

Maine Developmental Services Oversight and Advisory Board

Introduction to the HHS Committee of the 130th Legislature – January 27, 2021

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A Brief History of the MDSOAB: Where Did We Come From, How Did We Get Here?

The Maine Developmental Services Oversight and Advisory Board (“MDSOAB,” “OAB,” “the Board”) was created by the 123rd Legislature in 2007 as part of what came to be called “the mechanisms of future compliance” legislation.

The history of the Board can be traced back to the class action lawsuit seeking to address the care and treatment of residents of the Pineland Center that was filed in the Southern District Court of Maine in July, 1975. The lawsuit resulted in the settlement known as the Pineland Consent Decree in July, 1978 which was supervised for compliance by a federal master. In November of 1983, the court determined that the state had met the terms of the decree and discharged the special master.

At this time, a citizen advisory board was created, the Consumer Advisory Board (“CAB”) to provide independent oversight of Maine's system of care for those with intellectual and developmental disabilities. When the CAB recognized that the State had not kept up with the terms of the decree, the CAB became the plaintiff in a new lawsuit in 1991. That litigation ended with another out of court settlement, the Community Consent Decree, in September, 1994, and another federal master was appointed to oversee the second consent decree.

Part of that second settlement was a requirement that Maine must have a way to insure **future** and continued compliance with the decree before the court could release the state from the supervision of the federal master. The “mechanisms of future compliance legislation” – which included the creation of the OAB – allowed the state to satisfy the requirements of the Court, and the Community Consent Decree was discharged in March, 2010.

Duties of the Board:

The OAB was staffed in 2010 as the successor to the CAB. By statute the Board was created to

- A. Provide independent oversight over programs and services for adults with intellectual disabilities or autism that are provided, authorized, funded or supported by the department or any other agency or department of State Government. The board shall focus on systemic concerns affecting the rights of persons with intellectual disabilities or autism, including but not limited to issues surrounding health and safety, inclusion, identification of needs and desires of persons eligible for services by the department, the timely meeting of the identified needs and effective and efficient delivery of services and supports

- B. Provide advice and systemic recommendations to the commissioner, the Governor and the Legislature regarding policies, priorities, budgets and legislation affecting the rights and interests of persons with intellectual disabilities or autism

The Board also provides a member to the three-person Regional Review teams who must approve and monitor restrictive Behavior Management Plans and Safety Plans. The other members of the review teams are a representative from Disability Rights Maine and an OADS Crisis Team leader. In addition, there is a similarly constituted Statewide Review Panel that makes recommendations to the Commissioner on the Level 5 (the most restrictive) Plans.

Finally, the OAB administers the Volunteer Correspondent Program.

From the Executive Summary of the 2020 Annual Report

Recommendations:

Increase Rates and Reimbursements.

- A) Support legislation that sets pay for **Direct Care Workers** at 125% of the minimum wage and provides indexing to keep pace with raises to the minimum wage.
- B) Support legislation to create a reimbursement rate structure for Direct Care workers that allows for incremental pay increases and **differential pay rates based on training and experience.**
- C) Support legislation to increase the reimbursement rates for **targeted case managers.** Overloading case managers contributes to turnover. Case manager turnover contributes to problems navigating the system.
- D) Create a reimbursement structure that recognizes the costs involved in supporting **residents with severely challenging behaviors.** We have a differential rate for those with severe medical needs. Funding to make environments safe and for repairs and replacement of damaged property needs to be extended to providers who serve those with severe behavioral needs, or their needs will go unmet.

Improve Transition between Children's and Adult Services.

Increase flexibility and choice within waivers.

Recognize the Importance of Case Management by providing training and career development. Improve retention and reduce turnover.

Promote self-advocacy and full participation in the Person-Centered Planning process.

Support the Volunteer Correspondent Program.

Support appointments to the MDSOAB.

Noteworthy:

Legislation from 2020 for the creation of an independent Mortality Review Board has been included in the Governor's budget for the next biennium. This board will address the issue raised by the Office of the Inspector General's 2018 report which found Maine deficient in investigating deaths among those under care. Insofar as it is required, the OAB urges the HHS Committee to support this key provision of the Governor's budget.

