Investigations into the abuse of disabled adults in Maine have slowed, without explanation

BANGOR, Maine — During the past four years, Geneva Belden has fallen twice. The first fall, in May 2013, broke her nose. The second, in October 2016, broke her thumb, according to the home care agency Branches, which assists her in the Bangor group home where she lives.

Belden is intellectually disabled, and while she can converse with others and care for herself, she has trouble with critical thinking and long-term planning.

After the first fall, Branches staff didn't take her to the hospital for two days until they noticed her black eyes. When Branches administrators learned of this, they reported these incidents to the Office of Aging and Disability Services, as required by state regulations, said Brian Noble, the owner of Branches. They did the same after the second fall.

State regulations specify those who care for people with intellectual disabilities must report all potentially dangerous situations within a day of learning of them — and the most pressing situations immediately — even if actual harm or injury did not occur.

It's expected that these reports would trigger an independent investigation by state regulators with Adult Protective Services, a division of the Maine Department of Health and Human Services, which is required to investigate abuse and neglect — which can range from sexual assault to group home staff members falling asleep on the clock — of people with intellectual disabilities such as Down syndrome or autism.

But to date, neither Belden nor Noble say they've heard from the state regarding these reports.

According to several providers who have came forward to the Bangor Daily News to share concerns about the state's system for investigating suspected abuse and neglect, this silence has become increasingly common.

Five health care service providers in York, Penobscot, Androscoggin and Kennebec counties shared their referral numbers with the BDN. Combined, they had reported 555 allegations of possible abuse, neglect or exploitation between 2011 and 2015. Adult Protective Services had produced final reports for just 40 of them.

What's not known is whether the state is declining to investigate allegations, if the investigation reports are being shielded, perhaps because of privacy concerns, or if there has been a policy shift away from what health care service providers believe should occur.

"Agencies don't receive reports any more. So what happens is an agency files a reportable event as they are required to and doesn't necessarily ever hear anything again," said Charlene Kinnelly, a recently retired lobbyist for the Maine Association for Community Service Providers, which represents residential or day-program providers' interests.

The Maine Developmental Services Oversight and Advisory Board, which provides independent oversight of services for adults with intellectual disabilities or autism, also has expressed grave concern over the state's lack of responsiveness.

"When staff of the [advisory board] contacted, or tried to contact the investigator or the supervisor to find out the status of the investigations, no calls were returned," the board wrote in comments to the state in August 2016.

It continued, saying it "believes that what has happened is that the [Adult Protective Services] unit has indeed been overwhelmed and that it cannot function effectively to protect the persons it is mandated to protect."

'Not keeping the promise'

The current problems have their origins in a legal battle dating back to 1975 when a class action lawsuit was filed on behalf of people involuntarily admitted to the Pineland Center, a state-run mental health institution in New Gloucester.

Conditions at the facility were poor, with residents spending much of their time in large, open rooms, half-dressed, with, in many cases, no individualized treatment.

"There might be 30 to 40 people standing in a room and one staff person. And the staff person's job was to clean up urine and feces on the floor. That's how it was," said Richard Estabrook, who was the chief advocate in the Office of Advocacy from 1985 to 2012, monitoring people with intellectual disabilities and autism served by Maine DHHS.

Estabrook worked at Pineland as an advocate for patients and later became a member of the Maine Developmental Services Oversight Advisory Board, the group charged with overseeing the state's care of people with developmental and intellectual disabilities.

A judge first ordered a consent decree in 1978 to force the state to improve conditions. The move prompted the state to phase out the facility and attempt to better care for people in the community. In 1994, a new decree sought to better support people's health and safety in their community environment.

It was this consent decree that U.S. District Court Judge George Singal lifted in 2010 because, as he ruled, the state had "made a substantial and sustained

good faith and largely successful effort to achieve compliance." Maine Attorney General Janet Mills argued in favor of lifting it.

Maine had mechanisms in place to prevent the state from slipping on its obligation to protect vulnerable people, including the work of Adult Protective Services and the Consumer Advisory Board, Singal wrote in his order.

He said he understood people's concerns that the state could regress, especially given financial pressures. "The fear that history may repeat itself will always be present," he wrote, requiring those who advocate for people with disabilities "to be forever vigilant."

The Maine Developmental Services Oversight Advisory Board — the successor to the Consumer Advisory Board — has been paying attention. But though state regulations spell out that it will receive final reports of Adult Protective Services investigations, it hasn't received one since it formed in 2011, its chairman, Cullen Ryan, said.

Without information, the 10-member board can't oversee the state's work — or even determine how much of the required work it's doing.

