UNITED STATES DISTRICT COURT DISTRICT OF MASSACHUSETTS

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ROBERT SIMPSON RICCI, et al.)	Civil Action Nos.	72-0469-T (Belchertown)
)		74-2768-T (Fernald)
Plaintiffs,)		75-3910-T (Monson)
)		75-5023-T (Wrentham)
ROBERT L. OKIN, et al.)		75-5210-T (Dever)
)		
Defendants.)		
)		

MEMORANDUM IN SUPPORT OF WRENTHAM ASSOCIATION'S MOTION TO RE-OPEN CASE AND RESTORE TO COURT'S ACTIVE DOCKET

Following years of improved performance of its obligations under this Court's oversight and the May 25, 1993 Disengagement Order, Department of Mental Retardation ("DMR") efforts have fallen short in recent years. After two years of meetings in which the Wrentham Class made specific requests for information and policy changes to address shortcomings in DMR's service system, with little or no movement by DMR¹, the Wrentham Class is again compelled to seek the Court's oversight in requiring DMR to provide all Class members, regardless of where they reside, a safe and secure environment in which they will receive the care to which they are entitled under the Disengagement Order and their Individual Service Plans ("ISPs").

The late 1980s and early 1990s were the best of times for Class members and their guardians. Under this Court's oversight, funding became available for existing facilities to be

¹ On April 12, 2004, pursuant to Paragraph 7(c) of this Court's 1993 Order, Attorney Lisa Goodheart notified DMR of its failure to comply with the Order. The parties then met on May 28, June 7, June 8, September 15, 2004, and November 11, 2004 in an attempt to resolve the issues raised in the 7(c) letter, but to no avail. The agenda for the initial 7(c) meeting is attached hereto as Ex. 1. The agenda included staffing issues in the community; periodic independent review of community programs; facility closure issues and the Equal or Better Transfer Certifications. Each of these topics is a subject of the Wrentham Association's Motion.

rehabilitated and new group homes were developed. Class members who left facilities during this time period were assured of, and in fact received, care that was equal or better than that provided in the facilities. Having righted the wrongs that had persisted for decades, the Disengagement Order created the roadmap for maintaining all the progress that had been made. Those heady times are far behind us. Once again, the money is tight, other problems are considered more pressing, and Class members are suffering as a result.

The landscape, in many ways so different from what was presented to the Court in the 1970s, has much in common with that era. Neglect and substandard care is the inevitable result of an equation in which there are thousands of vulnerable people, and a state agency that is strapped for funds is doing the best it can. As was the case thirty years ago, the Commonwealth's "best" is plainly not good enough. This time, the majority of Class residents are not "warehoused" in large facilities. Instead, Class members who are the victims of sexual abuse, medication errors, physical assaults and outright neglect are three times more likely to be living in the community. The services provided by DMR through its point of sale ("POS") contractors are not equal to what they were fifteen years ago, and for many Class members the care they currently receive is far worse than when they first moved into the community. For many Class members, the care hasn't been "equal or better" for years. It is once again necessary for this Court to scrutinize DMR's performance.

I. Class Members In Community-Based Homes Need Protection From Their Caregivers Because DMR's Does Not Provide Adequate Staff.

There has been a consistent effort by DMR to decrease its involvement in direct care – fewer and fewer DMR employees actually provide hands-on care to Class members. Instead, the trend has been to have service coordinators monitor the care provided by POS vendors. Thus, the large majority of staff at community-based homes are contractors. There are almost 300 POS

vendors, many of whom operate multiple sites. As of June, 2003, there were a total of 10,768 DMR clients receiving services in residential settings that were not their homes.² Of that total, 2,156 individuals lived in state settings (992 in DMR-operated group homes and 1,164 in facilities).³ Accordingly, 8,612 individuals, or 80% of this population was cared for by POS vendors in 2003.

Of the 4,400+ Class members, approximately 25% continue to reside in intermediate care facilities for the mentally retarded ("ICFMRs" or "facilities") and approximately 75% live in the community, mostly in group homes. While the numbers are not clear, it is estimated that more than 3,000 Class members are cared for by POS contractors. That ratio is likely to be higher now, given the recent transfers from Fernald.

A. <u>Class members in group homes are subjected to higher rates of medication errors, sexual abuse and violence.</u>

The Disabled Persons Protection Committee ("DPPC") investigates claims of abuse against individuals with mental disabilities who are between the ages of 18-59 under Mass. Gen. L. c. 19C. In response to a public records request, the DPPC provided abuse summaries for fiscal years 2002 and 2003 for claims in residential settings where the abuse allegations were substantiated under the c. 19C requirements (i.e., abuse which results in serious physical or serious emotional injury to a person with a disability). 118 CMR 2.02. In FY 2002, there were 114 substantiated claims of abuse in residential, non-facility settings, and 121 substantiated reports in FY 2003. This is not to say that DMR facilities are immune from the same reports. In

² Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2004 (July 2005), Research and Training Center on Community Living Institute on Community Integration/UAP, College of Education & Human Development, University of Minnesota (Robert W. Prouty, Gary Smith, and K. Charlie Lakin, Editors) at 65, Table 2.2, available at http://rtc.umn.edu/docs/risp2004.pdf.

³ These figures differ from those reported in the DMR Quality Assurance Report, Fiscal Years 2002-2003, Ex. 2, which states that DMR population residing in community homes in 2003 was 12,417. The increase could be attributable the 1,550+ individuals receiving services in host/foster families. QA Report, Table 18, at page 32 (listing total community and facility populations).

fact, there were 14 substantiated reports of abuse in DMR facilities in FY 2002, and 11 in FY 2003.

Based on the DPPC data, the rate of substantiated abuse at DMR facilities in FY 2003 was 10/1000, but it was 12.4/1000 for individuals who resided in vendor-operated group homes.⁴ Because the population of individuals in community-based homes is 8,612, compared to 1,164 in the facilities (as of June 2003), if the rate of abuse were equal, then one would expect that the substantiated claims of abuse in community homes could be estimated by multiplying the substantiated reports at facilities by a factor of 7.4. Yet that is far from the case – the FY 2002 substantiated claims in which the victims resided in community-based homes exceeded 104 (7.4 x 14 substantiated reports in facilities), and the FY 2003 disparity is even greater. Using the 7.4 factor, one would estimate the number of abuse incidents at 81 (7.4 x 11), yet the actual number of substantiated reports of abuse in community-based homes in FY 2003 was 121 – 50% higher than would be expected. Because the DPPC complaints are confidential, there is no way to determine if Class members are among the victims, but on average, one out of every four DMR clients is a Class member.

There are other troubling disparities in two specific types of complaints. Most disturbing is the fact that 13% of substantiated complaints against POS vendors involved sexual abuse. Only 4% of the substantiated complaints against DMR care providers involved sexual abuse. Additionally, medication errors represent 7% of the substantiated complaints against POS vendors, but only 2% of the complaints against DMR as a care provider (including DMR-operated group homes). The summaries of the abuse can be graphic and shocking, at times heartbreaking because they demonstrate that this is such a vulnerable population.

⁴ Of the 121 substantiated reports of abuse, 15 involved individuals who resided at DMR-operated group homes, such that 106 of the reports described abuse suffered by residents of vendor-operated homes.

Substantiated claims of sexual abuse include the following:

PROVIDER	DATE	SUMMARY
Center Of Hope- QRADH	12/11/2002	ALV reported that ALAB had taken her into a ladies room on a community outing last June and put his hands down her pants and put his fingers in "her hole". ALV does not need assistance going to the bathroom. There should have been another staff person as well as other CLTS during this outing. When ALV reported this she was nervous, not crying but worried about being in trouble.
C-Marc Industries	5/7/2003	The ALV reported that another client "spanked me hard in my bum, and put his penis in my bum". This other client has a history of sexualized behaviors toward peers.
Community Enterprises	6/19/2003	ALV was sexually assaulted vaginally and anally at the workshop. The ALV was sent back to the workshop today where she met David again.
Community Resources For Justice	2/24/2003	ALAB entered the program through the ALV's bedroom window and they had intercourse twice. ALAB tried entering the program again last evening and he was caught.
Community Strategies	6/27/2003	ALV alleges that between the summer and October of 2002 that she had performed oral sex on the ALV several times, they had anal sex twice and vaginal sex once.
Community Strategies	6/27/2003	Last summer the ALAB raped the ALV sexually. ALAB gave the ALV \$200.00 to keep quiet.
Community Systems, Inc.	3/4/2002	There has been three incidents where another client has placed her hands inside ALV's pants. This same client has also walked in on ALV while he has been using bathroom. Since episodes ALV's has been more upset. Each time after incident ALV was crying.
Delta Projects, Inc.	11/16/2001	Although the ALV has previous recent suicide attempt (with shoelaces) and the ALAB was told to check her room daily to ensure that there were no dangerous items within her reach, the ALV was able to attempt suicide again with shoelaces. There is also concern for past rapes of the ALV during restraints and for the ALV's 100 pound weight loss since January of this year.
Eliot Community Human Services, Inc. Kelliher Cent.	10/21/2002	ALV has been touched inappropriately by another client on several occasions. The staff are aware of the other client's sexual behaviors toward the ALV, and are continuing to let him be in contact with the ALV. The other client has a history of this type of behavior.

PROVIDER	DATE	SUMMARY
Greater Lynn Mental Health And Retardation Assoc.	5/12/2003	The other CLT ran down the stairs and staff asked the ALV, "what was he doing in there". The ALV responded, that he was touching her. A female staff spoke to the ALV and the ALV claimed that the other client just touched her. The ALV told the staff that she asked the other CLT to stop, but he continued to touch the ALV on her legs and her private area, and also on her chest.
Greater Marlboro Programs, Inc.	11/18/2002	The ALAB raped the ALV over a 4-year period, holding her down using physical restraint to stop her from fighting him off, and threatening her that he would kill her if she told anyone. Several things have occurred with other clients, and the parents of the other clients dropped the charges.
Groom Company	1/17/2003	ALV reported to her mother that ALAB may grabbed/touched or fondled ALV's hand and rept doesn't know where else. ALV stated that "he tried touching me" but rept did not get specifics.
Grow Associates	5/28/2002	Another client told ALV to go into the bathroom and into a stall. The other client pulled his pants down and told the ALV to sit on his lap. He bounced her up and down and according to the ALV, he peed on her. It is unknown if penetration actually occurred. Day program did not notify anyone. ALV states this has happened before.
Kennedy Donovan Center	3/25/2003	The ALV was touched by another client on the penis. The other client is supposed to be supervised at all times as he is a pedophile. The ALAB had left the ALV and the other client alone.
Metro West Human Services Alternative, Inc.	10/4/2001	The ALAB was tugging on ALV to get up. The ALAB grabbed the ALV's breast and was rubbing and caressing it. The ALV would not get up and the ALAB said, "well I guess she doesn't want to go to the bathroom". Later the reporter#2 went back in the room and the ALV was crying.
People, Inc.	1/7/2003	While CLTs from residence were reporting that they don't like the ALAB, ALV advocated for himself, he is an adequate rept and he said that he was touched in an inappropriate manner. ALV said that ALAB touched him and he pointed to his penis and genital area and motioned up and down with his hand. Also pointed to his neck, and said "he scratched me on my neck and he teases me". ALV made a pinching motion on the back of his neck when he said this.
Riverside Community Care	1/22/2003	The ALV alleges that the ALAB put his hands on her, and touched her in the wrong place. ALAB touched the ALV and stated that it would be their secret. ALV stated that the ALAB

PROVIDER	DATE	SUMMARY
		put his hands on her vagina and that ALAB had his penis out and had her touch his penis. The ALV asked ALAB to stop, but he continued.
Riverside Community Care	1/24/2003	ALV initially said there was inappropriate touching. When staff sat down with ALV on 1/22 ALV wrote a statement that stated ALAB played with her vagina. ALV was lying down on the couch, ALAB took his penis out and put it inside her vagina and had sex with ALV. ALV said that this happened at 11 pm on Monday 1/20.
Riverside Community Care	1/27/2003	The ALV told the reporter, that Fri. Night (1/24/03?) She was touched by the ALAB. She said he was "messaging her breasts".
Seven Hills Foundation	8/6/2001	ALV reports that another client raped him on two separate days.
Seven Hills Foundation	11/22/2002	The ALV states that another client touched her two times today. Once at the center waiting to go to the workplace, and again at the workplace. Some staff both at the center and at the residence were aware of this behavior of the other client. Nothing has been done to alleviate this situation.
Seven Hills Foundation	11/15/2001	The ALAB should have been supervising the ALV at a community dance, where the ALV reports that another client had touched him while they were in the bathroom. The other client admitted he touched the ALV inappropriately. ALAB is aware of this ALV's HX of sexually acting out, even if they might not be aware of the other CLT's.
South Shore Mental Health	11/19/2001	ALAB was instructing ALV to go up to a male client (T.B.) and grab his genitals. After ALV would do what ALAB instructed - ALAB would then reprimand ALV in front of everybody.
Till/Toward Independent Living And Learning	10/31/2002	The ALAB came into the group home between 8am and 9am on 10/30/02, he went up to her room, and sexually molested her with his hand. The reporter states that the ALV said, he put his hand down her pants, and then inserted his fingers into her vagina, and also touched her breasts.
Vocational Adjustment Center	6/17/2003	ALV has reported that she and ALAB are having a romantic/intimate relationship. She reports that they meet at the mall and that ALAB brought her a pager. ALV also reported that they were intimate at her parents house when her parents went away.
Waltham	8/30/2002	The ALV said that the ALAB put his mouth on her breast last

PROVIDER	DATE	SUMMARY
Committee, Inc.		night. The ALV is nervous and upset about this.

