end of the hall and held it for me to walk through he said "I'll be back in about 15 minutes, the mop, shovel and pail are next to the door; don't turn your back on them." So saying he released the door which clicked locked. As I turned from the door, I saw I was in a room with high cathedral ceilings and only two pieces of furniture -- two 4 foot long backed wooden benches, no wall decorations, drab orange-yellow undecorated walls with heavily security grated windows around the three outer walls. In this room, the "day hall", were about 48 persons -- 1 was curled up on one of the two benches, about half the rest were lying or sitting on the floor and the remainder; 20 plus people, were milling around aimlessly in the cavernous room or, in the case of five to seven clients/patients, they were spinning rather rapidly while making a whooping sound which echoed off the walls of the hard cavernous room.
- 6. The scene was disturbing and unsettling, but, to make it worse, at almost 12 noon none of the clients/patients in the room were wearing normal clothing. A little over half of the residents in the room had hospital johnnies on, the rest were naked. The temperature in the room was well over 70 even on a late fall day with several of the large windows open; the smell of urine and feces was overwhelming.
- 7. I would learn later that there was a bathroom in the inner left hand corner of the room which was made inaccessible to clients/patients by a locked bottom half of a Dutch door. I also learned later that this was done to keep the clients from going into the

bathroom as it was harder to clean the bathroom than the "day hall". After 25 minutes, the staff person came back and I went back to see Mr. O'Toole, my interviewer.

- 8. I'm not sure what exactly I said to Mr. O'Toole. I was very disturbed by what I had seen, but part of the description of my concerns included the words: concentration camp, shameful, criminal and ended with a clear statement that I didn't believe I could teach or even work in the environment he had sent me to and that it was my opinion that a shovel, mop and bucket made very poor teaching tools. Mr. O'Toole showed no surprise at my words and his only response was "you college kids I don't know what you expect".
- 9. As I was leaving the administration building, upset and a bit disorientated, a man from the very last office in the hallway came out and stopped me. He introduced himself as Art Bannister and explained that he was the director of Children and Youth Residential Services. He said "... it's pretty awful around here but we're trying to make a difference for kids... would you be interested in coming and seeing what we're doing for them?" I agreed to walk over to Pownal Hall (a two-story cruciform designed building with virtually the same layout as Yarmouth Hall); we arrived there shortly before one o'clock.
- 10. The front door of Pownal Hall was wide open. We walked in and turned down the short left-hand arm of the building down a 20 foot hallway and into a room whose basic dimensions were similar to that of the day hall at Yarmouth Hall. The room however was brightly painted and had been divided with chest high dividers and shelving into eight two bed sleeping cubicles and two slightly larger cubicles which had couches, chairs, a television and radio, as well as a few book and toys for the use of the young boys in that 15 person unit. While I was there, three staff members were working with six or seven boys in the two front recreation areas. One of the staff there was teaching a young man how to tie his shoes, another was reading a book to two young boys, and the third was assisting a young man to change his clothes.
- 11. Mr. Bannister said "...things are considerably different here in the children's units; you can actually do some teaching... I understand that's what you wanted to do". He asked me if I'd be willing to work in the children's unit and then asked if I could start that afternoon. I agreed to try out the job and agreed to start the following day. I arrived at Pownal Hall at 6 a.m. the following morning and was assigned to work with the "older active boys" in a unit similar to the children's unit I had seen the previous day, but at the end of the long hallway and on the second floor.
- 12. I worked with 15 boys aged 13 to 18, assisting/training them in basically all aspects of daily living: dressing, personal hygiene (dental care, bathing, toileting, etc.), eating, as well as a range of social and recreational activities. The building supervisor, who met with me the first morning of my employment at Pineland Center, told me I was

basically responsible for these 15 boys for the eight hours I was on duty. She said anything I could do to make their lives better would be acceptable, but, my primary duty was to assure that no one got seriously hurt or lost and that they showed up for medical and program appointments on time.

