



New York Lawyers  
For The Public Interest, Inc.  
151 West 30<sup>th</sup> Street, 11<sup>th</sup> Floor  
New York, NY 10001-4017  
Tel 212-244-4664 Fax 212-244-4570  
TTY 212-244-3692 www.nylpi.org

August 27, 2018

Office for People with Developmental Disabilities.  
Office of Counsel, Bureau of Policy and Regulatory Affairs  
44 Holland Avenue  
Albany, New York 12229  
Fax: (518) 474-7382  
E-mail: [RAU.unit@opwdd.ny.gov](mailto:RAU.unit@opwdd.ny.gov)

**RE: Comment on the Proposed Regulation 14 NYCRR Section 629.1**

To whom it may concern:

I am writing on behalf of New York Lawyers for the Public Interest (NYLPI) to comment on the proposed regulation 14 NYCRR § 629.1 relating to the process of determining eligibility for services from OPWDD. This office functioned as part of the New York State Protection and Advocacy network for many years. As part of our work, we negotiated with OPWDD regarding numerous due process violations and substantive deficiencies in their administration of the eligibility process. Our negotiations resulted in the standardizing of the process of applying for eligibility now formalized in the proposed regulations. I applaud the Department for finally engaging in notice and comment rulemaking with regard to the eligibility process but write to point out a number of deficiencies in the proposed regulations in addition to those identified in the comments from the current Protection and Advocacy office, DRNY, which we agree.

The most prominent deficiency in the regulation is the failure to specify, either in the regulations or in the accompanying memo whether or not the pre-existing Advisory Guideline of August, 2001 and the Clarification Memo of December, 2002 remain in effect in whole or in part. Taken together, these two documents have many effects other than merely specifying the steps in the process of determining eligibility. They mandate timelines, provide form notices which must be used at each step of the three-step process, and, of course, provide substantive guidance relating to the interpretation of the definitions of both qualifying conditions and substantial handicap. It is hard to understand why, after going through the effort of engaging in formal rulemaking with

regard to the process of determining eligibility itself the Department failed to include in the regulation these critical aspects of the guidelines and engage in a more robust public discussion as part of the notice and comment process.

## **PROCEDURAL ISSUES**

With regard to the failure of the current proposed regulations to mandate specific time frames for each step of the application process, the proposal is a step backward from the guidelines. The 2002 clarification requires that a Step One determination be made within 30 days of the application; that a Step Two determination be made within 14 days of the receipt of any additional information requested by the DDRO; and that any Step Three determination be made within 30 days of the referral of the matter to the Third Step Committee. No such timelines are found in the proposed regulation. The regulation does not even specify that the application must be completed within the timelines relating to Medicaid determinations. Applicants and their families are entitled to prompt determinations and the regulations must specify them. In addition, if the department has determined to only require that applications be determined within the 90 day timeline applicable to Medicaid determinations of disability, that should be spelled out so families know that it could be a quarter of a year before the application is decided.

In addition to failing to provide time limits, the regulations do not specify the contents of notices to be provided, especially in cases in which eligibility is denied. It is as true now as it was back in 2004 when I first wrote to then Commissioner Maul, that most denials simply recite some version of a circular formulation such as “you are not eligible because you have not shown the existence of a qualifying disability” or “you are not eligible because your adaptive behavior scores are too high”. This leads applicants to have to guess at the objection and have difficulty obtaining appropriate documentation to overcome any perceived deficiencies in their applications. In addition, applicants are unable to properly prepare for Medicaid fair hearings challenging the denial. This is very inefficient and often results in remands and further delay for applicants. The regulations should require that any denial letter should disclose to the applicant the factors identified by the decision makers with specificity.

With regard to due process rights, the regulation should require that all notices to applicants of unfavorable decisions regulation inform them of any deadlines for appeals, including seeking a Third Step review. In addition, applicants must be told at the outset that a failure to apply for Medicaid funded services will result in them not receiving an on the record hearing and that they will be limited to a paper review by the Third Step review committee. Many applicants have no concept of which services are Medicaid funded and which are not, let alone understanding the consequences flowing from that distinction.

## SUBSTANTIVE ISSUES

If it is the intention of OWPDD to continue using the 2001 and 2002 guidelines with regard to their substantive discussion of eligibility for OPWDD, it is deeply disappointing that the agency did not take advantage of this opportunity to update those guidelines and engage in true notice and comment rulemaking by convening national experts in the field, along with stakeholders from the community to discuss substantive eligibility issues in light of the more than 15 years' worth of developments in knowledge in the field of developmental disabilities since those guidelines were written. To cite only a few examples: the field of intellectual disability has moved away from bright line rules where any score over 70 is considered disqualifying; the definition of autism has changed and expanded dramatically; knowledge relating to the lifelong effect of prenatal alcohol or drug exposure has increased; and, in general, the whole field has moved away from a deficit based medical model. While the DDRO's must certainly have flexibility to apply their expertise, as matters stand now, their discretion is completely unfettered and there is no consistency amongst regions.

In addition to its failure to update the regulations relating to the definition of qualifying conditions overall, the proposed regulations also failed to take advantage of the opportunity to provide any clarification of the manner in the existing guidelines interpret two key terms of the statutory definition of developmental disability found in section 1.03 (22) of the Mental Hygiene Law: "attributable to"; and "substantial handicap". With regard to the former term, DDRO's have often denied eligibility to individuals who had co-existing mental health diagnoses, especially if treatment during the developmental period resulted in a focus on the mental health symptoms. With regard to the second term, "substantial handicap", OWPDD's decision to rely on measures of adaptive functioning may make sense for individuals with intellectual or cognitive impairments but is unsupported with regard to any other diagnoses, especially other neurological impairments. In addition, the current adaptive measures of functioning fail to take into account the effect of formal or informal supports provided by families, schools, and other service providers. Finally, the regulation should explicitly provide for the use of retrospective assessments of adaptive functioning during the development period for those individuals who only seek eligibility much later.

Finally, we object to OWPDD's assertion in the regulation that it has the unfettered right to review grants of eligibility at any time for any reason. 629.1 (b) (3). While *Jason B. v. Novello*, 12 N.Y.3d 107 (2009) does hold that there is no res judicata bar to OWPDD reviewing an administrative finding of eligibility, that case arose in a situation where there were clear indications that the individual in question exhibited behaviors that were inconsistent with his original diagnosis. At a minimum, OWPDD should specify that it cannot review a finding of eligibility after an unappealed Medicaid fair hearing in favor of the service recipient (since the lack of an on the record hearing was the basis for the New York State Court of Appeals finding that res judicata did not apply) and should specify those situations in which a review would be appropriate. This should not include

improvements in functional behaviors; to do otherwise would punish individuals for making progress and create a disincentive for providers to help beneficiaries to become more independent. To grant OWPDD unfettered discretion to remove individuals from their service system creates a grave danger of abuse by voluntary agencies seeking to rid themselves of expensive or troublesome consumers. It also runs counter to the mission and values of OWPDD to allow individuals with developmental disabilities.

Thank you very much for the opportunity to comment on the regulations. If you have any questions.

Sincerely,

Roberta Mueller  
Senior Supervising Counsel  
N Y L P I  
New York Lawyers for the Public Interest  
151 West 30th Street, 11th Floor, New York, NY 10001-4017  
tel: (212) 244-4664 fax: (212) 244-4570  
rmueller@nylpi.org