Since the Pandemic

First, we have to comment on the dramatically improved relationship between the Board and the leadership of OADS. Someone from the OADS leadership team, usually more than one, has attended each of the Board's monthly meetings, shared information, and engaged the Board on various topics (e.g. Adult Protective Services, case management, the federal Home and Community-Based Settings rule).

Two areas of particular concern were the placement of Maine citizens in out-of-state treatment facilities and the use and prevalence of highly restrictive Behavior Management Plans. There are still unanswered questions, but the Board has determined that there are only about seven adults with intellectual disabilities in out-of-state placements and about the same number with severely restrictive Behavior Management Plans.

Working on these last two questions, it also became apparent how difficult it is for OADS to extract information from its computer systems. It's labor-intensive and time-consuming and it hampers quality assurance and regular reporting. The department's willingness to share information is much improved, but the availability of key data is often still limited.

What's Next

There are still hundreds of people with intellectual disabilities or autism on waiting lists for Section 21 or Section 29 services. Some have limited services; others are getting no services beyond case management. The Governor's budget provided funds to take 30 additional people per month off the Section 29 waiting list, but attention must be paid to those who need Section 21 (residential) care.

For those who are receiving residential services in small group homes, they are experiencing much uncertainty during the pandemic. Pay rates for Direct Support Professionals have fallen below minimum wage. It's hard to attract and retain people who are willing to do the work, but who can make more working at fast-food restaurants or stocking shelves at big box retailers. Low pay (for sometimes difficult and challenging work) has exacerbated the workforce shortage, and caused some providers to close and/or consolidate group homes. Once a licensed home goes out of service, it's difficult and expensive to start a new one, and housing choices (and personal freedoms) are reduced.

The Board has requested that OADS prioritize COVID-19 vaccinations for everyone with an intellectual disability or autism. People who live in group homes have been prioritized, but we've urged that the state also prioritize those who receive only community based services, those who live on their own or at home with parents, those in shared living homes, and those with only case management services. They need the same level of protection as those who are in residential care.

Volunteer Correspondent Program

The Volunteer Correspondent Program (“VCP”) began as residents were moving out of the Pineland Center into smaller community-based settings. Many residents of Pineland had no families or had lost touch with family, and as a result, lost their connections to the world outside the institution. Volunteer Correspondents were matched with former residents of the Pineland Center and served as advocates, links to the community, friends, and “the next best thing to family.” Volunteer Correspondents look out for the welfare of the person they’re matched with by the VCP, but have no financial responsibility for that person. The program continues today, matching volunteers with people with intellectual or developmental disabilities who need an advocate and a link to the larger community.

For several years prior to 2019, the VCP had received little data from OADS to update its records of volunteers, residents who’d requested a correspondent, case managers, guardian contact information, etc. In 2019 and 2020, OADS provided a tremendous boost, sharing information on residents who were deceased, updating case managers, residence addresses for over a thousand individuals who were matched with a Volunteer Correspondent or who had been identified with an unmet need for a Correspondent. The department provided current addresses for the consumers, case manager/agency contact information, and guardian(s) contact information. Approximately 30% of those in our files were found to be deceased, many of whom were members of the original class action suit that led to the closing of Pineland. The VCP database has been updated and the folders have been removed from the active files.

For living members, their current case managers were contacted to learn whether there was still a need for a Volunteer Correspondent, and about 25% proved not to need a correspondent at this time, due to strong family involvement, or occasionally a correspondent who has become a guardian.

The VCP continues to process requests for a correspondent and applications to become a correspondent. With the cooperation of OADS and better access to contact information, the process has become more streamlined, so requested are being cleared more quickly, rather than remaining open through lack of follow-up contact information.

The VCP stills need more new volunteers, with more emphasis on recruiting correspondents and publicizing the program, which the OAB hopes to undertake in the next biennium. The website of the Volunteer Correspondent Program is at this link: <https://vcpmaine.org/>