- 13. The normal staff ratio was one staff to 15 or 16 children in the unit I was assigned to as well as all the units at Pownal Hall (the number of staff I had seen on the previous day at Pownal Hall were as a result of staff overlap between shifts as well as the fact that the previous day had been a payday and a number of staff were there to pick up their checks).
- 14. Of the 15 boys I worked with, over half had significant behavioral problems (aggression and/or serious self injurious behavior); two were diagnosed as deaf; half had to be monitored for choking risks while eating; three or four had a history of seizures; none were fully continent of bowel or bladder; all, if not well supervised, wandered off/ran away and only one was generally "safe" to access Pineland grounds unescorted.
- 15. Although all 15 boys I worked with were school-age, only two attended school on any regular basis and that was only about 1 1/2 hours three days a week. If there were any problems at school (toileting accidents, disruptive or aggressive behaviors, etc.) for boys with whom I worked, as well as any of the other school-age children, residential staff were called to remove them back to the residence.
- 16. Pineland Center at that time suffered from chronic shortage of staff, especially in the adult residential units. As a result, it was not unusual to be pulled from one's usual staffing assignment and deployed at units that had a need for staffing. Over the nearly 2 years I worked as direct care at Pineland Center I had, as a result of the staffing problems, the opportunity to work in all but one building on Pineland grounds.
- 17. I provided direct care to clients at Pineland Center for over eight months before having any in-service training regarding the job functions at Pineland Center. The little training that was available was contradictory and often inappropriate advice from a variety of supervisory staff on the units, as well as -- sometimes very good and sometimes very bad -- advice from fellow workers on the units.
- 18. Pineland Center had originally operated as a vocational training school which required for admission a determination that a person was able to work sufficiently well to defray their cost of care. Over time, Pineland developed units for individuals who required significant levels of care and supervision. In order to provide that care and supervision, with the limited staff that Pineland Center had, some of the "working boys and girls" (who previously worked on one of the farms, in the gardens, in the sewing or crafts rooms) were required to care for other individuals who needed assistance and

supervision. Over time the expectation that "working boys and girls" would be supplying the majority of supervision and care, as well as laundry, housekeeping, maintenance, and grounds-keeping duties at Pineland Center became a part of the fabric of the facility. The hierarchical delineation of "working boys and girls" caring for "low grades" was a recognized and socially significant categorization by both staff and residents at Pineland Center.

- 19. The artificial social layering engineered at the institution had and has a significant impact on people who lived at Pineland Center. A higher status afforded "working boys and girls" and the negative stigma attached to being a "low grade" or one who got care from the "working boys and girls" impacts many former residents of Pineland Center in the community today. Many of these former residents find it difficult to bond with or even socially interact with other clients, some have an openly voiced dislike of "people with disabilities", and not a few former residents of Pineland Center are disdainful and/or openly prejudiced against individuals who function with less capability than themselves In group living situations in the community it is not unusual to have clients who do not interact with other clients but only with staff, and significant incidences of client to client abuse may well be attributed to some of the learned behaviors of clients in forcing order on other clients at Pineland Center.
- 20. Use of residents to provide significant services at Pineland Center was a reality well into the 60s, however the move to "de- institutionalize" large, state run mental health and mental retardation facilities across America, including Pineland Center, would substantially change the mix of clients available to assist other clients at Pineland Center. Increasingly during the 50s and 60s and even into the 70s those more capable and job ready (the "working boys and girls") clients at Pineland Center were placed out on farms and in domestic jobs throughout the state. These individuals, often placed out of Pineland conditionally on "Temporary or Permanent Visitation" status (meaning for the slightest cause or no cause at all they could be returned to Pineland Center), provided cheap, often free, unskilled labor to motels, hotels, inns, dairy farms, egg farms, wood lots, etc. around the state. The declining numbers of capable "working boys and girls" was not countered with significant hiring of appropriate paid staff at Pineland Center. By 1975 when I went to work at Pineland Center, staffing crisis at Pineland Center was at its worst. Even basic custodial care was not possible.
- 21. During my time as a direct care staff at Pineland Center it was openly acknowledged that there was a shortage in: appropriate education for school-age children; appropriate education and training in independent living for adults; speech, language and general communication training and services; occupational therapy and physical therapy evaluations and direct services; vocational training and paid jobs for individuals interested and willing to work; psychiatric and psychological services of all kinds; as well as consistent and coordinated training in the development of basic daily living skills.