Substantiated claims of abuse involving medical errors in vendor-operated homes include:

PROVIDER	DATE	ALLEGATION SUMMARY
Advocates, Inc.	3/31/2003	ALAB (alleged abuser) gave ALV (alleged victim) 13 sleeping pills over the course of the night. In the morning ALAB could not get ALV up. ALV is not prescribed this medication-ALAB brings the medication to work to give to ALV because she wants the ALV to be quiet and sleep.
Bay Cove Human Services	12/28/2001	The ALV was hospitalized for receiving the wrong medications. The ALAB never admitted to the error until the witness asked how the ALV was doing.
Communities For People/CFP	8/20/2001	ALV suffered severe seizure after being seizure free for 12 years. When his blood level for anti seizure medication was checked at the hospital it was far below therapeutic range. The only explanation is that ALAB was not giving ALV his medication properly.
Coop For Human Services	7/31/2001	This past weekend ALV went without his seizure meds and yesterday had a seizure at day program and at residence. ALV was taken to hospital - blood work indicated lack of med in blood stream.
Coop For Human Services	8/1/2001	ALV had 2 seizures yesterday 7/31/01. He went to ER. When they did blood levels there were questions in regards to ALV's meds- whether he was taking them. There are concerns over lack of follow with med, lab work and med monitoring.
Greater Lynn Mental Health And Ret. Assoc.	10/18/2002	ALV received an overdose of medication. ALV fell down and then vomited as a result of this overdose.
May Institute, Inc. (The)	8/26/2002	ALV was not given her seizure meds for several days, and had a seizure during transport from program to home.
May Institute, Inc. (The)	1/7/2003	On 1/5/03 ALV was brought into Lahey clinic due to an overdose of Levoxyl. She took approximately 35 pills. At clinic ALV was observed to have a bruise on chest. ALV reported that a house mate hits her and another kicks her. ALV reported not wanting to return home. Concerns as to how ALV gain access to all the pills.

PROVIDER	DATE	ALLEGATION SUMMARY
Multi Cultural Services	2/6/2003	The ALV is a diabetic, and was taking medicine for this. On 1/22/03, the ALV's blood sugar was 34. The ALV needed to be taken to Baystate Hospital. After returning to the residence, the doctor determined that the ALV would no longer need to take his medication, and that his sugar level would be monitored by diet. ALV was sick all week, sweaty, and running a 103 degree fever. Residential staff did not recognize that the ALV was as sick as he was, and that his condition worsened all week, culminating in the day program needing to get the ALV to the hospital today. ALV is still hospitalized.
North Suffolk Mental Health Assoc.	1/31/2002	ALV has a seizure disorder, but had not had a seizure in 11 years. He did not received Tegretol for two days on 1/23 and 1/24/02. On the evening on 1/24 and 1/25 he had a seizure. On 1/24 ALV was taken to ER. Residential nurse checked and noticed the issue with med.
Pioneer Developmental Services	4/22/2003	ALV has an ulcer/sore on his toe that his prior residential staff(ALAB) failed to seek medical attention for. ALV also has a bad urinary tract infection which ALAB should have noticed and should have sought medical treatment.
Reach Out Independence	12/17/2001	ALV takes Depakote for her seizure disorder. ALV was without medication for four [4] days, causing her to have seizures. Seizures started at 8:30 am and fire dept. did not receive an emergency call until 3 pm when the 3rd shift came on duty and called.
Road To Responsibility	6/17/2002	ALV was lethargic and ambulating was difficult because her legs were weak. ALV was taken to Jordan Hospital and blood work was done. ALV had levels of a medication in her blood that she is not prescribed to take.
South Shore Mental Health	12/30/2002	There has been on-going concern that the ALAB's agency was not giving the ALV his medications as prescribed. Yesterday the ALV had 3 seizures. He lost consciousness and his heart stopped. He is presently in a coma in the cardiac care unit.
Sullivan And Associates	2/28/2002	ALV was not given her meds at the residence because staff could not open the locked box. ALV takes asthma meds. ALV was sent to her day program without her meds. She was complaining of discomfort and was wheezing.

Physical abuse is also a common complaint. The summaries below describe caregivers who are violent, profane, neglectful, and downright cruel. The victims experience humiliation, serious injury, hospitalization, and even death. There can be no valid reason or excuse for any of the behavior described below. While it is impossible to rank the severity of the abuse, some of the most outrageous are in bold font.

Substantiated Neglect/Physical Abuse Complaints:

PROVIDER	DATE	SUMMARY
Advocates, Inc.	7/22/2002	Alleged Victim ("ALV") has had stitches under his chin and on the back of his head numerous times. ALV is a 1:1 at day program. Reporter of Complaint ("REPT") feels he should also be a 1:1 at residence. Reporter has observed house director pick ALV up and have him walk on his own in front. This morning ALV arrived with a fat lip. From hearsay REPT heard that a staff punched ALV in the mouth. A couple of weeks ago ALV returned to day program with bruises on wrist.
Advocates, Inc.	7/23/2002	The ALV is possibly being neglected. There have been little round marks on his wrist like his hands have been held together, like friction marks. ALV has also fallen and had stitches on the back of his head and under his chin. On 7/22 ALV came in with swollen lower lip and it looks infected. ALV also has pneumonia.
Advocates, Inc.	8/12/2002	REPT states that the ALV was left in his bedroom for several hours, covered in feces and urine. The ALV kept saying he was sorry about this situation, and was very upset, even though it was not his fault. The ALV appears to be much redder and sore, in the area where he was wet.
Advocates, Inc.	12/14/2001	ALV was observed with bruise. ALV was taken to hospital. ALV has fractured rib and 2 abrasions. It is unknown how the injuries occurred.
Anodyne, Inc.	8/29/2002	ALAB is employed with the Anodyne Agency, at respite location/foster care program. The ALV's wife passed away recently, and the ALV was placed there. RPTR stated that DMR has been contacted by the reporter, and DMR has not returned calls, nor have they responded to these recent injuries and lack of supervision by the ALAB, and the ALAB's agency. RPTR has also attempted to contact the ALV's service coordinator. Numerous times, and still no response.

PROVIDER	DATE	SUMMARY
Bamsi/Brockton Area Multi Services	10/7/2002	The ALV went to the day program crying and was flustered. The ALV stated the ALAB hit her with a belt on her back because she was angry. The ALV had two welts above the bra and one below the bra about 1-3 inches in length. There were marks on her hip, but they could be from the depends that she wears. The ALAB is not scheduled to work.
Berkshire County Arc	4/4/2002	The ALAB was seen holding the ALV down and forcing a spoon into her mouth to give her meds. The ALV's lip was cut in the process.
Berkshire County Arc	6/6/2003	ALV got a hold of some Pinesol in the middle of the night and ingested some of the liquid. ALV is currently in intensive care.
Berkshire Meadows	8/6/2002	Screened in for omission. The ALV was choking on 2 latex gloves and died.
Better Community Living	3/21/2002	The ALV received a large bruise on his shin. Staff did not know how the ALV received his injury. Staff did not seek immediate medical attention for the ALV. REPT #2 stated that ALV's whole leg is bruised and is concerned about staffing in the house.
Bfair/Berkshire Family And Individual	5/28/2002	Yesterday there was a disagreement between ALV and ALAB. ALAB denied ALV access to the phone and she yelled at him. ALV was emotionally upset about this. There have been other times that ALAB has yelled and screamed at ALV. ALAB is mean and belittles ALV. ALV is quiet and withdrawn when ALAB works.
Bfair/Berkshire Family And Individual	1/3/2003	ALV was bitten by another client, who requires 1:1 supervision, and has aggressive behaviors. ALAB had left the other client unsupervised when the incident occurred. ALV sustained bruising from the bite.
Cadmus Lifesharing Assoc. Inc.	10/16/2001	While on hike trip ALV wandered off. ALV was missing from 4:55 pm till the next day at about 10 am. ALV was taken to hospital to be checked. She was checked and discharged. ALV seemed fine- both physically and emotionally.
Charles River A.R.C.	9/3/2002	ALV was left unsupervised, and sustained a black eye. ALV was left alone with another client who has a history of assaultive behavior. All clients in the residence are not receiving proper medical care. RPTR feels that the agency is covering up things, and that the clients are at risk.
Co-Op For Human	12/2/2002	That there was no one at the residence to see that the ALV got into the residence to let him in. According to the driver, the

PROVIDER	DATE	SUMMARY
Services		ALV got upset about this situation and started to beat up on the driver, and other clients in the van. ALV broke the nose of another client in the van, and allegedly beat up on the van driver. ALV is known to be unstable about any transition with his home & residence. This is a behavior that staff were aware of, due to this occurring in the past. This was clearly noted in his last ISP.
Delta Projects, Inc.	12/17/2002	Several clients and staff have witnessed the ALAB abuse the ALV. The abuse includes kicking the ALV while ALV was laying on the floor, throwing sneakers at the ALV and then putting the ALV in the basement, ALAB then put his foot in the ALV's face. The ALAB has been suspended. The ALV was seen with bruises on his back.
Gmpi/Greater Marlboro Programs	5/27/2003	The ALAB thought the ALV was in the car and began to drive away. The ALV was standing by the side of the car and the ALAB ran over the ALV's left foot. The ALV was taken to the ER. The ALV's foot was red and swollen, but was not broken. The ALV needs to keep his foot elevated.
Greater Lynn Mental Health And Retardation Assoc.	3/10/2003	The supervisor stated that the ALV's little toe on one foot was black, and smelled very bad. The house Mgr. said that he thought it was black fungus or gangrene. RPTR states that the Dr. disclosed to the guardian, that the ALV could lose part of the toe, as a result of the injury or infection, cut, crack in the skin, that the staff did not treat in time.
Growthways, Inc.	8/21/2002	ALV sustains frequent injuries due to falls. ALV continues to fall and sustain injuries. Most recently on 8/19/02 ALV had a swollen lip and arrived at day program with a bloody nose and shaky. He was taken to ER. ALV is totally neglected by vendor and DMR- they have done nothing to improve situation and prevent ALV's injuries.
Horace Mann Educational Associates	8/21/2002	On 8/5 there was a car accident. ALV needed to be removed with jaws of life. ALV sustained an injury to right leg that required surgery. On 8/20/02- REPTR visited ALV at a nursing home. ALV reported she was not wearing a seat belt at the time of the accident because seat belt was broken.
Horace Mann Educational Associates	2/22/2002	ALV has a body check every morning at the day program because ALV has had several injuries and ALV's mother is concerned about ALV and this is part of his support plan. On 2/22/02 it was discovered that ALV has 2 large, orange sized red splotches on his back with a red strip in the middle connecting the marks. The marks are half way up ALV's back. REPT stated that it looks like a friction burn.

PROVIDER	DATE	SUMMARY
Horace Mann Educational Associates	1/23/2002	The ALAB put the ALV in his wheelchair in the bedroom and locked the wheelchair. The ALAB then propped the ALV's legs up on a chair so he would not be able to move himself. Staff are not supposed to do this. The reporter does not know how long the ALV was left like this. RPTR also stated she is unsure if this actually happened or not. The residential director told RPTR this happened.
IPP/Institute For Professional Practice	9/24/2001	Police were called due to a man found lying on side of road. ALV was wet, hungry and thirsty. ALV had cuts on hand and scratches on legs. Police knocked on doors and located ALAB who stated that ALV belonged to them. Ambulance had arrived they felt ALV should be taken to hospital. ALAB disagreed and stated ALV was fine.
Latham Center, Inc./Gilbough Center	7/19/2001	The ALV duct taped shut the mouth of another client at the direction of the ALAB. The ALV said she felt weird placing tape over another clients mouth. She said she did what the ALAB # 1 told her to do because she was afraid of upsetting the ALAB # 1. The ALV expressed being uncomfortable and confused during and after the incident.
Leslie Educational Alternatives	2/12/2003	ALV has known OCD behaviors with regard to coffee. ALAB made ALV a cup of coffee and placed it on the counter away from ALV. ALV grabbed a cup of coffee and spilled it on his thigh. Blisters kept popping up the next day and ALV was taken to ER. Visiting nurse was sent in twice daily to dress the wound. VN requested that staff take ALV to ER last night. ALV is currently hospitalized and is having skin grafts today.
Martha's Vineyard Community Services	3/12/2002	On 3/11/02 ALV slapped ALAB in the face very hard. ALV went after ALAB a second time. ALAB picked up the ALV off the floor and stated "don't you ever put your hands on me again." REPT checked ALV, underneath ALV's left armpit, there was a long red mark. No other apparent injury at this time. REPT spoke with ALV and he stated that he was just joking with the ALAB and apologized after the fact.
May Institute, Inc. (The)	5/7/2003	The May Institute, Inc. is not providing adequate care and safety to the ALV. ALV has been brought into the police station 4 times with various scratches. Staff will not disclose additional information to ALV's father and police are looking into it. Police are having a difficult time getting information from May Institute Staff, but believe that the injuries are being caused by another client.
North Suffolk	6/20/2002	The ALV stated that she found a lid from a can and cut herself

