Testimony of Michael F. Wilcox on the proposed amendments to DDS 115 CMR 2.00 (definitions) and 6.00 (eligibility)

March 5, 2015

I was unable to attend the hearing in Marlborough on February 5 to present my thoughts in person, because of winter weather, so I offer the following written comments for your consideration.

I have spoken with or corresponded with many of my friends and colleagues, some of whom have also testified. Because I know that some of what they offered addressed many practical aspects of these proposed regulations, I will confine myself to a more philosophical approach.

I am concerned about the tone and scope of the proposed regulations, which I believe are not entirely in keeping with the original intent, as I understand it, of the new legislation that they are meant to address.

By way of introduction, I will offer some background information on myself, to reveal my possible prejudices and to provide insight as to why I might be qualified to speak to the proposed regulations and the legislation they relate to. I served on the Special Commission Relative to Autism during its entire first incarnation, which lasted from December 2010 until we published our findings and recommendations in March of 2013. I was the only openly autistic member of the Commission, and at the time I was also serving on the Board of AANE (then, the Asperger's Association of New England, now the Asperger/Autism Network).

I am currently on the Executive Committee of AFAM (Advocates for Autism of Massachusetts), and I serve on the Board and Executive Committee of Community Resources for People with Autism (which is the Autism Resource Center for the western four counties of Massachusetts), and teach graduate-level courses in the autism program at The Elms College in Chicopee.

My academic background is in Economics. I hold a Master's degree in Economics from Trinity College in Hartford. My career was in financial economics, which involved the quantitative analysis of investment products and strategies. I worked for many years on Wall Street, including a stint as a Principal with Morgan Stanley, during which I published extensively, and traveled to all the world's financial centers to explain my research and assist clients in realizing the investment goals of their organizations. My clients were managers of large pools of institutional money, such as banks, governments, mutual funds, labor unions, and foundations.

In contrast, I have no formal training in autism. Approximately ten years ago I figured out that I'm autistic, and I set about learning all I could about what that means. I have met hundreds of autistic people, and I have written extensively, and presented in conferences, and other settings, what it has meant for me to be autistic. For several years now, I have co-led a series of support groups for couples.

So, although I have no academic credentials that relate to autism, I do consider myself an expert on what it has been like for me to be autistic. I also recognize that my experience has been unique, and that autistic people, as a group, have the same variety of skills, interests, and experiences as does the rest of the world. I don't pretend to speak here for anyone except myself.

Moving to consideration of the specific piece of legislation that gave rise to the need for these new regulations, I can claim more than passing familiarity. I was deeply involved in the drafting of, and the advocacy for, the portion of House Bill 4047 that addresses the expansion of eligibility for DDS services to include autistic adults. For many years, AANE, as well as other organizations and advocates, tried to make this happen, and it was because of the work of the Autism Commission that this finally came to pass.

In fact, this expansion of eligibility was the number one priority in the Commission's final report. Because of my involvement with AANE, and their key role in advocating for this provision, I volunteered to take the lead in creating new legislation.

During the more than two years that the Commission and its subcommittees met, we received enormously helpful comments and information from the Patrick Administration. Relative to this issue, we were given much support and guidance from the Assistant Secretary for Disability Policy as well as from the DDS Commissioner and other high-level members of the Department. We also received extremely useful information and guidance from the Disability Law Center (DLC), which, among other things, conducted a study comparing the statutes and regulations in Massachusetts with those of every other state.

I first went to the DLC for guidance on how to draft the legislation we wanted, since that sort of legal expertise is well beyond my grasp. At first blush, I was told not to bother, because such a bill had almost no chance of being passed by the legislature, and even if it were, it would have almost no chance of being funded. I successfully counterargued that the idea had the full backing of the Autism Commission, key people in the Administration, and among many legislators with whom I had spoken. The DLC was persuaded, and proceeded to draft a bill that would change the definition of DDS eligibility for adults from being one that mostly related only to intellectual disability to a broader definition that would include all developmental disabilities.

You all know the success story that followed. Thanks to the efforts of the AANE Advocacy Committee, as well as many other organizations and literally hundreds of individuals, who provided testimony and lobbied their legislators, we ended up with over 90 sponsors for the legislation (and would have had more if we'd not had such a tight deadline). In the end, after some amendments, the bill was consolidated with some others into the Autism Omnibus Act, which was passed unanimously by both chambers of the legislature.

I then worked with the Governor's Office to secure funding for the needed DDS expansion, and they did introduce a supplemental budget request, which passed. And that is why we have come to this point, needing to discuss expanded regulations.