- 22. One of the more disturbing memories of my early days at Pineland was talking to families who described how many skills their loved ones had lost since they'd come to Pineland. Children who had rudimentary spoken language when they came to Pineland were now nonverbal adults; individuals who were fully toilet trained had lost those skills and were now diapered; other individuals lost skills in the areas of: self care, personal hygiene, dressing, dental care, and even in some cases ambulation.
- 23. With limited professional services of all kinds available at Pineland Center and significant waiting lists for all professional services, the general feeling among residential staff was that those clients who needed the services the least (i.e. those clients who were least disruptive, most capable of self care, verbal, and in general, the most fun to work with) got the limited services available. Residents with significant behavior problems, significant communication impediments, medical or physical limitations, as well as issues with: incontinence, drooling, screaming or screeching, etc. were most often left as the responsibility of ill trained and understaffed residential units.
- 24. Within the residential units by far the best staffing ratios were in the children's units where the average staffing was one staff to from 8 to 20 residents. In the adult units, with the exception of the medically oriented units, the average staff ratio ranged from about one to 25 up to one to 50. Even in children's units with the best possible ratios it was almost impossible to give the kind of personal attention desired or in some case demanded by the residents.
- 25. When I was working in Pownal Hall I found it almost impossible to get 15 boys up, bathed and dressed between six o'clock and 7:30 when breakfast was served. It took about 4 min. to sufficiently fill the tub, 4-5 min. to bathe an individual, and at least 3-4 min. to empty and minimally clean the tub while 14 other boys were getting into mischief; after bathing individuals, they needed to be dried off and assisted with dressing. When I discussed the difficulty with the building supervisor, I was "trained" that "there is no need to clean the bathtub after every bath, no need to empty/refill the bathtub after each bath, and to lock the unit door while I was busy doing baths, dressing, and personal hygiene with the clients".
- 26. These expediencies were obviously wrong and were only recommended for a lack of adequate staffing. In the adult units things were far worse. Bathing most often consisted of being hosed down. Often adult clients who were unable to dry themselves were put into hospital johnnies wet and sent to bed.
- 27. Personal hygiene was a serious problem for residents both because of lack of training and because, in the vast majority of units, toilets were not accessible to clients. Even in those units where toilets were accessible, soap and toilet paper were only accessible if one requested them of staff. Incontinence was a constant problem for clients of Pineland Center; many staff praised clients for relieving themselves virtually anywhere

without wetting or soiling their clothing. During all the time I worked at Pineland Center it was not at all unusual to see clients relieving themselves openly around the grounds of Pineland and being praised for not wetting themselves. Teaching clients to expose themselves in public may have been beneficial for staff at Pineland but to this day some clients living in the community have problems understanding why public exposure is an issue with which current personal assistants must intervene.

- 28. It was generally axiomatic at Pineland Center that the clients that caused no problem got no attention. The desire on the part of clients for attention, touch, or human interaction often compelled them to act out in extreme ways. Extremely self abusive behaviors (pounding their head on the floor or on furniture, banging their head with their fist, biting their hands or arms, etc.) or assaultive behaviors could not generally be ignored. Many residents at Pineland facing almost complete isolation from positive human interaction would gladly accept negative attention rather than no attention at all. Learning to get attention by negative actions has carried over into the community and a significant number of individuals with severely intrusive behavioral plans have these plans as a result of the learned behaviors at Pineland Center.
- One of the more disturbing things about Pineland Center's staffing problems was that understaffing all too often led to actions that were inappropriate and on occasion abusive. Mistreatment of clients was never officially tolerated at Pineland Center; however, over the years, the use of increasingly ill suited and ill trained clients to care for other clients led to many problems, including mistreatment and abuse. Long after the official practice of having the "working boys and girls" care for other residents of Pineland had stopped, it was still an informal practice among direct care staff. Through a combination of bribery, fear and intimidation the most capable clients within residential groupings were often forced into doing much day-to-day "ward" work (mostly housekeeping and janitorial duties, but often including care and management of other clients) assigned to paid residential staff. Perhaps most disturbingly some staff used clients as "enforcers" to carry out punishment and intimidation of other clients, actions which these staff knew were not allowed and would have resulted in discipline/job action if engaged in by them. Many of these clients learned that "might makes right," and have carried these negative learned behaviors into community placements. Client to client assaults continue to be a frequent and significant problem in many community settings. The rate of domestic violence/client-to-client assaults in current day residential community facilities for persons with mental retardation is many times that reported in the general population. This fact can, I believe, be attributed in very large part to behaviors learned and witnessed by former residents of Pineland Center.
- 30. In my two years working direct care at Pineland Center, I witnessed and reported a number of events which I felt were inappropriate and in some cases abusive. I was never made aware of what action, if any, was taken concerning my reports and it was never made clear what the process was for reviewing such concerns. What I perceived,