"We have not seen the department be responsive to requests for information, and we are looking for that information so we can help ensure that the department is doing what it's responsible to do to meet the needs of folks with intellectual disabilities," Ryan said.

Maine DHHS is legally required to prepare a report for the Legislature every two years about its services for people with intellectual disabilities and autism. Those reports state it is choosing few cases to investigate: It "accepted" 428 cases out of 1,293 referrals in fiscal year 2015; 428 cases out of 1,377 referrals in fiscal year 2014; and 159 cases out of 1,311 referrals in fiscal year 2012.

In FY2016, the Crisis Teams admitted 64 individuals into Crisis Residential Services, and provided in-home crisis support to 40 individuals. For full FY2015 and FY2016 data, see Table 1.

Adult Protective Services (APS): Maine statute requires OADS to protect incapacitated and dependent adults from abuse, neglect and exploitation; enhance the welfare of these vulnerable adults; and promote self-care where possible. Adult Protective Services receives reports, promptly investigates and determines the validity of reports alleging abuse, neglect, or exploitation. Protective services include social, medical and psychiatric services necessary to preserve the adult's rights and resources and to maintain the adult's well-being. For Fiscal Year 2015 (Developmental Services only), OADS received a total of 1,293 APS Referrals, of which 428 were accepted for investigation.

State Plan Residential Services (PNMI and ICF/IID): Under MaineCare State-Plan services, OADS supported 281 individuals in FY2015 and 266 individuals in FY2016 in licensed residential care facilities (PNMI - Private Non-Medical Institution) in settings of less than 16.

In FY2015 another 177 individuals resided in Intermediate Care Facilities for Individuals with Intellectual Disabilities, and 169 individuals in FY2016. Known as ICF/IID and ICF/Group programs, these residential treatment facilities are considered "institutional" settings by the Federal government and were designed to meet the intensive, active treatment needs of persons with intellectual disabilities.

1915c Waiver Services (Section 21 and Section 29): The two 1915c Waivers offer a broad array of services including Home Support, Community Support and Work Support. Other services are available and may be identified through the Person Centered planning process.

These programs are designed to support individuals who live with their families or on their own in the community. These benefits are often referred to as Home and Community Based Services (HCBS). The service is offered in a community-based setting as an alternative for members who qualify to live in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). The Benefit supplements, rather than replaces, supportive, natural personal, family, work, and community relationships and complements.

Individuals may access one of two waivers: Section 21: Home and Community Based Benefit for Members with Intellectual Disabilities or Autism; or Section 29: Support Services for Adults with Intellectual Disabilities or Autism.

In FY2015 and FY2016, OADS authorized the following amount and types of service:

Fiscal Year 2015 APS referrals (p. 7) View entire document on DocumentCloud

Person Centered Planning (PCP): Every adult with an intellectual disability or autism who is eligible for developmental services must be provided with the opportunity to engage in a personal planning process in which the needs and desires of the person are articulated and identified. PCP involves identifying and describing the person's needs and goals, as well as the support services the person requires to live a meaningful and self-directed life. Maine's PCP Process is defined to ensure personal choice and opportunities. At the same time, it meets regulatory requirements, addresses the resource allocation process, communicates changes, and ensures consistency and accountability.

Since the implementation of the new PCP process within the person's electronic record which started in 2012, 5072 active PCP's have been entered in to Enterprise Information System. This provides for a streamlined consistent process for all service providers while ensuring full consumer and guardian participation.

Public Guardianship and Conservatorship: OADS acts on behalf of the DHHS Commissioner as the public guardian and/or Public Conservator representative for adults with intellectual disabilities or autism who have been found to be incapacitated by the Probate Court when no private party is willing or suitable. A guardian is a person appointed by the court to make decisions on behalf of another individual. OADS assists individuals under these circumstances to make decisions about their life and how to safely live. There are currently 628 individuals receiving this service.

Statewide Crisis Prevention and Intervention Services: Services are provided 24 hours per day, 7 days a week, for adults with developmental disabilities and brain injury throughout the State of Maine. The overall goal of this responsive crisis system is to provide assistance to individuals, families, guardians, and providers in order to maximize individuals' opportunities to remain in their homes and communities, before, during and after crisis incidents.

When it is necessary for an individual to be supported in a state operated crisis home or other contracted short-term residential service, it is the goal of the crisis service system to assist that individual to return home as soon as possible or to work with the person's team to assess and identify a safe alternative. In FY '13 and FY '14, the OADS crisis teams experienced the following number of contacts:

Crisis Services	Persons Served – FY '13	Persons Served – FY '14
Crisis Residential Services	28 Admissions	28 Admissions
Outreach	338	330
In-Home Crisis Support	60	74
Telephone Support	4,186	4,232
Permission for Medical Treatment	683	708
Consultation/Education	1,287	1,290
TOTAL	6,582	6,661

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Untitled Note (p. 8) View entire document on DocumentCloud

The state's reports say the cases involved "Developmental Services only." It's not clear from the reports whether the department is tracking data related to complaints involving people with intellectual disabilities.