Along the way, though, we took a few lumps. The funding was not as much as we had hoped for. Funding never is adequate, it seems, for programs like this. I really admire how people in Human Services labor under constant constraints imposed by inadequate funding. In my comments that follow, I will mention some things that I feel are too restrictive about the proposed regulations, but I do understand the motivation behind setting those limits. If money were not an issue, the job of DDS and these regulations would be a lot simpler.

In anticipation of what would almost certainly be an atmosphere of limited resources and therefore capacity constraints, DDS persuaded the legislature to modify the bill that was originally introduced. Instead of extending services to all developmental disabilities, as had been the original intent, the bill was restricted to include only intellectual disability, autism, Prader-Willi syndrome, and Smith-Magenis syndrome.

This bowdlerizing has led to a complicated set of proposed regulations that I believe are overly restrictive and compartmentalized. As I said, I understand that the motivation here is to live within the funding that has been granted, and that the folks who carry out the mission of DDS do not enjoy being restricted any more than I like seeing the result of that parsimony. But I think it is possible to preserve some of the original intent of the legislation without constructing quite so many silos.

Even though this new law and its associated funding have brought Massachusetts in out of the cold — prior to the enactment of this bill, we were the only state in the country that did not have a law on the books recognizing the needs of adults with developmental disabilities other than ID — we still have some of the most restrictive guidelines in the nation. The difference, I believe, is that here in the Bay State, we take ourselves seriously, and when we pass a law we attempt to honor it by implementing it and providing some funding. The funding may be inadequate to the overarching purpose of the law, but it is an honest attempt to do the best we can. Other states may have better laws, but they provide little or no funding, and so in these states it is just not possible to get services!

In an ideal society, everyone who needs assistance to achieve full inclusion would receive it. The intent of this legislation, at least as I intended it, was to identify, though a pragmatic test, as outlined in the definition of developmental disability, all those people who need assistance in living as independently and in as self-directed a way as they are able. In an environment of limited resources, choices have to be made. Not everyone can get all the help they need. This is unfortunate, but it is reality.

In choosing who gets all the help they need versus who gets some of the help they need versus who gets no help at all, there are no proper choices. Denying help to anyone is a moral failing of our society, in my view. I am embarrassed, as a voter and a taxpayer, and I apologize to DDS that we have put you in a position of having to choose.

One specific worry I have is that there are many people who do not need much assistance at all, but who are at risk of getting nothing. I think of people like me, who are fairly self-reliant, but who may need training or direction if they are to find suitable employment, or obtain the education they desire, or develop the skills they need to live on their own. I feel that people like this may get shunted to the end of the line when there are other people with more obvious struggles in getting through the day.

With the same amount of money that it might take to provide support to one person with very intense support needs, it might be possible to greatly improve the lives of dozens of people who need only minimal support. Which needs should we ignore? This is a Sophie's Choice, of course. There is no right answer.

I do not mean to sound ungrateful for what DDS and the Commonwealth are doing here. It is simply part of my advocacy work to continue to ask for nothing but the very best. Disabled people deserve full inclusion, and advocates will not rest until that happens. The legislation we are discussing here is a huge step in the right direction, and I am very grateful for that. But it is not enough. Unfortunately, though, we play with the hand that we were dealt.

Moving, therefore, to the specifics of the regulations here under consideration, I begin at the beginning. The first change in the first section (2.01 Definitions) adds a definition of “Adult Supports.” This is a good example of what I mean by the proposed regulations being too restrictive. This definition concerns itself only with intellectual disability (ID), not with developmental disabilities (DDs) as a broad category. I wonder why this definition cannot include all of the individuals who would be qualified for services under the new guidelines.

This brings up another overriding principle that was behind the original definition of the bill, which covered all DDs, and then was later modified as already mentioned. A developmental disability is evidenced by a person’s behavior. The first definition in Section 2.01 is for “Adaptive Behavior” and talks about the “quality of everyday performance.” This is the key to the federal definition that was used in the original draft of this legislation. It was taken from the federal DD Act, and it also appears in the IDEA as well as in other places. It is a functional definition. A determination is made for an individual based on how well they are able to perform certain essential life skills. If they are not able to demonstrate an ability to live independently without assistance, then they are, by definition, disabled. For persons who have multiple conditions, such as, for example, autism and intellectual impairment, the definition does not try to parse out which skill deficits are attributable to which condition, nor should it matter.