as a direct care staff, was that all issues, problems, or concerns regarding staff activity were handled, generally informally, by the shift or unit supervisors. In general, and I'm sure in part due to the chronic understaffing prevalent at Pineland Center during the period I was working direct care, supervisors tended to be very tolerant of inappropriate staff activities. Because of the lack of available substitute staffing, when the unit was short staffed - because of sick staff, job action/discipline of staff, or any other reason - supervisors were expected to work as fill-in staff. On several occasions I witnessed activities that very clearly today would be considered neglect or abuse which were handled (on occasion in my presence) by a supervisor simply saying "cut that out", often in an almost joking manner. On more than one occasion I heard several different supervisors say "I don't care what you do with the clients as long as I don't get calls and no one gets hurt or lost".

- 31. Clients/residents of Pineland Center were, when I began work there, afforded virtually no day-to-day privacy, and had, effectively, no personal property. In the general adult units, people slept in bed wards of 25 to 40 people with long rows of beds packed close together. No provision was made for personal property in the bed wards. Items of personal clothing, what there were of them, were shelved in the "personal laundry room" which was locked and could be accessed only with staff assistance. Most clients had insufficient personal clothing to meet their needs. Some adult units, especially those with primarily incontinent clients, made no attempt to dress clients in standard clothing. In those units it was more convenient for staff to use hospital gowns/Johnnies. Even on those units where clients had sufficient personal clothing for their own use, the general shortages of clothing led to the use within a unit of anyone's clothing just to keep up with the general demand for clothing. There were a number of units at Pineland Center where many of the clients had no outerwear or in some cases even footwear. These individuals never left the unit in anything but the best of summer weather - if then. The central laundry had perennial problems handling the volume of clothing, which led to forced sharing of personal clothing, even on the children's units, where generally individuals had personal clothing. Even on those units where personal storage places (usually shelves sometimes divided into small personal cubicles) were available, they were not secured. Any personal property of value that was yours one day was likely to be missing property the following day. And Pineland Center's general policy regarding personal property was that if you wanted it secured it should be locked up by staff and would be made available on request.
- 32. Client bathrooms (separate staff bathrooms existed in all units) consisted of a line of from six to 10 toilets no privacy here either. There were no doors on the toilet stalls as there were no toilet stalls. Toilet tissue was not readily available; it was kept locked and had to be requested from a direct care staff. Shower rooms were generally 10 by 15 foot fully tiled rooms with a center drain and 10 to 20 showerheads around the walls.

- 33. As one could easily suspect from reading the previous paragraph, clients who lived in this environment and are now in the community have been affected in significant ways regarding their personal habits. Many former clients of Pineland Center are either very ill equipped to understand the nature and expectations of others regarding personal privacy; or, in the other extreme, are extremely sensitive to any encroachments on their privacy. A number of clients in the community have significant problems with "hording" behavior; in extreme cases these clients will throw nothing away. Some clients react violently to anyone touching their "personal property" even when health and safety issues become apparent, or when landlords threaten to evict clients because of the clutter or cleanliness of their rents. A client who has no understanding or concept of personal property cannot really be expected to honor the personal property of others; "theft" among and between clients living in community settings is an all too common occurrence.
- 34. Pineland Center was in, a very real sense, a self-contained community. In 1908 at Pineland Center's inception and for most of the first half-century of its existence the public wanted persons with mental retardation to be "in a safe place", "with their own kind", or, "where they can be cared for". Whatever our feelings now about these sentiments there is no question that Pineland Center, the institution, was not like the regular mainstream community. Attempts from the 1950's on to reintegrate Pineland's clients into the community, and more importantly to place them in the community, was in a very large part hampered by the very fact that Pineland was not like the community.
- 35. As a result of the class-action suit, which had been filed in July of 1975, by the spring of 1976 attempts were being made to get some Pineland Center residents out into the community at least occasionally. Unfortunately Pineland Center did not have adequate or appropriate transportation or sufficient staff available on a regular basis to take significantly large groups of people off the grounds. Groups of 15 plus people were the norm for community outings because staffing was insufficient for smaller groups. Outings were an "all or nothing" proposition; if everybody couldn't go, no one could. Since the staff to resident ratio was so low, community outings were not truly community integration but were more like viewing the community from a sightseeing bus.
- 36. Trips for Pineland Center clients generally consisted of going off-season to beaches and parks; country drives; an occasional drive through the city; and, if the group was small enough and things were going well and the money was available, a trip to a fast food restaurant drive-through. Many former Pineland Center clients continue to have problems adjusting to involvement in normal community activities. Significant numbers of former Pineland clients still cannot tolerate active public spaces and have still not acquired the understanding and requisite safety skills to negotiate their communities in safety. It is unfortunate that community integration, even today, is often being "in the community" as opposed to being "part of the community." The increasing budgetary pressures on community providers have recently caused larger groupings of clients to go