PROVIDER	DATE	SUMMARY
Mental Health Assoc.		with this. The ALV arrived at the program with superficial cuts and abrasions on her arms. Reporter is very concerned because the ALV is supposed to be on one to one/supervised at all times. ALV also has a history of this type of behavior.
North Suffolk Mental Health Assoc.	7/26/2001	ALV arrived at the day program having difficulty exiting the van, and staff had to assist with a wheelchair. The ALV was shaking and trembling. The ALV had a temperature of 106. ALV was taken to the ER and admitted.
Rehabilitative Resources, Inc.	5/13/2002	ALV is currently at Norwood hospital. She is on a morphine drip. ALV is in complete renal failure. Staff who brought her in this weekend reported that ALV had not been eating or drinking for the past month.
Riverside Industries	6/10/2002	When REPT arrived ALV was screaming that she had a bad day at work. ALV stated that she wet herself in the morning. ALV said Angela was upset because she wet herself. ALV said nobody changed her. ALV remained in wet clothes all day. ALV did not eat her lunch or snacks. ALV cried all the way home. ALV said she felt "yucky."
Seven Hills Foundation	6/25/2002	ALV's behaviors have been increasing over the last two weeks. ALV is adamant when ALAB is on that she doesn't want ALAB near her. ALV stated that she was dragged across the floor by ALAB and she cut the bottom of her feet. ALAB cleaned up the blood. Staff found a large burn mark on ALV's back that was 3" x 1/2" and 3 smaller marks which all appear to be friction burns.
Seven Hills Foundation	5/2/2003	ALV has unexplained injuries. He has a broken arm, which will require surgery and bruising on his face. Staff are unable to explain the injuries. Reporter is very concerned for the ALV and reported that ALV never suffered any injuries or broken bones until placement at this residence.
Seven Hills Foundation/ New England Residential S	9/13/2001	ALV is not receiving appropriate care. ALV sustained sore in bottom. When REPT visited on Tuesday 9/11/01 ALV was noticeably very lethargic. ALV complained of being very tired. ALV was still in his pajamas. ALV had not been showered or shaven. ALV smelled. It was about 2 pm. ALV had not used coughalator that enables him to breathe easier. Blood pressure was low, respiration high.
South Shore Mental Health	3/21/2003	ALV's toenails are very long. ALV's glasses broke last summer and staff has failed to make an appointment to get new ones. ALV has poor depth perception and has been having trouble functioning without his glasses.

PROVIDER	DATE	SUMMARY
South Shore Mental Health	6/13/2003	ALV has been having behaviors due to a possible med error. ALV was in discomfort, he was walking with a hunch and when he stopped he would stand in a marching position. ALV was yelling at people and required help with normal activities. ALV's arm muscles were tight and he was having difficulty swallowing.
South Shore Mental Health	9/12/2001	One staff person told REPT that ALAB has a stick and he would tap ALV on the leg with it and told ALV that he was going to hit ALV on the head with it if he didn't comply. REPT doesn't believe that ALV has bruising on his leg. Other staff have heard that ALAB has a stick that he threatens the clients with. REPT stated that no one has actually seen him do this but have heard him threatening clients. Several people called REPT and told her that ALV had bruises on his lower back, a mark on his upper left arm, looks like a grab mark. The day program had called REPT about this and staff from the residence has told the REPT that the ALV has little bruises all over his body.
South Shore Mental Health	7/1/2002	The ALAB should have been ensuring that the pacemaker was checked every 3 months, but she did not have it checked for 2 years. The ALV's pacemaker battery was found to be dead. She collapsed and "almost died."
South Shore Mental Health	1/24/2002	ALV's right armpit appears to be infected and oozing. The area looked wet, there was dried, green drainage on the brace lining (ALV has a fracture and is wearing a brace). If someone was bathing ALV properly they should have noticed the infected area. Infection could have been from friction and skin on skin contact.
SWCRC	11/6/2002	ALV was left alone for 4 hours. ALV is only allowed 2 hours of unsupervised alone time. A few weeks ago when the same ALAB was on duty the ALV was in the kitchen heating some food and when he took a bowl out of the microwave he put it on his lap and received burns. ALV went to the ER. ALAB was in the other room when this happened and ALV is not allowed to cook anything on his own.
SWCRC	4/11/2002	On Saturday 4/6/02 ALAB was verbally and emotionally abusive to ALV. ALV was incontinent with urine and with bowel. ALAB called ALV "fuckin bitch." ALAB did this to ALV more than once. ALV started escalating behaviors-ALV stomps her feet, kicks and slams door-after incident ALV was doing all these things.
The Consortium	10/10/2002	The ALV is not able to understand well, and communicate very well. The ALV was not seen leaving the house, fell, and hit his

PROVIDER	DATE	SUMMARY
		head, and scraped his knee badly. The ALAB appears to have let the ALV out of her sight, and he injured himself. ALAB-2 and ALAB-3 appear to have minimized the incident, and did not take appropriate steps to ensure the ALV's health and safety.
Till/Toward Independent Living And Learning	12/19/2002	On or about 8/9/02 when changing the ALV for hygiene care "several open red areas" were observed on the "right side of his groin". The ALV's father had reported that the ALV complained that night staff were leaving him wet. This information was noted in the agency nursing log.
Till/Toward Independent Living And Learning	10/21/2002	When REPT went to visit ALV - ALV could not be located. ALV was found in a closet- he had his left orthotic (arm support) off of his arm and his arm was bleeding. ALV is known to bite himself which is why he has to wear the orthotic. ALV is supposed to be supervised.
Vinfen	6/11/2002	ALV arrived at day program and staff that drove ALV in stated that there had been a restraint at the house and ALV had a carpet burn on her chin. The carpet burn 1" x 2" ALV also has a bruise on top of left shoulder which looked like finger marks. Company policy is no face down restraints.
Vinfen	10/30/2002	The reporter states that the ALAB was on top of the ALV, pulling her hair, and saying to the ALV, "how do you like it when someone pulls your hair". The ALAB and the reporter discussed this and the ALAB swore at the reporter, and asked where she was when the ALV was doing the same thing to the ALAB. Screened out - based on the information received, there is no indication that the ALV sustained a serious injury. A mistreatment/administrative review is recommended. DPPC should be contacted if it is found that the ALV did sustain any bruising or other injuries.
Vinfen	11/8/2001	ALV arrived to the day program on 11/08/2001 with a bruise on his arm, back/shoulder area, upper arm area. A scrape on his right inner thigh. ALV also had broken blood vessels all over his face. ALV also had a bruise on his right eye lid. ALV also has a scratch behind his left ear. ALV is stating that staff restrained him on 11/07/2001 but staff stated that ALV had a good night. ALV does not have self-injury behavior.
Vinfen Corp.	6/3/2002	When ALV arrived this morning 6/3/02 he had massive bruising on upper chest area and left arm. It is swollen. ALV has difficulty weight bearing on arm. Program director was called and should be arriving shortly.
Vinfen, Inc.	3/10/2003	During the course of an investigation involving ALV, reporter noticed additional injuries on the ALV, including what appeared

PROVIDER	DATE	SUMMARY
		to be a friction burn to the left side of ALV's face, near her left ear. There was also a small dime sized bruise to the left side of ALV's face, that was a yellowish, green color. ALV also showed the reporter a 4-5 inch round bruise just above her left knee on the outer aspect of her leg. She indicated that "Tony hit me."
WMTC	9/21/2001	ALV was outside at 6:00 am and ALAB didn't notice ALV missing until 8:00 am. ALV was found laying in the mud in a field behind the residence. ALV was quite disoriented and suffering from some hypothermia. ALV was seen at the ER. Body temperature was 95. ALV has some infection in his eyes and scratches on his arms.

B. Class member abuse in community homes is much worse than in facilities.

In contrast to the examples of abuse that took place in vendor-operated homes in the recent past, the overwhelming majority of substantiated claims of abuse at facilities is the result of falls, usually from wheelchairs, or out of bed, or because the Class member was not closely supervised. One Class member went "awol" from a facility for one hour – a far cry from the three reports summarized above where the individuals were gone for hours, including overnight, with caregivers who apparently did not notice or care. The abuse against DMR clients in community homes is the result of malfeasance – it is conduct that is intended to cause harm, or represents gross recklessness in the care of individuals who need to be constantly monitored in order to be safe from themselves, other clients, or abusive staff.

C. <u>DPPC fulfills its mission despite budget cuts</u>.

In 1993, the year this Court entered the Disengagement Order, the DPPC hotline received 3,293 calls. In 2004, the hotline received 5,979 calls – an increase of more than 80%.⁵ At a time when its call volume set a new record, DPPC was forced to reduce its staff by 21%. As a result, DPPC staff investigated only 5% of the abuse complaints, and referred the others to other state

⁵ DPPC 2004 Annual Report, p. 4, Ex. 3.

agencies for investigation. In fact, the DPPC referred out more than 60% of abuse reports to the DMR to investigate. While the referrals to the DMR are the result of practical necessity, it is difficult for any entity to police itself as strictly as would a third party. The increase in calls to the DPPC hotline correlates with the DMR's increased reliance on POS vendors as direct care providers – outsourcing has its price.

The DPPC determined that the abuse allegations in 880 of the complaints it processed in 2004 involved conduct that is criminal in nature. Of these complaints of criminal conduct, 42% involved physical violence, and 40% involved sexual assaults, and 11% involved larceny. Given that approximately one out of four DMR clients is a Class member, it is quite likely that more than 200 Class members were victims of a crime in the recent past. Criminal charges were brought in 130 cases, including the following:

June 2004 investigation of sexual assault on a 42 year old woman with developmental disabilities, who is both deaf and non-verbal. The suspect, the van driver who drove the woman to and from work every day, admitted that he would pull the van over at a soccer field on the way back to the woman's home and have sexual intercourse with her. He admitted that he raped on five separate occasions.⁷

The DPPC also investigated 23 deaths, and substantiated that five of the deaths were the result of abuse. Four other death investigations are "pending." The State Police Detective Unit assists the DPPC in its investigations and reviews all complaints to identify criminal conduct. According to the Commander of the State Police Detective Unit at the DPPC, cases that are forwarded to local police or the district attorneys' offices to consider criminal charges are

⁶ <u>Id</u>. at p. 12.

⁷ Id. at 15.

⁸ Id. at 5.

⁹ <u>Id</u>. at 11.

classified as "pending" or "open" cases. There is no hyperbole in stating that DMR clients are dying at the hands of their caregivers.

D. <u>DMR Views Results Through Rose-Colored Glasses</u>.

Currently, more than one-quarter of all abuse, neglect or mistreatment allegations investigated by the DPPC are substantiated. That means that hundreds of individuals receiving services from DMR and its POS vendors are being abused, neglected or mistreated. Even more compelling is the fact that the DPPC's substantiation rate was 22% in fiscal years 2000-2002. DPPC's 2004 Annual Report notes that there were 1,779 claims of abuse investigated that year, of which 252 were substantiated in 294 were "pending." If the "pending" cases are removed from the total, the substantiation rate for 2004 would have been 27%. If all "pending" cases from 2004 were counted as substantiated, the DPPC's substantiation rate would have been 31%. Either way, the substantiation rate has increased significantly from the stable 22% rate in the early 2000s.

The DPPC data is quite damning. DMR, however, takes a different view of the situation. Last year, DMR released its first ever Quality Assurance Report. The DMR Quality Assurance Report ("DMR QA Report"), Ex. 2, covered fiscal years 2002-2003 (the same years that were the subject of Wrentham Association's public records request to DPPC), and it contends that the number of substantiated complaints of abuse has shown a "somewhat steady decline." The DMR, however, failed to include the number of open investigations in its calculations.

In 2002, the DPPC investigated 1,351 complaints, and substantiated 431 of them. Forty complaints are still open. In 2003, DPPC investigated 1,257 complaints, and substantiated 358

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¹⁰ See DPPC Combined Annual Report 2000-2001-2002, at 10, Ex. 4. The table of data relied upon to calculate the substantiation rates identified the rate as 262 claims substantiated out of 1,171 investigations in 2000; 302 claims substantiated out of 1,369 investigations in 2001; and, 331 claims substantiated out of 1,493 investigations in 2002.

¹¹ DPPC Annual Report at 7, Ex. 3.

of them, but the QA Report notes there are still 109 open complaints. To its credit, the DMR noted that the large number of open complaints contributed to the lower substantiation rate in 2003. DMR also recognizes that "the vast majority of open cases are those that were deferred to law enforcement agencies," and that the DPPC has placed an increased emphasis on referring cases out for prosecution. Had the DMR treated the "open" or "pending" cases as substantiated, the substantiation rates would have been 35% and 37% for 2002- 2003, at least according to the information set forth in the DMR QA report. These rates are comparable to the 38% substantiation rate for 2001 cited in the DMR QA Report.

Additionally, the substantiation rates should not be viewed in isolation. DMR likely chose to focus on the substantiation rate because it masks the increasing numbers. The call volume to DPPC has increased every year, such that it is conducting more investigations. Even if the substantiation rate is stable, more DMR clients are being victimized. DMR should not be allowed to hide its head in the sand any longer. Something is critically wrong with this service system, and DMR must do more to protect Class members and all of its clients.

Another example of the positive spin that DMR seeks to cast on bad news is reflected in its discussion of why "critical incident reports" doubled between 2001-2003 (12.3 reports per 1000 served in 2001 versus 27.3 reports per 1000 served in 2003). Such reports are filed when there are "unusual incidents that place individuals at risk in order to provide DMR with a mechanism to track incidents and assure appropriate corrective actions are taken." Incidents

¹² DMR QA Report at 16.

