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January 13, 2015

TO: Catherine Hancock, Director of Part C Services  
Dept. for Behavioral Health and Developmental Services

FROM: Heidi L. Lawyer 

CC: Connie Cochran, Assistant Commissioner, DBHDS

RE: *Emergency Regulation: 12VAC35-225, Requirements for Virginia's Part C Early Intervention System*

Thank you for the opportunity to provide public comment on this regulation on behalf of the Virginia Board for People with Disabilities, Virginia's Developmental Disabilities Council. The Board supports the promulgation of this regulation designed to ensure that the Commonwealth is in compliance with federal requirements and that certain of its current policies and guidance will now have the force of law. The proposed regulation is comprehensive and the Board's comments are limited to the regulatory provisions listed below.

**12VAC35-225-20-Definitions**

**Consent.** The Board recommends that a definition of "consent" be added to this section to ensure that it is understood that consent means "informed consent". While parental consent is described in detail in section 12VAC35-225-320, it appears late in the regulation, and many references to parental consent are made prior to that section. Used throughout the document, "consent" is discussed in reference to multiple, complex issues for which families are asked to make decisions, including, but not limited to, use of private insurance (12VAC-225-250). The federal Part C regulations include "consent" in its Definitions section; and adding it to Virginia's regulations then is more consistent with federal regulations. The additional language describing the uses of and processes relating to consent could remain in 12VAC35-225-320. Federal regulation that defines "consent" follows.

**CFR §303.7 Consent.**

*Consent* means that—

- (a) The parent has been fully informed [*emphasis added*] of all information relevant to the activity for which consent is sought, in the parent’s native language, as defined in §303.25;
- (b) The parent understands and agrees in writing to the carrying out of the activity for which the parent’s consent is sought, and the consent form describes that activity and lists the early intervention records (if any) that will be released and to whom they will be released; and
- (c)(1) The parent understands that the granting of consent is voluntary on the part of the parent and may be revoked at any time.  
(2) If a parent revokes consent, that revocation is not retroactive (*i.e.*, it does not apply to an action that occurred before the consent was revoked).

(Authority: 20 U.S.C. 1439)

**Prior Written Notice vs. Notice.** The Board recommends addition of definitions differentiating “prior written notice” with “notice”. These terms have two different meanings which could be confusing for parents trying to understand their rights. The explanation of prior written notice in 12VAC35-225-310 comes late in the regulation, after the term is used a number of times and the proposed definition, while consistent with, is not as detailed as the federal definition. The Board also recommends that the entire regulation be carefully reviewed to ensure that the proper term (notice vs. prior written notice) is being used in the various regulatory provisions. The related federal provisions are below.

**CFR §303.421. Prior written notice and procedural safeguards notice.**

- (a) *General.* Prior written notice must be provided to parents a reasonable time before the lead agency or an EIS provider proposes, or refuses, to initiate or change the identification, evaluation, or placement of their infant or toddler, or the provision of early intervention services to the infant or toddler with a disability and that infant’s or toddler’s family.
- (b) *Content of notice.* The notice must be in sufficient detail to inform parents about:
  - (1) The action that is being proposed or refused;
  - (2) The reasons for taking the action; and
  - (3) All procedural safeguards that are available under this subpart, including a description of mediation in §303.431, how to file a State complaint in §§303.432 through 303.434 and a due process complaint in the provisions adopted under §303.430(d), and any timelines under those procedures.
- (c) *Native language.* (1) The notice must be:
  - (i) Written in language understandable to the general public; and

- (ii) Provided in the native language, as defined in §303.25, of the parent or other mode of communication used by the parent, unless it is clearly not feasible to do so.
- (2) If the native language or other mode of communication of the parent is not a written language, the public agency or designated EIS provider must take steps to ensure that:
  - (i) The notice is translated orally or by other means to the parent in the parent's native language or other mode of communication;
  - (ii) The parent understands the notice; and
  - (iii) There is written evidence that the requirements of this paragraph have been met.

