

Good morning/afternoon, ladies and gentlemen.

My name is Charles Hart and I live in Melrose. And, I greatly appreciate this opportunity to share with you certain incontrovertible facts regarding COFAR at this Joint Informational Hearing today.

I am one of the co-founders of COFAR, (the Coalition of Families and Advocates).

I also co-founded a family advocacy group, CCMR, in 1976, at Hogan Regional Center in Danvers.

As the parent of a profoundly retarded son, who also had seizures, skeletal problems, and other medical issues, I have “walked the walk”. And, have a deep personal understanding of hundreds of families similarly situated.

Upon birth, my son was diagnosed with hydrocephalus or, water on the brain, and as a result, he was profoundly retarded. At his best, his functional level was approximately 12 to 18 months. Christopher lived at home until he was 14 years of age and due to an extraordinary family situation, he lived for almost 18 years at Hogan Regional Center until his death in 1996.

(If I may say so, it is my firm belief that my son Christopher would not have lived until he was 32 years of age without the outstanding care he received at Hogan Regional Center.)

For the past 45 or so years I have been and continue to be an advocate on behalf of ALL persons with developmental disabilities regardless of the living arrangement. The person’s needs, and/or the family’s situation, were always the prime motivator to become involved. It is, in my experience, impossible to divorce a loving family from their loved one with developmental disability. As the

system of care has become more dispersed, the roles of families and the treatment of families by the bureaucracy has become more important to me and many others

I would take a few moments to thank each and every person who made the effort to attend this Joint Informational Hearing and thereby demonstrate their support for all persons who have developmental disabilities. Even though we may disagree about the value of developmental centers, it is an honor to share this microphone with family members who have had good and bad experiences with group homes, or with a loved one living at home. It is especially wonderful to see self-advocates, whose courage and determination inspire us all. That we disagree does not diminish my respect for every family's individual experience and every person's individual experiences.

Now, the persons I am attempting to represent -- developmentally delayed persons with extreme medical and physical needs -- are unable to be here today and tell their own stories due to the severity of their disabilities. Their lives are so fragile---both mentally and physically -- they are incapable of being transported from their homes to attend this hearing. They are a minority of the people DDS supports, yet they are thousands, and thus involve thousands of families. Most of the people who now remain in the six developmental centers are in this group, and many of the residents of state operated group homes.

Keep in mind, these people who cannot easily be transported here today, are the same people Governor Deval Patrick's plan would evict from their longtime homes, as if they were pieces on a game board.

This is one of the strongest things to come from the great civil rights case against the Department of Mental Retardation -- the systematic requirement to look at each person served as an

individual with different strengths and weaknesses. That people who may qualify for services from the Department of Developmental Services each have an individual path in life, and must have an Individual Service Plan, is the great victory of civil rights in this field.

It is more important that Judge Tauro's insistence that those who wanted to leave the vast state facilities of the bad old days be allowed to do so. It is even more important than his insistence that a proper community residential system be funded for people leaving the facilities.

That one size does not fit all is also more important than Judge Tauro's insistence that the people who wanted to stay in the facilities had a right to stay, and a right to return if their community experience did not work out. It is more important than his insistence that all remaining facilities in Massachusetts be brought up to the staffing ratio, active treatment, and medical standards for Intermediate Care Facilities under federal law.

Because the principle that One Size Does Not Fit All implies all the actions of the court's disengagement order, and all the protections won in the Supreme Court's review of *Olmstead vs. L.C. and A.C.* a few years later.

You have heard a lot today about the *Olmstead* decision, and lot of what you have heard is wrong. A simple reading of that civil rights case – and COFAR has sent every member of the legislature a [factsheet](#) – will show that it too insists that One Size Does Not Fit All.

The case was brought by two women with mental retardation who had been treated for co-existing psychiatric issues in a Georgia mental hospital. Their doctors said that their mental illness was controlled enough for them to live successfully in the community,

but the state would not release them. This was clearly discrimination, and the plurality opinion – in a 6-3 case with three different concurring opinions – held that unnecessary segregation of people with any disability was discrimination under the Americans with Disability Act. This part was very exciting to advocates who believe that only one size can be made to fit all, since it appeared to tell them that all comprehensive treatment facilities had to be closed, and that states needed a so-called “Olmstead Plan” to do so.

In fact the plurality opinion carefully says the contrary. **"We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it."**

The concurring opinion by Justice Kennedy with Justice Souter in agreement is even more explicit: **"It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision."**

The plurality opinion ends by setting three conditions: "...we conclude that, under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."

The first condition means that the people in developmental centers today are those who have required the unmatched medical and therapeutic resources of a developmental center, who didn't want to go, and who could not be supported at significant savings in a community setting.

Those who advocate against the continued existence of the developmental centers must answer to each of these conditions. I respectfully submit that after 25 years of advocacy by group-home providers to close the developmental centers, thousands of people have transferred to the community system with varying degrees of success. Those who remain on the whole require medical supports beyond what is provided in the community system, do not want to leave their longtime homes, and cannot be adequately supported with greater safety and efficiency in group homes or at home.

The last condition, I would suggest, is the source of the shrill rhetoric today against the House of Representatives demanding a cost study. The self-styled "community providers" would not oppose such a study if they had confidence that their usual trick of comparing less-disabled people now in the community system with the aging, multiply-disabled people in the developmental centers was going to work another time.

The second condition has led, today and over the years, to increasing attacks on families and guardians. If the Representatives and Senators present will read the Governor's "Olmstead Plan," they will find almost no mention of families. Yet the Congress in writing the developmental disability act has always placed a goal of family involvement in decision making as a priority.

And the first condition has forced advocates against a full continuum of care to repeat endlessly that Massachusetts has six of the seven ICFs/MR in New England, and that the trend is against it. The trend is in favor of piercing the tongue, but I don't notice

any requirement for DDS to do that to everyone. In fact, some 41 states have ICFs/MR. The only large state that has none is Indiana. Delaware is building a new one. California closed several in the 1990s, and then reopened admissions.

Not all ICFs/MR are large facilities. Some states have many small ones. Some states have private ones. Massachusetts has never permitted small or private ICFs/MR. It is hard to understand why the state is so bent on abolishing the only treatment centers required by license to maintain 24-hour nursing availability. Members of COFAR have given input on DMR documents that might lead to a future funding system that could make medical supports available for such people in newly built group homes, but there is no proof this will actually be funded, can actually be done, will actually work, will be preferred by the individuals and their families and guardians, or can be done at a reasonable cost. The documents we reviewed implied that for most of the people to be moved, costs would increase. That is why we supported the feasibility study amendment, why the House of Representatives voted it, and why the Senate and the Governor should go along.

Thank you