¹³ Neither the 2001 substantiation rate nor the total number of investigations for that year, set in Table 4, at p. 15 of the DMR QA Report match the data presented in the DPPC's report covering 2001. It may be that DMR is providing information only on the investigations it performs on behalf of the DPPC, since the DPPC's staffing has been cut repeatedly in recent years.

¹⁴ DMR QA Report at 20-21.

¹⁵Id. at 18-21.

associated with "inappropriate behavior," (a euphemism for sexual contact), criminal activity, assault, and accidents were the most frequent subjects of critical incident reports for all three years.

DMR goes to great lengths to rationalize the 120% increase in the rate of critical reports between 2001 – 2003. DMR repeatedly states that the increase in these reports is most likely because an increased emphasis on reporting, "not actual changes in the frequency of real incidents." Even if that were true, that distinction provides no comfort to Class members, since it means that these types of incidents, including inappropriate sexual contact and physical abuse, have always been occurring – but that it is only recently that this misconduct has been reported to DMR. At least now the incidents are reported, but that does not guarantee that DMR will actually take steps remedy the problem.

D. <u>Criminal Background Check Violations.</u>

It is worth repeating that direct care providers have the most access to, and control over, community home residents. It is for this reason that criminal background checks are required for all employees who will be providing services to this at-risk population. Yet the number of audited providers with CORI violations has increased, and the violations are confined to a small group of POS vendors. There were 20 vendors with a total of 200 violations – that means that vendors could not prove that they had run the CORI background checks on 200 direct care workers. The DMR QA Report is silent on whether DMR required those 20 vendors to verify that the 200 employees are, in fact, cleared to work with such a sensitive population. DMR's lack of follow-through demonstrates a systemic failure in protecting residents, including *Ricci* class members, from harm.

^{16 &}lt;u>Id</u>. at 20.

In another example of DMR taking a very optimistic view of its findings, it states that the vendors' inability to document that it performed CORI checks "does not necessarily mean that a CORI was not requested and completed." Unfortunately, even if CORI checks are done, they may be of limited value. In February 2005, the Massachusetts Inspector General faulted the process that social service agencies, including the DMR, use to check criminal backgrounds. During the ten year period reviewed, there were 284 reported cases of abuse in which the abuser did not live in Massachusetts. State agencies only check on applicants' criminal records in Massachusetts, so anyone with a criminal record in a surrounding state would escape review.

E. <u>DMR Hides Behind Unfounded "Confidentiality" Concerns To Stonewall Inquiries.</u>

DMR wants Class members, their guardians, Class counsel, and this Court to believe its statements that staffing is "adequate" and that despite the deep budget cuts and challenges the agency faces, it is meeting its obligations under the Disengagement Order. It would be easier for the DMR if no one tried to test those statements by looking at documents or statistics it maintains. The House Committee on Post Audit and Oversight Bureau ("HPAOB") conducted a multi-year review of DMR, with a report released in 1997. The review was precipitated, in part, by two high-profile cases in which individuals who received services from DMR lived in squalor and subjugation while their "caretakers" lived off their SSI checks, and two other cases in which individuals with mental retardation died while in DMR's care — one drowned and the other choked to death on his diaper. The HPAOB concluded:

DMR protects itself from public scrutiny and from accountability by delay tactics and asserting confidentiality of DMR clients and client records to prevent oversight of its actions. DMR has used confidentiality of clients and client records as a means of making oversight of the agency extremely difficult. DMR's

¹⁷ DMR QA Report, 18.

¹⁸ Boston Globe, Feb. 24, 2005, IG Faults Screening of Caregivers.

methods of operations, particularly their excessive and subjective redaction of documents and delays of document production, make identifying systemic problems difficult and tremendously time consuming. . . . The Department's current regulations on the creation, maintenance, destruction, and access to records, 115 CMR 4.00 et seq., take client confidentiality to the extreme. This ultimately allows them to hide poorly done work, and results in client safety being jeopardized.¹⁹

Under Commissioner Morrissey's leadership, the DMR has been much more responsive to both *Ricci* stakeholders and other state or legislative entities with oversight responsibility. Yet, DMR continues to deny stakeholders access to the most basic information, contrary to the requirements of the Disengagement Order. For example, Karen Mutanen, a *Ricci* class member who left Wrentham in 1979, was found dead, with her mother who was also dead, in a trashinfested house in West Roxbury in 2000. Karen's cause of death is still unclear. Many Wrentham Association members believe that Karen's mother died first, and that Karen eventually died because she did not know how to care for herself. Karen didn't die from abuse, or because of a medication error. Nevertheless, DMR likely has some culpability in her death. Karen never received any services or medication from DMR in the years prior to her death because DMR claimed that her mother refused services in 1986. DMR apparently never made any other attempt to contact Karen after 1986 to determine if there was a need or desire for services.

Even if Karen had refused services in 1986, DMR's policy of ignoring Class members for years after services are refused violates the Disengagement Order. DMR is required to substantially care for Class members for the rest of their lives. Following Karen's death, the Wrentham class representative asked DMR for a copy of the letter in which Karen's mother refused services. DMR refused to provide it – claiming confidentiality. In July, 2000, Class

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¹⁹ Report on the Massachusetts Department of Mental Retardation: An investigation by the House of Representatives Post Audit and Oversight Bureau, including "Are you sure about this guy?" An analysis of the abuse of two mentally retarded men in Raynham, Massachusetts (1997) at 19.

Counsel formally requested the letter. DMR responded three months later – admitting that it was "not in possession" of a letter from Karen or anyone acting on her behalf, refusing DMR services. DMR took the position that class counsel was not entitled "to inspect the records of a deceased DMR consumer." Ex. 5. DMR eventually provided a redacted hand-written note from Karen's mother apparently in response to a service coordinator's request for a "progress note" on Karen. Nothing in that letter could be read as refusal of services. Indeed, Mrs. Mutanen wrote, "Due to a back injury, I need help." This is another example of DMR hiding behind "confidentiality" to prevent disclosure of its error, and Karen Mutanen fell through the cracks and died as a result.

II. DMR Does not Provide Adequately Trained and Experienced Personnel in Vendor-Operated Group Homes.

Pursuant to Paragraph 2(c) of the Disengagement Order, DMR is required to provide "[s]ufficient adequately trained and experienced personnel . . . to substantially meet the needs set forth in each class member's ISP." DMR is not complying with this provision because it and its vendors have failed to provide adequate salaries and benefits to the staff who care for Class members. There is no escaping the effect of inadequate resources. There are systemic deficiencies in the provision of care, including escalating turnover among POS vendors, continuous vacancies in staff positions, decreasing levels of service, and significant risk of personal harm and injury to Class members. These problems will only be magnified as Class members continue to age and develop increased therapeutic and medical needs.

A. DMR staff cuts have decreased Class member services.

The percentage of DMR's own professional staff such as counselors and speech and other allied health therapists is relatively small given the many thousands of DMR clients, including Class members. According to the 2004 listing of staff and budget codes for the DMR, fewer

than 50 full-time equivalent psychologists are available to support the entire population and only approximately 18 of the psychologists are PhD level professionals. There are fewer than 23 allied health therapists, most of whom are occupational therapists. The sheer numbers (e.g. 50 full-time psychologists for 10,000 individuals) demonstrate that the staffing levels are inadequate and only getting worse.

The caseload for human service coordinators ("HSC") is also quite high, as described in the letter filed on behalf of the Service Employees International Union, Local 509 ("SEIU") in this case one year ago. DMR describes service coordinators as the "first line of quality assurance" and the means by which it provides accountability and oversight for the care provided to Class members. Service Coordinators now carry caseloads in the 50's, covering individuals who are widely dispersed. They also prepare ISPs. A number of Wrentham guardians have provided counsel with copies of their wards' ISPs. Some do not even include a reference to the fact that the person is a Ricci Class member, so apparently many of the service coordinators themselves do not understand that DMR is responsible for all care, at no cost to the Class member or guardian.

DMR itself agrees that there is a pressing need to recruit, train, hire and retain qualified staff in the POS system, yet continues to claim that current staffing is "adequate." ²⁰ This position is nonsensical – if current staffing levels are adequate, then there would be no pressing need to recruit, train and retain qualified staff. DMR's assertion of the adequacy of staffing levels is based on the periodic reviews it conducts, but DMR has declined to provide the Wrentham Association with that information due to "privacy concerns." While DMR has made

²⁰ Marianne Meacham, DMR General Counsel, July 1, 2004 letter to Attorney Lisa Goodheart, Wrentham Class Counsel, at 6, Ex. 6.

efforts to recruit staff through advertising and other means, such efforts will not address the problem, because it is based on inadequate salaries, not lack of recruitment efforts.

Even as it experiences difficulty in recruiting and retaining employees, DMR continues to eliminate positions. Since 1993, due to continued budget constraints, DMR direct care staff have also been cut back. The SEIU states that 543 personnel reductions have taken place, including 162 reductions plus 225 early retirements offered and accepted in FY2002 followed by an additional loss of 156 staff members who accepted early retirement in 2003. In 2004, DMR eliminated 20 non-supervisory HSCs, leaving approximately 380 to serve a population of approximately 34,000 individuals and their families. Service coordinators are supposed to serve as the safety net for Class members. Given how far they are stretched by dangerously high caseloads, it is not surprisingly Class members fall through the cracks.

B. <u>High turnover rates make the understaffing problem worse.</u>

Turnover is a well-documented concern with service providers, and is a direct result of low compensation. Turnover among direct care workers is 40% nationally and up to 50% in some places.²¹ Contributing to this problem is competition from other service-related industries such as restaurants, hotels, travel and telemarketing, which can provide higher pay and less stress.²² With wage rates as low as \$9.50 per hour, it is not surprising that "[s]ervice providers often compete with McDonalds and Wal-Mart for workers, resulting in a work force that is not only transient but also less apt to bring basic literacy skills to the job."²³

²¹ James Stergios, "Social Services Network Needs Tune Up," *Boston Herald*, May 20, 2002 at 21.

²² Amy Hewitt and Susan Ormell, "People Need People: The Direct Service Workforce," Impact Vol. 10, No. 4, pg. 1 (The College of Education and Human Development, University of Minnesota, Winter, 1998).

²³ James Stergios, "Social Services Network Needs Tune Up," *Boston Herald*, May 20, 2002 at 21.

Average turnover rates in private community residential settings are from 57% to 71% per year nationwide.²⁴ "In addition to effecting service quality and consumer satisfaction, high turnover rates increase costs, decrease quality of communication between staff, decrease continuity of supports, increase administrative costs, increase job stress, reduce productivity and satisfaction, and lead to staff shortages."²⁵ Fundamentally, "[t]here is a national crisis in securing an adequate supply of qualified direct support professionals, and the inability to recruit and retain qualified direct support workers threatens the fulfillment of the national promises made [by] law, and in judicial and regulatory interpretations of those laws."²⁶ The problem is caused by low salary, wages and compensation. Studies of this crisis "found that private community agency wages for direct support professionals equal three-quarters (75%) of those of state employees in the same roles and barely half (55%) of the state's average wage."²⁷ Despite this, most states, including Massachusetts have only made modest efforts to increase compensation, and even these improvements have been rolled back because of budget cuts. Thus, any progress that had been made after the 1993 Order is being lost.

In 1996, the average direct care service wage of \$8.06 per hour in Massachusetts was below the federal poverty guideline for a family of four.²⁸ Although the current workers in

²⁴ Amy Hewitt and Susan Ormell, "People Need People: The Direct Service Workforce," Impact Vol. 10, No. 4, pg. 1 (The College of Education and Human Development, University of Minnesota, Winter, 1998).

²⁵ Id

²⁶ "Shortage of Direct Support Professionals—A Growing Crisis in the Developmental Disabilities Community," by AAMR, available at http://www.aamr.org/Reading_Room/pdf/direct_support_workforce.pdf. See also ADDP Charts on the impact of the salary reserve on workers funded through the DMR, attached as Ex. 7.

²⁷ Id

²⁸ The State of the States in Developmental Disabilities: 2002 Study Summary, David Braddock et al., Coleman Institute for Cognitive Disabilities, University of Colorado, 2002, at 90, Table 2.4., at 89. Relevant portions attached as Ex. 8.

private programs may not be officially below the poverty line, ²⁹ such low salary levels make it difficult to live in the Boston metro area, which has the fifth highest cost of living in the country. ³⁰ Direct care workers are required to take on enormous responsibilities, yet have a difficult time making a living. For example, Tracy Adams, a 22 year old psychology major at Emmanuel College, works 40 hours per week at a group home in Newton. Ms. Adams cares for mostly nonverbal men ranging in age from 34 – 58. As part of her duties, she has to be able to lift each man, one of whom weighs close to 200 pounds, from a wheelchair, into the bathtub and back. She also helps to change their diapers, does laundry and helps clean the house. Ms. Adams barely earns \$12 per hour (or \$25,000 per year), although she is one of the lucky ones who receives health and dental benefits.

Because she is the assistant manager, she is paid more than the rest of the staff, who make about \$10.00 per hour.³¹ This pay differential underscores why there is a recruiting and retention problem, especially since "[p]roviders of supports and services to individuals with mental retardation or other developmental disabilities typically draw from a labor market that competes with other entry level jobs that provide less physically and emotionally demanding work, and higher pay and other benefits and therefore these direct support jobs are not currently competitive in today's labor market."³²

Recognizing the problem, the Legislature established an additional salary reserve in 2001 had a small impact, raising salaries for community workers to between \$19,607.00 (direct care

²⁹ The 2004 Department of Health and Human Services Poverty Guidelines are published at Federal Register, Vol. 69, No. 30, pg. 7336 (Feb. 13, 2004).

