

STATE OF DELAWARE

STATE COUNCIL FOR PERSONS WITH DISABILITIES

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The Honorable John Carney, Governor John McNeal, Director SCPD

MEMORANDUM

DATE: August 29, 2022

TO: Lynda Lord, Director of Professional Services

Division of Developmental Disabilities Services

FROM: Terri Hancharick, Chairperson TH

State Council for Persons with Disabilities

RE: Proposed DDDS Regulation 2100 [Eligibility Criteria, 26 Del. Register of

Regulations 89 (August 1, 2022)]

The State Council for Persons with Disabilities (SCPD) has reviewed the Division of Developmental Disabilities Services (DDDS) proposed regulations to modify 16 Del. Admin. C. § 2100 establishing eligibility criteria for the Division. The proposed regulation strikes the existing regulation in its entirety and replaces it with new language. This proposed regulation is intended to:

- Update terminology.
- Clarify details regarding age and citizenship.
- Add provisional eligibility to individuals ages three (3) through eight (8) who do not have requisite assessments.
- Allow DDDS discretion to decide eligibility without all required assessments.

The proposed regulation was published as 26 DE Reg. 89 in the August 1, 2022, issue of the Register of Regulations. SCPD has the following observations and recommendations.

UPDATED TERMINOLOGY

The current regulation uses outdated terminology that is inconsistent with current diagnostic classifications and people first language. For example, the regulation utilizes the term "mental retardation" while the current version of the Diagnostic and Statistical Manual ("DSM-5-TR") and prior version ("DSM-5"), use the term "intellectual disability." This change occurred when the DSM-5 was published in 2013. See

https://www.psychiatry.org/File%20Library/Psychiatrists/Practice/DSM/APA_DSM-5-Intellectual-

<u>Disability.pdf</u> and https://www.psychiatry.org/psychiatrists/practice/dsm/history-of-the-dsm#:%7E:text=DSM%E2%80%935%20was%20published%20in%202013.

CLARIFICATIONS AROUND CITIZENSHIP

The regulation changes non-citizen residency from "a lawful alien of the United States" to "qualified alien according to DE Medicaid Requirements," referencing 16 DE Admin. Code § 14310, which utilizes an existing Medicaid regulation's definition to establish eligibility. Qualified aliens include individuals with permanent residency, refugees, asylees, victims of trafficking, and certain other immigrant classifications. SCPD recommends DDDS clarify in the regulation that the five-year bar, which qualified aliens are subjected to before eligibility for Medicaid services, does not apply to non-Medicaid DDDS services and would not be a barrier to DDDS eligibility.

The change in terminology does eliminate from eligibility "lawfully residing nonqualified aliens," including individuals with temporary resident Amnesty status, a spouse or child of a U.S. citizen who is waiting for their lawful permanent residency to be approved, and children with pending applications for Special Immigrant Juvenile Status ("SIJS") which is a type of benefit for abused, neglected, and abandoned children; these children would be eligible as qualified aliens once they become permanent residents). **SCPD recommends that DDDS include lawfully residing nonqualified aliens covered by §14350.**

CHANGES AROUND AGE

Addition of a Minimum Age

The proposed regulation adds a minimum age of three. This is a new addition with this regulation and eliminates eligibility for individuals ages 0-3. However, such children would likely be eligible and receiving services from Child Development Watch/Birth to Three program, which provides services to this age group.

Provisional Eligibility for Ages 3-8

The proposed regulation allows eligibility for potential service recipients between the age of three and eight who have not yet undergone the required diagnostic evaluations if certain circumstances are met. This could help younger children start sooner with DDDS.

Increased Flexibility When Records Before Age 22 Are Not Available

This proposed regulation adds that DDDS may accept a "comprehensive assessment and diagnosis of a qualifying condition by a licensed practitioner" that is completed after the age of 22, if there have been "unsuccessful attempts to obtain assessments and records from the developmental period." This will allow for an exception for older individuals applying for DDDS services, whose records from age 22 and earlier may no longer exist. An example would be individuals who were cared for at home and were not in the DDDS system, who may find themselves needing DDDS

services due to aging caregivers, or caregivers who pass away. Rather than being stuck without a way to receive appropriate services, this may assist those individuals to qualify for DDDS services.

SCPD supports the second two changes with respect to age.

CLINICAL CRITERIA

Intellectual disability and brain injury now share the same clinical requirements. The regulation now requires an IQ or equivalent score of approximately 70 or below, rather than scores. The regulation preserves the "approximately" here which allows for consideration of standard of error and other factors.

The proposed regulation removes Asperger's Syndrome and lists only Autism Spectrum Disorder. This is consistent with changes made in the DSM-5, to remove a separate classification for Asperger's and to instead use an Autism Diagnosis.¹

The adaptive functioning requirements were also updated to require either composite scores of approximately 70 or below and clarifies what to do when there are multiple responders. However, the way the subsections under 2.1.3.2 (adaptive functioning) appear is a bit unclear. **SCPD requests** clarification regarding this provision/issue.

This regulation does allow for some flexibility with the criteria; however, it continues to use a score driven approach rather than a functional approach. Taking a functional approach is more inclusive and would help to include some individuals who test too high for eligibility, but whose functioning is equivalent to those eligible for DDDS services. **SCPD recommends that DDDS explore moving to a functional approach in the future.**

ACCEPTED ASSESSMENTS

This section clarifies whose assessments may be accepted from (licensed practitioners and school psychologists), and where the "list" of accepted assessments can be found, rather than listing the assessments in the regulation. This allows DDDS to update acceptable assessments without the regulatory notice and comment process. This would allow them to respond more timely to changes in nationally accepted assessments, but also may not allow for the same public input.

The proposed regulation also adds that DDDS will accept other assessments if they are "comprehensive, structured," and use normed and standardized instruments. This also allows for more flexibility. Finally, the proposed regulation adds a requirement that Autism assessments include a detailed developmental history interview with evidence of the behavioral characteristics present during the developmental period (or rather before age 22).

EXCEPTIONS TO DOCUMENTAION REQUIREMENTS AND REDETERMINATION OF ELEIGIBILITY

¹ See https://www.autismspeaks.org/dsm-5-and-autism-frequently-asked-questions.

The proposed regulation includes a provision in cases of "bona fide extraordinary or exigent circumstances" that DDDS may determine eligibility without some of the required documentation, reserving the right to redetermine eligibility if such documentation is located later. **SCPD is** supportive of this provision, as it would permit DDDS to act in extraordinary circumstances, even if they do not have all of the documentation they need.

DDDS also adds a right for them to redetermine eligibility until an individual reaches age 22.

SCPD appreciates its collaborative relationship with DDDS and looks forward to working with the Division on Council's recommendations.

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations or recommendations on the proposed regulation.

cc: Ms. Marissa Catalon, DDDS Director

Mr. Jody Roberts, DDDS

Ms. Laura Waterland, Esq., DLP

SCPD Executive Committee

Governor's Advisory Council for Exceptional Citizens

Developmental Disabilities Council

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