(Authority: 20 U.S.C. 1439(a)(6)-(7))

**CFR §303.404. Notice to parents.**

The lead agency must give notice when a child is referred under part C of the Act that is adequate to fully inform parents about the requirements in §303.402, including:

- (a) A description of the children on whom personally identifiable information is maintained, the types of information sought, the methods the State intends to use in gathering the information (including the sources from whom information is gathered), and the uses to be made of the information;
- (b) A summary of the policies and procedures that participating agencies must follow regarding storage, disclosure to third parties, retention, and destruction of personally identifiable information;
- (c) A description of all the rights of parents and children regarding this information, including their rights under the part C confidentiality provisions in §§303.401 through 303.417; and
- (d) A description of the extent that the notice is provided in the native languages of the various population groups in the State.

(Authority: 20 U.S.C. 1417(c), 1435(a)(5), 1439(a)(2), 1442)

**Early Intervention Case Management Services.** The Board recommends addition of the definition of early intervention case management services as proposed in **12VAC30-50-415, Case management for individuals receiving early intervention (Part C) services**. To ensure clarity regarding early intervention support coordination and early intervention (targeted) case management for Medicaid recipients, a cross reference to that regulation should be made under section 12VAC35-225-170, Service delivery.

**12VAC35-225-40-Public awareness and child identification and referral.**

The Board appreciates the attention to information dissemination through primary referral sources, including hospitals that serve at-risk premature infants or those served in neonatal intensive care units (NICU) and their families. Although 12VAC35-225-50 requires referral to the single point of entry for early intervention within 7 days after being identified as potentially eligible, the regulation lacks a requirement for follow-up. The Board encourages inclusion of a requirement for follow up with families with premature infants or those who have been in the NICU at 3, 6, and 12 months after hospital discharge. It is extremely difficult for families whose infants are born with a significant complication—especially those that may be hospitalized for a lengthy period—to take in all of the information provided to them at discharge. The importance of timely entry into early intervention cannot be overstated, and a formal mechanism therefore should be developed and implemented to ensure that these babies do not miss critical intervention time. This was also a recommendation in the Board’s 2014 *Assessment of the Disability Services System in Virginia*.

**12VAC35-225-90-Eligibility determination process and 12VAC35-225-110, Assessment for service planning**

There is an inconsistency in language regarding the assessment tool to be used: Section 12VAC35-225-90 E (1) requires the “use of an evaluation instrument”, and section -110-E(2) provides for “use of a comprehensive assessment tool.” Do these references mean two different instruments? Although there may be more specificity in practice manuals, the Board believes that additional language should be considered for the actual regulation to provide clarity. Adding language from Part B of IDEA (CFR § 300.304) would be useful. The Board recommends consideration of the following language from federal regulations:

“Use technically sound instruments that

- a. are used for the purposes for which the assessments or measures are valid and reliable;
- b. administered by trained and knowledgeable personnel; and
- c. are administered in accordance with any instructions provided by the producer of the assessments.

**12VAC35-225-120-Individual family service plan (IFSP) development.**

In sub-section -120 (6), the Board recommends that language be changed from “peer-reviewed research” to “scientifically based research,” to be consistent with federal Part C regulation CFR §303.32 (Authority 20 U.S.C. 1435(a)(2)).

**12VAC35-225- 420-Appeal to the Department of Medical Assistance Services**

Sub-section 420(A)(3) specifies “the frequency and length of services in the IFSP” as actions that can be appealed by Medicaid or FAMIS recipients. The Board recommends adding “intensity of services” as another action for appeal. This proposed regulation defines “Intensity” as meaning “whether a service will be provided on an individual or group basis” (see -225-20, Definitions). The distinction between individual vs. group services is as important as the length and frequency of services, and therefore should be a basis for appeal.

**12VAC35-225-450-Certification required for early intervention service providers.**

The Board supports individual practitioner certification requirements, including the new requirements for behavior analysts. We are concerned, however, that this requirement may, at least temporarily, limit the number of providers available to deliver a critical service. We recommend, if this has not already occurred, that DBHDS and the Behavioral Analyst Certification Board consider creation of a time limited provisional certification or a grace period in which an individual is given a defined period of time to meet the behavior analyst certification requirements—if the individual can document that they are enrolled in a certification program. (Provisional certification already is in use as a component of the Board of Education teacher licensure system.)

Again, we appreciate the opportunity to comment. Should you need further information or have any questions, please don't hesitate to contact me at 804-786-9369 or [Heidi.Lawyer@vbpd.virginia.gov](mailto:Heidi.Lawyer@vbpd.virginia.gov)