³⁰ Statistical Abstract of the United States: 2004 – 2005, <u>The National Data Book</u>, U.S. Dept. of Commerce (124th ed. October 2004).

³¹ "Direct Care Workers Struggle to Make Ends Meet," The COFAR Voice, vol. 6, No. 6, pg. 1 (November 2004).

³² Congressional Record, Vol. 149, Oct. 22, 2003, S. Con. Res. 21, page 3.

worker I) and \$22,745.00 (direct care supervisors).³³ It is important to note that for state workers, depending upon the level, mental retardation care workers earn between \$26,148.00 and \$38,795.00.³⁴ The Operational Services Division ("OSD") conducted a legislatively mandated study of the impact of the salary reserves on the salaries of human service staff employed by the state in connection with contracts with the Executive Office of Health and Human Services and the Executive Office of Elder Affairs. The study found that the turnover rate among POS contractors and homemaker agencies rose from 1997 to 2000. In 1997, POS contractors had a turnover rate of 17.94%, which increased to 25.75% in 2000. ³⁵ The study concluded:

Wages levels tended to be the primary factor influencing contractors' ability to recruit and retain staff. Some contractors reported they received no responses to advertisements placed in newspapers due to the low starting salaries of their open positions. Several contractors gave examples of losing staff to retail jobs in the community that required less skill, offered high salaries and had less stress. . . . Other contractors gave examples of employees working an additional job in order to increase their wages. The salaries are stress and additional job in order to increase their wages.

The low salaries do not just create a recruiting problem, they also have a very real effect on care. One outrageous example from February, 2005 involved a former Wrentham resident,

³³ "Comparison Between the Average Salaries of Direct Support Staff Working State Operated Programs and Those Working Privately Operated Community Programs," Association of Developmental Disabilities Providers, attached hereto as Ex. 9.

³⁴ <u>Id</u>.

³⁵ "Outside Section 445 Study of the Impact of Salary Reserve Fiscal Year 1997 to Fiscal Year 2000," (January 2001), Ex. 10, (hereinafter "Outside Section 445 Study"). The six positions consisted of (1) POS case worker managers (individuals providing case work and case management services including service eligibility determination, service coordination and service plan development, resource development and advocacy); (2) POS direct care supervisors (staff members who supervise non-professional and para-professional direct care program staff in performing their program functions; duties which involve significant responsibility for program operations and logistics and may provide direct client care); (3) POS direct care workers II (staff with bachelor's degree experience or specific skills who are responsible for general daily care of clients or for primary program service delivery); (4) POS direct care workers I (staff responsible for general daily care of program clients or for primary program service).

³⁶ This is not very surprising considering that in 2000, there were still over 17,000 people who earned less than \$20,000 per year. <u>Id</u>. at 2.

³⁷ <u>Id</u>. at 9.

now living in a group home operated by a POS vendor, Brockton-Area Multi-Services, Inc. ("BAMSI"), was taken from the home, along with his three housemates, to the gas station where the BAMSI employee was working a shift at the same time as his BAMSI shift. Three of the group home residents were put in the manager's office at the Mobil station, while another was locked in the BAMSI van. A nurse recognized one of the men as someone who was in a day program with her brother, and notified police.³⁸ The BAMSI employee told police that he had to have two jobs because he earned only \$11/hour as a caregiver and he needed more money.³⁹

Since the Salary Reserve Impact Report was released in 2001, the situation has deteriorated further. The budgeted salary reserve in FY2002 was only directed to staff earning less than \$20,000 per year. Additionally, the Commonwealth has not allocated any cost of living increases to reflect increases in utilities, insurance and rent since the 1980s. Nor has there been a reserve to address the spiraling costs of healthcare in the last few years. Far from getting better, the crisis will continue to worsen because the FY 06 Budget included another \$20 million salary reserve that only passed over the Governor's veto. However, the 19-cent pay increase that it will probably give is not likely to make a significant difference in the continued personnel shortage. A lack of any substantial change will continue to interfere with DMR's ability to provide sufficient adequately trained and experienced personnel and will continue to interfere with DMR's ability to provide required services to each class member on a life-time basis, all of which are required by the Order.

³⁸ Patriot Ledger, March 1, 2005.

³⁹ Patriot Ledger, March 2, 2005

⁴⁰ H.4200, 184th Gen. Ct., 1599-6901 (Mass. 2005).

⁴¹ See Fact Sheet: Salary Equity Legislation for Direct Support Workers in Community Programs Funded by the Department of Mental Retardation, Association of Developmental Disabilities Providers, available at http://www.addp.org/documents/salary equity factsht.pdf.

C. <u>Inadequate staffing and experience levels harm Class members.</u>

In addition to creating staffing shortages, high turnover creates major problems with training and experience. First, it takes time and resources to train new people to perform the work and to care for individuals, including the Class members. High turnover directly impacts the level of experience of care workers because fewer and fewer stay on the job long enough to gain the requisite experience. As a DMR official stated "about 30 percent of direct-care workers last less than 18 months on the job."

High turnover directly affects Class members by failing to provide them with care workers with whom they are familiar. This is important because a number of the Class members fare much better when dealing with care workers with whom they have developed a personal relationship. This issue, while rooted in common sense, is also explicitly addressed in many ISPs. The lack of experienced, qualified staff jeopardizes Class members' physical well-being.

i. <u>Medication errors are a symptom of DMR's failure to provide adequately trained staff.</u>

In addition to the general concerns regarding staffing, other issues about quality of care revolve around a lack of regulations and licensing requirements.⁴³ One of the most critical areas requiring trained staff involves the administration of medication. DMR's record on this issue is dismal. In 1988, the Massachusetts State Auditor disclosed that unlicensed and untrained individuals were administering medication to consumers in community-based programs overseen by both the Department of Mental Health ("DMH") and DMR.⁴⁴ Thus, in 1993, the Department

⁴² Patriot Ledger, Special Reports, High-level Responsibility, Fast-Food Pay, March 23, 2004.

⁴³ Lutsky, et al (2000), as cited in "Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research," Reprinted from Mental Retardation, Vol. 41, No. 2, April 2003, pg. 116.

⁴⁴ "Independent State Auditor's Report on the Administration and Oversight by the Departments of Public Health, Mental Health, and Mental Retardation of the Medication Administration Program at 48 Community Residences and 12 Human Service Providers," September 28, 2001 (hereinafter "Sept. 28, 2001 Report"), Introduction, Ex. 11.

of Public Health promulgated 105 C.M.R. 700.003, authorizing non-licensed individuals to administer medication, if certain requirements were met, including successful completion of the Medication Administration Program ("MAP"), which provided training and certification to direct care staff working in residential programs. This program, however, has serious deficiencies. Specifically, in 1998, the MAP Advisory Group expressed concern over the appropriateness of the MAP curriculum and the lack of independence of the certification test, because each state agency certified its own staff. The Advisory Group recommended that an independent consultant be hired to develop a new curriculum and administer the test. In September 1999, the new curriculum was implemented, consisting of only twelve (12) hours of training provided by registered nurses and pharmacists. This training is inadequate and raises serious safety concerns.

In 2001, the State Auditor conducted a survey of other states, seven of which responded with useable data, and found that Massachusetts is the <u>only</u> state that authorizes unlicensed individuals to administer medications without supervision. Some states with similar programs require much stricter training and continuing education requirements than Massachusetts. Of the seven states that responded with useable data, <u>all</u> required unlicensed individuals to be supervised to some degree by a licensed professional. Additionally, six of the seven required significantly more training hours than Massachusetts. Oregon, for example, required eighty (80) hours. The Massachusetts Nursing Association expressed concern to the Auditor that MAP gives direct care staff members responsibilities that are usually limited to professionals with a clinical background, but direct care staff are not given the training, nor do they have the experience, to recognize adverse reactions to medications. One nurse who teaches the

⁴⁵ Sept. 28, 2001 Report, at 4.

⁴⁶ Sept. 28, 2001 Report, at 27.

⁴⁷ Sept. 28, 2001 Report, at 27.

certification course said that many workers don't know enough English to understand the material, much less pass the test.⁴⁸ In 2003, less than half of the applicants passed the certification test on their first try.

The Commonwealth's House Post-Audit and Oversight Bureau ("HPAOB") conducted a review of medication administration and identified several areas of concern including that the number of Medication Occurrence Reports ("MORs"), which are supposed to be completed for any error in medication, was in all likelihood <u>understated</u>, because direct care staff would likely not want to jeopardize their employers' contracts with DMR.⁴⁹ Issues such as staff turnover and confusion about what constitutes an "incident" can also lead to underreporting. In addition, "the personnel assigned responsibility for the administration of medication to clients may be inadequate given the low salaries and continuing problems with staff turnover."⁵⁰ The Audit concluded that the oversight, training and turnover issues in this area are significant and long-term.⁵¹

Additionally, MORs were not effectively utilized to ensure that individuals who made medication administration errors were identified and properly trained to prevent future medication errors.⁵² One of the most stunning revelations of the audit was DMR's admission that it did not have procedures for monitoring the training that providers give to direct care staff, and it therefore cannot determine whether individuals who commit medication errors received additional training to prevent future errors. In response to the Auditor's recommendation that the Department improve its oversight of the MOR process, DMR stated "[w]e believe that the report

⁴⁸ Patriot Ledger, Medicine, Language Collide, March 22, 2004.

⁴⁹ Sept. 28, 2001 Report, at 6.

⁵⁰ *Id*.

⁵¹ Sept. 28, 2001 Report, at 6.

⁵² Sept. 28, 2001 Report, at 9.

fails to give due consideration to the primary goals of the MOR system, which are to create a non-punitive environment conducive to the reporting of complete and accurate information and utilize MOR data for retrospective analysis."⁵³

Retrospective analysis is a nice academic exercise, but preventing medication errors is much more important to Class members. DMR's response to the monitoring/oversight suggestion is very disappointing since it appears that DMR was not concerned enough about medication errors to take any action to try to prevent them from recurring. It seems pointless to have a system to "monitor" medication administration if DMR makes no effort to respond to errors that are potentially life-threatening. With all due respect to DMR, a direct care worker who makes a medication mistake should be reprimanded if appropriate, and required to undergo additional training.

Class members have died as the result of medication errors and DMR's intransigence on this issue is a prime example of a systemic failure. Specifically, in 2002, David Malcolm, a resident of a community program on the South Shore, died after the manager of his community home failed to fill his prescription for medication to control his seizures. David's doctor gave a stronger prescription to the group home manager on December 11, 2002. It was never filled.⁵⁴ By late December, his other prescription ran out and he missed three doses. On December 29, 2002, David collapsed at 4 a.m. The house manager decided to wait until more staff arrived to bring him to the emergency room, although a doctor recommended that he be seen. David had another seizure at 6 a.m. The manager did not respond to a page, and there was apparently only one staffer on duty. Shortly after 8 a.m., the staffer heard another crash and found David lying in

⁵³ Sept. 28, 2001 Report, at 14.

⁵⁴ Patriot Ledger, David Malcolm Timeline, March 20, 2004.

the bathroom, bleeding from the nose and forehead, shaking and biting his tongue.⁵⁵ The staffer called 911 and David was taken to South Shore Hospital, where he had more seizures and suffered cardiac arrest. He died on January 4, 2003 at age 39.⁵⁶

Rachel Deline, a Wrentham Class Member, also suffered and died because of medication errors. On April 13, 2002, a pharmacist who filled her prescription accidentally gave her double the dose of lithium that was prescribed to control her mood swings. She developed diarrhea, a symptom of lithium poisoning that went unnoticed. Her doctor told staff it was probably a virus, and the group home manager told staff to limit her fluids, which increased the risk of dehydration. The diarrhea continued and Rachel soon became weak and unsteady. Noticing a bruise on her back, staffers brought her to the doctor for x-rays on May 10, 2002. There was nothing wrong with her back, though she had to be carried into the office. On May 11, her parents came from New Hampshire for their monthly visit. When they arrived, the staff were all watching television. Rachel's father found her moaning and crying, with half her body on a couch and the other half on the floor. The DPPC investigator subsequently determined that she had been in that condition for 90 minutes. She died, on May 13, 2002 at age 51, of dehydration and kidney damage.⁵⁷

ii. <u>Staffing deficiencies are accompanied by increased utilization of emergency restraints</u>.

A disturbing trend noted in DMR's QA Report is that the percentage of individuals in community settings subjected to emergency restraints has steadily increased over time. An emergency restraint occurs when a direct care provider limits the resident's freedom of

⁵⁵ Id.

⁵⁶ Patriot Ledger, David Malcolm Timeline, March 20, 2004.

⁵⁷ Sue Reinert, No One Punished for Woman's Death, and Her Family Asks, "Why Not?" The Patriot Ledger, March 22, 2004.

movement through the application of either a mechanical restraint, such as Velcro wrist, leg or body restraints; physical bodily contact, such as a direct care provider grabbing the resident's arms or legs to force stillness; or the administration of a non-consensual use of medication – such as a tranquilizer injection. ⁵⁸

DMR, and all reasonable people, agree that emergency restraints are to be avoided if possible. The fact that restraint usage is increasing in community-based homes raises a huge red flag – but at the same time, it could almost have been predicted. Use of emergency restraints has traditionally been higher in facilities because facility residents are less able to function in an appropriate way because of their disabilities – almost half of facility residents have behavior disorders. In 2001, the rate of restraint in DMR facilities was 50% higher than in communitybased homes. ⁵⁹ By 2003, the rate of restraint in community-based homes had risen to 5.7%, while the emergency restraint rate in the facilities decreased to 5.9%, such that the rates are essentially equal. What is disturbing about this trend is the fact that community residents are typically much more capable of appropriate behavior, therefore, one would expect that there would be less of a need for emergency restraint. However, direct care workers in the community sorely lack training and experience, so it is not surprising that they are less able to observe and recognize cues or signals that the resident is becoming upset or otherwise acting in a manner that may escalate to behavior that will be subject to emergency restraint. These staff members are likely unable to defuse situations with less intrusive interventions.

