

Terrence W. Macy, Ph.D., Commissioner
Department of Developmental Services
460 Capitol Avenue
Hartford, CT 06106

April 28, 2014

Dear Commissioner Macy,

It has recently come to our attention that DDS has made a change in how the department accounts for individuals on the residential Waiting List. Between the Management Information Report (MIR) of June, 2013 and the ones of September, 2013 and December, 2013, there was a change in the way that the wait list categories are defined. In the June, 2013 MIR (p. 11), Section 2A is called "Residential Waiting List." On the same page in the September, 2013 MIR and the December, 2013 MIR (which have just been issued), the same section is called "Residential Needs—Emergency and Priority One." Within that category, two subcategories have now been created, called "Waiting List" and "Other Residential Needs." The Waiting List category only includes "Home/IL (No Supports)." Based on this change in definition, the Waiting List in the September and December, 2013 MIRs show a 36-37% reduction in the number of individuals waiting for residential supports compared to the June, 2013 MIR!

The reason why this seemingly bureaucratic change is of great concern to us is that legislators depend on DDS data to try and understand how many of our loved ones are currently waiting for residential placements. They make funding decisions based on the data supplied to them by DDS. This is why we've been contacting our legislators to investigate. On April 17, 2014, Mr. R. O'Connor, DDS Legislative and Regulations Analyst offered the following explanation in an email to Rep. Linda Orange for her constituents, Denise and Frank King, Lebanon, CT: "*When someone on the waiting list receives an allocation, accepts in-home residential supports to address an unmet need, and their need is fully met, the individual is no longer on the Residential Waiting list because he or she has received funding for in-home residential supports.*" But when families are offered supports, it isn't clear who decides if their needs have been "fully met," or if they will remain eligible for a sought-after residential placement. We vehemently oppose any policy that removes individuals from the Waiting List without their knowledge based on their acceptance of In-Home Supports! For many of us, IHS funding is a band-aid approach to a much deeper issue. Our loved ones deserve the chance to live alone or with peers, leaving home like their siblings and other loved ones do. Some of us are getting older and are worried sick about what will happen to our loved ones when we pass away.

It seems as though DDS, through its changing classification systems, is attempting to downplay our loved ones' need for appropriate residential placements. Most of us have loved ones who are currently on the Waiting List, and all of us have concerns about people with I/DD who need residential placements. These individuals and their loved ones are being told that there aren't funds for placements except in cases of emergency, which seems to be defined as the death or illness of the caregiver. That is barbaric. We're committed to working together to make sure that all families have timely access to the services they need. An absolutely essential part of this process is accurate reporting from DDS.

Please contact our organizer, Lara Shepard-Blue at lshepard-blue@seiu1199ne.org or 860.251.6048 to let us know how you plan to address this issue.

Thank you in advance for your prompt attention.

Sincerely,

The Our Families Can't Wait (OFCW) Organizing Committee

Lauralyn Lewis, Old Saybrook	Joanne Oullette, Meriden
Collette and Ron Langner, Tolland	Peggy Embardo, Wallingford
Kathy Peters, Killingworth	Debbie Ramaya, Hamden
Lois Nitch, Rocky Hill	Brenda Brennan, East Windsor
Denise and Frank King, Lebanon	Ferne McAllister, Tolland
Mary Lou O'Connor, West Hartford	Renee Brown, Stamford
Ed Broderick, Hamden	Laurette Shrage, Weston
Velma Williams Estes, Meriden	Carmel and John Van Hare, Bloomfield
Dawn DeMatteo, East Haven	Donna and Richard Sadler, Norwich
Maryse Wicker, Stonington	

Cc: Governor Dannel Malloy
Jonathan Slifka, Governor's Liason to the Disability Community
Senator Beth Bye
Members of the Appropriations Committee
Members of the I/DD Caucus
DDS Families