Mental health professionals questioned the state's published numbers, given their knowledge of how many reports of potential harm each of Maine's more than 200 caretaker agencies are likely to make per year.

"There's no way that's credible," Estabrook, the oversight advisory board member, said.

They also questioned why the state was choosing to accept various cases, when they understand, based on the state's regulations, that it must look into every one.

"You do not want to send the message to the people out doing direct care or any kind of treatment … that you're going to be heavily triaging these allegations before they're even investigated," Estabrook said. That's because it could discourage them from reporting potential harm in the first place.

Kinnelly, with the Maine Association for Community Service Providers, served as the superintendent of Pineland after the original consent decree in the 1970s.

"It's heartbreaking," she said. "We're just not keeping the promise."

'We call them jumpers'

When cases are not resolved by the state, it means the employees who potentially put clients in harm's way are never entered into a state database that tracks misconduct, allowing them to find a new job at another agency.

"We call them jumpers," Noble said. "They jump to another agency, and there is no tracking this because there was never an investigation. Therefore it cannot be released to another agency."

It may also expose agencies to liability.

Peter Kowalski, CEO of John F. Murphy Homes in Auburn, said larger agencies with investigators on staff like his will look into allegations themselves if they don't hear back from the state. Otherwise, he said, the agency could be exposed to a lawsuit if it were to fire an employee without investigating.

For example: John F. Murphy Homes was asked by Adult Protective Services to investigate more than 30 allegations of abuse, neglect or exploitation it reported in 2014 and 2015. The state can delegate these investigations to an agency, but it is still required to issue a report outlining their findings.

The state accepted the agency's findings over the phone and never produced a final report, according to John F. Murphy Homes Chief Operating Officer Laurie Crane-Turton.

It's not ideal for an agency to look into abuse allegations without oversight from the state, said Frances Cartier of ISC for ME, a case-management company based in Bangor, which works with Belden.

"If there is an agency that looks at the reportable event as a personal insult, then it doesn't work," Cartier said. "I question the wisdom of the fox watching the hen house because if you are only doing investigations for your own agency, what is the result going to be?"

Her organization reported 58 allegations of possible abuse, neglect or exploitation between 2014 and 2016. She has seldom received calls from investigators following up, she said, and she hasn't seen a single final investigation report for any of the cases.

"If it were me not following the law, I probably would be put in jail and put out of business," said Cartier.

‘I feel bad for them’

The federal Office of the Inspector General within the U.S. Department of Health and Human Services confirmed in January it is investigating the state of Maine’s oversight of adults with intellectual and developmental disabilities.

The Office of the Inspector General did this recently in Massachusetts, where it found shortcomings in that state’s system for reporting and addressing incidents of suspected abuse and neglect. But the office said it could not describe the nature of the Maine investigation until it was complete.

The state’s position on the concerns about adult protective services is not clear.

Maine DHHS spokeswoman Samantha Edwards did not respond to five requests for comment.

Maine attorney general spokesman Timothy Feeley said the office is “unaware of any complaints about [Adult Protective Services] compliance or non-compliance with the regulation.”

But multiple providers and the developmental services oversight board say they rarely hear from Adult Protective Services about whether it even investigates, let alone when cases are closed. Caretakers assert the state is violating rules put in place after three decades of court orders meant to protect often-powerless residents.

“It was always the state’s responsibility, and remains to this day the state’s responsibility, to do all these adult protective investigations,” said Estabrook. “Nobody knows if they have been investigated at all.”

It is important for those running group homes or overseeing caseworkers to know the results of an investigation, so they can remove people from possible

danger, and prevent neglectful or abusive employees from continuing to work with vulnerable clients.

Like Geneva Belden.

Over the last couple months, an aide who was supposed to look after Belden fell asleep, according to Noble.

Then a family member tried to convince Belden to live with her. It didn't sit right with Noble, who did a background check and became suspicious that the family member was trying to trick Belden into paying the rent.

Belden's case manager from ISC for ME, which oversees her personal care and finances, and Noble from Branches both said they also reported these incidents involving Belden to the Office of Aging and Disability Services office in Bangor.

Again, nobody from Branches heard back, they say. Neither did ISC for ME, said Cartier.

For her part, Belden feels protected. But she's concerned others are at risk.

"There's a lot of people out there who need help, and they aren't getting it," Belden said. "And I feel bad for them. I think the state should do their job."