The problems in vendor-operated homes do not have a simple solution, although increased funding would certainly be a step in the right direction. DMR's failure to critically

⁵⁸ 115 CMR 2.01.

⁵⁹ DMR QA Report, Table 18, page 32 (population restrained at facilities was 6.3%, compared to 4.2% in community), Ex. 2.

evaluate care provided in vendor-operated community homes has contributed to its willful ignorance of the deficiencies in the system. DMR faces staffing-shortages and training concerns, high turnover rates, and salary deficiencies. Absent a major overhaul of the community care system, DMR is incapable of providing sufficient, adequately trained personnel. Additionally, DMR's plan to close the ICFMRs and transfer Class members to vendor-operated community-based homes will only add more individuals to an already overwhelmed and short-staffed system, resulting in services that are not equal or better to the care Class members were receiving in 1993, in violation of this Court's Order.

III. DMR's Surveys Do Not Comply with the Periodic Review Requirement.

The Court ordered "within nine months of the date of this Order, defendants shall enter into an agreement with contracted retardation professionals or with a nationally recognized evaluation group to review community programs on a periodic basis." DMR is not in substantial compliance with this requirement of the order. In order for DMR to comply with its obligations to Class members, periodic review should include the following factors: independent reviewers; regular and consistent periods of review; community focused reviews of whether Class members' needs, as set forth in their ISPs, are being met; and appropriate follow up.

DMR currently uses the services of Human Services Research Institute ("HRSI") and the National Core Indicators ("NCI") consumer survey tool. DMR staff, however, perform the datagathering function by administering the NCI tool and conduct the in-person interviews with individuals and their families. DMR's role in the review process compromises the goals of the review ordered by the Court. Furthermore, the HSRI studies and the NCI tool aggregate data for the purpose of identifying systemic issues and trends, which shape DMR policies and priorities.

There is no identifying information in the surveys, and accordingly, it is impossible to rely on that survey tool to identify and respond to the problems experienced by any particular individual.

Further, the questions utilized in the surveys are not always appropriate for gathering information from individuals with mental retardation. ⁶⁰ Specifically, quantitative judgments, time questions, direct comparisons, and abstract concepts are all problematic when interviewing a person with mental retardation. However, the survey utilizes all of the above types of questions. For example, the survey asks, "Do you work enough hours?," "On most days, are you usually happy or sad?," and "Can you be by yourself as much as you want to?" In addition, most of the questions call for a yes or no response. People with mental retardation are more prone to acquiescence. Therefore, the answers to the surveys may not be accurate. The questionnaire functions more as a satisfaction survey than as an oversight tool.

The interviews focus on whether individuals receive support to maintain relationships and develop new ones; whether they make choices about their routines and schedules, or develop and achieve personal goals. This is important information for DMR to collect, but it should not be to the exclusion of questions of a more fundamental nature: Does the Class member receive all the physical, recreational or occupational therapy provided for in his ISP? If the ISP calls for 1:1 care, is the Class member receiving it? Is the Class member's transportation adequate to allow him or her to participate in work, or day programs, or recreation? Has the Class member seen a doctor or a dentist within the past 12 months?

DMR's review is also deficient because it is conducted every two years, but the final report for each review cycle is not available until long after the data has been collected. The Massachusetts House Post Audit and Oversight Bureau ("HPAOB") the HPAOB noted in 1997

⁶⁰ W.M.L. Finlay and E. Lyons, *Methodological Issues in Interviewing and Using Self-Report Questionnaires with People with Mental Retardation*, Psychological Assessment Vol. 13, No. 3. 319-335 (2001).

that "DMR's system of oversight and monitoring is unable to isolate problem cases, move to take immediate protective actions, and remove clients from dangerous situations." The HPAOB also concluded that "DMR's approach to presumption of competency hinders a true assessment of potential risk to clients."

As a result, directly or indirectly, of the lack of the type of review contemplated by the Court, a number of tragedies have occurred in community programs. Additionally, stories abound about Class members in dangerous situations that could be prevented, or at least corrected, through oversight. A Ricci Class member was killed in February 2005 when an employee of North Shore ARC was trying to back out of an icy driveway. The Class member was standing near the car, and was run over when the car began moving backwards. In the DPPC Investigative Report of Rachel Deline's death from lithium poisoning, the investigator noted that previous reports regarding the site of abuse were "too many to list." The tragedy that befell Karen Mutanen—who left Wrentham in 1979 and was later found dead with her mother in a trash infested house in 2000—might have been prevented if someone at DMR had conducted any type of oversight or review of her needs.

A. Without any oversight, services have and will continue to decline.

In the years after the Disengagement Order was entered, Wrentham Class members began to experience frustration with a decline in services in group homes, in addition to instances of abuse or neglect. Requests to DMR for a systematic assessment of care fell on deaf ears. Recent studies have shown that individuals with mental retardation face problems with access,

⁶¹ Report on the Massachusetts Department of Mental Retardation: An investigation by the House of Representatives Post Audit and Oversight Bureau, including "Are you sure about this guy?" An analysis of the abuse of two mentally retarded men in Raynham, Massachusetts (1997) at 19.

⁶² Id.

utilization and quality of healthcare and personal care in community-based settings, ⁶³ individuals in community settings suffer higher rates of verbal abuse and relatively greater exposure to crime, ⁶⁴ and staff members in community settings generally lack organized approaches and skill sets to promote development in the residents of community settings. ⁶⁵ Surveys of Wrentham Class members, and the DPPC data, support each of these findings.

i. 2000 Class Member Survey.

In 2000, DMR agreed to participate in a small survey of Class members, largely because there was no way to separate data on Class members from DMR's aggregate surveys. The survey included 26 randomly selected Class members. Interviewers included DMR staff and several guardians. A large percentage of the Class members needed more support:

CD lived alone in a one-bedroom apartment. Her mother said she was lonely and depressed, and likely in need of mental health services after she stopped seeing her prior therapist. CD asked to be involved in a day program to give her something to do. She worked only four hours a week and wanted to work more. At the request of one of her neighbors, she took in a homeless couple and their baby, who stayed for weeks. CD did not feel that she could ask them to leave and she feared retribution from the man. CD doesn't like her apartment because it is too far from anything. She did not appear to have access to transportation on a regular or routine basis. CD's mother said she used to get 30 hours of direct support per week, she currently had 11 hours per week, and 4 hours of vocational support. Community activities seemed limited and sporadic.

TW had significant emotional/behavioral/psychiatric needs that were not being addressed. His house manager said there used to be a psychologist assigned to the program, but that was no longer the case.

WB was living in a nursing home, with no ISP in his file. He needed speech services, including a communication device. His guardian also asked for more support and services, including opportunities to participate in recreational activities in the community, and perhaps a

⁶³ Nobbe, et al. (1995); Larsson & Larsson (2001); Walsh & Kastner (1999), as cited in "Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research," Reprinted from Mental Retardation, Vol. 41, No. 2, April 2003, pg. 116.

 ⁶⁴ Emerson, et al. (2000), as cited in "Cost Comparisons of Community and Institutional Residential Settings:
 Historical Review of Selected Research," Reprinted from Mental Retardation, Vol. 41, No. 2, April 2003, pg. 116.
 ⁶⁵ Id. at 116-17.

day program one or two days a week. Staffing at the nursing home was quite low for 60 residents: 7 during the day; 5 staff in the evening and only 2 overnight.

CS's involvement in community activities had been impacted by staffing issues. In the past, he went to the Cape, went swimming at a pool of a local university, and participated in neighborhood cleanups. For the past two years, there were minimal community activities.

AV was supposed to receive 10 hours of support per week, but the "support" apparently was limited to a weekly phone call or short visit to see if he needed anything.

As a whole, the 2000 survey results showed definite needs on the part of the Class members: 35% were in need of better day programming; 30% had financial issues (paying for over the counter medications, Class member and advocate unaware of financial entitlements); 38% of Class members needed one or more clinical services (psychology, speech therapy, physical therapy, devices); 23% had transportation needs (one woman spent 90 minutes on a bus each way to get to her day program).

The 26-person survey did not support DMR's assurance that the system was working, and that service coordinators were adequately monitoring the care Class members received in the community. When asked to explain how such a small survey showed such significant needs, as well as decreasing levels of support given to Class members, DMR responded that these must be "isolated incidents" and dismissed the survey sample as too small to be representative of the Class as a whole. Having been rebuffed in their interpretation of the 26-person survey as being indicative that a larger survey of Class members' care should be done, the Ricci stakeholders asked for DMR's assurance that it would follow up with each of the Class members who expressed a need for more support. DMR agreed, and eventually assigned one person to be responsible for the follow-up. Despite repeated requests over the last five years, DMR has not provided any explanation of the steps it took to remedy the service problems experienced by almost half of the small 2000 survey sample.

ii. 2005 Wrentham Association Survey.

After the appointment of replacement Class Counsel for the Wrentham Class in 2004, DMR refused to provide new counsel with a list of guardians and Class members, citing privacy issues. It was only after this Court ordered DMR to provide the information under a confidentiality order, that it was produced. The Wrentham Association mailed a questionnaire to every guardian or Class member, if there was no guardian. The survey numbers are likely skewed because dozens of surveys, using the addresses provided by DMR, were returned as undeliverable. Additionally, guardians of Class members who still reside at the Wrentham Developmental Center represented 50% of the 277 survey respondents. The results, therefore, may not be representative of the entire Wrentham class since there are more than 850 Wrentham Class members, of whom approximately 300 still live at Wrentham.

Nonetheless, fifteen percent of the respondents said that the Class member had experienced emotional, physical or sexual abuse. Eight percent said that additional supports/services were needed, and 10% said that the Class members pay for their own transportation services. A number of guardians were willing to be interviewed and provided more detailed feedback:

RM's mother states that he has MassHealth insurance, but dental was eliminated. The Class member was told that he has to pay for his dental care. RM, who is also blind, wants someone to spend time with him on the weekend because staff is "too busy." Transportation has been a continuous problem because he has to depend on the MBTA's "Ride." He doesn't have the funds to pay for a taxi. The guardian states that the service coordinator is overworked and can't follow up. She feels that all planning for the ISP is done before she gets there and that limits her ability to request changes.

⁶⁶ The responses from the 140 guardians whose wards reside at Wrentham were strikingly similar. All but a small percentage are quite satisfied with the care provided at the Wrentham Developmental Center, where the staff are very experienced and caring. It is only fair to commend DMR on the job it and its staff are doing at Wrentham. Many guardians expressed great concern at the thought that their children and wards would be subject to a transfer in the future.

HC's guardian is dissatisfied with his day program because it is not challenging enough. She feels ignored/dismissed at the ISP when they discussed this, and is not sure if there have been any real changes. HC doesn't have dental insurance, but has continuing dental needs, so the house mgr. contacts guardian and expenses are paid out of his very small personal account (veteran's stipend). He also pays for his own bus fare. Last year a psychiatrist diagnosed HC with Asperger's Syndrome and recommended a specific type of counseling. Although he receives counseling, it is not of this particular sort.

MW has difficulties because of staff turnover – he only recognizes faces and feels comfortable with familiarity. When familiar faces disappear forever he is deeply troubled. There is no longer enough funding for a nurse that specializes in Alzheimer's care. The prior nurse used to help out and train staff and be on call, and her absence is very much felt. The staff are not particularly knowledgeable about Alzheimer's.

AJ is the only ambulatory member of his house, so social activities are very limited. For a very long time there was no weekend staff licensed to drive the van, so they did not go anywhere. His guardian feels it is very hard to find out information from anyone that works there. It seems to her that planning for activities and transportation is haphazard. For a while transportation problems were so bad he wasn't making it to his day program (the service they contracted was undependable, or something). The ride was a full hour each way. Guardian feels she must be responsible for calling the dentist and the foot doctor herself to make sure that AJ has been to appointments. Staff feels free to reschedule for months later if there is a conflict, so his 4-time a year dental needs are not met (similar for foot doctor). She feels she must supervise his care to make sure he gets it. As for staffing levels and training, she says they can't hang on to a house manager at all, and that the ones they have had cover multiple houses and so are often not on-site. There's no stability in low-level management. Guardian once noticed that bed linens were not being changed, and suggested to them that they make a "duty chart." Staff is disorganized and don't seem to have a real plan. Guardian is dissatisfied with the ISP process and feels that it is geared toward other professionals, and that once a year is not effective. However, she feels that her concerns are acknowledged and taken to heart. Over the years, many services have fallen by the wayside. AJ used to receive music, physical, speech, and occupational therapy, and now he does not. He has become much more unstable on his feet now that no one works with him. The current staff is not qualified to help him with any of these needs.