Federal Definition of Developmental Disabilities

> According to the Developmental Disabilities Act, section 102(8), “the term ‘developmental disability’ means a severe, chronic disability of an individual 5 years of age or older that:
> Is attributable to a mental or physical impairment or combination of mental and physical impairments.
> Is manifested before the individual attains age 22.
> Is likely to continue indefinitely.
> Results in substantial functional limitations in three or more of the following areas of major life activity:
> (i) Self-care;
> (ii) Receptive and expressive language;
> (iii) Learning;

> (iv) Mobility;
> (v) Self-direction;
> (vi) Capacity for independent living; and
> (vii) Economic self-sufficiency.
> Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided."

Notice that no attempt is made here to attribute any of these limitations to a specific condition. Yet, it seems to me, DDS is trying to do just that; to isolate autism from intellectual impairment. It is true that people with overlapping disabilities might need different services from those provided to persons with a single disability. But these regulations are not, or at least should not be, about the provision of services per se, but about who is eligible to receive assistance.

Moving on to other definitions in this section (2.01), in alphabetical order:

•Autism: I strenuously object to calling autism a "spectrum disorder" and also to using the DSM as an authority on autism. Autism is not a mental disorder, and it has therefore no place in the DSM. Autism is a difference that is so dramatic that it is a disability. Autism is not well understood by most people, including many autistic people. The differences we experience are extreme, and often crippling as a result. Autistic people think in a very different way, and communicate in a very different way. Autistic people may behave in ways that seem very odd to neurotypical people, and you can be sure that the reverse is true as well. Compared with autistic people, neurotypical people have a very poorly developed sensory system, and may therefore be unaware of the distress they are causing to autistics.

•Autism Spectrum: the word "spectrum" is this context has no commonly accepted (or commonly known) definition. It is often used to acknowledge that autistic people are all very different from each other. Well, so are neurotypicals. The word can also be used to mean the amount of support an autistic person needs, or their IQ, or any number of other things. Because of this vast array of usages, the word, in this context, has no pragmatic value.

•Autism Diagnosis: in my view (and that of many other autistic people), autism does not belong in the DSM, any more than homosexuality did before it was removed, not all that many years ago. The National Institute of Mental Health has rejected the DSM system of categorization, and is moving toward its own system of evaluating proposals and awarding research money. It seems to me that a valid definition of autism could be like some of the other diagnoses mentioned elsewhere in these regulations; a person could be recognized as being autistic if they receive an autism diagnosis from a qualified clinician.

•Community Supports: there are two types listed, “Developmental Disability” and “Living” which relate to, respectively, autism and intellectual disability. Again, I don’t see the need to differentiate. Services should be geared to an individual’s needs, not to the cause of their impairment. I understand that some of the services may be funded by Medicare, and some not, but I’m not clear why that needs to be made explicit in the regulations. It might also be argued, I suppose, that people will need different types of services depending on the source of their disability, but I’m not sure that’s entirely true, especially for people who have both disabilities.

•Later on, there is an attempt to distinguish “Significant Limitations” and “Substantial” limitations. This seems to me to be misguided and unnecessary. It may, in fact, be contrary to the statute as it is now written, and it is clearly contrary to the spirit of what we were trying to accomplish. The first (“Significant”) definition does not conform to the federal definition, as given in the statute, and the second (“Substantial”) definition does not specify how the limitations will be measured. Many other states have standards that are similar to the one mentioned in the first of these definitions, relating to scores on a standardized test. Some states, for example, state a threshold of scoring some number of standard deviations below average on three of the areas of major life activity or some number of standard deviations below average on the overall assessment. It seems to me that these two definitions should be combined and made consistent with the federal definition, as contained in the new statute.

•In between the two definitions just mentioned is an existing section of the regulations that defines “Signifcantly Sub-average Intellectual Functioning” as being a score of 70 or below on a standardized IQ test. It was our intention to eliminate the need for this standard by substituting the federal definition, which is a functional test. It is generally acknowledged that IQ is a poor (some would say “useless”) predictor of an individual’s ability to learn and display successful adaptive behavior. An IQ test has no place in today’s understanding of developmental disability.

I plan to share my comments here with legislators and other advocates. I realize that, in many ways, DDS does not control its own destiny. Again, I appreciate and admire how much good work is done by the department. DDS makes better the lives of countless people. Still, my self-appointed role, as a disability advocate, is to insist on full and equal inclusion and opportunity for all people, not just some people. I thank you for all you have done and are about to do, and I am grateful for your efforts, even as I continue my quest for more and better services, and, equally importantly, for full understanding and acceptance of people with disabilities.

Michael F. Wilcox, MA, CFA
217 East Road
Alford MA 01266

mfw@mfw.us