with smaller numbers of staff on visits to communities in which they are not really active members.

- 37. Significant numbers of persons living at Pineland had behavioral and social adjustment problems that presented as sometimes dangerous, assaultive, and other acting out behaviors. Limited staffing at Pineland Center limited the ability to supervise, resulting in unsupervised freedom for many of these "dangerous" clients on the grounds of Pineland and within and among the living units. At times, these "dangerous" individuals roamed the grounds of Pineland Center often preying on weaker and/or more vulnerable clients. I believe the high prevalence of emotional and mental health problems experienced by former Pineland clients is, in part, directly attributable to the uncertain and often unsafe situation in which they lived at Pineland Center.
- 38. On numerous occasions during my involvement with Pineland Center I became aware that staff -- often staff who didn't work with clients directly such as administrative and professional staff were fully aware of the level of dangerousness of some of the individual clients living on the grounds. On a number of occasions when celebrations and community events were taking place at Pineland (the community Fourth of July celebration, open houses, the opening of the gymnasium, opening up the pool, etc.), I witnessed administrative and professional staff consciously taking extra care to assure that their children would not come into unsupervised contact with specific individual clients. As a parent I fully understand the concern they were displaying for the safety of their loved ones, but it served to highlight the lack of concern for the more vulnerable clients who were preyed on with no protection.
- 39. When I began work at Pineland Center it was still the practice that when a family member wished to see a resident, they had to check in at the administrative office and wait until the resident in question could be brought to visit with them. No visitors were allowed in the residential units, unless accompanied by staff, since virtually all buildings and units were locked at all times. This policy was strictly adhered to.
- 40. Many of the parents of residents described to me how they were told it was Pineland policy to have no contact with their loved one during the first 60 days after admission, and how many of them were told the best thing they could do is just go home and forget their loved one.
- A1. No concerted efforts were made to maintain family contact for residents. No regular support for family visits to Pineland Center or client visits home were evident prior to the filing of the class-action suit in 1975. The active denial of phone calls both in and out of Pineland Center and the censoring of both incoming and outgoing mail had, for the most part, stopped within the first year that I worked at Pineland Center. However, even after these practices stopped, residents had to use the public payphone, which required grounds privileges to get off their unit, money for the payphone, and the

skill set necessary for using a pay phone which most clients lacked. The censoring of incoming and outgoing mail stopped in large part because only a very limited number of clients remaining at Pineland Center had the skills necessary to write or read or post a letter.

In preparation for this affidavit I took the opportunity to read many of the 42. early court filings regarding this case, including the July 3, 1975 complaint. Although I have no personal knowledge as to the numbers presented in the complaint, I can personally attest that all of the general statements about the nature and quality of life at Pineland Center and the availability and adequacy of staffing and professional services presented a true and accurate picture of the conditions at Pineland.

Dated at Portland, Maine this 6<sup>th</sup> day of November, 2009.

STATE OF MAINE CUMBERLAND, ss:

November 6, 2009

Personally appeared the above-named Carroll Macgowan, and made oath that the foregoing statements by him are true and correct and are made on the basis of his personal knowledge, information and belief, and to the extent that statements are based on information and belief, he believes them to be true. Before me,

My Commission Expires:

DEBORAH D. MCKENNEY Notary Public, Maine

My Commission Expires February 4, 2014