PW's guardian noted high turnover in management, but her only complaint is that service was much more personal, warm, and friendly at Wrentham. She felt pressured to move PW in 1995. Someone called or wrote and told her Wrentham was closing and PW had to move. She felt she didn't have a choice. The facility is fine and adequate and always clean, but because the staff have no relationship with PW, he has at times been destructive (ripped his blinds). They cannot communicate with him, and are impersonal, so they cannot address the behavior. She thinks some of their ideas at the ISP are ridiculous. For example, they were talking about registering him to vote and getting him involved in church, both of which are far outside his capability. The staff also rents videos, but none of the occupants can enjoy them and she feels it is mostly for the staff entertainment. She has asked about pool access since he moved ten years

ago, because PW enjoyed the warm pool at Wrentham, but nothing has ever come of that in ISP meetings.

TN lived at a motel from February to May because the house he was living in had a leak in the sprinkler system. Guardian is agitated because filing a complaint to the state takes a long time to see results. Outside of the house is in poor condition. The wood boards near the roof have holes in them. Bees and hornets have made nests up there. Sometimes they are able to get into the house through the holes. Guardian wonders who is supposed to take care of that problem and problems of that nature? She was thinking of asking her husband who is a construction worker to fix it because nothing has been done.

PT's guardian lives in California. They keep in touch by phone and she visits him a couple times a year. She is fed up with rent increases. When she began paying for his rent it was only \$200, now it is over \$1000. The staff has no skills in her opinion, and there is a high turnover rate. The new house manager supervises two different homes. Her time is divided and does not have concern for both houses. The communication with the guardians are very poor. There is a lack of continuity of the staff, and they do not know how to take care of him. For example: At an annual meeting wards and guardians attend, the staff brought PT to the meeting in a heavy jacket and sweater when it was very hot outside. He was clearly uncomfortable and sweating profusely when Guardian saw him there.

PT has no transportation besides for going to work. Everywhere else he wants to go, Guardian has to drive him. The staff does not bother to take him anywhere for recreational purposes. PT has to use his own money to buy personal things he needs for hygiene.

BD lives alone. There is one woman that comes over from 3pm, stays over night, and leaves when time for day program. This is fine and her family is thrilled with her care, but that one woman is the only person that works with BD, so her family must take care of her when her caretaker is ill or on vacation, and they have to miss work to do this. Guardian has asked staff for relief repeatedly at ISP's, with no change.

One guardian, who did not want to be named for fear of retaliation against the Class member, described how happy she was with the care when he first left Wrentham for a group home. He had five different kinds of therapists and many opportunities for community interaction. Someone on the staff used sign language, as does the Class member. The residents used to go for ice cream on a regular basis. Over the years, the therapists disappeared one by one. Then the staff shrunk in size, such that there is not adequate coverage if one member of the staff leaves the house for recreational purposes. None of the staff know sign language. As the guardian put it, the house residents are in "lock-down" once they return from their day program, and her ward must feel like a small Russian child living with Americans because he cannot communicate with his caregivers.

Another guardian, age 82, cares for her 42 year old son, who has Downs Syndrome, at home. Her own health issues are now making that more problematic. Her son has had his own health challenges, and required surgery. His guardian was billed \$800 for the cost of what insurance would not cover. After his surgery, her son was not able to walk long distances, and as

a result, they stopped going for walks in the neighborhood. After her hip surgery, she began to use a motorized scooter. She would like her son to have one so that they can go around the neighborhood and into town again, like they used to, but she can't afford it.

These comments, much like those from a much smaller sample in 2000, buttress the conclusion that DMR is not doing all that it can, and all that it is required to do, for Class members. Staffing levels are low, and prevent Class members from enjoying the benefits of living in the community. For example, DC's ISP states:

"The physical needs of the residents have increased in the last year, making it difficult for everyone to participate in community outings with the current staff/client ratio," which is 2:7. "DC has not attended any community outings due to safety concerns . . ." "DC enjoys going out into the community to purchase personal items and to eat out at restaurants. He does make choices as to what he wants to purchase. Coke is his favorite."

Why is it that guardians are unaware that Class members can access dental care through the facilities, where there are dental clinics, free of charge? Why are Class members using their own funds for transportation? Why are guardians desperate for respite care but get no relief? Because no one at DMR is providing the necessary information or support. The service coordinator should be able to address many of the financial issues with a simple phone call, and perhaps some advocacy on behalf of a Class member, but this is not happening. A systemic audit is necessary, as it has been more than ten years since the Disengagement Order and DMR has yet to perform an objective evaluation of the services Class members receive in the community. It appears that there is a lot of follow-up to be done. The anecdotal evidence supports only one conclusion – community care is much worse than it was in 1993, such that it is no longer "equal or better."

IV. DMR Has Not Certified "Equal or Better" Treatment at New Location Since 1997, and there are Systemic Deficiencies in ISP Process.

Pursuant to Paragraph 4 of the Order, before a Class member can be transferred, the Superintendent of the transferring school or the Regional Director must certify that the Class

member will receive "equal or better" services and that all services identified in the ISP are available at the new location. DMR simply stopped complying with this requirement. When notified of the deficiencies by Attorney Cohen in April 2002, DMR responded by claiming that no specific instances of such a failure were presented. As explained in Section III, above, as well as the *Report to the Court* filed by Fernald on February 2, 2006, it is virtually impossible to provide such information when DMR hides behind concerns over confidentiality as a reason for not allowing Class counsel to review the records that may support the Plaintiffs' position.

When the certification issue was raised again in April 2004, DMR admitted that it no longer completed the certifications form. Instead, DMR's practice starting in 1997 "has consistently been that for Ricci Class members the Facility Director or the Regional Director . . . certifies when signing the ISP that a transferred Ricci Class member's services meet the "equal or better" standard."⁶⁷ Such an "implicit" certification, by signing the ISP, does not comply with the Disengagement Order. In some instances, Class members do not even receive an ISP, in direct violation of applicable law and this Court's Order:

FG was admitted to Wrentham at age 14 due to increasing difficulty managing his behavior at home. He has a diagnosis of moderate mental retardation, Fragile X Syndrome and a degenerative neuromuscular disorder (Parkinson's disease). In 1982 he was placed in a staffed apartment with his brother, RG, and was later moved in March 1987, August 1987, 1990 and 1991. In 1994 he was admitted to the Greenery Nursing Home after being denied readmission to Wrentham State School.

RG's nursing home case manager made Herculean efforts to convince DMR to provide FG with respite care, which when DMR finally did so, was inconsistent and intermittent. This was first listed as a need before his admission, on his 1994 ISP and was apparently implemented in 1997, but inconsistently. It was again implemented in spring of 1999 after much advocacy on the part of the nurse case manager. The notes also detail enormous efforts to provide increased visitations with family members, even offering the nursing home van if a respite worker could be provided. Without the nursing home case manager and the resident's brother, this Class member may never have seen his other brothers with MR. The notes detail the excitement FG derived

⁶⁷ July 1, 2004 letter from Marianne Meacham to Lisa Goodheart and Beryl Cohen at pg. 9, Ex. 6.

from these visits – talking for the first time in months or years. Some staff were unaware that he could speak.

In 1999, the nurse case manager discovered FG's Class status and informed DMR that no ISP had been done since 1996. Upon admission to the nursing home, physical therapy and occupational therapy (as well as behavioral therapy) were discontinued. The DMR case manager said that a nursing home is not able to fund "maintenance" PT and OT. DMR, however, is allowed to do so, particularly for Class members – but did not.

Starting in February 1998, FG's mother asked DMR for assistance in locating a new guardian, as she was becoming ill. Mrs. G died in April or May of 1998. A new guardian was put in place in May of 1999. In 2001 FG was finally readmitted to Wrentham Development Center after advocacy from his guardian and family. He is doing very well there, enjoying visits with family and friends, appropriate clinical and support services, and annual ISPs. FG's health continues to decline due to the Parkinson's disease, but with adequate staffing and supports, his life is much better than before.

V. DMR's Closure Policy For ICFMRs Violates Disengagement Order.

With the system for providing direct care to Class members in community homes strained to the breaking point, DMR's closure policy will move hundreds more Class members to vendor-operated homes that are already under-staffed and are providing a sub-standard level of care under the POS contracts with DMR. Failure to address these problems will only lead to greater shortages, and a continuing violation of this Court's 1993 Order.

A. ICFMRs are appropriate for the residents who are there.

On March 12, 2003, Governor Romney announced that the Fernald Developmental Center would be closed, and that "[a]dditional large state institutions may be closed in the future." Class members, or perhaps more appropriately, the guardians and care providers for Class members, have never thought that transferring them into a community setting would satisfy the requirements of their ISPs, despite the fact that such moves became very common during the 1980s and 1990s. Nonetheless, at a meeting of *Ricci* stakeholders and counsel held at DMR's office on March 14, 2003, DMR explained that under the announced policy, large ICFMRs would be closed and DMR would maintain some long-term ICFMR capacity with "smaller"

ICFMRs. Of the six facilities, Fernald, Wrentham and Monson were described as "bigger" facilities, while Glavin, Hogan and Templeton were described as "smaller" facilities. More than 25% of Class members still reside in state facilities, and the average age of those Class members is 53.⁶⁸

The Class members who still reside in DMR facilities are there for a reason. The guardians who have chosen to have the residents remain in facilities have not made their choices based on whether a particular service model is "outdated" or "unenlightened" as characterized in the public policy debate over facility versus community-based care. Class members who reside at state facilities remain there because the facilities are best able to meet the needs set forth in their ISPs. Current residents of ICFMRs have more complex medical needs and are more functionally impaired. Approximately 80% of facility residents in general are severely or profoundly retarded. These individuals also tend to present more challenging behaviors than those in community settings – approximately 47% of facility residents have behavior disorders. As of 2000, DMR estimated that 44% of ICFMR residents need assistance or supervision in walking; 60% need assistance or supervision in dressing; 63% need assistance or supervision in using the toilet. Of Class members who reside in ICFMRs, 40% cannot understand simple verbal requests and 62% cannot communicate basic

⁶⁸ According to the DMR, there are 4,421 *Ricci* Class members. November 10, 2004 Hearing on Fernald Class Motion to Reopen, Transcript at 57. In 2003, there were more than 1,157 Class members residing in ICFMRs. DMR QA Report, Table 18, page 32. In contrast, there were more than 12,400 people residing in community settings. <u>Id.</u>

⁶⁹ Mental Retardation: Nature, Cause and Management, 3d Edition (1999), George S. Baroff, Ph.D. and J. Gregory Olley, Ph.D., at 350-51 (proportion of persons with profound retardation in large facilities has grown steadily while absolute number has declined).

⁷⁰ Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research, Kevin K. Walsh, Theodore A. Kastner, Regina Gentlesk Green, Mental Retardation, Vol. 41 No. 2 (April, 2003) at 103.

⁷¹ Id. at 104.

desires verbally.⁷² Residents in ICFMRs are the most medically fragile of all of the *Ricci* Class members,⁷³ so it is imperative that they have ready access to medical care that is available in the ICFMRs.

Individuals who reside in facilities after two decades of growth in community-based residential services tend to be older and have more problems with daily living skills. As community services expanded over the past two decades, the average functioning of individuals residing in facilities has declined, while their average age has increased. "Adults with severe physical disabilities are disproportionately represented among persons with severe and profound retardation," and their medical problems include: "seizures; multiple joint contractures, as in cerebral palsy; nutritional problems related to feeding difficulty, such as adults requiring tube feeding... and recurrent respiratory problems. The last-mentioned is the most common cause of death in this group." Access to medical care in a community-based home is hardly comparable to that offered at a facility where medical staff are available 24 hours.

Additionally, DMR has not acknowledged the fact that the transfers themselves pose a great risk of harm to the residents. Movement to a new residential setting is "a time of increased medical risk for all segments of the retarded population." Moving chronically ill or frail patients from one place of care to another is one of the most overlooked and significant sources

⁷² Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000 (June 2001), Research and Training Center on Community Living Institute on Community Integration/UAP, College of Education & Human Development, University of Minnesota (Robert W. Prouty, Gary Smith, and K. Charlie Lakin, Editors) (hereinafter referred to as "Residential Services Status and Trends") at Table 1.19, page 43. Ex. 12.

⁷³ Mental Retardation, 3d Ed. at 348.

⁷⁴ Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research, Kevin K. Walsh, Theodore A. Kastner, Regina Gentlesk Green, Mental Retardation, Vol. 41 No. 2 (April, 2003) at 105

⁷⁵ Mental Retardation, 3d Ed. at 347.

⁷⁶ Mental Retardation, 3d Ed. at 348.

of medical errors.⁷⁷ The reason for this risk is almost obvious – new care providers are not familiar with the resident and do not have the context in which to evaluate the resident's behavior, mood and other non-verbal signals. Studies increasingly demonstrate that patient safety is jeopardized during transitional care, which is the time period in which a patient transfers between different locations.⁷⁸ Medication errors also pose a significant threat to patients during transitions.

B. Closing ICFMRs will remove beds when more will be needed.

DMR is clearly being pulled in multiple directions: It continues to maintain the facilities where more than 1,000 Ricci Class members reside, as it has done for decades; it participated in the growth of the community-based residential services model over the past twenty years; and has steadfastly promised Class members that if they leave a facility and accept a placement under the Home and Community-Based Services ("HCBS") Waiver program, they can return to an ICFMR in the future if the community placement does not meet their needs. While DMR has not always honored this promise and does not always provide a "right to return" letter upon transfer, it has continued to tell Class members that they can return to an ICFMR in the future if necessary. The right to return has not always been quickly honored:

PR is a Wrentham Class member. He lived at home with his family until he was 6 years old when he went to live at Wrentham. PR was one of the first residents to leave Wrentham for a group home. His family lives in Hudson and PR was offered a placement in a group home in their town, seven minutes from their house, along with 7 other residents. It was run by TILL, Inc.

⁷⁷ Transitional Care for Residents: A Significant Source of Medical Errors, Annals of Internal Medicine, October 5, 2004.

⁷⁸ Eric A. Coleman, M.D., MPIT, and Robert Berenson, M.D., Lost in Transition: Challenges and Opportunities for Improving the Quality of Transitional Care, October 5, 2004, Annals of Internal Medicine, Vol. 141, No. 7, at 533.

⁷⁹ DMR's Admission/Readmission Policy (Policy #89-4), however, has been "under review" and unavailable on its website for more than a year.

Right from the beginning of the placement, PR's parents had worries and concerns about the placement. Staffing was very poor. There was insufficient staff to keep ill residents home, so they were sent to the day hab. Weekend staffing was worse.

In the 7-8 months he lived at the group home, PR went from 130 lbs. in weight to 80 lbs. PR made several trips to the Emergency Room of UMass Medical, accompanied by his parents and TILL staff. He was very ill and it could not be determined why. Immediately before one such trip, an LPN asked PR's mother if she knew that he had ingested a latex glove. PR's mother had never been told this. PR's mother told the ER staff about the glove and after X-rays, it was determined that there was another glove still in PR's system, caught in a difficult place in his bowel, and his inability to pass it was making him desperately ill. Emergency surgery was contemplated, but attempts were made over the next 6 days to allow the glove to pass through his system. An entire roll of toilet paper was also found in PR's system, which had solidified. Both items were eventually passed after the 6-day period. This process had further been hampered by TILL staff giving PR the wrong prescription for his condition prior to his hospitalization.

PR's parents took him home while they negotiated his return to Wrentham Development Center. They had been told by then Superintendent Francis Kelley that PR would be allowed to return if the placement was unsuccessful. When they went to return PR, however, they were not welcomed and had to fight for this return. After 3-4 months, PR was eventually readmitted to Wrentham and transitioned back into Cottage 5, where he still lives today.

Yet, at the same time DMR is making these promises, it is charged with the responsibility of implementing the policy of closing "large" ICFMRs and replacing them with "smaller" versions. Something has to give in this equation; it is simply impossible for DMR to honor its obligations to Class members over the next few, or more, decades if there is not enough ICFMR capacity to meet the Class members' needs.

As of November 11, 2004, during a meeting held at the suggestion of the Court, DMR indicated that there are only 25 open beds in the ICFMRs.⁸⁰ DMR's current maximum facility capacity is approximately 1,185 beds. Yet, in 2000, there were approximately 1,300 facility residents.⁸¹ In planning for the Fernald closure, DMR assumed that 2/3 of Fernald residents

⁸¹ The State of the States in Developmental Disabilities: 2002 Study Summary, David Braddock et al., Coleman Institute for Cognitive Disabilities, University of Colorado, 2002, at 90, Table 2.4.

⁸⁰ At a quarterly meeting of DMR and Ricci stakeholders held on August 28, 2003, DMR stated that there were 51 funded facility vacancies. The decrease from 51 to 25 vacancies is presumably attributed to the transfers taking place from Fernald to the other facilities.

would be transferred into one of the five other facilities, and that the remaining 1/3 would be transferred into a community home. If one-third of all Class members who currently reside in facilities transfer to community homes, there will still be <u>770</u> Class members residing in facilities, and almost 3,700 in community-based homes.

After Fernald is closed, assuming that one-third of the population is placed in community-based homes, and that mortality rates stay the same over the next two years, there will be approximately 1,030 ICFMR residents in Massachusetts. If DMR closes Wrentham next, only a small fraction of the 330 Wrentham residents would be able to stay in an ICFMR. DMR remains silent on how it will comply with the "equal or better" requirement in the Disengagement Order while shuffling Class members in and out of the ICFMRs, closing "large" ICFMRs and shifting to a service model of smaller ICFMRs with fewer beds.

DMR has been either unwilling or unable to identify the total number of ICFMR beds the Commonwealth will have at the end of DMR's implementation of the policy to close all "large" ICFMRs and retain a reduced ICFMR capacity. Yet, after Fernald is closed, DMR's ICFMR capacity at the other five facilities will be approximately 935. If Wrentham is closed, the Commonwealth's ICFMR capacity will be reduced to 605. Throughout this closure process, Class members will have fewer and fewer real options –under DMR's current planning guideline, 2/3 of the Fernald residents will be transferred to other ICFMRS. The Fernald Class members will be filling every available bed.

If Wrentham is the next facility targeted for closure, the Wrentham Class members will not be able to transfer to an ICFMR- vacancies at Monson, Templeton, Glavin and Hogan will open up only if a resident dies or, even more unlikely at this point in time, if a resident chooses

⁸² If DMR closes the third of the "largest" facilities, Monson, the Commonwealth's ICFMR capacity will be reduced to approximately 405.

to move to a community home. The guardians for the hundreds of severely-to-profoundly retarded Class members at Wrentham will not have the option of a transfer that will meet all the needs set forth in the Class members' ISPs, needs which have been met for decades at an ICFMR. ⁸³ It is clear that the closure plan will take away much needed beds without any consideration for the increasing needs of an aging population. Of the more than 4,000 Class members, it is reasonable to expect that as they get older they will encounter more challenges in living in a community-based setting, much like senior citizens in the general population, who become incapable of living independently, but instead reside in assisted-living facilities or nursing homes.

In order to adopt prudent planning practices, the DMR should anticipate that the percentage of Class members who will ask to return to ICFMRs as they age will <u>increase</u> over time. It is fair to estimate that the readmission rate for *Ricci* Class members is likely to be consistent with the national average, which was approximately eight percent (8%) in 2000, measured against all ICFMR discharges in 1989.⁸⁴ If anything, the readmission rate will increase over time, not decrease, since *Ricci* Class members are part of the aging "baby boom."

The full impact of the first-wave baby boom generation will begin to be felt within the intellectual disability service community within the next [0-5] years. This generational cohort will be making the transition into pensioner-age community services as well as posing new challenges for health and disability service agencies. . . . These services also have to be better positioned to accommodate the needs of older adults . . . who grow frail due to advanced age or who will be affected by dementia or other incapacities. 85

⁸³ Potentially even more devastating is the fact that some Fernald residents will have been transferred to Wrentham – and they will have no choice but to pack their bags and move again when Wrentham closes – this time to a community home because there will not be ICFMR capacity to absorb the 330 Wrentham residents.

⁸⁴ Readmissions in 2000, nationwide, totaled 558. Ex. 12 at Table 1.21, page 45.

⁸⁵Matthew P. Janicki, Arthur J. Dalton, C. Michael Henderson, and Philip W. Davidson, Mortality and Morbidity Among Older Adults With Intellectual Disability: Health Services Considerations, Disability and Rehabilitation, 1999: Vol. 21, No. 5/6, at 292.

Despite needs increasing, DMR is tasked with eliminating, or at least reducing, the availability of much needed facilities. DMR will not be able to comply with the Disengagement Order and ISPs in the future if it has closed two or three of the largest ICFMRs by the time *Ricci* Class members request readmission, whether those requests are made five, ten or twenty years from now.

The trend of increasing readmissions to ICFMRS has already started. For fiscal year 2000, large state-run ICFMRS were responsible for more than 96% of all readmissions. ⁸⁶

Between 1991 – 2000, there was a steady increase in both the number and percentage of individuals with profound retardation among readmissions to ICFMRs nationwide. ⁸⁷ Increasing readmissions "reflects the growing numbers of former residents who have moved to community settings as well as the difficulties those settings have faced in meeting their needs." Of the readmissions to ICFMRS between 1985 – 2000, an increasing percentage of those individuals resided at group homes immediately prior to readmission to the ICFMRS (less than 20% of readmissions were from group homes in 1985, increasing to 31% of readmissions by 1998). ⁸⁹

⁸⁶ Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000 (June 2001), Research and Training Center on Community Living Institute on Community Integration/UAP, College of Education & Human Development, University of Minnesota (Robert W. Prouty, Gary Smith, and K. Charlie Lakin, Editors) (hereinafter referred to as "Residential Services Status and Trends") at 44, and Table 1.21.

⁸⁷ Id. at 44. The percentage of this population among all readmissions rose from 26% to more than 37% in those nine years. The 2005 edition of this study noted a break in the pattern of growing number of readmissions, which may or may not reflect improve services. July 2005, at 42.

⁸⁸ Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000 (June 2001), Research and Training Center on Community Living Institute on Community Integration/UAP, College of Education & Human Development, University of Minnesota (Robert W. Prouty, Gary Smith, and K. Charlie Lakin, Editors) (hereinafter referred to as "Residential Services Status and Trends") at 44, and Table 1.21.

⁸⁹ Id. at Table 1.24, p. 48.

C. <u>Aging Class members create additional care needs that cannot be met in community settings.</u>

If *Ricci* Class members are unable to maintain the functional and medical level of well-being required to live in a community-based home over the next 10-30 years, DMR will not have sufficient ICFMR capacity for their readmission. Without sufficient ICFMR capacity, DMR will not be able to provide the level of care that is likely to be referenced in Class members' ISPs in the future, and will violate the Disengagement Order.

Just as it is inevitable that a certain percentage of Class members will die over the next several years, ⁹⁰ it is similarly certain that some Class members who currently reside in community homes will become increasingly infirm and need more care than required by their current ISP. DMR itself recognizes that increasing age is associated with more complex needs of facility residents when it states that the "facility death rate is higher because of increased age, etc." The life expectancy of individuals with mental retardation is increasing – from 59 in the 1970's to 66 in 1993 – and is approaching average life expectancy of seventy (70) years in the United States. ⁹²

In addition to usual health and care needs of aging patients, additional problems arise with Class members with Down Syndrome. Among older persons with Down syndrome, the aging process is accelerated and, unfortunately, the disorder has a chromosomal connection to Alzheimer 's disease. By age 60, approximately 40% of people with Down syndrome will show

⁹⁰ According to the 1999 mortality data relied upon by DMR, the annual rate of death per 1000 facility residents is 21. DMR Opposition to Fernald Motion to Reopen; Affidavit of Gail Grossman, Ex. 1, DMR 1999 Mortality Review Report. As such, of the current 1157 facility residents, it is reasonable to assume that approximately 24 will die within the next year. Underscoring the fact that Class members who reside in facilities are older and sicker than those who currently reside in the community is the comparison of the annual 10.9% death rate among the population residing in community homes.

⁹¹ DMR Opposition to Fernald Motion to Reopen, at 12.

⁹² Promoting Healthy Aging, Family Support and Age-Friendly Communities for Persons Aging with Developmental Disabilities, Report of the 2001 Invitational Research Symposium on Aging with Disabilities, Dept. of Disability and Human Development, University of Illinois at Chicago, at 1, Ex. 13.

symptoms of the Alzheimer's form of dementia.⁹³ Progressing more rapidly in Down syndrome, initial Alzheimer's changes include memory loss, both general and visual memory, and behavior changes.⁹⁴ Its middle stages are marked by a loss of social skills and decline in the ability to care for one's personal needs. DMR has already recognized that Class members with dementia and/or Alzheimer's disease require specialized care. At the Wrentham facility, approximately five percent (5%) of the population has Down syndrome. Of those with Down syndrome, fifty percent (50%) have already developed Alzheimer's. Traditionally, all the Alzheimer's patients were in their own apartment, and even as the numbers have increased, each resident has been able to remain in his or her own apartment. However, this will not be able to continue if DMR is allowed to close Fernald and other facilities because there simply will not be enough room. In short, as they age, *Ricci* Class members will require more care than they currently need.⁹⁵

Before the 2003 decision to downsize the capacity of the Commonwealth's ICFMRs, DMR forecast its expected needs for ICFMR beds in the future. It determined that by fiscal year 2011, DMR would require anywhere from 671-912 beds. By 2010, the *Ricci* class will have decreased in size to approximately 4,075 (again, assuming mortality rates are constant). In ten years, approximately 3,750 people will still be members of the class. As they age, the readmission rate will be at least the current national average of 8%. The readmission rate may double as Class members' who live into their seventies and eighties will require increased medical care and monitoring. Even a 10% readmission rate means that DMR will need to provide hundreds of ICFMR beds to *Ricci* Class members – and it will not have them. In sum, if

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⁹³ Mental Retardation: Nature, Cause and Management, 3d Edition (1999), George S. Baroff, d J. Gregory Olley, Ph.D., at 350-51 (citing Schupf, Silverman, Sterling & Zigman, 1989).

⁹⁴ Mental Retardation, 3d Ed. At 351.

⁹⁵ Introduction to Special Issue on Aging: Family and Service System Supports, American Journal on Mental Retardation, Vol. 109, No. 5:350 (Sept., 2004).

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DMR is allowed, or more appropriately, required to close the large ICFMRs, it will not be able to

meet the needs set forth in Class member' ISP's. The greater medical and personal care that is

provided in ICFMRs is simply not available in vendor-operated group homes.

VI. Conclusion.

DMR has been placed in an unenviable position. It must comply with the Disengagement

Order, and it seeks to comply with that Order. Given the current budgetary, organizational and

policy constraints imposed upon DMR, it lacks the tools and resources to fulfill its mission, as

was the case when this action was first filed.

WHEREFORE, the Wrentham Association respectfully requests that the Court restore the

Wrentham action to its active docket for the purpose of compelling the Commonwealth of

Massachusetts, through DMR, to comply with the Disengagement Order.

Respectfully submitted,

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